



The Dignity Digest

Issue # 253

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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	<u>What Donald Trump's Medicaid cuts mean for caregivers</u> NPR 1A (podcast) September 30, 2025 Looking out for a family member who's aging or disabled can take a huge toll on caregivers. And the burden just got heavier thanks to President Donald Trump's cuts to Medicaid — the single largest source of funding for long-term care of disabled and elderly people. It accounts for more than half of the roughly \$415 billion that's dedicated to these services each year. A panel of experts to talk about what cuts to federal benefits mean for the caregivers who rely on them. Guests Kat McGowan caregiver; journalist Jason Resendez president and CEO, National Alliance for Caregiving Danilyn Rutherford caretaker; president, Wenner-Gren Foundation for Anthropological Research; author, "Beautiful Mystery: Living in A Wordless World" This is a summary of a 1A podcast episode discussing the impact of recent Medicaid cuts on caregivers in the United States. The conversation features host Todd Zwilich, Jason Resendiz of the National Alliance for Caregiving, journalist Kat McGowan, and Dannielynn Rutherford, a caregiver for her disabled adult daughter. The Financial Strain of Caregiving • High Costs: Caregiving for an aging, ill, or disabled family member carries a significant financial burden. AARP estimates that caregivers spend an average of \$7,200 annually out-of-pocket and lose over \$43,000 in income due to caretaking demands.

	• Case Example: Dannielynn Rutherford, whose 25-year-old daughter Millie requires constant care, estimates the annual cost to be around \$300,000 if caregivers are paid a living wage. • Primary Funder: Medicaid is the single largest source of funding for long-term care in the U.S., covering over half of the \$415 billion spent on these services annually. Crucially, Medicare does not cover long-term care, forcing many middle-class families to spend down their assets until they qualify for Medicaid. Impact of Medicaid Cuts • Scope of Reductions: The Trump administration's budget will cut federal Medicaid spending by approximately \$900 billion over ten years and add new work requirements. • Reduced Services: States will likely respond to funding shortages by cutting optional services first, such as home and community-based care, respite care, and caregiver training. This pushes more people toward more expensive institutionalized care. • Administrative Hurdles: New work requirements and increased paperwork will make it harder for caregivers and their loved ones to qualify for and maintain benefits. These administrative tasks are often compared to working a second full-time job. • Fraud Misconceptions: While a caller expressed support for cutting fraud, data shows that only 2% of Medicaid fraud convictions are against beneficiaries; the vast majority are committed by providers like nursing homes and labs. The Emotional and Social Toll • Widespread but Isolating: While there are an estimated 63 million caregivers in the U.S., the role is often incredibly isolating. Over 60% of caregivers report high levels of emotional stress, anxiety, and depression. • A Labor of Love: Despite the challenges, more than half of caregivers find a deep sense of purpose in their role. The goal is not to eliminate caregiving but to make it sustainable through better support systems. • Lack of Public Dialogue: The speakers noted that unlike parenting, there is little public conversation about adult caregiving, which contributes to the stigma and isolation felt by many. Potential Solutions and Next Steps • State-Level Advocacy: With federal funding reduced, advocates must focus on state governments to create
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	broad exemptions from work requirements and pass policies like caregiver tax credits and paid family leave. • Increase Public Conversation: Raising public awareness is a crucial first step to reducing the stigma and isolation associated with caregiving. • Organize and Collaborate: Care providers and families who benefit from the system must organize to find common cause and advocate for their needs. https://the1a.org/segments/what-donald-trumps-medicaid-cuts-mean-for-caregivers/
Quotes	<i>“We have a window of time, but it’s not a very big window. If we don’t change the way we do things, the way we develop economically, then it will be too late.”</i> Jane Goodall in her last interview recorded on September 24, 2025, Dr. Jane Goodall's Urgent Call To Action: 'We've Been Stealing Our Children's Future', Forbes (podcast), September 24, 2025 <i>We’ve come too far to go back to a time when autism was a stigmatized condition defined solely in terms of deficits; when mothers were made to feel guilty; when the pressures for conformity so outweighed the desire for diversity that people with autism had few chances to get an education or a job; when one person with power could dominate the discourse on autism; and when the people whose well-being was at stake were excluded from shaping the narratives and policies that can alter their lives and happiness.</i> Autism Has Always Existed. We Haven’t Always Called It Autism. (*New York Times, September 24, 2025) <i>Before the Affordable Homes Act, Massachusetts had no statewide standard for ADU zoning, leading to a complex patchwork of local requirements that often made it difficult to build these units. Now, ADUs under 900 square feet can be built by-right in single-family zoning districts across the state, with the exception of Boston, which has its own ordinance.</i> Massachusetts accessory dwelling units rise, easing housing shortage (WWLP.com, September 26, 2025)

Department of Mental Health Commissioner Brooke Doyle is leaving her post, following a contentious budgeting cycle at the agency after the Healey administration attempted to slash half of the case manager workforce.

[State mental health commissioner stepping down](#) (*State House News, October 3, 2025)

“This is the big, horrible bill. People are going to go hungry.”

Ms. Porter-Norton, a La Plata County (Colorado) Commissioner, [In Some States, Strapped Counties Must Impose Trump's Medicaid Cuts](#) (*New York Times, September 30, 2025)

“By helping people get and keep housing, we improved their health and reduced public costs. These services save lives.”

Kevin Lindamood, chief executive, Baltimore's Health Care for the Homeless, [Trump's Medicaid Cuts Could Hamper Efforts to House the Homeless](#) (*New York Times, September 17, 2025)

Some 90,000 cases of Parkinson's are now diagnosed each year in the United States, about one every six minutes, on average. It is the world's fastest-growing neurodegenerative disease, causing tremors, stiffness, and balance problems. It is also the 13th-leading cause of death in the United States.

[The Clue to Unlocking Parkinson's May Be All Around Us](#) (*New York Times, September 14, 2025)

President Trump has turned Make America Healthy Again into one of his administration's signature promises. It is a laudable goal, too. By several measures, the United States is the world's [least healthy high-income country](#).

[Trump's Policies Are Endangering Your Health](#) (*New York Times, September 12, 2025)

“[The Trump] administration seems to care a lot about autism as a supposed epidemic. It does not seem to care much at all about autistic people.”

Colin Killick, executive director of the Autistic Self Advocacy Network, [‘Autism Doesn’t Need a Cure’: Trump’s Message Rankles People Living With the Disability](#) (***New York Times**, September 23, 2025) [Editor’s note: Colin Killick is the former executive director of the Disability Policy Consortium and a DignityMA participant.]

“There is definitely much more fear about autism.” Adding that the [Trump] administration was treating it like a terrible disease, “instead of an intellectual disability.”

Jonathan Gardner, a 22-year-old disability advocate from East Bridgewater, MA, who was diagnosed with autism before he turned 2, [‘Autism Doesn’t Need a Cure’: Trump’s Message Rankles People Living With the Disability](#) (***New York Times**, September 23, 2025) [Editor’s note: Jonathan Gardner is the co-leader of the advocacy effort to enact supported decision making legislation in Massachusetts.]

“This is Phase One of the Republican campaign to force Americans to work into old age to access their earned Social Security benefits and represents the largest cut to disability insurance in American history. Americans with disabilities have worked and paid into Social Security just like everybody else, and they do not deserve the indignity of more bureaucratic water torture to get what they paid for.”

U. S. Senator Ron Wyden (D-OR), [Trump plan seeks to overhaul disability benefits](#) (***Boston Globe**, October 6, 2025)

“There’s a common misconception that older adults are very asset rich and have a lot to work with. The reality is that the majority are in the red or are carrying debt — they don’t have substantial savings or assets to rely on to meet health care costs.”

Jane Tavares, gerontologist, University of Massachusetts, Boston, [Millions of Poor Retirees Have Lost an Easier Path to Help With Medicare](#) (***New York Times**, October 4, 2025)

In 2023, [more than one-third \(36%\)](#) of beneficiaries said they had delayed or gone without a visit to the doctor's office, vision services, hearing services, prescription drugs or dental care in the past year because of the cost. Medicare households also spend a [larger share of their total budgets on health care](#) than non-Medicare households, and are more likely to need [expensive long-term services and supports](#) over an extended period of time, which are [not covered by Medicare](#).

[Millions of Poor Retirees Have Lost an Easier Path to Help With Medicare](#) (*New York Times, October 4, 2025)

"We are in a very difficult time, both from budgetary standpoints and just in terms of our culture as a society — things have changed. There are things that we completely believed in just 10 years ago that now as a society, we're questioning, and I think that one of the reasons that I decided to apply for the job is that I really wanted to be in a position to mitigate the most negative effects on the most vulnerable. When things get tough, in an undesigned system — and we have an undesigned system — it's very easy for the most vulnerable to lose a lot, because they don't have as much political strength."

Massachusetts Health and Human Services Secretary Kiame Mahaniah, [Still a doctor on Mondays, now a secretary every day: Kiame Mahaniah's balancing act](#) (*State House News, October 6, 2025)

"The key measure is what happens to patient outcomes when corporatization occurs. . . The real challenge is ensuring that profits are aligned with value for patients."

Amitabh Chandra, [Ethel Zimmerman Wiener Professor of Public Policy and Director of Health Policy Research](#) at the Harvard Kennedy School of Government, and the Henry and Allison McCance Family Professor of Business Administration at Harvard

	Business School, Corporatization of healthcare gets too much of a bad rap, analyst says (The Harvard Gazette, October 2, 2025)
Life Well Lived   Jane Goodall, 1934-2025	Jane Goodall Listen to Jane Goodall's final — and urgent — message Vox.com October 1, 2025 By Benji Jones Jane Goodall, one of the most influential environmental figures in human history, has died at 91 while doing what she's done for most of her later years — touring the country to deliver an urgent message about nature and human existence. Goodall, who revolutionized what we know about chimpanzees and animal intelligence, was interviewed as recently as last week, during New York City Climate Week. And her message was clear, consistent, and timely. "It seems these days everybody is so involved with technology that we forget that we're not only part of the natural world, we're an animal like all the others," Goodall, founder of the Jane Goodall Institute, a conservation group, said last week during the Forbes Sustainability Leaders' Summit in NYC. "We're an animal like all the others. But we depend on it for clean air, water, food, clothing — everything." And yet — "We're destroying the planet," she said. In a separate conversation with the Wall Street Journal last week, Goodall said the problem is the pernicious idea that economic development should come before the environment. In reality, we're on a planet with finite resources, and if we exhaust them, it could spell our own end. "Humans are not exempt from extinction," Goodall said in the Wall Street Journal's podcast, <i>The Journal</i>. One of the most compelling messages from her last interviews is that while we're the most "intellectual animals" to ever walk the planet, "we're not intelligent," said Goodall, who's an expert in animal behavior. "Because intelligent creatures don't destroy their only home." Ultimately, she said, it's that intellect that gives us the best shot at saving ourselves and the planet. That's what's ushered in solutions to living in greater harmony with the natural world, Goodall said, including renewable energy and plant-based foods. She emphasized that we know what's killing the planet: industrial agriculture, including livestock, and burning fossil fuels. "We have a window of time," Goodall, who's authored more than two dozen books, said in <i>The Journal</i>. "But it's not a very

	big window. If we don't change the way we do things, the way we develop economically, then it will be too late." Video of Jane Goodall's last interview recorded on September 24, 2025: <u>Dr. Jane Goodall's Urgent Call To Action: 'We've Been Stealing Our Children's Future'</u>
Remembering with Dignity To access the submission form scan  or click on: <u>https://tinyurl.com/DignityRemembrance</u> or <u>https://forms.gle/GbzP2H9RG1sWSzA3A</u>. For more information or questions, contact: Deborah W. Coogan Chair, DignityMA's "Remembering with Dignity" initiative <u>dwc@cooganlaw.com</u> 617-332-8828	<i>Dignity Alliance Massachusetts Launches "Remembering with Dignity," a Digital Memorial to Honor Those who Died During the COVID-19 pandemic</i> To honor the more than 25,000 Massachusetts residents who died during the COVID-19 pandemic, Dignity Alliance Massachusetts (DignityMA) has launched "Remembering with Dignity," a new online memorial. The public is invited to submit remembrances of those lost between January 2020 and May 2023. The COVID-19 pandemic caused unprecedented upheaval, and yet the 1.2 million Americans who died from the disease have no official national day or place of remembrance. During the COVID-19 emergency, widespread closures led to profound isolation. Many individuals died in healthcare and other facilities without the comfort of family, and survivors were often deprived of the ability to hold traditional funerals or grieve with their families and friends. "The pandemic left a void, not just in our families but in our collective memory," said Deborah W. Coogan, Chair of the 'Remembering with Dignity' initiative. "So many died in isolation, and their stories risk being lost in the statistics. 'Remembering with Dignity' provides a way to honor their essence – the values they lived by – and ensures they are remembered as more than just a number. It is a first step toward healing and advocating for a future where we better protect our most vulnerable." The platform seeks to capture the spirit of each individual. Submissions can be made at DignityMA's website. How to Submit a Remembrance: • Visit <u>www.dignityalliancema.org</u> and navigate to the "Pandemic Memorial" page under the "Resources" tab or click on <u>https://tinyurl.com/DignityRemembrance</u> or <u>https://forms.gle/GbzP2H9RG1sWSzA3A</u>. The QR code below can also be used.

	• A remembrance should be no more than 175 words. • Rather than a formal obituary, each submission should describe the person's essence, values, and their story. • Please include the circumstances of their passing (e.g., if they lived or worked in a high-risk setting such as a nursing home, rest home, group home, or hospital, or as a caregiver or essential worker). DignityMA will host a virtual event in the fall of 2025 or early 2026. This gathering will provide a forum for survivors to honor their loved ones and channel their grief into advocacy for policies that better protect vulnerable populations during future public health crises. Details will be announced at a later date.
Ageism Awareness Day on Oct. 9 	The Commonwealth of Massachusetts <i>A Proclamation by Governor Maura Healey and Lt. Governor Maura Healey</i> <i>Whereas, Ageism refers to the stereotypes (how we think), prejudice (how we feel) and discrimination (how we act) toward others based on age; and</i> <i>Whereas, There are an estimated 1.7 million older adults in Massachusetts over the age of sixty who are impacted by ageism; and</i> <i>Whereas, Ageism toward older adults affects their dignity, health and longevity, financial well-being, and the economy of Massachusetts; and</i> <i>Whereas, Preventing ageism in education, employment, housing, culture, and healthcare will benefit all; and</i> <i>Whereas, Recognizing that it is up to all of us to ensure that older adults are respected and portrayed as capable, competent, effective, and valued in all areas of society; and</i> <i>Whereas, Ageism awareness and prevention of ageism is beneficial to all citizens of Massachusetts by improving quality of life within the Commonwealth,</i> <i>Now, Therefore, I, Maura T. Healey, Governor of the Commonwealth of Massachusetts, do hereby proclaim October 9th, 2025, to be,</i> AGEISM AWARENESS DAY

	<i>And urge all the residents of the Commonwealth to take cognizance of this event and participate fittingly in its observance.</i> <i>Given at the Executive Chamber in Boston, this first day of October, in the year two thousand and twenty-five, and of the Independence of the United States of America, the two hundred and forty-ninth.</i> American Society on Aging <u>Get Ready for Ageism Awareness Day</u> Ageism Awareness Day shines a light on how ageism—through stereotypes, prejudice, and discrimination—affects health, well-being, financial security, and our communities. Join ASA in taking action to build a more age-inclusive society. Visit the Ageism Awareness Day website for facts, guides and tools to spread awareness and get involved. This Ageism Awareness Day, spread the word that aging is a rich and varied experience, but one that unites us, and offers an opportunity to build a society that works for all ages.
October Is Resident Rights Month 	The Commonwealth of Massachusetts <i>A Proclamation by Governor Maura Healey and Lt. Governor Maura Healey</i> <i>Whereas, As of January 2025, there were 34,500 residents living in 348 nursing homes, over 17,500 individuals living residences, and approximately 2,000 individuals living in 58 rest homes in the Commonwealth of Massachusetts; and</i> <i>Whereas, The federal Nursing Home Reform Act of 1987 guarantees residents their individual rights to promote and maintain their dignity and autonomy; and</i> <i>Whereas, All residents should be aware of their rights so they may be empowered to live with dignity and self-determination; and</i> <i>Whereas, All We wish to honor and celebrate these residents, to recognize their rich individuality, and reaffirm their right to vote and participate politically, including the right to have a say in their care; and</i> <i>Whereas, This year's theme is "Stand with Me," highlighting the importance of solidarity and support for residents who stand up and support their rights. As well as the values of encouraging the commentary to join long-term care facility residents in sharing their voices;</i>

Now, Therefore, I, Maura T. Healey, Governor of the Commonwealth of Massachusetts, do hereby proclaim October 2025, to be,

RESIDENTS' RIGHTS MONTH

And urge all the residents of the Commonwealth to take cognizance of this event and participate fittingly in its observance.

Given at the Executive Chamber in Boston, this first day of October, in the year two thousand and twenty-five, and of the Independence of the United States of America, the two hundred and forty-ninth.

From the Consumer Voice

[Residents' Rights Month](#)

In recognition of [Residents' Rights Month](#), celebrated next month, we have created new resources and promotional materials:

[Staying Engaged: Enrichment Booklet](#) - The 2025 edition of the Staying Engaged enrichment booklet for long-term care residents has a variety of activities aiming to keep you mentally engaged, prompt self-reflection, and remind you of the importance of advocating for your rights, especially your right to make choices about how to live your life. [Download for free](#) or [order hard copies in our store](#).

[Social Media Toolkit](#) - Use our new toolkit to effectively use social media to spread awareness about Residents' Rights Month. Get social media tips, hashtags, and sample posts and graphics.

[Promotional Templates](#) - Spread the word about residents' rights by contacting your local newspaper or encouraging your governor and mayor to declare October Residents' Rights Month. Find templates on our website

What's going on in your city or state for RRM? [Fill out this form](#) to add your celebration or media coverage to our new interactive map, which will highlight activities and media from across the country.

[50 Resident Reflections](#) - In honor of Consumer Voice's 50th anniversary in 2025, we've created this book, *50 Resident Reflections*, to highlight a series of entries from residents of long-term care facilities from across the country, with residents sharing their insights on quality care and offering advice to family, friends, and caregivers.

[Residents' Rights T-Shirts – Pre-Order](#)

Join Consumer Voice in showing support for Residents' Rights! Too often, those around us don't put much thought into long-term care until it directly affects them. These shirts are a great way to let others know that long-term care residents have rights; Dignity & Respect, Privacy & Confidentiality, Freedom from Abuse & Neglect, the Ability to Voice Concerns, and Freedom from Retaliation are not just suggestions.

	T-shirts are navy blue, 100% cotton. <i>Currently available for pre-order. Shirts are expected to ship by the end of October.</i> https://theconsumervoice.org/product/residents-rights-t-shirts/
Healthy to 100: The Science of Social Connection SUBSCRIBE	Excerpt from the September 29, 2025 issue of the newsletter: <i>The Social Spotlight</i> Informal volunteering is an under-recognized but hugely important component of the American social fabric. Over half of the adults in the US report helping a neighbor, and 10 percent report doing it on a regular basis. It is critical to communities, and it is also an important source of social connection and meaning, both for those who are helping, and those who are being helped. It's an important idea to remember this week, because yesterday was National Good Neighbor Day - a reminder that small acts of kindness can make a big difference. First proclaimed by President Jimmy Carter in 1978, the day celebrates compassion, connection, and unity within our communities. People mark the occasion by sharing food, lending a hand with chores, striking up a friendly conversation, or checking in on someone who lives alone.
Wheelchair Repair Advocacy Day	Wheelchair Repair Advocacy Day Thursday, October 9, 2025, 11:00 a.m. Accessible entrance of the State House at 122 Bowdoin St., Boston Organized by the Disability Policy Consortium Disability advocates and wheelchair users gather at the State House to urge action on legislation addressing delays in wheelchair repairs. Similar bills have been filed in past sessions, with advocates describing long repair wait times as a "crisis of equity" that strips away independence and puts health at risk, but the measures have repeatedly stalled in the Legislature. Supporters are again backing bills (S 210 / H 1278) that would set repair timelines and eliminate certain insurance hurdles. This is priority legislation for Dignity Alliance Massachusetts. RSVP so there is enough time to schedule meetings with legislators: tinyurl.com/4358RSVP
Reports	Income and Assets of Medicare Beneficiaries in 2024 KFF August 25, 2025 By Alex Cottrill, Juliette Cubanski, Tricia Neuman, and Karen Smith Issue Brief Close to 70 million people ages 65 and older and younger people with long-term disabilities receive their health insurance coverage through the federal Medicare program. While overall satisfaction with the program is high, paying for health care services can prove challenging for Medicare beneficiaries. In 2023, more than one-third (36%) of beneficiaries said they had delayed or gone without a visit to the doctor's office, vision services, hearing services, prescription drugs or dental care in the past year because of the cost. Medicare households also spend a larger share of their total budgets on health care than non-Medicare households, and are more likely to

	need expensive long-term services and supports over an extended period of time, which are not covered by Medicare. The cost of health care may become even more burdensome for Medicare beneficiaries in the coming years. A recent KFF analysis found that 7 million Medicare beneficiaries spent more than 10% of their annual income on Part B premiums alone in 2024, a number that may grow over the next decade if Part B premiums grow faster than income. Part B premiums are projected to nearly double between 2024 and 2034, from \$2,100 per year to more than \$4,000 per year. While people with relatively low incomes and limited financial resources can qualify for financial assistance with Medicare premiums and cost sharing through the Medicare Savings Programs, many beneficiaries with modest incomes do not qualify for this assistance, because their income or savings exceed the maximum amount. Other eligible beneficiaries may not receive these benefits because they don't know about them or find the application process too challenging. In addition, provisions in the GOP's recently enacted tax cut and spending law are expected to make it more difficult for eligible low-income Medicare beneficiaries to enroll in these programs, which is estimated to reduce the number of people receiving this coverage by 1.3 million beneficiaries. To understand the financial resources available to people with Medicare that can be used to cover their health care costs, this brief examines the income, assets, and home equity of Medicare beneficiaries, overall and by age, race and ethnicity, and gender, using data derived from the Dynamic Simulation of Income Model (DYNASIM) for 2024. Due to data limitations, estimates for beneficiaries in some racial and ethnic groups, including Asian, American Indian and Alaska Native, and Native Hawaiian or Other Pacific Islander beneficiaries, as well as beneficiaries who identify as two or more races, are unavailable (see Methods for additional details on the model). This analysis highlights that a large share of Medicare beneficiaries live on relatively low incomes and have modest financial resources to draw upon if they need to cover costly medical care or long-term services and supports, with notable differences by age, race and ethnicity, and gender. For example: • One in four Medicare beneficiaries – 16.5 million people with Medicare – lived on incomes below \$24,600 per person in 2024. Half (32.9 million) of all Medicare beneficiaries lived on incomes below \$43,200 per person. At the upper end of the income spectrum, the top 5% (3.3 million) of Medicare beneficiaries lived on incomes above \$169,700 per person. • One in four Medicare beneficiaries had savings below \$18,950 per person in 2024, while half had savings below \$110,100 per person. At the higher end of the savings distribution, the top 5% of Medicare beneficiaries had savings above \$1.7 million per person. • One in four Medicare beneficiaries had no home equity at all in 2024, while half of all Medicare beneficiaries had home equity below
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	\$128,200 per person. The top 5% of Medicare beneficiaries had home equity above \$886,800 per person. • Per person estimates of income and savings varied by characteristic and were generally lower for beneficiaries ages 85 and older than for beneficiaries ages 65 to 84, lower for women than men, and lower for Black and Hispanic beneficiaries than White beneficiaries. Income and savings were also lower for beneficiaries under 65 with long-term disabilities than those ages 65 and older. • Nearly half of all Black and Hispanic beneficiaries had no home equity, and roughly one in five Black and Hispanic beneficiaries had no savings or were in debt, compared to one in five White beneficiaries with no home equity, and fewer than one in ten White beneficiaries with no savings or in debt.
Recruitment	See: Listings on MASterList.com's Job Board for all current listings
Guide to news items in this week's <i>Dignity Digest</i>	Nursing Homes Managed care states reduce nursing home stays, but not among low-need residents (McKnights Long-Term Care News, October 5, 2025) CMS Expands Nursing Homes' Ability to Tap Civil Monetary Penalty Funds for Projects (Skilled Nursing News, September 29, 2025) Housing NLIHC President and CEO Statement on the Partial Shutdown of the Federal Government and the Impact on Housing Programs (National Low Income Housing Coalition, October 1, 2025) Massachusetts accessory dwelling units rise, easing housing shortage (WWLP.com, September 26, 2025) Behavioral Health State mental health commissioner stepping down (*State House News, October 3, 2025) Disability Topics Trump plan seeks to overhaul disability benefits (*Boston Globe, October 6, 2025) Autism Has Always Existed. We Haven't Always Called It Autism. (*New York Times, September 24, 2025) 'Autism Doesn't Need a Cure': Trump's Message Rankles People Living With the Disability (*New York Times, September 23, 2025) The Clue to Unlocking Parkinson's May Be All Around Us (*New York Times, September 14, 2025) Guardianship The Hospital to Guardianship Pipeline (American Bar Association, July 23, 2025) Private Equity Corporatization of healthcare gets too much of a bad rap, analyst says (The Harvard Gazette, October 2, 2025) Medicare Millions of Poor Retirees Have Lost an Easier Path to Help With Medicare (*New York Times, October 4, 2025) Medicaid

	<u>States are cutting Medicaid provider payments long before Trump cuts hit</u> (VPM NPR, October 5, 2025) Federal Policy <u>A Freeze on Medicaid Payments Is Forcing Cuts to Rural Health Care</u> (*New York Times, October 4, 2025) <u>Trump's Medicaid Cuts Could Hamper Efforts to House the Homeless</u> (*New York Times, September 17, 2025) <u>Trump's Policies Are Endangering Your Health</u> (*New York Times, September 12, 2025) State House News <u>Still a doctor on Mondays, now a secretary every day: Kiame Mahaniah's balancing act</u> (*State House News, October 6, 2025) <u>Sen. Edward Kennedy of Lowell Dies, at 74</u> (*State House News, October 2, 2025) From Around the Country <u>In Some States, Strapped Counties Must Impose Trump's Medicaid Cuts</u> (*New York Times, September 30, 2025) Public Sessions Massachusetts Public Health Council (Wednesday, October 8, 2025, 9:00 a.m., <u>Monthly public meeting</u>) Massachusetts Coalition for the Homeless, (Wednesday, October 8, 2025, 10:00 a.m., State House, Room 222)
DignityMA Study Sessions <i>Special Focus on Changes in Federal Policies, Programs, and Services</i>	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. 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. 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. The presenters are: • 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

	Recordings of Jim Roosevelt's and Steve Schwartz's presentations are available at https://dignityalliancema.org/videos/. Bob Blancato's presentation is being rescheduled.
DignityMA Study Session  Bob Blancato, National Coordinator, Elder Justice Coalition	<i>Aging Policy Update: What We Know, What We Don't Know, and What We Should Fear</i> Wednesday, May 21, 2025, 2:00 p.m. Unfortunately, this session is being rescheduled. Date to be announced. Presenter: Bob Blancato, National Coordinator of the bipartisan 3000-member Elder Justice Coalition Registration required: https://us02web.zoom.us/meeting/register/kQRVG7FiR2iVrmQWN52M6g 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. 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.
Community hearing and Resource Fair	Permanent Commission on the Status of Persons with Disabilities <u><i>Meeting the Moment, A Community Hearing and Resource Fair</i></u> Tuesday, November 4, 2025, 5:00 to 7:00 p.m. Needham Town Hall 1471 Highland Ave. Needham This is the first in a series of community hearings to listen and learn from individuals with disabilities, families, caregivers, service providers, and advocates, and to connect with local organizations, state agencies, and disability commissions at a resource fair. The evening will include: • An introduction to the work of the Commission • An opportunity for community members to share their experiences, needs, and priorities • A resource fair with community organizations, state agencies, and local disability commissions Community members are welcome to submit written testimony in advance. Testimony during the event will be limited to 2 minutes each, and if time allows, there will also be space for day-of sharing. Testimony can be submitted during registration here or via email at cspwdinfo@mass.gov. ASL and CART services have been requested. Register

In Person Events	1. The Petrie-Flom Center Wednesday, October 8, 2025, 12:20 to 1:20 p.m. RSVP for location <u>How Old is Too Old to Govern?</u> Is the advanced age of many leaders cause for concern? Should we have maximum age limits for lawmakers and judges? What can neuroscience research tell us about the aging process and efforts to increase the “health span,” particularly for cognitive functions? Francis X. Shen, a pioneer in the interdisciplinary field of law and neuroscience, will lead a discussion of the legal and ethical implications of aging. Panelists • Moderator: <u>Francis X. Shen</u>, JD, PhD, Professor of Law, University of Minnesota; Member, Harvard Medical School Center for Bioethics; Founding Director, Dana Foundation Career Network in Neuroscience & Society; Former Petrie-Flom Senior Fellow, Project on Law and Applied Neuroscience • Honorable <u>Nancy Gertner</u>, JD, Senior Lecturer on Law, Harvard Law School; Retired Federal Judge; Author; and Managing Director, Center for Law, Brain and Behavior, Mass General Hospital • <u>Benjamin C. Silverman</u>, MD, Assistant Professor of Psychiatry and Faculty member, Center for Bioethics, Harvard Medical School; Director of Ethics, McLean Institute for Technology in Psychiatry, McLean Hospital
Webinars and Online Sessions	2. City of Boston <u>National Disability Employment Awareness Month 2025 Webinar Series</u> This webinar series is intended to help break down barriers for people with disabilities seeking employment, financial security, and economic mobility, including employment with the City of Boston. You are invited to attend one or all the webinars. We welcome you to join us on Wednesdays in October on Zoom for the following webinars. Wednesday Webinars • <i>Employees - Know Your Rights (90 minutes) October 8th, 6pm - 7:30pm</i> Workers in the City of Boston face many injustices: wage theft, discrimination, unsafe or unhealthy working conditions and more. Regardless of immigration status, workers have legal protections about which many are unaware. When workers know their rights, they are able to exercise those rights. In partnership with the City's Office of Labor Policy and Worker Protections, this webinar will give an overview of these legal protections with a focus on the rights of workers with disabilities. • <i>Financial Empowerment & Economic Mobility (60 minutes), October 15th, 6-7pm</i> This webinar is an opportunity for people with disabilities to learn about free financial wellness resources that the City of Boston has available for you and your family. Including help building credit, finding free

	banking options, and free tax preparation, come learn how we can help you on your financial journey. • <i>Finding Affordable, Available, Accessible Housing (60 minutes)</i> <i>October 29th, 6 - 7pm</i> Finding housing can be incredibly difficult. This webinar will include information on accessible housing - what features are included in "accessible" or "ADA" housing units including mobility or sensory units. It will also include information about how to search for accessible and affordable housing and how housing "lotteries" work. Registration 3. National Health Law Thursday, October 9, 2025, 4:00 p.m. Access to Care: Cost Sharing, Premiums, and Retroactive Eligibility This webinar will discuss changes introduced by OBBA to the Medicaid Act's cost-sharing, premiums, and retroactive eligibility provisions and their potential impact on access to health care services. What We Know and What Happens Next: OBBBA and its Impact on Health Care Coverage is a new webinar series from the National Health Law Program launching this summer and continuing through the fall. It helps advocates prepare for the harmful provisions in the so-called "One Big Beautiful Bill" Act by offering legal and policy analysis on key topics, including work requirements, due process, automation, and barriers to care like cost-sharing and attacks on sexual and reproductive health. Each webinar offers tools and strategies to support advocates in protecting coverage and advancing health equity. Register Now 4. Health Begins Tuesday, October 21, 2025, 3:00 p.m. Hospital-Driven Models for High-Impact Food Is Medicine Fewer and fewer U.S. households can afford or access the food they need to be healthy. One emerging tool, Food Is Medicine (FIM), has broad bipartisan backing and strong potential to help address this problem. To fully realize its impact, however, it needs sustainable, scalable support. In this webinar, we highlight hospitals that are stepping into this gap and leveraging their influence and resources to support FIM implementation in their communities. These include public, private, and community-based hospitals forging deep community partnerships to accelerate some of the best emerging innovations in Food Is Medicine. Hear hospital leaders explain innovative program design and financing models to effectively improve health by providing essential nutrition. Strategies include community food hubs, grocer partnerships, novel ways to deploy hospital cafeteria food services, and intentional use of community reinvestment and total-cost-of-care funding to move care upstream. Speakers: Kathryn Jantz, MSW, MPH, Consulting Director, Health Begins (host) Lauren Espy, MPH, Director of Equity and Community Programs, MLK Community Healthcare Maxfield Kaniger, CEO, Kanbe's Markets
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[REGISTER HERE](#)

5. National Information & Referral Support Center

Thursday, October 23, 2025, 3:00 to 4:00 p.m.

[*Supporting Kinship/Grandfamilies: What Information & Referral Professionals Need to Know*](#)

Nationwide, grandparents, other relatives, and close family friends are raising over 2.5 million children whose parents are unable to do so for various reasons, including death, military deployment, and substance use. While research shows that both kin caregivers and the children they raise benefit from being part of kinship/grandfamilies, studies also indicate that these families are disproportionately impacted by financial instability, disability, and trauma. The well-being of each family member improves when they receive appropriate services. Information and Referral (I&R) professionals often are the first point of contact for kin caregivers seeking assistance, but many professionals are not familiar with who kinship/grandfamilies are, their strengths and challenges, and the services available to help. This webinar will orient I&R professionals to the strengths and challenges of these families, and to resources and tools they can use to assist kin caregivers they may encounter.

[Click here](#) to register.

6. Joint Center for Housing Studies at Harvard University

Friday, October 24, 2025, 12:00 p.m.

[*Unlocking the Missing Middle: Legal Reforms and Other Solutions to Expand Housing Options in Massachusetts*](#)

Missing middle housing (buildings larger than single-family homes and smaller than mid-rise apartment buildings) is increasingly viewed by policymakers, advocates, architects, planners, and developers as one possible solution to the affordable housing crisis. However, zoning regulations, development review processes, complicated financing structures, and other obstacles have made it difficult, if not impossible, to build missing middle housing not only Massachusetts but around the country. Amy Love Tomasso, a graduate research assistant at the Center, will discuss her series of working papers, which examine the current landscape for middle housing in Massachusetts, policy approaches drawn from around the country, and strategies beyond policy that could help expand the supply of missing middle housing.

[Register to attend](#)

7. National Council for Mental Well Being

Friday, October 24, 2025, 1:00 to 2:00 p.m.

[*Beyond Patient Portals: The Future of Consumer Collaboration in Behavioral Health*](#)

Traditional patient portals often leave individuals as passive viewers of their health data, falling short of true engagement and collaboration. Explore the next evolution: comprehensive consumer engagement hubs. These hubs bring together multiple engagement tools into one coordinated, connected experience — empowering individuals to actively participate in their mental health and substance use recovery journey. Webinar participants will: • Learn how emerging digital tools can strengthen engagement and empower individuals in their mental

	health and substance use recovery journey. • Gain insight into how these emerging hubs can improve client outcomes. • Redefine the role of behavioral health staff in supporting consumer access and engagement. Speakers: • Jorge Petit, MD, Chief Clinical Advisor, Cantata Health Solutions • Jeremy Attermann, Senior Director, Partnerships and New Business Ventures, National Council for Mental Wellbeing Register Today!
Previously posted webinars and online sessions	Previously posted webinars and online sessions can be viewed at: https://dignityalliancema.org/webinars-and-online-sessions/
Nursing Homes	8. McKnights Long-Term Care News October 5, 2025 Managed care states reduce nursing home stays, but not among low-need residents By Kimberly Marselas A new study published in the <i>Journal of the American Geriatrics Society</i> reveals that while managed care has reduced the number of long-stay nursing home residents, it has not successfully transitioned low-need residents to less restrictive care settings. Researchers point to "perverse incentives" within the payment structures as a potential cause. Key Findings • Overall Reduction: States using managed care for Medicaid long-term services and supports (LTSS) saw a 5.8% decrease in their long-stay nursing home populations between the program's start and 2021. • Low-Need Residents Unaffected: There was no corresponding decline in the proportion of nursing home residents with low care needs. These individuals, who don't require assistance with activities like bed mobility, toileting, or eating, are considered prime candidates for home or community-based care. Potential "Perverse Incentives" The study, which analyzed nearly one million residents across 24 states, suggests that the payment models used by managed care organizations (MCOs) may inadvertently encourage keeping low-need residents in more expensive institutional settings. • Blended Payment Rates: When MCOs receive a single "blended" payment rate regardless of where a beneficiary lives, they may be disincentivized from moving residents to less expensive home care. A higher share of residents in cheaper home care would lead to a lower blended payment rate for the MCO in the following year. Therefore, keeping low-

*need individuals in nursing homes can help MCOs **maintain higher payment rates.***

- **Carving Out Services:** Conversely, if payments for institutional care are "carved out," MCOs are no longer financially responsible for residents in nursing homes. This creates an incentive to move high-need, expensive beneficiaries **out of home care and into institutional settings.**

The study's authors conclude that these findings raise questions about the overall value of managed care programs in providing less expensive care options for LTSS beneficiaries.

9. Skilled Nursing News

September 29, 2025

[CMS Expands Nursing Homes' Ability to Tap Civil Monetary Penalty Funds for Projects](#)

By Tim Mullaney

CMS Updates Civil Monetary Penalty Reinvestment Program

The Centers for Medicare & Medicaid Services (CMS) has announced several updates to the Civil Monetary Penalty Reinvestment Program (CMPRP), affecting how nursing homes can apply for and use these funds.

New Funding Opportunities

- **Workforce Enhancement:** Applications are now being accepted for projects aimed at improving staff training, implementing culture change, and providing professional development for frontline nursing home staff, including RNs, CNAs, and LPNs. These projects are intended to complement the Nursing Home Staffing Campaign.
- **Mental and Behavioral Health:** Following a pause, CMS is again accepting applications for mental and behavioral health projects. This move encourages the development of innovative projects to enhance the quality of behavioral health services for residents.

Application Process Changes

- **Standardized Application Form:** A new, standardized application form has been created for all CMP projects. Use of this form will become mandatory 45 days after the release of the memo, but it is available for immediate use.
- **Elimination of Application Categories:** The "extension" and "continuation" categories for applications have been eliminated. All applicants will now use the same form and must include results from any previous projects when seeking to expand them.
- **Submission Process:** Applicants must submit their completed forms to the relevant state agency for an initial review.

Increased Funding Caps

- **Per-Project Increase:** The funding cap for projects related to resident or family councils, consumer information, quality of care training, and quality of life activities has been increased from \$5,000 to \$6,000 per project.

	• Maximum Funding Per Facility: Nursing homes can now receive funding for up to three separate, three-year training programs, raising the maximum possible CMP funding per facility to \$18,000. Other Updates The CMS memo also outlines changes to: • Allowable technology parameters • Project reporting requirements • The CMPRP website
Housing	10. National Low Income Housing Coalition October 1, 2025 <i>NLIHC President and CEO Statement on the Partial Shutdown of the Federal Government and the Impact on Housing Programs</i> By Renee M. Willis, President and CEO, National Low Income Housing Coalition Here is a summary of the provided text. Federal Shutdown's Impact on Housing Programs • Government Shutdown: The federal government has entered a partial shutdown after failing to agree on a short-term funding bill. • Immediate Rent Assistance: Rent payments for households assisted by the U.S. Department of Housing and Urban Development (HUD) and the U.S. Department of Agriculture (USDA) will continue on time through November. • Agency Staffing Concerns: The shutdown adds to an already strained housing system. An Office of Management and Budget memo has instructed federal agencies to furlough non-essential staff and consider permanent layoffs. ◦ HUD has already lost an estimated 2,300 employees (23% of its workforce) since January, straining its ability to perform core functions. • Administration's Policy Actions: The text frames the shutdown as part of a broader trend by the Trump administration to weaken anti-poverty initiatives. Other actions mentioned include: ◦ Proposing significant budget cuts to rental and homelessness assistance. ◦ Weakening Fair Housing Act protections. ◦ Limiting housing access for immigrants and LGBTQ+ individuals. ◦ Withholding congressionally approved funding. • Prospects for Resolution: Distrust in the White House's willingness to abide by a negotiated agreement is complicating efforts to end the shutdown. 11. WWLP.com September 26, 2025 <i>Massachusetts accessory dwelling units rise, easing housing shortage</i>

	By Ashley Shook Following the enactment of Governor Maura Healey's Affordable Homes Act, Massachusetts has seen a significant increase in applications for Accessory Dwelling Units (ADUs). Key Statistics & Impact • High Approval Rate: In the first half of 2025, over 550 ADU applications were approved out of 844 submitted across 170 communities. • Affordable Housing Solution: The act promotes ADUs, also known as in-law apartments, to increase affordable housing options. • Economic Benefits: ADUs provide homeowners with an additional source of income and offer more independent living options for seniors and individuals with disabilities. Legislative Changes • Streamlined Process: The Affordable Homes Act allows for the by-right construction of ADUs under 900 square feet on single-family properties, removing previous complex local zoning restrictions. • Statewide Standard: This creates a consistent standard across the state, with the exception of Boston, which has its own ordinance.
Behavioral Health	12. *State House News October 3, 2025 State mental health commissioner stepping down By Alison Kuznitz MA Mental Health Commissioner Resigns Amid Controversy Leadership Change • Brooke Doyle, Commissioner of the Massachusetts Department of Mental Health (DMH) since 2020, is stepping down, effective October 6. • DMH Deputy Commissioner Beth Lucas will take over as acting commissioner. Conflict Over Proposed Cuts • Doyle's resignation follows a contentious budget cycle where the Healey administration proposed eliminating half of the agency's case manager positions (170 jobs). • The plan was intended to cut costs and prioritize inpatient psychiatric care. • SEIU Local 509, the union representing case managers, strongly opposed the cuts, arguing that thousands of clients would lose essential services. • In April, the union took a vote of "no confidence" in Doyle, calling for her removal due to "mismanagement of services" and a "lack of transparency." • The administration ultimately reached a deal with the union in July to avert the layoffs.

	Doyle's Tenure - Doyle highlighted accomplishments during her tenure, including launching the state's Behavioral Health Help Line, expanding community-based services, and reducing wait times for certain residential programs. - Her departure is the latest high-profile change in the Healey administration, following the exits of the Health and Human Services Secretary and the Public Safety and Security Secretary.
Disability Topics	13. *Boston Globe October 6, 2025 <u>Trump plan seeks to overhaul disability benefits</u> By Meryl Kornfield and Lisa Rein Direct Impacts on Applicants Harder to qualify, especially for older workers (ages 50-60) Currently, people over 50 have an easier time qualifying because age is recognized as limiting their ability to adapt to new work - The proposed changes would either eliminate age as a factor entirely or raise the threshold to 60 - This fundamentally changes who can access benefits they've paid into through payroll taxes Potential financial hardship - If denied disability benefits, older workers would likely take early retirement at 62 instead - This results in 30% less in monthly benefits for the rest of their lives - Research shows most older Americans denied disability benefits don't find another job Scale of impact - An estimated 750,000 fewer people could receive benefits over the next decade (assuming 10% reduction in eligibility) - An additional 80,000 widows and children would lose benefits due to a spouse or parent's ineligibility The Rights Issues There are significant rights concerns: Earned benefits question: People have paid into Social Security disability insurance through mandatory payroll taxes their entire working lives. The system operates on a social insurance model - you contribute when you're working to protect yourself if you become disabled. Changing eligibility criteria after people have paid in raises questions about the government's obligation to honor that social contract. Age discrimination concerns: Eliminating or reducing age considerations could be viewed as age discrimination. The current system acknowledges the real-world difficulty older workers face in retraining or finding new employment - removing this consideration ignores labor market realities. Due process and procedural fairness: While the article notes there will be a public comment period, the substance of making it harder to access benefits you've contributed to raises fairness questions,

	particularly for those who planned their financial futures around existing eligibility criteria. Equity issues: The article notes this disability program is already "far more difficult to qualify for" than veterans' disability benefits. Making it even harder creates questions about equal treatment of disabled Americans. Senator Wyden frames this as people being denied access to "their earned Social Security benefits" - emphasizing that this isn't welfare, but insurance people paid for. The fundamental rights question is: Can the government significantly restrict access to a social insurance program that workers have been required to fund throughout their careers? While the government has broad authority to change program rules, doing so in ways that deny benefits to people who contributed based on different expectations raises legitimate concerns about fairness and the social contract. 14. *New York Times September 24, 2025 <u>Autism Has Always Existed. We Haven't Always Called It Autism.</u> By Roy Richard Grinker An article by cultural anthropologist Roy Richard Grinker argues that the recent political discourse framing autism as a preventable "epidemic" is a dangerous oversimplification that ignores the condition's complex history and scientific reality. The Evolving Definition of Autism • Historical Context: The understanding and diagnosis of autism have changed dramatically over time. What was once considered a rare and devastating diagnosis is now understood as a broad spectrum. • From Rare Disorder to a Spectrum: The author uses the example of his daughter, diagnosed in 1994 with P.D.D.-N.O.S. (a now-obsolete term), to show how clinicians were once hesitant to use the word "autism." Today, the diagnosis of "autism spectrum disorder" is far more common and encompasses a wide range of experiences and support needs. • Not One "Autism": Researchers now believe in the concept of "autisms" rather than a single, uniform disorder. With over 100 associated genes interacting with environmental factors, there are likely many different genetic causes. Debunking Harmful Myths • The Vaccine Myth: The article refutes the claim that vaccines cause autism, citing the retraction of Andrew Wakefield's fraudulent 1998 study and subsequent research covering millions of children that shows no link. • The "Refrigerator Mother" Theory: It revisits the discredited and harmful theory from the mid-20th century, promoted by Bruno Bettelheim, which wrongly blamed cold and distant mothers for their children's autism.
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- **Critique of Political Rhetoric:** The author directly criticizes statements by the Trump administration and Robert F. Kennedy Jr. for promoting a narrative of a preventable "crisis," arguing this approach is scientifically unfounded and reinforces stigma.
- The Expansion of Diagnostic Criteria**
- **Changing Manuals:** The diagnostic criteria in the American Psychiatric Association's diagnostic manual (DSM) have broadened significantly since "infantile autism" was first introduced in 1980.
 - **Reclassification:** The increase in autism prevalence is not just due to a rise in cases, but also to greater awareness and reclassification. A 2000-2010 study found that 64% of the increase in autism classifications in special education was accounted for by a decrease in "intellectual disability" classifications.
 - **Racial and Social Factors:** Historically, Black children have been more likely to be misdiagnosed with "conduct disorder." Recent data suggests this gap is narrowing, indicating better identification in underserved communities.
- The Path Forward**
- **Focus on Lifespan Research:** The author calls for a shift in research away from a simplistic search for a single cause and toward understanding the genetics of autism, co-occurring conditions (like A.D.H.D. and anxiety), and how to best support autistic individuals throughout their entire lives.
 - **Support Over Blame:** The ultimate goal should be to provide the social supports and opportunities necessary for autistic people to build meaningful lives, not to find something or someone to blame. The voices and experiences of autistic self-advocates are crucial in shaping policies and narratives.

15. *New York Times

September 23, 2025

['Autism Doesn't Need a Cure': Trump's Message Rankles People Living With the Disability](#)

By Sonia A. Rao

A recent New York Times article details the conflict arising from the Trump administration's messaging on autism, specifically its unproven claims linking the condition to Tylenol use during pregnancy.

Administration's Unproven Claims

- **President Trump** and his health secretary, **Robert F. Kennedy Jr.**, have publicly suggested a link between acetaminophen (the active ingredient in Tylenol) and neurodevelopmental disorders, urging pregnant women to avoid the painkiller.
- The administration has labeled autism a "horrible, horrible crisis" and pledged **\$50 million** to study its causes, also pointing to a disproven connection with childhood vaccines.

Scientific and Medical Community Response

- Medical groups and mainstream scientists **overwhelmingly disagree** with the administration, stating that no causal link has been found between acetaminophen and autism despite decades of study.

- Experts defend acetaminophen as a **safe and important treatment** for fever and pain during pregnancy, noting that untreated fever can be dangerous.
- The **Food and Drug Administration (FDA)** has stated that a "causal relationship has not been established" and the matter is an "ongoing area of scientific debate."

Reaction from the Autism Community

- **Mistrust and Concern:** Many autistic individuals and their families expressed deep mistrust of the administration's motives and fear that its rhetoric will increase stigma. They worry about the focus on finding a "cure" or something to blame, rather than providing support.
- **Focus on Needs, Not Cures:** Advocates like Jordyn Zimmerman and Lizzy Graham argue that the administration should focus on providing necessary resources, such as communication technology and other support systems for people with disabilities, stating, "Autism doesn't need a cure."
- **Parental Guilt:** The claims have caused anxiety and concern among parents, who worry about being blamed for their child's diagnosis.
- **Mixed Views on Research:** While some welcome more funding for research, they are dismayed by the administration's depiction of autism. Disability advocate Russell Lehmann expressed he would appreciate treatment for some behaviors but found the officials' language "very disheartening."

16. *New York Times

September 14, 2025

[*The Clue to Unlocking Parkinson's May Be All Around Us*](#)

By Nicholas Kristof

Parkinson's Disease and Environmental Toxins

This article from The New York Times explores the growing evidence linking Parkinson's disease to environmental toxins, particularly pesticides and industrial chemicals. The author, Nicholas Kristof, argues that the rise in Parkinson's cases may be a "man-made disease" and criticizes the regulatory environment in the United States for failing to protect public health.

Key Points

- **Rising Parkinson's Cases:** Parkinson's is the world's fastest-growing neurodegenerative disease, with 90,000 new cases diagnosed in the U.S. each year.
- **Paraquat and other Chemicals:** The herbicide paraquat, along with chemicals like trichloroethylene (TCE) and perchloroethylene (PCE) used in dry cleaning, are strongly linked to an increased risk of developing Parkinson's.
- **Personal Stories:** The article highlights the stories of individuals like Steve Phillips, who was exposed to paraquat as a teenager, and former NBA player Brian Grant, who was exposed to contaminated water at Camp Lejeune, both of whom later developed Parkinson's.

	• Industry Influence: Companies like Syngenta, a major manufacturer of paraquat, have a history of downplaying the health risks of their products, similar to the tobacco industry's tactics. Despite internal concerns, they have publicly defended their products and worked to discredit opposing scientific research. Regulatory Failures • U.S. vs. Europe: The United States has a more lenient regulatory approach compared to Europe. The U.S. tends to allow substances until there is conclusive proof of harm, while Europe often bans substances based on potential risks. • Lax Regulations: Dozens of countries have banned paraquat, yet it is still widely used in the U.S. In fact, much of the paraquat used in America is manufactured in countries where its use is illegal. • Lobbying Power: The chemical industry spends millions of dollars on lobbying, which influences regulatory decisions and prioritizes corporate profits over public safety. Conclusion The author concludes by emphasizing the need for a more cautious approach to chemical regulation. While absolute proof of causation is difficult to establish, the accumulating evidence suggests a strong link between environmental toxins and Parkinson's. The article advocates for taking proactive measures to protect public health rather than waiting for definitive proof of harm.
Guardianship	17. American Bar Association July 23, 2025 The Hospital to Guardianship Pipeline By Anita Raymond, LISW, CMC Summary: The "Hospital to Guardianship Pipeline" Problem This refers to the problematic trend of hospitals seeking court-appointed guardians for patients, particularly elderly ones, who are ready for discharge but cannot return home and are being refused by long-term care facilities without a legal guardian. This practice often occurs when a patient is deemed to lack decision-making capacity and is refusing the recommended discharge plan. The result is a loss of the patient's rights, placing them in a legal limbo, often stuck in a hospital or in a long-term care setting against their will. Why Hospitals Seek Guardianship Hospitals often turn to guardianship as a seemingly straightforward solution for complex discharge situations. Key reasons include: • Patient Refusal: The patient will not consent to the proposed discharge plan. • Lack of Placements: Suitable long-term care facilities are unavailable due to staffing shortages or the inability to manage the patient's complex needs. • Perceived Efficiency: Guardianship is mistakenly seen as a faster and simpler way to handle a discharge, especially when time is critical.

	• Facility Requirements: Nursing homes or other care providers demand that a patient have a legal guardian before admission, often due to concerns about payment and liability. Issues with Over-Relying on Guardianship Seeking guardianship is often a premature step with significant legal and ethical consequences. • Last Resort Requirement: Most state laws mandate that guardianship should only be granted after all less restrictive alternatives have been thoroughly attempted and failed. • Ineffectiveness: A guardian can provide consent but cannot force a patient to comply. If the core issue is a lack of resources (like adequate home care staffing), guardianship solves nothing. • Violation of Rights: Requiring a guardian as a condition for admission can be discriminatory and may violate federal laws protecting a resident's right to self-determination. It inappropriately removes a person's civil rights for a problem that might not even occur. Alternatives to Guardianship There are numerous less restrictive options that should be explored before pursuing the removal of a person's rights. • Supported Decision-Making: Involving family, friends, or professionals to help a person with cognitive impairments understand their situation and make their own choices. This requires patience and individualized communication strategies. • Existing Legal Documents: The patient may have already appointed a decision-maker through a Power of Attorney for financial matters or a Health Care Directive for medical decisions. These documents provide a legal and immediate alternative. • Informal Surrogates: Family members may be willing to assist with decisions without the formal, intimidating process of becoming a legal guardian. Many states have laws that allow physicians to turn to a defined list of default surrogates. • Improved Communication: Direct conversations between hospital discharge planners and nursing home staff can often clarify a patient's situation and needs more effectively than faxed referrals, preventing misunderstandings that lead to refusals
Private Equity	18. The Havard Gazette October 2, 2025 <u>Corporatization of healthcare gets too much of a bad rap, analyst says</u> By Christina Pazzanese <i>For-profits, private equity can boost innovation, growth, care, according to co-author of new paper. But gains need to be aligned with patient outcomes.</i> Corporatization in Healthcare • Definition: Corporatization is a deal where a medical organization receives capital from investors in exchange for a share of the profits. This funding can be used for new technologies, upgraded facilities, research, or competitive salaries. The core idea is to "unlock" money for growth, but it prioritizes profits to satisfy investors.

	The Role and Impact of Private Investment • Benefits: ○ Private investment fills a critical funding need that governments and nonprofits cannot meet, especially in capital-intensive areas. ○ In sectors like in vitro fertilization (IVF), corporate networks use scale and technology to improve success rates, leading to competition based on outcomes and price. ○ In the biopharmaceutical industry, private capital is essential for funding the high costs of drug development, enabling the creation of new treatments. The industry invests around \$275 billion globally in R&D annually, compared to the NIH's budget of about \$35 billion. • Drawbacks: ○ The push for profit can sometimes lead to reduced quality and choice for patients. ○ In areas with poor quality measurement, like nursing homes, private equity owners may cut staffing to boost profits, which has been linked to higher patient mortality. Aligning Profit with Patient Value • The central challenge is not the existence of profit itself, but how well profit incentives are aligned with patient well-being. • Successful Alignment: Alignment works well in sectors where quality is observable and regulated. ○ IVF clinics compete on measurable success rates (pregnancy). ○ Pharmaceuticals are regulated by the FDA, which ensures drugs are safe and effective, helping to align corporate goals with patient outcomes. • Misaligned Incentives: In sectors like nursing homes, where quality of care is difficult to assess and regulation is weak, the profit motive can lead to harm. Proposed Solutions • The most critical step is to strengthen regulation. • Regulators at agencies like the Centers for Medicare and Medicaid Services (CMS), the Federal Trade Commission (FTC), and the Department of Justice (DOJ) need to be well-resourced, independent, and insulated from political interference. • Better quality measurement, enforcement of antitrust rules, and the authority to stop deals that do not benefit society can help ensure that corporate investment improves access and quality without harming patients.
Medicare	19. *New York Times October 4, 2025 Millions of Poor Retirees Have Lost an Easier Path to Help With Medicare By Mark Miller

	<i>The budget bill signed by President Trump suspended an effort to enroll more low-income older Americans in programs that assist them with rising health care costs.</i> A recent federal budget law has suspended a program designed to simplify access to Medicare assistance for low-income retirees, exacerbating financial hardships for a growing number of older Americans. The Core Issue: Blocked Access to Medicare Help • The budget bill, signed by President Trump, has halted a Biden-era initiative until 2034. This initiative was intended to make it easier for low-income seniors to enroll in Medicare Savings Programs (M.S.P.s). • These state-run programs help cover out-of-pocket Medicare costs, such as premiums and deductibles, and automatically enroll individuals in the federal Low-Income Subsidy (L.I.S.) for prescription drugs. • The suspended plan would have streamlined enrollment by reducing paperwork, a change opposed by some Republicans citing desires to cut waste and fraud in programs like Medicaid. Financial Impact on Low-Income Seniors • An estimated 5.8 million eligible seniors are currently not enrolled in these crucial cost-saving programs, often due to a lack of awareness and complex application processes. • This comes as Medicare costs are rising. The Part B premium is projected to increase by 11.6% next year, consuming most of the Social Security cost-of-living adjustment for many. • The poverty rate for Americans 65 and older increased to 15% in 2024. Healthcare expenses are a primary driver of this trend. • Enrolling in both the M.S.P. and L.I.S. can save an individual up to \$8,400 annually. Barriers to and How to Apply for Assistance • Enrolling can be difficult due to applications that are sometimes up to 30 pages long and require extensive documentation. • Despite the federal setback, individuals can still apply for these programs at any time: ○ Medicare Savings Programs (M.S.P.s): Contact your local State Health Insurance Assistance Program (SHIP) for screening and enrollment help by calling the national line at 877-839-2675. ○ Extra Help (L.I.S.): Apply for this federal prescription drug assistance program online at the Social Security Administration website or by calling 800-772-1213.
Medicaid	20. VPM NPR October 5, 2025 <u>States are cutting Medicaid provider payments long before Trump cuts hit</u> By Bram Sable-Smith and Sarah Jane Tribble States Slashing Medicaid Payments, Impacting Patients and Providers

	States are cutting payments to Medicaid providers to address budget shortfalls, a move that is creating significant challenges for patients and healthcare providers even before potential federal funding cuts take effect. • Nationwide Trend: States like North Carolina and Idaho have already implemented cuts, while others, including Michigan, Pennsylvania, and Washington, are in the process of debating or have approved similar reductions. These cuts are largely a response to state budget deficits. North Carolina's Reductions North Carolina's Medicaid agency has implemented significant pay cuts for healthcare providers, leading to immediate consequences for patient care. • Specific Cuts: The state has instituted a minimum 3% pay reduction for all Medicaid providers, with primary care doctors facing an 8% cut and specialty doctors a 10% reduction. • Impact on Patients: These cuts are making it harder for patients with complex medical needs, such as Ysadore Maklakoff, to access necessary care. His mother, Alessandra Fabrello, has already seen his dentist stop accepting Medicaid patients and struggles to find adequate nursing and therapy services. • Provider Response: A former North Carolina Medicaid official warns that reduced payments will lead to fewer providers in the Medicaid network, resulting in "an immediate loss of access to care, worse outcomes, and cause higher downstream costs." Idaho's Healthcare System at Risk In Idaho, a 4% across-the-board cut to Medicaid pay rates is threatening the viability of nursing homes and small, rural hospitals. • Financial Strain: The Idaho Hospital Association has expressed concern that small hospitals, some with less than two days of cash on hand, may be forced to close essential services like labor and delivery or behavioral health units. • Nursing Home Concerns: Leaders of a nursing home company have stated that the cuts will force them to either reduce staff or accept fewer residents. The Broader Financial Picture Medicaid constitutes a significant portion of state budgets, making it a target for cuts during times of financial strain. • State Budgets: On average, Medicaid accounts for 19% of a state's general fund spending, second only to K-12 education.
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	• Economic Factors: Slowing state revenue growth, following a period of economic expansion, combined with increased spending in other areas, has put pressure on state budgets. The Personal Toll of Medicaid Cuts The payment reductions have a direct and personal impact on the lives of patients and their caregivers. • Caregiver Hardship: Alessandra Fabrello, who receives compensation for the round-the-clock care she provides for her son, now faces a pay cut. This adds to the financial and emotional strain on families who are already struggling to care for their loved ones.
Federal Policy	21. *New York Times October 4, 2025 <u>A Freeze on Medicaid Payments Is Forcing Cuts to Rural Health Care</u> By Jenna Russell and Anna Griffin <i>The Trump administration has cut off funding for certain providers around the country whose offerings include abortion. Patients in Maine are among those who will feel the fallout.</i> A recent Trump administration policy has cut off Medicaid funding to reproductive health clinics that also offer abortions. This change is significantly impacting healthcare access, especially in rural areas of states like Maine. The Funding Cut • Policy: The administration has stopped Medicaid payments to reproductive health clinics that receive over \$800,000 annually in Medicaid funding and also provide abortion services. • Target: While primarily aimed at Planned Parenthood, the measure has also affected smaller providers, including Maine Family Planning and Health Imperatives in Massachusetts. • Clarification: Federal funds were not used for abortions. The Medicaid payments covered other essential healthcare services provided by these clinics to low-income patients. Impact on Maine Family Planning • Financial Strain: The organization is losing approximately \$165,000 per month. • Service Cuts: As a result, Maine Family Planning will cease providing primary care services on October 31st. This includes routine physicals and management of chronic conditions like diabetes and asthma. • Patient Base: The clinics serve about 30,000 patients, with 70% being low-income and half relying on Medicaid. Many patients in isolated regions depend on these clinics due to a shortage of other primary care providers. National Consequences and Responses • Widespread Closures: Planned Parenthood has stated that the cuts could lead to the closure of 200 of its 600 clinics nationwide. Clinics in Louisiana and Ohio have already closed.

- **State-Level Action:** Democratic-led states such as Washington are trying to cover the funding gap with state money.
- **Legal Fights:** Several federal lawsuits, including one from 21 Democratic-led states, have been filed to challenge the constitutionality of the funding cut.

22. *New York Times

September 17, 2025

[Trump's Medicaid Cuts Could Hamper Efforts to House the Homeless](#)

By Jason DeParle

President Trump's signature domestic policy law could make it harder for states to fund programs to help people find stable housing.

Medicaid Cuts Threaten Housing Programs

President Trump's signature domestic policy law, which cuts Medicaid spending by over \$900 billion over the next decade, could jeopardize state-funded programs that help homeless and other vulnerable individuals secure stable housing.

The Role of Medicaid in Housing

- **Expanded Use:** Over the last decade, states have increasingly used Medicaid funds for housing support services, such as case management, which helps individuals find landlords, navigate paperwork, and manage their health.
- **Services Provided:** These services, which require federal approval, can also include assistance with security deposits and short-term rent in some states.
- **Proven Benefits:** The article highlights several personal stories where Medicaid-funded caseworkers were instrumental in preventing homelessness, managing health conditions, and avoiding costly emergency room visits. A study of Maryland's program showed a 30% drop in high-frequency users of emergency rooms.

The Debate and Future Outlook

- **Arguments for:** Proponents argue that providing housing support through Medicaid saves lives and money. People with stable housing are healthier, less likely to need expensive emergency care, and have better health outcomes.
- **Arguments Against:** Critics view this as "mission creep," arguing that housing is not healthcare and that this use diverts funds from Medicaid's core mission. They question the long-term savings.

23. *New York Times

September 12, 2025

[Trump's Policies Are Endangering Your Health](#)

By The Editorial Board

An opinion piece from The New York Times Editorial Board argues that the Trump administration's policies are actively harming the health of Americans. The article outlines five key areas where these policies are having a detrimental effect.

Undermining Disease Prevention

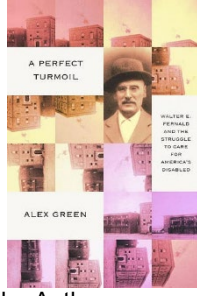
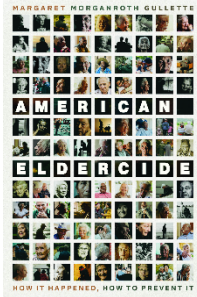
- The administration, led by Health and Human Services Secretary Robert F. Kennedy Jr., is promoting hostility towards vaccines, which has contributed to a rise in measles.

	• By appointing vaccine conspiracists to federal panels and supporting states like Florida in repealing vaccine mandates, the administration is eroding herd immunity against preventable diseases like polio, smallpox, and Covid-19. Increasing Pandemic Risk • The administration has dismantled the United States Agency for International Development (USAID), withdrawn from the World Health Organization (WHO), and emptied the White House Office of Pandemic Preparedness and Response. • Experts who monitored global outbreaks have been fired, leaving the U.S. more vulnerable to future pandemics. • Funding for the development of future mRNA vaccines has been canceled, which could slow down the response to new pandemic threats. Halting Medical Research • The administration has significantly cut federal funding for medical research, citing "government efficiency" and the "wokeness" of universities. • This will halt or delay research into treatments for diseases like cancer, cardiovascular disease, dementia, and addiction. • Basic scientific research, which often leads to major breakthroughs but is not immediately profitable for private companies, is expected to lose a third of its federal funding. Worsening Environmental Pollution • The Environmental Protection Agency (EPA) is being hollowed out, with regulations being rolled back and support for clean energy withdrawn in favor of promoting polluting energy sources. • Industrial facilities have been given a temporary pass on pollution rules, and coal-fired power plants that were set to close are being forced to stay open. • These actions are expected to increase air and water pollution, leading to a rise in pollution-related illnesses, particularly in industrial-heavy red states. Reducing Access to Healthcare • Recent domestic policy legislation is estimated to leave 10 million Americans without health insurance, with another 4.2 million at risk of losing coverage if Affordable Care Act tax credits are not extended. • Cuts to Medicaid, used to finance tax cuts for the wealthy, will disproportionately affect poor adults and those with opioid addiction. • The same law includes cuts to food stamps, reducing the ability of low-income families to afford food and stay healthy.
State House News	24. *State House News October 6, 2025 <i>Still a doctor on Mondays, now a secretary every day: Kiame Mahaniah's balancing act</i> By Ella Adams

	This article profiles Kiame Mahaniah, the new Secretary of Health and Human Services (HHS) for Massachusetts. Background and Path to Public Service • Originally from the Democratic Republic of the Congo, Mahaniah planned to return after college in the U.S., but the civil war prevented him from doing so. • He found his calling in community health centers, seeing it as the closest approximation to helping in an underdeveloped area by serving marginalized people in the U.S. • He was appointed HHS Secretary in July, leading an agency with a budget of over \$22.5 billion and more than 23,000 employees. Leadership and Current Role • Mahaniah continues to see patients every Monday at the Lynn Community Health Center, which he says provides a "window" into how state policies affect communities. • As secretary, he faces significant challenges, including budgetary pressures and policy battles with the Trump administration over Medicaid, reproductive care, and food benefits. • His predecessor, Kate Walsh, and Governor Maura Healey praise his experience, empathy, and operational skills, viewing him as a "physician first" who brings a sense of reality to government. Leadership Style and Philosophy • Colleagues describe Mahaniah as a calm, "values-based," and "visionary leader" with a deep commitment to social justice. • He is known for his even-keeled temperament, his "wicked" sense of humor, and posting a new poem on his office door each week. • A key motivation for his work is preventing children from suffering due to their parents' circumstances. Career Motivation • Mahaniah became a champion for substance use disorder treatment after an experience in Lawrence where he saw young children buying junk food for dinner because their parents had a substance use disorder. • This motivated him to establish and expand Medication-Assisted Treatment (MAT) programs at several community health centers. • He says his desire to advocate for people with substance use disorders pushed him into leadership roles, believing it would be "so much easier if I was the boss." 25. *State House News October 2, 2025 <u>Sen. Edward Kennedy of Lowell Dies, at 74</u> By Colin A. Young State Senator Edward Kennedy, a fourth-term Democrat from Lowell, has passed away at the age of 74. • His death was announced on Thursday, October 2, 2025, by Senate President Karen Spilka. He reportedly died Wednesday night at Lowell General Hospital. • Kennedy had a long career in public service, including multiple terms on the Lowell City Council (1978-1985 and 2011-2019),
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	serving as mayor (2016-2017), and as a Middlesex County commissioner (1992-1996). • He was remembered by colleagues, including Gov. Maura Healey, UMass President Marty Meehan, and U.S. Rep. Lori Trahan, as a dedicated public servant and a champion for his hometown of Lowell.
From Around the Country	26. *New York Times September 30, 2025 <i>In Some States, Strapped Counties Must Impose Trump's Medicaid Cuts</i> By David W. Chen New Federal Requirements for Social Programs • President Trump's domestic policy law, the "One Big Beautiful Bill Act," introduces new work requirements for adults to receive Medicaid and food stamps (SNAP), unless they have children under 13. • While presented as a way to encourage work, the new rules are projected to cut spending by \$317 billion on Medicaid and \$69 billion on food assistance over the next decade. • The implementation of these complex changes, including new deadlines and documentation, has been left to the states. Burden on Colorado Counties • In Colorado, the responsibility for administering these new federal rules falls to its 64 county governments, which are already facing financial constraints. • Counties are expected to face an estimated \$850 million in new administrative costs to hire and train staff and manage potential software issues. • This financial pressure is worsened by Colorado's Taxpayer's Bill of Rights, which limits local government spending, and a state budget shortfall caused by recent federal tax cuts. Local Concerns and Impacts on Residents • County officials from both political parties have expressed concern about the rapid rollout of the new requirements and the lack of guidance, fearing it will be difficult to pay for and implement. • Residents who rely on these benefits are worried about losing their assistance. The article highlights the stories of individuals and families dealing with health issues and unstable employment who fear they will be deemed ineligible. • The article profiles Krissy Rhoades, the single employee in the San Juan County Department of Social Services, to illustrate the immense pressure on local officials who will be responsible for enforcing these new, stricter rules.
Public Sessions	27. Massachusetts Public Health Council Wednesday, October 8, 2025, 9:00 a.m. Monthly public meeting Agenda includes updates from and a vaccine Q&A with Public Health Commissioner Goldstein, a vote on a request from Emerson Endoscopy

	and Digestive Health Center, Inc., and an informational presentation from the Bureau of Family Health and Nutrition. Agenda & Access 28. Massachusetts Coalition for the Homeless Wednesday, October 8, 2025, 10:00 a.m. State House, Room 222 Massachusetts Coalition for the Homeless holds a legislation briefing on bills from Rep. Arriaga and Sen. Jehlen (H 4015 / S 475) that would expand a bridge subsidy program for low-income older adults ages 60+ who are facing housing instability. The initiative is currently funded as a pilot in Somerville, according to a summary from Jehlen. The Joint Committee on Aging and Independence, which Jehlen chairs, favorably reported Jehlen's bill in mid-July and it's now awaiting action in the Joint Committee on Rules. Arriaga's bill had a hearing before the Housing Committee on July 23 and is under an extension order for lawmakers to act until Oct. 31.
<i>A Raise for Mom: Campaign to Increase the Personal Needs Allowance (PNA)</i>	<i>The Campaign to Increase the Personal Needs Allowance (PNA)</i> For nearly 20 years, the Personal Needs Allowance for Nursing Home and Rest Home residents has been stuck at \$72.80 per month. If inflation had been factored since the amount was last set, the allowance should now be about \$113.42. Costs for everything have increased over the last two decades, but the PNA has remained unchanged. That means that folks residing in nursing homes and rest homes have been paying ever higher prices for their personal needs – items not covered within the care, room, and board required to be provided by nursing and rest homes. These residents are obligated to pay almost all their monthly Social Security and other income for their basic care leaving the PNA to cover all other life's necessities. Amplifying this situation, Massachusetts has the highest cost of living of any state in the continental United States – meaning these vulnerable residents can afford less each and every year. Three similar bills have been filed in the Massachusetts Legislature this year and are awaiting a public hearing with the Joint Committee on Health Care Financing, chaired by Senator Cindy Friedman and Representative John Lawn. The bills to raise the PNA are Senate Bill 887 by Senator Joan Lovely and others; Senate Bill 482 by Senators Patricia Jehlen and Mark Montigny and others; and House Bill 1411 by Representative Thomas Stanley and others. As of the middle of May, twenty-nine legislators (11 senators, 16 representatives) have already co-sponsored one or more of these bills. DignityMA, AARP Massachusetts, and LeadingAge Massachusetts are among the statewide organizations that have indicated support of the PNA legislation. There's still time for other legislators to become co-sponsors. Please contact your state senator and representative using this link: https://dignityalliancema.org/take-action/#/25. It literally takes less than a minute to deliver the message.

	If you are a nursing or rest home resident, family member, or caregiver and have a story about the inadequacy of the current PNA, your story can help put an important human face on why this raise is so necessary. Please submit your story via https://tinyurl.com/ForgetMeNotPNA or you can email your story to Dignity Alliance MA (info@DignityAllianceMA.org), noting at least your first name and town where you live so that we can include your story in the testimony submitted to the Legislature. <i>*We selected the Forget-me-not as our symbol to encourage legislators to remember older adults in nursing and rest homes who have gone so long without a raise in the PNA.</i>
Books by DignityMA Participants  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.	<u>A Perfect Turmoil: Walter E. Fernald and the Struggle to Care for America's Disabled</u> By Alex Green 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. 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. <u>Buy the book here</u>
Books by DignityMA Participants  About the Author: Margaret Morganroth Gullette is a cultural critic and anti-ageism pioneer whose prize-winning work is foundational in critical	<u>American Eldercide: How It Happened, How to Prevent It</u> By <u>Margaret Morganroth Gullette</u> A bracing spotlight on the avoidable causes of the COVID-19 Eldercide in the United States. 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 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,

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.	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. 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. Buy the book here.
Bringing People Home: The Marsters Settlement	Webpages: https://www.centerforpublicrep.org/court_case/marsters-et-al-v-healey-et-al/ https://marsters.centerforpublicrep.org/
Support Dignity Alliance Massachusetts Please Donate!	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. 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. 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. https://dignityalliancema.org/donate/ Thank you for your consideration!
Dignity Alliance Massachusetts Legislative Endorsements	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 Questions or comments can be directed to Legislative Work Group Chair Richard (Dick) Moore at rmoore8473@charter.net .
Websites	
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 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	MassHealth Money Follows the Person 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	
Nursing Home Closures	List of Nursing Home Closures in Massachusetts Since July 2021: https://dignityalliancema.org/2025/04/07/nursing-home-closures-since-july-2021/	
Determination of Need Projects	List of Determination of Need Applications regarding nursing homes since 2020: https://dignityalliancema.org/2025/04/07/list-of-determination-of-need-applications/	

	Recent approval: <u>Town of Nantucket – Long Term Care Substantial Capital Expenditure</u> Approved May 5, 2025
List of Special Focus Facilities	Centers for Medicare and Medicaid Services <i>List of Special Focus Facilities and Candidates</i> <u>https://www.cms.gov/files/document/sff-posting-candidate-list-march-2025.pdf</u> Updated March 26, 2025 CMS has published a new list of <u>Special Focus Facilities</u> (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? • 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 <u>https://www.adviniacare.com/adviniacare-salem/</u> Nursing home inspect information: <u>https://projects.propublica.org/nursing-homes/homes/h-225644/</u> • Fall River Healthcare <u>https://www.nextstephpc.com/fallriver</u> 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://somersetridge rehab.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: https://projects.propublica.org/nursing-homes/homes/h-225546/ • Medway Country Manor Skilled Nursing & Rehabilitation, Medway (1) https://www.medwaymanor.com/ Nursing home inspect information: https://projects.propublica.org/nursing-homes/homes/h-225412 • Pine 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-225523
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	- West Newton Healthcare, West Newton (9) https://www.nextstephc.com/westnewton Nursing home inspect information: https://projects.propublica.org/nursing-homes/homes/h-225324/ No longer operating - South Dennis Healthcare, South Dennis https://tinyurl.com/SpecialFocusFacilityProgram																																																
Nursing Home Inspect	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?) <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> Updated April 23, 2025	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	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 better understanding of certain staffing information and concerns at facilities. This information will be posted for each facility and includes: 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. 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. https://tinyurl.com/NursingHomeCompareWebsite		
Data on Ownership of Nursing Homes	Centers for Medicare and Medicaid Services <i>Data on Ownership of Nursing Homes</i> 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.		
DignityMA Call Action	• 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	Email: info@DignityAllianceMA.org Facebook: https://www.facebook.com/DignityAllianceMA/ Instagram: https://www.instagram.com/dignityalliance/ LinkedIn: https://www.linkedin.com/company/dignity-alliance-massachusetts Twitter: https://twitter.com/dignity_ma?s=21 Website: www.DignityAllianceMA.org		
Participation opportunities with Dignity Alliance Massachusetts Most workgroups meet bi-weekly via Zoom. Interest Groups meet periodically (monthly, bi-monthly, or quarterly).	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	jimlomastro@comcast.net
	Home and Community Based Services	Meg Coffin	mcoffin@centerlw.org
	Legislative	Richard Moore	Dickmoore1943@gmail.com
	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	baskinfrank19@gmail.com

Please contact group leaders for more information.		Chris Hoeh	cdhoeh@gmail.com
	Covid / Long Covid	James Lomastro	jimlomastro@comcast.net
	Incarcerated Persons	TBD	info@DignityAllianceMA.org
Bringing People Home: Implementing the Marsters class action settlement	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/		
REV UP Massachusetts	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 .		
The Dignity Digest	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> : • Judi Fonsh • 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>			