

# The Dignity Digest

Issue # 133 April 3, 2023

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

# \*May require registration before accessing article.

# Spotlight

Where Do the Billions of Dollars Go? A Look at Nursing Home Related Party Transactions,

The National Consumer Voice for Quality Long-Term Care March 28, 2023

https://tinyurl.com/BillionsOfDollarsGo

Last week, Consumer Voice released its new report, "Where Do the Billions of Dollars Go? A Look at Nursing Home Related Party Transactions," which documents how each year nursing homes funnel billions of dollars through related party companies (companies they own) with little to no oversight by the Centers for Medicare & Medicaid Services (CMS). The report provides a detailed look at related parties and how nursing homes potentially use them to hide how much money they are making and to give the illusion that their facilities are not profitable.

The report uses cost data submitted to the federal government by nursing homes to illustrate the industry-wide practice of related party transactions and how at the same time, residents face inadequate staffing and poor care.

The report found:

- Despite billions of dollars being funneled through related party companies each year, there appears to be little to no scrutiny by the federal government on how this money is spent.
- Nursing home owners and operators routinely pay their related parties more than the reported costs, in some instances by nearly 1200%.
- Related parties make nursing homes look less profitable, while a closer look at the parties involved reveals that profits may be hidden in these transactions.
- Cost reports do not capture enough information on related party transactions to enable CMS to fulfill its regulatory obligation to ensure taxpayer dollars are going towards care and not profits to owners and operators.

The constant refrain from the nursing home industry is that they need more money. Yet, the report shows that billions of dollars go unaccounted for each year and are potentially being siphoned off to the profits of nursing home owners and operators. In the report, Consumer Voice offers solutions to the lack of transparency and accountability for how nursing home dollars are spent. CMS must

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take action now to ensure that taxpayer dollars are spent on care and that the safety and well-being nursing home residents is assured. Join the webinar Thursday, April 6th to hear more about the report in detail: Register Now https://tinyurl.com/BillionsOfDollarsGo Where Do the Billions of Dollars Go? A Look at Nursing Home Related Party Dignity Study Session **Dignity Study Sessions Transactions** provide in depth Webinar: Thursday, April 6, 2023, 2:00 p.m. considerations of a major Last week, Consumer Voice released its new report, "Where Do the topic regarding some form of Billions of Dollars Go? A Look at Nursing Home Related Party long-term care and related <u>Transactions</u>," which documents how each year nursing homes subjects. Sessions involve informational presentations funnel billions of dollars through related party companies (companies combined with discussions by they own) with little to no oversight by the Centers for Medicare & participants. Medicaid Services (CMS). The report provides a detailed look at related parties and how nursing homes potentially use them to hide how much money they are making and to give the illusion that their facilities are not profitable. The report uses cost data submitted to the federal government by nursing homes to illustrate the industry-wide practice of related party transactions and how at the same time, residents face inadequate staffing and poor care. Join us for a webinar to hear more about the report in detail. **Register Now** Discussion: Thursday, April 6, 2023, 3:30 p.m. Dignity Alliance Massachusetts will host a state level discussion of nursing home finances and the need for more financial transparency through state audits and the passage of Senate Bill 377/House Bill 633 following the National Consumer Voice Webinar. Sam Brooks, Public Policy Director at The Consumer Voice, will be a participant. Registration for DignityMA Study Session: https://tinyurl.com/April6StudySession Please note that separate registrations are necessary for the webinar and the study session. Contact: <u>info@DignityAllianceMA.org</u> for more information. Quotes of the Week There is no one way to be autistic — each individual with autism experiences it differently — but together, autistic people make industries, communities, and our Nation stronger. Today, we celebrate the achievements of neurodiverse people everywhere and champion the equal rights and dignity of all those living on the autism spectrum. President Joe Biden, A Proclamation on World Autism Awareness Day, 2023, The White House, March 31, 2023, https://tinyurl.com/ProclaimationAutismAwareness

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In its most recent survey of unpaid caregivers, published in 2020, AARP found that there were nearly 42 million people caring for an aging friend or family member — more than tenfold the number in 1989. The fastest growth is happening among younger generations; the share of caregivers who are under 45 quintupled over the past two decades, to nearly 66 percent from 16 percent, as their parents — many of the 72 million baby boomers — are living longer but doing so with more chronic diseases and disability and less means than the generation before them.

The Agony of Putting Your Life on Hold to Care for Your Parent, s\*New York Times Magazine, , March 28, 2023, <a href="https://tinyurl.com/AgonyOfLifeOnHold">https://tinyurl.com/AgonyOfLifeOnHold</a>

"In this era, any civil rights case that goes to the court gives one agita."

Robert Dinerstein, director of the Disability Rights Law Clinic at American University, referencing a case before the U.S. Supreme Court regarding the Americans with Disabilities Act, Supreme Court's new target: the Americans with Disabilities Act, \*Boston Globe, March 29, 2023, https://tinyurl.com/SupremeCourtsNewTargetADA

"Exercise is not just for the young," said, who was not involved in the research. "Older individuals can also reap the benefits of exercise and should be encouraged to do so.

Mikel Izquierdo, professor of health sciences at the Public University of Navarra in Spain, Exercise with a buddy. Your brain will thank you for it. **^Washington Post,** March 29, 2023, https://tinyurl.com/WPWorkoutBuddy

"Socializing exercises our cognitive function, providing more resilience to late-life decline — a concept known as building cognitive reserve. Being more socially active may also encourage healthy lifestyle behavior and reduce stress."

Andrew Sommerlad, associate professor of psychiatry at the University College London, Exercise with a buddy. Your brain will thank you for it. **^Washington Post,** March 29, 2023, <a href="https://tinyurl.com/WPWorkoutBuddy">https://tinyurl.com/WPWorkoutBuddy</a>

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"People are living longer. This is an expensive state for people. And we need to do everything we can to make life more affordable for seniors as they age."

Governor Maura Healey, 'An expensive state.' Healey says tax and budget plans will help struggling seniors, \*Boston Globe, April 1, 2023 (updated), <a href="https://tinyurl.com/AnExpensiveState">https://tinyurl.com/AnExpensiveState</a>

"Ready? I've wrapped my head around being dead, certainly. Not sure if I'll ever really be ready. It's not like packing a bag and standing outside waiting for a taxi."

A 60 year old dying man in conversation with his physician, *As a Doctor, I Know Being Ready to Die Is an Illusion,* \*New York Times, March 29, 2023, <a href="https://tinyurl.com/ReadyToDieIsAnIllussion">https://tinyurl.com/ReadyToDieIsAnIllussion</a>

I once felt that I would rather die than go blind. Now I feel the opposite. Daily life has a renewed delight and vigor. I am learning new things constantly. The most ordinary tasks, like going to the post office, have become terrifically interesting. In terms of everyday life, I feel that I am finally in there, more mindful and alert, more fully present. I have chosen curiosity over despair.

Edward Hirsch, a poet, a critic, *I Am Going Blind, and I Now Find It Strangely Exhilarating*, \*New York Times, March 28, 2023, https://tinyurl.com/StrangelyExhilarating

Despite their notable political differences, Texans and Californians agree. Supported decision-making advances self-determination. We're not surprised. Making your own decisions is at the heart of what it means to be a person.

Britney Spears Called Out Her Guardianship. Supported Decision-Making Offers a Different Approach. \*New York Times, April 3, 2023, <a href="https://tinyurl.com/SpearsSupportedDecisionMaking">https://tinyurl.com/SpearsSupportedDecisionMaking</a>

"[Massachusetts Commission for the Blind head David D'Arcangelo is] an inept and destructive leader. I've never seen the agency deteriorate as much as it has under him."

Amy Ruell, a former member of the commission's statutory advisory board, Inside the state commission for the blind: alleged verbal abuse, shrinking services, questionable spending, \*Boston Globe, April 2, 2023, https://tinyurl.com/AllegedVerbalAbuse

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# Legislative Committee Hearing

### 1. Joint Committee on Elder Affairs

Committee Hearing

Monday, April 10, 2023, 9:30 a.m. to 1:00 p.m.

Bills to be heard:

- <u>S.379</u> / <u>H.648</u>; An Act to improve quality and oversight of long-term care; Sen. Jehlen and Rep. Stanley
- <u>S.380</u> / <u>H.649</u>; An Act to improve Massachusetts home care; Sen. Jehlen and Rep. Stanley
- <u>S.374</u> An Act authorizing common sense health services in assisted living; Sen. Jehlen

The Joint Committee on Elder Affairs will hold a public hearing on Monday, April 10, 2023 at 9:30am in Room A-1 of the State House with an option for testimony to be offered virtually.

To testify virtually, registration to present oral testimony is required in advance. To register to testify virtually, please complete this form before \*Friday April 7th\* - late registrants may not be accepted. Once registered, you will receive further instructions via email on how to participate in the hearing.

To testify in person, participants are also requested to pre-register; however, same-day registration for in-person testimony will be available to those present in the Hearing Room.

The Chairs will limit testimony to 3 minutes per speaker. Please be advised that the schedule and agenda are subject to change at the discretion of the chairs. If you plan to testify as a panel, please note the name(s) of your co-panelist(s) on the form when registering. All panelists listed will need to register individually via the sign-up form if testifying remotely. Panels are requested to present themselves as a group either fully in-person or fully remotely.

Written testimony will continue to be accepted after the hearing until the relevant bill is acted upon. Such testimony may be submitted via email to <a href="mailto:joseph.russo@mahouse.gov">joseph.russo@mahouse.gov</a> and <a href="mailto:victoria.halal@masenate.gov">victoria.halal@masenate.gov</a>. Please include "Elder Affairs Committee Testimony, [Relevant Bill Number]" in the subject line of the email.

More details on bill titles, sponsors, and the livestream of this hearing are and will be available on the Legislature's website at <a href="www.malegislature.gov">www.malegislature.gov</a>. This hearing will be recorded and archived. By registering to submit testimony, you agree to release to the public all information you have included. The Committee will make reasonable efforts to ensure the email address or other contact information provided will not be published. Do not include any information you do not intend to make public, such as medical or other personally identifiable information.

Access link to the hearing will be posted on <a href="https://www.mass.gov/topics/legislative-branch">https://www.mass.gov/topics/legislative-branch</a>

# State Budget

#### 2. \*Boston Globe

April 1, 2023 (updated)

'An expensive state.' Healey says tax and budget plans will help struggling seniors

By Robert Weisman

Some progressive Democrats are questioning whether Healey's measures would go far enough, and whether tax relief to more affluent older residents who might flee the state could drain revenue that could help those who can't afford housing, food, fuel, and transportation.

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But in the interview, the governor said, "We need to do both."

Healey also discussed her views and priorities on a range of senior issues, including pending legislation that would allow medical aid in dying for terminally ill residents, preparations for a next pandemic, and the possibility of rebranding the state executive office of elder affairs.

But her primary focus now is on affordability for older residents. Her tax relief plan would double from \$1,200 to \$2,400 a "senior circuit breaker," the maximum credit homeowners and renters can claim to offset property taxes. That would benefit more than 100,000 residents over 65...

She also pledged relief for "seniors generally who are trying to make decisions right now about where they're going to live," she said. One of her proposals would revamp the state's estate tax — often cited as a reason retirees relocate to lower-tax states — by eliminating taxes on estates valued at \$3 million or less through tax credits worth as much as \$182,000. . .

At an earlier stop at the Jamaica Plain Neighborhood Development Corporation on Wednesday, the governor and Jennifer Maddox, her undersecretary for housing and community development, announced more than \$60 million in funding for 450 affordable housing units for low-income seniors and others at a dozen sites across the state.

The governor's budget, released in March, includes \$595 million, a 6 percent increase, for home care programs that help tens of thousands of older residents "age in place"; and \$26 million, a 4 percent increase, for local councils on aging. It also includes more money for senior nutrition and adult protective services programs responding to elder abuse. . .

·Healey said she and Kate Walsh, her secretary of health and human services, will work to rebuild a "decimated" labor force in hospitals, nursing homes, and home health care to prepare for new outbreaks or a future pandemic. . .

The governor said she's open to changing the name of the state executive office of elder affairs. With some contending the word "elderly" carries a negative connotation, many aging organizations across the country have rebranded. Close to home, a city agency known for a half-century as Boston's Commission on Affairs of the Elderly formally changed its name in 2019 to the Age Strong Commission.

"What we call things does matter," the governor said.

The elder affairs office is conducting market research to understand what older adults think about the agency's name, how they connect with its services, and how they want to receive information.

https://tinyurl.com/AnExpensiveState

#### World Autism Month

#### 3. The White House

March 31, 2023

A Proclamation on World Autism Awareness Day, 2023

There is no one way to be autistic — each individual with autism experiences it differently — but together, autistic people make industries, communities, and our Nation stronger. Today, we celebrate the achievements of neurodiverse people everywhere and champion the equal rights and dignity of all those living on the autism spectrum.

Here in the United States, more than 5.4 million adults are autistic, and 1 in every 44 children has been diagnosed with autism. Yet this developmental disability is still misunderstood. Autistic people continue to face obstacles when seeking employment, health care, education, and housing, and the immense

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contributions of people with autism are often overlooked. We owe it to our fellow Americans to address the disparities they face and to support autistic people with tools that facilitate clearer communication, increased productivity, and greater independence.

That is why my Administration is funding cutting-edge research to enable earlier autism diagnoses and to develop more resources to help neurodiverse people of all ages thrive. Recognizing that Autism Spectrum Disorder is categorized as a disability, my American Rescue Plan provided \$25 billion to States to make it easier for people with disabilities, including autism, to receive care at home. We also rolled out new tools and strategies for partner organizations to connect disabled Americans with stable housing while helping them pay rent, fight eviction, and prevent homelessness.

Last year, I was proud to reauthorize Kevin and Avonte's Law, which expands training for first responders and others giving care to people with autism. And in my recent State of the Union Address, I called on the Congress to increase its support for community living for people with disabilities.

My Administration is also boosting employment opportunities for autistic and other historically marginalized Americans. I was proud to sign an Executive Order advancing diversity, equity, inclusion, and accessibility in the Federal workforce, which will help create new jobs for Americans with autism and make space for their voices in the policy-making process.

We are helping State and local governments, employers, and nonprofits tap Federal funds to hire more Americans with disabilities like autism through competitive integrated employment practices. We are cracking down on employers who discriminate on the basis of disability, and we are fighting to end the unfair use of sub-minimum wages. I continue to urge States that have not yet expanded Medicaid coverage under the Affordable Care Act to do the right thing and provide health insurance to those currently locked out of Medicaid support that would otherwise be available to them from the Federal Government. Medicaid expansion would help many Americans with disabilities, including those with autism.

To support students with autism, the Department of Education is ensuring that public schools uphold their obligation to provide free and appropriate public education in the least restrictive environment to all

students. My Administration has also issued new guidance to help schools avoid the discriminatory use of discipline, which too often impacts autistic students, whose needs and behaviors are commonly misunderstood. As we build a more inclusive, just, and equal Nation, we aim to lead by the power of our example. I reestablished the role of Special Advisor on International Disability Rights at the Department of State to prioritize disability rights in our policy discussions with foreign nations. The United States Agency for International Development is advancing disability inclusion as part of its democracy, climate, humanitarian, and peacebuilding activities. And as co-chair of the Global Action on Disability Network and a participant in the Global Disability Summit, the United States continues to promote the equal human rights of people with disabilities worldwide.

America is founded on the idea that all people are created equal and deserve to be treated equally throughout their lives. Today and always, let us strive to live up to this ideal. Let us embrace our diversity; empower each other to reach our

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full potential; and promote the basic decency, acceptance, and fairness we know is right.

NOW, THEREFORE, I, JOSEPH R. BIDEN JR., President of the United States of America, by virtue of the authority vested in me by the Constitution and the

America, by virtue of the authority vested in me by the Constitution and the laws of the United States, do hereby proclaim April 2, 2023, as World Autism Awareness Day. I call upon all Americans to learn more about autism to improve early diagnosis, to learn more about the experiences of autistic people from autistic people, and to build more welcoming and inclusive communities to support people with autism.

IN WITNESS WHEREOF, I have hereunto set my hand this thirty-first day of March, in the year of our Lord two thousand twenty-three, and of the Independence of the United States of America the two hundred and forty-seventh.

JOSEPH R. BIDEN JR.

# https://tinyurl.com/ProclaimationAutismAwareness

# CTAA Seeks Teams for Accessibility Institute and Community of Practice

# 4. Community Transportation Association of America (CTAA)

CTAA Seeks Teams for Accessibility Institute and Community of Practice Transit Planning 4 All, funded by ACL and operated by the Community Transportation Association of America (CTAA), is hosting a Transportation Accessibility Institute in Oklahoma City, OK on May 22, 2023. Participants will discuss inclusive mobility planning, barriers that older adults and individuals with disabilities encounter in accessing public transportation services and facilities, and solutions to overcome those barriers.

Teams will be comprised of a representative from each of the following groups: individuals with disabilities, older adults, caregivers, disability and aging organizations, health care providers or plans, public transportation, and local government/planning agencies.

To participate, assemble a representative team and apply by **April 12**. Teams will be selected and notified by April 21.

Institute team members receive reimbursement for transportation expenses to and from Oklahoma City, two nights' lodging, and meals not provided during the Institute.

Learn more and apply

# Webinars and Online Sessions

#### 5. AARP Massachusetts

Tuesday, April 4, 2023, 10:30 a.m.

Virtual Event Via Zoom

On Tuesday, April 4th, AARP volunteers and advocates from across Massachusetts will come together for a <u>virtual advocacy event</u>. Join other advocates to hear from legislative leaders and learn how you can make a difference advocating for change here in the Bay State.

Help make a difference in the lives of older Massachusetts residents and their families by attending this event, then join us as we work on issues important to our members like caregiving, nursing home reform, retirement savings, and financial security.

#### **AGENDA**

10:30	Welcome – Jessica Costantino, AARP Massachusetts
10:32	Speaker of the House Ronald Mariano video
10:35	Jessica – Introduction – AGING IN THE COMMONWEALTH
10:36	Sandra Harris, State President
10:39	Senator Patricia Jehlen, Elder Affairs Committee Priorities

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10:42	Representative Thomas Stanley, Elder Affairs Committee Priorities
10:45	Secretary of Elder Affairs, Elizabeth Chen, Healey Administration
	Priorities
10:48	QUESTIONS/COMMENTS
10:53	Jessica – Introduction - CAREGIVING
10:54	Senate President Karen Spilka video
10:57	James Lomastro – Family Caregiver
11:00	Rep. Dave Rogers, sponsor – The Family Caregiving Tax Credit
11:03	Sen. Jason Lewis, sponsor – The Family Caregiving Tax Credit
11:06	QUESTIONS/COMMENTS
11:11	Jessica – Introduction – SENIOR PROPERTY TAX DEFERRAL
11:12	Pat Walker – Advocate
11:15	Rep. Tommy Vitolo, sponsor, Senior Property Tax Deferral
11:18	QUESTIONS/CONCERNS
11:23	Jessica – Introduction – ACTION STEPS
11:24	Sandra Harris – ACTION STEPS & CLOSING
11:30	Adjourn
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Register Now at: mobilize.us/aarpma

#### 6. The Arc

Thursday, April 6, 2023, 12:00 p.m.

State & Federal Update with Maura Sullivan

For April's State and Federal Updates session, join Maura Sullivan for a webinar on "Advocacy to Bring People Back to Services and Supports." She will be breaking down The Arc's FY24 State Budget Ask, plus three more priority bills to review.

### **Register Here**

#### 7. The Arc

Monday, April 10, 2023, 12:00 p.m.

Leo Live: Webinar Series with Leo Sarkissian

Mary Price, Director of the Massachusetts Inclusive Concurrent Enrollment Initiative (MAICEI) will join Leo Live. Since 2007, MAICEI has been giving students with intellectual and developmental disabilities and autism the opportunity to attend college alongside their non-disabled peers in a fully inclusive environment. Currently, 15 colleges and universities offer MAICEI and it continues to grow.

**Register Here** 

#### 8. The Arc

Monday, April 10, 2023, 6:00 p.m.

Preparation Session to Support HST Legislation with Senator Moran and Representative Domb

Join Senator Susan Moran, Representative Mindy Domb, and the Human Services Transportation Coalition to learn more about their priority legislation [H3303, S1434, H3302, and S121] which establish ways for us to influence and improve the safety, reliability, and quality of these services.

This will be a training session to prepare and strengthen our advocacy for these bills, share our stories, and organize testimony for the public hearings on the legislation. These HST bills need your support and the legislature needs to hear your lived experience and insights in order to understand current barriers to using the service, including your experience with:

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- Improper equipment and training of drivers to safely secure wheelchair users.
- Significant delays in pick up or cancellation resulting in missed appointments.
- Inappropriate treatment of passengers and people with mental health or intellectual disabilities.
- Difficulty scheduling on phone, online or app.
- Failure to inform consumers of their rights.
- Poor follow up of complaints regarding serious safety or missed appointments.
- Inadequate oversight and enforcement of contracts with brokers and transportation providers.

Your thoughts on how a continuation of the HST Task Force (H3302/S121) and a HST Consumer Advisory Board (H3303/S1434) will help address these issues.

Register Here

# 9. National Center on Advancing Person-Centered Practices and Systems Wednesday, April 12, 2023, 3:00 to 4:30 p.m.

Stories and Lessons Learned from Pennsylvania's Housing Demonstration Project For many people, finding and making a home of their own is a key turning point in their lives. From this point, other life goals begin or expand, such as starting or building a career, nurturing a family, or being a part of their neighborhood or community. In short, many people define their quality of life first by where and with whom they choose to live. However, this is often not the case for many people with disabilities who use home and community-based services (HCBS), despite funding and policy mandates to ensure one's housing is separate from services.

In 2018, the Pennsylvania Developmental Disabilities Council funded projects to change this and to compel systemic change through individual experiences that demonstrate the power of resources being directed by the person with the guidance and support they need to find and make a home of their own. This webinar will feature people with lived experience and the professionals who support them sharing their stories and highlighting challenges and the importance of collaboration. Panelists hope to spark ongoing discussion and shared learning about the shift from provider owned and managed housing. Presenters:

- Marian Frattarola-Saulino respects everyone as the experts of their own lives and works to build coalitions where people themselves decide the expertise they need, to build the lives they want.
- **Abby Martucci**, Families CCAN Program Director, has 20 years of experience with strengths-based, person-centered planning.
- Pamela Zotynia is the Service Director for Values into Action's Participant
  Directed Services where she uses her knowledge and expertise to assist
  individuals and families who use Participant Directed Services to create the
  lives they deserve and desire.
- Robert Zotynia is a 36-year-old artist, self-advocate, and change-maker.
   Sara Crimm is Director and co-founder of Families CCAN (Families Creating Communities for Adults with Special Needs).
- Dana Thompson has worked in the disability field for over 32 years.
   David Gates has worked with numerous self-advocates and families since
   2003 to develop creative housing models including home ownerships,
   microboards and projects with housing developers.

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Jeremy Yale joined the Office of Developmental Programs (ODP) in January 2019 as the Director of the Bureau for Policy and Quality Management. **Lisa Tesler** is a passionate advocate and visionary who supports inclusion, self-determination, and meaningful lives for people with developmental disabilities. Dr. Amber Borreli, Housing Resource Coordinator for Values into Action, has been working alongside people seeking housing for over 20 years. Register for the webinar 10. The Arc Monday, May 15, 2023, 12:00 p.m. Leo Live: Webinar Series with Leo Sarkissian Vicky Pulos, Senior Health Law Staff Attorney at the Massachusetts Law Reform Institute, will join Leo for a session on MassHealth Redetermination. Vicky Pulos joined MLRI in 2000 as a health law attorney. Her work concentrates on assuring low-income people access to health care, through advocacy, training, technical support, and litigation. She received her law degree from Harvard Law School. She is the author of MLRI's MassHealth Advocacy Guide. Her current work focuses on defending coverage in the MassHealth and ConnectorCare programs. **Register Here** Previously posted webinars and online sessions can be viewed at: https://dignityalliancema.org/webinars-and-online-sessions/ 11. Fox 61 Nursing Homes March 31, 2023 Nursing home files petition to close after 50 years in West Hartford By Bill Flood The owners of Hughes Health & Rehabilitation say the "facility is not viable" with declining occupancy. Hughes Health and Rehabilitation, a nursing and healthcare facility in West Hartford, has filed a <u>Petition for Closure</u> with the state Department of Social Services (DSS). The facility has operated on Highland Street for over fifty years but has notified the state that it "is not viable" due to a lack of patients, as well as cost increases "not covered by Connecticut's reimbursement program and the growing trend towards the use of home and community-based services." In a letter to DSS, Hughes Health said the facility's occupancy rate last year was 57% and only 51% for the first four months of 2023. The facility has 170 beds; 93 notices were sent to patients or their guardians, family, and conservators. "This decision has not come lightly and comes after numerous attempts to revitalize the center's declining census," the letter said. https://tinyurl.com/WestHartfordNHClosing 12. McKnight's Long-Tern Care News March 29, 2023 Plaintiffs' lawyers gaining edge against nursing homes with staffing issues By Jessica R. Towhey The staffing challenge is the biggest issue facing nursing homes, said Caroline J. Berdzik, chair of the Employment and Labor and Healthcare practice groups at Goldberg Segalla. The New York state staffing mandate has played out as a

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"true nightmare" as anticipated, she said.

"It's really becoming impossible," Berdzik said, adding that Payroll-Based Journal data in New York shows that 75% of the state's 614 nursing homes cannot meet its 3.5-hour staffing mandate. The state now has 6,700 empty beds, which is causing problems throughout the care continuum as hospitals cannot find facilities to which they can discharge patients.

https://tinyurl.com/PlaintiffsLawyersGainingEdge

#### 13. Harlem World

Undated

Nursing Home Complaints Number in The Thousands Each Year, Many Unreported

Residents of nursing homes, assisted living and other adult care facilities from <u>Harlem to Hollis</u> file thousands of complaints a year ranging from gross neglect. Including physical and sexual abuse – poor care, involuntary discharge and eviction, poor food, inattentive staff, and shoddy management.

Yet the State oversight program tasked with serving as an advocate for residents – some of <u>New York's</u> most vulnerable people – remains understaffed and underfunded.

In this year's state budget negotiations, the Governor proposed no additional funding for the program, while the State Senate only offered a modest increase. The State Assembly has proposed an additional \$12.5 million for the program, which would go a long way toward addressing these woes if adopted in a final state budget.

AARP New York and other advocates for the aging have been pushing for a \$15 million increase in funding for LTCOP in the 2023-24 State Budget, which was due today but is still being negotiated. The additional funding would allow for the hiring of 235 full-time staff to meet LTCOP's self-set standard of a weekly visit to each nursing and adult care facility, including more than 500 in <a href="New York City">New York</a> City and on Long Island.

There are likely far more complaints that aren't being reported to the State Office for the Aging (SOFA) because its federally-required Long Term Care Ombudsman Program (LTCOP) doesn't have enough staff to visit each of the state's approximately 1,400 adult care facilities on a regular basis and interact with residents and their family caregivers.

Over 5,000 complaints (5,073) were filed between Oct. 1, 2021 and June 30, 2022, according to the latest data available from SOFA. The overall number of complaints increased nearly 37%, from 1,445 during the first three months of that period (Oct. 1, 2021-Dec. 31, 2021) to 1,979 during the last three months (April 1, 2022-June 30, 2022).

"Lack of adequate funding is having an adverse impact on the care provided to our loved ones living in nursing homes and other adult care facilities," said AARP New York State Director Beth Finkel. "The program is supposed to act as the eyes and ears of residents and their families, yet so many aren't getting the chance to have their concerns formally documented because LTCOP is not sufficiently funded to carry out its oversight responsibilities. The Governor and state legislators should correct this in the next state budget."

According to SOFA's data, major areas of concern reported across the state include:

 Care – 1,591 complaints involving facility staff failure to provide care, including poor quality care, planning and delivery, accidents and falls, response to requests for assistance, care planning, medications, personal

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- hygiene, access to health-related services, symptoms unattended, incontinence care, assistive devices or equipment, rehabilitation services physical restraints, chemical restraints, and infection control.
- Autonomy, Choice, Rights 942 complaints involving facility staff failure to honor and promote a resident's right or preferences including choice of health care, living in less restrictive setting, dignity and respect, privacy, response to complaints, retaliation, visitors, resident or family council participation, or any other rights and preferences.
- **Dietary 327 complaints** regarding food service, assistance including choice, quantity and quality of food, assistance with dining or ensuring hydration, and therapeutic or special diets.
- Admission, Transfer, Discharge, Eviction 294 complaints against facilities involving issues regarding admission, transfer, discharge and/or eviction, including appeals process and room issues.
- Abuse, Gross Neglect, Exploitation 47 complaints including serious complaints of willful mistreatment of residents by facility staff, resident representative/ family/friend, other residents, or an outside individual including physical, sexual, or psychological abuse, financial exploitation, or gross neglect.

Details for the most recent three quarters for which data is available can be found here:

- <a href="https://aging.ny.gov/system/files/documents/2022/04/ltcop-complaints-ffy-2022-quarter-1.pdf">https://aging.ny.gov/system/files/documents/2022/04/ltcop-complaints-ffy-2022-quarter-1.pdf</a>
- <a href="https://aging.ny.gov/system/files/documents/2022/08/ltcop-complaints-ffy-2022-quarter-2.pdf">https://aging.ny.gov/system/files/documents/2022/08/ltcop-complaints-ffy-2022-quarter-2.pdf</a>
- <a href="https://aging.ny.gov/system/files/documents/2023/01/ltcop-complaints-ffy-2022-quarter-3.pdf">https://aging.ny.gov/system/files/documents/2023/01/ltcop-complaints-ffy-2022-quarter-3.pdf</a>

What's particularly troubling is how many additional potential complaints likely went undocumented; 52% of adult care facilities statewide and nearly 80% in New York City failed to receive a single ombudsman visit from April 1 to June 30, 2022, according to a report released in February by AARP New York. AARP is the nation's largest nonprofit, nonpartisan organization dedicated to empowering people 50 and older to choose how they live as they age. With a nationwide presence and nearly 38 million members, AARP strengthens communities and advocates for what matters most to families: health security, financial stability, and personal fulfillment. AARP also produces the nation's largest circulation publications: AARP The Magazine and AARP Bulletin. https://tinyurl.com/NHReportsUnreported

# **Public Policy**

#### 14. \*State House News

April 3, 2023

Housing Secretariat

A report is due by Thursday from the State Administration and Regulatory Oversight Committee on their approval or disapproval of Gov. Maura Healey's housing-focused Cabinet reorganization plan. The proposal has drawn support, and no opposition, and the timing of legislative action, or inaction, is shaping up as an indicator of how seriously the Legislature considers housing affordability as an issue. The Article 87 proposal (H 43) would create a new Executive Office of Housing and Livable Communities and rename EOHED as the Executive Office of Economic Development. Gov. Healey's bill also duplicates the existing legislative authorization for the Mass Works program in a new "Housing Works"

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statute intended to fund municipal infrastructure for new or redeveloped housing. The Legislature has 60 days to approve or disapprove a reorganization bill from the date that the governor files the proposal. Unlike a typical bill, the measure is also not subject to amendment. If the branches don't act on it within those 60 days, which in this case would be on April 30, then Healey's plan would take effect.

https://tinyurl.com/StateHouseNewsThursday

# **Supported Decision Making**

## 15. \*New York Times

April 3, 2023

Britney Spears Called Out Her Guardianship. Supported Decision-Making Offers a Different Approach.

By Emily Largent, Andrew Peterson, and Jason Karlawish

Drs. Largent and Karlawish are senior fellows at the Leonard Davis Institute of Health Economics at the University of Pennsylvania, where they are also professors at the Perelman School of Medicine. Dr. Peterson is an assistant professor at the George Mason University Institute for Philosophy and Public Policy.

Conservative Texans and liberal Californians disagree on much in politics. But legislators in both states agree on a new approach to giving people with cognitive impairments a greater chance for self-determination. It's called <a href="supported decision-making">supported decision-making</a>, and it is shaping up to be the most consequential change in the care of older people and others with limitations in mental functioning since the rise of advance care directives in the 1990s.

The difference between guardianship, the traditional way to help those with such impairments, and supported decision-making is analogous to the difference between a dictatorship and self-rule. Unlike guardianship, which creates an all-powerful guardian and strips the subject of the right to make decisions, in supported decision-making, the individual retains final control over key decisions. That person enlists one or more trusted others, such as family members or close friends, to aid him in making decisions. The supporters are there only to assist.

The National Council on Disability rightfully <u>describes this approach</u> as "the most promising and comprehensive alternative to guardianship." More support for these life-affirming arrangements is needed.

<u>Britney Spears's public efforts</u> to end the nearly 14-year guardianship she was under cast a light on problems with the arrangement that too often remain in the shadows. In seeking to end her guardianship, Ms. Spears <u>testified in court</u>: "I truly believe this conservatorship is abusive. I don't feel like I can live a full life." A judge in Los Angeles <u>concluded</u> in 2021 that the guardianship was no longer needed and terminated it.

Of course, some people can't make decisions even with support. They may be suffering from the effects of a severe traumatic brain injury or late-stage dementia. For them, guardianship remains necessary. But many others with limitations don't entirely lack the ability to make their own decisions. Forcing them to surrender authority to a guardian strips away their self-determination and dignity and could leave them prone to abuse.

In 2015, Texas became the first state to recognize supported decision-making. And last fall, California joined Texas and at least 13 other states and the District of Columbia in establishing comprehensive legal frameworks for these arrangements. Several more states require that such agreements be considered before a guardian is appointed. Legislation has previously been introduced in states as varied as Massachusetts, Oregon, New Mexico, and West Virginia.

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At the federal level, the Senate Special Committee on Aging held a hearing last week on supported decision-making and other less restrictive alternatives to guardianship. Committee members from both parties applauded states backing supported decision-making innovation, and Senator Bob Casey, the committee chairman, said he planned to introduce legislation that would require courts to consider supported decision making and other approaches for people who need help managing their lives.

Though more evidence is needed, <u>small studies</u> report overwhelmingly positive outcomes, with most of those receiving support saying they were more confident, happier and better able to do what they want. With a greater sense of freedom comes <u>a greater sense of dignity</u>.

Millions of Americans stand to benefit from this shift. Supported decision-making gained prominence with the 2006 approval of the United Nations Convention on the Rights of Persons With Disabilities, which endorsed the approach. It has since been championed by people with intellectual and developmental disabilities, who often find themselves under unwanted guardianships as adults. But it has clear benefits for others with disabilities that affect decision-making, especially as the population ages and is at increasing risk for cognitive impairment caused by diseases such as Alzheimer's. In Texas, California and other states that recognize supported decision-making, individuals can craft an agreement without court oversight that specifies the kinds of decisions they need help in making — from medical care to finances — as well as the kinds of help they want. For example, older adults who experience forgetfulness or inattention might ask their supporters to join them at appointments and take notes.

Supporter agreements are structured to curb the abuses of guardianship. A network of supporters can provide important checks on one another to prevent improper influence. Guardianship can be hard to escape, as Ms. Spears found, but a supported decision-making agreement can be changed or exited by the subject with fewer impediments. An independent monitor can also be added to an agreement to assure that sensitive decisions on matters like finances are made without undue influence. In Texas and elsewhere, supporters and third parties aware of agreements are required to report suspicions of abuse, neglect or exploitation.

People with disabilities and their families can educate themselves about supported decision-making and incorporate it into their daily lives informally as well. For example, the A.C.L.U. <u>offers a guide</u> that explains supported decision-making and offers self-assessment tools for considering the kinds of assistance that might be useful.

Those facing or contemplating guardianship can reach out to a lawyer or a legal services organization focused on people with disabilities or older adults to determine if <a href="less restrictive alternatives">less restrictive alternatives</a> like supported decision-making might be more appropriate. Supported decision-making could be used alone or in combination with other legal tools, such as a power of attorney, to avoid an unnecessary guardianship.

And more states should formally recognize this approach, validating its value. Some health care facilities and banks already insist on written agreements before they allow supporters at appointments or accept decisions made using support. Laws are an important means to ensure that people with cognitive disabilities have their decisions respected. Education is also important; even in

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	states that already recognize supported decision-making, there may be little
	public awareness about this approach. The more that is known about it, the
	more professionals will accept and strengthen it as needed.
	Despite their notable political differences, Texans and Californians agree.
	Supported decision-making advances self-determination. We're not surprised.
	Making your own decisions is at the heart of what it means to be a person.
	https://tinyurl.com/SpearsSupportedDecisionMaking
Medicare	16. STAT News
	April 3, 2023
	A softened blow for Medicare Advantage
	By Bob Herman
	The Biden administration caved to MA insurers on Friday, choosing to delay the
	full impact of its changes to the program's risk adjustment rules, my colleague
	John Wilkerson reports. There's plenty more to wade through in the 200-page
	rule, but the takeaway is clear: the insurance industry's lobbying campaign
	worked.
	Medicare had planned to remove and/or consolidate codes for certain
	conditions, like peripheral artery disease and chest pain, that it said often led to
	inflated payments. It was a way to rein in problematic coding; Medicare officials
	and experts have long pointed out that insurers exploited the system in some
	cases by reporting that their members are sicker than they are, leading to
	higher payments. Those changes will still happen – but they'll be phased in over
	three years, now, rather than all at once.
	It's hard not to assume that the softening was politically motivated, at least in
	part— insurers had decried the administration's efforts, saying they would lead
	to fewer benefits for seniors. A <u>new survey</u> by the Kaiser Family Foundation
	found that the insurers' arguments played on concerns held by a broad swath
	of Americans. About 80% of respondents said they worried that Medicare will
	not be able to provide the same level of benefits in the future, and a similar
	percentage said changes must be made to keep the program sustainable. (On
	that subject: the Medicare Trustees Report, which says the trust fund will be
	able to pay 100% of benefits through 2031, also dropped Friday.) More on the
	big MA news here.
Substance Use	17. STAT News
	March 29, 2023
	FDA approves over-the-counter Narcan. Here's what it means
	By Geoff Mulvihill AP News
	The U.S. Food and Drug Administration on Wednesday approved selling
	naloxone without a prescription, setting the overdose-reversing drug on course
	to become the first opioid treatment drug to be sold over the counter
	What is Narcan?
	The approved branded nasal spray from Gaithersburg, Mdbased Emergent
	BioSolutions is the best-known form of naloxone.
	It can reverse overdoses of opioids, including street drugs such as heroin and
	fentanyl and prescription versions including oxycodone.
	Making naloxone available more widely is seen as a key strategy to control the
	nationwide overdose crisis, which has been linked to more than 100,000 U.S.
	deaths a year. The majority of those deaths are tied to opioids, primarily potent
	synthetic versions such as fentanyl that can take multiple doses of naloxone to
	reverse.

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	Does making naloxone over-the-counter improve access?
	It clears the way for Narcan to be made available in places without pharmacies
	<ul> <li>convenience stores, supermarkets, and online retailers, for instance.</li> </ul>
	https://tinyurl.com/OverTheCounterNarcan
Caregiving	18. *New York Times Magazine
	March 28, 2023
	The Agony of Putting Your Life on Hold to Care for Your Parents
	By Jaeah Lee
	Randi Schofield is the sole provider for an ailing father and, at the same time,
	for her own children — a situation now common among Americans in their 30s
	and 40s.
	Randi Schofield tried her best to not dwell on all the ways her life changed, on
	the pieces of herself that got lost in the shuffle. She was a 34-year-old single
	mother who, not long ago, was in the throes of a big life transition. She had left
	her full-time job of eight years as a personal bailiff to a local judge. She was
	burned out, ready for something new.
	She pulled \$30,000 from her retirement savings and was planning to give
	herself all of 2022 to expand the small catering business she had always
	dreamed about. This would be the year she bet on herself. It was risky, but she
	had a plan. She applied for part-time, remote office jobs so she could keep up with the bills, maybe save up for a summer vacation with her two daughters,
	Alicia, then 13, and Amira, who was 15. She felt guilty for having spent so much
	of her time working at the courthouse or on-call by her laptop. She started
	going to bed early and updated her budget every two weeks. She got the girls
	ready to begin the spring semester feeling like a new person. Then, in late
	January 2022, she received the news that medics were pulling her father out of
	his car.
	Randi's father, Keith Schofield, then 61, had been driving home from the gym
	after a snowstorm when a car in the next lane lost control and sent Keith's
	Chevy over a Cleveland freeway overpass. The collision splintered the bone in
	his left thigh down to his knee; three days later, a metal rod held the broken
	pieces together. Until his leg recovered from the surgery, he would not be able
	to walk without assistance.
	In hindsight, there were warning signs that her father's health could upend
	Randi's life — the heart episodes that landed him in the emergency room
	almost every year; the tray full of open medicine bottles that he swore he took
	on time. But he was also youthful and spirited, and it was easy to believe that
	everything was fine, that he was fine and that if she were to take care of him
	some day, it would be occasional and in a distant future where she had more of
	life figured out. She didn't see this day coming the way it did, so abruptly and so
	Soon.
	Yet increasing numbers of adult children are taking care of their parents, often
	shouldering the burden with no pay and little outside help — making their meals, helping them shower, bandaging their wounds, and holding them up
	before they can fall. (The number of people living in <u>nursing homes</u> or <u>assisted-</u>
	living facilities make up less than 5 percent of the population 65 and older.) In
	its most recent survey of unpaid caregivers, published in 2020, AARP found that
	there were nearly 42 million people caring for an aging friend or family member
	— more than tenfold the number in 1989. The fastest growth is happening
	among younger generations; the share of caregivers who are under 45
	among younger generations, the share of earegivers who are under 45

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quintupled over the past two decades, to nearly 66 percent from 16 percent, as their parents — many of the 72 million baby boomers — are living longer but doing so with more chronic diseases and disability and less means than the generation before them. . .

An unprecedented number of people in their 30s (and to a lesser degree, 20s) are entering what the social-work scholar Dorothy A. Miller once called a "peculiar position" in the modern American nuclear family, between the care they give to their aging parent and to their children. Today's "sandwich generation" is younger than the version Miller described four decades ago, but they face the same "unique set of unshared stresses" that she warned of then: acute financial strain, a lack of reciprocated support and "fatigue from fulfilling the demands of too many roles."...

Most American households make too little to afford a hired caregiver or a bed in a nursing home, the median costs of which are about \$3,000 and \$8,500 a month, respectively. Yet most Americans also make too much to qualify for the public benefits that exist for this very reason. The price of long-term care, meanwhile, has risen for nearly two decades in a row. In 2019, the average cost of in-home care for one year equaled 80 percent of the median household income for seniors; a year in a nursing home cost more than two times the median income. The result is a kind of generational compounding effect for family caregivers inheriting the financial burdens of their parents while facing their own precarious future. . .

In a pioneering study of adult-children caregivers, the social worker Elaine Brody found that in every family in which an aging parent required care, there was usually one "burden bearer" — a <u>single member who bore the brunt of the responsibilities</u>, even when there were, in theory, others who could help. "This phenomenon appears with striking regularity and frequency," Brody co-wrote in the journal, Family Process, in 1966.

https://tinyurl.com/AgonyOfLifeOnHold

# Disability topics

# 19. \*Boston Globe

April 2, 2023

Inside the state commission for the blind: alleged verbal abuse, shrinking services, questionable spending

The agency's labor union and the state's largest advocacy group have called for the ouster of Commissioner David D'Arcangelo.

For more than 25,000 blind and visually impaired people across the state, the Massachusetts Commission for the Blind is a critical lifeline: providing training, accessible technology, and many other services.

It's also, by many accounts, a state agency in distress.

Workers have filed a litany of complaints in recent years against Commissioner David D'Arcangelo, alleging verbal abuse and inappropriate comments, with some of those investigations still ongoing, a Globe investigation found. Five current employees, and six former members of the agency, told the Globe that D'Arcangelo has slashed resources and services while pursuing costly and quixotic projects such as a television studio in Boston and a <a href="commissione">comic book</a> that's unavailable in Braille and nearly unusable on the screen readers used by many blind people.

These conflicts led last month to a call for his ouster and a vote of noconfidence in D'Arcangelo by the union representing a majority of the agency's 130 employees. And, on March 20, the board of the state's largest advocacy

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group for blind and visually impaired people wrote to Governor Maura Healey's office saying D'Arcangelo, who has led the agency since 2018, needed to go. . . Money is not the issue. The agency's funding from the state budget has steadily grown from fiscal year 2017 to 2022, from \$22 million to \$28 million, records show.

State leaders may be hamstrung in addressing the issues raised about D'Arcangelo's leadership. Unlike with most other agencies, state law allows for each MCB commissioner to serve a term of at least five years — without exceptions. D'Arcangelo's five-year term ends in August.

The commission, with a roughly \$36 million annual budget drawn from a mix of state and federal funds, has a long, storied history. Since its creation in 1906 by a small group of people, including Helen Keller, it has been one of 22 state-level agencies in the United States that remain dedicated to people who are blind and visually impaired. That specialization, advocates say, is critical to providing such services.

When someone in the state is declared legally blind, eye care providers are required to send their information to the agency so the patient can be registered and the commission can offer its services.

https://tinyurl.com/AllegedVerbalAbuse

#### 20. \*Boston Globe

March 29, 2023

Supreme Court's new target: the Americans with Disabilities Act By Kimberly Atkins Stohr

A ruling could essentially rewrite the ADA, which was designed to put enforcement partly in the hands of those best positioned to recognize public access discrimination: those with disabilities.

With a <u>one-line order</u>, the Supreme Court put disability rights advocates on edge Monday.

"In this era, any civil rights case that goes to the court gives one agita," said Robert Dinerstein, director of the Disability Rights Law Clinic at American University.

As we await rulings this term that <u>could gut the already battered Voting Rights</u> Act, <u>weaken laws protecting the LGBTQ community</u>, and <u>eviscerate affirmative action</u> in college admissions, the court teed up a new target for next term: the Americans with Disabilities Act.

The court <u>agreed to decide</u> whether disability rights advocates can sue hotels, restaurants, or other businesses that provide public accommodations for violating the anti-discrimination law when the advocates have no intention of patronizing those establishments. In other words, do so-called "testers," whose sole intention is to force those businesses to comply with the ADA's accessibility requirements, have standing to sue?

If the court decides the answer is no, it would be a win for businesses that claim such suits — sometimes filed by the hundreds by single litigants — are nuisance cases that threaten to destroy businesses that do not have the financial resources to engage in lengthy and costly legal battles.

"This case does not involve any allegations of discriminatory treatment," states a brief from attorneys representing the Coast Village Inn and Cottages in Wells, Maine, one of many businesses disability activist Deborah Laufer sued after visiting its website and finding no information about ADA accommodations.

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"Instead (Laufer) merely alleges that a public website did not contain information she did not need."

But disability rights advocates say such a ruling would essentially rewrite the ADA, which was designed to put enforcement partly in the hands of those best positioned to recognize public access discrimination: those with disabilities. Businesses that claim they are being unfairly targeted "leave out one critical factor: that very few have ever complied with the ADA voluntarily," Laufer's attorney wrote in a brief. "Rather, nearly everybody waits until they are sued." Dinerstein said the fact that Laufer, who uses a wheelchair and has vision impairments, has filed hundreds of suits doesn't necessarily mean she's a vexatious plaintiff.

"The way I'd hope someone would look at it is, she really has an interest in this," Dinerstein told me. "This is not somebody who randomly decided to file suit. She really is functioning like a private attorney general."

And that function is crucial if the ADA is going to have any teeth at all in ensuring people with disabilities are able to have the same access and civil rights protections.

"No government agency can possibly be on top of all these things," Dinerstein said.

What's troubling here is that there are ways to curtail frivolous or abusive lawsuits designed more to rack up attorney fees and cash judgments than to pursue justice. States can pass or amend laws governing attorney fee awards, and Congress could amend the ADA to allow, for example, businesses to have a grace period to correct accessibility violations before suits can be filed. By leaving it to the court, if past is prologue, a crucial part of the ADA will be in peril.

Start with the fact that this conservative-leaning court has been a boon to businesses. According to a 2022 study, businesses have prevailed 63.4 percent of the time in cases before the Roberts Court. Compare that to the second most business-friendly court in history, the Rehnquist Court, where businesses came out on top 48.3 percent of the time.

Add the court's appetite for rolling back civil rights protections — especially when those protections seem to get in the way of parties that the majority of justices seem to have sympathy for, like <u>businesses that want to refuse service</u> to <u>LGBTQ clients</u> or Republican lawmakers who want to <u>gerrymander their</u> districts.

And this is all despite the fact that testers who challenge businesses engaged in discrimination have historically been a crucial tool in protecting civil rights. Consider the bombshell 2020 report — using testers that had no intention of actually renting properties — that found that Black would-be renters in Greater Boston experienced discrimination by real estate brokers and landlords in a whopping 71 percent of cases. The use of testers has been foundational in addressing racial discrimination, gender bias, anti-LGBTQ practices, and more. But all that could be in peril if the court strips that tool from ADA litigation. I'm not naive enough to think Congress might act to clarify the ADA in a way that ensures fairness to businesses while keeping the private right of action intact, which would be the ideal solution. But if there is any appetite for lawmakers to act, now is the time — before the Supreme Court does first. https://tinyurl.com/SupremeCourtsNewTargetADA

21. \*New York Times

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March 28, 2023

I Am Going Blind, and I Now Find It Strangely Exhilarating By Edward Hirsch

I have been gradually going blind for the past 20 years. I didn't pay attention — I thought I needed better glasses — until one night I popped out to go to the bathroom in a crowded movie theater. When I returned, the people and the seats had disappeared. I couldn't see anything except the screen. I stood in the back of the theater until my partner, Laurie, came to find me. This was disconcerting, but I went about my business in my usual state of cheerful denial. My doctor mentioned that with my vision at less than 20/200, I was legally blind and advised me to go get certified. . .

To start, I called Lighthouse Guild, an organization that helps people affected by vision loss. Taking seemingly simple steps like this can be difficult. It can feel shameful. Psychological barriers can get in the way. I've learned that you first need to publicly identify and acknowledge your disability. Then you must acknowledge, to yourself and to others, that you need help. And, finally, you must be willing to accept the help that is offered. You have to say yes. Some people never make that leap. For me, it was a relief. A burden was lifted. After I got my diagnosis from Lighthouse and it was confirmed by the state, a world opened for me. I qualified for all sorts of free services that enable me to function more or less normally. I now have an advocate for the visually impaired. In the past year, I've gotten help from an eye doctor who specializes in low vision, an ophthalmologist, and a computer specialist. Someone even came to the house to teach me to do things, including cook. Her specialty is Peruvian stew. My apartment is newly outfitted. My cooking teacher brought me a scale that calls out my weight — I haven't convinced it to lie. On my own, I've purchased an array of handy tools. I have glow-in-the-dark tape on the light switches and a long string of motion-activated lights in the hallway. I carry a tiny, high-intensity flashlight everywhere. A magnifying glass is close at hand. I have a Seeing AI app on my phone that reads documents. It also describes scenes and people: "73-year-old man standing in front of a bookstore looking happy ...."

https://tinyurl.com/StrangelyExhilarating

#### **Aging Topics**

#### 22. ^Washington Post

March 29, 2023

Exercise with a buddy. Your brain will thank you for it.

By Meeri Kim

Regular social exercise by older adults may counter physical inactivity and low social participation, both of which contribute to about 40 percent of dementias worldwide, research findings suggest.

Social exercise — working out with another person — has many advantages, and new research suggests it also may extend to your brain.

Having a <u>workout buddy</u> has been shown to help boost your motivation, sense of adventure and the likelihood of showing up. For older adults, the potential benefits are even more pronounced. Compared with those who exercise solo, people older than 65 who exercise with others are <u>more physically active</u>, have a lower risk of <u>functional disability</u> and suffer <u>fewer falls</u>.

A new <u>study</u> of 4,358 older adults in Japan has found that participants who worked out with others at least twice a week had a lower risk of developing cognitive impairment than those who did so alone or not at all. . .

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The importance of exercise in preventing and managing age-related conditions is becoming increasingly clear. A recent <u>consensus statement</u> based on the available scientific evidence recommends <u>older adults engage in physical activity</u> to promote <u>health</u>, prevent diseases and treat a wide range of conditions. . .

The World Health Organization recommends that adults 65 and older engage in at least 150 minutes of moderate activity or 75 minutes of vigorous activity per week, along with at least two or more days of muscle-strengthening activity. But only 16 percent of older Americans meet these guidelines. . .

"No matter your age, it's never too late to start contracting those muscles and reaping the benefits of exercise."

https://tinyurl.com/WPWorkoutBuddy

#### End of Life

# 23. \*New York Times

March 29, 2023

As a Doctor, I Know Being Ready to Die Is an Illusion

By Sunita Puri

It's been almost a decade since I finished my medical residency and became a "real doctor." After training ended, I faced one final hurdle: passing a grueling eight-hour-long internal medicine board exam. Back then, it seemed as though there was nothing more important than knowing the right answers. What I didn't know was that when practicing palliative care, it's really about asking the right questions.

As a resident, I would have never let myself consider only the most obvious diagnosis for a patient's illness. But when it came to my patients' personal lives, I too easily assumed the simplest narratives: Amid a health crisis, previously divided families would surely rally around their loved one. A person dying at the age of 90 must have lived a long and fulfilling life. Agreeing to hospice care meant that a patient had accepted that they were dying.

Back then, I didn't question what "accepting" death really meant, or whether it was something I could expect from my patients. I struggled to ask about their suffering unless they seemed ready to embrace their fate, fearful that I might inadvertently worsen it. But as I write in my guest essay this week, I've learned that awaiting specific imaginings of acceptance only justified avoiding having necessary conversations with patients and loved ones about what they fear and need as death nears.

Several days ago, I sat in the corner of a hospital room with the daughter of a patient suffering from incurable cancer. She was a nurse and told me that she was worried that her mother hadn't come to terms with the end of her life. I know the stages of grief, she said, and I think she is in denial, but maybe you could help her understand she needs to accept what is coming.

Ten years ago, I would have nodded, confident that I might help her mother, earnest in my naïveté. I still feel the initial rush of my inclination toward rescue. I knew the answer she wanted, but instead I asked a question. "I'm happy to speak with your mother and understand how she is making sense of what she is going through. But is this conversation also a way to help you to find peace?" She considered my question. Then she met my gaze, her eyes brimming with emotion, whispering, only, "Yes."

https://tinyurl.com/ReadyToDieIsAnIllussion

\*May require registration before accessing article.

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Dignity Alliance Massachusetts Legislative	Information about the legislative bills which have been endorsed by Dignity Alliance Massachusetts, including the text of the bills, can be viewed at:			
Endorsements	https://tinyurl.com/DignityLegislativeEndorsements  Questions or comments can be directed to Legislative Work Group Chair Richard  (Dick) Moore at rmoore8473@charter.net.			
Websites				
Previously recommended websites	The comprehensive list of recommended websites has migrated to the Dignity Alliance MA website: <a href="https://dignityalliancema.org/resources/">https://dignityalliancema.org/resources/</a> . 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 <a href="https://dignityalliancema.org/funding-opportunities/">https://dignityalliancema.org/funding-opportunities/</a> .			
Websites of Dignity Alliance Massachusetts Members	See: https://dignityalliancema.org/about/organizations/			
Nursing home closures	<ul> <li>Chapin Center, Springfield         160 beds; current census: 91         Owner: The Northeast Health Group, Inc.         Star rating: 3 stars         Notice date: February 6, 2023         Target closure: June 6, 2023         Notice of Intent to Close and Draft of Closure and Relocation Plan (PDF)     </li> <li>Governor's Center, Westfield         100 beds; current census: 70         Owner: The Northeast Health Group, Inc.         Star rating: 1 star         Notice date: February 6, 2023         Target closure: June 6, 2023         Notice of Intent to Close and Draft of Closure and Relocation Plan (PDF)     </li> <li>Willimansett Center East, Chicopee         85 beds; current census: 65         Owner: The Northeast Health Group, Inc.         Star rating: 4 stars         Notice date: February 6, 2023         Closed: March 2023     </li> <li>Willimansett Center West, Chicopee         103 beds; current census: 71         Owner: The Northeast Health Group, Inc.         Star rating: 5 stars         Notice date: February 6, 2023         Target closure: June 6, 2023         Notice of Intent to Close and Draft of Closure and Relocation Plan (PDF)     </li> <li>Voluntary nursing home closure process         When a facility decides to voluntarily close, there are several requirements that it must fulfill before it can complete the closure. This process is outlined in the Licensure Procedure and Suitability Requirements for Long-Term Care</li> </ul>			
Nursing homes with admission freezes	Facilities regulations (105 CMR 153.000).  Massachusetts Department of Public Health Temporary admissions freeze			

 On November 6, 2021 the state <u>announced</u> that it would require certain high risk nursing homes and rest homes to temporarily stop all new admissions to protect the health and safety of residents and prevent further COVID-19 transmission.

Stopping admissions enables homes to focus resources such as staff and PPE on the health and safety of its current residents and enables the home to stabilize before taking on new residents. Homes that meet certain criteria will be required to stop any new admissions until the Department of Public Health has determined that conditions have improved, and the facility is ready to safely care for new residents. The Commonwealth will work closely with homes during this time and provide supports as needed to ensure resident health and safety.

- There are a number of reasons why a facility may be required to stop admissions, and the situation in each facility is different. Some of the factors the state uses to make this decision include:
- Number of new COVID-19 cases within the facility
- Staffing levels
- Failure to report a lack of adequate PPE, supplies, or staff
- Infection control survey results
- Surveillance testing non-compliance

Facilities are required to notify residents' designated family members and/or representative when the facility is subject to an admissions freeze. In addition, a list of facilities that are currently required to stop new admissions and the reason for this admissions freeze will be updated on Friday afternoons, and as needed when the Department of Public of Health determines a facility can be removed from the list.

Updated on March 30, 2023. Red font - newly added

Name of Facility	City/Town	Date of Freeze	Qualifyin g Factor	Star Rating	
Chapin Center	Springfield	2/1/2023	Closure	3	
Governor's Center	Westfield	2/1/2023	Closure	1	
Labelle's Rest Home	Shelburne	3/29/2023	Cases	N/A	
Sancta Maria Nursing Facility	Cambridge	3/29/2023	Cases	3	
Springside Rehabilitation and Skilled Care Center	Pittsfield	3/22/2023	Cases	2	
Willimansett – West	Chicopee	2/1/2023	Closure	5	

# List of Special Focus Facilities

#### **Centers for Medicare and Medicaid Services**

List of Special Focus Facilities and Candidates

https://tinyurl.com/SpeciialFocusFacilityProgram

Updated October 26, 2022

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.

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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 July 27, 2022) Newly added to the listing

None

### Massachusetts facilities not improved

 Attleboro Healthcare, Attleboro https://tinyurl.com/AttleboroHealthcare

### Massachusetts facilities which showed improvement

 Marlborough Hills Rehabilitation and Health Care Center, Marlborough https://tinyurl.com/MarlboroughHills

## Massachusetts facilities which have graduated from the program

- Oxford Manor, Haverhill
- Worcester Health Center, Worcester

#### Massachusetts facilities that are candidates for listing

 Charwell House Health and Rehabilitation, Norwood <u>https://tinyurl.com/Charwell</u>
 Nursing home inspect information:

https://projects.propublica.org/nursing-homes/homes/h-225208

 Medway Country Manor Skilled Nursing and Rehabilitation, Medway <a href="https://www.medwaymanor.com/">https://www.medwaymanor.com/</a>

https://projects.propublica.org/nursing-homes/homes/h-225412

 Mill Town Health and Rehabilitation, Amesbury No website

Nursing home inspect information:

Nursing home inspect information:

https://projects.propublica.org/nursing-homes/homes/h-225318

 Plymouth Rehabilitation and Health Care Center https://plymouthrehab.com/

Nursing home inspect information:

https://projects.propublica.org/nursing-homes/homes/h-225207

 Savoy Nursing and Rehabilitation Center, New Bedford No website
 Nursing home inspect information:

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https://projects.propublica.org/nursing-homes/homes/h-225423 South Dennis Healthcare, South Dennis https://www.nextstephc.com/southdennis Nursing home inspect information: https://projects.propublica.org/nursing-homes/homes/h-225320 Tremont Health Care Center, Wareham https://thetremontrehabcare.com/ Nursing home inspect information: https://projects.propublica.org/nursing-homes/homes/h-225488 Vantage at Wilbraham No website Nursing home inspect information: https://projects.propublica.org/nursing-homes/homes/h-225295 Vantage at South Hadley No website Nursing home inspect information: https://projects.propublica.org/nursing-homes/homes/h-225757 Watertown Rehabilitation and Nursing Center, Watertown (added in June) No website Nursing home inspect information: https://projects.propublica.org/nursing-homes/homes/h-225425 https://tinyurl.com/SpeciialFocusFacilityProgram **ProPublica** Nursing Home Inspect **Nursing Home Inspect** Data updated November 2022 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?) # reported **Deficiency Tag** 250 В C 82 7,056 D 1,850 Ε F 546 487 G 31 Н 1 1 40 K **Centers for Medicare and Medicaid Services (CMS) Nursing Home Compare** *Nursing Home Compare Website* 

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	<ul> <li>Beginning January 26, 2022, the Centers for Medicare and Medicaid Services (CMS) is posting new information on the 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:         </li> <li>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.</li> <li>Weekend staff: The level of weekend staffing for nurses and registered nurses at a nursing home over a three-month period.</li> <li>Posting of 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.</li> <li><a href="https://tinyurl.com/NursingHomeCompareWebsite">https://tinyurl.com/NursingHomeCompareWebsite</a></li> </ul>
Data on Ownership of	Centers for Medicare and Medicaid Services
Nursing Homes	Data on Ownership of Nursing Homes  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 <a href="mailto:data.cms.gov">data.cms.gov</a> and updated monthly.
Long-Term Care Facilities	Massachusetts Department of Public Health
Specific COVID-19 Data	Long-Term Care Facilities Specific COVID-19 Data Coronavirus Disease 2019 (COVID-19) reports related to long-term care facilities in Massachusetts.  Table of Contents  COVID-19 Daily Dashboard COVID-19 Weekly Public Health Report Additional COVID-19 Data CMS COVID-19 Nursing Home Data
DignityMA Call to Action	The MA Senate released a report in response to COVID-19. Download the
	<ul> <li>DignityMA Response to Reimagining the Future of MA.</li> <li>Advocate for state bills that advance the Dignity Alliance Massachusetts' Mission and Goals – <u>State Legislative Endorsements</u>.</li> <li>Support relevant bills in Washington – <u>Federal Legislative Endorsements</u>.</li> <li>Join our <u>Work Groups</u>.</li> <li>Learn to use and leverage Social Media at our workshops: <u>Engaging Everyone</u>: <u>Creating Accessible</u>, <u>Powerful Social Media Content</u></li> </ul>
Access to Dignity Alliance	Email: info@DignityAllianceMA.org
social media	Facebook: https://www.facebook.com/DignityAllianceMA/
	Instagram: https://www.instagram.com/dignityalliance/
	LinkedIn: https://www.linkedin.com/company/dignity-alliance-massachusetts
	LinkedIn: <a href="https://www.linkedin.com/company/dignity-alliance-massachusetts">https://www.linkedin.com/company/dignity-alliance-massachusetts</a> Twitter: <a href="https://twitter.com/dignity">https://twitter.com/dignity</a> ma?s=21

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Participation opportunities	Workgroup	Workgroup lead	Email	
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	Behavioral Health	Frank Baskin	baskinfrank19@gmail.com	
Most workgroups meet bi-	Communications	Pricilla O'Reilly	prisoreilly@gmail.com	
weekly via Zoom.		Lachlan Forrow	<u>Iforrow@bidmc.harvard.edu</u>	
Weekly via 200111.	Facilities (Nursing	Arlene Germain	agermain@manhr.org	
	homes, rest homes,			
	assisted living)			
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	Community Based			
	Services			
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	Transportation	Frank Baskin	baskinfrank19@gmail.com	
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	Covid / Long Covid	James Lomastro	jimlomastro@comcast.net	
Please contact group lead	Incarcerated Persons	TBD	info@DignityAllianceMA.org	
for more information.				
The Dignity Digest	For a free weekly subso	cription to The Dign	ity Digest:	
	https://dignityalliancer	ma.org/contact/sign	-up-for-emails/	
	Editor: Paul Lanzikos			
	Primary contributor: Sa	andy Novack		
	MailChimp Specialist: Sue Rorke			
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	Wynn Gerhard			
	Dick Moore			
	Julian Rich			
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	If you have submissions for inclusion in <u>The Dignity Digest</u> or have questions or			
	comments, please submit them to <u>Digest@DignityAllianceMA.org</u> .			
Dignity Alliance Massachusetts	Dignity Alliance Massachusetts is a broad-based coalition of organizations and individuals pursuing fundamental			

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. Our guiding principle is the assurance of dignity for those receiving the services as well as for those providing them. The information presented in "The Dignity Digest" is obtained from publicly available sources and does not necessarily represent positions held by Dignity Alliance Massachusetts.

Previous issues of The Tuesday Digest and The Dignity Digest are available at: <a href="https://dignityalliancema.org/dignity-">https://dignityalliancema.org/dignity-</a> digest/

For more information about Dignity Alliance Massachusetts, please visit www.DignityAllianceMA.org.

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