

# The Dignity Digest

Issue # 110 October 17, 2022

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



Paul Spooner, 1955-2022 Advocate, Leader, Devoted Friend

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|                       | *May require registration before accessing article.  |
|-----------------------|--|
| Paul Spooner Tributes | Boston Globe   |
|                       | October 15, 2022   |
|                       | Paul Spooner, advocate who expanded opportunities for the disabled, dies at 67   |
|                       | When Paul Spooner was diagnosed as a boy with a form of muscular   |
|                       | atrophy and left unable to walk, he had the good fortune to be part of a   |
|                       | family that insisted he could still do whatever he wanted.   |
|                       | "My parents never really treated me as having a disability that limited  |
|                       | my abilities," he said in <u>an interview</u> for the Massachusetts Tales of   |
|                       | Independence website.  |
|                       | So instead of mourning the loss of certain physical abilities, "I  |
|                       | volunteered. I became an advocate. I participated in civil rights  |
|                       | demonstrations. I got really involved in the early days of the   |
|                       | Massachusetts disability programs and disability movement."  |
|                       | A powerful voice for those with disabilities, and the <u>executive director</u>  |
|                       | of the MetroWest Center for Independent Living for 30 years, Mr.   |
|                       | Spooner died Oct. 8 in Beth Israel Deaconess Hospital in Plymouth, just a  |
|                       | couple of days after telling those close to him that he wasn't feeling well  |
|                       | and should check into a hospital.  |
|                       | He was 67 and lived in Taunton. Decades ago, a doctor had predicted he   |
|                       | wouldn't live past 30.   |
|                       | "Paul Spooner passionately lived disability rights. It defined him and he  |
|                       | helped define the cause," said Bill Henning, executive director of the   |
|                       | Boston Center for Independent Living.  |
|                       | Among the most significant legacies left by Mr. Spooner, who began his   |
|                       | advocacy work in his 20s, is that he "was one of the biggest champions   |
|                       | of the state's <u>Personal Care Attendant</u> program, relentlessly speaking out for enrollees and their right — and it was his right, too, as a PCA |
|                       | user — to control their personal care," Henning wrote in an e-mail.  |
|                       | Over the course of decades, Mr. Spooner "worked with and spiritedly  |
|                       | challenged advocates and state policy-makers, helping the program  |
|                       | grow into one of the most successful independent living programs in the  |
|                       | US," Henning added.  |
|                       | He said that statewide, about 40,000 people whose lives are fuller and   |
|                       | less restricted because of their access to personal care attendants "owe   |
|                       | some element of their independence to Paul."   |
|                       | "I always say that he's an advocate's advocate," said Joe Bellil, board  |
|                       | president at MetroWest Center for Independent Living. "He's the person   |
|                       | you want to have by your side when you're trying to get some   |
|                       | legislation passed. He's the one who's going to push it more than  |
|                       | anyone else."  |
|                       | While working as executive director at the MetroWest Center in   |
|                       | Framingham, Mr. Spooner served at various times as president and vice  |
|                       | president of the National Council on Independent Living, and as a board  |
|                       | member of the National Rehabilitation Association. He also had been  |
|                       | the chair and vice chair of the Massachusetts Statewide Independent  |
|                       | Living Council.  |
|                       | "When I became president of the board, we always had an  |
|                       | understanding that we were going to share Paul, if you will," Bellil said  |

of Mr. Spooner's work at the center. "Paul was always going to do advocacy. He did it well and people needed him."

Mr. Spooner also found time to speak with those who were born with disabilities or who, like him, found themselves confronting a life-changing diagnosis at an early age.

"The best sense of reward I get is talking, particularly to young kids with disabilities, about understanding that they have the potential to do just about everything or anything they set their mind to," he said in the Massachusetts Tales of Independence video.

"I was taught that from my parents, and I really didn't succumb to some of the negative stereotypes of having a disability," Mr. Spooner said. "But that's an always present issue even to this day, with all of the legislation and protections we have."

The younger of two siblings, Mr. Spooner was born on April 17, 1955, in Honolulu, when his parents were teachers in Hawaii.

His mother, Margaret Andrews Spooner, taught social studies, and his father, William Merton Spooner, taught math.

His parents' work then took them to Japan, where "my sister and I spoke English and Japanese," he said in the Tales of Independence interview, and he was 7 when his father landed a job in Switzerland. It was there, Mr. Spooner recalled, that "my disability began to show up in complications with walking."

His family decided he should live in Brockton with his paternal grandparents to be close to good medical care. Despite the treatments, some of which Mr. Spooner recalled as "really archaic," his condition worsened and he ended up permanently disabled and unable to walk. Homeschooled initially, he eventually spent two high school years at the Massachusetts Hospital School in Canton.

Mr. Spooner graduated in 1981 from what was then Southeastern Massachusetts University with a bachelor's degree in sociology and political anthropology. In 1989, he received a master's in rehabilitation counseling from Assumption College.

Through the 1980s and into the early 1990s, until he became executive director of the MetroWest Center, Mr. Spooner's work included positions at the Massachusetts Hospital School, Boston University School of Medicine, and a Brockton agency, in each case helping those living with disabilities.

He and Winifred McGraw became a couple 43 years ago.

"When I was first dating him, he was going to college," said McGraw, an executive assistant at the MetroWest Center. "You didn't look at him and see a disability. You just saw this massively dynamic person. You wanted to be around him to see what happened next."

Though Mr. Spooner is best known for his advocacy and leadership, she said, "he also found time to just be himself and do the things that brought him joy, like traveling around the country, and camping, and photography."

Mr. Spooner also ensured that photography would be part of the center's new offices, which the agency moved into in late September. Walking into the offices, people see two walls featuring photos of those who have been involved with disability rights advocacy — "Paul would

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call them the dinosaurs of the movement," said Rose Quinn, the longtime assistant director of the center.

Through oral histories and photos, Mr. Spooner wanted to preserve those memories "so the struggle would not be forgotten by the new generation," Quinn said.

The photo display includes a shot of the signing, on the South Lawn of the White House, of the Americans with Disabilities Act on July 26, 1990, an event Mr. Spooner attended.

"To this day I still feel like July 26 is my Fourth of July," he said in the video interview, "because that's really when I, as an American, got my full civil rights to be an American in this society."

A memorial gathering was held Saturday for Mr. Spooner, whose only immediate survivor is Wini McGraw, his longtime partner.

Mr. Spooner, who was appointed by state Senate President Karen Spilka to serve on the state's <u>new Commission</u> on the Status of Persons with Disabilities and became treasurer of the group, recalled that he was introduced to the idea of fighting for civil rights while watching the evening TV news with his grandparents when he was a boy. Until his final days, he kept up his own civil rights advocacy for those with disabilities.

"We face oppression, we face discrimination, we face racism, we face ableism — we face all kinds of barriers," he said in the video interview. "And the most important thing I do every day is hopefully help people understand that as a group, we can fight that."

https://tinyurl.com/PaulSpoonerAdvocate

#### **GBH News**

October 11, 2022

Disability community mourns the death of 'fierce' advocate Paul Spooner

Paul Spooner, a longtime disability advocate whose work is credited
with improving the lives of thousands of people in Massachusetts, died
unexpectedly early Saturday morning after a brief illness and
hospitalization. He was 67.

Spooner had a form of muscular atrophy since he was a child, and he used a power wheelchair. His 40 years of advocacy spanned key moments in disability history, including being on the White House lawn when the Americans with Disabilities Act was signed in 1990. He said he considered that day, July 26, 1990, his 4th of July because he finally felt like he reached a form of equality that had been denied disabled people for so long. But he felt there was still much work to be done.

Since the early 1990s, Spooner had been the executive director of the MetroWest Center for Independent Living in Framingham. He was a past president of the National Council of Independent Living, and a relentless advocate for improving the lives of people with disabilities through legislation affecting health care, transportation, housing, and employment.

Spooner's "crowning achievement," according to Bill Henning, executive director of the Boston Center for Independent Living, was his work growing the Personal Care Attendant program, which he saw as instrumental to enabling disabled people to live independently in their communities. The MassHealth program provides funding to people with

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disabilities so they can hire attendants to assist with daily living activities like getting out of bed, dressing, taking medication and eating.

"In the early 90s, this program had 3,000 people on it and now has over

"In the early 90s, this program had 3,000 people on it and now has over 40,000 people on it," Henning said. "So, there's at least 40,000 people with disabilities in the state who can trace much of their independence to Paul."

Henning had been Spooner's peer and collaborator in disability policy for almost 40 years, and notes that while Spooner was always "on the front lines" of every single protest, he was also in the backroom making deals and ironing out the details of complicated legislation.

Spooner was "fierce" and determined in his advocacy, yet collaborative and practical when it came to working with public officials, according to Henning. He "basically marched up to the offices of [Governors] Bill Weld, Paul Celucci, Mitt Romney, Deval Patrick and Charlie Baker and demanded that they rescind cuts," Henning said. "And ultimately everyone ended up working with Paul ... He collaborated; he became partners with them."

Spooner's advocacy extended to improving working conditions for personal care attendants, and he was instrumental in writing legislation to allow attendants to unionize in the early 2000s.

"That's something we [the Boston Center for Independent Living] thought was really terrific ... but it was a jolt to lots of people," Henning said. "And Paul crossed the bridge between the Patrick administration, SEIU and the consumer community."

Spooner grew up in the 1960s, well before the ADA was passed, when he would regularly encounter buildings without ramps or be barred access to public spaces. He attended Massachusetts Hospital School at a time when education for kids with disabilities was still segregated. "He didn't go to a regular school. They put kids in wheelchairs for no reason other than disability in a hospital," Henning said. "He didn't like it. Paul was a rebel — I think that was very formative for him as well." Spooner witnessed how the language of the civil rights movement — of dignity, fairness, equality — could be extended to disability justice. "There was this coming of age, as a teenager, there was this hangover of all the protests, of the justice demands of the 1960s, of the civil rights marches. And I know that impacted him," Henning said.

Spooner carried the lessons from that era with him throughout his career and passed it on. Alex Green, a public policy professor at the Harvard Kennedy School of Government says Spooner had recently become a "driving force" behind his own disability rights work, most recently helping pass <a href="Legislation to create a special commission">Legislation to create a special commission</a> to study the history of state institutions for people with intellectual or developmental disabilities.

Green observed that Spooner was always thinking about how to sustain and diversify the next generation of leaders.

"I think he was very aware [that] the people who'd been involved since the 1970s, that that generation of folks was predominantly white and predominantly male," Green said. "And I think Paul was one of a handful of leaders to really say, 'If you are not white and not male, come in too,

 and we need you and you are the next generation of leaders and you are the ones who I will support.'"

One person who Spooner influenced was Keith Jones, a local musician and advocate who collaborated with Spooner on issues like PCA unionization, health care policy, the cost of transportation and voting access.

Jones said he is still processing the news of Spooner's sudden death and reflecting on the importance of learning from the "elders" of the disability justice movement.

"Have we stacked the bench deep enough with young leaders or new leaders so that, whatever the momentum we've gained with Paul won't be lost?" Jones wondered. "Paul was an icon ... I have learned a lot from him and I have tried to pass that on."

Spooner was focused on the "post-ADA" generation of people born after the passage of the law and spoke to Green's public policy students about disability rights.

"I think everyone was in awe of Paul," Green said. "He could simultaneously balance his incredible expertise on things that are, you know, public policy that's very confusing and complex, with an incredible humanity and a real sort of forward-looking vision." Spooner was a commissioner and treasurer of the state's new Commission on the Status of Persons with Disabilities, established in 2020 to bring together the disability community and make legislative recommendations on issues like affordable housing, transportation, and workforce development.

"If there is one in place that could really embrace the fullness of Paul's vision and thinking and put it into practice, it would be that commission," Green said.

Rep. Denise Garlick of Needham, chair of the commission, said, "Paul was instrumental in creating a vision for our Commission that would modernize accessibility rights in Massachusetts. He was driven, passionate, and strategic in his advocacy, where his voice impacted policy and programs that improved the lives of countless individuals with disabilities."

According to Henning, Spooner's priorities at the time he passed included shoring up funding for the attendant program, increasing funding for independent living centers, passing legislation to change the rules of the State Architectural Access Board to require more accessibility at home and in workplaces and supporting the alternative housing voucher program to help people with disabilities get affordable housing.

"The general public doesn't know about [these issues], but they're the meat and potatoes of what drives independence and quality lives for lots of people with disabilities," Henning said. "That's what he was about."

https://tinyurl.com/FierceAdvocatePaulSpooner

MA Tales of Independence: My Life, My Story, and the Meaning of Independent Living in Videos

Civil Rights Movement and Disability Rights – Paul Spooner

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12-minute video of Paul Spooner explaining how became involved as a leading advocate in the civil rights movement for persons with disabilities.

<a href="https://matalesofindependence.net/civil-rights-movement-and-disability-rights-paul-spooner/">https://matalesofindependence.net/civil-rights-movement-and-disability-rights-paul-spooner/</a>

# Quotes of the Week

"There's at least 40,000 people with disabilities in the state who can trace much of their independence to Paul."

Bill Henning, Executive Director, Boston Center for Independent Living, Disability community mourns the death of 'fierce' advocate Paul Spooner, GBH News, October 11, 2022, https://tinyurl.com/FierceAdvocatePaulSpooner

"I think everyone was in awe of Paul. He could simultaneously balance his incredible expertise on things that are, you know, public policy that's very confusing and complex, with an incredible humanity and a real sort of forward-looking vision."

Alex Green, public policy professor, Harvard Kennedy School of Government, *Disability community mourns the death of 'fierce' advocate Paul Spooner*, **GBH News**, October 11, 2022, https://tinyurl.com/FierceAdvocatePaulSpooner

"I always say that he's an advocate's advocate. He's the person you want to have by your side when you're trying to get some legislation passed. He's the one who's going to push it more than anyone else."

Joe Bellil, board president, MetroWest Center for Independent Living, Paul Spooner, advocate who expanded opportunities for the disabled, dies at 67, Boston Globe, October 15, 2022, https://tinyurl.com/PaulSpoonerAdvocate

"My parents never really treated me as having a disability that limited my abilities."

Paul Spooner, Executive Director, MetroWest Center for Independent Living, *Paul Spooner, advocate who expanded opportunities for the disabled, dies at 67*, **Boston Globe,** October 15, 2022, <a href="https://tinyurl.com/PaulSpoonerAdvocate">https://tinyurl.com/PaulSpoonerAdvocate</a>

"People believe disability is synonymous with negativity, and they don't have a more expansive understanding of what disability is or an experience that's more

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comprehensive. They don't understand that you could be in need of care, a caregiver, and a community builder all at once. They see disability through the prism of a limitations lens only, and it has a much wider lens than that."

Heather Watkins, a Boston disability rights activist and board member of the <u>Disability Policy Consortium</u>, *Ableism is on the Ballot*, **Boston Globe**, October 16, 2022,

https://www.bostonglobe.com/2022/10/16/opinion/ableism-is-ballot/

"Every day I tell myself I'm trying to do as much as I can, that my body allows me to, but many, many nights I've spent awake thinking about our financial situation. I don't know. It's just always there."

Melissa Hamre, who has had long COVID since March 2020, *Long COVID took their health. Then it took their money,* \*Boston Globe, October 15, 2022, <a href="https://tinyurl.com/LongCovidTookHealth">https://tinyurl.com/LongCovidTookHealth</a>

The key is "to stay active and connect with others. People who engage in meaningful, productive activities with others feel a sense of purpose and tend to live longer."

Elizabeth Necka, program director at the National Institute on Aging, Forget Wordle. Here are 5 secrets to living better, longer. Practical, proven methods for staying healthy and active later in life. \*Boston Globe, October 13, 2022, https://tinyurl.com/5SecretsLivingBetter

"It's going to be the wild, wild west for a few years, but I mean that in a good way. There is so much market opportunity here. It's never been done this way."

Frank Lin, director of the Cochlear Center for Hearing and Public Health at Johns Hopkins's Bloomberg School of Public Health, *Listen up: You can now buy hearing aids without a prescription*, \*Washington Post,
October 16, 2022, https://tinyurl.com/HearingAidsWithoutPrescription

The implications of this are immense. If the prevalence of long covid turns out to be 1 in 5 people, that's 124 million of the 623 million infected so far worldwide who will carry the scars of the pandemic into the future,

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# creating potentially large burdens on health-care systems.

After the pandemic, heavy burdens for a covid generation, \*Washington Post, October 14, 2022, <a href="https://tinyurl.com/PandemicHeavyBurdens">https://tinyurl.com/PandemicHeavyBurdens</a>

### Dignity Votes 2022

# REMINDER: GENERAL ELECTION DAY IS TUESDAY, NOVEMBER 8th #TheArcVotes

Virtual Disability Forum with Gubernatorial Candidate Maura Healey Thursday, October 27, 2022, 12:00 p.m.

The Arc of Massachusetts, Advocates for Autism of Massachusetts, Boston Center for Independent Living (BCIL), Disability Law Center (DLC), Massachusetts Advocates Standing Strong (MASS), and the Massachusetts Developmental Disabilities Council (MDDC) are pleased to organize Virtual Disability Forums with Candidates running for Governor of the Commonwealth of Massachusetts. The second forum, with Candidate Maura Healey (D), will be on October 27 at 12:00PM. Registration is now open here.

# Candidates for Governor, Lieutenant Governor, Attorney General, Secretary State, and State Auditor

Responses to questionnaires from candidates for these offices have been posted at <a href="https://dignityalliancema.org/state-candidates/">https://dignityalliancema.org/state-candidates/</a>.

Forum with gubernatorial candidate Geoff Diehl
 The forum, held on Wednesday, September 28, was organized by
 Advocates for Autism of Massachusetts, Boston Center for Independent
 Living, the Disability Law Center, Mass Advocates Standing Strong,
 Massachusetts Developmental Disabilities Council, and the ark of
 Massachusetts. The transcript is posted on
 https://dignityalliancema.org/state-candidates/.

#### **Congressional office candidates**

Questionnaires for congressional candidates have been distributed. Responses are being posted on <a href="https://dignityalliancema.org/congressional-candidates/">https://dignityalliancema.org/congressional-candidates/</a> as they are received.

## State legislative candidates

Questionnaires for legislative office candidates have been distributed. Responses are being posted on <a href="https://dignityalliancema.org/state-candidates/">https://dignityalliancema.org/state-candidates/</a> as they are received.

#### **Fact Sheets and Issue Briefs**

Prepared by Dignity Alliance Massachusetts Workgroups

#### **Nursing Homes**

- Nursing Home Fact Sheet
- Nursing Home Staffing Issues
- Pandemic Issues in Nursing Homes
- Nursing Homes Financial Responsibility
- Nursing Homes Oversight, Licensures, Closures
- Nursing Homes Small Home Model

#### **Home and Community Based Services**

- HCBS Fact Sheet
- HCBS Staffing Issues

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# **HCBS Care Coordination Issues Behavioral Health** Behavioral Health Fact Sheet BH Elder Mental Health Outreach Teams (EMHOT) Issues BH Nursing Homes and Psychotropic/Antipsychotic Drugs Issues Social Work Staffing Issues Housing **Housing Issues Veterans** Veterans Issues https://dignityalliancema.org/2022-facts-and-issues/ **State Election Information** The following websites contain useful, timely information about this year's elections. (Source: AARP Bulletin July / August 2022) AARP Voter Guides Information about the voting process from registration to Election Day voting locations and hours. www.aarp.org/electionguides Ballotpedia Information about statewide races and ballot measures. www.ballotpedia.org OpenSecrets Tracks flow of money within the electoral process. www.opensecrets.org Vote411 Election year information provided by the League of Women Voters. www.vote411.org Vote Smart On demand detailed information about individual candidates www.votesmart.org October: Resident Rights Month October is Resident Rights Month October 1st marked the beginning of a month-long celebration of residents' rights. Spend time this month honoring residents living in all long-term care facilities, including nursing homes, sub-acute units, assisted living, board and care, and retirement communities. Plus, take time to focus on individuals receiving care in their homes or communities. Being a part of a community is essential to our well-being. Throughout the pandemic, residents of long-term care facilities were disconnected from the resident and staff communities within their facilities when activities and group dining were limited. Residents were disconnected from the broader local community when visitation was restricted, and many residents were unable to leave their facilities to participate in outside activities. This year's Residents' Rights Month theme - Inspiring Unity within Our **Community** - emphasizes the importance of fostering meaningful community

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2. Joint Center for Housing Studies at Harvard University

community.
Learn More →

Reports

within the facility and encouraging residents' connection to their local

Advancing Housing and Health Equity for Older Adults: Pandemic Innovations and Policy Ideas

A report released October 6 from the Joint Center for Housing Studies of Harvard University looks at provider responses to social isolation and to disruptions in access to food, medical care, and supportive services by older adults during COVID-19. The report considers how these responses might offer lessons that can improve housing and supports for older adults going forward.

Advancing Housing and Health Equity for Older Adults: Pandemic Innovations and Policy Ideas.

# 3. The Massachusetts Advisory Council on Alzheimer's Disease and All Other Dementias

'Age- and Dementia Friendly Design Considerations for Physical Infrastructure'

The Massachusetts Advisory Council on Alzheimer's Disease and All Other Dementias created a workgroup with a goal of defining age-and dementia friendly design considerations for physical infrastructure, disseminating those findings and advocating for their inclusion in relevant state funding programs. The workgroup has shared the culmination of its work in the form of a guide titled <u>Age and Dementia Friendly Design Considerations for Physical Infrastructure</u>, which highlights design considerations supporting people living with dementia and focused on four types of infrastructure:

- Buildings
- Public Outdoor Spaces
- Transportation
- Housing Developments

The resource promotes commonly accepted physical traits of age and dementia friendly communities focus on design principles that incorporate:

- Inclusive design that considers many aspects of human diversity affecting a person's ability to use the environment, such as ability, gender, age, and culture.
- Easily recognizable design features that are unambiguous and meet people's expectations in terms of appearance, size, and usability.
- Design that clearly designates the purpose for which the place is intended, and uses color, contrast, and clear signage to provide clues to orientation and wayfinding.

The guide can be found at <a href="https://www.mass.gov/doc/af-df-design-considerations-for-physical-infrastructure/download">https://www.mass.gov/doc/af-df-design-considerations-for-physical-infrastructure/download</a>

## Biden / Federal Policies

#### I. The White House

October 17, 2022

Cheaper Hearing Aids Now in Stores Thanks to Biden-Harris Administration Competition Agenda

To lower the price of hearing aids and expand access, President Biden's Executive Order on Promoting Competition in the American Economy called on the Food and Drug Administration (FDA) to make hearing aids available over the counter, without a prescription. That is now reality. Starting today, hearings aids are now on store shelves across the country—for thousands of dollars less than they previously cost.

Specifically, today, under a final rule issued by the FDA, adults with mild-to-moderate hearing loss can buy hearing aids at a store or online without a

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prescription, exam, or audiologist fitting. FDA estimates this could lower average costs by as much as \$3,000 per pair—providing significant breathing room for the nearly 30 million Americans with hearing loss, including nearly 10 million adults under age 60.

Retailers across the country are now selling over-the-counter hearing aids. Options available today or coming soon include:

- Starting today, Walgreens is selling hearings aids at stores nationwide and online for \$799 per pair. According to Walgreens, comparable models sold by specialists range from \$2,000 to \$8,000 a pair.
- Starting today, CVS will start selling over-the-counter hearing aids on CVS.com, with varying options on model and price point. CVS will also offer hearing aids in select CVS Pharmacy locations beginning in November.
- Starting today, Walmart will offer an assortment of over-the-counter hearing aids on Walmart.com, SamsClub.com, and in over 1,000 Vision Centers in Walmart stores across Colorado, Michigan, Missouri, Ohio, Pennsylvania, Tennessee, and Texas, as well as 474 Sam's Club Hearing Aid Center locations. Available products will range in price from \$199 to \$999 per pair, while according to Walmart, comparable prescription hearing aids are priced at \$4,400 to \$5,500 per pair.
- Starting this week, Best Buy will offer nearly 20 different hearing devices online. By the end of October, it will offer hearing aids in nearly 300 stores across the country. Devices will range in price between \$200 and \$3,000.
- Starting this week, Hy-Vee will sell over-the-counter hearing aids online and in 34 locations across Iowa, Kansas, Minnesota, Missouri, Nebraska, and Wisconsin. Hy-Vee plans to offer hearing aids in 100 locations by the end of the year. Hy-Vee will offer four models ranging in price from \$499.99 to \$999.99.

https://tinyurl.com/WhiteHouseCheaperHearingAids

#### 5. \*Washington Post

October 16, 2022

Listen up: You can now buy hearing aids without a prescription Five years after Congress told the FDA to act, new rules give consumers greater control over hearing care

The government on Monday will begin allowing pharmacies and big-box stores to sell hearing aids without prescriptions, a move that is expected to shake up an industry that has long been dominated by a handful of manufacturers under a model of care that critics said raised costs and stifled innovation. . .

The substantial learning curve will be a worthwhile tradeoff for consumers, giving them more options without having to see a doctor, said advocates. The Food and Drug Administration has limited retail, no-prescription sales to devices designed for people 18 and older with mild to moderate hearing loss. . .

Hearing specialists are excited that more people with untreated hearing loss will have access to crucial devices. Untreated hearing loss can lead to cognitive decline, isolation, and dementia, but only a fraction of the 28.8 million who could benefit from hearing aids use them, according to the National Institute on Deafness and Other Communication Disorders. Of

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|                                | those who could benefit, just 16 percent of adults under 69 and just 30 percent over 70 have them, the agency said.  Studies have shown that it takes up to seven years from the time someone first learns they have hearing loss to the point they purchase a hearing aid. Cost and negative stigma are often the biggest factors, say specialists, and over-the-counter sales can ease those consumer concerns  [The] long-standing state of the marketplace caught the attention of Congress. In 2017, a bipartisan law sponsored by Sen. Elizabeth Warren (D-Mass.) and Sen. Charles E. Grassley (R-lowa) directed the FDA to develop rules for over-the-counter sales. It took five years for FDA to finish the job After seeking to blunt over-the-counter sales for years, earning the wrath of members of Congress, the trade association representing the "Big Five" global hearing aid manufacturers has declared its support. Asked why GN's Jabra entered the market with its Enhance Plus hearing aid, Calum MacDougall, Jabra's senior vice president for marketing, said it makes sense to seek out new customers with mild to moderate hearing problems. https://tinyurl.com/HearingAidsWithoutPrescription |
|--------------------------------|---|
| Mahinana and Online Co.        |   |
| Webinars and Online Sessions   | 6. #TheArcVotes Thursday, October 27, 2022, 12:00 p.m. Virtual Disability Forum with Gubernatorial Candidate Maura Healey The Arc of Massachusetts, Advocates for Autism of Massachusetts, Boston Center for Independent Living (BCIL), Disability Law Center (DLC), Massachusetts Advocates Standing Strong (MASS), and the Massachusetts Developmental Disabilities Council (MDDC) are pleased to organize Virtual Disability Forums with Candidates running for Governor of the Commonwealth of Massachusetts. The second forum, with Candidate Maura Healey (D), will be on October 27 at 12:00PM. Registration is now open here.   |
| Previously posted webinars and | Previously posted webinars and online sessions can be viewed at:  |
| online sessions                | https://dignityalliancema.org/webinars-and-online-sessions/   |
|                                | 7. The Arc Massachusetts  |
| In-person educational session  | <ul> <li>Fine Arc Massachusetts         Educational Series for Aging Caregivers of Individuals with Developmental &amp; Intellectual Disabilities         These sessions will focus on topics of interest to families and caregivers including overviews of legal and financial planning, medical issues and supports for individuals with disabilities as they age, Options Counseling, and various available community supports.         <ul> <li>Tuesday, October 18: Special Needs Legal &amp; Estate Planning with Karen Mariscal, Esq</li> <li>Tuesday, October 25: Financial Planning for Special Needs with Cynthia Haddad, Founder &amp; Partner, Affinia Financial Group</li> <li>Tuesday, November 1: Medical and Developmental Issues Related to Aging with Disabilities with James Bath, MD, Director of Primary Care, Lurie Center for Autism &amp; Kathy Service, N.P., Department of Developmental Services</li> <li>Tuesday, November 15: Dept. of Developmental Services Presentation on Meeting the Needs of Older Caregivers presented by a panel of DDS Leadership staff</li> </ul> </li> </ul>  |

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- Tuesday, November 22: Local Transportation and Options for Community Access with Susan Barrett, Transportation Manager, Town of Lexington
- Tuesday, November 29: Overview of Supports Offered for Aging Individuals with Disabilities and their Caregivers by Minuteman Senior Services and Boston Center for Independent Living with Lesli May-Chibani, Asst. Director, Minuteman Senior Services & Maura Donahue, Community Living Advocacy Program Coordinator, Boston Center for Independent Living

All sessions will be held at the Lexington Community Center, 39 Marrett Road in Room 139 from 10:00 to 11:30 a.m.

Sessions are open to the public. Register in advance of the session date. For more specific information on speakers and topics covered, visit <a href="mailto:thearcofmass.org/lexington">thearcofmass.org/lexington</a> or email <a href="mailto:rs.edes@comcast.net">rs.edes@comcast.net</a> Register Now!

#### 8. The Arc of Massachusetts

2021-2022 Transition Conference: Part Two Saturday, October 29, 2022, 8:30 a.m. to 1:30 p.m.

The Arc of Massachusetts will be hosting area panels of young adults, families and professionals who will share their Transition experience and information. Attendees will learn about available services in Southeast Massachusetts by visiting resource tables, connecting with local families and individuals, and learning about the unique offerings in your local community.

Morning refreshments and a box lunch will be offered. Registration is \$25 per individual. For scholarship information or any questions, contact Kerry Mahoney at <a href="Mahoney@arcmass.org">Mahoney@arcmass.org</a>. Register Now!

# Home and Community Based Services

9. The Executive Office of Health and Human Services (EOHHS)

\$42.5M in Grant Funding to Support Provider Home and Community Based Service (HCBS) and Human Services Workforce Development

The Executive Office of Health and Human Services (EOHHS) will award up to \$42.5M in grants to support training, recruiting, and retaining initiatives that support provider home- and community-based services (HCBS) and human services workforce. This is one of several provider grants rolling out over the next six months, including the forthcoming Respite Innovation Grants and Provider Technology Grants.

Any Massachusetts provider, education/training institution, community organization, existing workforce program, or private foundation can apply. Applications are due by 5:00PM on November 4.

Grant proposals must support workers in at least one of the below categories:

- · Direct Care Staff
- Nurses
- · Behavioral Health Staff
- · Community Health Workers
- Long-Term Service and Support (LTSS) Workers

Grant funds can be used for activities to train, recruit, or retain the above categories of workers. Examples of eligible funding proposals include

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developing internships or fellowships, expanding training programs,
converting in-person training to online training, and making IT
improvements.
More detailed lists of workers and activities that are eligible for funding can
be found in the <u>FAQs here</u>.
For more information and answers to frequently asked questions, please

visit the <u>EOHHS website</u>.

Apply for the HCBS and Human Services Workforce Grant

#### Caregiving

#### 10. The Arc Massachusetts

Educational Series for Aging Caregivers of Individuals with Developmental & Intellectual Disabilities

These sessions will focus on topics of interest to families and caregivers including overviews of legal and financial planning, medical issues and supports for individuals with disabilities as they age, Options Counseling, and various available community supports.

- Tuesday, October 18: Special Needs Legal & Estate Planning with Karen Mariscal, Esq
- Tuesday, October 25: Financial Planning for Special Needs with Cynthia Haddad, Founder & Partner, Affinia Financial Group
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#### 11. Health Affairs Branded Post

October 10, 2022

Expanding The Resources Available to Caregivers to Care for Themselves, Their Patients, and Their Families

## The Caregivers Are Not Alright

It's no surprise that the world is at a critical inflection point for mental health. <u>Teens</u>, <u>parents</u>, and <u>older adults</u> are all struggling. And caregivers are certainly no exception.

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While caregiving is a rewarding role for many, it doesn't change the fact that 39% of caregivers across the world say the person they care for, often a loved one, is <u>relying on them more than ever before</u>. From making sure their patient – often a loved one – adheres to their treatment plan to providing emotional support, caregivers take on extreme levels of responsibility to ensure the best outcomes for their patient. This is not a light load, physically or emotionally, for unpaid caregivers to add to their own responsibilities, jobs, and families.

On top of that, 58% of caregivers report that they struggle with their own mental health. And through conversations with them, we know that it is only well into the journey – or after it has ended – that they understand the importance of prioritizing their mental health. The American Psychiatric Association estimates that more than half of people with mental illness avoid or delay treatment due to stigma, including concerns about being treated differently or losing their jobs and livelihood.

#### **Embracing Caregivers and Inspiring Change**

So how do we better support patients and their caregivers? By helping them tend to their mental health early on. From the very beginning, it's important that caregivers not only know how valuable their role is in supporting their patient but also understanding that their own mental health plays a vital role, too. Knowing that there are resources available to them and that there's additional support when they need it is the first step towards making a difference in both the caregiver's and their patient's lives.

Aside from a caregiver experiencing their own health and personal challenges, research shows that when the mental health of the caregiver is compromised, <u>patient mortality is greater</u>, even when accounting for risk factors. By equipping caregivers with a variety of resources that touch on their physical and mental wellbeing, we are creating a healthier, more stable environment for both them and the patient. And when the caregiver feels comfortable, supported, and refreshed, they are able to show up as their best self, providing more focused, positive support for patients – and even help <u>reduce rehospitalizations for chronically ill adults</u>.

https://tinyurl.com/ExpandingResourcesCaregivers

#### 12. Department of Labor

\$80 Million Grant Funding to Address Shortage of Nurses
On October 3, the U.S. Department of Labor (DOL) announced an \$80 million funding opportunity through its Nursing Expansion Grant Program.
The DOL announcement points out "the unprecedented demands that the pandemic placed on the nation's nurses – combined with retirements and an aging workforce – have greatly increased the need for nursing workers in the U.S." The agency also indicates these grants align with the DOL.
Good Jobs Initiative.

#### Long Covid

#### 13. \*Boston Globe

October 15, 2022

Long COVID took their health. Then it took their money.

[Melissa] Hamre, [at the Holyoke Soldiers' Home,] is one of thousands of people in Massachusetts and millions across the country who face significant limitations resulting from long COVID — the term coined for the array of long-term health problems that can arise after a COVID-19

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infection. Ailments, which often don't show up on routine tests, range from "brain fog" to joint pain to heart palpitations.

Long COVID is not only having a profound impact on the health and financial stability of patients, but on the US economy as well, adding to the nation's already acute labor shortage. A report from the <u>Brookings Institution in August</u> estimated that anywhere from 2 million to 4 million people are not able to work because of it, with the toll in lost wages ranging from \$105 billion a year to \$230 billion. . .

Yet little is happening on the policy front to bring financial relief to patients. It's been more than a year since the federal government declared that <u>long COVID could be considered a disability</u> under the Americans with Disabilities Act "if it substantially limits one or more major life activities." But many patients say it is a grueling process to get that designation, much less any financial assistance associated with it, since there are still no best practices for diagnosing or treating long COVID. . .

Many people with long COVID find themselves volleyed from specialist to specialist, from test to test, in search of evidence of their condition in order to qualify for financial assistance. Even with health insurance, copays can stack up, and the quest for proof of their illness can quickly prove exorbitant in its own right. . .

For those unable to keep working, short- and long-term disability insurance may be an option. But those benefits are temporary and often <u>not available</u> to the <u>lower-wage workers hit hardest by the pandemic</u>, said Massachusetts-based disability attorney Patrick Hartwig.

<u>Social Security disability benefits</u> are often the next line of defense, said Hartwig, who has seen a "slow but steady increase" in long COVID clients coming to him for help getting federal benefits. But this, too, is a <u>notoriously slow and difficult process</u>. And, even if clients are approved, with an <u>average monthly payout</u> of \$1,362 per disabled worker, the funds are hardly enough to live on. . .

It remains to be seen whether new policies will come to fruition. A \$1.15 billion federal research effort into long COVID is underway, with several Boston-area hospitals conducting studies to better understand the condition. Representative Ayanna Pressley and Senator Edward Markey sponsored bills related to long COVID treatment and research earlier this year, though neither has made much headway in their respective chambers. https://tinyurl.com/LongCovidTookHealth

### 14. \*Washington Post

October 14, 2022

After the pandemic, heavy burdens for a covid generation

Ask anyone who has experienced the lingering maladies of the pandemic, and they'll tell you long covid is no figment of the imagination. Tiredness, breathlessness, body aches and "brain fog" hang around for millions of people. Some of these symptoms are also common without covid, and researchers are trying to pin down with precision the lasting damage this virus can do to the human body. They are far from a full understanding. That's why a new <a href="study">study</a> in Scotland is important. It was aimed at discovering the frequency, nature, determinants, and impact of long covid on a large scale, to improve on previous partial results in other investigations. The first findings in the Long-COVID in Scotland Study are based on medical records

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and the experiences of more than 33,000 patients who had laboratory-confirmed covid and 62,957 who had never been infected. The researchers, Jill P. Pell of the University of Glasgow and colleagues, found about 6 percent of those infected had "not recovered" and 42 percent "only partially."

This reinforces earlier findings that a large segment of people who are infected continue to experience one or more symptoms long after the infection has passed. In a <u>study</u> published in August from the Netherlands, researchers found post-covid symptoms lingered in about 1 in 8 people. The Centers for Disease Control and Prevention <u>found in a recent large study</u> that 1 in 5 adults from 18 to 64 years old who had covid, and 1 in 4 ages 65 years and older, had at least one persisting health condition related to their covid infection. Yet another <u>survey</u> in April put the prevalence at 43 percent. A new <u>study</u> just published about long covid in Germany put prevalence at 28.5 percent. . .

The implications of this are immense. If the prevalence of long covid turns out to be 1 in 5 people, that's 124 million of the 623 million infected so far worldwide who will carry the scars of the pandemic into the future, creating potentially large burdens on health-care systems. There will be cascading effects in mental health and disability. The impacts will most certainly extend to jobs and education. When the pandemic is over, the world will be left with how to treat and remedy the troubles of the long-covid generation. https://tinyurl.com/PandemicHeavyBurdens

#### Ableism

#### 15. \*Boston Globe

October 16, 2022

Ableism is on the ballot

"People believe disability is synonymous with negativity, and they don't have a more expansive understanding of what disability is or an experience that's more comprehensive," Heather Watkins, a Boston disability rights activist, told me during a recent conversation. "They don't understand that you could be in need of care, a caregiver, and a community builder all at once. They see disability through the prism of a limitation's lens only, and it has a much wider lens than that."

"It's either pity or pedestal. Sadness or 'super-crip.' It's not that full-bodied range of experience," Watkins said. "People tend to focus on what they believe are these small facets that really are just so reductive. It's not surprising, but it's troubling."

More than 795,000 people in the United States will suffer strokes  $\underline{\text{this year}}$ . As a result of Fetterman's, he has some hearing issues and uses a closed-captioning video to read reporters' questions in real time. Occasionally he swings and misses before hitting the word he wants to say. But his speech is not garbled. His answers aren't canned or scripted. . .

There's a reason why two of this nation's most popular presidents concealed their health issues. The public never knew that Franklin D. Roosevelt had polio or that John F. Kennedy suffered from various chronic illnesses. Politicians want to project strength. Selina Meyer, the fictional vice president on HBO's "Veep," shunned wearing her glasses in public because she says they're "like a wheelchair for the eye."

Such attitudes are a disservice to voters, said Watkins, who was born with muscular dystrophy. She views the narrow focus on Fetterman's health as a

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|  | missed opportunity for rare conversations about having a disability and what it means to live in an ableist culture.  "If you're going to talk about his disability, can we hear about how it's contributing to his experience?" asked Watkins, who serves on the board of the Boston-based <a href="Disability Policy Consortium">Disability Policy Consortium</a> . "You don't have to reduce it or erase it. You can include it in a way that informs his perspective and helps contribute to policy measures that he would put forth now and in the future." <a href="https://www.bostonglobe.com/2022/10/16/opinion/ableism-is-ballot/">https://www.bostonglobe.com/2022/10/16/opinion/ableism-is-ballot/</a>   |
|--|--|
| Aging Topics   | October 16, 2022  Wait, Who Did You Say Is Middle-Aged? There's a brutal moment in youth when you go from looking up to your elders to looking somewhat down on them. Or at least seeing them with a more jaundiced eye. Maybe it happens at a party. You glance around the room and realize the gentleman you once saw as distinguished has cheerfully dipped a half-eaten chicken wing into a bowl of hummus. You see what one might politely refer to as a "not young" woman waving her arms around with a little too much gusto on the dance floor. And it hits you: They don't realize that they're old.  https://tinyurl.com/WholsMiddleAged  17. *Boston Globe October 13, 2022 Forget Wordle. Here are 5 secrets to living better, longer. Practical, proven methods for staying healthy and active later in life. We now live in a world with growing numbers of old people, including people older than 100. So, what is accounting for longer lives? Essentially, we have had a safer environment since the 1900s, with basic public health standards when it comes to such things as water, working conditions, refrigeration, and vaccinations, says Tom Perls, professor of medicine at Boston University and director of the New England Centenarian Study, the world's largest ongoing study of people age 100 and older. Those factors have allowed more people to live past childhood illnesses and injuries into adulthood.  But making it to 100? Or 105? At that point, Perls says, it's not good behavior so much as pure luck — in the form of genes. The centenarians he has studied all fit 27 genetic patterns. These genes slow aging and decrease the risk of age-related illnesses such as heart disease, stroke, cancer, diabetes, and dementia.  Here are five ways that you can live a healthier, longer life.  1. Exercise your body for your brain  2. Unlock the mysteries of the microbiome  3. Win the inflammation war  4. Reduce fall dangers at home  5. Make time for friends https://tinyurl.com/5SecretsLivingBetter  *May require registration before accessing article. |
| Dignity Alliance Massachusetts<br>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: <a href="https://tinyurl.com/DignityLegislativeEndorsements">https://tinyurl.com/DignityLegislativeEndorsements</a>   |

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|                                 | Questions or comments can be directed to Legislative Work Group Chair Richard  |  |  |  |  |
|---------------------------------|--|--|--|--|--|
|                                 | (Dick) Moore at <u>rmoore8473@charter.net</u> .  |  |  |  |  |
| Websites                        | MA Tales of Independence   |  |  |  |  |
|                                 | My Life, My Story, and the Meaning of Independent Living in Videos   |  |  |  |  |
|                                 | https://matalesofindependence.net/   |  |  |  |  |
|                                 | At the heart of most of these stories is the Disability Rights Movement.   |  |  |  |  |
|                                 | Even more than 25 years after the Americans with Disability Act was  |  |  |  |  |
|                                 | passed, we see services and accommodations, which are the rights of  |  |  |  |  |
|                                 | every person regardless of age or disability, being taken away,  |  |  |  |  |
|                                 | threatened, or never implemented. People with disabilities do not yet  |  |  |  |  |
|                                 | have full access to society in the U.S. But thanks to many activists,  |  |  |  |  |
|                                 | including some interviewed here, people with disabilities can live full,   |  |  |  |  |
|                                 | independent lives in the community of their choice.  |  |  |  |  |
|                                 | MA Tales of Independence shares the video stories of individuals with  |  |  |  |  |
|                                 | disabilities who live in Massachusetts. Many remember the times before the ADA was passed, some worked to get it passed and others were  |  |  |  |  |
|                                 |  |  |  |  |  |
|                                 | born after 1990. Each video star has been active in the fight to improve access, services, and civil rights for people with disabilities.  |  |  |  |  |
| Proviously recommended          | The comprehensive list of recommended websites has migrated to the Dignity   |  |  |  |  |
| Previously recommended websites | Alliance MA website: https://dignityalliancema.org/resources/. Only new  |  |  |  |  |
| websites                        | recommendations will be listed in <i>The Tuesday Digest</i> .  |  |  |  |  |
| Duania valvo pasta diferendina  | , -  |  |  |  |  |
| Previously posted funding       | 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> . |  |  |  |  |
| opportunities                   |  |  |  |  |  |
| Nursing Home Closures           | Quincy Health and Rehabilitation Center LLC, Quincy  |  |  |  |  |
|                                 | 126 beds; current census: 77   |  |  |  |  |
|                                 | Owner: Waschusett Healthcare<br>Star rating: 2 stars   |  |  |  |  |
|                                 | Target closure: December 7   |  |  |  |  |
|                                 | Attleboro Healthcare, Attleboro  |  |  |  |  |
|                                 | 120 beds   |  |  |  |  |
|                                 | Owner: Next Step Healthcare  |  |  |  |  |
|                                 | Star rating: Special Focus Facility  |  |  |  |  |
|                                 | Target closure: December 29  |  |  |  |  |
|                                 | Dedham Healthcare, Dedham  |  |  |  |  |
|                                 | 145 beds   |  |  |  |  |
|                                 | Owner: Next Step Healthcare  |  |  |  |  |
|                                 | Star rating: 1 star  |  |  |  |  |
|                                 | Target closure: December 29  |  |  |  |  |
|                                 | Gloucester Healthcare, Gloucester     101 beds   |  |  |  |  |
|                                 |  |  |  |  |  |
|                                 | Owner: Next Step Healthcare  |  |  |  |  |
|                                 | Star rating: 3 stars Target closure: December 30   |  |  |  |  |
|                                 |  |  |  |  |  |
|                                 | Chetwynde Healthcare, West Newton  |  |  |  |  |
|                                 | 75 beds  |  |  |  |  |
|                                 | Owner: Next Step Healthcare  |  |  |  |  |
|                                 | Star rating: 2 stars   |  |  |  |  |
|                                 | Target closure: December 30  |  |  |  |  |
|                                 | NOTE: Admission freezes have been initiated in all facilities with closure plans.  |  |  |  |  |

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|  | Closure Notices and Relocation Plans available at:   |                 |              |                       |  |
|--|--|-----------------|--------------|-----------------------|--|
|  | https://tinyurl.com/MANursingHomeClosures  |                 |              |                       |  |
| Pending nursing home change                        | Royal Health Cape Cod  |                 |              |                       |  |
| of ownership in Massachusetts                      | Royal Health Cotuit  |                 |              |                       |  |
|  | <ul> <li>Royal Health Falmouth</li> <li>Royal Health Megansett</li> <li>Royal Health Meadow View – North Reading</li> </ul>  |                 |              |                       |  |
|  |  |                 |              |                       |  |
|  |  |                 |              |                       |  |
|  | <ul> <li>Royal Health Wayland</li> <li>Royal Wood Mill – Lawrence</li> </ul>   |                 |              |                       |  |
|  |  |                 |              |                       |  |
|  | Royal Health Fairhaven   |                 |              |                       |  |
|  | Royal Health Braintree   |                 |              |                       |  |
|  | Royal Health Norwell   |                 |              |                       |  |
| W L :: (B: :: All:                                 | https://www.royalhealthgroup.  |                 | -:+:/        |                       |  |
| Websites of Dignity Alliance Massachusetts Members | See: <a href="https://dignityalliancema.org/about/organizations/">https://dignityalliancema.org/about/organizations/</a>   |                 |              |                       |  |
| Assisted Living Residences                         | Motif by Monarch (previous   | slv Landmark at | Ocean View   | ). Beverly. July 2022 |  |
| Closures   | Connemara Senior Living, B   | -               |              | ,,                    |  |
| Closures   | Landmark at Longwood, Mi   |                 |              | . 2022                |  |
| Nursing homes with admission                       | Massachusetts Department of I  |                 | , 000000. 0  | , = = =               |  |
| freezes  | Temporary admissions freez   |                 |              |                       |  |
| 1100203  |  |                 | t would requ | ire certain high risk |  |
|  | On November 6, 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 safet   | •               |              |                       |  |
|  | 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   |                 |              |                       |  |
|  | <ul> <li>admissions, and the situation in each facility is different. Some of the factors the state uses to make this decision include:</li> <li>Number of new COVID-19 cases within the facility</li> <li>Staffing levels</li> </ul>  |                 |              |                       |  |
|  |  |                 |              |                       |  |
|  |  |                 |              |                       |  |
|  |  |                 |              |                       |  |
|  | Failure to report a lack of adequate PPE, supplies, or staff      Infantian accepted a supplies and the staff  |                 |              |                       |  |
|  | <ul> <li>Infection control survey results</li> <li>Surveillance testing non-compliance</li> <li>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</li> </ul> |                 |              |                       |  |
|  |  |                 |              |                       |  |
|  |  |                 |              |                       |  |
|  |  |                 |              |                       |  |
|  |  |                 |              |                       |  |
|  |  |                 |              |                       |  |
|  | determines a facility can be removed from the list.  Updated on October 13, 2022. Red font – newly added   |                 |              |                       |  |
|  |  |                 |              |                       |  |
|  | Name of Facility  City/Town  Date of Freeze  Qualifying Facility   |                 |              |                       |  |
|  | Attleboro Healthcare   | Attlleboro      | 8/31/2022    | Closure notice        |  |

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| CareOne at Lowell                                      | Lowell      | 10/11/2022 | New cases         |
|--|-------------|------------|-------------------|
| Charwell House Health and Rehab                        | Norwood     | 9/14/2022  | Infection Control |
| Chetwynde  | West Newton | 9/1/2022   | Closure notice    |
| Dedham Healthcare                                      | Dedham      | 7/6/2022   | Infection Control |
| Gloucester Healthcare                                  | Gloucester  | 9/1/2022   | Closure notice    |
| Lanessa Extended Care                                  | Webster     | 10/4/2022  | Infection control |
| Laurel Ridge Rehab and Skilled Care<br>Center          | Boston      | 10/4/2022  | New cases         |
| Life Care Center of Plymouth                           | Plymouth    | 10/11/2022 | New Cases         |
| Quincy Health and Rehabilitation<br>Center LLC, Quincy | Quincy      | 8/10/2022  | Closure notice    |
| Queen Anne Nursing Home                                | Hingham     | 10/4/2022  | New cases         |
| St. Mary Health Care Center                            | Worcester   | 10/4/2022  | New cases         |
| St. Patrick's Manor                                    | Framingham  | 10/11/2022 | New cases         |

List of Special Focus Facilities

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

List of Special Focus Facilities and Candidates https://tinyurl.com/SpecialFocusFacilityProgram Updated June 29, 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.

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

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None

#### Massachusetts facilities not improved

None

#### Massachusetts facilities which showed improvement

• Attleboro Healthcare, Attleboro

https://tinyurl.com/AttleboroHealthcare

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

### Massachusetts facilities which have graduated from the program

None

#### Massachusetts facilities that are candidates for listing

- Parkway Health and Rehabilitation Center https://tinyurl.com/ParkwayHealthCenter
- Plymouth Rehabilitation and Health Care Center https://plymouthrehab.com/
- Revolution Charwell

https://tinyurl.com/RevolutionCharwell

- Savoy Nursing and Rehabilitation Center, New Bedford (added in June)
   No website
- South Dennis Healthcare, South Dennis (added in July) https://www.nextstephc.com/southdennis
- Tremont Health Care Center, Wareham https://thetremontrehabcare.com/
- Vantage at South Hadley

No website

- Vero Health and Rehabilitation Center of Amesbury https://tinyurl.com/VeroAmesbury
- Vero Health and Rehabilitation Center of Revere https://tinyurl.com/VeroRevere
- Watertown Rehabilitation and Nursing Center, Watertown (added in June)

No website

https://tinyurl.com/SpeciialFocusFacilityProgram

#### Nursing Home Inspect

#### **ProPublica**

#### **Nursing Home Inspect**

Data updated August 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

249

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|   | <u>79                                    </u>   |  |  |  |
|---|---|--|--|--|
|   | 7,092 <u>D</u>  |  |  |  |
|   | 1,857 E   |  |  |  |
|   | 552 <u> </u>  |  |  |  |
|   | 489 <b>G</b>  |  |  |  |
|   | 1 <u>H</u>  |  |  |  |
|   | 33 <u> </u>   |  |  |  |
|   | 7 K   |  |  |  |
|   |   |  |  |  |
| Nursing Home Compare  | Centers for Medicare and Medicaid Services (CMS)  |  |  |  |
|   | Nursing Home Compare Website  |  |  |  |
|   | 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:   |  |  |  |
|   | ,   |  |  |  |
|   | 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 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.  |  |  |  |
|   | https://tinyurl.com/NursingHomeCompareWebsite   |  |  |  |
| Data on Ownership of Nursing  | Centers for Medicare and Medicaid Services  |  |  |  |
| Homes   | Data on Ownership of Nursing Homes  |  |  |  |
| Tiomes  | 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 <u>data.cms.gov</u> 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 f in Massachusetts. |   |  |  |  |
|   |   |  |  |  |
|   | COVID-19 Daily Dashboard  |  |  |  |
|   | COVID-19 Weekly Public Health Report  |  |  |  |
|   | Additional COVID-19 Data  |  |  |  |
|   | CMS COVID-19 Nursing Home Data  |  |  |  |
|   | Since Correct to Training Home Batta  |  |  |  |

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| DignityMA Call to Action  Access to Dignity Alliance social  | <ul> <li>The MA Senate released a report in response to COVID-19. Download the DignityMA Response to Reimagining the Future of MA.</li> <li>Advocate for state bills that advance the Dignity Alliance Massachusetts' Mission and Goals – State Legislative Endorsements.</li> <li>Support relevant bills in Washington – Federal Legislative Endorsements.</li> <li>Join our Work Groups.</li> <li>Learn to use and leverage Social Media at our workshops: Engaging Everyone: Creating Accessible, Powerful Social Media Content</li> </ul> Email: info@DignityAllianceMA.org  |                       |   |  |
|--|--|-----------------------|---|--|
| media  | Facebook: https://www.facebook.com/DignityAllianceMA/  |                       |   |  |
|  | Instagram: https://www.  |                       |   |  |
|  | The state of the s | •                     | any/dignity-alliance-massachusetts              |  |
|  | Twitter: https://twitter.c   |                       | <u>=21</u>                                      |  |
| Double in a band of the control of t | Website: www.DignityAl   | Workgroup             |   |  |
| Participation opportunities with Dignity Alliance  | Workgroup  | lead                  | Email   |  |
| Massachusetts  | General Membership   | Bill Henning          | bhenning@bostoncil.org                          |  |
| Wassachusetts  | '  | Paul Lanzikos         | paul.lanzikos@gmail.com                         |  |
| Most workgroups meet bi-   | Behavioral Health  | Frank Baskin          | baskinfrank19@gmail.com                         |  |
| weekly via Zoom.   | Communications   | Pricilla O'Reilly     | prisoreilly@gmail.com                           |  |
| ,  |  | Samantha              | svanschoick@cil.org                             |  |
| Please contact workgroup lead  |  | VanSchoick            | If a many of his days a barry and a dec         |  |
| for more information   | Facilities (Nursing  | Lachlan Forrow Arlene | Iforrow@bidmc.harvard.edu<br>agermain@manhr.org |  |
|  | homes, rest homes, assisted living)  | Germain               | agermaniemini.org                               |  |
|  | Home and Community<br>Based Services   | Meg Coffin            | mcoffin@centerlw.org                            |  |
|  | Housing  | Bill Henning          | bhenning@bostoncil.org                          |  |
|  | Legislative  | Richard Moore         | rmoore8743@charter.net                          |  |
|  | Legal Issues   | Jeni Kaplan           | jkaplan@cpr-ma.org                              |  |
|  | Veteran Services   | James<br>Lomastro     | jimlomastro@comcast.net                         |  |
| The Dignity Digest   | For a free weekly subscription to <i>The Dignity Digest:</i> <a href="https://dignityalliancema.org/contact/sign-up-for-emails/">https://dignityalliancema.org/contact/sign-up-for-emails/</a> Editor: Paul Lanzikos  Primary contributor: Sandy Novack  MailChimp Specialist: Sue Rorke   |                       |   |  |
| Note of thanks  Dignity Alliance Massachusetts is a k  | <ul> <li>Thanks to the contributors to this issue of <i>The Dignity Digest</i></li> <li>Charles Carr</li> <li>Dick Moore</li> <li>Special thanks to the MetroWest Center for Independent Living for assistance with the website and MailChimp versions of <i>The Dignity Digest</i>.</li> <li>If you have submissions for inclusion in <u>The Dignity Digest</u> or have questions or comments, please submit them to <u>paul.lanzikos@gmail.com</u>.</li> </ul>   |                       |   |  |

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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-digest/">https://dignityalliancema.org/dignity-digest/</a>

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

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