

# Dignity The Dignity Digest

Issue # 151 August 21, 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

How Nursing Homes Failed to Protect Residents from Covid New York Times (free access) August 19, 2023

**Nursing Homes Failed to Protect** 

#### By Paula Span

The first terrifying wave of Covid-19 caused 60,000 deaths among residents of nursing homes and other long-term care facilities within five months. As the pandemic wore on, medical guidelines called for promptly administering newly approved antiviral treatments to infected patients at high risk of severe illness, hospitalization, or death.

Why, then, did fewer than one in five nursing home residents with Covid receive antiviral treatment from May 2021 through December 2022?

It's hardly the only way that the nation's nursing homes proved unable to keep patients safe. A series of studies assessing their attempts to protect vulnerable patients and workers from Covid, along with interviews with experts inside and outside the industry, presents a very mixed pandemic report card.

Brian McGarry, a health economist at the University of Rochester, and David Grabowski, a health care policy researcher at Harvard Medical School, both gave the health care system a D grade overall for nursing homes' pandemic performance.

"I kept waiting for the cavalry to come, and it really hasn't, even today," Dr. Grabowski said. "At no time during the pandemic did we prioritize nursing homes." More than <a href="167,000 residents have died">167,000 residents have died</a>, Medicare reported this month, along with at least 3,100 staff members.

It was Dr. McGarry, Dr. Grabowski and their co-authors who discovered the <u>failure to deliver antiviral medications</u>. Early on, antivirals meant monoclonal antibodies, a difficult treatment. The drugs were in short supply and administered intravenously; patients might need to leave the facility to receive them.

But in December 2021, the Food and Drug Administration granted emergency authorization to Paxlovid, a pill taken for five days. It drastically improves the prognosis for eligible patients who are 65 and older, sick, and frail.

Virtually every nursing home resident meets that description. This is

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"the highest of the high-risk groups," Dr. McGarry said. Age and chronic illnesses make the residents vulnerable, "and they're living in an environment that's perfect for spreading airborne viruses," he added, with shared rooms, communal spaces and staff moving from one patient to the next.

As the saying went, a nursing home was like a cruise ship that never docked.

But research recently published in JAMA found that only a quarter of infected residents received antivirals, even during the last six weeks of the study — by which time Paxlovid was widely available and free. About 40 percent of the nation's approximately 15,000 nursing homes reported no antiviral use at all.

"They're basically depriving people of treatment," said Dr. Karl Steinberg, a medical director at three nursing homes in Southern California and former president of AMDA, the medical association representing providers in long-term care. "It's surprising and disturbing."

One bright spot, several industry leaders agreed, was the federally coordinated rollout of the Covid vaccine, which sent providers to facilities in late 2020 and early 2021 to vaccinate residents and staff. "A remarkable achievement, a collaboration between science and government," said Dr. Noah Marco, chief medical officer of Los Angeles Jewish Health, which cares for about 500 residents in three skilled nursing facilities.

By early 2022, Medicare reported, <u>87 percent of residents and 83 percent of employees had been vaccinated</u>, though it took a federal mandate to reach that staff rate. Studies have shown that high <u>staff</u> vaccination rates prevent infections and deaths.

But "we totally dropped the ball on boosters," Dr. McGarry said. "We just left it up to each nursing home." Medicare reported this month that about 62 percent of residents per facility, and just 26 percent of staff, <u>are up-to-date on Covid vaccinations</u>, including recommended boosters.

"It's disappointing," Dr. Steinberg said. But with workers less likely to perceive Covid as a deadly threat, even though <u>hospitalization and death rates recently began</u> climbing again, "people say no, and we cannot force them," he said.

Other grounds for poor grades: Early federal efforts prioritized hospitals, leaving nursing homes <u>short of critical protective</u> <u>equipment</u>. Even after the federal government began sending point-of-care testing kits to most nursing homes, so they wouldn't have to send tests off to labs, getting results took too long.

"If we can find and detect people carrying Covid, we'll keep them out of the building and prevent transmission," Dr. McGarry explained. That largely meant staff members, since Medicare-mandated lockdowns shut out visitors.

 Nursing homes apparently didn't make much use of the testing kits. By fall 2020, <u>fewer than a fifth had the recommended turnaround</u> of less than 24 hours. "It negates the value of doing the test in the first place," Dr. McGarry said.

As for those lockdowns, which barred most family members until November 2021, the consensus is that however reasonable the policy initially seemed, it continued for far too long.

"In retrospect, it caused <u>a lot of harm</u>," Dr. Steinberg said. "We saw so much failure to thrive, people losing weight, delirium, rapid onset of dementia. And it was usually the staff who were bringing in Covid anyway. A big lesson is that family visitors are essential," assuming those visitors are tested before they enter and that they use protective gear.

Dr. David Gifford, a geriatrician and the chief medical officer of the American Health Care Association, which represents long-term care providers, pointed to a variety of frustrating problems that prevented nursing homes from doing a better job during the pandemic. Point-of-care kits that required 15 minutes to read each test and thus couldn't screen workers arriving for a shift. Prescribing information emphasizing such a long list of possible drug interactions with Paxlovid that some doctors were afraid to use it. And the same suspicion and resistance toward boosters and antivirals that now affect the country as a whole.

"Nursing homes did as much as they could with what they had," he said. "The health care system as a whole sort of ignored them." Staffing, already inadequate in many facilities before Covid, took a hit it has yet to recover from. "It's our No. 1 issue," Dr. Gifford said. His association has reported that <u>nursing homes lost nearly 245,000</u> <u>employees</u> during the pandemic and have regained about 55,000. "The people working in nursing homes certainly get an A for effort" for persevering at their dangerous jobs, Dr. Steinberg said. But so many have left that nursing homes now often restrict new admissions. Some long-proposed changes could help protect residents and staff from future pandemics.

Facilities could improve their ventilation systems. They could abandon "semiprivate" rooms for private ones. Dividing buildings into smaller units with consistently assigned staff — an approach pioneered by the <u>Green House Project</u> — would both bolster relationships and reduce residents' exposure to infection from workers coming and going. All those changes would require more investment, however, principally from Medicaid, which underwrites most nursing home care. And with more money would come increased federal oversight, which the industry rarely welcomes.

"Investment in our industry, in order for us to provide the highestquality care, is absolutely necessary," Dr. Marco said. "But where is the government and public will to do that? I personally don't see a lot

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	of encouragement right now."
Quotos	Nursing Homes Failed to Protect
Quotes	"I kept waiting for the cavalry to come, and it really
	hasn't, even today. At no time during the pandemic did we
	prioritize nursing homes."
	Dr. David Grabowski, a health care policy researcher at Harvard Medical School, How Nursing Homes Failed to Protect Residents From Covid, New York Times (free access), August 19, 2023, Nursing Homes Failed to Protect
	Some long-proposed changes could help protect residents
	and staff from future pandemics. Facilities could improve
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	into smaller units with consistently assigned staff — an
	approach pioneered by the <u>Green House Project</u> — would
	both bolster relationships and reduce residents' exposure
	to infection from workers coming and going.  How Nursing Homes Failed to Protect Residents From Covid, New York Times  (free access), August 19, 2023, Nursing Homes Failed to Protect
	"[Medical] debt is not a morality issue."
	Dr. Donald Berwick, IHI Senior Fellow, <i>The Crisis of Medical Debt in the US,</i> Institute for Healthcare Improvement, August 3, 2023, Crisis of Medical  Debt
	Over 100 million individuals in the US have health care
	debt. It disproportionately affects historically and
	currently marginalized groups and can infiltrate all
	aspects of an individual's life.  The Crisis of Medical Debt in the US, Institute for Healthcare Improvement, August 3, 2023, Crisis of Medical Debt
	"[At the onset of the Covid pandemic,] many hospitals in
	New York were at a point of having to ration dialysis care
	to patients with acute kidney injury, nobody was
	adequately prepared for the volume of need that
	erupted."
	Dr. Jeffrey Silberzweig, chief medical officer of the Rogosin Institute in New York and chair of the Emergency Partnership Initiative at the American

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Society for Nephrology, Kidney doctors push to protect patients by including

dialysis machines in emergency stockpile, **STAT News,** August 7, 2023, <u>Dialysis Machines In Emergency Stockpiles</u>

"In a sense, the rest of society has gone back to work, school, and activities in their lives, and then people with these higher support needs... they're kind of stuck in conditions that are close to COVID-like quarantine."

Hilliary Dunn Stanisz, the Disability Law Center, *Thousands with complicated disabilities languish as Massachusetts struggles with staff shortages at care programs*, \*Boston Globe, August 8, 2023, Complicated Disabilities

"Every night, I come downstairs and cry for what he's lost, what I've lost. That our lives are just so different."

Betsy Bourne, mother of 37-year-old Tyler Bourne who was born with a rare chromosomal disorder that caused profound developmental disabilities, Thousands with complicated disabilities languish as Massachusetts struggles with staff shortages at care programs, \*Boston Globe, August 8, 2023, Complicated Disabilities

Now researchers believe wildfire smoke may impact the brain too. Scientists found that people living in areas with high levels of fine particulate matter, or PM2.5, could have a greater risk of developing dementia in their late stage of life.

Long-term exposure to particulates from wildfire smoke linked to dementia risk, new study finds, **STAT News**, August 14, 2023, <u>Wildfire Smoke Linked to Dementia</u>

As strange as it seems, I know my experience isn't unique. 1 in 6 means that 1.6 billion people have to navigate the world in a disabled body — visible, or invisible, or somewhere in between. And that? That doesn't feel as lonely.

Cheyenne Smith, *I've been disabled my entire life. But only strangers can tell.* **The Washington Post (free access),** August 20, 2023, <a href="https://wapo.st/3YG47V0">https://wapo.st/3YG47V0</a>.]

"She also did a lot of walking, so maybe that explains some of her longevity. Her life was always pretty simple: early to bed, early to rise, work hard, then come home and

### make a nutritious meal and be with family."

Ethel Harrison, age 68, granddaughter of 114 year-old Elizabeth Francis, *At age 114, here's her advice: 'Speak your mind and don't hold your tongue',* \*The Washington Post, August 18, 2023, <u>At age 114</u>

"I asked for her advice, and she said, 'Speak your mind and don't hold your tongue'. She also told me, 'If the Lord gave it to you, use it.'"

Ethel Harrison, age 68, granddaughter of 114 year-old Elizabeth Francis, At age 114, here's her advice: 'Speak your mind and don't hold your tongue', \*The Washington Post, August 18, 2023, At age 114

Gardening helped me normalize the fact that I have needs and that's okay. I don't think my plant is a burden because it needs more nutrients. I don't fault it for getting bugs and not being able to fight against it.

Amanda Morris, *Gardening changed how I see myself as a disabled woman,* **The Washington Post (free access),** August 20, 2023, https://wapo.st/47HDmne.

"If you look at the brains of people with Alzheimer's disease and Parkinson's, you find higher concentrations of these toxic metals: lead, iron from brake pads, platinum from catalytic converters. They are probably bypassing the blood-brain barrier. The nose may be the front door in exploiting the normal protective mechanisms of the brain."

Ray Dorsey, professor of neurology at the University of Rochester, *After the blaze, coping with 'fire brain'*, \*The Washington Post, August 20, 2023, Fire Brain

There were 80,000 people 100 years old or older living in the U.S. in 2020, according to the <u>U.S. Census Bureau</u>. The agency doesn't have a separate category for Americans who are 110 or older, but one of its <u>previous reports</u> estimated they make up 0.6% of the centenarian population, which would translate into 480 supercentenarians living in the U.S.

Texas woman, 114, the 2nd oldest in the US, shares simple tips for a long life, **Today Show,** August 16, 2023, <u>Second Oldest</u>

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"We must have outrage, but we must have optimism as well."

David Lammy, agenda-setter for racial and social justice, *How to be a leader for climate justice*, **Ted Talks**, July 2023, <u>Climate Justice</u>

### "Where's the help for them?"

Clifford Abihai, whose 97-year-old grandmother, Louise Abihai, is still listed as missing, *It was an oasis for Maui elders. The fire brought terror and death.*\*Boston Globe, August 19, 2023 (Updated), Maui Elders

Even dogs have it better than some held in our prisons and jails, which can be like kilns in the summer, sickening those inside and making conditions dangerous for everybody.

Where there is no escape from the heat, \*Boston Globe, August 19, 2023 (updated), No Escape from the Heat

In 2011, researchers Ann Williams and Shirley Moore proposed the Universal Design of Research as a way to "design research so that all people can be included as potential participants, to the greatest extent possible, without the need for adaptation or specialized design."

The definition of clinical trial diversity must include disabled people, **STAT News,** August 17, 2023, <u>Clinical Trial Diversity</u>

"It's good that state regulators are still encouraging vaccination. It will protect residents' lives, but this [proposed] policy leaves some pretty big loopholes that you can drive a truck through."

David Grabowski, professor of health care policy at Harvard Medical School, commenting on the Department of Public Health's vaccination <u>proposal</u> which allows for many exemptions, *Proposed COVID and flu vaccination rules for health workers allow many exceptions,* \*Boston Globe, August 10, 2023 (Updated), <u>Proposed Vaccination Policy</u>

"Vaccination rates of health care personnel could significantly decrease, increasing infection risk for patients and staff."

Massachusetts Health & Hospital Association, in a recent letter to the state Health Department expressing concern regarding proposed vaccination

 regulations, *Proposed COVID and flu vaccination rules for health workers allow many exceptions,* \*Boston Globe, August 10, 2023 (Updated), Proposed Vaccination Policy

"I had to leave a dentist because the building is not ADA compliant. There is a 24-inch step to get into the office. I couldn't believe it in this day in age."

Vivian Quint, an 89-year-old Pocasset resident who uses a walker, *After Senator Duckworth shared she couldn't access theatre, Mass. residents with disabilities say problems persist here too,* \*Boston Globe, August 2, 2023 (Updated), Senator Duckworth

"By creating [the Elder Justice] Unit, we are prioritizing the rights of elderly residents to live with dignity – free from abuse, neglect, and exploitation."

Attorney General Andrea Campbell, *AG Campbell Announces Mary Freeley As Director Of Elder Justice Unit*, **Office of the Attorney General**, August 18, 2023, Elder Justice Unit

## The Resident's Voice Challenge

#### 1. The Consumer Voice

The Resident's Voice Challenge

What does it mean to be heard?

How do you make yourself heard?

Creative writing and artistic expression are meaningful and compelling ways to highlight the importance of residents' rights and how these rights can be carried out in all long-term care settings. The Resident's Voice Challenge, a part of Residents' Rights Month in October, encourages residents to submit essays, poems, artwork, drawings, or videos related to the theme.

This year's theme emphasizes a community of long-term care residents coming together to make their voices heard. As part of the Resident's Voice Challenge, we are inviting residents to create videos amplifying their voices. Residents are encouraged to create a video sharing who you are and how you amplify your voice by answering the questions: What does it mean to be heard and how do you make yourself heard? Alternatively, residents can respond to the Resident's Voice Challenge in writing (essays, poems, word collages), artwork (posters, paintings, drawings), audio (songs or spoken word), or photos.

<u>Visit our website for more information on how to participate.</u>
Submissions are due September 1, 2023.

## Office of the Attorney General

#### 2. Office of the Attorney General

August 18, 2023

AG Campbell Announces Mary Freeley as Director of Elder Justice Unit
The new Unit will amplify the AGO's existing work to advance the rights, safety, and well-being of elders across the Commonwealth
Attorney General Andrea Joy Campbell has announced Mary Freeley to lead the office's Elder Justice Unit, a new unit established under AG Campbell. The Unit will convene existing resources to protect and promote the safety and well-being of elders through enforcement actions, legislative advocacy, and community engagement and education.

"With over a decade of experience in the AG's Office, and a robust expertise

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in these issues, I'm confident Mary will serve our elders with urgency and empathy," said AG Campbell. "By creating this Unit, we are prioritizing the rights of elderly residents to live with dignity – free from abuse, neglect, and exploitation. My office will continue to serve as a dedicated resource for older adults, address their most-pressing needs and advocate for and implement solutions."

Specifically, the Elder Justice Unit will work with staff from the Attorney General's Criminal, Public Protection and Advocacy, and Health Care and Fair Competition Bureaus to:

- Convene internal and external elder justice groups to listen to priorities and ongoing issues
- Enhance the existing work of the office to prosecute the abuse and exploitation of vulnerable older adults, including in the areas of

long-term care, financial exploitation, and scams

- Work with the AG's Community Engagement Division to conduct intentional outreach to elders
- Advocate for state and national policy that aligns with and advances the work of the Elder Justice Unit

"I want to thank AG Campbell for this opportunity. In the AG's Office, we continue to see bad actors prey on older adults, whether that's targeting them for financial scams or neglecting care in long-term facilities. The Elder Just Unit will serve as a resource and advocate for elders who face these issues across the Commonwealth," said Mary Freeley, Director of the AG's Elder Justice Unit.

As an Assistant Attorney General, Mary's work has included significant consumer protection and antitrust cases, including investigations and litigation in the health care, pharmaceutical, education and financial markets. Mary also coordinates the office's elder advocacy and protection work, focusing on the protection of residents of long-term facilities.

Since 2015, Mary has served as Deputy Chief of the AG's Health Care and Fair Competition Bureau where she helps oversee the Office's Antitrust, False Claims, Health Care, Medicaid Fraud and Non-Profit/Charities Divisions. She will continue in that role in addition to directing the office's elder protection work. The Attorney General's Office has a statewide, toll-free hotline to help elders with a range of issues: 888-243-5337. More information on the hotline can be found, here.

**Elder Justice Unit** 

#### Videos

#### 3. National Center on Law & Elder Rights

Property Tax Foreclosures & Older Adults: Tyler v. Hennepin
Property tax liens and foreclosure pose a significant threat to older
homeowners' ownership and equity, with a disproportionate impact on
historically marginalized communities. On May 25th, the Supreme Court held in
Tyler v. Hennepin that when a local government takes a home at a property tax
foreclosure and keeps the homeowner's equity after the tax debt is paid, it
violates the Takings Clause of the Fifth Amendment to the United States
Constitution.

<u>Watch our new short video</u> with National Consumer Law Center attorneys Andrea Bopp Stark and John Rao as they explain the case and its impact on older adults and property tax foreclosures. They also discuss how advocates can assist older adults, including exercising redemption options and connecting older adults with legal assistance to help them preserve their home equity.

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		Watch the video
Podcasts	4.	The Consumer Voice
		Arbitration in Long-Term Care Facilities
		Description
		When a person enters a nursing home, one of the first things they usually do is
		sign their admissions contract. Typically, these contracts contain pre-dispute
		arbitration agreements. These agreements take away your right to hold your
		nursing home accountable in court for any potential negligence or wrongdoing.
		"Pre-dispute" arbitration agreements require you to give up this right before the
		harm even occurs so you will never have the chance to decide if going to court is
		the right option for you. Nursing home residents have the right to refuse pre-
		dispute arbitration.
		In this episode, Consumer Voice's Jocelyn Bogdan speaks with Victoria Schall, an
		experienced trial attorney in the field of elder law, about why nursing home
		residents should not sign pre-dispute arbitration agreements, what rights
		residents have regarding these agreements, and what arbitration may look like
		for residents who have already signed their contracts.
		YouTube video: https://www.youtube.com/watch?v=3msjEGplyJg
Mahinaya and anline	5.	Podcast: Arbitration  Resources for Integrated Care
	Э.	Wednesday, September 13, 2023, 12:00 to 1:00 p.m.
sessions		Webinar on Promoting Person-Centered Communication and Care Coordination
		Join Resources for Integrated Care (RIC) for "Promising Practices for Promoting
		Person-Centered Communication and Care Coordination."
		This webinar will highlight key takeaways from discussions among health plans
		that participated in the Integrated Care Community of Practice focused on care
		coordination of dually eligible individuals. Health plans will share their promising
		practices for promoting person-centered care coordination with an emphasis on
		communication-focused strategies that health plans and providers serving dually
		eligible individuals can use to overcome common barriers to care coordination.
		Communication strategies highlighted in this webinar will address both
		accessible member communication, as well as impactful communication across
		care coordination staff and team members.
		By the end of this webinar, participants should be able to:
		Understand and implement actionable strategies for member outreach and
		engagement.
		Identify approaches to structuring interdisciplinary care team
		communication and information sharing to promote care coordination.
		<ul> <li>Recognize strategies for facilitating continued member engagement during transitions of care.</li> </ul>
		Featured Speakers:
		Kim Kunz, Director of Care Management Health Plan Programs, My Choice
		Wisconsin
		Gabriel Uribe, Director of Community Health, Inland Empire Health Plan
		On the day of the live event, please use the web link to join the webinar. You can
		access the platform using a computer, smart phone, or tablet. The webinar will
		provide real-time captioning (CART services). A recording will be available to
		view 45 minutes after the conclusion of the event. You can access the recording
		at any time by clicking the registration link.
		If you have questions for presenters ahead of the event, please submit those

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through the registration form. If you have any questions after the event, please contact RIC@lewin.com.

Register for the webinar

#### 6. National Center on Law & Elder Rights

Wednesday, August 23, 2023, 11:00 a.m. to 12:15 p.m.

Closing the Justice Gap for Older Adults Part 4: You Can Make a Difference— Defending Against or Terminating Guardianship

The fourth webinar in the Closing the Justice Gap for Older Adults training series will prepare legal aid attorneys to represent individuals who may be subject to guardianship or who are under guardianship. When representing a person with a guardian or someone who is allegedly in need of a guardian, an attorney may need to take extra steps to ensure their client has the right to counsel of their choice and to be a strong advocate on behalf of the client. This includes ensuring the client is present in the proceedings and treated with dignity and that the client's due process rights are upheld. By using procedural and evidentiary tools—including alternatives to guardianship—advocates can increase clients' independence and autonomy and restore their civil rights. This training will build on the concepts discussed in the second training in this series, Representing Clients with a Range of Decisional Capabilities.

Presenters will share:

- Considerations for representing clients with a range of decisional capabilities;
- Strategies for advocating for clients' rights;
- Standards and burdens for opposing, modifying, or terminating guardianship; and
- Building systems and partnerships to engage with clients in need of these services.

#### **Presenters:**

- Introduction: Francis Nugent, Legal Services Corporation and Hilary Dalin, Administration for Community Living
- Jim Berchtold, Justice in Aging
- Gabrielle Marshall, Texas Rio Grande Legal Aid

Capacity for this session is limited to 3,000 participants, and all participants will have the option of accessing audio through the computer or by phone. Closed captioning will be available. Please be sure to log onto the webinar a few minutes early in order to secure your place for the live presentation on Zoom. This webinar will be recorded and available on our website shortly after the presentation. The recording and training materials will also be emailed to all registrants within a few days after the training. We are unable to offer CEU's or other certifications.

Register Here

#### 7. Transit Planning 4 All Project

Thursday, August 24, 2023, 1:00 to 2:00 p.m.

Inclusive Planning Webinar with Transit Planning 4 All

If you've ever wanted an introduction to inclusive planning, this is the webinar for you! In this hour-long webinar, Transit Planning 4 All staff will provide an overview of inclusive planning with examples from projects over the past 10 years.

ASL interpretation and captioning will be provided. Please email <a href="lee@ctaa.org">lee@ctaa.org</a> for other accessibility requests.

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### Register for the webinar 8. National Alzheimer's and Dementia Resource Center Tuesday, August 29, 2023, 3:00 to 4:00 p.m. Helping Families Navigate Dementia with a Menu of Options Join the National Alzheimer's and Dementia Resource Center (NADRC) for "Memory Connections: Helping Families Navigate Their Dementia Journey with a Menu of Program Options." During this webinar, participants will learn about Memory Connections, an ACLfunded initiative through Senior Services Inc. in North Carolina. Memory Connections is a multi-faceted project that offers support, creativity, education, and engaging activities for people living with dementia and their caregivers. Senior Services Inc. and their partners Novant Health, Atrium Health Sticht Center, Winston-Salem State University Occupational Therapy Department, and the Maya Angelou Center for Health Equity are working together to create a unique continuum of dementia care. Because Hispanic Americans and African Americans are more likely to develop Alzheimer's disease or a related dementia than white Americans, the project includes a specific focus on reaching out to these populations. Presenters will highlight the Maya Angelou Center for Health Equity's Caregiver College, a weeklong program that educates African Americans about Alzheimer's disease and related dementias. Caregiver College graduates apply their newly acquired knowledge by delivering presentations to their social groups, churches, family members, friends, and business connections. NADRC webinars are free of charge and open to the public, although preregistration is required. The webinars are recorded and will be available for future viewing on the NADRC website. Closed captioning is available during the webinar and will be included in the recording. Contact NADRC-Webinars@rti.org with any questions. Register for the webinar 9. Transit Planning 4 All Project Thursday, August 31, 2023, 1:00 to 2:00 p.m. How do you form a successful steering committee? This virtual roundtable will explore inclusive strategies and lessons learned for developing steering committees that increase trust, strengthen communication, and ultimately improve coordinated transportation services for older adults and adults with disabilities. ASL interpretation and captioning will be provided. Please email lee@ctaa.org for other accessibility requests. Register for this virtual roundtable Previously posted webinars Previously posted webinars and online sessions can be viewed at: and online sessions https://dignityalliancema.org/webinars-and-online-sessions/ 10. \*Boston Globe Covid August 10, 2023 (Updated) Proposed COVID and flu vaccination rules for health workers allow many exceptions By Kay Lazar All health workers in Massachusetts would be required to receive COVID-19 and flu vaccinations under proposed new state rules, even as federal regulators abandon similar COVID vaccination requirements. But the new proposal allows so many exemptions — including for medical, religious, and personal reasons —

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that some health care leaders are pushing back.

The Massachusetts Health & Hospital Association, in a recent letter to the state Health Department, warned that such latitude could lead to uncertainty about how to implement and enforce the rules as well as to "unnecessary and costly litigation."

Already, some of the state's largest hospital systems — Mass General Brigham and Beth Israel Lahey — are fending off lawsuits from workers fired for refusing COVID shots earlier in the pandemic. The workers say their requests for religious or medical exemptions were denied without a reasonable process for discussion or appeal. The hospitals have denied those assertions.

The hospital association said the proposed new rules, allowing workers to decline shots for "any reason," could also undermine the high flu vaccination rates — some as high as 98 percent of their workforce — in hospitals with more strict mandates. . .

Current state rules do not require most health care workers to be vaccinated against COVID, but mandate it for those working in hospice and nursing homes. Those workers are allowed medical and religious exemptions.

In the interim, hospitals have enacted their own COVID rules, and they vary greatly. UMass Memorial Health, the largest health system in Central Massachusetts, does not require COVID shots. In a statement, spokesperson Debora Spano said that the health system is following the new federal rules, which do not require the shots, but that UMass "strongly encourages our caregivers to get the vaccines.".

The state's nursing home industry, which was especially hard hit by COVID as well as staffing shortages, said it welcomes the proposed rules. It said 20 percent of caregiving positions are still vacant in nursing facilities, forcing over one-third of facilities to limit or deny new admissions, and described a "dire need" to immediately hire 6,100 people to stabilize the industry. . .

The latest state data for flu vaccinations among health care workers shows what can happen when leaders allow a lot of exemptions. Among the state's hospitals, where flu shots are generally mandated with limited exceptions, 91 percent of workers received the vaccines this past winter. But in nursing homes, where enforcement was not as stringent, just 62 percent of workers got vaccinated. That figure was even lower for dialysis centers, where just 53 percent were vaccinated.

**Proposed Vaccination Policy** 

#### **Incarcerated Persons**

#### 11. \*Boston Globe

August 19, 2023 (updated)

Where there is no escape from the heat

By Yvonne Abraham

Even dogs have it better than some held in our prisons and jails, which can be like kilns in the summer, sickening those inside and making conditions dangerous for everybody. . .

Even here, in our supposedly progressive state, many prisons and jails have no air conditioning and lousy ventilation. Some facilities are like kilns, the sun streaming directly into buildings that retain sickening heat, even at night. . . "When you're locked in your cell, you can't escape it," said one person held at Old Colony Correctional Center in Bridgewater, replying to questions via email. His attorney asked that his name be withheld to protect him from retaliation. "You just lay there with the only relief being a 12-inch [fan] blowing a

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meaningless breeze of hot air onto your suffocating body, until the mercy of sleep overtakes you," he wrote. . .

"It shouldn't be an accident of geography or how you're classified that [determines] whether you have air conditioning," said Jesse White, policy director at Prisoners' Legal Services of Massachusetts, who has been working to mitigate heat for incarcerated people since 2011, with minimal success. Now she and others say complaints are becoming more frequent, as summers get hotter and longer. . .

During a recent hot stretch, those who run a puppy-training program at Old Colony, where inmates raise service dogs for veterans, temporarily took their dogs out of the prison, according to the incarcerated man and a spokesman for the program.

"Conditions here are considered too cruel to house a dog but are okay to house human beings," the man incarcerated there wrote. "Many inmates became depressed when the dogs were taken out, not because they're great for mental health, but because they began feeling they were lower than an animal and not considered deserving of equal care."

Dangerous heat is a huge problem <u>in prisons and jails across the country</u>, but we have a confluence of especially dangerous factors here. Climate change is having dramatic effects in this part of the country, and a 2023 <u>study</u> found that the effect of heat on death rates in prisons <u>is highest in the Northeast</u>. We also have an older and sicker group of people locked up in Massachusetts, and buildings so old that they magnify the already dangerous effects of heat. . .

Heat makes people sick, and those most vulnerable to its effects – inmates who are elderly or ailing, those with respiratory or heart ailments – need medical care and costly hospital stays. It makes people irritable, which drives up tensions inside prisons and jails and endangers everybody, including correctional officers. Suicide attempts, self-injury, and violent attacks rise along with temperatures. . Prisoner advocates and investigators from the Disability Law Center say that, whatever the state's standards are, relief from heat is inconsistent, and often subject to the whims of administrators. They have piles of complaints from those inside about windows that don't open, air conditioning on the blink or not switched on, and water that is always lukewarm. . .

Chance should not decide whether an inmate is held in a potentially deadly oven. That's why <u>Senator Cynthia Creem</u> and <u>Representative Brandy Fluker</u> <u>Oakley</u> have proposed legislation that would create one, enforceable, standard for all of the state's prisons and jails, mandating that the temperature be kept below 78 degrees. The bills will get a hearing in the fall. Advocates are also pushing the Department of Public Health to demand more humane heat standards in every prison and jail in the Commonwealth.

No Escape from the Heat

#### 12. The New Republic

December 17, 2020

"No Choice but to Do It": Why Women Go to Prison

By Justine van der Leun

Many of the 230,000 women and girls in U.S. jails and prisons were abuse survivors before they entered the system. And at least 30 percent of those serving time on murder or manslaughter charges were protecting themselves or a loved one from physical or sexual violence. . .

I found limited studies, conducted in single prisons or states, consistently

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showing that <u>up to 94 percent</u> of people in some women's detention facilities experienced physical and sexual violence prior to incarceration. However, I couldn't find systemic data to support what experts told me, and what I witnessed while reporting: Women's prisons are populated not only by abuse and assault survivors, but by people who are incarcerated for their acts of survival.

About 230,000 women and girls are incarcerated, an increase of more than 700 percent since 1980. The female prison population is dwarfed by the larger population of more than two million men, on whom conversations about mass incarceration center. For most people in prison, the criminal legal system has stripped away context and circumstance, leaving only a conviction on record. . . Mental illness, which affects nearly half of those in prison, was another hurdle: "Every prosecutor describes women convicted of murder as cunning, diabolical, monster, and evil," Kwaneta Harris wrote from Texas. "I've yet to encounter these 'monsters.' Although I've met plenty of women with mental illness, untreated and undiagnosed ... the ones who you really need to talk to are too mentally damaged to talk to you.". . .

A confluence of life factors usually converged—many beyond a person's control. I received a letter in purple crayon from a 32-year-old Black woman who wrote that "the judge ... gave me to [sic] much time and I was 11 when I did the murder." I looked up her story, which was public record: As a child, she had been raped, abandoned, neglected, cycled through abusive foster homes, and diagnosed as mentally ill and developmentally disabled. Before her twelfth birthday, she stabbed a stranger in the heart with a kitchen knife. For nearly two years, she lived in an isolated cell in an adult jail before being sent to a facility for children with mental illnesses. When she turned 18, a judge sentenced her to 18 to 40 years.

Why Women Go to Prison

## Alzheimer's and Other Dementia

#### 13. STAT News

August 14, 2023

Long-term exposure to particulates from wildfire smoke linked to dementia risk, new study finds

By Abdullahi Tsanni

Smoke permeates everything and impacts everyone. The visible stew of carbon and particulates typically from emission sources travels in the air, shrouds buildings, suffocates birds, and penetrates deep into the lungs. Now researchers believe wildfire smoke may impact the brain too.

Scientists found that people living in areas with high levels of fine particulate matter, or PM2.5, could have a greater risk of developing dementia in their late stage of life. "We saw specifically that emissions from agriculture and wildfires may be more harmful to the brain," said Boya Zhang, the lead author of a <a href="mailto:new\_study">new\_study</a> published Monday in JAMA Internal Medicine. "It's really intriguing to us," the doctoral student at the University of Michigan's School of Public Health in Ann Arbor told STAT. . .

With <u>Health and Retirement Study</u> data from a nationally representative group of Americans older than 50, Zhang and her team conducted cognitive assessments on nearly 30,000 people with no dementia but who were exposed to different air pollution sources in areas across the U.S. They analyzed the study participants' exposure levels to PM2.5 between 1998 and 2016, due to emissions from sources including agriculture, road traffic, industry energy, coal

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combustions, and wildfires. Those who had higher residential PM2.5 levels were linked with increased risk of developing dementia. . .

With the <u>global burden of dementia</u> projected to increase, Zhang said the study suggests interventions that target specific air pollution sources could be an effective way to cut down the dangerous PM2.5 particle levels among populations in the U.S. Weisskopf agreed. "It sort of helps us to identify the best levers to pull from a regulatory perspective to try and reduce levels of dementia," he said.

Wildfire Smoke Linked to Dementia

#### **Emergency Preparedness**

#### 14. STAT News

August 7, 2023

Kidney doctors push to protect patients by including dialysis machines in emergency stockpile

By Carrie Arnold

[Ariel] Brigham's story reflects the vulnerability of people on dialysis who are often overlooked in official emergency plans. A 2022 study in the Journal of the American Society of Nephrology showed that <u>dialysis patients have a significantly higher risk of death</u> in the 30 days following a hurricane compared to non-storm periods.

"It's really a problem when you're stuck with patients who cannot get dialyzed and they will die without it," said Jose Arrascue, a nephrologist in southern Florida. "We need to have some kind of reserve of machines that can be quickly accessed and used in time of need. It's public health."...

To help such patients in times of crisis, some advocates have begun pushing for dialysis equipment to once again be included in the U.S. Strategic National Stockpile (SNS), a cache of essential medical supplies stored in warehouses around the country. In a public health emergency, which includes everything from pandemics and nuclear accidents to hurricanes and wildfires, the federal government can tap into the stockpile to keep local authorities from running out of necessary equipment. Dialysis machines were, for the first and only time, part of the stockpile from 2019 to 2022. . .

#### 'Dialysis patients need to be a priority'

Dialysis machine access became a pressing concern in the wake of hurricanes like Katrina, Sandy, and Maria, which prevented patients from accessing care across broad regions of the country, according to Jeffrey Silberzweig, chief medical officer of the Rogosin Institute in New York and chair of the <a href="Emergency Partnership Initiative">Emergency Partnership Initiative</a> at the American Society for Nephrology. He noted that kidney failure <a href="disproportionately affects people">disproportionately affects people</a> who live in poverty and are part of marginalized racial and ethnic groups, who often have the fewest resources at their disposal to mitigate the effects of a disaster.

"Dialysis patients need to be a priority. They can't wait for treatment," he said.

#### What's included in the Strategic National Stockpile?

In the mid-1990s, then-President Bill Clinton began to conceive of a national repository of supplies that could be used in the event of a bioterrorist attack. Some of these supplies, such as vaccines against smallpox and anthrax, were not available commercially. Others, such as the antibiotic ciprofloxacin, might be needed in amounts that would outstrip existing supply. . .

Whether the HHS secretary and Administration for Strategic Preparedness and Response ultimately decided to use the pandemic-preparedness funding to add dialysis machines to the SNS remains to be seen. But to kidney patients like

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Brigham, the situation is a matter of life and death.

Dialysis Machines in Emergency Stockpiles

Disability Topics

15. The Washington Post (free access)

August 20, 2023

I've been disabled my entire life. But only strangers can tell.

Perspective by Cheyenne Smith

[Editor's note: This is a pictorial essay. It can be viewed for free at <a href="https://wapo.st/3YG47V0">https://wapo.st/3YG47V0</a>.]

The disconnect between my outward appearance and inner experience makes both states of being feel somewhat ... performative.

Disabilities are usually categorized as visible or invisible — but what about the in-between? I was born with a congenital foot deformity that affects the muscles, bones, and tendons. But thanks to early surgeries and years of casting, I look pretty normal to the average person. The only catch? Chronic pain, limited mobility and a "special occasions" wheelchair that my friends and family have never seen.

https://wapo.st/3YG47V0

#### 16. The Washington Post (free access)

August 20, 2023

Gardening changed how I see myself as a disabled woman

By Amanda Morris and Sonaksha

[Editor's note: This is a pictorial essay. It can be viewed for free at <a href="https://wapo.st/47HDmne">https://wapo.st/47HDmne</a>.]

Asking for help can bring up complicated feelings for people with disabilities. One such feeling is called "self-perceived burden," which happens when people who need care from others feel frustrated or even guilty that someone else had to help them.

For Rosemary McDonnell-Horita, a 21-year-old with multiple disabilities, gardening gave her an opportunity to be a caregiver rather than a care receiver. Taking care of plants shifted the way she thought about her own body. https://wapo.st/47HDmne

#### 17. STAT News

August 17, 2023

The definition of clinical trial diversity must include disabled people

Despite constituting the largest minority group in the U.S. and regularly expressing interest in participating in clinical trials, people with disabilities remain heavily excluded from the process. And it's not just quadriplegics like

Terry [Moakley who died at the age of 69]. He represents one of many groups of people with disabilities that are often left out of the process. Recently, another First Opinion author shared a powerful essay about the potential of including more people with Down syndrome in research for Alzheimer's therapies. In that article, she cited an advocate with Down syndrome who warmly expressed to Congress his willingness to contribute to clinical research, reinforcing how much enthusiasm can exist in underrepresented groups — many of whom have unique attributes that could accelerate clinical discovery.

However, even though these groups can bring insights to the table, disability exclusion is often systemic. An October 2022 Health Affairs study conducted by researchers at Harvard, Brigham and Women's Hospital, Mass General Brigham, Columbia, and the University of Utah examined the eligibility criteria of 97 trials, specifically looking at instances of disability exclusion. Of the protocols they

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examined, the research team found that those with disabilities, psychiatric or substance use disorders, cognitive or intellectual disabilities, and various impairments were regularly excluded from participation.

People with disabilities are often excluded on the basis of either ethical reasons like added burden or disadvantages, or scientific reasons like increased medical risk. There are certainly some occasions in which the exclusion is justifiable. But the current industry standard for inclusion criteria allows for broad exclusions rather than inclusive writings that give specific reasoning and prevent discrimination.

Undeniably, this results in a <u>lack of generalizable trial findings</u>. It also contradicts laws put into place to protect those with disabilities from unjustified discrimination. . .

In 2011, researchers Ann Williams and Shirley Moore <u>proposed the Universal Design of Research</u> as a way to "design research so that all people can be included as potential participants, to the greatest extent possible, without the need for adaptation or specialized design." The concept of universal design is nothing new. Curb cuts, wheelchair ramps, and large, color-contrasting prints are all examples of accessible designs.

If universal design can be implemented to enable accessibility in our day-to-day, why not in trials? At present, just  $\underline{18\%}$  of trials explicitly allow patients to utilize forms of support (such as canes, hearing aids, or other assistive devices) to complete a trial. . .

An ongoing blocker to integrating more people with Down syndrome is the rigid consent processes. At present, one-third of trials deem individuals with intellectual disabilities directly ineligible for participation on the basis of their diagnosis or capacity to provide consent. If you include the number of studies that indirectly exclude that population through limitations like reading ability, it soars up to three-quarters of trials. In fact, a study published in the Disability and Health Journal found that only 12.7% of studies "explicitly included adults with intellectual disability" when it came to legally authorized consent. . . The October 2022 Health Affairs study found that 85% of trial protocols assigned investigators the ability to exclude patients using "broad discretion in determining eligibility," meaning subjective decisions were made on a patient's eligibility based on nonspecific language. A whopping 93% of protocols excluded patients with "other chronic conditions" without specifying the conditions that fall into that category, and few provided justifications. Rather than carrying on with eligibility defined with vague subjectivity, trial protocols should be written with the intent for inclusion. More forethought into inclusion and thoughtfully written justifications would allow for more insight into the necessity of inclusion and perhaps even enable modifications to the study to overcome the limitations. **Clinical Trial Diversity** 

#### 18. \*Boston Globe

August 8, 2023

Thousands with complicated disabilities languish as Massachusetts struggles with staff shortages at care programs

By Jason Laughlin

[Tyler] Bourne is among roughly 2,000 individuals, most of them people with complex medical or behavioral needs, who have been effectively exiled from day hab since the pandemic, placed on waiting lists for a service that is much more than just day care. The programs also provide skilled nursing, physical therapy,

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speech therapy, group outings, and opportunities to socialize. But they are currently so understaffed, according to state officials and providers, that some are finding it difficult to provide one-to-one care for everyone who needs it. Advocates for people with disabilities argue the state has a legal obligation to do better. The state's 151 day hab programs, they noted, are a Medicaid service, and must be made available to anyone who qualifies.

The Disability Law Center and The Arc of Massachusetts, both disabled advocacy groups, question the legality of keeping people on wait lists for years. . .

The problem is so serious that MassHealth took <u>emergency action last month</u>, including offering day hab providers \$12,000 bonus payments for each former client brought back.

Like the rest of the healthcare sector, the COVID-19 pandemic threw the day hab space into turmoil. Statewide, 25 programs — about 14 percent — have either closed or merged with others since the pandemic began, according to Ellen Attaliades, chief executive of the Association of Developmental Disabilities Providers.

Meanwhile, many <u>overworked and underpaid healthcare workers</u> realized they could make more money in less taxing jobs in other industries. From 2019 to 2021, Massachusetts lost more than 10,000 workers from healthcare support jobs, which includes home health and personal care aides, according to a Globe analysis of US Census data. Attaliades noted staffing was typically at 80 percent of pre-pandemic levels among members of her association. . .

In July, the Executive Office of Health and Human Services took emergency actions to address the staffing shortage. The governor's fiscal year 2024 budget proposal included an additional \$200 million for day hab and Adult Day Health. Along with the \$12,000 for providers who bring back former clients, the office also offered providers in July \$2,000 for each person admitted to day hab for the first time.

The state's \$200 million commitment promises to allow the companies that provide day hab to bring hourly wages to around \$19 an hour, Attaliades said. Complicated Disabilities

#### 19. \*Boston Globe

August 2, 2023 (Updated)

After Senator Duckworth shared she couldn't access theatre, Mass. residents with disabilities say problems persist here too

By Maggie Scales

Disabled Massachusetts residents agree that buildings and transportation are too often not accessible.

Illinois Senator Tammy Duckworth <u>recently shared</u> that she was unable to enter a movie theatre in her wheelchair to see "Barbie" with her daughters in July due to a broken elevator.

The incident, Duckworth <u>told media outlets</u>, happened just ahead of the anniversary of the Americans with Disabilities Act of 1990, which is supposed to protect people with disabilities from discrimination and ensure they have equal opportunity in all aspects of public life.

But 33 years after the ADA's passage, several Massachusetts residents say Duckworth's experience is far from uncommon. . .

[Don] Summerfield, [a resident of Cambridge who uses a wheelchair,] has found that some movie theaters aren't accessible because they might mistakenly believe they are grandfathered in, and don't need to comply with accessibility

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laws. "which sucks, nothing should be grandfathered in," he said, because the state's accessibility law, 521 CMR — the building code regarding access for persons with disabilities for buildings — is supposed to take precedence.

The ADA refined its standards in 2010 in various ways, but created a clause that exempts buildings that comply with the original 1991 standards from having to undergo further renovations. Many mistake this as a "grandfather clause" that protects buildings from having to be ADA compliant, but that is not the case.

The state also has its own building code regarding access to buildings for persons with disabilities, 521 CMR, and it is intended to make public buildings and facilities accessible to, functional for, and safe for use by all.

Senator Duckworth

#### **Aging Topics**

#### 20. \*The Washington Post

August 18, 2023

At age 114, here's her advice: 'Speak your mind and don't hold your tongue' By Cathy Free

Elizabeth Francis, born in 1909, lives in Houston with her 94-year-old daughter Not many 94-year-olds still have their mothers around, but Dorothy Williams does — and the two women live together in Houston.

Her mother, Elizabeth Francis, just turned 114. . .

Harrison said Francis is believed to be the <u>second oldest</u> living supercentenarian in the country, and the seventh oldest living person in the world. A supercentenarian is someone who lives to be 110 years old or older. <u>Edie Ceccarelli</u>, 115, beats Francis for the title in the United States, and <u>Maria Branyas Morera</u> tops the world charts at age 116, according to several groups that track the oldest living people, including the <u>Gerontology Research Group</u>...

"She never learned to drive, so she took the bus to work or people in the family would give her a ride," Harrison said. "She also did a lot of walking, so maybe that explains some of her longevity."

"Her life was always pretty simple: early to bed, early to rise, work hard, then come home and make a nutritious meal and be with family," Harrison added. . . Francis has joked that eating whatever she wants is the secret to a long life, but there are other possible reasons that some people become supercentenarians, said Ben Meyers, the chief executive of LongeviQuest, an organization that tracks the oldest people in the world.

"What they all have in common is a healthy relationship with stress," Meyers said.

His organization has verified 35 <u>supercentenarians</u> alive in the United States, far fewer than the number of centenarians, which is <u>about 90,000</u>, he said.

At age 114

#### 21. Today Show

August 16, 2023

Page 20

Texas woman, 114, the 2nd oldest in the US, shares simple tips for a long life By A. Pawlowski

She was born on July 25, 1909, a few months after William Howard Taft was inaugurated president, and has lived through two World Wars, the Great Depression, the Spanish Flu, and the COVID-19 pandemic.

Francis recently celebrated her birthday with a party attended by several generations of her family and other guests.

She was particularly excited that longevity researchers from Norway came to talk with her.

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Francis is currently the second oldest person living in the U.S., the seventh oldest living human on the globe and is included on the list of supercentenarians people who are 110 and older — validated by the Gerontology Research Group, which verifies and tracks the world's oldest people. (The oldest person living in the U.S. is currently Edith Ceccarelli, a California woman who turned 115 in February.) Longevity runs in Francis' family: One of her sisters lived to be 106, another sister made it to 95, and their father died at 99, says Ethel Harrison, Francis' granddaughter... There were 80,000 people 100 years old or older living in the U.S. in 2020, according to the U.S. Census Bureau. The agency doesn't have a separate category for Americans who are 110 or older, but one of its previous reports estimated they make up 0.6% of the centenarian population, which would translate into 480 supercentenarians living in the U.S. **Second Oldest Health Care Topics** 22. Centers for Disease Control and Prevention June 29, 2023 CDC Recommends RSV Vaccine for Older Adults CDC Director Rochelle P. Walensky, M.D., M.P.H., endorsed the CDC Advisory Committee on Immunization Practices' (ACIP) recommendations for use of new Respiratory Syncytial Virus (RSV) vaccines from GSK and Pfizer for people ages 60 years and older, using shared clinical decision-making. This means these individuals may receive a single dose of the vaccine based on discussions with their healthcare provider about whether RSV vaccination is right for them. Adults at the highest risk for severe RSV illness include older adults, adults with chronic heart or lung disease, adults with weakened immune systems, and adults living in nursing homes or long-term care facilities. CDC estimates that every year, RSV causes approximately 60,000–160,000 hospitalizations and 6,000-10,000 deaths among older adults. These new vaccines – which are the first ones licensed in the U.S. to protect against RSV – are expected to be available this fall. These vaccines provide an opportunity to help protect older adults against severe RSV illness at a time when multiple respiratory infections are likely to circulate. Healthcare providers should also talk to their adult patients about what other vaccines they will need this fall to help prevent respiratory infections. **RSV Vaccination Recommendation Health Care Policy** 23. Institute for Healthcare Improvement August 3, 2023 The Crisis of Medical Debt in the US By IHI Team An elderly woman experiences a medical emergency. She receives a hospital bill for thousands of dollars. Her insurance does not cover all of it, and she does not have the money to pay the rest. To save money, pay off the debt, and avoid adding to what she owes, she does not fill her prescriptions for multiple chronic illnesses and avoids preventative care. Her health suffers. This leads to another health emergency, which generates more debt. This vicious cycle traps too many patients in the US. Over 100 million individuals in the US have health care debt, according to a 2022 Kaiser Health News and NPR investigation. In a recent episode of the Institute

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for Healthcare Improvement (IHI) *Turn on the Lights* podcast, Berneta L. Haynes, a staff attorney with the <u>National Consumer Law Center</u> and former Director at <u>Georgia Watch</u>, joined IHI President and CEO Kedar Mate and IHI President Emeritus and Senior Fellow Don Berwick to discuss this uniquely American problem.

#### The Inequitable and Far-Reaching Impacts of Medical Debt

Like many issues in health care, medical debt disproportionately impacts historically marginalized groups. Haynes notes that uninsured patients and those with chronic conditions deal with this burden at higher rates. Medical debt is also more highly concentrated in the South, where many states have not expanded Medicaid. Black families — many of whom live in the South and also have chronic conditions — are hit disproportionately hard by debt. A nationwide KFF poll found that 56 percent of Black adults owe money for a medical bill compared to 37 percent of White adults.

Medical debt can infiltrate all aspects of an individual's life. For instance, as debt collectors repeatedly make contact, people will often sacrifice paying for food and rent to make debt payments. Medical debt can also have a negative impact on credit scores, making it more difficult to secure housing or <a href="even a job">even a job</a>. "Outside of material consequences . . . there is this persistent stress people experience when they are dealing with medical debt," added Haynes. This chronic stress worsens well-being and can aggravate health outcomes.

#### "Debt is not a morality issue"

In their conversation, Berwick raised the "cultural misperception" linking "debt and merit, debt and personal effort" in the US. "Debt is not a morality issue," Haynes agreed. She added that the view that many Americans hold — that debt represents a moral failing — deters individuals from seeking and accepting assistance. When Haynes counsels individuals to declare bankruptcy — explaining that "bankruptcy is a legal instrument that allows you to get back on clear footing" — they are often resistant to do so. Haynes wants those struggling with debt to understand that needing or asking for help is no reason for shame.

#### **Reason for Cautious Optimism**

According to recent <u>data from the White House</u>, 8.2 million fewer Americans are struggling with medical debt compared to the start of 2020. While Haynes said she is "hesitant to claim victory so early," she noted that the COVID-19 pandemic threw many health inequities, including medical debt, into sharp relief and led to an uptick in energy to address the issue.

Haynes also pointed to recent policy changes that have helped prevent patients from going into debt, including Medicaid expansion and the <u>No Surprises Act</u>, a law that protects patients from unexpected medical bills when they receive most emergency services, non-emergency services from out-of-network providers at in-network facilities, and services from out-of-network air ambulance service providers.

While these policies are steps in the right direction, Haynes emphasized that more action is needed. She suggested making changes to the Affordable Care Act, including broadening income eligibility requirements for Medicaid, ensuring providers screen patients for financial assistance eligibility before billing them, providing reasonable notice to patients before debt collection action is taken, and allowing patients to hold hospitals accountable for violating financial assistance laws in court. Haynes also recommended creating a federal program that offers an insurance plan for those in states that have not expanded

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Medicaid, incorporating medical debt cancellation and Medicaid expansion in a larger strategy towards racial justice reparations, and enacting a national publicly funded single-payer health plan administered at the state and local levels.

Despite challenges, continued efforts to cancel and prevent health care debt are creating real change. Haynes remains hopeful as the "groundswell of interest" continues around fixing the medical debt crisis in the US.

To learn more, listen to the complete IHI Turn on the Lights Podcast episode Penalized for Being Sick: The Uniquely American Crisis of Medical Debt with Berneta L. Haynes.

Crisis of Medical Debt

## Emergency Preparedness / Climate Change

#### 24. \*The Washington Post

August 20, 2023

After the blaze, coping with 'fire brain'

By Marlene Cimons and Kim Bellware

Many people escaped the deadly Maui wildfires — some in harrowing fashion — but their ordeal may not be over.

The <u>harmful effects of wildfire exposure</u> don't disappear once the flames are extinguished, experts said. There is <u>growing research</u> that suggests breathing in the tiny particles from wildfire smoke can produce cognitive deficits, which may appear in as little as six to 12 months or even years later.

Surviving a near-death experience also raises the risk of post-traumatic stress, with such symptoms as depression, sleep disorders, anxiety and survivor's guilt, researchers said.

"Of course, the immediate most important thing is to survive," said Marc Weisskopf, professor of environmental epidemiology and physiology at Harvard T.H. Chan School of Public Health, who studies the relationship between air pollution and brain health. "But unfortunately, those who do survive also may be vulnerable to both long- and short-term effects on the brain caused by this exposure."

Some survivors of wildfires describe their cognitive struggles after escaping the blaze as "fire brain.". .

Trauma from surviving natural disasters related to climate change is also different from other one-time events such as a car accident or sexual assault, said <a href="Dhakshin Ramanathan">Dhakshin Ramanathan</a>, associate professor in residence in psychiatry at the University of California at San Diego.

"People see the environment as a refuge, a positive healing thing," he said. "When something you see as positive turns against you, that's a difficult thing for many people to deal with."

There is added stress from not being able to predict whether survivors will be exposed again. "Climate will be a sustained stress that will be harder to treat," Ramanathan said. . .

There also is guilt, along with increased anxiety and depression, experts said. "Survivors often feel they should have done more to help others, which can be psychologically damaging and guilt-producing — and totally irrational," said <a href="Andrea Roberts">Andrea Roberts</a>, senior research scientist in environmental health at the Chan school, who was not involved in the Camp Fire study. "In most cases, there is nothing they could have done."

Fire Brain

#### 25. \*Boston Globe

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August 19, 2023 (Updated)

It was an oasis for Maui elders. The fire brought terror and death.

By Jack Healy

Before fire tore through the Hale Mahaolu Eono senior-living complex, trapping a wheelchair-bound man in his apartment and forcing a 95-year-old grandmother to flee through a blizzard of embers, before it killed two close friends and left neighbors missing, people felt lucky to live there.

The independent-living complex in Lahaina was one of the few housing options for low-income older adults on Maui, where soaring rents have forced more and more seniors into homeless shelters or onto five-year waiting lists for subsidized housing. . .

They did not think death would come like this.

Their 35-unit apartment complex in Lahaina may have been one of the first major buildings consumed as a brush fire tumbled down from the hills on Aug. 8. Two residents of Eono have been named among the 111 confirmed deaths, and another half-dozen residents are still not accounted for, families said in interviews.

Now, survivors and families of the missing are asking whether Maui officials and managers at the complex could have done more to save one of the most vulnerable clusters of people in Lahaina from the fast-moving inferno. . . Older people are often at greater risk when natural disasters strike, often trapped in sweltering nursing homes after hurricanes or pinned down by fires. The authorities on Maui have only begun to identify the dead, but the six victims whose names and ages have been released are older than 70.

"They had a duty to keep people safe," [72-year-old resident Tina] Bass said. "Knock on their doors, drag them by the hand and stick them in your car." Maui Elders

#### 26. Ted Talks

July 2023

How to be a leader for climate justice

By David Lammy and Justin J. Pearson

Climate justice is taking center stage -- geopolitically, socially, and morally. In a contagiously courageous conversation, Member of Parliament in the UK David Lammy and Tennessee state representative Justin J. Pearson discuss how brave leadership can shepherd global movements and uplift historically marginalized communities in the face of humanity's greatest challenge: climate change. "We must have outrage, but we must have optimism as well," says Lammy. Speakers:

- David Lammy is a leading agenda-setter for racial and social justice in the UK.
- Justin J. Pearson is a Tennessee state representative, community organizer and advocate for social and environmental justice.

#### **Climate Justice**

Dignity Alliance Massachusetts Legislative Endorsements Information about the legislative bills which have been endorsed by Dignity Alliance Massachusetts, including the text of the bills, can be viewed at:

https://tinyurl.com/DignityLegislativeEndorsements

Questions or comments can be directed to Legislative Work Group Chair Richard (Dick) Moore at <a href="mailto:rmoore8473@charter.net">rmoore8473@charter.net</a>.

Websites

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Previously recommended	The comprehensive list of recommended websites has migrated to the Dignity				
websites	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	For open funding opportunities previously posted in <i>The Tuesday Digest</i> please see				
opportunities	https://dignityalliancema.org/funding-opportunities/.				
Websites of Dignity	See: https://dignityalliancema.org/about/organizations/				
Alliance Massachusetts					
Members					
Nursing homes with	Massachusetts Department of Public Health				
admission freezes	Temporary admissions freeze				
	There have been no new postings on the DPH website since May 10, 2023.				
Massachusetts	Massachusetts Department of Public Health				
Department of Public	Determination of Need Projects: Long Term Care				
Health	2023				
Determination of Need	Navigator Homes of Martha's Vineyard, Inc. – Long Term Care Substantial Capital				
Projects	Expenditure				
	Royal Wayland Nursing Home, LLC – Conservation Long Term Care Project 2022				
	Ascentria Care Alliance – Laurel Ridge				
	Ascentria Care Alliance – Lutheran Housing				
	Ascentria Care Alliance – Quaboag				
	Berkshire Healthcare Systems, Inc. – Windsor Long Term Care Conservation				
	Fairlawn Rehabilitation Hospital-Hospital/Clinic Substantial Capital Expenditure				
	Long Term Centers of Lexington – Pine Knoll – Long Term Care Conservation				
	Long Term Centers of Wrentham – Serenity Hill – Long Term Care Conservation				
	Next Step Healthcare LLC-Conservation Long Term Care Project				
	Royal Falmouth – Conservation Long Term Care				
	Royal Norwell – Long Term Care Conservation				
	Wellman Healthcare Group, Inc				
	2020				
	Advocate Healthcare, LLC Amendment				
	Campion Health & Wellness, Inc. – LTC - Substantial Change in Service				
	Heywood Healthcare, Inc. – Hospital/Clinic Substantial Capital Expenditure Notre				
	Dame Health Care Center, Inc. – LTC Conservation				
	2020				
	Advocate Healthcare of East Boston, LLC. Belmont Manor Nursing Home, Inc.				
	beimont Manor Nursing nome, inc.				
List of Special Focus	Centers for Medicare and Medicaid Services				
Facilities	List of Special Focus Facilities and Candidates				
. domeres	https://tinyurl.com/SpeciialFocusFacilityProgram				
	Updated March 29, 2023				
	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				

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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 March 29, 2023) Newly added to the listing

• Somerset Ridge Center, Somerset

https://somersetridgerehab.com/

Nursing home inspect information:

https://projects.propublica.org/nursing-homes/homes/h-225747

• South Dennis Healthcare

https://www.nextstephc.com/southdennis

Nursing home inspect information:

https://projects.propublica.org/nursing-homes/homes/h-225320

#### Massachusetts facilities not improved

None

#### Massachusetts facilities which showed improvement

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

Nursing home inspect information:

https://projects.propublica.org/nursing-homes/homes/h-225063

#### Massachusetts facilities which have graduated from the program

• The Oxford Rehabilitation & Health Care Center, Haverhill https://theoxfordrehabhealth.com/

Nursing home inspect information:

https://projects.propublica.org/nursing-homes/homes/h-225218

 Worcester Rehabilitation and Health Care Center, Worcester https://worcesterrehabcare.com/

Nursing home inspect information:

https://projects.propublica.org/nursing-homes/homes/h-225199

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

Charwell House Health and Rehabilitation, Norwood (15)

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https://tinyurl.com/Charwell

Nursing home inspect information:

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

Glen Ridge Nursing Care Center (1)

https://www.genesishcc.com/glenridge

Nursing home inspect information:

https://projects.propublica.org/nursing-homes/homes/h-225523

Hathaway Manor Extended Care (1)

https://hathawaymanor.org/

Nursing home inspect information:

https://projects.propublica.org/nursing-homes/homes/h-225366

 Medway Country Manor Skilled Nursing and Rehabilitation, Medway (1) https://www.medwaymanor.com/

Nursing home inspect information:

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

• Mill Town Health and Rehabilitation, Amesbury (14)

No website

Nursing home inspect information:

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

Plymouth Rehabilitation and Health Care Center (10)

https://plymouthrehab.com/

Nursing home inspect information:

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

• Tremont Health Care Center, Wareham (10)

https://thetremontrehabcare.com/

Nursing home inspect information:

https://projects.propublica.org/nursing-homes/homes/h-225488

• Vantage at Wilbraham (5)

No website

Nursing home inspect information:

https://projects.propublica.org/nursing-homes/homes/h-225295

Vantage at South Hadley (12)

No website

Nursing home inspect information:

https://projects.propublica.org/nursing-homes/homes/h-225757

https://tinyurl.com/SpeciialFocusFacilityProgram

#### Nursing Home Inspect

#### **ProPublica**

#### **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?)

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	# reported Deficiency Tag					
	<u>250</u> <b>B</b>					
	82 <u>C</u>					
	7,056D					
	<u>1,850</u> <b>E</b>					
	546 <b>F</b>					
	487 <b>G</b>					
	31 <u> </u>					
	1I					
	40 <u>J</u>					
	7K					
	2L					
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 that will help consumers have a better					
	understanding of certain staffing information and concerns at facilities.					
	This information will be posted for each facility and includes:					
	Staff turnover: The percentage of nursing staff as well as the number of					
	administrators who have stopped working at a nursing home over the past					
	12-month period.					
	Weekend staff: The level of weekend staffing for nurses and registered					
	nurses at a nursing home over a three-month period.					
	Posting this information was required as part of the Affordable Care Act, which					
	was passed in 2010. In many facilities, staffing is lower on weekends, often					
	meaning residents have to wait longer or may not receive all the care they need.					
	High turnover means that staff are less likely to know the residents, recognize					
	changes in condition, or implement preferred methods of providing care. All of					
	this contributes to the quality-of-care residents receive and their quality of life.					
	https://tinyurl.com/NursingHomeCompareWebsite					
Data on Ownership of	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					
Lana Tana Cara Facilities	data.cms.gov 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					
	<ul> <li>COVID-19 Weekly Public Health Report</li> <li>Additional COVID-19 Data</li> </ul>					
	<u>CMS COVID-19 Nursing Home Data</u>					

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Access to Dignity Alliance social media	<ul> <li>DignityMA Response</li> <li>Advocate for state bit and Goals – State Leg</li> <li>Support relevant bills</li> <li>Join our Work Group</li> <li>Learn to use and leve Creating Accessible,</li> <li>Email: info@DignityAllian</li> <li>Facebook: https://www.finstagram: https://www.LinkedIn: https://www.lin</li> <li>Twitter: https://twitter.c</li> </ul>	e to Reimagining the ills that advance the gislative Endorsements in Washington – Formula in Stage – Markedin.com/Companiom/dignity ma?s=2	ents. ederal Legislative Endorsements. et our workshops: Engaging Everyone: dia Content  tyAllianceMA/ nityalliance/ ny/dignity-alliance-massachusetts		
Doubisia shi su	Website: www.DignityAll		Fmail		
Participation	Workgroup  General Membership	Workgroup lead	Email		
opportunities with Dignity	General Membership	Bill Henning Paul Lanzikos	bhenning@bostoncil.org paul.lanzikos@gmail.com		
Alliance Massachusetts	Behavioral Health	Frank Baskin	baskinfrank19@gmail.com		
	Communications	Pricilla O'Reilly	prisoreilly@gmail.com		
Most workgroups meet bi-	Communications	Lachlan Forrow	Iforrow@bidmc.harvard.edu		
weekly via Zoom.	Facilities (Nursing homes)	Arlene Germain	agermain@manhr.org		
	Home and Community Based Services	Meg Coffin	mcoffin@centerlw.org		
	Legislative	Richard Moore	rmoore8743@charter.net		
	Legal Issues	Jeni Kaplan	jkaplan@cpr-ma.org		
	Interest Group	Group lead	Email		
Interest Groups meet	Assisted Living and Rest Homes	In formation			
periodically (monthly, bi-	Housing	Bill Henning	bhenning@bostoncil.org		
monthly, or quarterly).	Veteran Services	James Lomastro	jimlomastro@comcast.net		
	Transportation	Frank Baskin	baskinfrank19@gmail.com		
		Chris Hoeh	cdhoeh@gmail.com		
	Covid / Long Covid	James Lomastro	jimlomastro@comcast.net		
Please contact group lead for more information.	Incarcerated Persons	TBD	info@DignityAllianceMA.org		
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				
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comments, please submit them to <u>Digest@DignityAllianceMA.orq</u>.

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

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

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