



# The Dignity Digest

Issue # 84

April 8, 2022

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

\*May require registration before accessing article.

## Quotes of the Week

*“The pandemic has lifted the veil on what has been an invisible social ill for decades.”*

The daughter and caregiver of two parents with dementia who needed nursing home care, *U.S. nursing home care is ineffective, inefficient, inequitable, fragmented, and unsustainable*, **STAT News**, April 6, 2022, <https://tinyurl.com/NursingHomeCareIneffective>

*The pandemic has indeed “lifted the veil” on U.S. nursing homes. The big question is whether the country has the will to do anything about it. If so, implementation of the committee’s integrated set of recommendations will, as we wrote, “move the nation closer to making high-quality, person-centered, and equitable care a reality for all nursing home residents, their chosen families, and the nursing home staff who provide care and support them in achieving their goals.”*

*U.S. nursing home care is ineffective, inefficient, inequitable, fragmented, and unsustainable*, **STAT News**, April 6, 2022, <https://tinyurl.com/NursingHomeCareIneffective>

*“I will stress that this is a comprehensive package of reforms. Many stakeholders will want to grab their preferred recommendations and ignore the ones that are more challenging. That is a mistake. We can’t nibble around the edges and expect transformative change.”*

David Grabowski, Ph.D., Harvard healthcare policy expert, *U.S. nursing home system ‘ineffective,’ ‘unsustainable,’ National Academies report says*, **McKnight’s Long-Term Care News**, April 6, 2022, <https://tinyurl.com/IneffectiveUnsustainable>

*“[The National Imperative to Improve Nursing Home*

***Quality**] report is a piercing wake-up call for policymakers. Decades of underfunding have left America's nursing home system in desperate need of an overhaul. [A]s the commission notes, our country's system of financing, oversight and support for nursing homes is 'ineffective, inefficient, fragmented, and unsustainable'."*

LeadingAge President and CEO Katie Smith Sloan, *U.S. nursing home system 'ineffective,' 'unsustainable,' National Academies report says*, **McKnight's Long-Term Care News**, April 6, 2022, <https://tinyurl.com/IneffectiveUnsustainable>

*"It still hits you at times that they are really gone."*

Connie Houtz, resident of Mifflin County, PA, who had two adult sons die of Covid, *As US Nears 1 Million Covid Deaths, One Hard-Hit County Grapples with Unthinkable Loss*, **Kaiser Health News**, April 1, 2022, <https://tinyurl.com/MifflinCounty>

*Crucial questions about long Covid remain, including exactly how it will be defined, how prevalent it is among people who are infected with Covid-19, and who is most at risk.*

**STAT News**, April 5, 2022, *Biden administration ramps up long Covid research efforts following criticism*, <https://tinyurl.com/RampsUpLongCovidResearch>

*"They don't need a cane or walker, but they are as impaired or more impaired in their daily living than someone who might be older and who is hospitalized. More than half of the patients who we see who were previously working before Covid are unable to work or have reduced schedules because of their symptoms."*

John Baratta, founder and co-director of the University of North Carolina's COVID Recovery Clinic in Chapel Hill, *'Good, not great': Some long Covid patients see their symptoms improve, but full recovery is elusive*, **STAT News**, February 8, 2022, <https://tinyurl.com/GoodNotGreatLongCovid>

*"It's going to be a pandemic of long Covid. We're going to have a lot of people who are quite disabled and a lot of people with chronic illness."*

Neurologist Svetlana Blitshteyn, director and founder of the Dysautonomia Clinic at the University at Buffalo Jacobs School of Medicine and Biomedical Sciences, *'Good, not great': Some long Covid patients see their symptoms improve, but full recovery is elusive*, **STAT News**, February 8, 2022, <https://tinyurl.com/GoodNotGreatLongCovid>

*“As a society, we’re craving a return to quote-unquote ‘normalcy’. That return to normal is a return to not recognizing the value of the lives of people with disabilities and the elderly.”*

Nicole Jorwic, chief of advocacy and campaigns for Caring Across Generations, *Vaccine Hesitancy Has Seeped into Home Health Care*, **The Atlantic**, February 9, 2022, <https://tinyurl.com/VaccineHesitancyHomeHealth>

*“COVID-19 was not only a healthcare crisis but an extended test of the nation’s recognition of their human and civil rights.”*

*The Impact of COVID-19 on People with Disabilities*, **National Council on Disability (NCD)**, October 29, 2021, <https://tinyurl.com/NCDImpactOfCovid19>

*“Many phenomena that patients have been highlighting since the beginning are only now gaining momentum in formal research—clotting problems, cardiovascular issues, sudden drops in oxygen levels, autoantibodies.”*

Elisa Perego, a long-hauler who is an archaeologist, *Long-Haulers Are Fighting for Their Future*, **The Atlantic**, September 1, 2021, <https://tinyurl.com/FightingForTheirFuture>

*The risk is that long COVID becomes yet another neglected disease whereby some uncounted number of people become debilitatingly sick every year and fruitlessly bang for help on the door of an unconcerned medical establishment. But a better future is also possible, in which long-haulers—vocal, united, and numerous—finally galvanize research into the long-term consequences of viral infections; in which such research proceeds quickly as patient experts become partners; in which the world gets ways of preventing and treating long COVID, ME/CFS, and other marginalized conditions; and in which the ents’ interminable meeting ends in action and victory.*

*Long-Haulers Are Fighting for Their Future*, **The Atlantic**, September 1, 2021, <https://tinyurl.com/FightingForTheirFuture>

*“We are talking about \$20 million to cover building out care*

*coordination strategies for a mass disabling event [i.e., long Covid] that is affecting an estimated at least 2 percent of all Americans with a multisystem, multi-organ condition. This is complex care — \$20 million doesn't get you very far."*

David Putrino, director of rehabilitation innovation for the Mount Sinai Health System, *Biden announces long covid strategy as experts push for more*, \*Washington Post, April 5, 2022, <https://tinyurl.com/BidenLongCovidStrategy>

*"Mental health problems in youth are often associated with other behavioral risks such as drug use, experiencing violence and higher risk sexual behaviors and these problems can have lasting negative effects well into adulthood."*

Dr. Jonathan Mermin, director of the CDC's National Center for HIV, Viral Hepatitis, STD and TB Prevention, *'Youth are in crisis': Mental health of US high school students worsened during the Covid-19 pandemic, CDC survey finds*, **CNN Health**, March 31, 2022, <https://tinyurl.com/YouthInCrisis>

*"Lifestyle factors such as smoking, exercise and diet influence our development of Alzheimer's, and acting to address these now is a positive way of reducing risk ourselves. However, 60-80% of disease risk is based on our genetics and therefore we must continue to seek out the biological causes and develop much-needed treatments for the millions of people affected worldwide."*

Julie Williams, center director at the UK Dementia Research Institute at Cardiff University, *42 previously unknown genes discovered for Alzheimer's disease*, **CNN Health**, April 5, 2022, <https://tinyurl.com/42UnknownGenes>

*"To care for them, you have to give them dignity. That is the main factor they stress at the job, yet you don't give us the staff to provide that. They look to you for comfort, but then when you don't have time to adequately give them the comfort they deserve, it's not fair and then it's on your conscience."*

Holly Ward, a geriatric nursing assistant at a Baltimore MD nursing home, *Nursing home residents suffer from staffing shortages, but the jobs are hard to fill*, **NPR**, April 6, 2022, <https://tinyurl.com/StaffingShortagesHardToFill>

*“If you’re not on your way to that clinical trial by the beginning of May, it is very difficult to have collectively across manufacturers enough product to meet that demand.”*

Robert Johnson, the director of an infectious disease division within the Department of Health and Human Services, *Officials outline a tight deadline if the U.S. wants to redesign its Covid vaccines before the fall* \***New York Times**, April 6, 2022, <https://tinyurl.com/TightDeadline>

*“We want to make sure the money is being spent properly and for resident care, that resident care needs are coming first and not taking a back seat to other kinds of expenses like related-party transactions or even putting profit before people. To that end, if it looks like we still need to be focusing on finding additional funds to put into the system, (those) should go directly toward providing direct patient care.”*

Lori Smetanka, executive director of The Consumer Voice, *Reforms could start sooner than one year, Becerra says in ‘monumental’ nursing home meeting*, **McKnight’s Long-Term Care News**, April 1, 2022, <https://tinyurl.com/ReformsSoonerThanOneYear>

*“When interest rates are going up, it’s an enormous business problem for long-term care. Many providers are on loans with banks that mature every five years. So, the terms of those loans change every five years, and when interest rates go up, it’s just more money you have to pay every month on the mortgage. A 2% rise in interest rates is a very material event for a provider.”*

Mark Parkinson, American Health Care Association President and CEO, *Parkinson warns of new ‘enormous’ business problem for nursing homes; highlights staffing-minimum alternative*, **McKnight’s Long-Term Care News**, March 31, 2022, <https://tinyurl.com/EnormousBusinessProblem>

*“I finally saw a deaf actor on the screen showing deaf culture in a film. That night changed my life. If she did it, I could do it.”*

Marlee Matlin, after seeing a deaf actress on the ‘70s sitcom “Happy Days”, *CODA strikes a blow for representation*, \***Salem News**, February 7, 2022, <https://tinyurl.com/CODARepresentation>

*For now, most of us can enjoy the warm spring sun on our unmasked faces. But we can also do a lot more to control Covid. If we learn quickly and act quickly, we can outmaneuver the virus. As Covid continues to adapt, our response needs to adapt along with it. We could be entering the endgame for Covid. How we play it will determine what happens next.*

*The Next Covid Wave Is Probably Already on Its Way, New York Times (free access), March 22, 2022, <https://tinyurl.com/NextCovidWave>*

*"I think DPH's mission has been much less concerned with the broader issues of affordability and competition. I hope the state as a whole takes a more active role in trying to model a market that is affordable and maintains some level of competition."*

*Nancy Kane, adjunct professor at the Harvard School of Public Health, 'A new reality': State's decision against Mass General Brigham's suburban expansion could mean tighter regulation of costs and hospital growth, \*Boston Globe, April 5, 2022, <https://tinyurl.com/ANewRealityMGBExpansionDenied>*

*"I got you."*

*Lady Gaga to Liza Minelli, Lady Gaga's moment with Liza Minnelli was a beautiful example of caring with dignity, Upworthy.com, March 30, 2022, <https://tinyurl.com/LadyGagasMoment>*

*"I know."*

*Liza Minelli in reply to Lady Gaga, Lady Gaga's moment with Liza Minnelli was a beautiful example of caring with dignity, Upworthy.com, March 30, 2022, <https://tinyurl.com/LadyGagasMoment>*

Inspiration

**1. Upworthy.com**

March 30, 2022

*Lady Gaga's moment with Liza Minnelli was a beautiful example of caring with dignity*

Legendary actress [Liza Minnelli](#) joined Lady Gaga to announce the nominees and the winning film. Minnelli, 76, sat in a wheelchair while Gaga stood beside her and introduced her, with Minnelli relishing the welcoming cheers from the crowd.

As she was introducing the category and nominees, Minnelli appeared to get a little lost, and Gaga helped her out. At one point, the mic picked up Gaga leaning over and quietly telling Minnelli, "I got you," with Minnelli responding, "I know."

Lady Gaga's genuine love for the elders in the showbiz community shows in the care she shows them. Far from being patronizing or infantilizing, Gaga beautifully

	<p>balances being helpful with respecting and honoring their dignity.  <a href="https://tinyurl.com/LadyGagasMoment">https://tinyurl.com/LadyGagasMoment</a></p>
Dignity Votes 2022	<p><b>2. Rappaport Center for Law and Public Policy (Boston College)</b>          Tuesday, April 12, 2022, 12:00 to 1:15 p.m.  <i>A Conversation with Massachusetts Attorney General Candidates</i>          Candidates:</p> <ul style="list-style-type: none"> <li>• Andrea Campbell, Former Boston City Councilor</li> <li>• Shannon Liss-Riordan, Attorney, Lichten &amp; Liss-Riordan, P.C</li> <li>• Quentin Palfrey, Former Assistant Attorney General</li> </ul> <p>Moderator:</p> <ul style="list-style-type: none"> <li>• Kimberly Atkins Stohr, Senior Opinion Writer and Columnist, Boston Globe</li> </ul> <p>Location: Boston College Law School, East Wing 115          Register to attend in-person: <a href="http://bit.ly/rapp-AG-inperson">bit.ly/rapp-AG-inperson</a>  <i>*Lunch and Parking Provided</i>          Register to attend virtually: <a href="http://bit.ly/rapp-AG-virtual">bit.ly/rapp-AG-virtual</a></p>
Lives Lived Well	<p><b>3. ABC News</b>          March 25, 2022  <i>Dagny Carlsson, centenarian blogger, dies at age 109</i>          Dagny Carlsson, who started blogging after her 100th birthday and became a social media star in her native Sweden, has died.          At the age of 99, Carlsson attended a computer course and a year later, she started her blog where she called herself Bojan. Her friend Elena Ström wrote in an email to the Expressen daily that they had been "inseparable since 2011 when she became a student in one of my computer courses. . .          On her blog, Carlsson described herself as "a tough aunt, who likes most things," has a sense of humor and is "a little straightforward." She posted photos of herself and said she had "always been curious." . .          She continued to live independently until last year, when she moved into a retirement home. Her last blog post was on Jan. 28 when she wrote "like a cat, I have at least nine lives, but I do not know what I should use so much of life for."          She was also looking forward "to celebrating my 110th birthday in May, preferably with a small party."  <a href="https://tinyurl.com/DagnyCarlssonBlogger">https://tinyurl.com/DagnyCarlssonBlogger</a></p>
Ukraine	<p><b>4. *New York Times</b>          March 18, 2022  <i>For a Ukrainian Poet, Putin's War Is All Too Familiar</i>          Ihor Kalynets, 83, spent a lifetime resisting Soviet domination. Now, he says, he's not going anywhere.          At 83, no longer a young poet, Ihor Kalynets knows something of life under Russia's thumb.          Having spent nine years in the Soviet Gulag, including hard labor cutting stone, he secretly wrote on cigarette papers what are regarded as some of his best verses. They were crumpled into tiny balls and smuggled out of prison.          For 30 years of his professional life — during Soviet times — he was only able to publish abroad, infuriating the authorities, or through samizdat, the underground self-publishing network.          Today he lives on a leafy street in Lviv, a city in western Ukraine inundated with Ukrainians displaced by Russia's invasion of their country. His daughter and son-in-law live up the street, and he has opened his art-filled home to a family of</p>

	<p>refugees.  <a href="https://tinyurl.com/UkrainianPoet">https://tinyurl.com/UkrainianPoet</a></p>
CODA	<p><b>5. *Salem News</b>  February 7, 2022  <i>CODA strikes a blow for representation</i>  “I was speechless at first,” Beverly resident April Dooley told reporter Gail McCarthy.  Dooley was born to deaf parents and has two siblings who are also deaf. Her first language was American Sign Language.  “I grew up not watching movies and not a lot of TV because my parents couldn’t access it,” she said. “CODA” was the first film she could see with them in the theaters, without having to wait for the subtitled version to arrive via streaming or DVD.  “One movie is not going to represent the entire community, but this is a huge steppingstone,” Dooley said. “The notoriety the movie has gotten opens doors. It represents opportunities for deaf actors to be represented in Hollywood.”  It’s a sentiment echoed by Matlin in an interview with the online movie site IMDB. “Representation of the Deaf community is crucial in film because these days everyone is talking about authenticity,” she said. “In fact, most people understand the importance of playing roles authentically with actors who understand the character that they are playing.  <a href="https://tinyurl.com/CODARepresentation">https://tinyurl.com/CODARepresentation</a></p>
Report: <i>The National Imperative to Improve Nursing Home Quality</i>	<p><b>6. Dignity Alliance Massachusetts</b>  April 6, 2022  <i>Information about The National Imperative to Improve Nursing Home Quality Report</i>  The following information summary was prepared by Arlene Germain, Chair of DignityMA’s Facilities Workgroup.  With support from a coalition of sponsors, the National Academies of Sciences, Engineering, and Medicine (NASEM) formed the Committee on the Quality of Care in Nursing Homes to examine how the United States delivers, finances, regulates, and measures the quality of nursing home care. The resulting report [National Imperative to Improve Nursing Home Quality: Honoring Our Commitment to Residents, Families, and Staff] identifies seven broad goals and supporting recommendations which provide the overarching framework for a comprehensive approach to improving the quality of care in nursing homes. The new Committee on the Quality of Care in Nursing Homes examined how our nation delivers, regulates, finances and measures quality of nursing home care, including the long-standing challenges brought to light by the COVID-19 pandemic. Here’s a synopsis of the reports, conclusions, and goals:</p> <ol style="list-style-type: none"> <li>1. The webinar was a good review of the issues --- covered in a 600-page report! The webinar will be online within a week, but the report and summaries are online now.</li> <li>2. Highlights and Recommendations: In this link, scroll down to Publications <a href="https://www.nationalacademies.org/nursing-homes">https://www.nationalacademies.org/nursing-homes</a>. You’ll see to the right, links to Highlights and Recommendations</li> <li>3. Webinar Presentation slides found on this link <a href="https://tinyurl.com/NationalImperativeWebSlides">https://tinyurl.com/NationalImperativeWebSlides</a></li> </ol>



Overarching Conclusions

1. The way in which the United States finances, delivers, and regulates care in nursing home settings is ineffective, inefficient, fragmented, and unsustainable.
2. Immediate action to initiate fundamental change is necessary.
3. Stakeholders need to make clear a shared commitment to the care of nursing home residents.
4. Ensure that quality improvement initiatives are implemented using strategies that do not exacerbate disparities in resource allocation, quality of care, or resident outcomes.
5. High-quality research is needed to advance the quality of care in nursing homes.
6. The nursing home sector has suffered for many decades from both underinvestment in ensuring the quality of care and a lack of accountability for how resources are allocated.
7. All relevant federal agencies need to be granted the authority and resources from the U.S. Congress to implement the recommendations of this report.

GOALS:

GOAL ONE: DELIVER COMPREHENSIVE, PERSON-CENTERED, EQUITABLE CARE THAT ENSURES THE HEALTH, QUALITY OF LIFE, AND SAFETY OF NURSING HOME RESIDENTS; PROMOTES RESIDENT AUTONOMY; AND MANAGES RISKS

GOAL TWO: ENSURE A WELL-PREPARED, EMPOWERED, AND APPROPRIATELY COMPENSATED WORKFORCE

GOAL THREE: INCREASE TRANSPARENCY AND ACCOUNTABILITY OF FINANCES, OPERATIONS, AND OWNERSHIP

GOAL FOUR: CREATE A MORE RATIONAL AND ROBUST FINANCING SYSTEM

GOAL FIVE: DESIGN A MORE EFFECTIVE AND RESPONSIVE SYSTEM OF QUALITY ASSURANCE

GOAL SIX: EXPAND AND ENHANCE QUALITY MEASUREMENT AND CONTINUOUS QUALITY IMPROVEMENT

GOAL SEVEN: ADOPT HEALTH INFORMATION TECHNOLOGY IN ALL NURSING HOMES

**7. STAT News**

April 6, 2022

*U.S. nursing home care is ineffective, inefficient, inequitable, fragmented, and unsustainable*

About 1.3 million Americans live in the country's 15,000 nursing homes, where they are cared for by roughly 3 million staff members. As we write this, nearly 170,000 nursing home residents [are estimated](#) to [have died from Covid-19](#). Many, many more were isolated from family and friends during the [20-month lockdown](#). Bed sores, severe weight loss, depression, and mental and functional decline have [spiked](#) among nursing home residents. And nurses, certified nurse aides, and others who work in these facilities, [putting their own lives at risk](#), have worked in the most challenging of conditions without adequate pay or support. . .

President Biden [recommended](#) several reforms for nursing homes during his State of the Union address. These included minimum staffing standards, increased oversight, and better financial transparency. Although these provide a start, much more comprehensive and system-level action is necessary to transform this care in the United States. . .

Over the past 18 months, we served on a 17-member committee assembled by the National Academies of Sciences, Engineering, and Medicine that was charged with making bold, actionable recommendations to improve nursing home care.

	<p>The committee’s <a href="#">report</a>, which was released Wednesday, concluded that the way the U.S. finances, delivers, and regulates care in nursing home settings is ineffective, inefficient, inequitable, fragmented, and unsustainable.  <a href="https://tinyurl.com/NursingHomeCareIneffective">https://tinyurl.com/NursingHomeCareIneffective</a></p> <p><b>8. McKnight’s Long-Term Care News</b>  April 6, 2022  <i>U.S. nursing home system ‘ineffective,’ ‘unsustainable,’ National Academies report says</i></p> <p>A long-awaited national report has found that the way the United States finances, delivers and regulates nursing home care is ineffective and unstable. Immediate action is needed to bring meaningful changes to the system to better meet the needs of residents and staff, the vast team of researchers added. . .</p> <p>What’s promising about <a href="#">the report</a> is how comprehensive and detailed it is in laying out the actions needed and by whom, said Terry Fulmer, Ph.D., president of the John A. Hartford Foundation, one of the study’s sponsors.</p> <p>Fulmer said legislators on both sides of the aisle, regulators, state policymakers and nursing home operators should all back this report and its actionable recommendations.</p> <p>“The recommendations are an interrelated and complete set that gives us the blueprint for transformative change that is desperately needed for our nursing home staff and residents.  <a href="https://tinyurl.com/IneffectiveUnsustainable">https://tinyurl.com/IneffectiveUnsustainable</a></p>
<p>Reports</p>	<p><b>9. National Council on Disability (NCD)</b>  October 29, 2021  <i>The Impact of COVID-19 on People with Disabilities</i></p> <p><b>Key Findings</b></p> <ul style="list-style-type: none"> <li>■ Residents of congregate care facilities such as nursing homes, assisted living homes, psychiatric facilities, and board and care homes, where bedrooms, direct care workers, and amenities are shared, and infection control is highly challenging, caught the virus and died in large numbers, largely due to lack of personal protective equipment (PPE), close contact with others in confined settings, and the higher susceptibility to the virus due to other health conditions. The institutional model was once again shown to be detrimental to vulnerable individuals.</li> <li>■ People with disabilities of varying ages relied on direct care workers to aid with daily activities needed to remain functional in their communities, and neither they nor their workers could fully shelter in place or obtain needed personal protective equipment (PPE).</li> <li>■ The growing shortage of direct care workers that existed prior to the pandemic got worse during the pandemic. Many such workers, who are women of color earning less than a living wage and lacking health benefits, left their positions for fear of catching or spreading the virus, leaving people with disabilities and their caregivers without aid, and placing people with disabilities at risk of losing their independence or being institutionalized.</li> <li>■ Researchers have increasingly documented how physicians and other healthcare providers hold implicit biases concerning disability that lead to a primary focus on the functional limitations of people with significant disabilities and an assumption that they have a low quality of life as a result. Those assumptions have guided treatment decisions, with deadly consequences. People with intellectual and developmental disabilities, and those who were medically fragile and technology dependent, disabilities faced a uniquely high and explicit risk</li> </ul>

	<p>of being triaged out of COVID-19 treatment when hospital beds, supplies, and personnel were scarce, denied the use of their personal ventilator devices after admission to a hospital, and at times, denied the assistance of critical support persons during hospital stays. Informal and formal Crisis Standards of Care (CSC), documents that guided the provision of scarce healthcare in surge situations, targeted people with certain disabilities for denial of care.</p> <ul style="list-style-type: none"> <li>■ People with disabilities and chronic conditions who were at particularly high risk of infection with, or severe consequences from, COVID-19 were not recognized as a priority population by many states when vaccines were given emergency use authorization and had to advocate from a position of weakness because of a longstanding failure to collect detailed functional disability data in healthcare. Physical, online, communication, and procedural barriers remained common in multiple key activities that were commonly needed during the pandemic, such as the administration of testing for COVID-19 and, later on, vaccination.</li> <li>■ Students with disabilities did not receive needed in-person special education services and supports that made learning possible and were given last or no priority when districts attempted to preserve educational opportunity. Some students with special education needs, who were under the jurisdiction of the Bureau of Indian Education, experienced an especially challenging combination of internet barriers on Indian and rural lands.</li> <li>■ People with disabilities have historically been underrepresented in the workforce even in robust economic times and the pandemic exacerbated this long-standing problem.</li> <li>■ Employed people with disabilities and the family members of people with disabilities encountered the difficult choice between the income needed from work and the social distance and isolation needed to keep people with high-risk disabilities safe from the coronavirus, especially in the face of gaps in disability employment protections such as the absence of the ability to seek leave as a care provider for a family member with disabilities.</li> <li>■ Deaf, Hard of Hearing, Deaf-Blind, and Blind persons experienced a profound communication gulf as masks became commonplace, making lipreading impossible and sign language harder, while the virus made touch dangerous for blind persons and people with visual impairments who typically experience the world through touch.</li> <li>■ The financial, social, and familial adjustments that had to be made over the course of the pandemic, in addition to the constant threat of contracting COVID-19 itself, had a negative impact on everyone’s mental health, and mental health symptoms were experienced by some who acquired the virus. But both youth and adults who had mental health disabilities that predated the beginning of the pandemic experienced measurable deterioration over its course, made worse by a preexisting shortage of community treatment options, effective peer support, and suicide prevention support.</li> </ul> <p><a href="https://tinyurl.com/NCDImpactOfCovid19">https://tinyurl.com/NCDImpactOfCovid19</a></p>
Action Alert	<p><b>10. Boston Center for Independent Living, the Disability Law Center, and the American Civil Liberties Union</b>  <i>Video Day of Action for Remote Access!</i>  Please send a video—<i>no more than 60 seconds in length</i>— to BCIL at <a href="mailto:rchartier@bostoncil.org">rchartier@bostoncil.org</a> <b>by April 9</b> at the latest. We will post them, along with our allies, on April 11.</p>

	<p>Call on the legislature to do two things related to open meetings:</p> <ul style="list-style-type: none"> <li>• Allocate money in the state budget for grants to municipalities that need IT improvements to facilitate remote participation beyond the pandemic.</li> <li>• Update the open meeting law so members of the public can choose to participate remotely in public meetings on a permanent basis, even after the pandemic emergency ends</li> </ul> <p>Key messages you might share in your video:</p> <ul style="list-style-type: none"> <li>• How you were able to attend public meetings because of remote access.</li> <li>• How transparent and accessible government means a stronger democracy for all.</li> <li>• How remote access removes longstanding barriers to participation in civic life for residents with disabilities, seniors, people with limited access to transportation, and people with work and family obligations that otherwise prevent them from spending hours at municipal buildings.</li> </ul> <p>How to record your video (60 seconds or less):</p> <ul style="list-style-type: none"> <li>• Hold your cell phone horizontally while recording the video.</li> <li>• Ensure that the light source is in front of you, rather than behind you.</li> <li>• Choose a quiet location to avoid background noises, and make sure the mouthpiece/microphone area on your cell phone is unobstructed.</li> </ul> <p>For more information contact Rachel at BCIL at 617-338-6665 x 203 or <a href="mailto:rchartier@bostoncil.org">rchartier@bostoncil.org</a>.</p>
<p>Healthcare Decisions Month</p>	<p><b>11. Honoring Choices Massachusetts</b>  <i>9th Annual April Healthcare Decisions Month</i>  Every year the Honoring Choices Partners &amp; Friends celebrate April 16 National Healthcare Decisions Day by helping adults in their community make a personal care plan and get connected to good care.  <u>Easy to use tools and event ideas to:</u></p> <ul style="list-style-type: none"> <li>• Make your own personal care plan- its quick &amp; easy;</li> <li>• Co-host a fun &amp; informative webinar for your community group;</li> <li>• Support professional staff to confidently engage adults in planning conversations.</li> </ul> <p><b>To Get Started:</b> To help ensure every adult has <b>EQUAL ACCESS</b> to the free, multi-lingual tools, you can-</p> <ul style="list-style-type: none"> <li>• <b>Spread the word!</b> Include the <a href="#">9th Annual April Healthcare Decisions Month Flyer</a> in your newsletters, social media, emails and communications. Thank you!</li> <li>• <b>Choose an idea</b> to celebrate in April &amp; May. Honoring Choices will post your event on the <b>2022 Events Calendar below</b>.</li> </ul> <p><a href="https://www.honoringchoicesmass.com/nhdd-2022/">https://www.honoringchoicesmass.com/nhdd-2022/</a></p>
<p>Medical / Scientific Research Participation Opportunities</p>	<p><b>12. Survivor Corps</b>  Involvement in medical, scientific, and academic research is urgently needed. This section outlines the wide range of COVID-19 related medical studies, clinical trials and surveys presently being conducted that will broaden our understanding of the disease, improve our ability to treat and prevent it, and assist in the recovery of those suffering from Long COVID symptoms.  Research is focused in the following categories:</p> <ul style="list-style-type: none"> <li>• Long COVID</li> <li>• COVID Recovery and Healthcare Strategies</li> </ul>

	<ul style="list-style-type: none"> <li>• Therapeutics</li> <li>• Vaccines</li> </ul> <p>National and local state opportunities available.  <a href="https://www.survivorcorps.com/medical-research">https://www.survivorcorps.com/medical-research</a></p>
Webinars / Online sessions	<p><b>13. Honoring Choices Massachusetts</b>  Thursday, April 7, 2022, 12:00 to 12:30 p.m.  Wednesday, April 13, 2022 12:00 to 12:30 p.m.  <i>Health Equity at End of Life: Enhancing Access to Advance Directives &amp; Palliative Care.</i>  For all care professionals. Hosted by Healthcentric Advisors, IPRO QIN-QIO  As part of their Small Talk Series, Healthcentric Advisors, provides this timely webinar that recognizes racial and ethnic health disparities in accessing care for adults with serious illness. A panel of expert speakers will discuss the inequities in receiving hospice and palliative care, where adults may be more likely to experience worse pain and symptom management, as well as a higher rate of hospitalization at end of life. The speakers will explore strategies and interventions for addressing end-of-life care disparities.  Register for <a href="#">4/7 Webinar</a>  Register for <a href="#">4/13 Webinar</a></p> <p><b>14. Gray Panthers of New York City</b>  Tuesday, April 19, 2022, 2:00 to 3:00 p.m.  <i>Nursing Home Policy Updates: What is the Strategy</i>  The webinar will feature a panel of government officials and non-profit leaders.  Registration: <a href="https://tinyurl.com/Transformation-TuesdayApril19">https://tinyurl.com/Transformation-TuesdayApril19</a></p> <p><b>15. Honoring Choices Massachusetts</b>  Wednesday, April 20, 2022, 12:00 to 1:00 p.m.  <i>"Become a Health Care Planning Ambassador" Webinar</i>  Open to all care, community, faith-based professionals- anyone who engages adults in simple planning conversations.  Hosted by Honoring Choices MA  Starting a simple planning conversation is the key to empowering adults to take control of their health care decisions and start to make a personal plan. Come join the 3500 strong Ambassador Network of health care and community professionals. The popular 45-minute webinar provides up to date information on MA planning documents to confidently engage adults in simple planning conversations to complete a Health Care Proxy and Personal Directive (Living). Learn about 5 MA planning documents and our Next Steps Tool Kit.  Participants receive the Honoring Choices MA Health Care Planning Ambassador Certificate.  <a href="#">Register Here.</a></p>
Previously posted webinars and online sessions	<p><b>Previously posted webinars and online sessions can be viewed at:</b>  <a href="https://dignityalliancema.org/webinars-and-online-sessions/">https://dignityalliancema.org/webinars-and-online-sessions/</a></p>
Nursing homes	<p><b>16. McKnight's Long-Term Care News</b>  April 1, 2022  <i>Reforms could start sooner than one year, Becerra says in 'monumental' nursing home meeting</i>  The federal government will meet or exceed a goal of implementing key nursing</p>

	<p>home reform measures within a year, Health and Human Services Secretary Xavier Becerra said Wednesday. His pronouncement came during a meeting with seven national organizations hoping to influence just what that reform will look like. . .</p> <p>On Thursday, LeadingAge officials and four members met with Centers for Medicare &amp; Medicaid Services Administrator Chiquita Brooks-LaSure. AHCA President and CEO Mark Parkinson and his members had their time with her Monday. . .</p> <p>During the 50-minute meeting, each organization was able to give a three-minute presentation. Then Becerra followed up with three questions, Sloan said. Those focused on transparency, staffing and continued efforts around vaccinating staff and residents against COVID-19.</p> <p><a href="https://tinyurl.com/ReformsSoonerThanOneYear">https://tinyurl.com/ReformsSoonerThanOneYear</a></p> <p><b>17. McKnight’s Long-Term Care News</b>  March 31, 2022  <i>Parkinson warns of new ‘enormous’ business problem for nursing homes; highlights staffing-minimum alternative</i></p> <p>Interest rates, which are expected to rise as many as six more times in 2022, will present many nursing home leaders with challenges they have never before seen, American Health Care Association President and CEO Mark Parkinson told <i>McKnight’s Long-Term Care News</i> in an interview Tuesday.</p> <p>“An underreported worry is the interest rate risk that many providers have. Most providers have never operated in an environment where interest rates were stable or going up,” Parkinson explained. “For the last 30 years, interest rates were going down so people were used to that.” . .</p> <p>“When interest rates are going up, it’s an enormous business problem for long-term care,” Parkinson told <i>McKnight’s</i>. “Many providers are on loans with banks that mature every five years. So, the terms of those loans change every five years, and when interest rates go up, it’s just more money you have to pay every month on the mortgage. A 2% rise in interest rates is a very material event for a provider.”</p> <p><a href="https://tinyurl.com/EnormousBusinessProblem">https://tinyurl.com/EnormousBusinessProblem</a></p>
Behavioral health	<p><b>18. CNN Health</b>  March 31, 2022  <i>‘Youth are in crisis’: Mental health of US high school students worsened during the Covid-19 pandemic, CDC survey finds</i></p> <p>Mental health concerns among high school students in the United States were exacerbated during the Covid-19 pandemic, according to <a href="#">survey results</a> published Thursday by the US Centers for Disease Control and Prevention.</p> <p>There have been significant increases in high school students reporting persistent feelings of sadness or hopelessness, considering suicide, or attempting suicide over the past decade -- and findings from the new CDC survey suggest youth mental health was even worse during the pandemic.</p> <p>Overall, more than a third (37%) of high school students in the United States experienced poor mental health at least most of the time during the Covid-19 pandemic, the CDC survey found. More than two out of five students (44%) had felt persistent sadness or hopelessness that caused them to stop doing some usual activities. About one in five seriously considered suicide, and about one in 10 students had attempted suicide.</p> <p>Poor mental health was most prevalent among lesbian, gay and bisexual youth, as well as female high school students, the CDC survey found.</p>

	<a href="https://tinyurl.com/YouthInCrisis">https://tinyurl.com/YouthInCrisis</a>
Alzheimer's / Dementia	<p><b>19. *New York Times</b>  April 6, 2022  <i>Inside a Campaign to Get Medicare Coverage for a New Alzheimer's Drug</i>  Medicare's proposal to pay for Aduhelm only for participants in randomized clinical trials was welcomed by many Alzheimer's experts and other doctors. They say it would protect patients and families whose desperation might lead them to try anything, while also rigorously evaluating whether Aduhelm actually works. But the Alzheimer's Association and similar groups, along with Aduhelm's manufacturer, <a href="#">Biogen</a>, strongly object. They say that Aduhelm, a monoclonal antibody that is the first drug approved for Alzheimer's in 18 years, should be covered for anyone with mild Alzheimer's-related cognitive decline and that usage decisions should rest with patients and their doctors.  <a href="https://tinyurl.com/InsideMedicareCampaign">https://tinyurl.com/InsideMedicareCampaign</a></p> <p><b>20. CNN Health</b>  April 5, 2022  <i>42 previously unknown genes discovered for Alzheimer's disease</i>  An additional 42 genes connected to the development of Alzheimer's disease have been uncovered in the largest study of genetic risk for Alzheimer's to date. "This is a landmark study in the field of Alzheimer's research and is the culmination of 30 years' work," study co-author Julie Williams, center director at the UK Dementia Research Institute at Cardiff University, said <a href="#">in a statement</a>. . . The previously unknown genes point to additional pathways for disease progression besides the well-known APOE e4 gene or the development of amyloid beta and tau, two hallmark proteins that build up in the brain with devastating results as Alzheimer's progresses. . . Another key insight of the study was that brain disorders such as Parkinson's, frontotemporal dementia, Lewy body disease and amyotrophic lateral sclerosis may have the same underlying genetic basis: "Taken as a whole, these data may thus emphasize a potential continuum between neurodegenerative diseases," the study said. . . "People want to know, 'what are my chances?' and then 'what can I do about it?'" Isaacson said. "Not today, but in the near future, we'll be able to calculate a person's likelihood of developing Alzheimer's or another brain disorder in a more precise way, and that will help with precision medical and lifestyle management."  <a href="https://tinyurl.com/42UnknownGenes">https://tinyurl.com/42UnknownGenes</a></p>
Guardianship	<p><b>21. *New York Times</b>  March 24, 2022  <i>She Starved and Nearly Died on Guardian's Watch, Family Says</i>  All Bonnie Lee Apple would tell a friend on the phone was "I don't feel good." A disturbing photo indicated problems.  <a href="https://tinyurl.com/NearlyDiedObGuardiansWatch">https://tinyurl.com/NearlyDiedObGuardiansWatch</a></p>
Workforce / Caregivers	<p><b>22. NPR</b>  April 6, 2022  <i>Nursing home residents suffer from staffing shortages, but the jobs are hard to fill</i>  Numerous studies have shown that understaffing nursing homes can harm the health of residents, who suffer more bedsores, more weight loss, more overprescribing of anti-psychotic medications, and — during the pandemic — more COVID-19 cases and deaths.</p>

	<p>[Chiquita Brooks-LaSure, administrator for the Centers for Medicare &amp; Medicaid Services (CMS)], says her agency will determine how much staff nursing homes should be required to have and then enforce that through a rule. She aims to have a rule in place within a year, an optimistic time frame given the lengthy federal rulemaking process and other challenges. . .</p> <p>Nationwide, nursing homes are down more than 240,000 employees since the start of the pandemic, according to the Labor Department. Facilities across the country are grappling with numerous unfilled positions as a result of staff departures during the pandemic.</p> <p><a href="https://tinyurl.com/StaffingShortagesHardToFill">https://tinyurl.com/StaffingShortagesHardToFill</a></p> <p><b>23. The Atlantic</b> February 9, 2022 <i>Vaccine Hesitancy Has Seeped into Home Health Care</i> Many direct-care workers are unsure about the COVID-19 vaccines, leaving the people who depend on their labor that much more vulnerable. . . Balancing the need for care and the stress of dependence on people who might infect you with COVID-19 is just one more way the pandemic is concentrating risk among the most vulnerable, and even more so the longer it goes on. . . In one important way, the risk of home health care continues to be unnecessarily high: Direct-care workers tend to be unsure about the COVID-19 <a href="#">vaccines</a>. When they first became available, some struggled to gain access. By the spring of 2021, just <a href="#">one-quarter</a> of direct-care workers had been vaccinated, compared with about two-thirds of hospital workers and half of nursing-home workers, . . Outside of such private, unregulated arrangements, the requirements that direct-care aides be vaccinated aren't totally clear. November's federal vaccine mandate through the Centers for Medicare and Medicaid Services—which was upheld by the Supreme Court last month—clearly covers Medicare-certified home health agencies, but not necessarily Medicaid providers of home-based services (whose availability and funding vary greatly from state to state). And because 90 percent of direct-care workers are employed by small agencies, federal rules requiring vaccination or regular testing at companies with 100 or more employees—which the Supreme Court sent back to the lower courts on the same day—will also not broadly apply to the industry. . . Even if the risk of COVID disappeared tomorrow, the pandemic would have left home-care clients in a more vulnerable position—and added to their numbers. In 2019, 41 states had waiting lists for home and community-based health services—a nationwide total of about <a href="#">820,000 people</a> enduring an average wait of 39 months. “That was before the pandemic,” Caring Across Generations’ Jorwic said. “That number has certainly gone up.” Given what we know about <a href="#">long COVID</a>, Bogart said, the pandemic could represent “a mass disabling event.” Already, at least <a href="#">26 percent</a> of U.S. adults have a disability, and she and others say we are neglecting their needs by neglecting the home-care industry. “I am very worried, looking forward. What does this mean for all of us down the line?” Madad, the epidemiologist, said. “There’s going to be a huge demand for it, and we’re not doing enough.” <a href="https://tinyurl.com/VaccineHesitancyHomeHealth">https://tinyurl.com/VaccineHesitancyHomeHealth</a></p>
Covid-19	<p><b>24. Office of the Assistant Secretary for Preparedness and Response (ASPR)</b> March 2022 <i>Test to Treat</i> The Biden-Harris Administration launched a new nationwide Test to Treat initiative</p>



in March to give individuals an important way to quickly access free lifesaving treatment for COVID-19. Through this program, people are able to get tested and – if they are positive and treatments are appropriate for them – receive a prescription from a health care provider, and have their prescription filled all at one location. These “One-Stop Test to Treat” sites are available at hundreds of locations nationwide, including pharmacy-based clinics, Health Resources Services Administration (HRSA)-supported federally-qualified health centers (FQHCs), and long-term care facilities. People can continue to be tested and treated by their own health care providers who can appropriately prescribe these oral antivirals at locations where the medicines are distributed.

A [Test to Treat locator](#) is available to help find participating sites. A call center is also available at [1-800-232-0233](tel:1-800-232-0233) (TTY [1-888-720-7489](tel:1-888-720-7489)) to get help in English, Spanish, and more than 150 other languages – 8:00 am to midnight ET, 7 days a week. The [Disability Information and Access Line](#) (DIAL) is also available to specifically help people with disabilities access services. To get help, call [1-888-677-1199](tel:1-888-677-1199), Monday-Friday from 9:00 am to 8:00 pm ET or email [DIAL@usaginganddisability.org](mailto:DIAL@usaginganddisability.org).

**25. \*New York Times**

April 6, 2022

*Officials outline a tight deadline if the U.S. wants to redesign its Covid vaccines before the fall.*

A top federal health official outlined a tight time frame on Wednesday if the Biden administration hopes to have new coronavirus vaccines by the fall that better meet the threat of a fast-evolving virus, saying clinical trials would have to be underway by next month in order to produce the shots. . .

A number of clinical studies are already underway, conducted both at the National Institutes of Health and by vaccine manufacturers themselves. The trials are too small to give efficacy data of the type that first led to the authorization of the existing vaccines. But they could produce enough immune response data for federal health officials to determine whether a retooled vaccine will work better than current ones.

Expert after expert described how much guesswork is involved in trying to design a better vaccine at this point. No one knows which variant of the virus will dominate in the fall when some consider a new surge highly likely. There is some chance another variant like Omicron will emerge that redraws the coronavirus picture in a wholly unexpected way — a factor that can be neither measured nor discounted.

<https://tinyurl.com/TightDeadline>

**26. \*New York Times**

April 5, 2022

*The C.D.C. director says she ‘really would encourage’ second boosters for older people and many with chronic conditions.*

Dr. Rochelle P. Walensky, director of the Centers for Disease Control and Prevention, said Tuesday that her agency “really would encourage people who are over 50 who have underlying medical conditions and those over the age of 65” to get a second booster shot. . .

[booster of Pfizer-BioNTech or Moderna’s vaccines](#) for everyone over 50 and many immunocompromised people, four months after the first booster. At the time, Dr. Walensky said that the option was “especially important” for those over 65, as well as for those over 50 with chronic health problems, such as diabetes or obesity. Still, before Tuesday’s briefing, some health experts said they were unsure whether to

recommend the second booster for those groups. . .

The decision to offer a second booster [continues to generate controversy](#), with some immunologists and vaccine experts arguing that the federal government lacked enough data to justify the move, at least for those younger than 65. Some of that criticism will likely be aired on Wednesday [at a public meeting of the F.D.A.'s outside advisory committee of experts](#) where the broader U.S. booster strategy is set to be discussed.

<https://tinyurl.com/EncourageSecondBoosters>

#### **27. McKnight's Long-Term Care News**

April 4, 2022

*CMS revises COVID-19 vaccine mandate guidance*

Workers at skilled nursing and other long-term care facilities that have been suspended or are on extended leave won't count against the providers as "unvaccinated staff," according to new updated guidance from the federal government.

The Centers for Medicare & Medicaid Services on Tuesday issued revisions to its guidance for the COVID-19 vaccine mandate rule. CMS also emphasized that "good-faith efforts" by providers will be rewarded, and gave examples, in the guidance.

The revisions clarified that contract staff who fail to provide evidence their vaccination status reflects as being non-compliant with the rule and should be cited.

The federal vaccine rule requires facilities to ensure that staff who haven't been fully vaccinated or are exempt adhere to additional precautions that are intended to slow the spread of COVID-19. Examples currently listed in the guidance range from reassigning them to non-patient areas, requiring weekly testing and use approved-masks on the job.

CMS on Tuesday said this requirement "is not explicit and does not specify which actions must be taken."

<https://tinyurl.com/CMSRevisesCovidMandate>

#### **28. Kaiser Health News**

April 1, 2022

*As US Nears 1 Million Covid Deaths, One Hard-Hit County Grapples with Unthinkable Loss*

The United States is nearing 1 million deaths from covid — an almost incomprehensible number of lives lost that few thought possible when the pandemic began. Pennsylvania's Mifflin County offers a snapshot into how one hard-hit community, with over 300 dead, is coping. . .

Mifflin has one of the highest covid death rates among U.S. counties with at least 40,000 people, according to [government data](#) compiled by Johns Hopkins University — 591 deaths per 100,000 residents as of mid-March, compared with 298 deaths nationally. . .

Reaching a million deaths seemed even more improbable when safe and effective vaccines came onto the market in December 2020. More than 60% of the 977,000 deaths have occurred since then. . .

Health experts point to several factors behind Mifflin County's high death rate:

- A large older population — [22% of residents](#) are 65 or older.
- A low covid vaccination rate (51% of residents are fully vaccinated, compared with 63% statewide).
- The prominent Amish and Mennonite populations; Amish people make up over 8% of county residents. Members of those communities largely did not get

	<p>vaccinated and often gathered for large weddings and funerals during the past two years, according to county officials. Amish, in particular, have low rates of vaccination because they are leery of government intervention and rely on family traditions for preventive medicine.</p> <p><a href="https://tinyurl.com/MifflinCounty">https://tinyurl.com/MifflinCounty</a></p> <p><b>29. New York Times (free access)</b>  March 28, 2022  <i>Reducing Covid's Toll</i>  Many experts expect Covid caseloads to rise soon. Here are four steps to protect people.</p> <ol style="list-style-type: none"> <li>1. More boosters</li> <li>2. The immunocompromised</li> <li>3. Post-infection treatments</li> <li>4. Masks</li> </ol> <p><a href="https://tinyurl.com/ReducingCovidsToll">https://tinyurl.com/ReducingCovidsToll</a></p> <p><b>30. New York Times (free access)</b>  March 22, 2022  <i>The Next Covid Wave Is Probably Already on Its Way</i>  The most important lesson of the Covid pandemic is that the only constant is change. Variants spread, cases surge and abate, treatments change, and knowledge expands. This means that we — the public, elected officials, and public health leaders — need to learn constantly and adapt quickly, acting on the insight that no one policy response is likely to stay effective for long.</p> <p>Now is the moment to put that flexibility into practice. Rising Covid cases in <a href="#">Europe</a>, the toll Omicron is taking particularly on unvaccinated elderly people in <a href="#">Hong Kong</a> and slowing vaccinations are warnings that another wave of infections is likely approaching the United States. But we are by no means helpless. We can prepare better, save lives, and reduce disruption. . .</p> <p>The risks for the United States are clear. BA.2 is <a href="#">increasing</a> and will likely soon account for most new cases in the country. Masks have come off and approximately 60 percent <a href="#">of</a> Americans, including more than <a href="#">one third</a> of people above age 65 — more than 15 million seniors — are not up-to-date with vaccination. This doesn't mean that BA.2 will inevitably cause a deadly surge. But it does mean that cases may increase soon, and that unvaccinated and under-vaccinated elderly and medically vulnerable people could face a deadly threat.</p> <p><a href="https://tinyurl.com/NextCovidWave">https://tinyurl.com/NextCovidWave</a></p>
Long Covid	<p><b>31. *Washington Post</b>  April 5, 2022  <i>Biden announces long covid strategy as experts push for more</i>  President Biden on Tuesday <a href="#">directed government agencies</a> to take additional steps to research and treat long covid, a condition that remains often mysterious even as it has sickened millions of Americans.</p> <p>Under a memorandum issued by Biden, the Department of Health and Human Services will coordinate a government-wide action plan to address long covid, which is estimated to afflict anywhere from 7.7 million to 23 million Americans, <a href="#">according to a recent federal watchdog report</a>.</p> <p>The government also will issue a report in 120 days detailing available services and support for those who suffer from long covid, accelerate efforts to enroll participants in a clinical research study and pursue federal protections for people</p>

with the condition.

<https://tinyurl.com/BidenLongCovidStrategy>

### 32. STAT News

April 5, 2022

*Biden administration ramps up long Covid research efforts following criticism*

The Biden administration on Tuesday announced plans to ramp up research into long Covid, following scathing criticism from patients and experts.

The White House's plan includes efforts to improve sluggish enrollment in a major study run by the National Institutes of Health and to create a new research task force to coordinate research into long Covid across federal agencies.

Crucial questions about long Covid remain, including exactly how it will be defined, how prevalent it is among people who are infected with Covid-19, and who is most at risk. Millions of people in the United States are experiencing persistent symptoms after Covid-19 infections, and research will help determine the long-term burden of the pandemic on the health care system and on the economy. . .

The Biden administration's new efforts also come after [a group of two dozen prominent Covid-19 experts](#) issued a scathing critique of the federal government's research efforts so far, describing them as "siloed, with barriers to sharing resources and data."

<https://tinyurl.com/RampsUpLongCovidResearch>

### 33. STAT News

March 29, 2022

*'A slow-moving glacier': NIH's sluggish and often opaque efforts to study long Covid draw patient, expert ire*

The National Institutes of Health is fumbling its first efforts to study long Covid. Fifteen months ago, Congress showered the agency with a massive \$1.2 billion to research the mysterious cases of patients who never fully recover from Covid-19 infections. But so far, the NIH has brought in just 3% of the patients it plans to recruit.

Critics charge that the NIH's missteps are even bigger: that it is acting without urgency, that it is taking on vague, open-ended research questions rather than testing out therapies or treatments, and that it is not being fully transparent with patient advocates and researchers. . .

The success of the NIH's research into long Covid will shape the trajectory of the long-term burden of the pandemic on health care systems around the world for years to come, as millions of patients grapple with debilitating symptoms. If researchers can find answers, it also could provide a once-in-a-lifetime chance to give hope to a host of patients with other post-viral illnesses that have been long misunderstood. . .

To meet the moment, the NIH launched the four-year RECOVER initiative. Its [primary goal at the moment](#) is to enroll 40,000 adults and children to learn more about who gets long Covid, how prevalent it is, and to define its biological causes and symptoms. The project will also collect tissue samples from autopsies and real-world data. . .

[S]ome prominent long Covid patient advocacy groups [started raising concerns in November](#) that the patient engagement efforts weren't as robust as they had hoped. At the time, they were concerned by the lack of a comprehensive patient engagement structure, the dearth of involvement by experts involved in

researching other post-viral illnesses, and little evidence that patient suggestions were actually being implemented.

<https://tinyurl.com/SlowMovingGlacier>

**34. \*New York Times**

March 17, 2022

*What Long Covid Shows Us About the Limits of Medicine*

Long Covid symptoms, such as fatigue, shortness of breath, cognitive difficulties, erratic heart rate, headache, and dizziness, can be debilitating and wide-ranging. There is uncertainty about what ultimately causes long Covid and how to adequately [respond](#) to it.

In conventional medicine, illnesses without definitive markers of disease are often described as “medically unexplained.” As a medical anthropologist who has studied the [controversy](#) over whether treated Lyme disease can become chronic, I’ve been struck by the similarities between long Covid and other contested illnesses like chronic Lyme disease and myalgic encephalomyelitis, more familiarly known as chronic fatigue syndrome.

Patients with contested illnesses can often feel [unseen and unheard](#), and their providers often feel frustrated that they can’t do more. As [patient advocacy movements](#) have emerged, so has scientific disagreement about what causes these illnesses and how to address them. Contested illnesses pull back the curtain on medicine itself: how it understands the human body, what counts as evidence and how medicine draws on that evidence to produce medical truths.

Long Covid has a bigger spotlight than other contested illnesses and was recognized much faster. Post-Covid clinics have been [established](#) in nearly every state, the National Institutes of Health have [invested](#) \$1.15 billion to [study it](#), and it’s now [included](#) in the Americans With Disabilities Act. Long Covid has brought [increased attention](#) to other marginalized illnesses, along with hope that the needle might finally be moved on overdue research and funding. . .

“[Acknowledging uncertainty](#)” — what long Covid patients have called for — is a fitting refrain for our times. As much as they wanted answers, the Lyme patients I interviewed also wanted physicians who could admit what they didn’t know. Starting with what we don’t know — and leading with humility and empathy — seems like a good place to begin.

<https://tinyurl.com/LongCovidLimitsMedicine>

**35. STAT News**

February 8, 2022

*‘Good, not great’: Some long Covid patients see their symptoms improve, but full recovery is elusive*

Long Covid clinics started opening their doors in 2020, before there was an agreed-upon definition of the condition but inspired by patient advocacy groups. They now number at least [44 centers](#) in [48 states](#). Doctors and researchers give credit to organizations such as [Survivor Corps](#) and the [Body Politic Covid-19 Support Group](#) for helping to mobilize a response to post-Covid impairments that were dismissed by clinicians.

It’s now recognized by the National Institutes of Health as [PASC](#), which stands for post-acute sequelae of SARS-CoV-2 infection and covers an array of symptoms that persist for several weeks, months, and potentially years after an infection has been diagnosed. Symptoms run the gamut through both mental and physical health, spanning the neurologic and psychiatric, the cardiovascular and pulmonary, the gastrointestinal and musculoskeletal. Within each organ system, severity spans a

spectrum. In neurology, that could range from headache to encephalopathy to muscle weakness to “brain fog” that looks like dementia or [chemo brain](#): memory gaps, trouble finding words, inability to do simple math, such as calculating a tip, or worse. . .

A [study](#) conducted by the Centers for Disease Control and Prevention and published Friday in JAMA Network Open estimates roughly 1 in 10 people will develop long Covid symptoms more than a month after infection, with more severe Covid-19 raising that likelihood. That’s lower than an [estimate](#) from Oxford University that puts the toll at more than 1 in 3 people. With the staggering total of Covid cases in the U.S. since the pandemic began, even that more conservative number translates to more than 7 million people with long Covid.

<https://tinyurl.com/GoodNotGreatLongCovid>

### **36. The Atlantic**

September 1, 2021

*Long-Haulers Are Fighting for Their Future*

Many people with long COVID feel that science is failing them. Neglecting them could make the pandemic even worse. . .

The common wisdom was that people infected with SARS-CoV-2 mostly get mild symptoms that resolve after two weeks. And yet, thousands of “long-haulers” had already been debilitated by months of extreme fatigue, brain fog, breathing difficulties, and other relentless, rolling problems. More than a year later, several clinics care for long-haulers, while the biomedical community, like the ents, has begun to identify long-COVID patients as long-COVID patients. But some researchers still hesitate to recognize long COVID if it doesn’t present in certain ways; they’re running studies without listening to patients, and they’ve come up with their own arguably unhelpful name for the disease. . .

Despite long-haulers’ fight for recognition, any discussion of the pandemic still largely revolves around two extremes—good health at one end, and hospitalization or death at the other. This ignores the hinterland of disability that lies in between, where millions of people are already stuck, and where many more may end up. The coronavirus is here to stay, and even as vaccines diminish the threat of hospitalization and death, we don’t know yet how well they will protect against the disability of long COVID. The choice we make about how to study this condition will define the toll that SARS-CoV-2 takes for years to come. . .

One of the biggest misconceptions about long COVID is that it is entirely new. The SARS-CoV-2 coronavirus may have emerged in 2019, but many infections can lead to similar long-term symptoms. Long COVID shares traits with chronic illnesses including ME/CFS, fibromyalgia, mast cell activation syndrome (MCAS), and dysautonomia including postural tachycardia syndrome (POTS). Although long COVID isn’t identical to any of them, the overlaps are substantial. . .

The risk is that long COVID becomes yet another neglected disease whereby some uncounted number of people become debilitatingly sick every year and fruitlessly bang for help on the door of an unconcerned medical establishment. But a better future is also possible, in which long-haulers—vocal, united, and numerous—finally galvanize research into the long-term consequences of viral infections; in which such research proceeds quickly as patient experts become partners; in which the world gets ways of preventing and treating long COVID, ME/CFS, and other marginalized conditions; and in which the ents’ interminable meeting ends in action and victory.

<https://tinyurl.com/FightingForTheirFuture>

	<p><b>37. Office for Civil Rights U.S. Department of Health &amp; Human Services</b>  <i>Guidance on “Long COVID” as a Disability Under the ADA, Section 504, and Section 1557</i></p> <p>This guidance explains that long COVID can be a disability under Titles II (state and local government) and III (public accommodations) of the Americans with Disabilities Act (ADA),<sup>3</sup> Section 504 of the Rehabilitation Act of 1973 (Section 504),<sup>4</sup> and Section 1557 of the Patient Protection and Affordable Care Act (Section 1557).<sup>5</sup> Each of these federal laws protects people with disabilities from discrimination.<sup>6</sup> This guidance also provides resources for additional information and best practices. This document focuses solely on long COVID and does not address when COVID-19 may meet the legal definition of disability.</p> <p><a href="https://tinyurl.com/GuidnaceOnLongCovid">https://tinyurl.com/GuidnaceOnLongCovid</a></p>
Longevity	<p><b>38. New York Times (free access)</b>  March 24, 2022  <i>How to Live to 100</i></p> <p>For one sturdy wartime survivor, living intensely has been the best revenge. [Natalie] Harley, who turned 100 in January, was droll on a Zoom call early this month. Was she feeling her years? Not a chance. “Pfft, in my mind I am still 24,” she said. Her motto now, as it was in her youth: “Wherever the wind blows, you just pack a toothbrush and go.”</p> <p>As she chatted, her sometimes harrowing past seemed as vivid to her as the previous night’s supper, her story suggesting that in palmy, or punishing, times, living intensely is the best revenge.</p> <p><a href="https://tinyurl.com/NYTHowToLiveTo100">https://tinyurl.com/NYTHowToLiveTo100</a></p>
Well-Being	<p><b>39. The Ethel from AARP</b>  April 4, 2022  <i>5 Amazing Ways You Could Naturally Strengthen Your Bones</i></p> <p>Don't let balance issues get you down!</p> <p>Here are 5 ways we could naturally strengthen our bones:</p> <ul style="list-style-type: none"> <li>• Learn from the astronauts: Eat more fish.</li> <li>• Eat more vegetables and fruits.</li> <li>• Eat enough protein at each meal.</li> <li>• Don't overdo it with calcium supplements.</li> <li>• Exercise — but pick the right kind.</li> </ul> <p><a href="https://tinyurl.com/NaturallyStrengthenBones">https://tinyurl.com/NaturallyStrengthenBones</a></p>
Medical Care	<p><b>40. *Boston Globe</b>  April 5, 2022  <i>‘A new reality’: State’s decision against Mass General Brigham’s suburban expansion could mean tighter regulation of costs and hospital growth</i></p> <p>The Massachusetts Department of Public Health’s decision Friday to not recommend several components of Mass General Brigham’s massive, \$2.3 billion expansion may mark a turning point in how the state regulates hospital growth. MGB revealed on Friday that DPH staff refused to support MGB’s outpatient expansion plans in Westwood, Woburn, and Westborough. DPH staff also suggested the hospital chain trim a proposed expansion at Massachusetts General Hospital, saying in a report that the health system hadn’t demonstrated enough need for all the beds and equipment it wants to add.</p> <p><a href="https://tinyurl.com/ANewRealityMGBExpansionDenied">https://tinyurl.com/ANewRealityMGBExpansionDenied</a></p>
	<p>*May require registration before accessing article.</p>

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: <a href="https://tinyurl.com/DignityLegislativeEndorsements">https://tinyurl.com/DignityLegislativeEndorsements</a> 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	<p><b>Disability and Social Interaction Lab</b> <a href="https://liberalarts.oregonstate.edu/sps/dsil">https://liberalarts.oregonstate.edu/sps/dsil</a> Oregon State University, College of Liberal Arts, School of Psychological Sciences The Disability and Social Interaction Lab (DSIL), directed by Dr. Kathleen Bogart, studies the forgotten “ism,” ableism, or stereotyping, prejudice, and discrimination towards disability. Nearly 20% of Americans have a disability, making it the largest minority group in the U.S. They examine disability from a social psychological perspective, examining others’ attitudes toward disability and the way people with disabilities manage stigma. Their work extends social psychological theories of intergroup prejudice to examine ableism. Much of their work focuses on the psychosocial implications of living with rare disorders or disabilities, such as Bell's palsy and Moebius syndrome. In the U.S., rare disorders are defined as affecting fewer than 200,000 people per year. Although there are more than 7,000 different rare disorders, the 30 million Americans with rare disorders share similar challenges, including insufficient access to information, support, and treatment. Rare disorders can be stigmatizing because people with them are frequently misunderstood, isolated, and blamed. The lab is working to build social support and resist stigma in the rare disorder community.</p> <p><b>Survivor Corps</b> <a href="https://www.survivorcorps.com/">https://www.survivorcorps.com/</a> <a href="https://www.survivorcorps.com/">Survivor Corps</a> is the largest grassroots movement in America dedicated to actively ending this pandemic. They have quickly evolved into one the most active and robust COVID-19 data sets and research tools in the world. They are continually connecting, supporting, and educating those affected by COVID-19 (and their colleagues, families, and friends). They strive to motivate and mobilize as many as possible to <a href="#">support all ongoing Scientific, Medical and Academic research</a> in order to improve our understanding of this disease and help develop health care pathways and options for those suffering with acute and long term symptoms. They help get people back into their homes, their families, and their communities and, even better, back to work, all while fostering the spirit of unity, compassion and solidarity that is urgently needed during this time of crisis.</p>
Previously recommended websites	The comprehensive list of recommended websites has migrated to the Dignity Alliance MA website: <a href="https://dignityalliancema.org/resources/">https://dignityalliancema.org/resources/</a> . Only new recommendations will be listed in <i>The Tuesday Digest</i> .
Previously posted funding opportunities	For open funding opportunities previously posted in <i>The Tuesday Digest</i> please see <a href="https://dignityalliancema.org/funding-opportunities/">https://dignityalliancema.org/funding-opportunities/</a> .
Nursing Home Closures	Closure Notices and Relocation Plans available at: <a href="https://tinyurl.com/MANursingHomeClosures">https://tinyurl.com/MANursingHomeClosures</a>
Websites of Dignity Alliance Massachusetts Members	See: <a href="https://dignityalliancema.org/about/organizations/">https://dignityalliancema.org/about/organizations/</a>



State Budget	<p><b>Commonwealth of Massachusetts</b>  <i>Governor's Proposed Budget for FY 2023</i>  January 26, 2022  The annual budget process begins each year when the Governor files recommendations as a bill with the House of Representatives. Under the state Constitution, the Governor must submit a proposal by the 4th Wednesday of January or, in the event of a new term, within five weeks later. This bill is called House 1 or "House 2" depending on the year.  <a href="https://malegislature.gov/Budget">https://malegislature.gov/Budget</a></p>																																												
Nursing homes with admission freezes	<p><b>Massachusetts Department of Public Health</b>  <i>Temporary admissions freeze</i>  On November 6, the state <a href="#">announced</a> that it would require certain high risk nursing homes and rest homes to temporarily stop all new admissions to protect the health and safety of residents and prevent further COVID-19 transmission.  Stopping admissions enables homes to focus resources such as staff and PPE on the health and safety of its current residents and enables the home to stabilize before taking on new residents. Homes that meet certain criteria will be required to stop any new admissions until the Department of Public Health has determined that conditions have improved, and the facility is ready to safely care for new residents. The Commonwealth will work closely with homes during this time and provide supports as needed to ensure resident health and safety.  There are a number of reasons why a facility may be required to stop admissions, and the situation in each facility is different. Some of the factors the state uses to make this decision include:</p> <ul style="list-style-type: none"> <li>• Number of new COVID-19 cases within the facility</li> <li>• Staffing levels</li> <li>• Failure to report a lack of adequate PPE, supplies, or staff</li> <li>• Infection control survey results</li> <li>• Surveillance testing non-compliance</li> </ul> <p>Facilities are required to notify residents' designated family members and/or representative when the facility is subject to an admissions freeze. In addition, a list of facilities that are currently required to stop new admissions and the reason for this admissions freeze will be updated on Friday afternoons, and as needed when the Department of Public of Health determines a facility can be removed from the list.</p> <p><b>Updated on March 31, 2022</b></p> <table border="1" data-bbox="483 1381 1507 1858"> <thead> <tr> <th>Name of Facility</th> <th>City/Town</th> <th>Date of Freeze</th> <th>Qualifying Factor</th> </tr> </thead> <tbody> <tr> <td>Bear Mountain at Worcester</td> <td>Worcester</td> <td>3/29/2022</td> <td>Infection control</td> </tr> <tr> <td>Donna Kay Rest Home</td> <td>Worcester</td> <td>3/29/2022</td> <td>Noncompliance Testing</td> </tr> <tr> <td>Greenwood Nursing &amp; Rehab Center</td> <td>Wakefield</td> <td>3/29/2022</td> <td>Infection control</td> </tr> <tr> <td>Vero Health and Rehab of Watertown</td> <td>Watertown</td> <td>3/3/22</td> <td>Noncompliance Testing</td> </tr> <tr> <td>Wingate at Needham</td> <td>Needham</td> <td>2/16/22</td> <td>Infection Control</td> </tr> <tr> <td>Caldwell Home Extended Care</td> <td>Fitchburg</td> <td>2/9/22</td> <td>Noncompliance Testing</td> </tr> <tr> <td>South Dennis Healthcare</td> <td>Dennis</td> <td>1/20/22</td> <td>New Cases</td> </tr> <tr> <td>Oosterman's Melrose Rest Home</td> <td>Melrose</td> <td>12/18/21</td> <td>Noncompliance Testing</td> </tr> <tr> <td>Plymouth Rehabilitation &amp; Healthcare Center</td> <td>Plymouth</td> <td>10/27/21</td> <td>New Cases</td> </tr> <tr> <td>Highview of Northampton</td> <td>Northampton</td> <td>3/15/22</td> <td>Infection control</td> </tr> </tbody> </table>	Name of Facility	City/Town	Date of Freeze	Qualifying Factor	Bear Mountain at Worcester	Worcester	3/29/2022	Infection control	Donna Kay Rest Home	Worcester	3/29/2022	Noncompliance Testing	Greenwood Nursing & Rehab Center	Wakefield	3/29/2022	Infection control	Vero Health and Rehab of Watertown	Watertown	3/3/22	Noncompliance Testing	Wingate at Needham	Needham	2/16/22	Infection Control	Caldwell Home Extended Care	Fitchburg	2/9/22	Noncompliance Testing	South Dennis Healthcare	Dennis	1/20/22	New Cases	Oosterman's Melrose Rest Home	Melrose	12/18/21	Noncompliance Testing	Plymouth Rehabilitation & Healthcare Center	Plymouth	10/27/21	New Cases	Highview of Northampton	Northampton	3/15/22	Infection control
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List of Special Focus Facilities

**Centers for Medicare and Medicaid Services**

*List of Special Focus Facilities and Candidates*

<https://tinyurl.com/SpecialFocusFacilityProgram>

CMS has published a new list of [Special Focus Facilities](#) (SFF). SFFs are nursing homes with serious quality issues based on a calculation of deficiencies cited during inspections and the scope and severity level of those citations. CMS publicly discloses the names of the facilities chosen to participate in this program and candidate nursing homes.

To be considered for the SFF program, a facility must have a history (at least 3 years) of serious quality issues. These nursing facilities generally have more deficiencies than the average facility, and more serious problems such as harm or injury to residents. Special Focus Facilities have more frequent surveys and are subject to progressive enforcement until it either graduates from the program or is terminated from Medicare and/or Medicaid.

This is important information for consumers – particularly as they consider a nursing home.

**What can advocates do with this information?**

- 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 30, 2022)**

**Newly added to the listing**

- None

**Massachusetts facilities not improved**

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

**Massachusetts facilities which showed improvement**

- Attleboro Healthcare, Attleboro  
<https://tinyurl.com/AttleboroHealthcare>

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

- None

**Massachusetts facilities that are candidates for listing**

- Hillcrest Commons Nursing and Rehabilitation Center, Pittsfield  
<https://tinyurl.com/HillcrestCommons>
- Medway Country Manor Skilled Nursing and Rehabilitation  
<https://tinyurl.com/MedwayManor>
- Parkway Health and Rehabilitation Center  
<https://tinyurl.com/ParkwayHealthCenter>

	<ul style="list-style-type: none"> <li>• RegalCare at Worcester No website</li> <li>• Revolution Charwell <a href="https://tinyurl.com/RevolutionCharwell">https://tinyurl.com/RevolutionCharwell</a></li> <li>• Vantage at South Hadley No website</li> <li>• Vero Health and Rehabilitation Center of Amesbury <a href="https://tinyurl.com/VeroAmesbury">https://tinyurl.com/VeroAmesbury</a></li> <li>• Vero Health and Rehabilitation Center of Revere <a href="https://tinyurl.com/VeroRevere">https://tinyurl.com/VeroRevere</a></li> <li>• Braintree Manor Healthcare <a href="https://www.nextstephc.com/braintree">https://www.nextstephc.com/braintree</a></li> <li>• Hathaway Manor Extended Care <a href="https://hathawaymanor.org/">https://hathawaymanor.org/</a> <a href="https://tinyurl.com/SpecialFocusFacilityProgram">https://tinyurl.com/SpecialFocusFacilityProgram</a></li> </ul>																				
<p><i>Nursing Home Inspect</i></p>	<p><b>ProPublica</b> <b><i>Nursing Home Inspect</i></b> Data updated November 2021 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: <a href="https://projects.propublica.org/nursing-homes/state/MA">https://projects.propublica.org/nursing-homes/state/MA</a> <b>Deficiencies By Severity in Massachusetts</b> <a href="#">(What do the severity ratings mean?)</a></p> <table border="1"> <thead> <tr> <th># reported</th> <th>Deficiency Tag</th> </tr> </thead> <tbody> <tr> <td><a href="#">233</a></td> <td><b>B</b></td> </tr> <tr> <td><a href="#">70</a></td> <td><b>C</b></td> </tr> <tr> <td><a href="#">6,739</a></td> <td><b>D</b></td> </tr> <tr> <td><a href="#">1,754</a></td> <td><b>E</b></td> </tr> <tr> <td><a href="#">452</a></td> <td><b>F</b></td> </tr> <tr> <td><a href="#">517</a></td> <td><b>G</b></td> </tr> <tr> <td><a href="#">23</a></td> <td><b>H</b></td> </tr> <tr> <td><a href="#">59</a></td> <td><b>J</b></td> </tr> <tr> <td><a href="#">22</a></td> <td><b>K</b></td> </tr> </tbody> </table>	# reported	Deficiency Tag	<a href="#">233</a>	<b>B</b>	<a href="#">70</a>	<b>C</b>	<a href="#">6,739</a>	<b>D</b>	<a href="#">1,754</a>	<b>E</b>	<a href="#">452</a>	<b>F</b>	<a href="#">517</a>	<b>G</b>	<a href="#">23</a>	<b>H</b>	<a href="#">59</a>	<b>J</b>	<a href="#">22</a>	<b>K</b>
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<p>Nursing Home Compare</p>	<p><b>Centers for Medicare and Medicaid Services (CMS)</b> <i>Nursing Home Compare Website</i> 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:</p> <ul style="list-style-type: none"> <li>• <b>Staff turnover:</b> The percentage of nursing staff as well as the number of administrators who have stopped working at a nursing home over the past 12-month period.</li> <li>• <b>Weekend staff:</b> The level of weekend staffing for nurses and registered nurses</li> </ul>																				

	<p>at a nursing home over a three-month period.</p> <p>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.</p> <p><a href="https://tinyurl.com/NursingHomeCompareWebsite">https://tinyurl.com/NursingHomeCompareWebsite</a></p>		
Long-Term Care Facilities Specific COVID-19 Data	<p><b>Massachusetts Department of Public Health</b>  <i>Long-Term Care Facilities Specific COVID-19 Data</i>  <i>Coronavirus Disease 2019 (COVID-19) reports related to long-term care facilities in Massachusetts.</i></p> <p><b>Table of Contents</b></p> <ul style="list-style-type: none"> <li>• <a href="#">COVID-19 Daily Dashboard</a></li> <li>• <a href="#">COVID-19 Weekly Public Health Report</a></li> <li>• <a href="#">Additional COVID-19 Data</a></li> <li>• <a href="#">CMS COVID-19 Nursing Home Data</a></li> </ul>		
DignityMA Call to Action	<ul style="list-style-type: none"> <li>• The MA Senate released a report in response to COVID-19. <b>Download the <a href="#">DignityMA Response to Reimagining the Future of MA</a>.</b></li> <li>• <b>Advocate</b> for state bills that advance the Dignity Alliance Massachusetts’ Mission and Goals – <a href="#">State Legislative Endorsements</a>.</li> <li>• <b>Support</b> relevant bills in Washington – <a href="#">Federal Legislative Endorsements</a>.</li> <li>• <b>Join</b> our <a href="#">Work Groups</a>.</li> <li>• <b>Learn</b> to use and leverage Social Media at our workshops: <a href="#">Engaging Everyone: Creating Accessible, Powerful Social Media Content</a>.</li> </ul>		
Access to Dignity Alliance social media	<p>Email: <a href="mailto:info@DignityAllianceMA.org">info@DignityAllianceMA.org</a>  Facebook: <a href="https://www.facebook.com/DignityAllianceMA/">https://www.facebook.com/DignityAllianceMA/</a>  Instagram: <a href="https://www.instagram.com/dignityalliance/">https://www.instagram.com/dignityalliance/</a>  LinkedIn: <a href="https://www.linkedin.com/company/dignity-alliance-massachusetts">https://www.linkedin.com/company/dignity-alliance-massachusetts</a>  Twitter: <a href="https://twitter.com/dignity_ma?s=21">https://twitter.com/dignity_ma?s=21</a>  Website: <a href="http://www.DignityAllianceMA.org">www.DignityAllianceMA.org</a></p>		
<p><b>Participation opportunities with Dignity Alliance Massachusetts</b></p> <p>Most workgroups meet bi-weekly via Zoom.</p> <p>Please contact workgroup lead for more information</p>	<b>Workgroup</b>	<b>Workgroup lead</b>	<b>Email</b>
	General Membership	Bill Henning Paul Lanzikos	<a href="mailto:bhenning@bostoncil.org">bhenning@bostoncil.org</a> <a href="mailto:paul.lanzikos@gmail.com">paul.lanzikos@gmail.com</a>
	Behavioral Health	Frank Baskin	<a href="mailto:baskinfrank19@gmail.com">baskinfrank19@gmail.com</a>
	Communications	Pricilla O’Reilly Samantha VanSchoick Lachlan Forrow	<a href="mailto:prisoreilly@gmail.com">prisoreilly@gmail.com</a> <a href="mailto:svanschoick@cil.org">svanschoick@cil.org</a> <a href="mailto:lforrow@bidmc.harvard.edu">lforrow@bidmc.harvard.edu</a>
	Facilities (Nursing homes, rest homes, assisted living)	Arlene Germain	<a href="mailto:agermain@manhr.org">agermain@manhr.org</a>
	Home and Community Based Services	Meg Coffin	<a href="mailto:mcoffin@centerlw.org">mcoffin@centerlw.org</a>
	Housing	Shaya French	<a href="mailto:sfrench@bostoncil.org">sfrench@bostoncil.org</a>
	Legislative	Richard Moore	<a href="mailto:rmoore8743@charter.net">rmoore8743@charter.net</a>
	Topical Conversations	Lachlan Forrow	<a href="mailto:lforrow@bidmc.harvard.edu">lforrow@bidmc.harvard.edu</a>
	Veteran Services	James Lomastro	<a href="mailto:jimlomastro@comcast.net">jimlomastro@comcast.net</a>

<b><i>The Tuesday Digest</i></b>	<p>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</p>
Note of thanks	<p>Thanks to the contributors to this issue of <i>The Dignity Digest</i></p> <ul style="list-style-type: none"> <li>• Arlene Germain</li> <li>• Lisa Iezzoni, MD</li> <li>• Wynn Gerhard, Esq.</li> <li>• Dick Moore</li> </ul> <p>Special thanks to Paul Spooner with the MetroWest Center for Independent Living for assistance with the website and MailChimp versions of <i>The Dignity Digest</i>.  <i>If you have submissions for inclusion in <u>The Dignity Digest</u> or have questions or comments, please submit them to <a href="mailto:paul.lanzikos@gmail.com">paul.lanzikos@gmail.com</a>.</i></p>
<p><i>Dignity Alliance Massachusetts is a broad-based coalition of organizations and individuals pursuing fundamental changes in the provision of long-term services, support, and care for older adults and persons with disabilities. 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/the-tuesday-digest/">https://dignityalliancema.org/the-tuesday-digest/</a> For more information about Dignity Alliance Massachusetts, please visit <a href="http://www.DignityAllianceMA.org">www.DignityAllianceMA.org</a>.</i></p>	