The Dignity Digest

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*May require registration before accessing article.

Spotlight

New Yorker
August 25, 2022
When Private Equity Takes Over a Nursing Home
By Yasmin Rafiei
[Editor's note: This article is recommended to be read in its entirety: https://tinyurl.com/PrivateEquityTakesOver]
After an investment firm bought St. Joseph's Home for the Aged, in Richmond, Virginia, the company reduced staff, removed amenities, and set the stage for a deadly outbreak of COVID-19.
When St. Joseph's Home for the Aged, a brown-brick nursing home in Richmond, Virginia, was put up for sale, in October 2019, the waiting list for a room was three years long. "People were *literally* dying to get in there," Debbie Davidson, the nursing home's administrator, said. The owners, the Little Sisters of the Poor, were the reason. For a hundred and forty-seven years, the nuns had lived at St. Joseph's with their residents, embodying a philosophy that defined their service: treat older people as family, in facilities that feel like a home. . .
In the spring of 2021, an offer materialized from the Portopiccolo Group, a private-equity firm based in Englewood Cliffs, New Jersey, which then had a portfolio of more than a hundred facilities across the East Coast. "They said they like to keep things the way they are," Sister Mary John told me.
The deal was finalized by June. Portopiccolo's management company, Accordius Health, was brought in to run the home's day-to-day operations. . .
Since the turn of the century, private-equity investment in nursing homes has grown from five billion to a hundred billion dollars. The purpose of such investments—their so-called value proposition—is to increase efficiency. Management and administrative services can be centralized, and excess costs and staffing trimmed. In the autumn of 2019, Atul Gupta, an economist at the University of Pennsylvania, set out with a team of researchers to measure how these changes affected nursing-home residents. They sifted through more than a hundred private-equity deals that took place between 2004 and 2015, and linked each deal to categories of resident outcomes, such as mobility and self-reported pain intensity. The data revealed a troubling trend: when private-equity firms acquired nursing homes, deaths among residents increased by an

average of ten per cent. “At first, we didn’t believe it,” Gupta told me. “We thought that there was a mistake.” His team reëxamined its models, testing the assumptions that informed them. “But the result was very robust,” Gupta said. Cost-cutting is to be expected in any business, but nursing homes are particularly vulnerable. Staffing often represents the largest operating cost on a nursing home’s ledger. So, when firms buy a home, they cut staff. However, this business model has a fatal flaw. “Nurse availability,” Gupta and his colleagues wrote, “is the most important determinant of quality of care.”. .

The situation is growing more urgent. One in six Americans is sixty-five or older; by 2035, adults over sixty-five are expected to outnumber children for the first time in U.S. history. According to a report by IBISWorld, a market-research firm, this demographic shift—the “silver tsunami,” as it’s been called—will increase revenues in the United States’ nursing-home industry by twenty-five per cent in the next five years. Private-equity firms currently own only eleven per cent of facilities, as a federal report found. But about seventy per cent of the industry is now run for profit. “They all have the same operational approach, the same strategies for making money,” Harrington said. “It’s just that private equity tends to have higher expectations for profits.”. .

There’s an active debate over whether nursing-home deterioration is caused by private-equity acquisition, as senior-care advocates contend, or if private-equity firms tend to acquire homes that are already deteriorating. . .

Under the Little Sisters, the home had been lightsome and bustling. I could scarcely walk a few steps in the hallways without someone saying hello. “They came by to check on you, to see if there was anything you needed, how things could work better,” a resident told me. In the hallway, a television had blasted Dolly Parton’s “God Bless the U.S.A.,” and a nurse breezed by me, belting out the lyrics. I’d passed smiling women, their hair in curls from the salon, in the common area. When I’d told them they looked pretty, one had held a single finger to her mouth. She was watching television, and I was interrupting her.

Now the home was dimly lit and startlingly vacant. Signs of neglect were everywhere: a collapsed ceiling in a common room, its fragments strewn across the carpet; detergent scattered across the laundry room; tools and machine parts littered near equipment in need of repair. The resident who had waited an hour and a half for oxygen last June had requested a repair for the call light outside her room. Staff gave her a Schwinn bicycle bell and instructed her to ring it if she needed help. (Portopiccolo’s spokesperson said that they have no records of this incident.) I asked the son if anything had improved in the past few weeks. “Nurse staffing is better now,” he said, “because people have died.”

https://tinyurl.com/PrivateEquityTakesOver

How Nursing Homes Can Hide Profits While Claiming Losses and How This Impacts Residents

The New Jersey Long Term Care Ombudsman program has produced a webinar with Ernest Tosh, an attorney and analyst who specializes in the relationship between nursing home finances and resident care. The video presentation

	contains easy-to-understand graphics and explanations. Attorney Tosh clearly describes how nursing homes are able to report financial losses to regulators while actually funneling substantial funds to parent companies and other related parties. He also explains how private equity is involved in some nursing homes' operations and how all of these financial dynamics impact staffing and resident care. Finally, he summarizes existing financial reporting requirements and proposes changes to achieve real, needed fiscal transparency for this industry. The webinar is available at https://tinyurl.com/PrivateEquityNHVideo It runs 1 hour 39 minutes. The PowerPoint slides without narration are available at https://tinyurl.com/PrivateEquityNursingHomes. Thanks to our colleagues at the *Long-Term Care Community Coalition* in New York for making this information known to us.
Quotes of the Week	*(T)he need for preparedness is not going away. A transformation in public health requires a sea change in thinking. We must value this endeavor for our own protection, rather than continue to neglect it.* ***We have been warned****.* *The coming storm: America is not ready for a future pandemic,* **Washington Post (free access),** August 27, 2022, https://tinyurl.com/ComingStormFutureEpidemic *"When I ask people, 'What does successful aging mean to you?' people say they want to be independent, they want to maintain their function and quality of life, they want to do the things that they want to do. It's not necessarily just living as long as possible."* Dr. Kenneth Koncilja, a gerontologist at the Cleveland Clinic, *People Who Do Strength Training Live Longer — and Better,* ***New York Times,** August 24, 2022, https://tinyurl.com/CardioAndStrengthLonger *"When they wrote the Social Security laws, they weren't thinking that young people with disabilities would ever be marriage material. People didn't think we might have dreams and hopes like everybody else. We do."* *Seeking Marriage Equality for People with Disabilities,* **New York Times (free access),** August 25, 2022, https://tinyurl.com/MarriageEqualityDisbalities *"The complex bureaucracies that provide essential services and supports for people with disabilities were created*

piecemeal, and were based on outdated assumptions about marriage, paternalism and a limited understanding of the full and vibrant lives possible for people with disabilities."

Seeking Marriage Equality for People with Disabilities, **New York Times (free access),** August 25, 2022, https://tinyurl.com/MarriageEqualityDisbalities,

"Marriage is a cultural club you're not really allowed into if you're disabled."

Gabriella Garbero, 31-year-old St. Louis woman who was born with spinal muscular atrophy type two, *Seeking Marriage Equality for People With Disabilities,* **New York Times (free access),** August 25, 2022, https://tinyurl.com/MarriageEqualityDisbalities

"We're thinking about access as an ethic, as an aesthetic, as a practice, as a promise, as a relationship with the audience and it's not just us. The disability arts community is really in a moment of vast experimentation."

Alice Sheppard, founder and artistic director of Kinetic Light, *'Access as an Ethic': Giving Dance Myriad Points of Entry,* ***New York Times,** August 17, 2022, https://tinyurl.com/AccessAsAnEthic

What I found most successful and moving was the atmosphere of inclusiveness and the audience it attracted: buzzing, festive, with many more wheelchair users than I've seen before at a dance show.

Only Connect: Finding a Way into Kinetic Light's 'Wired,' ***New York Times,** August 26, 2022, https://tinyurl.com/Kineticslightwired

Lastly, a heaping dose of compassion and empathy will help begin the healing process for those who feel alone in the haunted house of their own body, lighting a candle toward recovery.

How long covid reshapes the brain — and how we might treat it, **Washington Post (free access),** August 25, 2022, https://tinyurl.com/LongCpovidReshapesBrain

***Current government agencies lack the resources to support active financial monitoring and evaluation**. CHIA, the attorney general's office, the Executive Office of Health and Human Services, the Health Policy Commission, and the*

Department of Public Health each have ways of obtaining financial information, but typically only when a system is already in crisis. None of these agencies is officially charged with overseeing potentially risky financial transactions such as sale/leasebacks before they occur, ***nor do they have the regulatory authority to pro-actively intervene or prohibit major financial transactions that put health access, affordability, and/or equity among communities at risk. .*** *(W)hat is lacking is the investment in staff capabilities to analyze and interpret for public policy purposes what the data tells us.* ***Additional resources should be provided to CHIA to carry out more comprehensive oversight and monitoring activities****.*

Nancy Kane and Paul Hattis, *Is state aid really helping the neediest hospitals,* **CommonWealth Magazine,** August 28, 2022, https://tinyurl.com/StateAidNeediestHospitals

"State governments that have yet to address the health, economic, and social challenges of caregiving for older adults should learn from the experience of states with caregiver supports and implement similar programs."

National Academies of Sciences, Engineering, and Medicine, *RAISE Act State Policy Roadmap for Family Caregivers: Public Awareness and Outreach to Family Caregivers,* **National Academy of State Health Policy,** September 2021, https://tinyurl.com/RAISEFamilyCaregivers

The price of insulin in the US is both outrageous and deadly to those who can't live without it.

Why the price of insulin is a danger to diabetics, **TED Talks (video),** August 26, 2022, https://tinyurl.com/PriceInsulinDanger

"As Wall Street firms take over more nursing homes, quality in those homes has gone down and costs have gone up. That ends on my watch."

President Joe Biden from his State of the Union Address January 2022, *When Private Equity Takes Over a Nursing Home,* ***New Yorker,*** August 25, 2022, https://tinyurl.com/PrivateEquityTakesOver

Given so much evidence about postviral conditions, why wasn't more done more quickly to address long Covid?

If You're Suffering After Being Sick with Covid, It's Not Just in Your Head, ***New York Times,** August 25, 2022, https://tinyurl.com/SufferingAfterBeingSick

Disappointed with last month's record-setting ride, [Robert Marchand] believes that he can improve his mileage . . . and may try again, perhaps when he is 106.

Lessons on Aging Well, From a 105-Year-Old Cyclist, ***New York Times,** February 8, 2017, https://tinyurl.com/105YearOldCyclist

"We need to have accurate data if we are going to provide accurate solutions."

Donald Whitehead, executive director of the National Coalition for the Homeless, *America's first homelessness problem: Knowing who is actually homeless,* ***Washington Post,** August 24, 2022, https://tinyurl.com/WhoIsActuallyHomeless

Americans must demand from their elected officials more transparency on health care costs, especially hospital costs.

Surgeons fold against Medicare's stacked deck, **STAT News,** August 25, 2022, https://tinyurl.com/MedicaresStackedDeck

"For a disabled individual, a lot of time, maintaining eligibility is critical. I can't tell you how many times family members, with the best of intentions, will name a disabled adult child as a beneficiary, not understanding that getting that money could immediately jeopardize their ability to access public benefits,"

Joellen Meckley, executive director of the American College of Financial Services' center for special needs, *Planning for Your Retirement, and for a Child's Special Needs, All at Once,* **New York Times (free access),** August 27, 2022, https://tinyurl.com/ChildsSpecialNeeds

"I could not sleep. It was driving me crazy. I was having migraines. I was sick to my stomach. I hate having debt. I didn't want to think about it. Obviously, that didn't work because I'm still thinking about it."

	Dani Yuengling of Conway, South Carolina who had a surprise bill of $17,797 for a biopsy procedure, *An $18,000 biopsy? Paying cash might have been cheaper than using her insurance,* **NPR Shots,** August 23, 2022, https://tinyurl.com/18000Biopsy *"This is about allowing vulnerable people to remain in their homes; it's more than a real estate transaction."* Barbara Salisbury, Chief Executive Office, MAB Community Services, Brookline, MA, *Brookline's MAB Community Services Receives $13M To Buy Group Homes,* **Patch.com,** August 27, 2022, https://tinyurl.com/BuyGroupHomes
Dignity Votes 2022	**Candidates for Governor, Lieutenant Governor, Attorney General, and Secretary State** Responses to questionnaires from candidates for these offices have been posted at https://dignityalliancema.org/state-candidates/. Interviews are in the process of being conducted and recorded. They will be posted when captioning is finished. **Congressional office candidates** Questionnaires for congressional candidates are in the process of being prepared and will be distributed in September. **State legislative candidates** Questionnaires for legislative office candidates are in the process of being prepared and will be distributed in September. **Fact Sheets and Issue Briefs** Prepared by Dignity Alliance Massachusetts Workgroups **Nursing Homes** • Nursing Home Fact Sheet • Nursing Home Staffing Issues • Pandemic Issues in Nursing Homes • Nursing Homes – Financial Responsibility • Nursing Homes – Oversight, Licensures, Closures • Nursing Homes – Small Home Model **Home and Community Based Services** • HCBS Fact Sheet • HCBS Staffing Issues • HCBS Care Coordination Issues **Behavioral Health** • Behavioral Health Fact Sheet • BH Elder Mental Health Outreach Teams (EMHOT) Issues • BH Nursing Homes and Psychotropic/Antipsychotic Drugs Issues • Social Work Staffing Issues **Housing** • Housing Issues **Veterans** • Veterans Issues https://dignityalliancema.org/2022-facts-and-issues/ **State Election Information**

	The following websites contain useful, timely information about this year's elections. (Source: *AARP Bulletin* July / August 2022) • *AARP Voter Guides* Information about the voting process from registration to Election Day voting locations and hours. www.aarp.org/electionguides • *Ballotpedia* Information about statewide races and ballot measures. www.ballotpedia.org • *OpenSecrets* Tracks flow of money within the electoral process. www.opensecrets.org • *Vote411* Election year information provided by the League of Women Voters. www.vote411.org • *Vote Smart* On demand detailed information about individual candidates www.votesmart.org
Inspiration	**1. *New York Times** February 8, 2017 *Lessons on Aging Well, From a 105-Year-Old Cyclist* At the age of 105, the French amateur cyclist and world-record holder Robert Marchand is more aerobically fit than most 50-year-olds — and appears to be getting even fitter as he ages, according to a revelatory new study of his physiology. The study, which appeared in December (2016) in The Journal of Applied Physiology, may help to rewrite scientific expectations of how our bodies age and what is possible for any of us athletically, no matter how old we are. Many people first heard of Mr. Marchand last month (January 2017), when he set a world record in one-hour cycling, an event in which someone rides as many miles as possible on an indoor track in 60 minutes. Mr. Marchand pedaled more than 14 miles, setting a global benchmark for cyclists age 105 and older. That classification had to be created specifically to accommodate him. No one his age previously had attempted the record. Mr. Marchand, who was born in 1911, already owned the one-hour record for riders age 100 and older, which he had set in 2012. . . A diminutive 5 feet in height and weighing about 115 pounds, he said he had not exercised regularly during most of his working life as a truck driver, gardener, firefighter, and lumberjack. But since his retirement, he had begun cycling most days of the week, either on an indoor trainer or the roads near his home in suburban Paris. He then went out and set the one-hour world record for people 100 years and older, covering about 14 miles. Mr. Marchand followed this program for two years. Then he attempted to best his own one-hour track world record. . . Unsurprisingly, his cycling performance subsequently also improved considerably. During his ensuing world record attempt, he pedaled for almost 17 miles, about three miles farther than he had covered during his first, record-setting ride. He was 103 years old. . .

	Lifestyle may also matter. Mr. Marchand is "very optimistic and sociable," Dr. Billat says, "with many friends," and numerous studies suggest that strong social ties are linked to a longer life. His diet is also simple, focusing on yogurt, soup, cheese, chicken, and a glass of red wine at dinner. But for those of us who hope to age well, his example is inspiring and, Dr. Billat says, still incomplete. Disappointed with last month's record-setting ride, he believes that he can improve his mileage, she says, and may try again, perhaps when he is 106. https://tinyurl.com/105YearOldCyclist
Request for Survey Input	**2. Massachusetts Senior Action Council** August 2022 COVID-19. Changed. Everything. No one knows this better than older adults, especially those living in long term care settings like nursing homes or assisted living, or who need long-term care services like home health care, help with dressing, bathing, or making meals or attending adult day care. The pandemic exposed many problems in the long-term care system. Mass Senior Action is exploring ways to improve the system today and to better plan for the needs of a growing and aging population in Massachusetts. They want to hear your views about how to do that. By responding to this short survey, your views and opinions about how we can improve the long-term care system will be heard by the people who are making policy in the Commonwealth. This survey should take about 10-12 minutes to complete. Participation in this survey is anonymous. Please contact MSAC staff member Eric Holmberg at 617-501-0648 with any questions or concerns. https://tinyurl.com/MSACSurveyAug2022
Reports	**3. Long Term Care Community Coalition** August 24, 2022 *Nursing Home Staff Turnover Above 50%* Staff retention is essential for nursing homes to provide quality care for their residents. Unfortunately, turnover continues to be a major problem for many of the nation's 15,000-plus facilities. The average nursing home turns over more than half (53.3%) of its nursing staff within a year, according to the latest federal data. **LTCCC announces the publication of the latest staffing data for every US nursing home** (in compliance with mandatory reporting requirements) during the first quarter of 2022. This staffing report includes information for every nurse and non-nurse staff position, facilities' use of contract (agency) staffing, and, for the first time, turnover and weekend staffing levels (the Centers for Medicare & Medicaid Services began publishing turnover and weekend staffing levels in 2022). The federal data show that average nursing home staffing (3.62 Total Nurse Staff Hours Per Resident Day, incl. 0.61 RN Staff HPRD) is far below the levels needed to meet basic care needs for the nation's 1.1 million nursing home residents. **Staffing Facts for Q1 2022** • Nationwide, **the average nursing home reported a nursing staff turnover rate of 53.3%** and **RN staff turnover rate of 51.9%.** (Note: 17.7%***** of nursing homes either submitted data that did not meet the criteria required to calculate turnover or did not submit staffing data).

	• Contract employees accounted for **9.7% of all nurse staff hours in Q1 2022**, nearly double the rate from Q1 2021 (5.0%). • Total RN Staff HPRD (0.61) **is down more than 10%** since the first quarter of 2021 while total staffing levels have decreased about **8% in that period**. • **Staffing levels are significantly lower on weekends**. The median nursing home provided 3.06 total nurse staff HPRD on weekends, about 15% lower than the overall staffing level. • **Roughly one in four (26.8%) nursing homes met the essential total care staff threshold** (4.10 HPRD), as determined by a landmark 2001 federal study. Though recent studies have found that adequate RN staffing is essential, only **30.5% of nursing homes met the RN staff threshold (0.75 HPRD)** indicated by the study. LTCCC's Q1 2022 report can help the public, media, and policymakers identify and assess the extent to which nursing homes in their communities provided sufficient staffing to meet basic clinical and quality of life needs. The report is based on the most recent payroll-based journal (PBJ) data reported by the federal Centers for Medicare & Medicaid Services (CMS). (See: PBJ Daily Nurse Staffing, PBJ Daily Non-Nurse Staffing, and Provider Information). Visit the **NursingHome411 Data Center** for more information on staffing, five-star ratings, and other important nursing home data. *A previous email indicated erroneously that 23.9% of nursing homes did not report nurse turnover data. The 23.9% rate applies to RN staff turnover, not total staff turnover.
Biden and Federal Policies	**4. STAT News** August 25, 2022 *Surgeons fold against Medicare's stacked deck* Surgeons whose patients cost Medicare less than the lump sum over 90 days get a portion of their savings as a reward. Surgeons who don't save Medicare money face penalties large enough to bankrupt them. . . With baby boomers coming of age and Americans enjoying longer lives than when Congress passed Medicare in 1965, Medicare will run out of funds in 2026. The BPCI-A program as it currently stands is pushing the best, lowest-cost surgeons out of Medicare, depriving people covered by Medicare of access to them. This year, Medicare again reduced surgeon reimbursement while recommending an 8.5% lift for hospitals. Hospitals, though, are prohibited from prescribing or directing care. Only physicians can do that. Therefore, they are best positioned to create value since they orchestrate the entire episode of care. How does rewarding hospitals with more taxpayer dollars and cutting pay for the surgeons who help bring in patients save money? . . Americans must demand from their elected officials more transparency on health care costs, especially hospital costs. This will save money while improving lives and overall satisfaction. Medicare should not turn health care into a high-stakes poker table where the house always wins. https://tinyurl.com/MedicaresStackedDeck **5. Health Affairs** August 24, 2022

	Congress Considers Strategies to Improve Medicare and Medicaid Integration for Dual-Eligible Individuals This article is the latest in the Health Affairs Forefront major series, Medicare and Medicaid Integration (https://tinyurl.com/MedicareMedicaidIntegration). The series features analysis, proposals, and commentary that will inform policies on the state and federal levels to advance integrated care for those dually eligible for Medicare and Medicaid. . . At the end of July, Senators Rob Portman (R-OH) and Sherrod Brown (D-OH) introduced legislation to create a new state option to fully integrate the financing and delivery of care for individuals eligible for full Medicaid and Medicare benefits. This legislation is among the most ambitious of a number of bills introduced this session that seek to improve Medicare and Medicaid integration for dual-eligible individuals. This article highlights the Portman-Brown bill and other recent legislative proposals related to integrated care for dual-eligible individuals, including support for states in undertaking planning and activities to improve the coordination of care, opportunities to expand the Program of All-Inclusive Care for the Elderly (PACE), and a proposal to create a federal structure for Medicare premium and cost-sharing subsidies for low-income individuals (exhibit 1). https://tinyurl.com/IntegrationDualEligibles
State Policy	**6. CommonWealth Magazine** August 28, 2022 *Is state aid really helping the neediest hospitals* Commentary by Nancy Kane and Paul Hattis As legislators ponder whether to resurrect a $350 million "relief" fund for Massachusetts hospitals, we suggest that they first step up the state's informational capacity to better assure that they are allocating funding to institutions truly in financial need. We worry that the proposed allocations in the 2022 relief package, as well as unanticipated and abrupt facility and service closures over the last decade or so, raise the concern that policymakers do not have clear criteria for determining which of our state's hospitals are truly in need and deserving of additional state support. Ideally, "distress" funding should go to hospitals whose primary cause of poor financial performance is due to a disproportionate commitment to serving low-income (high Medicaid) and/or underserved (behavioral health) populations, and not, for instance, due to over-expansion funded by excessive amounts of debt, or the strategic and financial priorities of out-of-state owners. Poor financial performance needs to be defined more broadly than simple operational measures of profitability. Here are the shortcomings as we see them: • Too much focus on individual hospitals, not systems. • Income statements given too much weight. • Failure to explore strategic decisions. • Too reactive, not pro-active. https://tinyurl.com/StateAidNeediestHospitals

Webinars / Online Sessions	**7. Administration on Community Living** Monday, August 29, 2022, 3:00 to 4:00 p.m. *Ending Homelessness - Developing Partnerships Between HUD Continuums of Care and Disability, Aging, and Health Services Providers* Homelessness is increasing in communities across the country – and the people experiencing it are disproportionately people with disabilities and older adults. Through its Continuum of Care (CoC) program, the U.S. Department of Housing and Urban Development (HUD) provides funding for efforts by nonprofit organizations, states and tribes, and local governments to quickly re-house people experiencing homelessness. CoCs bring together community partners that offer a variety of services to individuals and families experiencing (or at risk of) homelessness. The partners vary from community to community, but often include public housing and housing services agencies, health care organizations, providers of mental health services, and community-based organizations that provide supportive services (such as the aging and disability networks). This webinar will orient participants to CoC structures and cross-sector partnerships that address the needs of people experiencing homelessness. Participants also will hear first-hand the benefits of these partnerships, from two community-based organizations, that are members of their local CoCs. **Register for the webinar** **8. Consumer Financial Protection Bureau** Thursday, September 8, 2022, 2:00 p.m. *CFPB Field Hearing with Director Chopra on Nursing Home Debt Collection Practices* The Consumer Financial Protection Bureau (CFPB) Director Rohit Chopra will host a virtual discussion with advocates, service providers, community leaders, and members of the public to explore challenges around nursing home debt collection practices and the impact they can have on the financial wellbeing of caregivers, their families, and friends. This field hearing is a chance for the CFPB to listen and learn about consumer advocates' and individuals' experiences with nursing home debt and debt collection practices. The hearing will be live-streamed at consumerfinance.gov/NursingHomeDebt. **9. The Interagency Committee on Disability Research (ICDR)** Thursday, September 15, 2022, 11:00 a.m. to 12:00 p.m. *Understanding and Responding to the Cultural and Linguistic Differences in the Conduct of Disability Research* For this webinar, Tawara D. Goode, Director of the University Center for Excellence in Developmental Disabilities, Georgetown University Center for Child & Human Development, will present on understanding and responding to cultural and linguistic difference in the conduct of disability research. **Register for the webinar.** **10. Library of Congress** Wednesday, September 21, 2022, 1:30 to 4:30 p.m. *Library to Host Congress.gov Virtual Public Forum on Sept. 21* The Library of Congress will hold a free virtual forum to discuss Congress.gov, the authoritative source for federal legislative information, and to receive public feedback about the site. The Library encourages everyone interested in

	legislative data, from experienced Congress.gov users to those who may be new to tracking federal legislative activity to attend. The forum will feature presentations on recent enhancements to the site and a preview of updates in the works. Attendees will also hear from the data partners that make Congress.gov possible: the Library of Congress, the Government Publishing Office, the Secretary of the Senate and the Clerk of the House of Representatives. Partners will provide insight into a range of efforts underway to modernize and improve accessibility to legislative data. Registration is open to all
Previously posted webinars and online sessions	**Previously posted webinars and online sessions can be viewed at:** **https://dignityalliancema.org/webinars-and-online-sessions/**
Housing	**11. Patch.com** August 27, 2022 *Brookline's MAB Community Services Receives $13M To Buy Group Homes* MAB Community Services, a Brookline nonprofit that creates opportunities for individuals with a range of disabilities, has received over $13 million in financing from Rockland Trust to purchase sixteen group homes, which have been leased to house individuals MAB has served for as long as 18 years. The homes have been leased to house individuals MAB has served for as long as 18 years. This transaction will enable MAB to control the costs associated with the services they deliver to their 80 residents. "By financing the purchase of these houses, Rockland Trust is allowing MAB to stabilize the housing of more than 80 individuals with intellectual disabilities and brain injuries," Barbara Salisbury, Chief Executive Officer at MAB Community Services, said in a statement. "This is about allowing vulnerable people to remain in their homes; it's more than a real estate transaction." https://tinyurl.com/BuyGroupHomes **12. *Washington Post** August 24, 2022 *America's first homelessness problem: Knowing who is actually homeless* The unhoused are often hidden. Seattle is testing a new method to find them. Getting that figure right has gained new urgency as rising housing costs and a persistent shortage of affordable housing mean more people have fewer options when it comes to shelter. Tent cities now sprawl across sidewalks, along overpasses and over green spaces in many major American cities. The visibility of homelessness has triggered a wave of municipal and state laws criminalizing it. Advocates also say violent confrontations between the housed and unhoused appear to have increased. At the local, state, and federal level, governments rely on annual estimates of the homeless population to direct billions of dollars in spending. But few advocates, academics or public officials believe those estimates are accurate. Compiled by the Department of Housing and Urban Development (HUD), they are technocratic best-guesses, hammered together using a handful of methods many believe are inadequate. . . "Given this monumental task, it is likely that communities do not find every single person experiencing homelessness, but we are confident they identify most people, and this consistent counting effort allows an analysis of trends from year to year that help us gauge whether homelessness is rising or falling

	across the country," Goodloe said. "The PIT count data is the only data source that collects data on our unsheltered population across the entire country." https://tinyurl.com/WhoIsActuallyHomeless
Long Covid	**13. Washington Post (free access)** August 25, 2022 *How long covid reshapes the brain — and how we might treat it* The young man pulled something from behind both ears. "I can't hear anything without my new hearing aids," said the 32-year-old husband and father. "My body is broken, Doc." Once a fireman and emergency medical technician, he'd had covid more than 18 months before and was nearly deaf. He was also newly suffering from incapacitating anxiety, cognitive impairment, and depression. Likewise, a 51-year-old woman told me through tears: "It's almost two years. My old self is gone. I can't even think clearly enough to keep my finances straight." These are real people immersed in the global public health catastrophe of long covid, which the medical world is struggling to grasp and society is failing to confront. As such stories clearly indicate, covid is biologically dangerous long after the initial viral infection. One of the leading hypotheses behind long covid is that the coronavirus is somehow able to establish a reservoir in tissues such as the gastrointestinal tract. I believe the explanation for long covid is more sinister. The science makes it increasingly clear that covid-19 turns on inflammation and alters the nervous system even when the virus itself seems to be long gone. The virus starts by infecting nasal and respiratory lining cells, and the resulting inflammation sends molecules through the blood that trigger the release of cytokines in the brain. This can happen even in mild covid cases. Through these cell-to-cell conversations, cells in the nervous system called microglia and astrocytes are revved up in ways that continue for months — maybe years. It's like a rock weighing down on the accelerator of a car, spinning its engine out of control. All of this causes injury to many cells, including neurons. It is past time we recognized this fact and began incorporating it into the ways we care for those who have survived covid. For too long, the mysteries of long covid led many health-care professionals to dismiss it as an untreatable malady or a psychosomatic illness without a scientific basis. Some of this confusion comes down to the stuttering cadence of scientific progress. . . Medical researchers have recently learned that the coronavirus can also infect cells called astrocytes, the glue that holds the brain together. Instead of using the ACE2 receptor, it appears SARS-CoV-2 attacks astrocytes through completely different types of glycoprotein receptors. When the virus directly damages astrocytes and other cells in the nervous system, the supportive and nourishing environment for our 100 billion neurons breaks down. Even though neurons are not directly infected, the brain's cell-to-cell relationships are so intimate that infection of other types of cells creates a cascade of brain injury. . . The bad news is that this neurological injury is occurring most frequently in younger long-covid patients (20 to 50 years old) who were never hospitalized for covid. The good news is that, at least in some patients, it may not be permanent or progressive. So, what do we do now? First, we physicians must validate our patients' stories and complaints.

Second, there is a need for well-designed, randomized, placebo-controlled clinical trials of medications and other treatment approaches for patients with long covid. . .

Lastly, a heaping dose of compassion and empathy will help begin the healing process for those who feel alone in the haunted house of their own body, lighting a candle toward recovery.

https://tinyurl.com/LongCpovidReshapesBrain

14. **US News & World Report**

August 25, 2022

16 Million Working-Age Americans Have Long COVID, Keeping Up to 4 Million Out of Work

A Brookings Institution report estimates that 16 million Americans ages 18 to 65 are experiencing lingering symptoms of COVID-19, and 2 million to 4 million of them are out of work due to long COVID. The report estimates that long COVID results in $170 billion in lost wages annually, a figure that "does not represent the full economic burden of long COVID, because it does not include impacts such as the lower productivity of people working while ill, the significant health care costs patients incur or the lost productivity of caretakers."

U.S. News & World Report

15. ***New York Times**

August 25, 2022

If You're Suffering After Being Sick with Covid, It's Not Just in Your Head

When the influenza pandemic of 1918-19 ended, misery continued.

Many who survived became enervated and depressed. They developed tremors and nervous complications. Similar waves of illness had followed the 1889 pandemic, with one report noting thousands "in debt and unable to work" and another describing people left "pale, listless and full of fears."

The scientists Oliver Sacks and Joel Vilensky warned in 2005 that a future pandemic could bring waves of illness in its aftermath, noting "a recurring association, since the time of Hippocrates, between influenza epidemics and encephalitis-like diseases" in their wakes.

Then came the Covid-19 pandemic, the worst viral outbreak in a century, and when sufferers complained of serious symptoms that came after they had recovered from their initial illness, they were often told it was all in their heads or unrelated to their earlier infections. . .

Long Covid sufferers who caught the virus early have entered their third year with the condition. Many told me they have lost not just their health but also their jobs and health insurance. They're running out of savings, treatment options and hope.

To add to their misery — despite centuries of evidence that viral infections can lead later to terrible debilitating conditions — their travails are often dismissed as fantasy or as unworthy of serious concern. . .

The Centers for Disease Control and Prevention defines long Covid as having "a wide range of symptoms that can last more than four weeks or even months after infection." The World Health Organization sets the line at three months and says symptoms must last "for at least two months and cannot be explained by an alternative diagnosis." Both highlight fatigue, shortness of breath, cognitive dysfunction, brain fog, pain, digestive symptoms, depression, anxiety, cough, headache, and sleep disturbances. . .

	One of the most important findings is that, as with many other illnesses, the elderly or those already in frail health seem more likely to have ongoing issues, especially if they had severe cases of Covid. Existing definitions fail to capture the subcategories of long Covid, with different symptom clusters and levels of severity and persistence, creating an obstacle to research and treatments. . . In late May the C.D.C. reported that one-fifth of U.S. adults under 65 who had Covid experienced symptoms that "might be attributable" to their previous infections. The administration's response to such studies didn't seem to fit the scale of the seeming threat if, indeed, 20 percent of those who have had Covid are at risk for debilitating chronic illness. . . We need a National Institute for Postviral Conditions, similar to the National Cancer Institute, to oversee and integrate research. Neither academia — prone to silos and drawn to work that leads to notable publications, which can leave important questions underexplored — nor the private sector — focused on profits — is up to the task alone. https://tinyurl.com/SufferingAfterBeingSick
Caregiving	**16. National Academy of State Health Policy** September 2021 *RAISE Act State Policy Roadmap for Family Caregivers: Public Awareness and Outreach to Family Caregivers* The purpose of this roadmap is to support states that are interested in developing and expanding supports for family caregivers of older adults by offering practical resources on identifying and implementing innovative and emerging policy strategies. Although families care for people across the lifespan, the focus of this roadmap is on policies, programs, and funding for family caregiver of older adults. The roadmap is organized into the following sections as a series: Section 1: Public Awareness and Outreach to Family Caregivers Section 2: Engagement of Family Caregivers in Healthcare Services and Systems Section 3: Services and Supports · Services and Supports for Family Caregivers · The Direct Care Workforce Section 4: Financial and Workplace Security for Employed Family Caregivers Section 5: Research, Data, and Evidence-Informed Practices https://tinyurl.com/RAISEFamilyCaregivers
Veteran Topics	**17. *Washington Post** August 25, 2022 *Millions in covid aid went to retrain veterans. Only 397 landed jobs.* Nearly $400 million went to a veteran retraining program as part of the American Rescue Plan. The program — part of an unprecedented wave of economic relief since 2020 — fell victim to a host of familiar problems: hasty design and poor timing by Congress, inadequate promotion by an overwhelmed Department of Veterans Affairs and for-profit career-training schools with a history of misusing VA funds. The rush and carelessness in crafting the coronavirus aid created a wellspring for fraud and waste — a mess that hundreds of federal investigators are still trying to clean up. https://tinyurl.com/397LandedJobs
Disability Topics	**18. New York Times (free access)**

August 27, 2022

Planning for Your Retirement, and for a Child's Special Needs, All at Once

People with children who cannot support themselves need to think well past their own lifetime and figure out how to provide for children after they are gone.

Rachel Nagler, 39, has worked part time since she was 22, but she will never be financially independent, according to her father. She is legally blind with a seizure disorder and mild cognitive impairment, the result of birth trauma.

For her parents, Sam and Debra Nagler of Concord, Mass., planning for retirement required them to focus on Rachel's future as well as their own.

"She has very limited earning capacity," Mr. Nagler, 70, said. "The concern is, is this sufficient for her for the rest of her life?"

His wife, who is 68, has been their daughter's primary caregiver since her birth. "Nobody knows Rachel, and takes care of Rachel, and knows every need of Rachel, and is on top of everything other than my wife," Mr. Nagler said. "That's a worry because she's not going to live forever." . .

Under the best of circumstances, caring for an adult child with special needs is physically and emotionally taxing. As these parents age, the question of who will house, feed, and drive their son or daughter after they no longer can becomes an urgent one. . .

Even when the disabled individual qualifies for public health assistance, finding affordable, adequate housing is especially difficult. Some people require supervised care in a group home, while others need in-home care in a dwelling modified to accommodate physical limitations. In both cases, waiting-list times are measured in years. . .

Since most of the public benefits available to special-needs and disabled people are administered at the state level through Medicaid, parents of a special-needs child might not be able to move to a state with a lower cost of living. Doing so could mean the adult child would lose access to their benefits and be placed at the bottom of waiting lists for services in a new state. . .

These financial struggles are magnified for single parents. "Care is inevitably more expensive when you have a single parent," Ms. Taylor said, because they have to rely much more on paid caregivers. . .

For parents of special-needs children, retirement planning and estate planning have to take place in tandem. Special-needs trusts and life insurance policies in one or both parents' names are two of the most commonly used tools. Both have to be structured in compliance with the complex eligibility regulations for public health benefits, since many are means-tested. . .

There are two main categories of special-needs trusts. First-party trusts are established with assets that belong to the individual. The drawback is that these trusts have a payback clause: After the individual dies, any money remaining in the trust goes to reimburse the state for the cost of their care over the years.

Third-party special needs trusts are established and funded by someone else for the benefit of the disabled individual. "A third-party one takes in the assets of other people, like gifts, inheritances or life insurance proceeds," said Brian Walsh, senior manager of financial planning at SoFi.

https://tinyurl.com/ChildsSpecialNeeds

19. ***New York Times**

August 26, 2022

Only Connect: Finding a Way into Kinetic Light's 'Wired'

Audio descriptions are one path into this disability arts ensemble's show. In some ways, these mirror the critic's job: putting dance into words.

. . . Kinetic Light, a disability arts ensemble whose work is made by and for disabled people, has an ethic and aesthetic of access that is exceptionally thoughtful and thorough. It ensures that no one way of experiencing the work is prioritized. No one person can experience it in every aspect. . .

It begins arrestingly with Sheppard and Lawson airborne in their wheelchairs, floating and spinning like astronauts in low gravity. The wires that hold them and that they hold cross aesthetically, but if the performers grab onto each other and let go, the wires (along with gravity) also pull them apart: abstraction, human drama. . .

What I found most successful and moving was the atmosphere of inclusiveness and the audience it attracted: buzzing, festive, with many more wheelchair users than I've seen before at a dance show. When the preshow announcer, accompanied by two A.S.L. interpreters, explained that phones should be silenced but that some audience members would be using devices for accessibility, the information was greeted with cheers. I'm sure that many people cheering then and during the bows got more out of the show — something different — than I did. I was happy to be among them.

https://tinyurl.com/Kineticslightwired

20. **New York Times (free access)**

August 25, 2022

Seeking Marriage Equality for People with Disabilities

(Lori Long) still wanted to marry (Mark Contreras), but not if it meant giving up the health care benefits that she relies on to live.

When one partner is disabled and the other isn't, getting married could mean giving up lifesaving health care and benefits from the government.

Ms. Long is caught in a governmental quagmire. She was diagnosed at 15 with ankylosing spondylitis, a condition that causes bone fractures and sometimes requires her to use a wheelchair. As a teenager, she said, she watched her family experience financial difficulties attempting to pay for her health care when she first got sick, even though she had private insurance at the time.

Because she qualifies for Social Security benefits through a program for adults whose medical disability started before age 22, she is considered a "disabled adult child." The designation, known as D.A.C., applies to 1.1 million Americans, according to the Social Security Administration website. . .

Ms. Long is among a nationwide network of people pushing for change in Social Security laws as they pertain to marriage. They include not just D.A.C. recipients like her, but also a larger group of disabled Americans — roughly four million — who get S.S.I., or Supplemental Security Income.

n September 2019, Ms. Long contacted Representative Jimmy Panetta, a Democrat in California's 20th Congressional district. Earlier this year, he introduced the Marriage Equality for Disabled Adults Act, which includes a provision nicknamed "Lori's Law" that would remove the D.A.C. marriage restriction. . .

But it is not just the prospect of losing that money if she marries her non-disabled fiancé, Juan Johnson, 28, that's keeping her from setting a wedding date. Ms. Garbero qualifies for S.S.I. as well as S.S.D.I.; she needs the S.S.I.

	designation to maintain her health care. "S.S.I. is the gateway for me to qualify for Medicaid," she said. "Medicaid is what keeps me alive." https://tinyurl.com/MarriageEqualityDisbalities **21. *New York Times** August 17, 2022 *'Access as an Ethic': Giving Dance Myriad Points of Entry* For the arts ensemble Kinetic Light, the needs of disabled people are sources of inspiration and innovation. Disabled bodies and perspectives define Kinetic Light's work. Its four core members — the choreographers and performers Alice Sheppard, Laurel Lawson and Jerron Herman, and the lighting, video, and projection designer Michael Maag — are disabled. So are nearly all of their collaborators. Though everyone is welcome in the audience, the group's art is intended specifically for disabled people. In addition to advancing a for-us-by-us approach, Kinetic Light is part of a broader movement, led by disabled artists, that positions the needs of disabled people as sources of inspiration and innovation. It's a philosophy of performance in which every element of a production, from the lighting to the audio description, is meant to reflect the artistic integrity of the whole, allowing all comers a rich experience of the work. . . Let's start with what most of the world generally means by access, which is, what do you have to do to make it possible for disabled people to participate, enter a space, enjoy a piece of art? It can sometimes be phrased as, "What do we need to do to be in compliance with the Americans With Disabilities Act?" . . We're approaching this from a really different place. Access is not a separate thing; access is *the* thing. So, the art itself is accessible in a way that does not prioritize one way of being, one way of experiencing, one way of entering into the art. . . One of the beautiful parts of this research and development is dissolving siloed experiences in disability culture. We're saying that there's no need to embody a certain impairment or have a certain disability narrative in order to "access access." . . One major area of research and exploration is haptic interfaces [interactive devices that simulate touch]. We are about to dive into how we can use multiple sensations of touch to produce the feeling of moving — perhaps even actual movement itself, where we're not just manipulating the skin, the muscles, the joints, but even the brain. https://tinyurl.com/AccessAsAnEthic
Healthcare Topics	**22. Washington Post (free access)** August 27, 2022 *The coming storm: America is not ready for a future pandemic* After the 9/11 attacks that killed 2,996 Americans, the United States responded with a sense of urgency and purpose, as a nation under siege. Congress and the executive branch created the 9/11 Commission; established the Department of Homeland Security; set up the Office of the Director of National Intelligence; launched a massive, years-long hunt for the perpetrators; and in many other ways, from airport screening to embassy security, redoubled efforts to prevent another terrorist attack. Now the country is suffering another momentous assault, a pandemic that has claimed about 400 U.S. lives every day for months

now and has killed more than 1 million Americans. Yet the nation is twiddling its thumbs.

The pandemic's lessons are plentiful and the threat is real, yet the preparation for next time — the ambitious, can-do spirit of the United States — is almost completely absent. Pandemic preparedness — the action needed to turn the lessons from the nation's covid-19 response into reality — must be an urgent priority for the White House, Congress, and the American people. Preparedness means having everything in place the day before it is needed, and no one knows when that will be.

It isn't enough to tweak organization charts and polish briefing papers. Rather, what's needed is a sustained, wide-ranging transformation in how the United States handles public health. Public health refers to "what we as a society do collectively to assure the conditions in which people can be healthy," the Institute of Medicine wrote in a landmark 1988 report. We have the raw material: scientific knowledge, innovation, and wealth. But we need better policies, programs, and practices to marshal these assets.

Unless the country changes course, more crises will come, perhaps quickly. Monkeypox, rarely seen outside of Africa, has spread in the United States from almost nothing to more than 16,920 cases in little more than three months, overwhelming public health systems and evading control. Polio virus, largely eliminated from the United States four decades ago, might have been circulating for up to a year, although the public alarm came only when a patient in New York was paralyzed. The first severe acute respiratory syndrome, or SARS, was highly pathogenic and killed 774 people, with a case fatality rate of about 10 percent; the next novel coronavirus, Middle East respiratory syndrome, had a case fatality rate of 36 percent. Neither was shown to be highly transmissible among humans. However, SARS-CoV-2, also known as covid-19, turned out to be highly transmissible and infected more than 500 million people. With a case fatality rate of 1 percent or less, it still led to at least 6 million deaths — and probably many more. What happens next? What if a coronavirus combines some of these characteristics of virulence and transmissibility? Almost every expert is warning: The dangers of another pandemic are real and severe.

The nation's experience with covid-19 exposed the risks. The pandemic response was badly fragmented among states and localities. The nation broke into warring camps about whether to be open or to adopt restrictions and whether to mandate masks or vaccines, and a checkerboard of jurisdictions fought against each other for diagnostic tests, supplies and therapeutics. Who can forget President Donald Trump's tweets — "LIBERATE MICHIGAN!" — attacking Democratic governors who imposed pandemic restrictions?

The splintering hampered efforts to understand what was happening on the ground — data networks failed to connect with each other; some communities were sending in their reports by fax machine. Mr. Trump predicted the virus would disappear and touted treatments that were useless, and his White House hampered the traditional leadership roles of the Centers for Disease Control and Prevention and the Food and Drug Administration. Mr. Trump's deliberate deception sullied one of the most important elements of an effective public health campaign: clear and transparent communications. This led to a loss of public trust. One of the few things the Trump administration got right was Operation Warp Speed, the breakneck vaccination development effort, which shows that concerted government effort can make a difference.

Unfortunately, neither Congress nor Presidents Trump or Biden were willing to create a 9/11-like national commission to diagnose what went wrong. It would have been invaluable. The Senate's Health, Education, Labor and Pensions Committee approved in March — with bipartisan support — the Prevent Pandemics Act, which would authorize a national commission, and it contains other useful provisions to modernize supply chains and improve data collection, but its prospects are uncertain, and time is running short in this session of Congress.

Many others have recognized the dangers stemming from lack of readiness. Mr. Biden advanced a national pandemic preparedness plan in March; the Rockefeller Foundation created the Pandemic Prevention Institute; the Commonwealth Fund published a report in June looking ahead; the Center for Strategic and International Studies has examined funding for pandemic preparedness; the Nuclear Threat Initiative's Global Health Security Index underscored a lack of preparedness worldwide. The Global Health Security Index in October 2019 was instructive. It rated the United States as the most prepared nation in the world for a pandemic — a wealthy country with advanced health capacity and capabilities. Those advantages were squandered when the pandemic occurred. Plans are not the only key — so is execution.

There are many reforms Congress and the White House should embrace.

The federal government must overcome the fragmentation of the nation's public health system. The 10th Amendment to the Constitution and many Supreme Court rulings have given state governments primary authority to control the spread of dangerous diseases within their jurisdictions. But the dedicated workers in this patchwork of localities are overburdened and underfunded. The Commonwealth Fund report calls for creating a national public health system that would provide more leadership, resources and direction, perhaps led by a new undersecretary or assistant secretary of Health and Human Services. While it wouldn't replace the work in states and localities, a national public health system would help ensure state and local health departments gain basic capabilities and resources to protect their communities, however different. The report says that government funding for core public health functions remains "grossly insufficient."

Every virus or bacteria has a genetic blueprint. With advances in bioinformatics, scientists can use genetic sequencing to identify the variant, spot mutations and chart possible spread among people. This ought to be harnessed into a nationwide — or even global — trip wire for disease among humans, animals, and plants. We already rely on early-warning systems to watch for hurricanes and tornadoes; radars and satellites keep watch for ballistic missile threats; prompt warning is critical to intelligence gathering and financial markets. But so far, early-warning systems exist only in fragments for disease. Also, there's a crying need to build better data-sharing systems to improve the link between genomics (genetic blueprints), health care (what doctors, hospitals and emergency rooms are seeing among people) and epidemiology (the patterns of disease in the population).

The nation's capabilities to create and manufacture vaccines must be strengthened. Operation Warp Speed showed what can be done. With years of previous research, and a mountain of government money, the mRNA coronavirus vaccines were developed and manufactured in record time and saved millions of lives. But the mRNA vaccines are not a long-term answer; their

effectiveness wanes. We need a second massive research and development effort, an Operation Warp Speed 2.0, to overcome many hurdles to a coronavirus vaccine that would work against all variants and for a long duration. It won't be easy. A universal flu vaccine has been an elusive goal for years. In parallel, we need an organized effort to create platforms for future vaccines with enough science and resources behind them to kick-start development as soon as a pandemic flares — to be ready to deploy shots rapidly.

The recent announcement of an overhaul at the CDC made a point to shift the agency's culture to be more action-oriented in the face of emergencies. The idea is a good one for more than just the CDC. The emergency side of public health should be organized like the military, with money, staffing, a clear command structure, exercises, and a mission of urgency.

Finally, the nation's public health authorities must rebuild trust. In an emergency, public trust is fragile — when broken, it is extremely difficult to regain. Transparency, promptness, and clarity were too often missing during this pandemic, and online disinformation further corroded public confidence. A concerted effort must be made to rebuild public trust in the digital age.

The prospects for wide-scale reform do not look good. Partisan conflict on Capitol Hill has stymied further funding to respond to the current pandemic, not to mention prepare for the next one. Where is the willpower that arose after 9/11? Where is the bipartisan consensus that existed during the Cold War? Clearly, the political scene has been clouded by pandemic fatigue and looming elections. But the need for preparedness is not going away.

A transformation in public health requires a sea change in thinking. We must value this endeavor for our own protection, rather than continue to neglect it. We have been warned.

https://tinyurl.com/ComingStormFutureEpidemic

23. **TED Talks (video)**

August 26, 2022

Why the price of insulin is a danger to diabetics

The price of insulin in the US is both outrageous and deadly to those who can't live without it. Diabetes advocate Brooke Bennett shares her own struggles living with type 1 diabetes and how the astronomical cost of a life-saving drug leaves millions struggling to survive. A rallying cry for an affordable and humane livelihood for those with chronic illness.

https://tinyurl.com/PriceInsulinDanger

24. **HealthDay**

August 25, 2022

Patterns of Undiagnosed Diabetes Examined in U.S. Adults

Using definition based on both fasting plasma glucose and HbA1c, analysis shows proportion of undiagnosed diabetes cases down in U.S. adults.

The prevalence of diagnosed diabetes increased from 4.6% between 1988 and 1994 to 11.7% between 2017 and 2020, but the prevalence of persistent undiagnosed diabetes and confirmed undiagnosed diabetes remained the same, according to a study in Diabetes Care. The populations with the highest prevalence of undiagnosed diabetes were racial and ethnic minorities, older adults, or those with obesity, and those with no health care access.

HealthDay News

25. **New York Times (free access)**

August 24, 2022

	People Who Do Strength Training Live Longer — and Better A consensus is building among experts that both strength training and cardio are important for longevity. In a new study published in The British Journal of Sports Medicine, researchers found that while doing either aerobic exercise or strength training was associated with a lower risk of dying during the study's time frame, regularly doing both — one to three hours a week of aerobic exercise and one to two weekly strength training sessions — was associated with an even lower mortality risk. Switching from a sedentary lifestyle to a workout schedule is comparable to "smoking versus not smoking," said Carver Coleman, a data scientist and one of the authors of the study. . . After adjusting for factors such as age, gender, income, education, marital status and whether they had chronic conditions, such as diabetes, heart disease or cancer, researchers found that people who engaged in one hour of moderate to vigorous aerobic activity a week had a 15 percent lower mortality risk. Mortality risk was 27 percent lower for those who did three hours a week. But those who also took part in one to two strength-training sessions per week had an even lower mortality risk — a full 40 percent lower than those who didn't exercise at all. This was roughly the difference between a nonsmoker and someone with a half-a-pack-a-day habit. Experts say it has been difficult to study longevity and strength training because so few people do it regularly. Even in the recent study, just 24 percent of participants did regular strength training (as opposed to 63 percent who said they did aerobic workouts). . . They found the largest reduction was associated with 30 to 60 minutes of strength training a week, with a 10 to 20 percent drop in the risk of mortality, cardiovascular disease, and cancer. . . This muscle loss usually starts in a person's 30s and progresses with age. However, "we can absolutely fend off the negative effects" with regular strength training, Dr. Ciolino said. And it's never too late to start. Research shows even septuagenarians with mobility issues can benefit from a regular strength-training program. https://tinyurl.com/CardioAndStrengthLonger **26. NPR Shots** August 23, 2022 *An $18,000 biopsy? Paying cash might have been cheaper than using her insurance* It's not uncommon for uninsured patients — or any patient willing to pay a cash price — to be charged far less for a procedure than patients with health insurance. For the nearly 30% of American workers with high-deductible plans . . . that means using insurance can lead to a far bigger expense than if they had been uninsured or just pulled out a credit card to pay in advance. https://tinyurl.com/18000Biopsy
	*May require registration before accessing article.
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

<table>
<tr><td></td><td>Questions or comments can be directed to Legislative Work Group Chair Richard (Dick) Moore at rmoore8473@charter.net.</td></tr>
<tr><td>Websites</td><td></td></tr>
<tr><td>Previously recommended websites</td><td>The comprehensive list of recommended websites has migrated to the Dignity Alliance MA website: https://dignityalliancema.org/resources/. Only new recommendations will be listed in The Tuesday Digest.</td></tr>
<tr><td>Previously posted funding opportunities</td><td>For open funding opportunities previously posted in The Tuesday Digest please see https://dignityalliancema.org/funding-opportunities/.</td></tr>
<tr><td>Nursing Home Closures</td><td>Closure Notices and Relocation Plans available at:
https://tinyurl.com/MANursingHomeClosures</td></tr>
<tr><td>Websites of Dignity Alliance Massachusetts Members</td><td>See: https://dignityalliancema.org/about/organizations/</td></tr>
<tr><td>Assisted Living Residences Closures</td><td>• Motif by Monarch (previously Landmark at Ocean View), Beverly, July 2022
• Connemara Senior Living, Brockton, Summer 2022
• Landmark at Longwood, Mission Hill, Boston, Summer 2022</td></tr>
<tr><td>Nursing homes with admission freezes</td><td>Massachusetts Department of Public Health
Temporary admissions freeze
On November 6, the state announced that it would require certain high risk nursing homes and rest homes to temporarily stop all new admissions to protect the health and safety of residents and prevent further COVID-19 transmission. Stopping admissions enables homes to focus resources such as staff and PPE on the health and safety of its current residents and enables the home to stabilize before taking on new residents. Homes that meet certain criteria will be required to stop any new admissions until the Department of Public Health has determined that conditions have improved, and the facility is ready to safely care for new residents. The Commonwealth will work closely with homes during this time and provide supports as needed to ensure resident health and safety. There are a number of reasons why a facility may be required to stop admissions, and the situation in each facility is different. Some of the factors the state uses to make this decision include:
• Number of new COVID-19 cases within the facility
• Staffing levels
• Failure to report a lack of adequate PPE, supplies, or staff
• Infection control survey results
• Surveillance testing non-compliance
Facilities are required to notify residents' designated family members and/or representative when the facility is subject to an admissions freeze. In addition, a list of facilities that are currently required to stop new admissions and the reason for this admissions freeze will be updated on Friday afternoons, and as needed when the Department of Public of Health determines a facility can be removed from the list.
Updated on August 26, 2022. Red font – newly added
<table>
<tr><th>Name of Facility</th><th>City/Town</th><th>Date of Freeze</th><th>Qualifying Factor</th></tr>
<tr><td>Attleboro Healthcare</td><td>Attleboro</td><td>8/2/2022</td><td>Infection Control</td></tr>
<tr><td>Dedham Healthcare</td><td>Dedham</td><td>7/6/2022</td><td>Infection Control</td></tr>
<tr><td>Lakeview House Skilled Nursing</td><td>Haverhill</td><td>8/16/2022</td><td>New cases</td></tr>
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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/SpeciialFocusFacilityProgram Updated June 29, 2022 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 July 27, 2022)** **Newly added to the listing** • None **Massachusetts facilities not improved** • None **Massachusetts facilities which showed improvement** • Attleboro Healthcare, Attleboro https://tinyurl.com/AttleboroHealthcare • Marlborough Hills Rehabilitation and Health Care Center, Marlborough https://tinyurl.com/MarlboroughHills **Massachusetts facilities which have graduated from the program** • None **Massachusetts facilities that are candidates for listing** • Parkway Health and Rehabilitation Center https://tinyurl.com/ParkwayHealthCenter • Plymouth Rehabilitation and Health Care Center https://plymouthrehab.com/

	• Revolution Charwell https://tinyurl.com/RevolutionCharwell • Savoy Nursing and Rehabilitation Center, New Bedford (added in June) No website • South Dennis Healthcare, South Dennis (added in July) https://www.nextstephc.com/southdennis • Tremont Health Care Center, Wareham https://thetremontrehabcare.com/ • Vantage at South Hadley No website • Vero Health and Rehabilitation Center of Amesbury https://tinyurl.com/VeroAmesbury • Vero Health and Rehabilitation Center of Revere https://tinyurl.com/VeroRevere • Watertown Rehabilitation and Nursing Center, Watertown (added in June) No website https://tinyurl.com/SpeciialFocusFacilityProgram
Nursing Home Inspect	**ProPublica** ***Nursing Home Inspect*** Data updated August 2022 This app uses data from the U.S. Centers for Medicare and Medicaid Services. Fines are listed for the past three years if a home has made partial or full payment (fines under appeal are not included). Information on deficiencies comes from a home's last three inspection cycles, or roughly three years in total. The number of COVID-19 cases is since May 8, 2020, when homes were required to begin reporting this information to the federal government (some homes may have included data on earlier cases). Massachusetts listing: https://projects.propublica.org/nursing-homes/state/MA **Deficiencies By Severity in Massachusetts** (What do the severity ratings mean?) # reported Deficiency Tag 249 **B** 79 **C** 7,092 **D** 1,857 **E** 552 **F** 489 **G** 1 **H** 33 **J** 7 **K**
Nursing Home Compare	**Centers for Medicare and Medicaid Services (CMS)** *Nursing Home Compare Website* Beginning January 26, 2022, the Centers for Medicare and Medicaid Services (CMS) is posting new information on the that will help consumers have a better understanding of certain staffing information and concerns at facilities. This information will be posted for each facility and includes:

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Staff turnover: The percentage of nursing staff as well as the number of administrators who have stopped working at a nursing home over the past 12-month period.
Weekend staff: The level of weekend staffing for nurses and registered nurses at a nursing home over a three-month period.

Posting of this information was required as part of the Affordable Care Act, which was passed in 2010. In many facilities, staffing is lower on weekends, often meaning residents have to wait longer or may not receive all the care they need. High turnover means that staff are less likely to know the residents, recognize changes in condition, or implement preferred methods of providing care. All of this contributes to the quality-of-care residents receive and their quality of life.
https://tinyurl.com/NursingHomeCompareWebsite
</td></tr>
<tr><td>Long-Term Care Facilities Specific COVID-19 Data</td><td>
Massachusetts Department of Public Health
Long-Term Care Facilities Specific COVID-19 Data
Coronavirus Disease 2019 (COVID-19) reports related to long-term care facilities in Massachusetts.
Table of Contents

COVID-19 Daily Dashboard
COVID-19 Weekly Public Health Report
Additional COVID-19 Data
CMS COVID-19 Nursing Home Data

</td></tr>
<tr><td>DignityMA Call to Action</td><td>

The MA Senate released a report in response to COVID-19. Download the DignityMA Response to Reimagining the Future of MA.
Advocate for state bills that advance the Dignity Alliance Massachusetts' Mission and Goals – State Legislative Endorsements.
Support relevant bills in Washington – Federal Legislative Endorsements.
Join our Work Groups.
Learn to use and leverage Social Media at our workshops: Engaging Everyone: Creating Accessible, Powerful Social Media Content

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<tr><td>Access to Dignity Alliance social media</td><td>
Email: info@DignityAllianceMA.org
Facebook: https://www.facebook.com/DignityAllianceMA/
Instagram: https://www.instagram.com/dignityalliance/
LinkedIn: https://www.linkedin.com/company/dignity-alliance-massachusetts
Twitter: https://twitter.com/dignity_ma?s=21
Website: www.DignityAllianceMA.org
</td></tr>
<tr><td>Participation opportunities with Dignity Alliance Massachusetts

Most workgroups meet bi-weekly via Zoom.

Please contact workgroup lead for more information</td><td colspan="2">
<table>
<tr><th>Workgroup</th><th>Workgroup lead</th><th>Email</th></tr>
<tr><td>General Membership</td><td>Bill Henning
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	Legal Issues	Clarence Richardson	Clarence@massnaela.com
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The Dignity Digest	For a free weekly subscription to *The Dignity Digest:* https://dignityalliancema.org/contact/sign-up-for-emails/ Editor: Paul Lanzikos Primary contributor: Sandy Novack MailChimp Specialist: Sue Rorke		
Note of thanks	Thanks to the contributors to this issue of *The Dignity Digest* • Charles Carr • Wynn Gerhard • Margaret Morganroth Gullette • Long Term Care Community Coalition • Dick Moore • Heather Watkins Special thanks to Paul Spooner with the MetroWest Center for Independent Living for assistance with the website and MailChimp versions of *The Dignity Digest.* *If you have submissions for inclusion in The Dignity Digest or have questions or comments, please submit them to paul.lanzikos@gmail.com.*		

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: https://dignityalliancema.org/dignity-digest/*
For more information about Dignity Alliance Massachusetts, please visit www.DignityAllianceMA.org.