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

***May require registration before accessing article.**

Spotlight

Editor’s note: This is a provocative essay. It includes a reference to the Worcester (MA) Recovery Center, a facility for 320 long-term patients with private rooms and “a recovery-inspired residential design” which opened in 2012. If you have observations or comments regarding the essay which you would like to share, please send them to Digest@DignityAllianceMA.org

It’s Time to Bring Back Asylums

Wall Street Journal

[Time to Bring Back Asylums](#) (free access)

July 21, 2023

By David Oshinsky

Recent cases of violence by the mentally ill highlight the need to reconsider a long-maligned institution that now offers a promising solution.

The ongoing saga of the severely mentally ill in America is stirring attention again in a sadly familiar way. In Los Angeles in early 2022, a 70-year-old nurse was murdered while waiting for a bus, and two days later a young graduate student was stabbed to death in an upscale furniture store where she worked. That same week in New York City, a 40-year-old financial analyst was pushed onto the subway tracks as a train was arriving, killing her instantly.

All three assaults, random and unprovoked, were committed by unsheltered homeless men with violent pasts and long histories of mental illness. In New York, the perpetrator had warned a psychiatrist during one of his many hospitalizations of his intention to commit that very crime.

Then came the chance encounter this May that led to the death of Jordan Neely on a Manhattan-bound subway car. Homeless and schizophrenic, Neely had spent most of his adult life in and out of emergency rooms, psychiatric wards, and prison. He had 42 prior arrests, mostly for nuisance crimes, but also for assault. He’d recently pleaded guilty to punching an elderly woman in the face, fracturing her eye socket.

What happened in the moments leading up to his death is still in dispute. While a jury will decide whether another passenger’s chokehold on Neely was second-degree manslaughter or an act of self-defense, the attention the incident received speaks volumes about the public’s fear of the aggressive and sometimes violent behavior of the mentally ill. Most of all, Neely’s death highlights the failures of a mental health system that allows profoundly disturbed people to slip through the cracks.

On an average night, according to the U.S. Department of Housing and

Urban Development, close to 600,000 people in the country will be homeless—a figure seen by many as an undercount. More than 40% will be “unsheltered,” or “living in places not suitable for human habitation,” and about 20% will be dealing with severe mental illness. Experts sharply disagree about the contribution of homelessness to rising crime rates. Some emphasize that most of these crimes are low-level victimless offenses, such as loitering or public urination. But others note the disproportionately high level of all crimes, including assaults and homicides, committed by those battling homelessness and mental issues simultaneously.

Had Jordan Neely and the others been born a generation or two earlier, they probably would not have wound up on the streets. There was an alternative back then: state psychiatric hospitals, popularly known as asylums. Massive, architecturally imposing, and set on bucolic acreage, they housed close to 600,000 patients by the 1950s, totaling half the nation’s hospital population. Today, that number is 45,000 and falling.

Asylums were created for humane ends. The very term implies refuge for those in distress. The idea was to separate the insane, who were innocently afflicted, from the criminals and prostitutes who were then commonly referred to as the “unworthy poor.” Asylums were popular because they provided treatment in isolated settings, far from temptation, while relieving families of their most burdensome members.

But “insanity” in these years cast a very wide net. A typical asylum included patients who were suffering from alcoholism, dementia, depression, and epilepsy, as well as such now defunct diagnoses as “lunacy” and “melancholia.” The usual stay was marked in years, not months, as evidenced by the rows of crosses in asylum graveyards. Over time, the number of institutionalized patients far outpaced the state’s willingness to support them. Funding and oversight disappeared. And this, in turn, produced a flood of exposés—some embellished, others sadly true—portraying these institutions as torture chambers where icepick lobotomies, electric shock, sterilization and solitary confinement turned humans into zombies. A seemingly revolutionary solution soon appeared—a new drug with the potential to treat psychotic disorders such as schizophrenia and bipolar disorder. First marketed in 1955 under the brand name Thorazine, it became the psychiatric equivalent of antibiotics and the polio vaccine. Why keep patients locked away in sadistic institutions when they could be successfully medicated close to home?

The promise of Thorazine coincided with a dramatic assault upon traditional psychiatry led by radical critics such as Michel Foucault and Thomas Szasz. Asylums existed to enslave those who ignored society’s norms, they believed. Who could say with assurance that the people locked away in these places were any more or less insane than the

authorities who put them there? It seemed a perfect fit for the 1960s, appealing to emerging rights groups and a counterculture scornful of elites. “If you talk to God, you are praying,” Szasz declared. “If God talks to you, you are schizophrenic.”

In October 1963, President John F. Kennedy put his signature to the last bill he would ever sign—the Community Mental Health Act. It aimed to demolish the walled-off world of the asylum in favor of 1,500 local clinics where patients could receive the drugs and therapies they needed. Kennedy had a personal stake in the legislation: His sister, Rosemary, had undergone an experimental lobotomy that left her severely disabled. On paper, at least, deinstitutionalization seemed both more humane and more likely to succeed. Then reality set in. Closing the asylums was the easy part. Getting people to accept a mental health clinic next to their local church or elementary school proved a much tougher sell. Asylum inmates returned home to find their former neighbors unprepared and often unwilling to help. Most of the clinics never materialized. And the promise of Thorazine was blunted, in part, by its nasty side effects. Surveys of those released from state asylums found that close to 30% were either homeless or had “no known address” within six months of their discharge. One critic likened it to “a psychiatric Titanic.”

A few voices had predicted as much. In 1973, a Wisconsin psychiatrist named Darold Treffert wrote an essay about the dangerous direction in which his profession was headed. His colleagues had become so fixated on guarding the patient’s civil liberties, he noted, that they had lost sight of the patient’s illness. What worried him was the full-throated endorsement of recent laws and court decisions that severely restricted involuntary commitments. What purpose was served by giving people who couldn’t take care of themselves the freedom to live as they wished? He titled his piece, “Dying with Their Rights On.”

Treffert was referring to cases like *Lessard v. Schmidt* (1972), where a federal court ruled that involuntary commitment must be limited to cases involving the “extreme likelihood” that someone “will do immediate harm to himself or others”—a very strict standard. Three years later, the Supreme Court tightened things further by asserting that authorities had been too cavalier in locking away the “harmless mentally ill.” In *O’Connor v. Donaldson*, it declared: “Mere public intolerance or animosity cannot constitutionally justify the deprivation of a person’s physical liberty.”

Enter Joyce Brown, a 40-year-old woman who went by the street name “Billie Boggs.” The year was 1987, and Brown was living atop a heating vent on New York’s tony Upper East Side. It was a tense time for the nation’s largest cities, with exploding crime rates, rampant crack addiction, the AIDS crisis and thousands of homeless people camping in parks, bus stations, subway tunnels and doorways. Under

extreme pressure, New York's Mayor Edward Koch authorized the involuntary commitment of those living unsheltered on the streets. Brown was the first to be confined.

Little was known about her beyond her struggles with heroin and a diagnosis of schizophrenia following her eviction from a New Jersey shelter. Brown was more of a nuisance than a threat to the neighborhood—stopping traffic, screaming at pedestrians, using the sidewalk as her toilet. Social workers who periodically visited her worried that she ate poorly, never bathed, and lacked the clothing to handle New York's brutal weather. Some viewed her as self-negligent to the point of being suicidal.

Taken to Bellevue Hospital, Brown was bathed, deloused, and given antipsychotic drugs. Four psychiatrists confirmed the diagnosis of chronic schizophrenia. Bellevue contained a courtroom where patients could challenge their confinement before a state-appointed judge. Most were represented by a public defender, but the American Civil Liberties Union took on Brown's case, claiming that her confinement violated federal court guidelines.

Ironically, Brown turned out to be her own best witness. Carefully medicated, she testified thoughtfully enough to convince the judge that the evidence before him was too ambiguous to merit the loss of her liberty. But he surely was conflicted, writing: "There must be some civilized alternatives other than involuntary hospitalization or the street."

Joyce Brown, whose involuntary commitment to New York's Bellevue Hospital sparked a civil-rights lawsuit, speaks at Harvard Law School in 1988. Photo: Carol Francavilla/Associated Press

Unfortunately, there weren't. An appeals court reversed the decision to free Brown, leading her to refuse all medication. Another trial was held to determine whether antipsychotic drugs could be forced upon her, and this time she prevailed. The city, weary of lawsuits, chose to discharge her rather than to appeal.

Brown became an instant celebrity. She traveled the TV talk show circuit as "the most famous homeless person in America" and even gave a lecture of sorts at Harvard Law School. "I like the streets, and I am entitled to live the way I want to live," she explained. Offered a room at a "residential hotel," she quickly returned to the life that she knew best, panhandling for drug money at the Port Authority Bus Terminal before fading from public view. She died in 2005 at age 58. The questions her case raised, however, are more relevant than ever. How does a civilized society deal with severely mentally ill people who refuse assistance? What constitutes the sort of behavior that requires forced hospitalization? Is it time to bring back the asylum?

These issues are intertwined with a fundamental change brought about by deinstitutionalization. Put simply, civil libertarians and disability rights advocates have largely replaced psychiatrists as the

arbiters of care for the severely mentally ill. And a fair number of them, with the best of intentions, seem to view the choices of those they represent as an alternative lifestyle rather than the expression of a sickness requiring aggressive medical care.

The enormous vacuum created by deinstitutionalization has been a calamity for both the mentally ill and society at large. The role once occupied by the asylum has been transferred to the institutions perhaps least able to deal with mental health issues—prisons and jails. The number of inmates in the U.S. in 1955 was 185,000; today, that figure is 1,900,000.

Unsurprisingly, the nation’s three largest mental health facilities are the Los Angeles County Jail, the Cook County Jail in Chicago, and Rikers Island in New York City. Approximately one quarter of their inmates have been diagnosed with a serious mental disorder.

In this massive system, the mentally ill are less likely to make bail, more likely to be repeat offenders and far more likely to be victimized by other inmates. Given the sheer numbers, maintaining order in these prisons and jails depends heavily on antipsychotic medication. It’s hard to imagine a worse environment for the safety, much less the treatment, of the mentally ill.

Meanwhile, state mental hospitals continue to shrink. Gone is the laundry list of afflictions that marked asylum life in the 1950s. The majority of the current patients are there “involuntarily”—people who have been judged a danger to themselves or to others, who have been found not guilty of a crime by reason of insanity, or who are being evaluated for their competency to stand trial. Because so many psychiatric beds have disappeared, the waiting period for admission can take months, which means that inmates languish in jail without having been convicted of a crime.

In the past decade, a growing number of scholars from across the ideological spectrum have suggested a return to asylums. Among them is Ezekiel Emanuel, a leading medical ethicist, who joined with two colleagues in 2015 to recommend the building of “safe, modern and humane” state institutions to end the revolving door of homelessness-hospitalization-prison that passes for policy today. Actress Louise Fletcher as the sadistic Nurse Ratched in the 1975 film ‘One Flew Over the Cuckoo’s Nest,’ starring Jack Nicholson (right).

Photo: United Artists/Getty Images

The model they suggested is the Worcester Recovery Center in Massachusetts, a facility for 320 long-term patients with private rooms and “a recovery-inspired residential design.” Opened in 2012 on the grounds of a long-abandoned state asylum, it cost \$300 million to complete, making it one of the most expensive non-road construction projects in the state’s history.

There is little doubt of the need for it, and the early signs, including surveys of recovery outcomes, are encouraging. Since the goal is to

	<p>serve patients, rather than to warehouse them, the price can be steep. In 2015 Massachusetts spent \$55,000 per prison inmate, with some additional costs for those with serious mental health issues. Meanwhile, the Worcester Recovery Center, with an annual budget of \$60 million, spent close to four times that sum per patient. How this will play out in the long run, and how many other states will follow, remains to be seen.</p> <p>The very word “asylum” brings shivers to those old enough to remember its abuses. It has a disturbing cultural legacy to confront in the sadistic Nurse Ratched of “One Flew Over the Cuckoo’s Nest.” Bringing it back in any form will face the twin obstacles of cost and image. But for the most vulnerable among us, who exist in a world of peril to themselves and to others, it is a far better option than the alternatives to homelessness and incarceration.</p> <p>[Editor’s note: David Oshinsky directs the Division of Medical Humanities at NYU Langone Health. His books include “Bellevue: Three Centuries of Medicine and Mayhem at America’s Most Storied Hospital” and “Polio: An American Story,” which won the 2006 Pulitzer Prize for history.]</p> <p>Time to Bring Back Asylums (free access)</p>
<p>Quotes</p>	<p><i>“Too often, fear of staff retaliation – the fear itself – prevents residents from voicing concerns and from receiving the care and services to which they are entitled. Ultimately, this inaction leads to unnecessary emotional, psychological, and physical harm to vulnerable residents.”</i></p> <p><i>“They Make You Pay”, Long Term Care Community Coalition, June 2023, “They Make You Pay.”</i></p> <p><i>“Staff acted like we were non-people. They don’t even acknowledge that we are human.”</i></p> <p><i>Interviewed nursing home resident, “They Make You Pay”, Long Term Care Community Coalition, June 2023, “They Make You Pay.”</i></p> <p><i>“Some staff treat residents like gold, but others are just not nice.”</i></p> <p><i>An Illinois nursing home resident to state surveyor, “They Make You Pay”, Long Term Care Community Coalition, June 2023, “They Make You Pay.”</i></p> <p><i>The enormous vacuum created by deinstitutionalization has been a calamity for both the mentally ill and society at large. The role once occupied by the asylum has been transferred to the institutions perhaps least able to deal</i></p>

with mental health issues—prisons and jails. The number of inmates in the U.S. in 1955 was 185,000; today, that figure is 1,900,000.

David Oshinsky, *It's Time to Bring Back Asylums*, **Wall Street Journal**, [Time to Bring Back Asylums](#) (free access), July 21, 2023

“This study demonstrates the profound effect of early detection of influenza in long-term care facilities. Nursing homes are collections of very vulnerable individuals, so anything we can do to protect them is very important.”

Dr. Jonathan Temte, professor of family medicine and community health at the University of Wisconsin School of Medicine and Public Health, *Study Reveals Importance of Early Influenza Detection for Nursing Home Residents*, **Skilled Nursing News**, July 21, 2023, [Early Influenza Detection](#)

The U.S. health-care system is costly to families and the country. Morally, improving access is the right thing to do for Americans in pain. Financially, it makes sense, too.

Health insurance is keeping your mind sick and wallet empty, **Washington Post**, July 21, 2023, [Keeping Your Mind Sick](#)

Health disparities, or preventable differences in the burden of chronic disease and health outcomes, are a driving force behind mental health inequities. Our health equity problem is of our own making, created by artificial caste distinctions, persistent racism, and how we structure our economy and investments in health care; the status of health care disparities is determined, largely, in the ways that the private sector either confronts them or looks away.

Addressing The Mental Health Equity Crisis: Can The Private Sector Lead?, **Health Affairs Forefront**, July 19, 2023, [Mental Health Equity Crisis](#)

So, by virtue of carving out a form of medical care for poor people – which is seen as welfare or a “handout” – the system can exploit them for financial gain while denying them the quality of care every other citizen deserves even though every form of healthcare received by Americans is

	<p><i>heavily subsidized in some way or other by government.</i></p> <p>Dave Kingsley, <i>Managed Care & Privatization was Supposed to Save Taxpayers Money & Work Better than Government Administered Medical Care, but That's Not What is Happening.</i> Tallgrass Economics, July 23, 2023, Managed Care & Privatization</p> <p><i>Three factors raise concerns that some people enrolled in Medicaid managed care may not be receiving all medically necessary health care services intended to be covered: (1) the high number and rates of denied prior authorization requests, (2) the limited oversight of prior authorization denials in most States, and (3) the limited access to external medical reviews.</i></p> <p><i>High Rates of Prior Authorization Denials by Some Plans and Limited State Oversight Raise Concerns About Access to Care in Medicaid Managed Care, U. S. Department of Health and Human Services Office of Inspector General</i>, July 17, 2023, Complete Report</p>
<p>From Our Colleagues from Around the Country</p>	<p>1. Tallgrass Economics July 23, 2023 <i>Managed Care & Privatization was Supposed to Save Taxpayers Money & Work Better than Government Administered Medical Care, but That's Not What is Happening.</i> By Dave Kingsley Managed Care for Poor Peoples' Medicine is a Chimera According to a report released by the HHS OIG's Office last week^[1], the massive Medicaid program intended for poor Americans is beset with denial of authorization for care and weak state oversight. What that means is this: poor people who are hard scrabble poor enough to qualify for Medicaid and have the moxie and luck in navigating the bureaucracy to the point of approval for the program, are far too often denied the treatment physicians think they need. The gigantic insurance companies contracting with states to run their Medicaid programs are denying care at double the rate of Medicare denials under managed care (i.e., Medicare Advantage). It is not difficult to understand why an undue administrative burden is placed on poor people for both qualifying for government health care in the first instance and then for receiving needed care once they are admitted to the program. Powerful insurance companies have a financial incentive to deny a large proportion of care medical professionals think Medicaid recipients need. Furthermore, a lobby for poor people is nonexistent; they are powerless; and they can be pushed around and/or ignored by state bureaucrats. Nevertheless, a puzzling and mistaken conventional wisdom proclaims that a corporatized and privatized system is a far more efficient and effective way to deliver taxpayer funded medical services. It is past time that the conventional wisdom undergoes strong pushback from medical professionals, academics, and the media. Background</p>

During the 2000 aughts (starting about 2010), states relying on the concept of “managed care” in which insurance companies (known as MCOs) are paid a “capitation rate,” i.e., a specific amount per enrollee, turned over their Medicaid programs to insurance corporations. If the insurers keep their costs below the total dollars committed for enrollees, they make money. Patients are, however, required to utilize medical services within “network.” They must use a medical practice or hospital that is part of the contracting MCOs network of physicians and other medical providers. Furthermore, care must be authorized by the MCO.

The size of federal expenditures for Medicaid has resulted in mushrooming revenue for major healthcare insurers such as UnitedHealth, Elevance, Cigna, Centene, and Aetna. In the early 2000s, no health insurers were in the top 30 corporations listed on the Fortune 500. By 2022, nearly one-third of the top 30 Fortune 500 companies were related to healthcare insurance and managed care contracting.

The idea of managed care began with the concept of health maintenance organizations (HMO) such as Kaiser Permanente and Ross Loos. Individuals can join an HMO, pay the premium and expect low deductibles and co-pays. However, the HMO or MCO in the case of Medicaid managed care have a network of physicians and other providers. Enrollees must “stay within network” and receive authorization from an insurer (MCO) for a host of medical services their primary physician thinks they need. This opens the door to tremendous power of insurance behemoths over Americans’ healthcare needs.

Has Privatization & Corporatization Through the Managed Care Concept Been Beneficial to the Health of Americans?

As I mentioned, it is conventional wisdom that private, for-profit corporations can do a better job of administering taxpayer funded healthcare than government agencies. But managed care is not working out in accordance with the widespread belief the government will pay less for healthcare if the profit motive incentivizes better care at a lower price. Medicare Advantage costs fifteen percent more per enrollee than traditional Medicare. Medicaid MCOs are paying robust dividends, buying back billions of dollars worth of their stock, and rewarding executives with exorbitant compensation packages while well baby care, infant mortality, heart disease, diabetes, and access to addiction treatment are not significantly improving across the Medicaid eligible population.

Aetna, UnitedHealth, Centene, and other major insurance companies are reaping huge financial rewards by keeping per capita costs low. That would not in itself be a bad thing if outcomes were improving. Perhaps having some healthcare is better than nothing. No doubt, people receiving Medicaid benefits have better health outcomes than people with nothing. But that is not the point. Comparing poor people with no health insurance to poor people with Medicaid is illogical.

Medicaid is lower tier medicine. So those individuals lucky enough to qualify for it and actually receive it are treated as second class citizens. So, by virtue of carving out a form of medical care for poor people – which is seen as welfare or a “handout” – the system can exploit them for financial gain while denying them the quality of care every other citizen deserves even though every form of healthcare received by Americans is heavily subsidized in some way or other by government.

Follow Us at the Center for Health Care Information & Policy (a newly formed nonprofit at <https://chipcenterus.org/>) and on this Blog as We Expose the

Illogic and Folly of Privatizing U.S. Healthcare

[Managed Care & Privatization](#)

[1] HHS OIG Report: *“High Rates of Prior Authorization Denials by Some Plans and Limited State Oversight Raise Concern About Access to Care in Medicaid Managed Care.”* <https://www.oig.hhs.gov/oei/reports/OEI-09-19-00350.asp#:~:text=Overall%2C%20the%20MCOs%20included%20in%20our%20review%20denied,rates%20greater%20than%2025%20percent-twice%20the%20overall%20rate.>

2. Long Term Care Community Coalition

June 2023

“They Make You Pay”

Fear of retaliation is a pervasive problem that results in emotional, psychological, and physical harm to vulnerable and frail residents. In far too many U.S. nursing homes, retaliation is a tool to scare and muzzle residents. Unfortunately, this phenomenon has been largely overlooked in policy and in academic literature.

In this project, we strive to raise awareness of this issue by capturing residents’ experiences of fear of retaliation and actual retaliation in their own words, using direct quotations from standard surveys and complaint investigation reports on U.S. nursing homes.

The title of this project, *“They Make You Pay,”* is inspired by a survey report which detailed how residents at a Florida nursing home (Boca Ciega Center) chose not to report or file grievances related to poor care because they feared retaliation by staff. In an interview with the surveyor, a resident said she did not file a grievance *“because they get back at you... They are watching even now to see which rooms you go to and listen to what you ask.”* According to the resident, staff and administration at this nursing home retaliated by delaying resident care or sabotaging meals. *“They make you pay,”* she said.

The resident then asked the surveyor to leave and return later because staff were lingering at the door.

This survey report is one of 100 examined in LTCCC’s project on resident fear of retaliation. In each report, we endeavor to highlight the lived experience of residents and show how they are directly impacted by this phenomenon. We hope that heightening awareness of fear of retaliation can result in real changes in policy, practice, and enforcement actions.

Project Goals

This project aims to raise awareness about the phenomenon of resident fear of staff retaliation and call for policy, practice, and research action to address and prevent it. Primary goals of this project include:

- Identifying different types of residents’ fear of retaliation

I. Fear of Retaliation,

II. Alleged Threats of Retaliation,

III. Perceived Retaliation, IV. Actual Retaliation).

- Raising awareness of the emotional consequences of retaliation.

- Shedding light on how the fear of retaliation inhibits reporting of (and, thus, accountability for) substandard care, abuse, and neglect.

Introduction

For several decades, researchers have reported on the phenomenon of staff

retaliation against residents in nursing homes. More recently, we have learned that the fear of staff retaliation – the fear itself – is preventing residents from voicing concerns and from receiving the care and services to which they are entitled.

When residents are silenced, the consequences (e.g., emotional/psychological suffering) can be dire. Too often, resident complaints are delayed or never reported and, thus, not investigated and resolved. Ultimately, this inaction leads to unnecessary suffering for residents and their families.

This project, “They Make You Pay”: How Fear of Retaliation Silences Residents in America's Nursing Homes, examines fear of staff retaliation and the consequences of this fear by capturing residents’ experiences in their own words. The residents’ experiences of fear of retaliation are obtained from 100 standard surveys and complaint investigation reports on nursing homes in 30 U.S. states. Using these reports, we detail the residents’ lived experience pertaining to the following aspects of retaliation:

I. Fear of staff retaliation; II. Allegations of staff threats of retaliation; III. Perceptions of staff retaliation; and IV. Actual (confirmed) staff retaliation. Additionally, the project identifies a wide range of disturbing emotional consequences residents suffer because of fear of or actual retaliation. Systematic examination of these consequences has yet to be conducted to date. In these regards, this project is novel and, we believe, groundbreaking. This project examines how fear of retaliation poses barriers to reporting complaints of mistreatment, substandard care, and inhumane conditions.

This project responds to a 2011 University of Connecticut study that called for the implementation of interventions to address, among other issues, residents’ fear of staff retaliation. While exploratory in nature, we believe that this review represents the most in-depth examination of this phenomenon to date and hope at it will contribute significantly to our understanding of this harmful yet largely invisible source of resident suffering in America’s nursing homes. The project’s overarching goal is to raise awareness of fear of retaliation and call for policy, practice, and enforcement actions to address this human rights issue. We hope that “They Make You Pay” encourages further study of this phenomenon in nursing homes, assisted living, and other settings in which vulnerable older adults and disabled people live and receive care services.

Findings

Forms of Retaliation

Our research led to the identification of extensive evidence revealing the four main aspects of the phenomenon under study, including:

- I. Residents’ fear of staff retaliation;
- II. Residents’ allegations of staff threats of retaliation;
- III. Residents’ perceived staff retaliation; and
- IV. Actual (confirmed) staff retaliation against residents.

The following section offers examples of situations underlying the four aspects of the phenomenon, including a discussion of themes of fear of retaliation.

Discussion & Policy Implications

Staffing

Staff retaliation causes significant emotional and physical harm to residents in U.S. nursing homes. As stated in CMS’s guidance to state surveyors, “retaliation by staff is abuse, regardless of whether harm was intended, and must be cited.”

Unfortunately, too many nursing homes are fostering environments in which mistreatment and retaliation against residents is tolerated. As one Illinois nursing home resident put it, “Some staff treat residents like gold, but others are just not nice.”

Many direct care staff members in U.S. nursing homes are caring, compassionate, and hardworking. They strive to keep residents safe and meet their physical and psychological needs while working in difficult conditions (i.e., understaffed and overworked, lacking adequate training for dementia care, lacking supportive guidance from managers, receiving minimal compensation and benefits, and lacking recognition).

Too often, however, staff are put in a position to fail residents as they work in nursing homes with dangerously low staffing levels and high staff turnover rates – problems that plagued LTC homes well before the COVID-19 pandemic. Some nursing homes are also hiring more unqualified or poorly vetted individuals to care for vulnerable and frail residents. Too many nursing home are prioritizing profits over people, failing to invest in sufficient and qualified staff that can meet the needs of their residents.

When nursing homes are not sufficiently staffed with trained and qualified employees, their residents are at greater risk of poor outcomes, including the phenomenon covered in this project: fear of retaliation.

Oversight, Enforcement, & Transparency

The policy implications of this project go far beyond staffing. Our examination of 100 standard surveys and complaint investigation reports on nursing homes in 30 states demonstrates a need for systemic improvements in oversight, enforcement, and transparency.

First, CMS does not currently track standard survey and complaint investigation reports containing violations specifically related to residents’ fear of staff retaliation, threats of retaliation, perceived retaliation, and actual (substantiated) retaliation. The wide range of circumstances identified in this project as underlying this phenomenon, combined with its serious and emotionally devastating effects on residents (described in residents’ own words), demonstrate the urgent need for such tracking. Specifically, CMS should develop a unique survey deficiency citation (F-tag) or other mechanism to efficiently capture all violations of federal laws and regulations related to this phenomenon in its F-tags coding system. The array of pertinent F-tags in this research project could serve as a starting point in the development of such tracking.⁴⁸ In addition, while the National Ombudsman Reporting System tracks complaints related to “Retaliation” (D06 complaint code), it does not track complaints related to residents’ fear of retaliation in the context of voicing care concerns and grievances. Bridging this major gap in centralized national tracking is critically important. The recommended centralized tracking could open new opportunities for sorely needed research aimed at improving understanding of this source of suffering and form of mistreatment. Insights gleaned from such research could inform the development of interventions and staff training programs to increase awareness, early detection, prevention, and adequate and safe response.

Second, the heartbreaking findings identified in this project show the urgent need for CMS to develop and implement a data-driven national campaign aimed at addressing retaliation in nursing homes. This national campaign should focus on educating and raising awareness among residents, families, nursing homes,

	<p>state survey agencies, Ombudsman programs, and other stakeholders. An effective campaign could ultimately help restore residents’ trust and confidence that they and their families should never have to fear staff retaliation when speaking up about care concerns and mistreatment in their home. Third, over a decade ago, the state of Connecticut passed a law entitled An Act Concerning Fear of Retaliation</p> <p>Training in Nursing Home Facilities requiring annual in-service training on residents’ fear of retaliation in nursing homes. The law states, “[a] nursing home administrator of a chronic and convalescent nursing home or a rest home with nursing supervision shall ensure that all facility staff receive annual in-service training in...residents’ fear of retaliation.”</p> <p>It requires that nursing home administrators ensure that the in-service training in residents’ fear of retaliation includes discussion of:</p> <p>(A) residents’ rights to file complaints and voice grievances. (B) examples of what might constitute or be perceived as employee retaliation against residents. (C) methods of preventing employee retaliation and alleviating residents’ fear of retaliation.</p> <p>There is an urgent need for other states to pass laws like Connecticut’s given the prevalence of fear of staff retaliation and its significant emotional and physical consequences for residents in LTC homes. Finally, Connecticut’s retaliation training law requires “the State Long-Term Care Ombudsman to create and periodically update a training manual that provides nursing home administrators guidance on structuring and implementing this new training requirement.” Insights gleaned from this report could inform awareness and educational initiatives as well as updates in the training manual.</p> <p>“They Make You Pay.” (141-page report)</p>
<p>Reports</p>	<p>3. U. S. Department of Health and Human Services Office of Inspector General July 17, 2023 <i>High Rates of Prior Authorization Denials by Some Plans and Limited State Oversight Raise Concerns About Access to Care in Medicaid Managed Care</i> KEY TAKEAWAYS Three factors raise concerns that some people enrolled in Medicaid managed care may not be receiving all medically necessary health care services intended to be covered: (1) the high number and rates of denied prior authorization requests, (2) the limited oversight of prior authorization denials in most States, and (3) the limited access to external medical reviews.</p> <p>WHY WE DID THIS STUDY As Medicaid managed care enrollment continues to grow, Medicaid managed care organizations (MCOs) play an increasingly important role in ensuring that people with Medicaid have access to medically necessary, covered services. In recent years, allegations have surfaced that some MCOs inappropriately delayed or denied care for thousands of people enrolled in Medicaid, including patients who needed treatment for cancer and cardiac conditions, elderly patients, and patients with disabilities who needed in-home care and medical devices. Ensuring access to appropriate care for people in Medicaid managed care is a priority for OIG. In addition, OIG received a congressional request to evaluate whether MCOs are providing medically necessary health care services to their enrollees.</p> <p>HOW WE DID THIS STUDY</p>

We identified and selected the seven MCO parent companies with the largest number of people enrolled in comprehensive, risk-based MCOs across all States. These 7 parent companies operated 115 MCOs in 37 States, which enrolled a total of 29.8 million people in 2019. We collected data from the selected parent companies about prior authorization denials and related appeals for each MCO they operated. We also surveyed State Medicaid agency officials from the 37 States to examine selected aspects of State oversight of MCO prior authorization denials and appeals, along with State processes for external medical reviews and fair hearings.

WHAT WE FOUND

Overall, the MCOs included in our review denied one out of every eight requests for the prior authorization of services in 2019. Among the 115 MCOs in our review, 12 had prior authorization denial rates greater than 25 percent—twice the overall rate. Despite the high number of denials, most State Medicaid agencies reported that they did not routinely review the appropriateness of a sample of MCO denials of prior authorization requests, and many did not collect and monitor data on these decisions. The absence of robust mechanisms for oversight of MCO decisions on prior authorization requests presents a limitation that can allow inappropriate denials to go undetected in Medicaid managed care.

Although the appeals process is intended to act as a potential remedy to correct inappropriate denials, several factors may inhibit its usefulness for this purpose in Medicaid managed care. Most State Medicaid agencies reported that they do not have a mechanism for patients and providers to submit a prior authorization denial to an external medical reviewer independent of the MCO. Although all State Medicaid agencies are required to offer State fair hearings as an appeal option, these administrative hearings may be difficult to navigate and burdensome on Medicaid patients. We found that Medicaid enrollees appealed only a small portion of prior authorization denials to either their MCOs or to State fair hearings.

In contrast to State oversight of prior authorization denials in Medicaid managed care, in Medicare managed care (called Medicare Advantage) CMS's oversight of denials by private health plans is more robust. For example, each year CMS reviews the appropriateness of a sample of prior authorization denials and requires health plans to report data on denials and appeals. Further, Medicare Advantage enrollees have access to automatic, external medical reviews of denials that plans uphold at the first level of appeal. These differences in oversight and access to external medical reviews between the two programs raise concerns about health equity and access to care for Medicaid managed care enrollees.

Given these findings, more action is needed to improve the oversight of denials in Medicaid managed care and the safeguards to ensure that enrollees have access to all medically necessary and covered services.

WHAT WE RECOMMEND

We recommend that CMS: (1) require States to review the appropriateness of a sample of MCO prior authorization denials regularly, (2) require States to collect data on MCO prior authorization decisions, (3) issue guidance to States on the use of MCO prior authorization data for oversight, (4) require States to implement automatic external medical reviews of upheld MCO prior authorization denials, and (5) work with States on actions to identify and

	<p>address MCOs that may be issuing inappropriate prior authorization denials. In its response, CMS did not indicate whether it concurred with the first four recommendations; CMS concurred with the fifth recommendation.</p> <p>Complete Report</p>
<p>Advocacy</p> <p>Use DignityMA’s automated system to communicate with Senators Warren and Markey and your Congressperson easily and directly:</p> <p>TAKE ACTION</p>	<p>4. Call to Action</p> <p><i>National Nursing Home Reforms</i></p> <p>TAKE ACTION</p> <p>Last year, the Biden administration proposed critical nursing home reforms. Among the key proposals are a minimum staffing standard for nursing homes and increasing transparency and accountability around ownership and finances. These proposals (https://www.whitehouse.gov/briefing-room/statements-releases/2022/02/28/fact-sheet-protecting-seniors-and-people-with-disabilities-by-improving-safety-and-quality-of-care-in-the-nations-nursing-homes/) are essential for the safety and wellbeing of nursing home residents who all too often suffer daily neglect when their facilities are understaffed. Numerous studies document that without adequate staff, residents routinely sit in soiled clothes and dirty diapers, receive poor hygienic care, and fail to receive necessary medication. Their call bells go unanswered, even in emergencies. Poorly staffed nursing homes are more likely to be cited for abuse, have worse health inspections, and have the lowest quality ratings.</p> <p>It is imperative that we take steps to hold nursing home owners accountable for how they use taxpayer dollars. This includes ensuring all necessary funds go towards direct care. Nursing home residents cannot be left neglected and suffering in inadequate and unacceptable conditions. They fully deserve to be treated with competence, compassion, and with their dignity respected.</p> <p>We are asking you to contact your Congressional Representative in Washington, and ask them to urge the Office of Management and Budget Director, Shalanda Young (shalanda.d.young@omb.eop.gov), to immediately release strong CMS regulations establishing minimum staffing standards in nursing homes, and holding owners and operators accountable for the quality of care they provide and how they spend public dollars. This, plus the resources for meaningful enforcement is essential for ensuring that nursing home residents receive the care they need and deserve.</p> <p>TAKE ACTION</p>
Webinars and Online Sessions	,
Previously posted webinars and online sessions	<p>Previously posted webinars and online sessions can be viewed at:</p> <p>https://dignityalliancema.org/webinars-and-online-sessions/</p>
Nursing Homes	<p>5. Yahoo! Finance</p> <p>July 23, 2023</p> <p><i>Nursing Home Residents Silenced by Fear of Retaliation</i></p> <p>By Elaine Silvestrini</p> <p>People who live in nursing homes endure abuse because they fear they will be punished further if they speak up, according to a new report. Patients in nursing homes are suffering because they too often fear if they complain about problems, they will be punished by staff, according to a horrifying report by the Long Term Care Community Coalition.</p> <p>“Fear of retaliation is a pervasive phenomenon that inflicts significant emotional harm on nursing home residents,” says Eilon Caspi, the principal author of the report, “They Make You Pay.”</p> <p>The report’s threatening title was inspired by a story about fear of retaliation</p>

detering residents at a Florida nursing home from reporting poor care. One resident said staff would “make you pay” by delaying care or sabotaging meals of complaining residents.

Fear causes harm

The report found that patients anticipating retaliation can be even more damaging than actual punishment: “Too often, fear of staff retaliation – the fear itself – prevents residents from voicing concerns and from receiving the care and services to which they are entitled. Ultimately, this inaction leads to unnecessary emotional, psychological, and physical harm to vulnerable residents.”

For example, a study at University of Connecticut Center on Aging on residents’ fear of retaliation in Connecticut long-term care homes included a survey that asked residents, “Do you worry about retaliation if you were to report a complaint or concern?”

According to the report, 23% of nursing home residents said they did worry about retaliation if they were to report a complaint or concern. In addition, 4% reported that they do not want to complain and 1% reported not wanting to get people in trouble.

Also, the Atlanta Long-Term Care Ombudsman reported that 44% of the residents who had seen abuse of other residents did not report it; half of the residents did not report it due to fear of retaliation.

You can share your own experience and find information about how to address long-term care issues, links to federal and state contacts and complaint forms and tools for resident-centered advocacy at <https://nursinghome411.org>.

Nursing home staffing low

The coalition also gathered federal data to reinforce prior reports that nursing homes in the U.S. remain understaffed, which [President Biden has pledged to address](#). According to that report, “Nursing homes are turning over more than half of their staff over a 12-month period. The median total nursing staff turnover is 53%, including 50% RN turnover. Higher turnover is associated with worse quality of care.”

Staffing levels are different in different parts of the country, with the lowest staffing levels in the region that includes Arkansas, Louisiana, New Mexico, Oklahoma, and Texas. The highest staffing levels are found in the region that includes Alaska, Idaho, Oregon, and Washington.

The coalition website also has information about [finding a good nursing home](#). Data about specific nursing homes, including staffing levels, can be accessed at the Center for Medicare and Medicaid Services [Care Compare](#) site.

[Fear of Retaliation](#)

6. Skilled Nursing News

July 21, 2023

Study Reveals Importance of Early Influenza Detection for Nursing Home Residents

By Shelby Grebbin

Nursing homes can cut hospitalizations, emergency room visits, and length of stay at hospitals with rapid on-site testing for influenza, leading to earlier detection of outbreaks and faster treatment.

Conducting rapid on-site flu testing and treatment cut emergency room visits by 22%, hospitalizations by 21%, and hospital length-of-stay by 36%, a recent study shows.

The cost of the rapid tests was around \$12 each, and this investment proved

	<p>beneficial, considering that the average daily hospital stay in the U.S. costs \$2,883, according to researchers. . .</p> <p>The study demonstrated that lowering the threshold for testing and obtaining faster test results led to a higher use of the antiviral medication oseltamivir, more commonly known as Tamiflu, for influenza prevention.</p> <p>Early Influenza Detection</p>
Behavioral Health	<p>7. *Washington Post July 21, 2023 <i>Health insurance is keeping your mind sick and wallet empty</i> By Kate Woodsome Americans are in pain, mentally as well as physically, and inadequate insurance is making it worse. Simply finding a therapist is absurdly difficult, and the care itself is often unaffordable. Here’s proof. Sixty-nine percent of insured Americans under 18 who sought behavioral health care from January 2019 to April 2022 did not receive treatment, a survey from researchers at the University of Chicago revealed this week. Adults didn’t fare much better. Fifty-seven percent who sought care received none. The Mental Health Parity and Addiction Equity Act that Congress passed in 2008 was supposed to prevent this situation by pushing for equal treatment of minds and bodies. Clearly, the law is not working. Congress and the Biden administration need to strengthen it. Health insurers also should recognize it is in their financial interest to improve their coverage of mental health and addiction treatments. . . The Biden administration is off to a good start in recognizing the importance of mental health. It launched the 988 suicide and crisis hotline, it’s pouring hundreds of millions of dollars into training and incentives for clinicians to work in rural and underserved communities, it’s investing in scientific research, and it’s funding wellness programs to reduce burnout among front-line health-care workers. Next, the administration needs to strengthen the Mental Health Parity and Addiction Equity Act with clearer guidelines on how to comply with it. As it stands, the law does not specify what exactly parity looks like for reimbursement rates and provider networks. Insurers take advantage of this vagueness to justify all but the most egregious inequity, Lloyd said. Clarity would enable state and federal insurance regulators to enforce the law. Lloyd said the Office of Management and Budget is reviewing proposed regulations to do this. Separately, the proposed Parity Enforcement Act making its way through Congress would bolster the law by enabling the Labor Department to issue fines for violations. Keeping Your Mind Sick</p> <p>8. Health Affairs Forefront July 19, 2023 <i>Addressing The Mental Health Equity Crisis: Can the Private Sector Lead?</i> By Wizdom Powell Political divisions, racial unrest, and economic uncertainty have surged, producing a perfect storm for a population-level mental health crisis. The number of Americans reporting stress, anxiety, and depression rose sharply during the COVID-19 pandemic and has continued climbing. Increases are reported among all demographic groups, from students (in 2021, 42 percent felt persistently sad or hopeless) to people aged 65-plus (24 percent reported</p>

[feelings of anxiety or repression, more than double the rate prior to COVID-19](#)).

While this emergent crisis is agnostic of demographic factors, data affirm that access to affordable, [high-quality mental health care is inequitably distributed across the U.S.](#) Historically marginalized communities continue to experience a widening disparity between mental health needs and therapeutic intervention and access: The impact of the mental health crisis has hit these communities harder than others.

The scale of this crisis is large, affecting everything from [workplace absenteeism and productivity](#) to [school-based absenteeism and academic performance](#). By any measure, an all-hands-on-deck approach is needed.

Policy thought leaders remind us that [health equity is not a zero sum game](#). Affirming this reminder are data documenting an estimated [\\$278 billion in total excess cost burden from premature death in Black, Indigenous, and other minoritized groups](#) between 2016 and 2020. Such estimates are coincident with evidence highlighting the [association between mental health inequities and worker productivity](#). In other words, the pervasive socioeconomic consequences of America's mental health crisis are shared and represent a significant threat to our collective capacity for growth, innovation, and global competitiveness. . .

Traditionally, we've talked about the mental health crisis in ways that position it largely as a problem to be addressed by the public sector. The challenge with this framing is that it produces an artificial diffusion of responsibility and limits our radical imagination regarding solution pathways. Regarding the colossus of health equity, what has plagued us from moving forward is the fear that this problem is too wicked, too big, too audacious, too hairy to solve. Make no mistake, the problem is massive, but its causes and consequences are clear. Health disparities, or *preventable* differences in the burden of chronic disease and health outcomes, are a driving force behind mental health inequities. Our health equity problem is of our own making, created by artificial caste distinctions, persistent racism, and how we structure our economy and investments in health care; the status of health care disparities is determined, largely, in the ways that the private sector either confronts them or looks away. It is also valuable to recognize that the wicked problem of health inequity is not immutable and that our lack of sustained advancement has more to do with internalized myths of complexity than with our societal capacity. . .

Private sector organizations and leaders need to make solid and measurable commitments to advancing mental health equity. A historic opportunity exists to reframe private sector commitment to mental health equity by aligning corporate social responsibility initiatives with targets set forth in the [United Nation's sustainable development goals \(SDGs\)](#). SDGs provide a universal health equity blueprint for the private sector to address the socioenvironmental challenges like persistent racism, climate change, economic uncertainty, gender inequities, and food insecurity that militate against population-level mental health outcomes. . .

We need ethical and moral courage. Our economic and psychological wellbeing, at a population level, are at stake. We have been far too passive about this challenge, heading towards a collapse that's being ignited by unresolved and unmet mental health challenges. The private sector is equipped and positioned to combat the problem. The solution can't be achieved solely by the federal government and public infrastructures—it's going to be a push, a pull, and a cooperation between public and private sectors that can truly galvanize

	<p>momentum, making mental health care equitable in a way that a just society demands.</p> <p>Mental Health Equity Crisis</p>
<p>Health Topics</p>	<p>9. *New York Times July 22, 2023 <i>How a Drugmaker Profited by Slow-Walking a Promising H.I.V. Therapy</i> By Rebecca Robbins and Sheryl Gay Stolberg The promising [new H.I.V.] drug, then in the early stages of testing, was an updated version of tenofovir. Gilead executives knew it had the potential to be less toxic to patients' kidneys and bones than the earlier iteration, according to internal memos unearthed by lawyers who are suing Gilead on behalf of patients. Despite those possible benefits, executives concluded that the new version risked competing with the company's existing, patent-protected formulation. If they delayed the new product's release until shortly before the existing patents expired, the company could substantially increase the period of time in which at least one of its H.I.V. treatments remained protected by patents. The delayed release of the new treatment is now the subject of state and federal lawsuits in which some 26,000 patients who took Gilead's older H.I.V. drugs claim that the company unnecessarily exposed them to kidney and bone problems. Slow Walking Approval</p> <p>10. NPR Shots July 18, 2023 <i>'Hospital-at-home' trend means family members must be caregivers — ready or not</i> By Kat McGowan For the past four years, Chad Semling has coped with serious illness, including chronic infections, a weakened liver, and a damaged heart. He became a regular visitor at his local hospital in Eau Claire, Wisconsin, where he and his wife, Clare Semling, got to know the downsides of hospital care a little too well: The isolation. Poor sleep, interrupted by bells and alarms. The food. In the spring of 2020, Chad was back at the Eau Claire Mayo Clinic emergency department for a flareup of cellulitis, a skin infection that can be serious. He was dreading yet another hospital stay. Instead, they said he was eligible for a new "hospital-at-home" pilot program that would outfit his house with equipment and send clinicians to make visits. "He was all for it, because he hates being in the hospital," says Clare. She was interested, too. During Chad's stints in the hospital, it would fall upon her to work, care for their two children, and check in on him. It was exhausting. Maybe this would be easier. So, they tried it out, joining one of the fastest-growing experiments in American health care. Hospital-at-home programs are for people sick enough to need the attention a hospital provides, but stable enough to be cared for at home. Research on outcomes is not conclusive, yet, but shows promise that it can provide good care and save health care dollars. But a big question looms: What about the family? Are unpaid, untrained family caregivers ready to take on the responsibility of overseeing a critically ill person at home — even with backup from visiting clinicians? "We've got to look at the consequences for family caregivers," says Susan Reinhard, director of AARP's Public Policy Institute.</p>

	<p>This question is about to become more important. For decades, hospital-at-home was a small-scale experiment. During the COVID pandemic, the idea went mainstream. In November 2020, the federal government changed rules so that hospitals could be paid the same amount to treat patients at home. Today, 290 hospitals in 37 states have signed up.</p> <p>Diagnoses often include chronic obstructive pulmonary disease, heart failure, pneumonia, or as with Semling, an infection. In addition to twice-daily nurse visits and daily telemedicine sessions with a doctor, services like physical therapy or blood tests can be brought to the house. A nurse is available for advice via tablet computer. Oxygen machines, drugs and infusions can be delivered. After Semling fractured his back last summer, he got a Wi-Fi enabled pill box that dispensed painkillers and other meds on schedule.</p> <p>For him, there's no debate. "Being able to be home made all the difference in the world," he says. He sleeps better and heals faster. He's now had five stints with hospital-at-home, and both the Semlings prefer it. But Clare has words of caution for caregivers: "There is a lot of responsibility on your shoulders." . . .</p> <p>Caregiver, or nurse's aide?</p> <p>For a caregiver, hospital-at-home eliminates the hardship that comes with a loved one's stint in the hospital, everything from overpriced parking to hours spent at bedside waiting for a doctor to make rounds. But it brings new concerns.</p> <p>These programs don't ask caregivers to handle medical tasks like dealing with an IV. But they might need to bring glasses of cold water in the middle of the night, help a weak person turn over in bed, change clothes, or get to the bathroom. In the hospital, nursing aids do those tasks. Programs can arrange home health aides for help, but usually for limited hours. It could be part of the reason why between 10 and 62 percent of people turn down the option to participate in these new programs. . .</p> <p>A recent AARP policy briefing delved into the implications. Hospital-at-home has strong potential, but the effects on caregivers need more attention, the report advises. "The family caregivers are completely invisible," says Reinhard of AARP. "They're not turning to wife, daughter, or husband, and saying: Can you handle this? That's the discussion we think needs to happen." The briefing recommends federal policymakers require programs to make sure family members know exactly what will happen and are on board with it. . .</p> <p>The Centers for Medicare & Medicaid, which oversees these programs, is considering adding rules to clarify caregivers' responsibilities. "CMS makes it very clear that during the hospital-at-home stay, hospitals are not to use family members, support persons, or caregivers to provide care that would otherwise fall to nurses or other hospital staff during an inpatient admission," said CMS chief medical officer Lee Fleisher in a statement provided to NPR. "Caregivers should have time to focus on a patient's emotional needs and overall well-being throughout the healing process." In April, an executive order from President Biden also nudged the agency to set clearer expectations.</p> <p>Hospital-at-Home</p>
Federal and State Policy	<p>11. National Conference of State Legislatures July 17, 2023 (updated) <i>America's retirement savings crisis could cost federal and state governments an estimated \$1.3 trillion by 2040</i> America's population is aging at an unprecedented rate. As the elderly</p>

population in the United States continues to grow, it becomes increasingly important that households plan appropriately to maintain their living standards in their retirement years. Most financial advisors recommend an ["income replacement" of 75-80%](#) of the average income between ages 45 to 64, with those below this target being considered economically vulnerable. Unfortunately, a substantial number of American households are not on track to comfortably pay for their retirement. If current trends continue, inadequate retirement savings will [cost states](#) \$334.3 billion in aggregate increased spending by 2040, and \$1.3 trillion in state and federal expenditures combined. Retirement savings shortfalls have significant implications for the quality of life and financial stability of millions of households across the country, as well as the government's fiscal position. In May 2023, The Pew Charitable Trusts and Econsult Solutions published [a report that analyzed how insufficient retirement savings would affect state and federal budgets](#). The following maps and charts illustrate the key findings of this report.

Elderly and Non-Elderly Household Populations for 2020 and 2040

Between 2020 and 2040, the number of households aged 65+ is projected to grow significantly, while the number of working age households is expected to decrease. This map shows the shifting demographics of elderly and non-elderly households by percentage change in each state. The lowest demographic shift is -11% in non-elderly households in Illinois. The highest demographic shift is in elderly households in Nevada, at 105%. Click anywhere on the map for demographic details in each state.

Elderly Household and Income Gaps by State

To maintain the living standards of households during their working years, replacing 75% of a worker's average income (between the ages of 45-64) is [recommended](#). Households that fall below this target replacement rate are considered economically vulnerable. By 2040, economically vulnerable households in the US are projected to fall well below their income replacement target. The chart below illustrates the projected average income of elderly households in 2040, and the annual income gap by household in each state.

Program Costs due to Insufficient Savings by State, 2021-2040 (\$B)

Insufficient retirement savings between 2021 and 2040 will significantly increase state and federal program expenditures for senior-targeted and social assistance programs. The map below shows the taxpayers contributions to federal costs. Click on any state for projected state program costs, state and federal costs combined and individual household costs in each state.

Savings Needed to Close the Retirement Income Gap for Households <\$75,000

Households in the US with an average income below \$75,000 are considered economically vulnerable. The increasing elderly population between 2020 and 2040 and a continuation of current income replacement trends will lead to an increase in vulnerable households and a significant retirement savings gap for those households. The chart below shows the average savings needed to close the retirement income gap based on midpoint assumptions, and the average savings needed to close the income gap with [Saver's Credit Match](#)—a federal program that offers a 50% match for those who qualify. The savings needed to close the retirement income gaps are expressed in annual figures in each state.

Conclusion

The elderly population in the United States is growing at an unprecedented rate,

	<p>while the number of working age households is shrinking considerably. Unfortunately, most Americans—particularly economically vulnerable households—aren’t adequately prepared for retirement. If current trends continue, the average annual income shortfall for elderly households is projected to be more than \$7,000 in 2040. This shortfall would lead to increased pressure on public assistance programs, reduce tax revenue, shift the financial burden to a shrinking population of working-age taxpayers and ultimately could cost state and federal governments \$1.3 trillion by 2040. However, under standard market assumptions, an additional monthly savings of \$140 over a period of 30 years would completely close the retirement savings gap for economically vulnerable households. This amount shrinks to just \$95 per month with the IRS Saver’s Match program.</p> <p>Another policy option some states are turning to is state-facilitated retirement programs, such as auto-IRA programs, to address the retirement savings shortfall. Typically, these programs require employers to either offer their employees retirement savings access through a financial provider, or allow their employees to participate in a state-facilitated retirement savings program. Evidence from the longest operating programs in Oregon, Illinois and California show these plans have received contribution levels that meet or exceed the required monthly savings of \$140. Outside of such programs, even modest levels of accumulated savings can still help vulnerable households achieve greater financial stability, improving the government’s fiscal position and the quality of life for millions of U.S. households.</p> <p>Retirement Savings Crisis</p>
Emergency Preparedness	<p>12. The Conversation July 21, 2023 <i>Is it really hotter now than any time in 100,000 years?</i> By Darrell Kaufman</p> <p>As scorching heat grips large swaths of the Earth, a lot of people are trying to put the extreme temperatures into context and asking: When was it ever this hot before?</p> <p>Globally, 2023 has seen some of the hottest days in modern measurements, but what about farther back, before weather stations and satellites?</p> <p>Some news outlets have reported that daily temperatures hit a 100,000-year high.</p> <p>As a paleoclimate scientist who studies temperatures of the past, I see where this claim comes from, but I cringe at the inexact headlines. While this claim may well be correct, there are no detailed temperature records extending back 100,000 years, so we don’t know for sure.</p> <p>Scientists concluded a few years ago that Earth had entered a new climate state not seen in more than 100,000 years. . . Earth was already more than 1 degree Celsius (1.8 Fahrenheit) warmer than preindustrial times, and the levels of greenhouse gases in the atmosphere were high enough to assure temperatures would stay elevated for a long time. . .</p> <p>Without rapid and sustained reductions in greenhouse gas emissions, the Earth is currently on course to reach temperatures of roughly 3 C (5.4 F) above preindustrial levels by the end of the century, and possibly quite a bit higher. At that point, we would need to look back millions of years to find a climate state with temperatures as hot. That would take us back to the previous</p>

	<p>geologic epoch, the Pliocene, when the Earth’s climate was a distant relative of the one that sustained the rise of agriculture and civilization.</p> <p>Is It Really Hotter</p>										
Dignity Alliance Massachusetts Legislative Endorsements	<p>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</p> <p>Questions or comments can be directed to Legislative Work Group Chair Richard (Dick) Moore at rmoore8473@charter.net.</p>										
Websites											
Previously recommended websites	<p>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 <i>The Dignity Digest</i>.</p>										
Previously posted funding opportunities	<p>For open funding opportunities previously posted in <i>The Tuesday Digest</i> please see https://dignityalliancema.org/funding-opportunities/.</p>										
Websites of Dignity Alliance Massachusetts Members	<p>See: https://dignityalliancema.org/about/organizations/</p>										
Nursing homes with admission freezes	<p>Massachusetts Department of Public Health</p> <p><i>Temporary admissions freeze</i></p> <p>On November 6, 2021 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.</p> <ul style="list-style-type: none"> • 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: <ul style="list-style-type: none"> • 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 <p>Facilities are required to notify residents’ designated family members and/or representatives 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>Updated on May 10 , 2023. Red font – newly added</p> <table border="1"> <thead> <tr> <th>Name of Facility</th> <th>City/Town</th> <th>Date of Freeze</th> <th>Qualifying Factor</th> <th>Star Rating</th> </tr> </thead> <tbody> <tr> <td>Hillside Rest Home</td> <td>Amesbury</td> <td>5/2/2023</td> <td>Cases</td> <td>N/A</td> </tr> </tbody> </table>	Name of Facility	City/Town	Date of Freeze	Qualifying Factor	Star Rating	Hillside Rest Home	Amesbury	5/2/2023	Cases	N/A
Name of Facility	City/Town	Date of Freeze	Qualifying Factor	Star Rating							
Hillside Rest Home	Amesbury	5/2/2023	Cases	N/A							

<p>Massachusetts Department of Public Health Determination of Need Projects</p>	<p>Massachusetts Department of Public Health <i>Determination of Need Projects: Long Term Care</i> 2023 Navigator Homes of Martha's Vineyard, Inc. – Long Term Care Substantial Capital Expenditure Royal Wayland Nursing Home, LLC – Conservation Long Term Care Project 2022 Ascentria Care Alliance – Laurel Ridge Ascentria Care Alliance – Lutheran Housing Ascentria Care Alliance – Quaboag Berkshire Healthcare Systems, Inc. – Windsor Long Term Care Conservation Fairlawn Rehabilitation Hospital-Hospital/Clinic Substantial Capital Expenditure Long Term Centers of Lexington – Pine Knoll – Long Term Care Conservation Long Term Centers of Wrentham – Serenity Hill – Long Term Care Conservation Next Step Healthcare LLC-Conservation Long Term Care Project Royal Falmouth – Conservation Long Term Care Royal Norwell – Long Term Care Conservation Wellman Healthcare Group, Inc 2020 Advocate Healthcare, LLC Amendment Campion Health & Wellness, Inc. – LTC - Substantial Change in Service Heywood Healthcare, Inc. – Hospital/Clinic Substantial Capital Expenditure Notre Dame Health Care Center, Inc. – LTC Conservation 2020 Advocate Healthcare of East Boston, LLC. Belmont Manor Nursing Home, Inc.</p>
<p>List of Special Focus Facilities</p>	<p>Centers for Medicare and Medicaid Services <i>List of Special Focus Facilities and Candidates</i> https://tinyurl.com/SpecialFocusFacilityProgram Updated March 29, 2023 CMS has published a new list of <u>Special Focus Facilities</u> (SFF). SFFs are nursing homes with serious quality issues based on a calculation of deficiencies cited during inspections and the scope and severity level of those citations. CMS publicly discloses the names of the facilities chosen to participate in this program and candidate nursing homes. To be considered for the SFF program, a facility must have a history (at least 3 years) of serious quality issues. These nursing facilities generally have more 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?</p> <ul style="list-style-type: none"> • Include the list of facilities in your area/state when providing information to consumers who are looking for a nursing home. Include an explanation of the SFF program and the candidate list. • Post the list on your program’s/organization’s website (along with the explanation noted above). • Encourage current residents and families to check the list to see if their

facility is included.

- Urge residents and families in a candidate facility to ask the administrator what is being done to improve care.
- Suggest that resident and family councils invite the administrator to a council meeting to talk about what the facility is doing to improve care, ask for ongoing updates, and share any council concerns.
- For long-term care ombudsmen representatives: Meet with the administrator to discuss what the facility is doing to address problems and share any resources that might be helpful.

Massachusetts facilities listed (updated March 29, 2023)

Newly added to the listing

- Somerset Ridge Center, Somerset
<https://somersestridgerehab.com/>
Nursing home inspect information:
<https://projects.propublica.org/nursing-homes/homes/h-225747>
- South Dennis Healthcare
<https://www.nextstephc.com/southdennis>
Nursing home inspect information:
<https://projects.propublica.org/nursing-homes/homes/h-225320>

Massachusetts facilities not improved

- None

Massachusetts facilities which showed improvement

- Marlborough Hills Rehabilitation and Health Care Center, Marlborough
<https://tinyurl.com/MarlboroughHills>
Nursing home inspect information:
<https://projects.propublica.org/nursing-homes/homes/h-225063>

Massachusetts facilities which have graduated from the program

- The Oxford Rehabilitation & Health Care Center, Haverhill
<https://theoxfordrehabhealth.com/>
Nursing home inspect information:
<https://projects.propublica.org/nursing-homes/homes/h-225218>
- Worcester Rehabilitation and Health Care Center, Worcester
<https://worcesterrehabcare.com/>
Nursing home inspect information:
<https://projects.propublica.org/nursing-homes/homes/h-225199>

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

- Charwell House Health and Rehabilitation, Norwood (15)
<https://tinyurl.com/Charwell>
Nursing home inspect information:
<https://projects.propublica.org/nursing-homes/homes/h-225208>
- Glen Ridge Nursing Care Center (1)
<https://www.genesishcc.com/glenridge>
Nursing home inspect information:
<https://projects.propublica.org/nursing-homes/homes/h-225523>
- Hathaway Manor Extended Care (1)
<https://hathawaymanor.org/>
Nursing home inspect information:
<https://projects.propublica.org/nursing-homes/homes/h-225366>
- Medway Country Manor Skilled Nursing and Rehabilitation, Medway (1)
<https://www.medwaymanor.com/>

	<p>Nursing home inspect information: https://projects.propublica.org/nursing-homes/homes/h-225412</p> <ul style="list-style-type: none"> • Mill Town Health and Rehabilitation, Amesbury (14) No website <p>Nursing home inspect information: https://projects.propublica.org/nursing-homes/homes/h-225318</p> <ul style="list-style-type: none"> • Plymouth Rehabilitation and Health Care Center (10) https://plymouthrehab.com/ <p>Nursing home inspect information: https://projects.propublica.org/nursing-homes/homes/h-225207</p> <ul style="list-style-type: none"> • Tremont Health Care Center, Wareham (10) https://thetremontrehabcare.com/ <p>Nursing home inspect information: https://projects.propublica.org/nursing-homes/homes/h-225488</p> <ul style="list-style-type: none"> • Vantage at Wilbraham (5) No website <p>Nursing home inspect information: https://projects.propublica.org/nursing-homes/homes/h-225295</p> <ul style="list-style-type: none"> • Vantage at South Hadley (12) No website <p>Nursing home inspect information: https://projects.propublica.org/nursing-homes/homes/h-225757 https://tinyurl.com/SpecialFocusFacilityProgram</p>																								
<p><i>Nursing Home Inspect</i></p>	<p>ProPublica <i>Nursing Home Inspect</i> Data updated November 2022 This app uses data from the U.S. Centers for Medicare and Medicaid Services. Fines are listed for the past three years if a home has made partial or full payment (fines under appeal are not included). Information on deficiencies comes from a home’s last three inspection cycles, or roughly three years in total. The number of COVID-19 cases is since May 8, 2020, when homes were required to begin reporting this information to the federal government (some homes may have included data on earlier cases). Massachusetts listing: https://projects.propublica.org/nursing-homes/state/MA Deficiencies By Severity in Massachusetts (What do the severity ratings mean?)</p> <table border="0"> <tr> <td># reported</td> <td>Deficiency Tag</td> </tr> <tr> <td>250</td> <td>B</td> </tr> <tr> <td>82</td> <td>C</td> </tr> <tr> <td>7,056</td> <td>D</td> </tr> <tr> <td>1,850</td> <td>E</td> </tr> <tr> <td>546</td> <td>F</td> </tr> <tr> <td>487</td> <td>G</td> </tr> <tr> <td>31</td> <td>H</td> </tr> <tr> <td>1</td> <td>I</td> </tr> <tr> <td>40</td> <td>J</td> </tr> <tr> <td>7</td> <td>K</td> </tr> <tr> <td>2</td> <td>L</td> </tr> </table>	# reported	Deficiency Tag	250	B	82	C	7,056	D	1,850	E	546	F	487	G	31	H	1	I	40	J	7	K	2	L
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Nursing Home Compare	<p>Centers for Medicare and Medicaid Services (CMS) <i>Nursing Home Compare Website</i> Beginning January 26, 2022, the Centers for Medicare and Medicaid Services (CMS) is posting new information that will help consumers have a better understanding of certain staffing information and concerns at facilities. This information will be posted for each facility and includes:</p> <ul style="list-style-type: none"> • 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. <p>Posting this information was required as part of the Affordable Care Act, which was passed in 2010. In many facilities, staffing is lower on weekends, often meaning residents have to wait longer or may not receive all the care they need. High turnover means that staff are less likely to know the residents, recognize changes in condition, or implement preferred methods of providing care. All of this contributes to the quality-of-care residents receive and their quality of life. https://tinyurl.com/NursingHomeCompareWebsite</p>
Data on Ownership of Nursing Homes	<p>Centers for Medicare and Medicaid Services <i>Data on Ownership of Nursing Homes</i> CMS has released data giving state licensing officials, state and federal law enforcement, researchers, and the public an enhanced ability to identify common owners of nursing homes across nursing home locations. This information can be linked to other data sources to identify the performance of facilities under common ownership, such as owners affiliated with multiple nursing homes with a record of poor performance. The data is available on nursing home ownership will be posted to data.cms.gov and updated monthly.</p>
Long-Term Care Facilities Specific COVID-19 Data	<p>Massachusetts Department of Public Health <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>Table of Contents</p> <ul style="list-style-type: none"> • COVID-19 Daily Dashboard • COVID-19 Weekly Public Health Report • Additional COVID-19 Data • CMS COVID-19 Nursing Home Data
DignityMA Call Action	<ul style="list-style-type: none"> • 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
Access to Dignity Alliance social media	<p>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</p>

	Website: www.DignityAllianceMA.org		
<p>Participation opportunities with Dignity Alliance Massachusetts</p> <p>Most workgroups meet bi-weekly via Zoom.</p> <p>Interest Groups meet periodically (monthly, bi-monthly, or quarterly).</p> <p>Please contact group lead for more information.</p>	Workgroup	Workgroup lead	Email
	General Membership	Bill Henning Paul Lanzikos	bhenning@bostoncil.org paul.lanzikos@gmail.com
	Behavioral Health	Frank Baskin	baskinfrank19@gmail.com
	Communications	Pricilla O'Reilly Lachlan Forrow	prisoreilly@gmail.com lforrow@bidmc.harvard.edu
	Facilities (Nursing homes)	Arlene Germain	agermain@manhr.org
	Home and Community Based Services	Meg Coffin	mcoffin@centerlw.org
	Legislative	Richard Moore	rmoore8743@charter.net
	Legal Issues	Jeni Kaplan	jkaplan@cpr-ma.org
	Interest Group	Group lead	Email
	Assisted Living and Rest Homes	In formation	
	Housing	Bill Henning	bhenning@bostoncil.org
	Veteran Services	James Lomastro	jimlomastro@comcast.net
	Transportation	Frank Baskin Chris Hoeh	baskinfrank19@gmail.com cdhoeh@gmail.com
	Covid / Long Covid	James Lomastro	jimlomastro@comcast.net
	Incarcerated Persons	TBD	info@DignityAllianceMA.org
The Dignity Digest	<p>For a free weekly subscription to <i>The Dignity Digest</i>: https://dignityalliancema.org/contact/sign-up-for-emails/ 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"> Dick Moore <p>Special thanks to 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 The Dignity Digest or have questions or comments, please submit them to Digest@DignityAllianceMA.org.</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.</i></p> <p><i>Previous issues of The Tuesday Digest and The Dignity Digest are available at: https://dignityalliancema.org/dignity-digest/</i></p> <p><i>For more information about Dignity Alliance Massachusetts, please visit www.DignityAllianceMA.org.</i></p>			