

# Dignity The Dignity Digest

Issue # 164 November 28, 2023

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

\*May require registration before accessing article.

#### Spotlight

Penny Shaw is a nursing home resident, a national advocate for nursing home reform, and Dignity Alliance Massachusetts supporter.



#### **Paralysis and Positioning**

By Penny Shaw

November 21, 2023

I have Guillain-Barre syndrome - a neuromuscular disorder - in my case with quadriparesis: paralysis of the legs and weakness of my upper extremities.

I have no control over my legs. I cannot stand or walk. I cannot bend or straighten them. When I am in bed I cannot turn or move myself in any way. Aides who provide my care must do all the positioning I need.

On the 7-3 shift I must be turned back and forth to be washed, and then turned back and forth to be dressed. Finally, to be transferred safely to my wheelchair - I must be positioned completely flat. This is important because I will be positioned in my wheelchair exactly the way I am in my sling. If straight up in the sling straight up in my chair. If tilted in bed then tilted in the sling and in my chair. This latter would cause my right leg to be twisted painfully on the footbox.

CNAs complain about positioning me. They make comments like "It's my shoulder." or "It's my back." I realize that my care is demanding physically. Boosting me. Turning me. Pulling me flat. All these tasks require my aides to use their muscles. But this care is essential to my safety and comfort.

Once, near the end of my 7-3 routine - when it was time to position me flat for the transfer to my wheelchair - one CNA pushed me so hard to the right I was flipped on my shoulder and not flat at all. My primary CNA then had to start the whole process over - pulling me flat again. Unnecessary extra physical work for her.

This CNA, who had to pull me flat again, was really nasty to me - telling me I liked injuring my CNAs! I told her it wasn't true. That I have no choice. That I am paralyzed and cannot position myself. That - if I am not transferred correctly - my right leg will be twisted in pain. She responded that I have a choice. I can choose to be in pain so that she will not be in pain from pulling me flat. She told me that I don't care about my aides.

One morning - when none of my regular 7-3 CNAs were working - a CNA who knows me well was asked to come to my unit to provide my care. She worked alone going from one side of my bed to the other. Only when it was time for my transfer did she get another aide to assist her. She never complained about any part of my care. So, personality has a lot to do with how I'm treated.

In the evening when I am put to bed I need to be positioned completely flat, not tilted to the right at the edge. If I am not flat my whole body is turned

and my right leg will slide off my bed. One night two agency CNAs did not understand this - and left me in bed, hanging off the right dangerously.

I grabbed the side rail on the right and hung on so I wouldn't slide off. I turned my call light on for help but no one answered. Luckily, I was able to reach my cell phone and called my local police for assistance. An officer contacted my nurse who came in and rescued me.

One evening I was being put in bed by an aide who knows me and provides excellent care. Assisting was a young inexperienced fellow that many of us - residents and staff - had previously had problems with. I asked him politely to push my legs over a little - so they'd be straight and I would not be in pain. Instead of doing this he walked out of my room and did not return. Being a 2-person-assist, my aide went out and got my nurse to help her in finishing my care.

My worst experience with an aide - who didn't like positioning me - is the following. I was in bed and asked her to push my legs over to the right. She angrily yelled at me "Push yourself!". "Push yourself!". While yelling at me she pushed both my legs off my bed - such that they were hanging off at the knees. If the aide on the other side had not grabbed both legs - and put them back on my bed - I surely would have slid off to the floor. I could have been injured or worse.

I considered this an assault. So, the next day I emailed my contact person at our local police station. He replied he could send an officer to come to my facility to write up the incident. He also told me I had the option to press charges. I decided not to. Instead, I informed my director of nursing that I would never permit this aide to provide care for me again. My DON made sure she was no longer assigned to my unit.

What can I do for my aides? I cannot stay in bed and not have a lifegetting pressure sores. I cannot have unsafe transfers. I cannot be left flat in bed at night and slide off onto the floor. CNAs have a choice. They can ask to be assigned to a different unit. But I personally have no other choices. I need this care and have been getting it in my facility for 21 years now.

The purpose of this piece is not to malign my caregivers - but to point out that CNA training should include the needs of individuals like me with paralysis.

And in closing I share that - in spite of my paralysis - I have a good life. I drive an electric wheelchair to go outside into my community. I can feed myself. I eat out in restaurants with friends. I read. I use a computer. I shop with only a little assistance from store staff or other customers - who hand me merchandise I can't reach.

Quotes

The recent arrival of thousands of immigrants has put an unprecedented strain on the emergency shelter system. But make no mistake — that system was broken to begin with. And not by accident, but by design: To avoid precisely the kind of overload our shelters are seeing right now, the

The Dignity Digest

Issue # 164

Page 2

November 28, 2023

system has long been set up to make sure not everyone who needs help gets it.

That is a <u>choice</u>, not an act of nature. And we can choose to change it.

For some families, the right to shelter isn't a right at all (\*Boston Globe, November 25, 2023 (updated))

"Staffing shortages, high employee turnover, a rise in the use of temporary staffing agencies, a shortage of inspectors, and a backlog of complaint investigations have all impacted care [in nursing homes].

Lori Smetanka, executive director of the National Consumer Voice for Quality Long-Term Care, <u>Tennessee sees spike in nursing homes battling serious problems since COVID-19 pandemic</u>, \*The Tennessean, November 26, 2023

"[Personnel from temporary staffing agencies] didn't know what they were supposed to be doing. We've had several residents say they don't want (the staff) even touching them because they don't know how to turn them properly. They don't know how to work the equipment."

Lori Smetanka, executive director of the National Consumer Voice for Quality Long-Term Care, <u>Tennessee sees spike in nursing homes battling serious problems since COVID-19 pandemic</u>, **The Tennessean**, November 26, 2023

"Every doll tells a <u>story</u> and every doll represents somebody, who has been through an incredible journey. For most of the kids, they will never see another kid that looks like they do, let alone a toy."

Amy Jandrisevits, the founder of <u>A Doll Like Me</u>, <u>More Than Just a Toy</u>

<u>Company: The Powerful Representation Message Behind A Doll Like Me</u>

<u>Exclusive</u>, **Nice News**, September 8, 2022

"When I am with others who have a hearing loss or who are deaf as well — it allows me to forget that there is something different about me and I can just be me. I hope to create this kind of environment for the girls, where they can forget that they have something different than everyone else and they can just be themselves."

Alexis "Lexi" Marman, who is deaf and a co-leader of Girl Scout Troop 8542 whose members are deaf or hard-of-hearing, <u>California Girl Scout Troop</u>

<u>Brings Members of the Deaf Community Together</u>, **Nice News**, November 25, 2023

In December 2022, 4 in 10 adults with disabilities (40 percent) reported experiencing unfair treatment in health care settings, at work, or when applying for public benefits because of their disabilities or other personal characteristics in the previous year. Adults with disabilities were more than twice as likely as adults without disabilities to report unfair treatment in one or more of these settings (40 percent versus 18 percent).

Four in Ten Adults with Disabilities Experienced Unfair Care Settings, at Work, or When Applying for Public Benefits in 2022 (Urban Institute, October 11, 2023)

"I love my friends who are the same age as me, but I adore meeting and knowing people of all ages. It keeps me more engaged with the world. It makes me feel part of a real community, a larger family."

Robyn Ringler, who is 66 and has opted not to move to an age-restricted housing complex, <u>When the Neighbors Are All Older, Too</u> (New York Times (free access), November 25, 2023)

"Nursing home residents who had COVID-19 experienced new decline in their function and needed substantially more help with daily activities after their acute infection period, lasting for months. This places an even greater burden on nursing home staff, who are already stretched thin."

Lona Mody, MD, interim chief of geriatrics and palliative medicine at UM Medical School, <u>Long COVID patients demand 9 months of ADL support from nursing home staff</u>, McKnights Long Term-Care News, November 27, 2023

"We recognize how important it is to support the independence of customers with disabilities by ensuring the proper care of mobility devices throughout their journey with us."

The Dignity Digest

Page 4

American Airlines' statement referencing wheelchair incident, <u>Buttigleg</u> <u>promises to investigate wheelchair incident from viral video</u>, \*Washington Post, November 22, 2023

"I think a lot of people think compliance with the building code is compliance with the fair housing laws Many are surprised by the additional requirements under the fair housing laws." A number of laws give people with disabilities a right to equal housing — like the Americans with Disabilities Act, the federal Fair Housing Act, the New York State Human Rights Law, and the New York City Human Rights Law.

Cori Rosen, a lawyer at Rosenberg & Estis, <u>The Cost of Being Disabled in New York City Housing</u>, \*New York Times, October 31, 2023

She lucked out when an acquaintance told her about the Nursing Home Transition and Diversion waiver program, which provides housing vouchers to people with disabilities who are transitioning out of nursing homes, allowing her to stay in the apartment at an even lower out-of-pocket cost. But when she wanted to move to a larger space, she said it was difficult to find another accessible apartment that accepted vouchers, so she stayed.

<u>The Cost of Being Disabled in New York City Housing</u>, \*New York Times, October 31, 2023

"People with vision disabilities held in jails and prisons should not be subjected to a higher risk of harm or exposed to greater restrictions than their sighted peers. They should not be denied trained aides, or accessible technology and materials that allow them to participate in work, education, and recreation programs."

Assistant Attorney General Kristen Clarke of the U. S. Justice Department's Civil Rights Division, <u>Justice Department Secures Agreement with Arizona Prison System Resolving Discrimination Against Incarcerated People with Vision Disabilities</u>, **U. S. Department of Justice**, November 16, 2023

"There are only four kinds of people in the world: those who have been caregivers, those who are currently caregivers,

those who will be caregivers, and those who will need caregivers."

Former First Lady Rosalynn Carter, <u>Supporting Family Caregivers: A Key Issue</u> <u>for ACL and for Our Time</u>, **Administration on Community Living**, November 20, 2023

Union Home Health Care Services, LLC, [Worcester, MA] allegedly received more than \$1.6 million from MassHealth for services not rendered, not medically authorized, and based on fraudulent documentation.

<u>Worcester-Based Home Care Company and Its Managers Indicted For \$1.6</u> <u>Million Medicaid Fraud Scheme</u>, **Office of the Attorney General,** November 17, 2023

### Dignity Alliance participants say . . .

Letter to the editor (Boston Globe):

Where is the Justice for Nursing Facility Residents after their COVID Catastrophe?

It is just that Maura Healey created an Office of the Veteran

Advocate and located it in her Cabinet. 78 veterans died at the Holyoke

facility in 2020, "in one of the most notorious and deadly COVID-19 outbreaks in the country."

But where is the Cabinet-level Office for Nursing Facility Residents, to get them the safety they need? Some 8,800 long-term care residents died of COVID-19 in the first year—"a staggering 1 in 5 of all the people living in senior care sites before the pandemic," according to a 2021 article in the Boston *Globe*. At one time Massachusetts had the worst nursing facility death toll in the country. Charlie Baker, then Governor, was warned early at a top-level MIT meeting that residents--40 percent of whom were over 85--should get protective equipment *first*, but Baker sent it to hospitals, which had better access. Even now, when everyone knows that understaffing maims and kills, only 26% (92 homes) meet the state's inadequate standard of 3.58 hours of attention per person per day. Elder Affairs used to be in the Cabinet and should be again. It is high time to treat our most vulnerable and impoverished elders with appropriate care.

Sincerely,

Margaret Morganroth Gullette

Newton

#### Opportunity for Comment

#### **Massachusetts Broadband Institute**

Massachusetts Internet for All Plan

As the state's leading agency for broadband and connectivity, MBI is dedicated to bringing affordable, high-speed internet to every person in Massachusetts. The <u>Bipartisan Infrastructure Law</u> has already allocated \$145 million to Massachusetts to expand high-speed internet access and digital equity programming across the state. The first step to deploying these funds is developing a strong plan, informed by organizational stakeholders and residents of the Commonwealth. Over the last year, MBI has <u>led a planning effort</u> that has resulted in the development of two guiding planning documents — a Statewide Digital Equity Plan and what is known as the Initial

The Dignity Digest Issue # 164 Page 6 November 28, 2023 www.DignityAllianceMA.org

Proposal for the Broadband Equity, Access, and Deployment (BEAD) Program. These two documents create the Massachusetts Internet for All Plan.

#### Public Comment Period: Nov. 13 - Dec. 15

Now that our planning documents have been drafted, we want to hear from you! MBI is collecting input from residents of Massachusetts to make sure we got the plan right. Your input is crucial during this public comment period as we want to understand your experiences and how we can enhance them to meet the needs of all Commonwealth residents. Below, you'll find the executive summary, a link to the Comment Form where you can provide us your feedback, and tips for submitting a helpful comment. You can provide feedback on any portion of whichever document(s) you read.

**Click to View Executive Summary PDF (English)** 

**Online Comment Form** 

MBI will also welcome typed or written public comments using this **printable form** which can be mailed to:

**Massachusetts Broadband Institute** 

**Attn: MBI Public Comment** 

75 North Drive

Westborough, MA 01581

Guide to news items in this week's *Dignity Digest* 

#### **Assisted Living**

What to Know About Assisted Living (KFF, November 20, 2023)

#### **Behavioral Health**

What Rosalynn Carter understood about mental health (STAT News, November 21, 2023

#### **Public Policy**

For some families, the right to shelter isn't a right at all (\*Boston Globe, November 25, 2023 (updated))

<u>Governor Healey, Attorney General Campbell, Auditor DiZoglio Appoint</u>
<u>Colonel Robert Notch as Veteran Advocate</u> (Office of the Attorney General, November 14, 2023)

#### Caregiving

**Health Affairs Sunday Update,** November 26, 2023: See "Caregiving" section for various links

Supporting Family Caregivers: A Key Issue for ACL and for Our Time

(Administration on Community Living, November 20, 2023)

#### **Elder Abuse**

<u>The OGs of Elder Justice: Jacque Gray & Cynthia LaCounte</u> (National Center on Elder Abuse (podcast), November 20, 2023)

<u>The OGs of Elder Justice: Georgia Anetzberger</u> (National Center on Elder Abuse (podcast), November 10, 2023)

#### Medicare

<u>UnitedHealth pushed employees to follow an algorithm to cut off Medicare</u> <u>patients' rehab care</u> (\*Boston Globe, November 14, 2023)

#### Medicaid

<u>Worcester-Based Home Care Company and Its Managers Indicted For \$1.6</u> <u>Million Medicaid Fraud Scheme</u> (Office of the Attorney General, November 17, 2023)

#### **Disability Topics**

International Day of Persons with Disabilities (National Today, Undated)

The Dignity Digest Issue # 164 Page 7 November 28, 2023 www.DignityAllianceMA.org

California Girl Scout Troop Brings Members of the Deaf Community Together (Nice News, November 25, 2023)

<u>Buttigleg promises to investigate wheelchair incident from viral video</u> (\*Washington Post, November 22, 2023)

<u>The Cost of Being Disabled in New York City Housing</u> (\*New York Times, October 31, 2023)

Four in Ten Adults with Disabilities Experienced Unfair Care Settings, at Work, or When Applying for Public Benefits in 2022 (Urban Institute, October 11, 2023)

<u>More Than Just a Toy Company: The Powerful Representation Message</u> <u>Behind a Doll Like Me — Exclusive</u> (Nice News, September 8, 2022)

#### **Aging Topics**

When the Neighbors Are All Older, Too (New York Times (free access), November 25, 2023)

<u>Americans Aging with Disabilities Are More Likely to Have Multiple Chronic Conditions</u> (Institute on Disability – University of New Hampshire, July 7, 2023)

#### **Persons Who Are Incarcerated**

<u>Justice Department Secures Agreement with Arizona Prison System Resolving Discrimination Against Incarcerated People with Vision Disabilities</u> (U. S.

**Department of Justice,** November 16, 2023)

#### **From Out of State**

<u>Four takeaways from a probe into residential care facilities</u> (The Maine Monitor, November 26, 2023)

<u>Tennessee sees spike in nursing homes battling serious problems since</u> <u>COVID-19 pandemic</u> (The Tennessean, November 26, 2023)

### Webinars and Other Online Sessions

#### 1. White House

November 30, 2023, 2:00 p.m.

White House Office of Public Aging and Disability Communities Engagement Call
Kevin Lavery, Associate Director of the President's Commission on White House
Fellows, will provide information about the White House Fellows Class of 20242025 application. Please submit any questions you have via the Zoom
registration page.

2. The Stanford Center on Longevity - The Longevity Book Club November 30, 2023, 2:00 p.m.

A Conversation with MT Connolly

In *The Measure of Our Age*, elder justice expert and MacArthur "genius" grant recipient, M.T. Connolly investigates the systems we count on to protect us as we age.

Weaving first-person accounts, her own experience, and investigative reporting, she exposes a reality that has long been hidden and sometimes actively covered up. But her investigation also reveals reasons for hope within everyone's grasp. Connolly's strategies and action plans for navigating the many challenges of aging will appeal to a wide range of readers—adult children caring for aging parents; policymakers trying to do the right thing; and, should we be so lucky as to live to old age, all of us. This book transforms how we think about aging. Register now!

3. Harvard Joint Center for Housing Studies

Thursday, November 30, 2023, 4:00 p.m.

Growing Unmet Need for Housing for Older Adults

The Dignity Digest Issue # 164 Page 8 November 28, 2023 www.DignityAllianceMA.org

Over the next ten years, the US population over the age of 75 will increase by 45 percent, from 17 million to nearly 25 million. The growth is widespread, across urban, suburban, and rural communities, and sharpest among the baby boomers who will begin entering their 80s in this decade.

As the population of older adults swells, so too does demand for housing that is both affordable and able to accommodate their changing needs. Millions of older adults are cost burdened, and homelessness is on the rise. Looking forward, the urgent need for affordable housing will continue to grow, not only because of the increasing number of older adults, but because of widening inequality and the challenge of providing both housing and care for this surging population. Alarmingly, the people most likely to need care and supportive services as they age are those with low and moderate incomes. The need is only growing, as is the urgency to act.

A panel discussion with:

- Mark Miller, Reuters (Moderator)
- Elizabeth Chen, Massachusetts Secretary of Elder Affairs
- Robert Kramer, Co-founder and Strategic Advisor, National Investment Center for Seniors Housing & Care (NIC)
- Jennifer Molinsky, Project Director, Housing an Aging Society Program, Harvard Joint Center for Housing Studies
- Meghan Rose, General Counsel and Chief Government Affairs Officer, LeadingAge California

#### 4. Health Affairs

Tuesday, December 5, 2023, 11:00 a.m. to 2:00 p.m. *Health Affairs Briefing: Global Lessons From COVID-19* 

The December 2023 issue of *Health Affairs* explores lessons learned around the globe from the COVID-19 pandemic.

Papers in the issue cover topics ranging from how modeling was used to respond to the pandemic, how global and national health inequities emerged and were addressed, and how countries attempted to protect their most vulnerable residents.

You are invited to join us on **Tuesday, December 5, 11:00 a.m. – 2:00 p.m.** (Eastern), for a virtual forum at which authors from around the world will present their work, engage in discussions, and answer questions on these important issues.

Featured speakers are:

- Esra Eren Bayindir, Senior Research Fellow, University of Hamburg, Hamburg Center for Health Economics
- Bernard Black, Nicholas D. Chabraja Professor, Northwestern University
- Ashley Fox, Associate Professor, Department of Public Administration & Policy, University at Albany, State University of New York
- Cesar Gonzalez-Gonzalez, Professor and Researcher, University of Colima
- Cristian A. Herrera, Senior Health Specialist, Latin America and Caribbean Region, World Bank
- Peter Hotez, Dean, National School of Tropical Medicine, Baylor College of Medicine
- Mark Jit, Professor of Vaccine Epidemiology, Head of the Department of Infectious Disease Epidemiology & Dynamics, and Codirector for the Global Health Economics Centre, London School of Hygiene and Tropical Medicine; Health Affairs Theme Issue Adviser

- Pedro Bernal Lara, Health Economist, Interamerican Development Bank
- Tse Yang Lim, Postdoctoral Research Fellow, Center for Communicable Disease Dynamics, Harvard T.H. Chan School of Public Health
- Malvikha Manoj, Associate, Johns Hopkins Bloomberg School of Public Health
- Corrina Moucheraud, Associate Professor, Department of Public Health Policy & Management; Codirector, Global Center for Implementation Science, New York University School of Global Public Health; Health Affairs Theme Issue Adviser
- David Ridley, Professor of the Practice and Dr. and Mrs. Frank A. Riddick, Jr.
   Research Fellow, Duke University Fugua School of Business
- Adolfo Luis Rubinstein, Founder and General Director, Institute for Clinical Effectiveness and Health Policy (IECS)
- Jennifer Seager, Associate Professor, Milken Institute School of Public Health, George Washington University
- Rory Smith, Research and Investigation Manager, Brown University
- Margaret Winchester, Senior Editor, Health Affairs
- Others to be announced

Online details to be shared with registrants no later than 24 hours before the event.

#### Register

#### 5. KFF

Tuesday, December 5, 2023, 12:00 p.m.

The Long-Term Care Crisis—Why Few Can Afford to Grow Old in America

A virtual conversation about "Dying Broke," based on joint investigation with The New York Times into America's long-term care crisis and what can be done to mitigate its growing financial and emotional toll.

Moderator

**Jordan Rau**, a senior correspondent at KFF Health News and co-author of "Dying Broke," will moderate the conversation.

**Panelists** 

**Reed Abelson** is a healthcare reporter at The New York Times and co-author of the "Dying Broke" series. She covers the business of health care, focusing in particular on health insurance and how financial incentives affect the delivery of medical care.

**Robert Ingenito** is caring for his 93-year-old father in the New York City suburbs. Robert cared for his father at home for five years, which required him to cut his work schedule to about 20 hours a week. Recently, his father's growing care needs required Robert to move him into an assisted living facility.

**Anne Tumlinson** is the founder of Daughterhood, which provides support to family caregivers by connecting them to information and other members with caregiving experiences. She is also the founder and CEO of ATI Advisory and has spent the last two decades improving how America cares for its frailest, most vulnerable older adults.

Angela Jemmott, along with her siblings, is helping care for her mother in Sacramento, California, so that she can remain in her home. She also is a volunteer for Hand in Hand, a national nonprofit network of employers of nannies, housecleaners and home attendants working for dignified and respectful working conditions that benefit the employer and worker alike.

To learn more about America's long-term care crisis, check out the <a href="Dying Broke">Dying Broke</a> project. Part one of the series examines America's high long-term care costs, including how they compare to costs in other countries. Part two examines the high costs and profits of assisted living facilities. Part three looks at the shortcomings of long-term care insurance. **RSVP** 6. The Green House Project – Center for Innovation Thursday, December 7, 2023, 2:00 p.m. Change the Incentives, Change the System: A Green House Medicaid Case Study All too often, people ask us the same question: Why aren't there more Green House homes? There's no simple answer, but a recurring theme is that the financial incentives in the long-term care system are misaligned, favoring the status quo and stifling new innovation. Jill Wilson, CEO of Green House partner organization Otterbein, recently worked to change that in her home state of Ohio. Join us to learn how advocates, providers, and lawmakers in the Buckeye State were able to achieve Medicaid rate incentives for operators of small-home nursing communities — and how changemakers across the nation can use the same strategies to encourage new alternatives in their home states. **Register Now** Previously posted webinars and online sessions can be viewed at: Previously posted webinars https://dignityalliancema.org/webinars-and-online-sessions/ and online sessions **Assisted Living** 7. KFF November 20, 2023 What to Know About Assisted Living By Jordan Rau Are you confused about what an assisted living facility is, and how it differs from a nursing home? And what you can expect to pay? Here's a guide to this type of housing for older people. What is assisted living? Assisted living facilities occupy the middle ground of housing for people who can no longer live independently but don't need the full-time medical supervision provided at a nursing home. They might be right for those who have trouble moving about, bathing, eating, or dressing, or who have Alzheimer's disease or other forms of dementia. Assisted living facilities can look like luxury apartments or modest group homes, but they are staffed with aides who can help residents take a shower, get out of bed, get to the dining room, take medications, or help with other daily tasks and

Assisted living facilities can look like luxury apartments or modest group homes, but they are staffed with aides who can help residents take a shower, get out of bed, get to the dining room, take medications, or help with other daily tasks and needs. Meals, activities, and housekeeping are usually provided. Some facilities have trained nurses on-site, but in many states the facilities are not required to have them at the ready, or at all. Popular buildings — or specialized units within them, such as ones for dementia — have waiting lists.

"The key is to start early," said Eilon Caspi, an assistant research professor at the University of Connecticut. "You don't want to wait for the crisis and then have 24 hours to make a decision."

#### How can I know how much assisted living will cost me?

The monthly costs to live in a facility generally range from \$3,000 to \$12,000 or more. Charges are frequently broken into two components: rent and a care plan. Rents are set similarly to the way landlords establish them for apartments, with larger units in more expensive regions having higher rents and rent concessions being more likely when many units are unoccupied.

The Dignity Digest Issue # 164 Page 11 November 28, 2023 www.DignityAllianceMA.org

The costs of care plans are based on how much assistance the facility thinks residents will need, at least when they first move in. Most of them assign residents a "level" or "tier" based on the extent of their needs, but some will itemize charges for specific services. It's like the difference between a prix fixe and an à la carte menu (except you don't get to choose which approach you prefer within each facility). Assisted living units or facilities devoted to dementia residents are more likely to set one comprehensive price, though many have tiers.

Make sure the facility's assessment reflects what the resident will need, or it might increase the price if it is providing more assistance than expected. Check if meals are priced separately.

#### What charges might catch me by surprise?

Facilities often have nonrecurring initial charges, like move-in fees or "community fees." You should ask whether there are extra charges for things residents might need or use, like nurse visits, cable television, or other kinds of assistance; such charges can pile up quickly if they're not detailed as included in the care plan. Some places even charge more if you get medications from a pharmacy other than the one they have a business relationship with. It's worth checking a few months after moving in to see if the care plan is more than the resident needs. If so, ask for the price to be lowered to remove services that aren't being used.

### Is it better to go with a facility that charges a set monthly amount or one that bills for each service?

If you want predictability in your monthly bill, you're safer with a facility that is all-inclusive or that charges by tiers or bundled services. That's also true if you need assistance with many things. If you don't need a lot of help, à la carte may be better. Some facilities have an independent-living wing or a program with à la carte pricing, which may be best for those who need only sporadic assistance. If you need more help as time goes on, you can transition to the assisted living section or program and get a care bundle.

#### What happens when a resident ages and becomes frailer?

Care plans for those needing the most assistance can be double or triple the cost of those for the most independent residents. Ask the facility to explain what causes price increases. Be honest with yourself, and the facility, about what you can afford when the bill rises, because it's going to. "You've got to understand your future is coming," said Karen Van Dyke, a certified senior adviser in San Diego who helps families find the right facility for them.

Also make sure you understand the maximum level of care the place can provide. If you require more, the home may make you move out. For instance, some places will care for people who have occasional lapses of memory or disorientation but not those whose dementia causes delusions, agitation, or aggression. There are fewer legal protections against evictions in assisted living facilities than in nursing homes. Be realistic about what you need: No one wants to move into a nursing home, but it's dangerous for residents to stay in an assisted living facility that can't take care of them.

#### What happens if I run out of money?

You may have to leave. Most assisted living facilities are for-profit, and they have no legal obligation to keep the indigent. About 1 in 5 facilities accept Medicaid to help pay for the cost of providing care, but Medicaid doesn't cover rent at assisted living facilities, so even then you may be forced out. Some states

The Dignity Digest Issue # 164 Page 12 November 28, 2023 www.DignityAllianceMA.org

or counties will help cover the cost of housing if you have no savings and little retirement income, so it's worth finding out if that's available. (Call your local <u>Area Agency on Aging</u> for assistance.) Some facility owners will accept lower fees for longtime residents, but they are the exception.

#### How can I find out how good a facility is?

While it's easy to get wowed by fancy dining options, sparkly chandeliers, and other building amenities, none of those are markers of quality care. If you're considering multiple facilities, ask about the ratio of residents to aides — on nights and weekends as well as weekdays — and whether there are licensed nurses in the building, and when they are there.

The person running the facility is often known as the administrator or director. Ask about how often this position has turned over. If a facility has churned through several administrators in a few years, that's a troubling sign about the quality of its management and owners.

#### Which are better — nonprofit or for-profit assisted living facilities?

Researchers have found that for-profit facilities in Minnesota and Florida are more likely to be cited for violating state health regulations, but there's not solid evidence nationwide. There are good and bad facilities of both ownership types: A small for-profit residence with an engaged owner on-site may provide better care than a mediocre nonprofit. Be aware that nonprofits generally aren't less expensive than for-profits; while they don't have to provide returns to investors, they do run like a business and need to earn more than they spend each month for capital improvements and to avoid cash flow problems. Nonprofits often use the same pricing methods as for-profits, and many charge more.

#### What should I look for during a tour?

Kristine Sundberg, executive director of <u>Elder Voice Advocates</u> in Minnesota, a coalition of family members, tells people to watch how residents engage with a facility's workers. "Are they active and busy with things, or are they slouched over in a chair, being ignored?" she said. You might aim to visit on weekends, when staffing is often lightest. Ask the facility if it will let families put cameras in residents' rooms so you can keep tabs on them remotely.

#### Who can help me?

Along with consumer groups like Sundberg's, some of the most knowledgeable independent experts are <u>long-term care ombudsmen</u>, who are federally funded advocates for residents of nursing homes and other facilities for older people. <u>Every state</u> has such a program with advocates assigned to particular regions. An Area Agency on Aging is another source. These agencies are local government or nonprofit organizations that each state designates to help older people. They can help you understand your financial options and find facilities. You can locate your agency via https://eldercare.acl.gov/Public/Index.aspx.

If you want to check out a facility's history of infractions, find the state agency that licenses assisted living facilities. In some states, it's part of the health department, while others assign this job to their human service or social service agency. A report is written up after a facility is inspected. Licensing agencies may publish inspection reports on their websites, although they aren't always easy to find. It's a red flag if a facility is repeatedly cited for the same problem.

#### Behavioral Health

#### 8. STAT News

November 21, 2023

What Rosalynn Carter understood about mental health

By Phyllis Vine

The Dignity Digest Issue # 164 Page 13 November 28, 2023 www.DignityAllianceMA.org

Decades ago, [Rosalynn Carter] took bold stances on mental health topics that, today, have become conventional wisdom: Mental health is health, stigma is deadly, and people with mental illness deserve to be part of society instead of hidden away in overcrowded, dangerous facilities. . .

In October 1980, this all-consuming work led Congress to pass the Mental Health Systems Act, which focused on the unmet needs of a whole category of people often overlooked: minorities, the elderly, children, people who were poor, and those in rural America. Performance grants required contracts, and this brought accountability. Patients' rights would be identified. A prevention program would become part of the National Institute of Mental Health (NIMH). These, and many others, could have been transformative.

But celebrations were short-lived. The next month, Ronald Reagan won a landslide election to the presidency, dealing a profound blow to the first lady

#### **Public Policy**

#### 9. \*Boston Globe

November 25, 2023 (updated)

By Yvonne Abraham

For some families, the right to shelter isn't a right at all

The recent arrival of thousands of immigrants has put an unprecedented strain on the emergency shelter system. But make no mistake — that system was broken to begin with.

This is a right-to-shelter state in name only. It is a promise kept just for those families who manage to meet the strict — for many, ridiculously strict — requirements to qualify for state-funded emergency shelters. Each year, the state formally denies hundreds of families seeking a temporary place to stay. Many more seek emergency shelter but never complete an application. In the last three months of 2022, there were 2,452 applications and requests for emergency shelter in Massachusetts, according to the latest state figures available. Of those, 840 families were granted shelter, and another 60 entered a rental assistance program called HomeBASE. That approval rate was higher than usual, reflecting the influx of migrants seeking housing. The state formally denied emergency shelter to 358 applicants in that period. And about 1,200 who requested help were neither approved nor denied, but failed to submit formal applications because they were told they were ineligible, or were defeated by the daunting process.

Many of the families denied shelter — about a quarter of them — can't afford rent, but they don't meet the system's ludicrously low-income cut-offs either. Others are denied because they were evicted from subsidized housing and found to be at fault, which shuts them out of emergency shelter for three years. Or they have retirement accounts or other assets that disqualify them, even if it isn't much money and will be spent down on necessities soon. Or they give up on their applications, defeated by the byzantine application process, or discouraged by overwhelmed state housing coordinators who tell them they haven't a chance. . .

Massachusetts leads the nation when it comes to housing poor people. And we are finally at a point where <u>our leaders agree</u> that <u>the lack of affordable housing</u> is a crisis we must face head-on. But look closer, and it becomes obvious that, even here, the right to shelter is no right at all for many people. And that was true long before Governor Maura Healey capped the system at 7,500 families this fall, forcing new applicants onto waiting lists. . .

The Dignity Digest Issue # 164 Page 14 November 28, 2023 www.DignityAllianceMA.org

To qualify for shelter, families at their lowest, most chaotic moments must present a laundry list of credentials: Social Security cards, birth certificates, school enrollment records, verification of disabilities or medical conditions, recent pay stubs, bank records — documents that may be in storage or in an apartment they had to flee. They must prove their income is low enough, their assets meager enough, and their housing options nil. They must provide three years of detailed housing history, complete with dates and contact details of those who have sheltered them, and reasons why they had to leave. State workers have sometimes gone down such lists and leaned on those former hosts to change their minds, said Laura Massie, senior attorney at Greater Boston Legal Services. Those who work with homeless families say they are bedeviled by technology issues, their applications slowed because they lack access to computers or printers.

#### **10.** Office of the Attorney General

November 14, 2023

<u>Governor Healey, Attorney General Campbell, Auditor DiZoglio Appoint Colonel</u> Robert Notch as Veteran Advocate

Governor Maura Healey, Attorney General Andrea Campbell and Auditor Diana DiZoglio today announced the appointment of <u>Colonel Robert "Bob" Notch</u> to lead the Massachusetts Office of the Veteran Advocate. In this role, Notch will oversee the newly established independent state agency whose focus is to ensure that veterans in Massachusetts receive humane, safe, and dignified treatment and effective services in a timely manner and compliance with existing laws and regulations.

The Office of Veteran Advocate was established by An Act relative to the governance, structure, and care of veterans at the Commonwealth's veterans' homes, which also created the Executive Office of Veterans' Services. In March, Governor Healey appointed Dr. Jon Santiago as the state's first ever Veterans' Services Secretary.

#### **About Colonel Notch**

Colonel Notch served for nearly 27 years as a commissioned officer in both the Army and Army Reserve. He retired in 2016 as a Colonel. He was commissioned as a Second Lieutenant in Army Aviation upon graduation from the United States Military Academy in May of 1989. He served in multiple tactical leadership assignments as a UH-60 Blackhawk pilot, operations officer, human resources manager, and force development officer, serving in Operations Desert Shield/Desert Storm in 1990 and in Operation Iraqi Freedom in 2003. His senior assignments include operational and strategic level positions on the Army Staff, Joint Staff and Office of the Chief of Army Reserve in the Pentagon. Colonel Notch is involved in multiple organizations supporting service members, veterans, and their families, including families of the fallen.

#### Caregiving

#### 11. Health Affairs Sunday Update

November 26, 2023

For the month of November, we are recognizing **National Family Caregivers Month**.

This month is a chance to celebrate family caregivers as well as provide awareness and support of caregiving experiences and issues. Throughout this month, we have been highlighting papers from over the years

Take a moment to look back at a number of featured articles.

that illuminate this role through a health policy lens.

Take a moment to look back at a mamber of reactive a relief

The Dignity Digest Issue # 164 Page 15 November 28, 2023 www.DignityAllianceMA.org

In the January 2022 issue, **Norma Coe** and **Rachel Werner** find that informal caregivers <u>provide considerable front-line support</u> in residential care facilities and nursing homes.

In the 2022 <u>Disability and Health</u> theme issue, <u>Courtney Van Houtven</u> observes that <u>integrating family caregivers into the health care team</u> is particularly important and valuable for patients with intellectual disabilities.

In September 2021, **HwaJung Choi** and coauthors explore family care availability and what <u>implications that could have for informal and formal care</u> utilized by adults with dementia in the US. She also spoke on our podcast *A Health Podyssey* <u>discussing the article</u>.

In the 2019 <u>Community Care For High-Need Patients</u> theme issue, **Katherine**Ornstein and coauthors consider the <u>effects of caregiving in the last years of life on surviving spouses</u> and how this can result in increased depression as well as negative health outcomes.

#### 12. Administration on Community Living

November 20, 2023

Supporting Family Caregivers: A Key Issue for ACL and for Our Time

By Alison Barkoff, Performing the duties of ACL Administrator and Assistant Secretary for Aging

Each year, more than 53 million Americans provide a broad range of assistance to support the health, quality of life, and independence of an older adult or person with a disability. Another 2.7 million grandparents — and an unknown number of other kinship caregivers — open their arms and homes each year to children who cannot remain with their parents.

Family caregivers are the backbone of the nation's system of long-term care — replacing the support they provide with paid services would <u>cost an estimated</u> \$600 billion

each year. The number of family caregivers continues to increase as the populations of disabled people and older adults grow, and the opioid crisis and other issues create thousands of new "grandfamilies" each year.

When family caregivers do not have training, support, and opportunities for rest and self-care, their health, well-being, and quality of life often suffer. Their financial future can also be put at risk; lost income due to family caregiving is estimated to be a staggering \$522 billion each year. And if they are unable to continue to provide care, nursing homes and other facilities, or foster care, can become the only option for the people they support. This makes supporting family caregivers not just a moral and economic issue, but an issue critical to community living.

It's fitting that we celebrate National Family Caregivers Month during the same month we celebrate Thanksgiving — we are all truly thankful for family caregivers and the support they provide. But family caregivers need more than our gratitude. They also need — and deserve — a comprehensive system of support.

#### **Remembering Rosalynn Carter**

When <u>former First Lady Rosalynn Carter passed away yesterday</u> at the age of 96, we lost a longstanding advocate for family caregivers, mental health, and women's rights. Famously quoted as saying, "There are only four kinds of people in the world: those who have been caregivers, those who are currently caregivers, those who will be caregivers, and those who will need caregivers," she was the first national leader to passionately champion support for family

The Dignity Digest Issue # 164 Page 16 November 28, 2023 www.DignityAllianceMA.org

caregivers. She created an awareness of the often-overlooked needs of family caregivers, was an early voice in recognizing caregivers as a crucial part the public health system, and founded the Rosalynn Carter Institute for Caregivers, which promotes the health, strength, and resilience of America's family caregivers. As President and First Lady Biden said in their statement, she inspired a nation and the world, and our lives are better, fuller, and brighter because of her life and legacy.

#### The First-Ever Family Caregiving Strategy

For over two decades, ACL has played a leading role in supporting family caregivers through our National Family Caregiver Support Program, the Alzheimer's Disease Programs Initiative, and the Lifespan Respite Care Program. In the past few years, that work has accelerated across ACL with new initiatives and programs to support caregivers of older adults and people with disabilities of all ages, as well as grandparent caregivers.

In 2018, recognizing the important and growing role of family caregivers, Congress passed the Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act and the Supporting Grandparents Raising Grandchildren (SGRG) Act, and directed HHS to develop a national family caregiving strategy. ACL has been thrilled to lead that effort, working together with two advisory councils made up of caregivers, people receiving support, and experts and 15 federal agencies with programs that can assist family caregivers and the people they support. Last September, after a year of close collaboration and extensive stakeholder and public engagement, we delivered to Congress the first ever National Strategy to Support Family Caregivers.

The national strategy is groundbreaking, holistic, and both visionary and concrete. One major component of the strategy is ensuring the federal government is doing all it can to support family caregivers and the people they support. Fifteen federal agencies made nearly 350 commitments, ranging from launching new caregiving initiatives, to changing policies, to addressing problems in existing programs. These are not just ideas but actions the agencies committed to do. And we are holding ourselves accountable. One year after the release of the strategy, nearly three-quarters of those actions are already in progress or completed.

Importantly, the strategy recognizes that federal agencies alone cannot address the issue — it will take an all of society approach. That's why the strategy also includes more than two dozen recommendations for legislative and policy changes, like federal legislation to improve paid family leave policies and expand access to services, along with over 150 recommendations that can be implemented by states, communities, businesses, philanthropy, and others. The strategy is a living document, one that will be adapted and updated as we make progress on our goals and as we learn even more. We swore in the new members of the advisory councils in July, and the councils met for the second time in September. At that meeting they started to dive into the analysis of the public comments we received on the strategy. They also heard updates from the federal partners about their progress on the strategy's actions. All of that will inform the update of the strategy that the councils will work on over the next year.

In addition, earlier this year we were excited to announce a \$20 million initiative to support implementation of the strategy. Through this initiative, ACL is awarding five four-year grants to support the development of state,

The Dignity Digest Issue # 164 Page 17 November 28, 2023 www.DignityAllianceMA.org

community, and tribal family caregiver support programs aligned with the strategy's principles and recommendations. The first four grants were awarded in September. Applications for the last grant, which will focus on strengthening financial and workplace security for family caregivers, are due December 11. Interconnectedness Between Family Caregivers and the Direct Care Workforce One issue that is prominent in the national strategy — and that comes up in nearly every conversation I have about caregiving — is the inextricable link between paid caregivers and family caregivers. People with disabilities and older adults often depend on services provided by direct care workers to live in the community, and family caregivers often depend on those same professionals for respite care. However, getting these services can be difficult — or impossible. For decades, service providers have been struggling with a workforce shortage due to low pay, little respect, lack of benefits, and limited advancement opportunities. That shortage reached crisis levels during the pandemic. Today, some states report nearly 50 percent employee turnover rates, and nearly 80 percent of service providers are declining referrals or cutting services despite

When it is harder to access paid services, families are forced to take on even more. And when family caregivers become overwhelmed and paid services are not available, people who need assistance often have no option except moving to a nursing home or other institution; people who want to leave these facilities are forced to stay; and the health and safety of those who live in the community is put at risk.

That's why ACL's work to support family caregivers is complemented by our focus on stabilizing and strengthening the direct care workforce. Last year, we created the Direct Care Workforce Strategies Center to improve recruitment, retention, training, and advancement of direct care professionals. Later this year, the Strategies Center will launch a website to serve as a national hub of resources and best practices. When fully operational, the center also will support states in developing and leveraging partnerships, including among aging, disability, Medicaid, and workforce agencies; providers of direct care services; and disability, aging, and labor advocates. We also are working with colleagues across HHS and the Department of Labor

to identify key priorities, review data, and recommend ways to fill critical gaps in knowledge about the direct care workforce.

#### **Unprecedented Support and Momentum**

growing demand.

We now have an incredible opportunity to strengthen the care infrastructure for disabled people and older adults — both family caregivers and the paid direct care workforce.

First, we have unparalleled support from both President Biden and HHS Secretary Becerra. President Biden called out the needs of America's caregivers in his State of the Union address this year and emphasized the importance of solidifying the care infrastructure to support and strengthen our nation's families. His recent Executive Order on Increasing Access to High-Quality Care and Supporting Caregivers

to support, strengthen, and grow the workforce — including direct care professionals — that provides health care and related services.

The Dignity Digest Issue # 164 Page 18 November 28, 2023 <u>www.DignityAllianceMA.org</u>

We also have a new — and extraordinary — momentum. The COVID-19 pandemic brought the need to support family caregivers to the forefront of conversations at dining room tables and board rooms

across the country. Coalitions, such as the <u>Care Can't Wait campaign</u>, have formed to advocate for resources and change at state and national levels. The National Strategy to Support Family Caregivers was the result of an unprecedented collaboration involving many agencies, organizations, and individuals in both government and the private sector — and stakeholders have organized advocacy efforts around it, like the <u>Act on RAISE</u> campaign. I recently had the privilege of joining a briefing for members of Congress organized by the campaign, and it was so exciting to see the level of bipartisan interest in our issues.

There also is international momentum. Last year, I had the honor of speaking at a convening of the U.N. Human Rights Council focused on caregiving issues. And just last week, I participated in the first-ever <a href="Canadian Caregiving Summit">Canadian Caregiving Summit</a>, which convened as Canada prepares to develop its own national caregiving strategy.

This work has really been about creating a movement — partnerships that erase old boundaries where we work together to make sure that all types of caregivers and people receiving care can get what they need and the respect they deserve.

#### We All Have a Role to Play

The responsibility for improving caregiver support touches every sector of our society — from federal, state, and local government, to business and philanthropy, to advocacy organizations, and to each of us. After all, as Rosalynn Carter said, caregiving is a universal issue — nearly all of us will either need or be a family caregiver at some point in our lives, and many of us will experience both

That's why I am so thankful for how far we have come and for the opportunities that lie before us. I am also grateful for the collaboration of so many people and organizations working to transform the way this nation supports its caregivers and the people who receive their support — and for the real changes we are seeing.

So, as we celebrate National Family Caregivers Month, I am calling on everyone to join us. I am excited and optimistic about what we can achieve together — and our work will only become more important as populations age, people with disabilities are living longer, and more people than ever want to live in the community and age in place. Building the care infrastructure — both supporting family caregivers and strengthening the direct care workforce — is THE issue of our time for the disability and aging communities and for advancing community living.

#### Elder Abuse

#### 13. National Center on Elder Abuse (podcast)

November 20, 2023

The OGs of Elder Justice: Jacque Gray & Cynthia LaCounte

In celebration of Native American Heritage Month, we're honored to host two trailblazers who have been at the forefront of addressing elder abuse in Indian Country. Dr. Jacque Gray is a Choctaw/Cherokee retired associate professor with the Center for Rural Health (CRH) at the University of North Dakota (UND) School of Medicine & Health Sciences. She also served as director of the National Indigenous Elder Justice Initiative (NIEJI) a national resource center to address elder abuse in Indian Country. She has worked to address health, mental

health, and health disparities across Indian Country for 40 years. Dr. Gray also serves on the NCEA's advisory board. Cynthia LaCounte is a proud member of the Turtle Mountain Chippewa. She is the Director of the Office for American Indian, Alaskan Native and Native Hawaiian Programs with the Administration for Community Living. Cynthia has oversight for Older Americans Act Programs (OAA) that serve American Indians, Alaska Natives, Native Hawaiians, and diverse elders of racial and ethnic heritage. 14. National Center on Elder Abuse (podcast) November 10, 2023 The OGs of Elder Justice: Georgia Anetzberger In our second installment of the "OGs of Elder Justice" series, Dr. Georgia Anetzberger discusses two interconnected topics: elder abuse work and the remarkable contributions of Elizabeth Lau (Betty) in the field of elder abuse. The episode addresses the importance of research, policy, and practice in advancing the field of elder abuse. Georgia Anetzberger, PhD, ACSW, FGSA has authored over one hundred scholarly publications on aging and elder abuse. She is widely regarded as THE OG of Elder Justice and has spent over forty years as a practitioner, educator, researcher, and community advocate. She serves on the Advisory Board for the National Center on Elder Abuse. Medicare 15. \*Boston Globe November 14, 2023 UnitedHealth pushed employees to follow an algorithm to cut off Medicare patients' rehab care By Casey Ross and Bob Herman The nation's largest health insurance company pressured its medical staff to cut off payments for seriously ill patients in lockstep with a computer algorithm's calculations, denying rehabilitation care for older and disabled Americans as profits soared, a STAT investigation has found. UnitedHealth Group has repeatedly said its algorithm, which predicts how long patients will need to stay in rehab, is merely a guidepost for their recoveries. But inside the company, managers delivered a much different message: that the algorithm was to be followed precisely so payment could be cut off by the date it predicted. Internal documents show that a UnitedHealth subsidiary called NaviHealth set a target for 2023 to keep rehab stays of patients in Medicare Advantage plans within 1% of the days projected by the algorithm. Former employees said missing the target for patients under their watch meant exposing themselves to discipline, including possible termination, regardless of whether the additional days were justified under Medicare coverage rules. Medicaid 16. Office of the Attorney General November 17, 2023 Worcester-Based Home Care Company and Its Managers Indicted For \$1.6 Million Medicaid Fraud Scheme Union Home Health Care Services, LLC Allegedly Received More than \$1.6 Million from MassHealth for Services Not Rendered, Not Medically Authorized, and Based on Fraudulent Documentation. The managers of Union Home Health Care Services, LLC (Union), a Worcesterbased group adult foster care (GAFC) company, were arrested and arraigned yesterday in connection with a scheme to defraud the state's Medicaid program

The Dignity Digest Issue # 164 Page 20 November 28, 2023 www.DignityAllianceMA.org

(MassHealth) of more than \$1.6 million, Attorney General Andrea Joy Campbell's Office has announced. Bernice Codjia, age 39, and Augustus Kormah, age 66, both of Worcester, were indicted by a Worcester County Grand Jury on November 15, 2023. Their company, Union, was also indicted. Each defendant was charged with Medicaid False Claims. Codjia and Union were also charged with Larceny Over \$1,200. MassHealth's GAFC program is designed to provide sufficient assistance to MassHealth members who are elderly or have disabilities to enable them to live independently. GAFC services assist MassHealth members with performing daily life activities, such as eating, bathing, housekeeping, and laundry. To be eligible for GAFC services, a registered nurse must conduct an assessment of the member and attest to their eligibility for GAFC services, which is then submitted to MassHealth. The AG's Office alleges that Union, as well as its former manager Codjia, used fraudulent nursing assessments and forms to sign up MassHealth members and bill MassHealth for GAFC services that had not been authorized by a registered nurse. The AG's Office further alleges that Union billed for services it never rendered to MassHealth patients, including periods when those members were receiving treatment from different providers at inpatient facilities. Covid / Long Covid 17. McKnights Long Term-Care News November 27, 2023 Long COVID patients demand 9 months of ADL support from nursing home staff By Josh Henreckson COVID-19 infections have an extended, months-long impact on nursing home residents, placing additional burdens on staff, according to new study results published in the Journal of the American Geriatrics Society. Residents infected with COVID struggled with cognitive issues and were more dependent on staff for activities of daily living for nine months on average after infection. Researchers from the University of Michigan observed 171 residents at two facilities in the state to quantify long COVID's effects. Facility residents who tested positive also died at twice the rate of uninfected residents during the study period. Few other studies have looked at the effects of long COVID in nursing homes, investigators said. This new data sheds light on how COVID affects residents and staff long after acute symptoms have passed. **Disability Topics** 18. National Today Undated International Day of Persons with Disabilities International Day of Persons with Disabilities on December 3 lets us focus on challenges faced by people living with disabilities. The day doesn't discriminate between mental and physical disabilities, and the spirit of the day is to ensure that all people in the world have equal opportunities for work, play, health, and success. People with disabilities can be and very often are contributing and valued members of society, and today is all about appreciating them. Why International Day of Persons with Disabilities is Important 1. It creates awareness People living with disabilities sometimes feel invisible in our society. People rush around them in their daily routines, barely noticing them. Today, try to make eye contact and smile and be available to help should they seem to be having difficulties.

The Dignity Digest Issue # 164 Page 21 November 28, 2023 www.DignityAllianceMA.org

#### 2. We understand the difficulties people living with disabilities have

The treasured parking space right in front of the pharmacy, the sloped curbs at intersections with the textured mats in place so the vision impaired folks can feel the curb end, the buttons to open doors automatically, even elevators on the Subway —are all in place to make a difficult life a little easier for a person with disabilities. Notice these accommodations today, and then notice how few of them there are.

#### 3. It's more than a day —it's the law

The Americans with Disabilities Act was created to define the rights of people with disabilities and the design standards which businesses and municipalities must incorporate to comply with the law. Called the ADA, it is quite explicit in the standards required, and a familiarity with it could be most helpful to anyone in.

#### 19. Nice News

November 25, 2023

<u>California Girl Scout Troop Brings Members of the Deaf Community Together</u>
By Ally Mauch

It's a little-known fact that <u>Juliette "Daisy" Gordon Low</u>, the founder of the Girl Scouts of the USA, was hard of hearing for much of her life. Now, more than a century after she started the enduring nonprofit, there's a Girl Scout troop in Orange County, California, that's carrying on her legacy in more ways than one. Troop 8542 is the only one of its kind, bringing together members of the Deaf and hard-of-hearing community in a cohesive group. It's the brainchild of Girl Scouts alumna Natalie Westfall, who had the idea to create a troop centered on the Deaf community and American Sign Language as her <u>Gold Award</u> in high school — considered the highest achievement within the organization.

#### 20. \*Washington Post

November 22, 2023

Buttigieg promises to investigate wheelchair incident from viral video

By Andrea Sachs and Heidi Pérez-Moreno

A TikTok filmed at the Miami airport shows a passenger's wheelchair spilling onto the pavement.

A video showing baggage handlers sending a passenger's wheelchair tumbling to the runway at Miami International Airport has racked up millions of social media views since Sunday, prompting sharp criticism from a top federal official and outrage from advocates for travelers with disabilities.

In the clip, which was first <u>posted to TikTok</u>, an American Airlines employee pushes the chair down a baggage chute on its wheels. It races down the track, slams into a gate and flips over several times before landing on the ground upside down.

Secretary of Transportation Pete Buttigieg criticized the handling of the wheelchair, calling it "totally unacceptable" in a post on X, formerly known as Twitter. He also wrote the department will investigate the incident. . . According to the Transportation Department, more than one in every 100 wheelchairs and scooters transported in cargo on domestic flights is damaged, delayed or lost. In 2022, U.S. airlines reported 11,389 mishandled wheelchairs and scooters, up from 7,239 the previous year. Spirit Airlines and JetBlue Airways had the highest percentage of mishandled devices, followed by American Airlines. . .

Disability rights advocates have been pushing the DOT to expand its accessibility policies and improve the airline industry's accountability when wheelchairs are mishandled. In addition to damaged equipment, travelers with extra needs have faced extended wait times for check-in assistance, inadequate help during boarding and delays in retrieving their wheelchairs upon arrival.

A few industry players are actively seeking solutions that will take the stress and dread out of flying with a wheelchair. The Transportation Department is considering a rule that would allow passengers to remain in their wheelchairs during flights. . .

The recent incident appears to violate several sections of the <u>Airline Passengers</u> <u>With Disabilities Bill of Rights</u>. Among them: "The Right to Be Treated with Dignity and Respect" and "The Right to Travel with an Assistive Device or Service Animal."

#### 21. \*New York Times

October 31, 2023

The Cost of Being Disabled in New York City Housing

By Claire Perlman

As a wheelchair user, I have always had to pay a premium to live in an apartment independently. In my nine years living in New York City, I have spent more than \$18,500 on automatic door openers, amenities just to make the places I've lived in accessible.

I shouldn't have had to do this; in almost every case, it was legally the landlord's responsibility, experts have told me. But in the early years, I didn't know better, and more recently, my landlords have refused to pay. I was worried that I would lose the apartment if I put up a fuss. I could afford it because I have had consistent income from my work as a journalist and private investigator, but it meant my savings during my 20s largely went toward making my homes accessible.

For thousands of other New Yorkers with disabilities, this kind of expense simply isn't feasible. In some cases, landlords are refusing to make accommodations or asking tenants to foot the bill, leaving even those with ample resources without an accessible place to live. Oftentimes, lawyers and disability rights advocates say, landlords are skirting the law to reject tenants.

Several factors determine whether I, and many other disabled people, can enter an apartment: There can't be steps at the building's entrance. The unit needs to be on the ground floor or the building needs an elevator. The doorways need to be at least 27 inches wide so my wheelchair can fit through them. The bathroom must be big enough to fit my wheelchair. Most crucially, since I don't have full use of my arms, I can't open doors without remote-control-operated door openers, which are installed on the doors of my unit and at the building's main entrance. . .

Accessible apartments that are also affordable are hard to come by. As of 2021, only 32 percent of the units in New York City could be entered without stairs, according to a <u>city analysis</u>, and the majority of those are in newly constructed luxury buildings where rents are far higher than in older structures.

A number of laws give people with disabilities a right to equal housing — like the Americans with Disabilities Act, the federal Fair Housing Act, the New York State Human Rights Law, and the New York City Human Rights Law. New York City has some of the strongest legal protections in the country, said Elizabeth Grossman,

The Dignity Digest Issue # 164 Page 23 November 28, 2023 www.DignityAllianceMA.org

the executive director of the Fair Housing Justice Center, an organization that provides legal support to New Yorkers fighting housing discrimination... For many disabled New Yorkers, the city's affordable housing lottery seems like the answer. Most of the buildings available through the lottery are newly constructed, so they are at least accessible by the A.D.A.'s standards, and while "affordable" is often an overstatement, the rent is below market rate. And yet it was far from a panacea. Under city guidelines, only 5 percent of units are set aside for tenants with mobility disabilities and 2 percent for people with hearing or vision disabilities, and zoning laws don't allow any crossover.

#### 22. Nice News

September 8, 2022

<u>More Than Just a Toy Company: The Powerful Representation Message Behind a</u> Doll Like Me — Exclusive

By Lauren Hando

Many of us still remember our favorite toy, spending countless hours with the object that reflected our childhood interests and brought us happiness and comfort. And since 2015, Amy Jandrisevits, the founder of A Doll Like Me, has been working tirelessly to make sure that kids with disabilities are uniquely represented in the toys they play with.

According to a <u>2021 report</u> by UNICEF, an estimated 240 million children across the globe have some form of disability. That's nearly a quarter of a billion children, most of whom are not represented in the industries that dominate our cultures.

While representation in the media has been growing, disabilities are still widely underrepresented. A <u>2020 report</u> by GLAAD discovered that the amount of regular primetime broadcast characters counted who have a disability is 3.1%, a record-high percentage that is vastly below the U.S. population of people with disabilities. And representation on children's television is even less: <u>Under 1%</u> of all leading characters have a physical, mental, or communication disability, according to the See Jane 2019 report.

#### 23. Urban Institute

October 11, 2023

<u>Four in Ten Adults with Disabilities Experienced Unfair Care Settings, at Work, or</u> When Applying for Public Benefits in 2022

By Dulce Gonzalez, Genevieve M. Kenney, Michael Karpman, and Sarah Morriss In this brief, we used December 2022 data from a nationally representative survey of adults ages 18 to 64 to examine rates at which adults with and without disabilities reported they were treated or judged unfairly in the past year in three settings: at doctors' offices, clinics, or hospitals; at work; and when applying for public benefits. We also examined the impact of such treatment on their well-being. . .

#### What we found

- In December 2022, 4 in 10 adults with disabilities (40 percent) reported experiencing unfair treatment in health care settings, at work, or when applying for public benefits because of their disabilities or other personal characteristics in the previous year. Adults with disabilities were more than twice as likely as adults without disabilities to report unfair treatment in one or more of these settings (40 percent versus 18 percent).
  - Disabled adults were more likely than adults without disabilities to report unfair treatment in each of the three settings: 32 percent

The Dignity Digest Issue # 164 Page 24 November 28, 2023 www.DignityAllianceMA.org

versus 10 percent in health care settings, 18 percent versus 11 percent at work, and 14 percent versus 3 percent when applying for public benefits.

- Many disabled adults reported experiencing unfair treatment because of their disabilities or health conditions in the prior year: 14 percent in health care settings, 9 percent at work, and 6 percent when applying for benefits.
- Among disabled adults, Black and Hispanic/Latinx adults were more likely than white adults to report unfair treatment or judgment in each of the three settings because of their race, ethnicity, country of origin, or primary language.
- Disabled adults frequently reported adverse consequences after experiencing unfair treatment, in many cases at rates higher than those of adults without disabilities.
  - About 71 percent of disabled adults who experienced unfair treatment in health care settings reported a disruption to care after such treatment, including delaying (54 percent) or not getting (50 percent) needed care.
  - Almost half (46 percent) of disabled adults who experienced unfair treatment in workplaces reported looking for a new job because of the way they were treated.
  - About 71 percent of disabled adults who experienced unfair treatment in social service settings had difficulty receiving public benefits, including delaying (45 percent) or not getting (57 percent) benefits.

#### **Aging Topics**

#### 24. New York Times (free access)

November 25, 2023

When the Neighbors Are All Older, Too

By Paula Span

Kathy Fitts loved her roomy house in suburban Atlanta. But after her children moved out, and the pandemic exacerbated the isolation she often felt as a divorced woman, she left for Latitude Margaritaville, a Jimmy Buffett-themed housing development in Daytona Beach, Fla., for those "55 and better." Visiting a friend who had relocated there, "I thought, wow, these people are having a good time," Ms. Fitts, 68, said. She bought a two-bedroom villa and settled in almost two years ago.

But the prospect of life in an age-restricted development makes Robyn Ringler shudder. She and her husband, both retired in upstate New York, downsized from a big house on 30 rural acres to a rented one near an elementary school in suburban Albany.

"I love my friends who are the same age as me, but I adore meeting and knowing people of all ages," said Ms. Ringler, who is 66. She meets people while biking through her neighborhood or walking her goldendoodle; she knows trickor-treaters by name.

"It keeps me more engaged with the world," she said. "It makes me feel part of a real community, a larger family." As for the couple's actual family, their adult daughter, who is about to start a new job, has moved in with them temporarily — something 55-plus communities typically ban.

Though surveys repeatedly show that most older people prefer to remain in their own homes as they age, about 800,000 were in assisted living last year, according to LeadingAge, which represents nonprofit aging services providers.

The Dignity Digest

Issue # 164

Page 25

November 28, 2023

An additional 745,000 lived in continuing care communities and three million in federally supported affordable senior housing.

The National Investment Center for Seniors Housing and Care estimates that 540 active adult communities with 82,000 units offer market-rate rental properties for seniors. In other 55-plus developments, residents purchase houses and condos.

Age-restricted housing often requires a middle- or upper-middle-class income. Homes at the Margaritaville community in Daytona Beach, for example, start at about \$300,000.

At Riderwood, a continuing care community in Silver Spring, Md., that Lynn Cave moved into in 2021, the entrance fee for her one bedroom-plus-den apartment was \$270,000 (90 percent is refundable after a resident moves out or dies). Her \$3,300 monthly fee includes utilities; cable, phone, and internet; use of the pool and fitness center; and 30 meals a month.

Often, as in Ms. Cave's case, the sale of a house covers the costs. Low-income seniors have far fewer options.

Yet research on whether age-segregated housing leads to improved health or quality of life is scant and dated; it's not a subject that lends itself to controlled studies. "It's still an open question," said Jennifer Molinsky, director of the Housing in Aging Society program at the Harvard Joint Center for Housing Studies.

The motives for relocating vary, of course. Ms. Cave, 67, moved to Riderwood because "I was the daughter who had to take care of parents from afar, and I swore I'd never do that to my kids," she said.

At first, Ms. Cave recalled, "I looked around and saw the walkers and the scooters and thought, 'My God, what have I done?'" Now, though, she appreciates the community college courses offered on campus, the square dancing and the pickleball, the shared meals. "The people are so interesting," she added.

Such graduated communities allow residents to transfer to assisted living, nursing care or memory care units as their health declines. It's a benefit that Carol Holmes Alpern, 81, learned to value after she and her husband, Bowen Alpern, moved into Foulkeways, a nonprofit Quaker-affiliated continuing care community in Gwynedd, Pa.

A healthy 68-year-old when he arrived in 2021, Mr. Alpern was diagnosed with a brain tumor the following year. When his wife could no longer care for him by herself, he entered hospice care in the Foulkeways nursing center, a short walk from the couple's apartment. Having the option of 24-hour aides and unlimited visiting hours "probably saved my life," Ms. Alpern said.

Her husband died last month, and now, "I can't imagine leaving," she said. Other residents "not only supported both of us, they cherished us."

No such safety net awaits residents of so-called active adult communities, agerestricted developments that can offer rentals or homeownership. But "I see why they're popular," Dr. Molinsky said.

"They're lower maintenance than a single-family home," she said. "They're more likely to have accessibility features. If the design is thoughtful, with proximity, you have opportunities to socialize." And municipalities are more apt to approve projects that don't increase school budgets.

But Toni Keyes, 65, moved into an apartment in a small 62-plus community in Clearlake, Calif., last year after the single-family homes she had been renting

The Dignity Digest Issue # 164 Page 26 November 28, 2023 <u>www.DignityAllianceMA.org</u>

were sold, twice. A retired library worker living on Social Security disability, she found the apartment rent affordable with her federal Section 8 voucher, but the environment unwelcoming and unpleasant.

"It's like a ghost town, always quiet," said Ms. Keyes, who also remains very conscious of being the only Black tenant. "It feels like a nursing home.

"Being surrounded by all seniors is very limiting," she added. "There should be a mix of age groups."

That's difficult to find, but "I definitely see growing interest in creating models of intergenerational housing," Dr. Molinsky said. Some developers and operators have introduced mixed-age programs within senior housing or have built complexes that place senior buildings next to all-age apartments.

In Long Island City, N.Y., for instance, the Gotham Organization last year opened an 11-story senior independent living building, part of 1,132 units of housing at rents that range from low to upper income.

Though older residents, whose units provide grab bars and other safety features, and younger tenants don't live side by side, they share a rooftop farm and other amenities and programs that encourage interaction. "They're in the same ecosystem," said Bryan Kelly, president of development.

Another Gotham development on the Lower East Side of Manhattan will incorporate a Jewish cultural center at the base of the senior building and a large community center in the adjacent all-ages building. "The days of the suburban model, the circular drive-up, are over," Mr. Kelly said. He expects "more integrated, walkable, active, mixed use" senior housing.

Creating intergenerational housing will require federal and local policy changes, said Robyn Stone, senior vice president for research at LeadingAge. "We don't have the regulatory environment that allows some of these things to happen, or the incentives to encourage and support them," she said.

A few experiments in intergenerational living serve as proof of concept. In Oregon, <u>Bridge Meadows</u> has developed three communities, with more to come, for older adults and for families adopting or fostering children from the foster care system.

<u>Treehouse Communities</u> has built a similar combination in Easthampton, Mass. <u>Olmsted Village</u> in Mattapan, a Boston neighborhood, will offer homeownership to middle-income families along with apartments to fostering and adopting families — and to seniors who will mentor them. Some <u>Cohousing</u> communities are seniors-only, but others draw residents of all ages.

For now, though, when older people want or need to leave their homes, they usually acquire neighbors who are also, exclusively, older.

"I don't know, if you asked people, if that's what they want," said Susan Popkin, a fellow and housing researcher at the Urban Institute. "But we haven't asked."

### 25. Institute on Disability – University of New Hampshire

July 7, 2023

<u>Americans Aging with Disabilities Are More Likely to Have Multiple Chronic Conditions</u>

By Debra L. Brucker, Eric A. Lauer, and Sarah Boege

#### **Abstract**

Using data from the 2010 to 2017 National Health Interview survey, bivariate and multivariate regression analyses were utilized to estimate the percentage and odds of having multiple chronic conditions (two or more, three or more) among U.S. adults ages 65 and over with and without disabilities, controlling for

The Dignity Digest Issue # 164 Page 27 November 28, 2023 www.DignityAllianceMA.org

	sociodemographic factors and presence of psychological distress. Older adults with and without disabilities in the United States most frequently reported having hypertension, arthritis, and diabetes. Regression results indicate that			
	older adults with disabilities are significantly more likely to experience two or			
	more and three or more chronic conditions than older adults without			
	disabilities, controlling for sociodemographic factors and health behaviors.			
	These findings highlight a need for improvement in coordinated care that			
	considers both disability and multiple chronic conditions in the management of			
2 14/1 4	patient health to support well-being in aging.			
Persons Who Are	26. U. S. Department of Justice			
Incarcerated	November 16, 2023			
	Justice Department Secures Agreement with Arizona Prison System Resolving Discrimination Against Incarcerated People with Vision Disabilities			
	The Justice Department announced today that the Arizona Department of			
	Corrections, Rehabilitation, and Reentry (ADCRR) has agreed to adopt			
	systemwide reforms to correct and prevent discrimination against incarcerated			
	people with vision disabilities.			
	The <u>agreement</u> resolves the Justice Department's <u>findings</u> that ADCRR violated			
	Title II of the Americans with Disabilities Act (ADA) by discriminating against			
	incarcerated individuals with vision disabilities, including those who are blind or			
	have low vision. The department found that ADCRR failed to reasonably modify			
	its policies or provide auxiliary aids and services, such as Braille materials and			
	displays, audio recordings and screen reader software, to ensure that people			
	with vision disabilities could communicate effectively while incarcerated. ADCRR			
	failed to provide accessible processes to request accommodations or file			
	disability-related complaints. ADCRR also over-relied on other incarcerated			
	people to help individuals with vision disabilities without properly training or			
	supervising those providing help.			
From Out of State	27. The Maine Monitor			
	November 26, 2023			
	Four takeaways from a probe into residential care facilities			
	By Rose Lundy			
	The Maine Monitor recently published the second part of its <u>investigation with</u>			
	ProPublica into the state's oversight response to serious incidents of abuse and			
	neglect in Maine's Level IV residential care facilities.			
	The Maine Department of Health and Human Services cited residential care facilities for dozens of resident rights violations and hundreds of other			
	deficiencies — but imposed only one fine in response.			
	Here are four takeaways:			
	Serious abuse and neglect cases			
	From 2020 to 2022, Maine DHHS cited Level IV residential care facilities for 59			
	resident rights violations — which include cases concerning abuse and neglect —			
	and about 650 additional violations involving anything from medication and			
	record-keeping errors to unsanitary conditions and missed mandatory training			
	sessions			
	Analysis of state inspection and investigation documents by The Maine Monitor			
	and ProPublica found the following examples in which DHHS cited facilities for			
	resident rights violations:			
	A resident with a well-documented severe peanut allergy was served a peanut			
	butter sandwich for lunch. Staff used an EpiPen to treat his anaphylactic shock			

The Dignity Digest Issue # 164 Page 28 November 28, 2023 <u>www.DignityAllianceMA.org</u>

and took him to the hospital. He died days later, though no official records were made available that show the cause of death.

- A resident was found to have sexually abused another resident multiple times.
- A certified nursing assistant slapped a resident who had spit at and attempted to bite her.

In each case, the state required the facility to submit a report, called a plan of correction, stating how it intended to address the deficiencies. But the state did not impose a fine or conditional license.

#### State oversight response

DHHS has the power under state regulations to impose a fine of up to \$10,000 or issue a conditional license to bar facilities from accepting new residents for up to 12 months.

Despite hundreds of regulatory violations from 2020 to 2022, the state imposed a fine only once: a \$265 penalty against a facility for failing to comply with background check rules for hiring employees. . .

#### **Nursing home penalties**

During the same time period, more than half of Maine nursing homes were fined, totaling nearly \$700,000.

The fines were sometimes for incidents that mirrored those in residential care facilities that didn't receive any additional sanctions. For example, a nursing home was fined \$41,000 after an employee hit a resident.

Residential care facilities are not intended to provide the same level of medical care as nursing homes. In fact, the state considers residential care facilities to be "nonmedical institutions."

But the <u>first part in this series</u> found that the state's decision in the mid-1990s to tighten the requirement to qualify for nursing home placement helped spur thousands of older Mainers, many with significant medical needs, to move to these nonmedical facilities. . .

#### State taking "no action"

The Maine Monitor and ProPublica also analyzed a database of incidents reported to the state by Level IV facilities themselves, which is required when a regulatory violation may have occurred or when a resident's safety was put at risk.

From 2020 to 2022, the state received more than 550 reports of abuse and neglect incidents from Level IV facilities, according to the Monitor and ProPublica analysis.

In nearly 85% of these incidents, state investigators took "no action," which means the health department decided not to investigate.

The analysis also shows that even when facilities repeatedly reported similar problems, DHHS did not step up its enforcement.

#### 28. \*The Tennessean

November 26, 2023

<u>Tennessee sees spike in nursing homes battling serious problems since COVID-19</u> <u>pandemic</u>

By Kelly Puente

[Cloria Oaks Post Acute and Rehabilitation Center in Palmyra, Tennessee] was among the worst in the nation for fines and deficiencies when it shuttered this year after the Centers for Medicare & Medicaid Services pulled payments for failing to follow health and safety codes.

By the time it closed, Cloria Oaks had racked up more than \$1.1 million in fines over a three-year period (the highest in the nation at the time) and was among the top five worst nursing homes for serious deficiencies, according to a database of CMS data compiled by the nonprofit investigative news organization ProPublica. It hasn't been the only nursing home raising concerns since the pandemic. Tennessee has seen an alarming spike in serious deficiencies in nursing homes, leaving advocates worried that the quality of long-term care has plummeted, not only in the Volunteer State but nationwide. . . From 2020 to 2022, the number of citations for the most serious federal deficiencies (those causing immediate jeopardy to resident health or safety) jumped 145% in Tennessee's nursing homes, according to a report from the state's Health Facilities Commission. Last year, the most serious deficiencies accounted for about 11% of all federal citations, up from 3% in 2018. . . In all, the program saw its largest ever number of complaints last year with 3,705, up from 1,932 in 2021. The most common complaints included abuse, neglect, and care quality. And as the number of complaints has skyrocketed, the Tennessee Health Facilities Commission, which last year took on oversight of the state's 313 active nursing homes from the Department of Health, remains buried in a backlog of investigations. In a report this year, the HFC said it has a backlog of 1,197 overdue complaint investigations and has resorted to hiring contract agency surveyors to help free up its own staff to address a backlog of facility recertifications. The agency is using \$1.7 million in existing funding for the extra contract work. . . Moreover, the agency said it has seen a 61% increase in complaints since it adopted a new incident reporting portal in October 2022. It expects a total of more than 6,500 complaints by the end of this year. Smetanka, with the long-term care advocacy group, said serious problems have increased as a growing number of facilities rely on temporary healthcare staffing agencies. Nursing homes have long struggled with staffing shortages, but the problem was especially bad in the pandemic as people left for better-paying jobs with less Smetanka said temporary staffing agencies do not have the same level of training for adequate nursing care. . . Last year, Tennessee nursing home facilities were expected to spend over \$100 million on temporary staff, up from \$9.8 million in 2019, according to a state Comptroller report. Dignity Alliance Information about the legislative bills which have been endorsed by Dignity Alliance Massachusetts, including the text of the bills, can be viewed at: Massachusetts Legislative https://tinyurl.com/DignityLegislativeEndorsements **Endorsements** Questions or comments can be directed to Legislative Work Group Chair Richard (Dick) Moore at <a href="mailto:rmoore8473@charter.net">rmoore8473@charter.net</a>. **Changing the Narrative** Websites https://changingthenarrativeco.org/ Changing the Narrative began by building on national work initiated by eight leading aging organizations that recognized a shared challenge: that what they were seeking to communicate about aging and ageism, and the social

The Dignity Digest Issue # 164 Page 30 November 28, 2023 www.DignityAllianceMA.org

	challenges and opportunities posed by demographic change, was not getting through in the way intended to the general public. They engaged FrameWorks Institute to research how the public thinks about aging and ageism, and to test messages that could shift thinking in a positive direction. This resulted in a toolkit and training trainers who could teach others effective ways of communication about aging and ageism.  Since, the Changing the Narrative has evolved into a leading national effort to end ageism, with educational workshops, advocacy and public campaigns engaging people in all 50 US states and countries on every continent.  Age Friendly Vibes  https://agefriendlyvibes.com/ Offers age friendly cards, buttons, gifts, and more. Offers a 20% off coupon for new purchasers.  Daughterhood https://daughterhood.org/ Daughterhood is a community of people supporting each other in the challenges, realities, and joys of caregiving through connection, support, and education.  Institute on Disability https://iod.unh.edu/ Mission The IOD promotes full access, equal opportunities, and participation for all persons by strengthening communities and advancing policy and systems change, promising practices, education, and research. Vision The IOD envisions a future where all people, including individuals living with disabilities, are fully engaged members of communities and where culturally appropriate supports that lead to independence, productivity, and a satisfying
Previously recommended websites	quality of life are available to individuals and families across the life span.  The comprehensive list of recommended websites has migrated to the Dignity Alliance MA website: <a href="https://dignityalliancema.org/resources/">https://dignityalliancema.org/resources/</a> . Only new recommendations will be listed in <i>The Dignity Digest</i> .
Previously posted funding opportunities	For open funding opportunities previously posted in <i>The Tuesday Digest</i> please see <a href="https://dignityalliancema.org/funding-opportunities/">https://dignityalliancema.org/funding-opportunities/</a> .
Websites of Dignity Alliance Massachusetts Members	See: https://dignityalliancema.org/about/organizations/
Nursing Home Closures	Massachusetts Department of Public Health  South Dennis Health Care  Target closure date January 30, 2024  Notice of Intent to Close (PDF)   (DOCX)
Nursing homes with admission freezes	Massachusetts Department of Public Health  Temporary admissions freeze  There have been no new postings on the DPH website since May 10, 2023.
Massachusetts Department of Public Health	Massachusetts Department of Public Health  Determination of Need Projects: Long Term Care  2023

The Dignity Digest Issue # 164 Page 31 November 28, 2023 www.DignityAllianceMA.org

## Determination of Need Projects

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** 

<u>Ascentria Care Alliance – Quaboag</u>

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** 

<u>Royal Norwell – Long Term Care Conservation</u>

**Wellman Healthcare Group, Inc** 

#### 2020

**Advocate Healthcare, LLC Amendment** 

Campion Health & Wellness, Inc. - LTC - Substantial Change in Service

<u>Heywood Healthcare, Inc. – Hospital/Clinic Substantial Capital Expenditure</u> <u>Notre</u>

Dame Health Care Center, Inc. – LTC Conservation

#### 2020

Advocate Healthcare of East Boston, LLC.

**Belmont Manor Nursing Home, Inc.** 

#### List of Special Focus Facilities

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

List of Special Focus Facilities and Candidates

https://tinyurl.com/SpeciialFocusFacilityProgram

Updated March 29, 2023

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

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

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

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

- Include the list of facilities in your area/state when providing information to consumers who are looking for a nursing home. Include an explanation of the SFF program and the candidate list.
- Post the list on your program's/organization's website (along with the explanation noted above).
- Encourage current residents and families to check the list to see if their facility is included.

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

### Massachusetts facilities listed (updated March 29, 2023) Newly added to the listing

• Somerset Ridge Center, Somerset

https://somersetridgerehab.com/

Nursing home inspect information:

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

South Dennis Healthcare

https://www.nextstephc.com/southdennis

Nursing home inspect information:

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

#### Massachusetts facilities not improved

None

#### Massachusetts facilities which showed improvement

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

Nursing home inspect information:

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

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

• The Oxford Rehabilitation & Health Care Center, Haverhill

https://theoxfordrehabhealth.com/

Nursing home inspect information:

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

Worcester Rehabilitation and Health Care Center, Worcester

https://worcesterrehabcare.com/

Nursing home inspect information:

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

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

Charwell House Health and Rehabilitation, Norwood (15)

https://tinyurl.com/Charwell

Nursing home inspect information:

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

• Glen Ridge Nursing Care Center (1)

https://www.genesishcc.com/glenridge

Nursing home inspect information:

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

Hathaway Manor Extended Care (1)

https://hathawaymanor.org/

Nursing home inspect information:

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

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

Nursing home inspect information:

https://projects.propublica.org/nursing-homes/homes/h-225412 Mill Town Health and Rehabilitation, Amesbury (14) No website Nursing home inspect information: https://projects.propublica.org/nursing-homes/homes/h-225318 Plymouth Rehabilitation and Health Care Center (10) https://plymouthrehab.com/ Nursing home inspect information: https://projects.propublica.org/nursing-homes/homes/h-225207 Tremont Health Care Center, Wareham (10) https://thetremontrehabcare.com/ Nursing home inspect information: https://projects.propublica.org/nursing-homes/homes/h-225488 Vantage at Wilbraham (5) No website Nursing home inspect information: https://projects.propublica.org/nursing-homes/homes/h-225295 Vantage at South Hadley (12) No website Nursing home inspect information: https://projects.propublica.org/nursing-homes/homes/h-225757 https://tinyurl.com/SpeciialFocusFacilityProgram **ProPublica** Nursing Home Inspect **Nursing Home Inspect** Data updated November 2022 This app uses data from the U.S. Centers for Medicare and Medicaid Services. Fines are listed for the past three years if a home has made partial or full payment (fines under appeal are not included). Information on deficiencies comes from a home's last three inspection cycles, or roughly three years in total. The number of COVID-19 cases is since May 8, 2020, when homes were required to begin reporting this information to the federal government (some homes may have included data on earlier cases). Massachusetts listing: https://projects.propublica.org/nursing-homes/state/MA **Deficiencies By Severity in Massachusetts** (What do the severity ratings mean?) # reported **Deficiency Tag** 250 В C 82 7,056 D 1,850 Ε 546 F 487 G Н 31 1 1 40 K **Centers for Medicare and Medicaid Services (CMS) Nursing Home Compare** Nursing Home Compare Website

	Beginning January 26, 2022, the Centers for Medicare and Medicaid Services				
	(CMS) is posting new information that will help consumers have a better				
	understanding of certain staffing information and concerns at facilities.				
	This information will be posted for each facility and includes:				
	Staff turnover: The percentage of nursing staff as well as the number of administrators who have stopped working at a nursing home over the past 12-month period.				
	nurses at a nursing home over a three-month period.  Posting this information was required as part of the Affordable Care Act, which was passed in 2010. In many facilities, staffing is lower on weekends, often				
	meaning residents have to wait longer or may not receive all the care they need.				
	High turnover means that staff are less likely to know the residents, recognize				
	changes in condition, or implement preferred methods of providing care. All of				
	this contributes to the quality-of-care residents receive and their quality of life.				
	https://tinyurl.com/NursingHomeCompareWebsite				
Data on Ownership of	Centers for Medicare and Medicaid Services				
Nursing Homes	Data on Ownership of Nursing Homes				
	CMS has released data giving state licensing officials, state and federal law				
	enforcement, researchers, and the public an enhanced ability to identify common				
	owners of nursing homes across nursing home locations. This information can be				
	linked to other data sources to identify the performance of facilities under common				
	ownership, such as owners affiliated with multiple nursing homes with a record of				
	poor performance. The data is available on nursing home ownership will be posted to				
	data.cms.gov and updated monthly.				
Long-Term Care Facilities	Massachusetts Department of Public Health				
Specific COVID-19 Data	Long-Term Care Facilities Specific COVID-19 Data				
	Coronavirus Disease 2019 (COVID-19) reports related to long-term care facilities in				
	Massachusetts.				
	Table of Contents				
	COVID-19 Daily Dashboard				
	COVID-19 Weekly Public Health Report				
	Additional COVID-19 Data				
	CMS COVID-19 Nursing Home Data				
DignityMA Call Action	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 – <u>State Legislative Endorsements</u> .				
	Support relevant bills in Washington – <u>Federal Legislative Endorsements</u> .				
	Join our Work Groups.				
	Learn to use and leverage Social Media at our workshops: Engaging Everyone:				
	Creating Accessible, Powerful Social Media Content				
	For this for ODI and Allian and A				
Access to Dignity Alliance	Email: info@DignityAllianceMA.org				
social media	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				
	Workgroup   Workgroup lead   Email				

The Dignity Digest Issue # 164 Page 35 November 28, 2023 www.DignityAllianceMA.org

Participation	General Membership	Bill Henning	bhenning@bostoncil.org		
opportunities with Dignity		Paul Lanzikos	paul.lanzikos@gmail.com		
Alliance Massachusetts	Behavioral Health	Frank Baskin	baskinfrank19@gmail.com		
	Communications	Lachlan Forrow	lforrow@bidmc.harvard.edu		
Most workgroups meet bi- weekly via Zoom.	Facilities (Nursing	Arlene Germain	agermain@manhr.org		
	homes)				
weekly via 200m.	Home and Community	Meg Coffin	mcoffin@centerlw.org		
	Based Services				
	Legislative	Richard Moore	rmoore8743@charter.net		
	Legal Issues	Jeni Kaplan	jkaplan@cpr-ma.org		
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2 , 2					
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	comments, please submit	t them to <u>Digest@Di</u>	ignityAllianceMA.org.		
Dignity Alliance Massachusetts	is a broad-based coalition	of organizations an	d individuals pursuing fundamental		

Dignity Alliance Massachusetts is a broad-based coalition of organizations and individuals pursuing fundamental changes in the provision of long-term services, support, and care for older adults and persons with disabilities.

Our guiding principle is the assurance of dignity for those receiving the services as well as for those providing them.

The information presented in "The Dignity Digest" is obtained from publicly available sources and does not necessarily represent positions held by Dignity Alliance Massachusetts.

Previous issues of The Tuesday Digest and The Dignity Digest are available at: <a href="https://dignityalliancema.org/dignity-digest/">https://dignityalliancema.org/dignity-digest/</a>

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