Dignity in Action: From Institutional Failure to Decentralized Empowerment

James Lomastro
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Everyone deserves to live a full life with dignity. Unfortunately, with healthcare for the elderly and disabled, dignity is often among the first values that are sacrificed.

But the good news is that another path is possible.

Since 2020, Dignity Alliance Massachusetts (DAM) has emerged as a grassroots coalition dedicated to dignified long-term care. Forged amid the suffering, deaths, and neglect that prevailed in nursing homes during the COVID-19 pandemic, this peer-led group is working to develop a model of care for nursing home residents, older adults, and people with disabilities that is guided by core principles of dignity, inclusivity, and collaboration.

A History of Care Neglect

To understand DAM's current work, it is crucial to understand institutional care's historical context. Initially, institutional care was perceived as a way of improving the care of individuals who were chronically ill, frail, or living with mental and physical conditions.

However, by the late 19th and early 20th centuries, these institutions had become little more than warehouses. Society deployed them to isolate and minimize those deemed different or inconvenient, effectively abandoning residents to the care of

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For advocates, institutionalization symbolized societal rejection, isolation, and neglect. It reflected an ableist and ageist ethic, one that marginalized and confined individuals, keeping them "out of sight and out of mind." Following the civil rights movement, many large centralized state-run institutions for people with disabilities and mental illness were eventually closed, and a new system of care emerged.

In the effort to close the larger facilities, smaller institutions, often labeled "homes," began to perform the same functions as their larger predecessors. Although some offered better care, they still perpetuated segregation, reinforcing ableism and ageism by keeping segments of society separate and apart—and one troubling trend has been the institutionalization of individuals with cognitive decline, further embedding a culture of "dementia."

Another significant shift was the emergence of privatized care. Many facilities came under the control of private entities contracted by the state, whose primary motive was profit. This profit-driven model often led to poor outcomes and scandals, as care quality was a lower priority than cost savings. This shift in care management is crucial in understanding the current state of care and what occurred due to COVID-19.

The Care Crisis Becomes Visible: COVID-19 and Nursing Homes

The COVID-19 pandemic revealed the inherent flaws in institutional care. The neglect, poor conditions, and systemic failings within these institutions led to devastating outcomes; nearly half of all deaths in the early days of the pandemic were among nursing home and long-term care patients.

While a Massachusetts Commission report had already documented problems in the nursing home system in 2019, the pandemic highlighted systemic failures in nursing home care and regulation in ways that no report could have done. In Massachusetts, a tragic COVID-19 outbreak at Holyoke Soldiers' Home, where 84 veterans died in a single facility, revealed complex and longstanding issues with institutional care. Ultimately, the state paid the veterans' families a minimum of $400,000 each as a settlement for its negligence.

At the same time, the state's strategy for managing hospital capacity during the pandemic involved using nursing homes as a "relief valve," sending infected patients into these facilities. Nursing home operators were incentivized to accept infected residents, yet personal protective equipment (PPE) was deemed too valuable to allocate in these settings.

For months, many nursing homes went without sufficient PPE or relied on what operators could independently procure. The result was catastrophic. Death tolls in nursing homes soared disproportionately compared to the general population. Massachusetts alone recorded over 8,600 deaths in long-term care facilities by March 2021, representing more than half of the state's total deaths. A year later, the national nursing home death toll from COVID-19 topped 200,000.

The federal administration's initial downplaying of the crisis contributed to a dismissive attitude toward its disproportionate effect on elderly and vulnerable populations. Public discourse often framed these individuals as expendable, enabling clusters of deaths to occur. There was insufficient intervention from regulatory agencies tasked with safeguarding those least able to protect themselves.

These outcomes were predictable. Nursing homes operate in a deregulated environment, with many owners prioritizing profits over care. Before the pandemic, this profit-driven approach led to cost-cutting measures, particularly in staffing and infection control, creating hazardous conditions. Advocates indicated that facilities were frequently understaffed by professional standards, and infection control protocols needed to be more adequately enforced. This combination of deregulation, profit-driven motives, and a lack of quality control set the stage for a "perfect storm."

While predictable, these outcomes were not inevitable.

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This situation highlighted advocates' claim that the crisis was preventable and the need for proactive measures in the future. As Margaret Morganroth Gullette, author of *American Eldercide*, wrote in *Dissent*, a New York state study found that "30 percent fewer residents died in unionized than in nonunionized facilities," a consequence, she adds, of better

worker treatment and stricter infection control practices.

Tragically, residents had no platform to voice their struggles or alert the public to their dire circumstances. Despite the staggering mortality rates among nursing home residents relative to their proportion in the general population, there has yet to be a comprehensive reckoning or systemic reform to address the root causes of these failures. This lack of action underscores advocates' calls for urgent change in the oversight and standards of nursing home care, and alternative organizational approaches for advocates.

Advocates Respond

For advocates for reform, particularly those focused on nursing home residents, the Holyoke Soldiers' Home became a focal point of outrage.

Organizing had begun in person before the pandemic. During COVID-19, advocates turned to digital and virtual platforms. These tools became powerful assets that accelerated advocacy work. Virtual platforms enabled advocates to connect across the state and leveled the playing field. Industry representatives, government officials, and advocates were forced to use the same tools and compete on the same platform, creating a more equitable environment for dialogue and advocacy.

Past exposés, such as those published by *The Boston Globe*, had had little systemic impact, but COVID-19 dramatically shifted the landscape. Moreover, the digital tools gave advocates an unprecedented capacity to organize and amplify their voices without requiring a central sponsoring organization or meeting place. This decentralized and digital approach emerged as a new and effective model for advocating for the needs of nursing homes and institutional residents across Massachusetts.

Dignity Alliance Massachusetts Develops a Decentralized Advocacy Model

From its beginnings, Dignity Alliance Massachusetts grew to include approximately 34 core members—representing a range of advocates including nonprofit organizations, healthcare professionals, and concerned citizens. This model not only demonstrates the potential of collective action using a digital platform but also provides a blueprint and model for other advocacy groups seeking to effect systemic change with minimal resources.

Unlike traditional advocacy models that rely on in-person meetings, DAM stands out with its unique digital framework. Drawing inspiration from decentralized autonomous organizations (DAOs)—commonly associated with blockchain and cryptocurrency communities—DAM operates with similar decentralized governance, even as it eschews blockchain or smart contract elements.

DAM's digital platform is not just a tool. Rather, it has proven to be key to its efficiency and inclusivity. By primarily operating on digital platforms, DAM minimizes operational costs and increases accessibility for members who face physical or financial barriers to traditional participation. This virtual space serves as a "town square," where stakeholders share information, insights, and experiences—and organize and advocate for systemic health policy reforms, making DAM a hub of activity and collaboration.

Joining DAM is a straightforward process. Once stakeholders, be they individuals or organizations, become members, they have an equal voice in policy decisions. The organization's collective and consensus-based governance embodies the democratic ideas of equity and fairness in DAO structures.

DAM's decentralized model also allows it to be highly adaptable, experimenting with practices and approaches that suit specific needs. Its digital framework has proven particularly beneficial for older adults, disabled individuals, and others with limited mobility or financial means who want to attend meetings or participate.

The virtual approach, in short, ensures that those directly impacted by its advocacy efforts have an accessible platform to contribute. It is also efficient, with online participation reducing administrative costs. The model allows for easy growth, and DAM can pivot quickly to address emerging issues and changing circumstances.

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Power to Reform

The DAO model has proven effective for DAM in advocating for the rights and wellbeing of older adults and individuals with disabilities in both institutional and community settings.

In response to the COVID-19 pandemic, DAM initially focused on addressing the dire conditions in nursing homes and other care facilities. One early achievement was lobbying successfully to end the practice of sending COVID-19-infected patients to nursing care facilities—a policy that had accelerated the spread of the virus, with devastating consequences.

DAM's advocacy extended to promoting alternatives to institutional care. Following the incident at the Holyoke Soldiers' Home, it played a critical role in securing a $400 million bond issue to fund housing options for veterans, emphasizing community-based models over traditional institutional settings. Although these efforts are ongoing, this initial win marked significant progress.

Additionally, DAM supported a class-action lawsuit against the state, resulting in a settlement that allowed 2,400 institutional residents the option to be discharged into community-based care—a major victory for personal autonomy and dignity.

Next Steps

Much more remains to be done. For instance, DAM continues to advocate for regulatory changes in nursing home operations, including those concerning staffing levels, infection control, and oversight.

DAM, of course, is not alone in recognizing how remote meeting technology, combined with decentralized decision-making, can reduce operational costs, speed mobilization and communication, and enable marginalized individuals to directly contribute to shaping the policies that affect their lives.

As the late Elandria Williams wrote for *NPQ* in 2020, "The real question we should be asking is: *How do we create the space and the conditions necessary for all the people that need and want to be here in our work, our lives, and in our communities to participate?"*

DAM's approach highlights how decentralized advocacy can help organizations promote health justice, advance structural and policy changes, and empower marginalized communities.

About the author

James Lomastro
James A. Lomastro, PhD, is a seasoned senior administrator with over 35 years of experie…