“Prisons for Sick People”: An Exploration of the Parallels Between Prisons and Nursing Homes

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Abstract

This brief documents parallels between the experiences of incarcerated individuals and nursing-home residents of color, particularly Black nursing-home residents. It describes three carceral themes present in nursing homes that restrict disabled people of color from transitioning into the community: limited freedom to venture outside, obstacles to transition, and nursing homes' systematic retribution against their own residents. Nursing homes consistently cited resident health and safety concerns to justify arbitrary and punitive restrictions. When residents did speak out and advocate for themselves and others, nursing homes redoubled their efforts to subvert those residents' autonomy.

Literature Review

Institutionalization in the United States traces its roots to at least as early as the 1600s, when communities confined individuals with mental disabilities to the attics, huts, and cellars of charity houses to "preserve the community" (Dershowitz, 1974). The first public psychiatric hospital in the nation, the Eastern State Lunatic Hospital, opened in 1793 in Williamsburg, Virginia (Appelman, 2018). Throughout the 19th and 20th centuries, the state continued to force individuals with mental disabilities into institutions where they remained isolated from the public in dilapidated, unhygienic, and overcrowded environments that resembled prisons (Appelman, 2018; Maisel, 1946; Goffman, 1961). Psychiatric hospitals peaked at 558,239 patients in 1955 before the deinstitutionalization movement began in the early 1960s (Appelman, 2018).

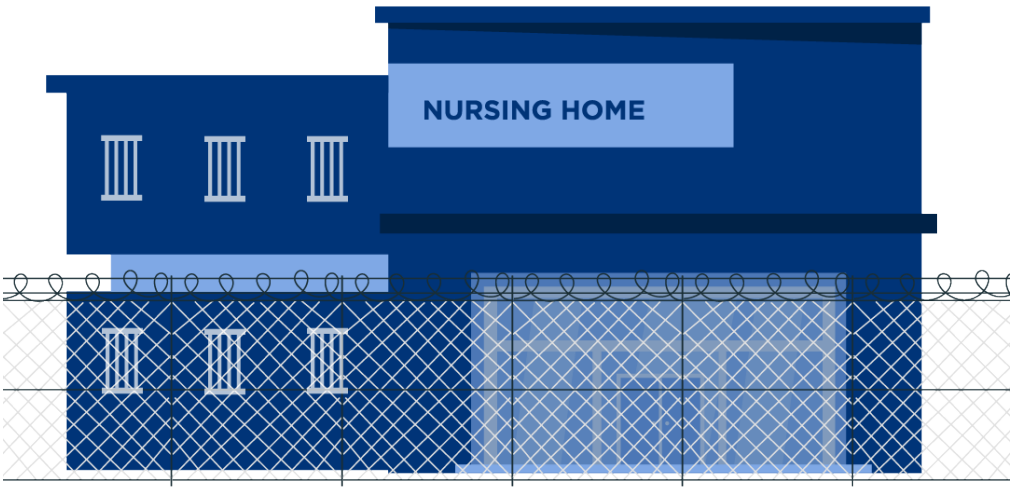
The legacy of state enforced isolation of disabled individuals continues in another type of institution: prisons. Although Lain (2024) and other scholars have cited deinstitutionalization as a direct cause of mass incarceration in the disability community, Patricia Erickson and Steven Erickson (2008) tie this phenomenon to a variety of other factors including the advent of the war on drugs in the 1960s and 1970s, tough on crime policies of the 1980s and 1990s, and cuts to mental-health care. From 1980 to 1992, the population of incarcerated individuals

with mental disabilities increased 154 percent (Ben-Moshe, 2014). A 2016 analysis of state and federal incarcerated individuals found that 66 percent of all incarcerated people had some form of disability (Bixby et al., 2022).

U.S. incarcerated individuals face widespread institutional mistreatment including "kangaroo court"[1] (Wang, 2024) style disciplinary hearings for often arbitrary rule violations, collective punishment, and retribution that dissuades individuals charged with a crime from filing grievances and punishes those who do (Wang, 2024; Keel, 2008; Betancourt, 2024). Incarcerated disabled individuals are at particular risk for arbitrary and severe punishment.

A 2005 federal court order found that incarcerated mentally disabled individuals from South Carolina were twice as likely to spend time in solitary confinement as incarcerated individuals without a mental disability (*T.R. v South Carolina Department of Corrections*). Although the United Nations classifies any solitary stay longer than 15 days as torture, incarcerated mentally disabled individuals from South Carolina spent on average 647 days in solitary confinement (*T.R. v South Carolina Department of Corrections*; United Nations, 2020). Another analysis of a state prison system found incarcerated mentally disabled individuals were 1.6 times more likely to experience violence inflicted by an incarcerated person and 1.2 times more likely to experience violence inflicted by staff, compared to incarcerated individuals without a mental disability (Biltz et al., 2008). Institutional retaliation is therefore prevalent in the U.S. carceral system, especially for incarcerated disabled people.

The available research on retribution exacted on nursing home residents who speak out against mistreatment illustrates similarities between nursing homes and prisons. A 2023 interview-based study found widespread retaliation in the form of neglect, physical abuse, sexual abuse, and verbal threats against nursing-home residents who spoke out about their treatment (Long Term Care Community Coalition [LTCCC], 2023). In Connecticut, 23 percent of nursing-home residents stated that they did not file a complaint out of fear of retaliation



[1] A kangaroo court refers to a proceeding in which the accused individual is presumed guilty and has no real opportunity to mount a defense.

(Robinson et al., 2007). Minnesota state ombudsman for long-term care, Cherly Hennen, stated that nursing-home retaliation was "a human rights issue" and that "vulnerable adults with complex medical issues are being retaliated against for the simple act of speaking up" (LTCCC, 2023).

Purpose of Study

The purpose of this brief is to examine how nursing homes restrict their residents' personal freedoms and explore parallels between nursing-home environments and prisons.

Methods

This study utilized a participatory action research approach (PAR). PAR is an approach that involves working with a community to do research on an issue that is important to them (Baum et al., 2006; Cornwall & Jewkes, 1995). It involves including the community at every step of the research (Baum et al., 2006; Cornwall & Jewkes, 1995). Researchers worked together with members of the disability community to create this study and center it around a prominent disability-rights issue—transition out of institutional settings into the community. An important component of this study was the insight of lived experience (LE) experts—disabled people of color who were involved in conducting the research study. There were five disabled people of color, and some had lived in nursing homes. The LE experts helped create the interview guide, did interviews, conducted data analysis, helped with manuscript writing, and supported sharing of findings.

Participants were 23 to 76 years old, with 38 percent between 20–50 years of age; 35 percent between 51–64 years of age; and 27 percent being 65 years and older. A little over 73 percent of the study population were Black/African American individuals. The remaining 27 percent of participants identified as Middle Eastern, Asian/Pacific Islander, Woman of Color, Latina, Puerto Rican, or "more than one race." The sample was almost evenly split across sex. Most individuals identified as having a physical disability (69 percent), followed by physical *and* psychiatric or mental disability (23 percent), psychiatric or mental disability (4 percent), and intellectual or developmental disability (4 percent).

All participants had experience living in a nursing home or rehabilitation facility, with 62 percent of individuals currently living in their own home, 31 percent living in nursing homes, and 7 percent living in supported-living facilities. Fifty-eight percent of participants lived on the East Coast, 31 percent lived in the Midwest, 8 percent lived in the South, and 4 percent lived on the West Coast. Participants' median length of institutional stay was 20 months, with a minimum of 2 months and a maximum of 420 months (35 years).

Positionality

I am an autistic researcher who faced arrest and prosecution when my disability was misinterpreted as a crime. Unlike the participants in this study, I am White and have never stepped foot inside a nursing home.

What Did We Find?

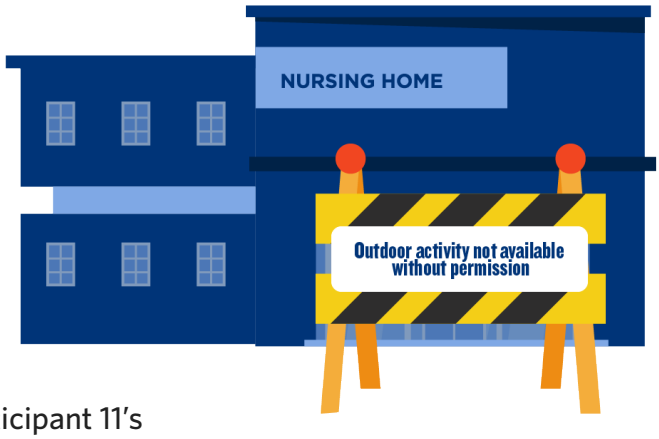
Parallels to Incarceration

Three participants explicitly compared the nursing homes they lived in to carcerality. Participant 6 stated that they "felt like that [they were] being enslaved" and that for them a nursing home is "just another form of violence, of slavery." Participant 9 believed that their nursing home's staff treated residents "like [they] were in jail." Participant 16 declared that nursing homes are "prison[s] for sick people."

Restriction on Movement

Five participants discussed how their nursing homes used arbitrary rules to restrict their freedom of movement. Participant 11 described how:

> We can't wander around. Before we tried to go out, we report ourselves to the person in charge.... Before we go out, we say the places we want to go to and they have been checked. If it's safe for going out, like the park, it's recommended we can go the park for breathing space.



Although the nursing home may have understandable concerns regarding residents' safety, it is clear from Participant 11's description that the nursing-home staff, rather than the residents themselves, make the final determination regarding what destinations they can visit in their communities. The nursing home's exercise of control is analogous to recreation time in a prison. Participant 11's experience also suggests that their nursing home does not collaborate with residents to facilitate outdoor activity, something that would likely be beneficial to residents' health.

Participant 1 also mentioned that their nursing home would not allow them to leave the building until "[physical therapy] comes to do this evaluation with [them]" and how they

were “a little set back by that.” If Participant 1’s nursing home was truly concerned about their physical health, they would allow them to build their strength on walks outside. Walking outdoors is often a valuable component of an outpatient physical therapy regimen as one likely cannot achieve optimal physical health confined to their home (Wohlrab et al., 2022). Participant 9 recounted how when one of their peers attempted to venture just outside their institution to feed birds, the staff “blocked that door off.” This nursing home demonstrated that in a quest to assert complete control over its residents' lives, it would not hesitate to crack down on any source of joy they may have.

Participant 12 described how their nursing home did not “allow them to bring in [their] wheelchair due to COVID protocols.” The resident further explained that they believed the nursing home enacted this restriction to prevent residents from “wandering the halls.” This suggests that residents are second-class citizens in their institutions just as incarcerated individuals are treated as second-class citizens. The notion that it is somehow better for the residents to remain trapped in their rooms and beds, while still at risk for COVID exposure from nursing-home staff who continue to leave at night and move freely throughout the facility, ignores the mental toll of social isolation and the physical risks of a completely sedentary lifestyle for months on end.

Participant 8 recalled how when they were a teenager, their nursing home forced them to go to bed at 7:00 p.m. and that they could only “verbally protest.” In the process, their nursing home robbed them of time during their teenage years where they could have socialized outside of their institution with their peers. Participant 8 further discussed how their nursing home reinforced their social isolation. They stated:

> Yeah, yeah. It was a contrast, and it was an eye awakening thing. I didn’t know you could lose friends that quickly. And I don’t blame them. It was something different. They were probably in shock too. I only had one friend that came to visit me and we’re still friends to this day.

Much like prison, Participant 8’s nursing home controlled when residents could leave, sleep, and socialize. Participant 17 lamented that they “do not know what it feels like to be in a wheelchair and live outside.” I have a lot of friends that tell me about life outside, and it is very hard.” The use of a wheelchair and living “outside” are not mutually exclusive. People in wheelchairs have the right to live full lives. However, the fact that Participant 17 needs to ask

others about what life is like outside suggests that the confines of their nursing home have served as prison walls.

Obstacles to Transition

Five participants encountered resistance from nursing-home staff when they attempted to transition into another living arrangement. Participant 20 described how the

> Social workers and the staff...did everything in their power not to release me, even to the very day of my release. They did not give my support planners all the information they needed to set my transportation, doctors, you know, kinds of things for after my release. Guidelines to be released.

If nursing homes collaborated with residents on a release plan, their efforts could help reduce government dependence, allocate government resources more efficiently (as in-home care is often cheaper), and promote patient welfare. Participant 2 stated that they "did not let any of the nursing-home staff stop me from going out in the community" and that they "went against medical advice" when they left their institution. They further stated, "People brought it up. How are you going to be able to manage your apartment with your physical disability?" In an ideal scenario, the nursing home would not only list systemic ableist barriers but rather collaborate with residents on how to overcome those barriers. Participant 2's experiences suggest that the nursing-home staff are not an aid, but rather a barrier to overcome in the transition process.

Participant 1 mentioned that the staff at their nursing home did not notify them that they were even eligible to transition out of their nursing home. In other words, they did not understand that leaving was even a viable option. Although participants were often hesitant to attribute their experiences to discrimination, Participant 26 explicitly compared their difficulty transitioning out of their nursing home to White residents who they believed were treated more respectfully by the largely White staff and "got out a lot faster." She suggested that this disparate treatment allowed White residents to transition out of their nursing home with greater ease than Black residents. Participant 4 relayed that when they offered guidance to another resident on the transition process, a nursing home staff member told them: "You can't give that information to people. You're stepping on other people's toes. That's the social workers' job." When they

then asked, “What if the social worker didn't give them the information?” the social worker responded, “Well, you can't give this information to them. That’s not your job.”

Participant 4 also believed that this restriction “was ridiculous but [the social workers were] always trying to push people to nursing homes versus community.” This repression suggests that Participant 4’s nursing home preferred residents remain completely ignorant of how to transition out of their institution and preferred that staff be the only source of information on the transition process. The starkest example of the poor treatment participants encountered is perhaps when Participant 15 implored the study interviewer to “just help [them] get out of this place.” This participant felt so entrapped in their nursing home they felt that the research staff, who they did not know before this interview and who lived in a different state, were their best available option to escape their nursing home. The participants’ combined experiences display a fundamental parallel between nursing-home environments and prison: the staff and institutions themselves are often designed to keep residents confined and isolated from society.

Retribution from Nursing Homes

Three participants described or suggested a system of outright retribution when they self-advocated for transition out of their nursing home. Participant 19 stated that if “you're being aggressive they'll send you to a psych facility and which maybe that would have been a good thing, because then maybe I could have got to a place where I would have gotten housing faster.” In this scenario, the nursing home’s administration used the psychiatric hospital setting as a threat against residents who dared advocate for themselves. Participant 14 also recounted gaslighting from their nursing home. They explained how when he “[requested] to speak to someone” or “[asked] a question,” he would be labeled “belligerent” and “a problem.” They further recalled that their nursing home even alleged to their mother that they were on heroin and crack cocaine when they requested to transition out of the nursing home to win the mother’s support for the continued institutionalization of her adult child. Both Participant 14's and Participant 19’s experiences suggest that their respective nursing homes would fabricate a psychological condition as retribution against residents who express a desire to live in an environment in which they could exercise greater autonomy.

According to Participant 20, "if you push, they'll make it look like you're the problem and they'll probably do everything they can in their power to make you end [up] back in the nursing home." Their experiences further reflect that nursing homes are incentivized to retain residents who wish to transition for financial gain. Participant 23 stated that their advice to other residents who wanted to leave a nursing home would be to follow "the rules here" and "[do] what you're told to do and don't offer too much — I guess just being polite, cordial, and going along with the program." A resident's level of compliance with arbitrary rules, often designed to constrict and suppress them, should have no bearing on their timeline to leave an institution. Here, this individual hopes that remaining compliant may help secure her release from a nursing home, similar to how good behavior is weaponized in prison.

Four participants described other forms of retribution within their respective nursing homes that were not related to a desire to transition. Participant 3 stated that a "a few people got fired when they tried to help [her]." They also recounted that their institution at one point limited the meals they received. Participant 3's experience is unique in that the retribution they witnessed extended to the nursing home's staff. This suggests that the nursing-home staff are also victims of the administration's oppression. Participant 9 recounted how when one of their peers was caught smoking in their rooms, the nursing home seized every resident's cigarette supply in a clear example of collective punishment. Participant 16 believed that their nursing home forced them to have a roommate who they "despised" as a "punitive measure." Much like incarcerated individuals, residents in Participant 16's nursing home do not have the option to choose who they live with: a fundamental right one has in the outside world. Participant 21 discussed how their nursing home was "trying to get rid of [them] because [they were] constantly calling, you know, telling the families what was going on," including the poor treatment they received. This illustrates that when residents do call attention to the mistreatment that they and their peers endure, they are punished and suppressed so that their advocacy does not undermine their nursing home's power. All these experiences imply that nursing homes, like prisons, have unchecked power to control and suppress their residents.

Conclusion

This brief demonstrates that the similar forms of ableism present in prisons and asylums also exists in nursing homes with vicious consequences for residents. As with any civil rights struggle, nursing-home residents and the broader disability community cannot fight this battle on our own. Although often invisible to the public, the daily indignities nursing-home residents suffer require urgent attention and action from the public, with consideration of intersections of race, class, and disability. Although the participants in this study are disabled

people of color, almost any American could one day find themselves disabled, drained of their savings, and vulnerable to the same abuse described here.

How to Cite This Brief

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