Social Isolation of Older Adults in Long Term Care as a Result of COVID-19 Mitigation Measures During the COVID-19 Pandemic

Protecting the Individual or a Means to an End?

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ABSTRACT

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In response to the threat of COVID-19, CMS issued unprecedented restrictions severely limiting the liberty of older adults residing in long-term care. Older adults are identified as at a high risk of becoming infected through exposure to SARS-Cov-2 and of suffering the most severe morbidity and mortality. While protecting the individual from disease, the restrictions also had a determinantal effect. The restrictions exacerbated social isolation and loneliness, two pervasive public health concerns within the older adult population. Legally, the restrictions pass constitutional muster. The ethical analysis presents more questions and debates. Initially, the restrictions to protect the older adult were grounded in public health ethics and bioethics principles. However, the ethical lines become blurred as the risk of harm secondary to isolation increased over the time that the restrictions remained in effect. The ethical point of view becomes more divergent considering the restrictions also preserved medical resources for the greater good of society, arguably diverting them to serve younger people. We have a moral obligation to reduce social isolation and recognize the older adult as a valuable member of society with equal worth and dignity.

INTRODUCTION

In response to the threat of COVID-19, CMS issued unprecedented restrictions severely limiting the liberty of older adults residing in long-term care. Older adults are identified as at a high risk of becoming infected from exposure to SARS-Cov-2 and from suffering the most severe morbidity and mortality. While protecting the individual from disease, the restrictions also had a determinantal effect. The restrictions exacerbated social isolation and loneliness, two pervasive public health concerns within the older adult population. Legally, the restrictions pass Constitutional muster. The ethical analysis presents more questions and debates. Initially, the restrictions to protect the older adult were grounded in public health ethics and bioethics principles. However, the ethical lines become blurred as the risk of harm secondary to isolation increased over the time that the restrictions remained in effect. The devastation of COVID-19 within the older adult population extends beyond the immediate risk and harm of infection.

At the beginning of the COVID-19 pandemic, experts determined that older adults, especially those living in long-term care, were at a greater risk of becoming infected and depleting scarce medical resources. Two days after WHO declared the pandemic, the Centers for Medicare & Medicaid Services (CMS) followed the Centers for Disease Control (CDC) recommendations and announced mitigation measures that required long-term care facilities

Keywords:

Pandemic, Long-term Care, Public Health, Resources, Social Isolation, Loneliness

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to (1) restrict volunteers and nonessential personnel from entering the facility; (2) cancel all group activities and communal dining; (3) screen residents and health care personnel for fever and respiratory symptoms; and (4) encourage residents to stay in their rooms. The social isolation resulting from the mitigation measures posed a credible threat to five core domains of healthy aging: (1) promoting health; preventing injury and managing chronic conditions; (2) cognitive health; (3) physical health; (4) mental health; and (5) facilitating social engagement.[1] (https://journals.library.columbia.edu/index.php/bioethics/workflow/index/8526/4/#_edn1)

I. Social Isolation and Loneliness

COVID-19 highlighted two pervasive public health concerns confronting older adults—social isolation and loneliness. Social isolation is an objective deficit in the number of relationships and the frequency of contact with family, friends, and the community.[2] (https://journals.library.columbia.edu/index.php/bioethics/workflow/index/8526/4/#_edn2) Social Isolation is a risk factor for loneliness. Loneliness is the subjective perception of a lack of meaningful relationships.[3] (https://journals.library.columbia.edu/index.php/bioethics/workflow/index/8526/4/#_edn3) Loneliness has three dimensions: (1) absence of a significant person to provide emotional support and affirm one's value as a person; (2) absence of a small group of people seen regularly, such as a card group; and (3) absence of a larger network group of people who provide support by being together as a group, for example, church services or rotary meetings.[4] (https://journals.library.columbia.edu/index.php/bioethics/workflow/index/8526/4/#_edn4) COVID-19 restrictions affected all three dimensions.

Social isolation can be as dangerous as smoking fifteen cigarettes per day, earning its designation as a public health priority.[5] (https://journals.library.columbia.edu/index.php/bioethics/workflow/index/8526/4/#_edn5) Isolation increases the risk of cardiovascular disease, obesity, anxiety, and depression. Loneliness can lead to depression, alcoholism, and suicidal thoughts.[6] (https://journals.library.columbia.edu/index.php/bioethics/workflow/index/8526/4/#_edn6) Some studies found that loneliness is also a factor in cognitive decline. For example, caregivers reported that 63 percent of older adults with cognitive impairment experienced cognitive decline during the COVID-19 pandemic.[7] (https://journals.library.columbia.edu/index.php/bioethics/workflow/index/8526/4/#_edn7)

In 2017, the American Association of Retired Persons (AARP) reported that social isolation accounted for $6.7 billion in additional Medicare spending although only 14 percent of older adults in the US reported being socially isolated.[8] (https://journals.library.columbia.edu/index.php/bioethics/workflow/index/8526/4/#_edn8) Approximately 24 percent of community-dwelling older adults in the US are socially isolated. Forty-three percent of adults aged 60 and older report feeling lonely. Those living in long-term care report loneliness at a rate of at least double of community-dwelling older adults.[9] (https://journals.library.columbia.edu/index.php/bioethics/workflow/index/8526/4/#_edn9)

WHO defines health as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity."[10] (https://journals.library.columbia.edu/index.php/bioethics/workflow/index/8526/4/#_edn10) A broad definition of health highlights the detriment of social isolation in older adults. There is a moral obligation to mitigate the effect of isolation.[11] (https://journals.library.columbia.edu/index.php/bioethics/workflow/index/8526/4/#_edn11) The additional Medicare spending costs attributable to the effects of social isolation secondary to COVID-19 will be extraordinary. Providing social support will directly benefit older adults and indirectly benefit society by reducing Medicare spending associated with the effects of social isolation. Combating the pervasiveness of social isolation requires immediate collaborative community action.

Many long-term care residents who depend on visits from family and friends to socialize increasingly felt lonely, abandoned, and despondent,[12] (https://journals.library.columbia.edu/index.php/bioethics/workflow/index/8526/4/#_edn12) increasing the risk of feeling grief and loss, including individual and collective trauma reactions.[13] (https://journals.library.columbia.edu/index.php/bioethics/workflow/index/8526/4/#_edn13) Also, normally social opportunities, medical, and legal appointments defaulted to telephone or virtual appointments. The cessation of in-person medical appointments interfered with optimal management of chronic conditions and preventive care. Some older adults lack access to the technology, are unfamiliar with technology, or cannot use technology for other reasons. At least one study supports the potential for older adults to benefit from technology and suggests that training could promote long-term benefits in older adults aged 80 years and over.[14] (https://journals.library.columbia.edu/index.php/bioethics/workflow/index/8526/4/#_edn14) Focusing on technological advances specific to older adults with input from older adults should be a priority.

When communal dining abruptly stopped, residents had to eat all their meals alone in their rooms. Older adults often mention the difficulty of eating meals alone, especially if recently divorced, widowed, or otherwise separated from a spouse or partner. Closure of the exercise facilities limited the ability of an older adult to stay physically active. Reduced physical activity creates long-term adverse health effects.[15] (https://journals.library.columbia.edu/index.php/bioethics/workflow/index/8526/4/#_edn15)

II. Measures to Mitigate Isolation

To facilitate some contact, long-term care facilities devised window visits. The resident remained safely inside the locked facility, standing or seated in front of a window. Visitors stood outside in the grass or parking lot. Any conversation took place over the telephone. To simulate physical contact, residents and visitors pressed their palms together, separated by the glass barrier. The window visits recall the prison visits depicted in movies and television.

In late June 2020, CMS relaxed the restrictions and advised that long-term care facilities could resume some communal activities and permit outdoor visits. Although CMS eased the restrictions, interpersonal contact remained minimal. Outdoor visits required scheduling an appointment during limited hours of availability. The facilities limited the visits per week and the duration of each visit to thirty minutes. In addition, the staff enforced wearing personal protective equipment and maintaining physical distancing.

Several impracticalities diminished the optimism of the relaxed restrictions. Residents could leave their rooms for meals but remained physically separated at a distance that prevented any meaningful interaction. Similarly, the limitations on the in-person visits presented problems. Non-resident spouses with mobility challenges found the outdoor access difficult, if not impossible. Residents or spouses with hearing and vision losses experienced challenges in communicating while sitting outside, six feet apart, and wearing masks.[16] (https://journals.library.columbia.edu/index.php/bioethics/workflow/index/8526/4/#_edn16)

III. Legal Precedent for Emergency Measures

The primary legal issue stems from the conflict between individual liberty and the public good or health. *Jacobson v. Massachusetts* provides a framework for balancing individual liberty rights and the public good during a pandemic.[17] (https://journals.library.columbia.edu/index.php/bioethics/workflow/index/8526/4/#_edn17)

Jacobson clarified an essential point of law - the rights and liberties secured by the US Constitution are not absolute.[18] (https://journals.library.columbia.edu/index.php/bioethics/workflow/index/8526/4/#_edn18) Faced with a pandemic, a community has the right to protect members of the community.[19] (https://journals.library.columbia.edu/index.php/bioethics/workflow/index/8526/4/#_edn19) *Jacobson* outlines four standards for imposing public health mandates during a pandemic. First, the State overreaches when it uses public health powers unnecessarily.[20] (https://journals.library.columbia.edu/index.php/bioethics/workflow/index/8526/4/#_edn20) Second, the state must use the least restrictive means to prevent harm.[21] (https://journals.library.columbia.edu/index.php/bioethics/workflow/index/8526/4/#_edn21) Third, the state must use reasonable means expected to prevent or ameliorate a health threat.[22] (https://journals.library.columbia.edu/index.php/bioethics/workflow/index/8526/4/#_edn22) Finally, the intervention must not pose an undue risk.[23] (https://journals.library.columbia.edu/index.php/bioethics/workflow/index/8526/4/#_edn23)

The guidelines in *Jacobson,* established during the smallpox pandemic, apply to COVID-19. In response to the threat of COVID-19, public health authorities enacted mandates to protect the public, especially older adults, against the highly contagious and virulent virus. The CMS restrictions specifically addressed older adults living in long-term care facilities. While the CMS directives obstructed residents' liberties, they also contradicted the Assisted Living Facility social model, which places autonomy and independence at the forefront.

Given the gravity of harm and the uncertainties in the early phases of the pandemic, the restrictions were arguably the least restrictive means to manage the immediate threat. The effectiveness varied from facility to facility, with many deaths throughout the US in long-term care facilities. While valuable early in the pandemic, at some point the continuation of the mitigation measures increased social isolation and its associated risks.

In *Jew Ho v. Williamson*, the Supreme Court overturned a quarantine order to contain the bubonic plague.[24] (https://journals.library.columbia.edu/index.php/bioethics/workflow/index/8526/4/#_edn24) The officials enforced the order only against a targeted ethnic population which did not present an identified risk.[25] (https://journals.library.columbia.edu/index.php/bioethics/workflow/index/8526/4/#_edn25) In reaching its decision, the Court determined that the quarantine order was not a reasonable regulation to prevent the spread of the bubonic plague. Rather, it was racially motivated. The Court ruled that the government cannot impose public health orders in a racially invidious manner.[26] (https://journals.library.columbia.edu/index.php/bioethics/workflow/index/8526/4/#_edn26) There are similarities between *Jew Ho* and the CMS restrictions. Like the quarantine order in *Jew Ho,* the restrictions targeted a specific population. But with COVID-19 older adults were an identified high-risk population because of their susceptibility to infection and severe illness. During the early phases of the pandemic, the directives were reasonable to accomplish the purpose of preventing the spread in the identified high-risk population. They were not discriminatory according to the rule of law in *Jew Ho*.

The argument supporting the constitutionality of the CMS restrictions wanes as the length of the safety precautions increased.

IV. Ethical Analysis of the Lengthy Social Isolation

The CMS restrictions require the ethical analysis of harm, proportionality, reciprocity, and transparency. As well as analysis under the principles of autonomy, beneficence, non-maleficence, and justice.

a. Harm and Proportionality

As previously discussed, older adult long-term care residents were more susceptible to COVID-19 and to severe physical effects requiring hospitalization. In addition, older adults are more likely to die from COVID-19. Based on a totality of the circumstances and what we knew about the virus in the early phases of the pandemic, the restrictions were the least restrictive means to protect this high-risk population. But the question of proportionality requires ongoing assessment and re-evaluation. While the initial uncertainty and chaos justified the restrictions, as the pandemic continued and the risk of harm from the restrictions increased, the pendulum began to swing. At some point, upon proof or likelihood of safety, less restrictive alternatives should have been adopted.

b. Reciprocity

The concept of reciprocity is a core principle of public health and requires the balancing of the benefits and burdens of the social cooperation.[27] (https://journals.library.columbia.edu/index.php/bioethics/workflow/index/8526/4/#_edn27) When individuals sacrifice their liberty for the benefit of others, they should not be penalized as a result of making the sacrifice, and thus society owes a reciprocal obligation to the individuals, such as providing individuals support and not discriminating against them.[28] (https://journals.library.columbia.edu/index.php/bioethics/workflow/index/8526/4/#_edn28)

Residents did not have any input or choice when CMS and the administrators stripped away their autonomy and liberties. While the restrictions protected the individual resident from the direct harm of infection, the restrictions also protected society from the indirect harm of the depletion of scarce medical resources. Public health officials identified long-term care residents as most likely to require significant medical resources. One talking point repeatedly broadcast was the need to prevent the depletion of hospital beds, ventilators, medications, and supplies. Most assisted-living facilities are for-profit, and residents pay for their food, shelter, and personal needs. What does society owe these long-term care residents in return for the liberty they sacrificed for the benefit of society at large? At the very least, I suggest we owe these individuals the commitment to conduct research exploring and addressing the effects of the restrictions.

c. Transparency by Government, the Media, and the Long-Term care Facilities

The communications from government and public health officials about the pandemic and the restrictions were opaque, leaving unanswered questions, doubts, and speculation. Some facilities provided families with basic information communicated through robocall messaging, with words of encouragement, painting rosy pictures of the residents' sequestered daily lives.

Public health officials assert the common good and protecting the public's safety and health justify paternalism and compulsory powers.[29] (https://journals.library.columbia.edu/index.php/bioethics/workflow/index/8526/4/#_edn29) One counterargument is that the compulsory interventions or restrictions push paternalism to new levels.[30] (https://journals.library.columbia.edu/index.php/bioethics/workflow/index/8526/4/#_edn30) The COVID-19 pandemic and the mitigation interventions highlight this tension between libertarian and epidemiological models based on (1) shortages that triggered rationing and prioritization; and (2) measures that safeguarded public health but infringed on individual rights.[31] (https://journals.library.columbia.edu/index.php/bioethics/workflow/index/8526/4/#_edn31)

d. Autonomy, Beneficence, and Non-Maleficence

Through a bioethical lens, we immediately see the clash between the CMS restrictions and the long-term care residents' autonomy. However, autonomy is not absolute. There was a benefit for the individual resident: the protection from a deadly virus. Thus, I argue that the initial restrictions were beneficent. Yet I also point to the deleterious secondary physical and emotional effects of the isolation and assert that the restrictions should have been safely modified as new information on viral spread and safety came about. We can accept the beneficence of protecting the high-risk resident from a deadly disease while acknowledging the associated harm. However, at some point, we must also ask if the harm experienced due to prolonged severe restrictions reached a level that exceeded the boundaries of beneficence and became maleficent.

Perceiving the long-term care resident as a passive recipient of care is paternalistic and antithetical to autonomy and a person-centered approach.[32] (https://journals.library.columbia.edu/index.php/bioethics/workflow/index/8526/4/#_edn32) Instead, society must recognize older adults as essential stakeholders in policymaking. The direct and active involvement of older adults allows the individual to retain agency rather than becoming a passive recipient of care.[33] (https://journals.library.columbia.edu/index.php/bioethics/workflow/index/8526/4/#_edn33) Prioritization of the older adult as an autonomous active participant counters ageism and promotes autonomy.

e. Justice

Justice calls for analysis of several discrepancies. First, the special protection of long-term care residents seems justifiable due to their special vulnerability. CMS treated long-term care facilities alike. Most community-dwelling older adults could decide whether to adhere to stay-at-home restrictions and were not subject to the same level of enforcement that existed within long-term care facilities. The restrictions were far more oppressive for long-term care residents. In response to the assertion that selective lockdown discriminates against older adults, the same arguments discussed above demonstrate the morally relevant justification: older adults are more likely to require hospitalization and die from COVID-19.[34] (https://journals.library.columbia.edu/index.php/bioethics/workflow/index/8526/4/#_edn34)

One convincing argument against restrictions on older adults echoing Kant's categorical imperative argues that selectively restricting older adults for the good of other people amounts to treating older adults as a means to an end for others.[35] (https://journals.library.columbia.edu/index.php/bioethics/workflow/index/8526/4/#_edn35) While the restrictions imposed on the individual might slow the spread of the disease within the specific long-term care facility, which protects that individual resident, they also impose on the individual resident to serve the greater good: the preservation of scarce medical resources. The second application pushes the restrictive measures closer to violating Kant's categorical imperative by treating the older adult as a means to the end of others. That is, younger people and those living outside of long-term care would have more hospital resources available to them if long-term care residents were more severely isolated keeping them from needing hospitalization.

From a Kantian perspective, the categorical imperative demands respecting the dignity of persons–Kant's supreme (formal) principle.[36] (https://journals.library.columbia.edu/index.php/bioethics/workflow/index/8526/4/#_edn36) When we consider the restrictions, I suggest that we must also consider the impact on dignity. It has been suggested that dignity is the "overarching principle of bioethics."[37]

(https://journals.library.columbia.edu/index.php/bioethics/workflow/index/8526/4/#_edn37) In the context of an analysis of the socially isolating COVID-19 mitigation measures on older adults in long-term care facilities, we should consider the relational aspect of dignity, recognizing the adult as having value and equal worth. The protracted imposed isolation of older adults to preserve medical resources devalues older adults. Ongoing COVID-19 restrictions should be analyzed for their unjustified harms.

A second justice concern outside the scope here is that long-term care facilities are resourced differently, and had different results due to quality of care, number of staff, infection control protocols, and previous health infraction records.

CONCLUSION

The myopic focus on mortality ignores the risks of morbidity secondary to the devastating effects of social isolation on the older adult's health and quality of life. The paternalistic prevention eclipsed the resident's autonomy. At some point, the attention and priority must shift. When formulating policies, we must figure out at what point or in which situations the negative impact of restrictions outweighs the protective benefits.

Although the restrictions may have slowed the spread of COVID-19, we must not discount the negative consequences, which may be long-term. From an ethical perspective, we must acknowledge the harm that has occurred within this population and accept the responsibility to redress the harm and prevent repeating the mistakes.

The prolonged restrictions stretched legal and ethical boundaries. The mixed purpose of the restrictions (protecting the individual resident and preserving healthcare resources) makes the ethical analysis more challenging. Yet doing something for someone's own good is still paternalistic and problematic. The public health justification includes the collective.

We must confront the tough questions about the efficacy of pandemic mitigation measures and the mitigation measures' adverse consequences. Leaving the doors to long-term care facilities open during the pandemic would have exposed every resident and staff member to a contagion that presented a significant risk of morbidity and mortality. But locking the doors exacerbated social isolation and loneliness, increasing the risk of morbidity and mortality. Julian Savulescu may be correct that there was no desirable solution. We must still work to find better solutions that will reduce social isolation and recognize the older adult as a valuable member of society with equal worth and dignity.

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The Devastating Effect of Lockdowns on Residents of Long-Term Care Facilities During COVID-19

A Survey of Residents' Families

JANUARY 15, 2021

The Devastating Effect of Lockdowns on Residents of Long-Term Care Facilities During COVID-19

A SURVEY OF RESIDENTS' FAMILIES

OVERVIEW

On March 13, 2020, the Centers for Medicare & Medicaid Services (CMS) issued a lockdown order, banning everyone but essential personnel from entering nursing homes. As a result, nursing home residents began a months long period of isolation - cut off from their families. Those who could, took advantage of electronic visitation, but because of a lack of resources or due to a resident's medical condition this was not always possible. The lack of family presence severely restricted the ability of families to monitor their loved one's care. Further compounding isolation was CMS barring state survey agencies and long-term care ombudsmen from entering homes.

From the start, Consumer Voice has been extremely concerned that nursing homes would not have sufficient staff to provide needed care to residents. For years, understaffing has been a problem in facilities. COVID-19 exacerbated these shortages. In addition, facilities have benefited from families providing care to residents-care the facilities themselves should have been providing. We feared that these factors, when combined with little or no oversight, would result in residents suffering and dying from neglect and isolation.

In September 2020, CMS eased the visitation restrictions and permitted visits under limited circumstances. This was the first time that residents and families could see each other in-person. Very quickly, Consumer Voice began hearing from family members that their loved ones were almost unrecognizable because of physical and mental decline. Families shared stories about residents who had lost extreme amounts of weight, not been washed, developed pressure ulcers, and suffered significant cognitive decline. To better understand the effects lockdowns were having on residents, we created a survey[1] asking families who had in-person visits to answer questions about their loved ones' appearance and functionality.

The results confirmed our concerns. Of the 191 respondents from across the United States, an overwhelming majority indicated that they had seen decline in both physical and mental conditions. Additionally, families reported that their loved ones were missing possessions ranging from glasses and hearing aids to wedding rings and clothes. Family members repeatedly noted the same issues - residents were unkempt, clearly had not been bathed or groomed in months, had lost significant weight, and were significantly depressed-even suicidal.

To prevent further suffering during this pandemic and in the future, Consumer Voice calls on Congress and federal agencies to address staffing; visitation; training and equipment; and oversight.

Key Findings

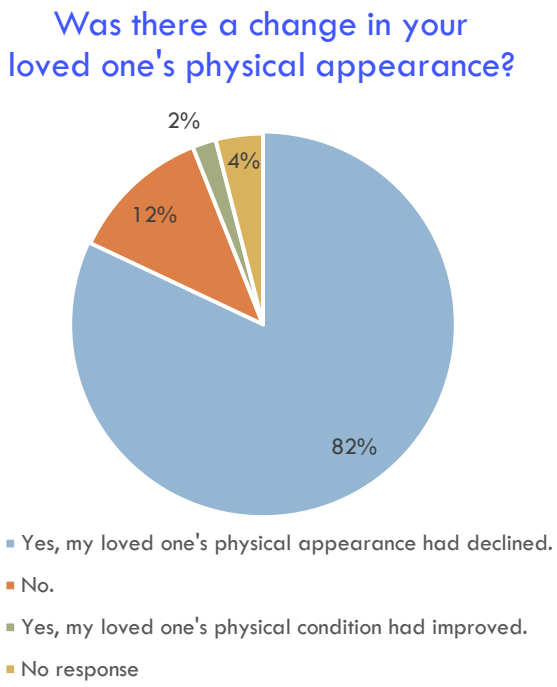
Of the family members who responded:

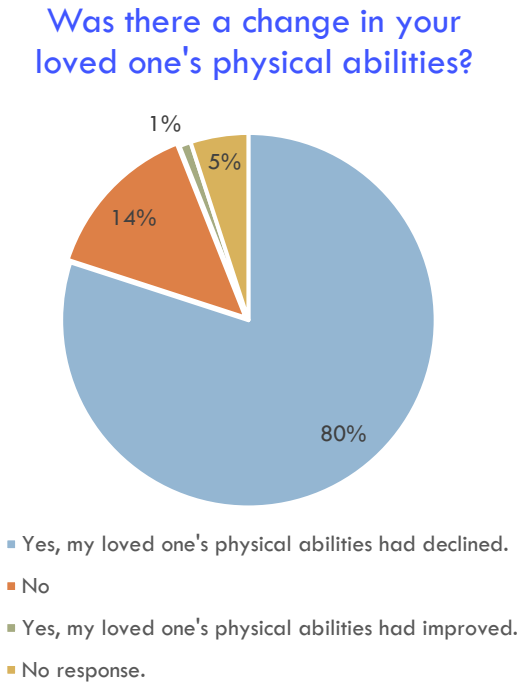
- **85%noted a decline in physical abilities.**
- **87% indicated their loved one's physical appearance had declined.**
- **91% of reported that their loved one's demeanor (mental status) had declined.**
- **40% indicated their loved ones were missing personal belongings.**
- **69% indicated the facility did not appear to have sufficient staff to care for residents.**
- **10% observed facility staff not wearing or properly using personal protective equipment (PPE).**

[1] https://theconsumervoice.org/issues/other-issues-and-resources/visitation/reentry-survey

Physical Decline

8 of 10 respondents indicated their loved ones had experienced physical decline. Among the problems family members reported were significant weight loss, bloating, weakness, and difficulty lifting objects and ambulating. Respondents also reported their loved ones suffered from pressure ulcers as a result of lying in bed for long periods of timewithout being repositioned.





What Family Members Said

"Horrible, so skinny and weak near death. Deprived of food, drink, activities and access to loves ones"

"Extreme weight loss…bedsores, extreme back pain. Kept in bed March 13 until October."

"My mom doesn't stand or try to walk as she used to before. She also had a bedsore."

"Declining cognitively due to severe weight loss."

"Not getting physical therapy or range of motion exercises. They keep his hands covered but once the sheet slipped and I was horrified at how contracted his hands are."

Resident Hygiene

In addition to physical problems, respondents reported significant and disturbing problems with their loved ones' hygiene. Residents were often unkempt, wearing dirty clothes, and disheveled. Some reported that teeth had not been brushed in months and that finger and toenails were long and dirty. Respondents noted how the failure to perform basic hygiene for residents contributed to despondency and cognitive decline.

"Mom's hair and nails haven't been cut in 7 months."

"Nails huge digging into her skin. No oral care. Room filthy and dusty. Cards we had sent were unopened and shoved in a drawer."

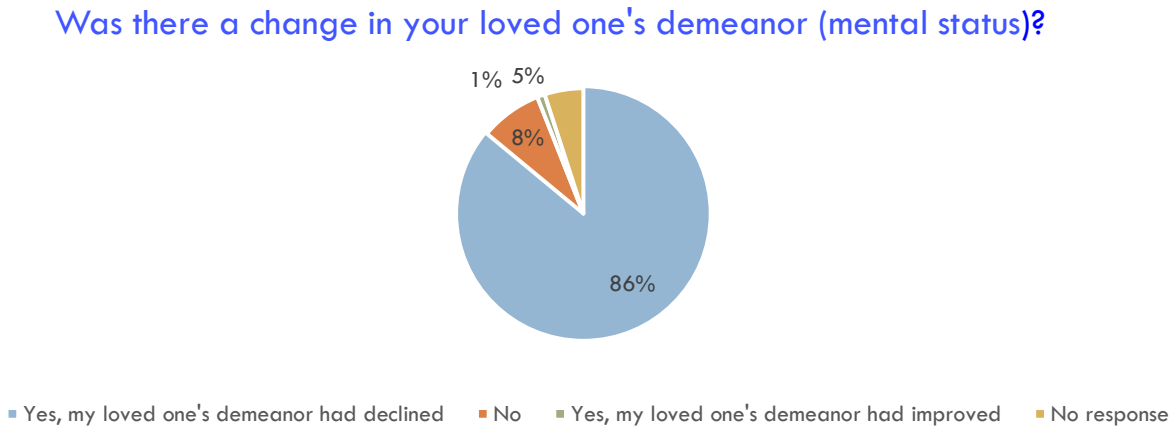
"Two of her regular teeth have turned brown. Her dentures were so beyond disgusting. I found out they had not brushed her teeth or cleaned her dentures since March 11."

"She has long dirty nails. Her hair was a greasy mess most days, causing mom to lose dignity. Mom asks why she is in prison.

"Besides looking depressed, he's unkept – his hair, facial hair, hands and toes."

Demeanor (Mental Status)

Only one respondent of all the persons surveyed indicated that their loved one had not experienced a decline in demeanor. Residents who, prior to the pandemic, were suffering from cognitive impairments, such as dementia, invariably declined. Families reported despondent residents who felt abandoned and did not understand why they had no visitors. Some residents expressed a desire to die rather than to continue living in isolation. Residents with cognitive impairments often rely on family, friends, and staff to help them cope with their declining mental health. Stripped of these supports, families reported precipitous declines, noting their loved one no longer recognized them or were completely unresponsive.



What Family Members Said

"Long term memory declined, started to believe that her stuffed animals could talk…Begging to be taken home."

"He was a very optimistic person. Now he frequently states 'this is not a way to live,' and cried."

"My mother doesn't understand why we can't be together. She is angry and upset most days and it is heartbreaking."

"Repeating same things over and over again. Can't remember names and information. Lack of stimulation."

"I just moved my dad home. He is screaming and crying now at night and when I leave to do errands. He says they just left him in a wheelchair all day long."

"Appears to be drugged, head hanging down, no or very little response when spoken to."

"Completely disengaged, disoriented, despair, left in same clothing and diaper days in a row…crying to be taken home."

"She said she has felt like she is in prison. She has been locked in her room for over a month never leaving and only having contact with people when they brought or picked up her meal trays."

Missing Possessions

43 % of respondents indicated residents were missing personal effects, such as eyeglasses, hearing aids, dentures, clothes, and jewelry. Adding to the isolation of being locked down in their rooms, some residents could not hear or read for weeks or months on end. Residents whose dentures were lost were forced onto mechanical diets of chopped, ground and pureed food because they could not chew their food. Some families were forced to pay thousands of dollars to replace hearing aids, clothes, and glasses. Many respondents noted that their loved one had been constantly moved between rooms because of COVID and that during these moves belongings often went missing.

What Family Members Said

"The facility lost hearing aids twice, making the isolation worse."

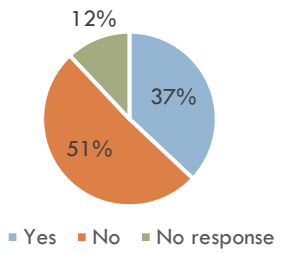
"Her wedding band disappeared the last week she was there."

"Three pairs of prescription glasses lost in six months, new dentures lost, and shoes lost."

"Two pairs of hearing aids. One dental plate."

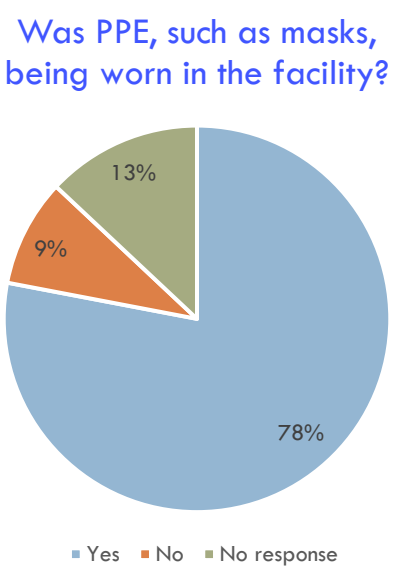
"She was missing her manual wheelchair for a month."

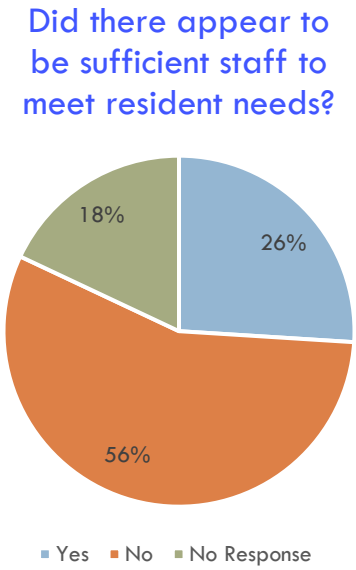
Was your loved one missing any personal belongings?



PPE Use and Staffing

We asked family members and loved ones to report whether they believed there was sufficient staff and whether staff were properly using PPE and following infection control procedures. Over half of respondents indicated that there did not appear to be sufficient staff to care for residents. Over 9% of respondents indicated they observed staff not wearing PPE, including masks, nor following appropriate infection control procedures.





"There was one nurse who worked 11 p.m. to 7 a.m. who never wore a mask."

"I have observed several people on camera inside my grandmother's room without masks on."

"Not enough staff, nurses station frequently un-manned, phones not always answered."

"The nurse manager had no mask and he walked from one unit to another."

"CNAs always working doubles. 1 CNA for 15 residents."

"One staff member in particular was not wearing even a mask, and she angrily stalked the hallways glaring at me."

Conclusions and Recommendations

Much of the focus of the impact of COVID-19 on nursing home residents has been on the physical effect of the virus itself on residents. Yet based on family reports, it is clear that the lockdown and resulting isolation have taken an unquantifiable toll on residents. A recent article[2] by the Associated Press detailing the disastrous effect lockdowns have had on residents estimated that there have been 40,000 excess deaths not attributable to COVID-19 in nursing homes in 2020 as compared to 2019.

Much of the harm is the result of facilities not having sufficient staff to provide required and necessary care and inadequate training of exisiting staff. Years of short-staffing by facilities and their reliance on family members to provide care proved to be catastrophic when nursing homes' doors shut in March. A significant amount of this suffering could have been prevented with adequate investment in staff and training by nursing homes.

Immediate steps should be taken to help prevent further suffering. The federal government, along with the states, should:

- **Staffing:** Invest in staff of long-term care facilities by increasing wages, providing hazard pay, benefits, and child care for staff. Require that any additional relief funds provided by Congress to nursing homes be used for increasing staff, obtaining PPE, and testing.
- **Visitation and Compassionate Care**: Enforce guidance from CMS requiring all facilities to allow compassionate care visits for residents who are experiencing decline. Ensure that all facilities are following the least restrictive visitation policies possible.
- **Training and equipment**: Ensure all facilities are provided necessary PPE and testing supplies. Hold facilities accountable for training staff in proper infections control procedures.
- **Monitoring and Oversight:** Immediately restart all annual and complaint surveys. Surveys must be comprehensive and assess facility conditions and resident care during all visits. As tens of thousands of nursing home residents died, state and federal regulators were absent from homes, compounding the tragedy.

It is likely we will never know the full extent of the horrors residents experienced or the true number of residents who died as a result of facilities being locked down. But we can take action now to save thousands of lives and stop avoidable and unspeakable suffering; we owe this to residents and their families.

The National CONSUMER VOICE for Quality Long-Term Care formerly NCCNHR

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[2] https://apnews.com/article/nursing-homes-neglect-death-surge-3b74a2202140c5a6b5cf05cdf0ea4f32

Limitations on Visitation Continue to Harm Nursing Home Residents

A SURVEY OF RESIDENTS' FAMILIES

JUNE 2021

NATIONAL CONSUMER VOICE FOR QUALITY LONG-TERM CARE

Limitations on Visitation Continue to Harm Nursing Home Residents

A SURVEY OF RESIDENTS' FAMILIES

OVERVIEW

In January 2021, the Consumer Voice released a report detailing the devastating effects on nursing home residents of visitation bans that had been imposed starting in March 2020 by the Centers for Medicare & Medicaid Services (CMS). Effects included significant physical and mental decline, with residents suffering and dying from neglect and isolation. Since then, CMS has gradually eased its guidance on visitation restrictions, with major changes in March 2021. However, despite the revised guidance, the proven efficacy of the vaccines, and the accompanying decline in COVID-19 cases and deaths, families and residents continue to face significant barriers to visitation, and residents continue to suffer from isolation and neglect.

The primary reason for continued limitations on visits is the almost complete discretion afforded facilities by the CMS guidance. Facilities persist in imposing their own visitation policies that restrict the length, frequency, and location of visits. These restrictions are commonplace even though the guidance states that facilities should allow indoor visitation at all times and for all residents, except in certain limited circumstances. Even when in-person visitation is allowed, visits are too short and infrequent to meet the significant needs of residents.

In May 2021, Consumer Voice began surveying families regarding their recent visitation experiences. Our survey found that families continue to face arbitrary barriers to visitation, such as time and frequency limits, and where the visits take place. Families also indicated that their loved ones were still significantly declining, both physically and mentally.

This report documents the responses of 392 family members, and contains Consumer Voice's recommendations, which include the full restoration of the resident's right to receive visitors.

KEY FINDINGS

- 77% of respondents indicated they were able to visit inside the facility with their loved ones.
- 88% of respondents indicated they were required to schedule a visit with their loved ones.
- 73% of respondents stated the facility did not require they be tested for COVID-19 before visiting with their loved ones.
- Only 62% of respondents stated that the facility allowed them to touch their loved ones.
- 76% of respondents indicated that the facility limited the length of their visits, while 63% stated the frequency of their visits was limited. On average, visits were 40 minutes and occurred only twice a week.
- 78% of respondents indicated that their loved ones had experienced physical decline.
- 79% of respondents indicated that their loves ones had experienced mental decline.
- 56% of respondents stated that visitation had been shut down temporarily at least once since March 2021, the date of CMS's most recent visitation guidance.
- 69% of respondents indicated the facility did not appear to have sufficient staff to care for residents.

FAMILY EXPERIENCE WITH VISITATION

While infrequent and short, 77% of respondents indicated that they were able to visit inside with their loved ones. 88% of respondents reported that they were required to schedule a visit to be with their loved ones. Many families complained that visitation only occurred during the week and when they were working, making it impossible for them to visit. Families faced other significant barriers as well, such as being prevented from touching their loved ones or being unable to visit in their rooms. Almost 8 in 10 respondents found that residents had experienced significant physical and mental decline, which they attribute to over a year of isolation and insufficient care.

Vaccination and Testing

CMS guidance states that facilities may not require visitors to be vaccinated. Nevertheless, 8% of respondents indicated the facility required them to be vaccinated before visiting their loved ones. Although this is contrary to the CMS guidance, family members obtained the vaccine so they could be with their loved ones.

Only 25% of families stated that facilities required them to be tested prior to visiting inside with their loved one, with 68% of those families indicating the facility provided the testing. The CMS guidance does not require testing, but many families agreed to be tested out of desperation to see their loved ones.

Visit Length and Frequency

76% of family respondents replied that facilities placed a time limit on the length of their visits, with those visits averaging roughly 40 minutes. 63% of families revealed that facilities were placing limits on the frequency of their visits, with visits averaging 2 times per week. Families expressed extreme frustration with these limitations, believing that more frequent visitation could help prevent further physical or mental decline, and help improve residents' well-being and functioning.

Location

Only half of respondents were able to meet with their loved ones in their rooms, with only 63% indicating the visits were private. Most respondents were frustrated at being barred from visiting in their loved one's rooms for several reasons. First, families wanted to be able to see the room to ensure their loved ones were in a clean and safe environment. Second, families expressed concern that their loved ones were missing items, such as glasses, dentures, clothes, and valuables, and they wanted to search for them. Finally, prior to the pandemic, many families provided significant assistance with activities of daily living, such as feeding, bathing, and dressing. Such assistance cannot be given if the resident is not in their own room.

Touch

Despite explicit language from CMS and the CDC that allowed families and residents to touch each other, only 62% of respondents indicated that they were allowed to touch their loved ones, with 33% of families stating that the facility did not allow them to touch. Numerous families were required to remain six feet away from their loved ones, which impeded communication and frustrated residents. Many residents have not been hugged by family for more than a year.

Personal Protective Equipment

48% of families indicated that facilities required PPE and provided it to visitors, such as masks and gowns. 39% of families stated the facility required them to provide their own PPE. 7% of families indicated there was no PPE requirement.

Visitation Continues to be Shut Down

56% percent of respondents reported that visitation in their loved one's facility had been shut down during an outbreak at least once in the previous two months. Many families attributed the shutdowns to unvaccinated staff members.

Significant Problems with Compassionate Care Visitation

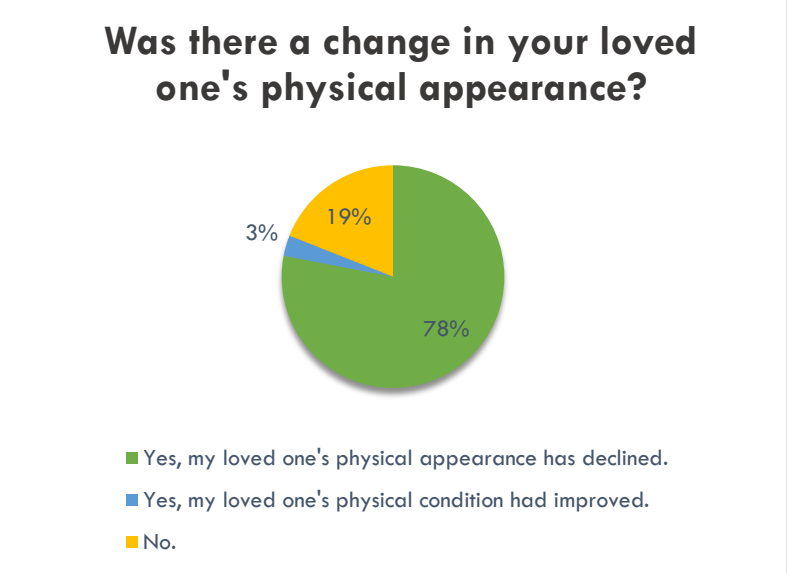
CMS guidance explicitly states that compassionate care visits must be allowed at all times, even when there is an outbreak. Further, the guidance is clear that compassionate care visitation is not just for residents who may be approaching death, but for residents who undergoing a variety of experiences, including grief, loneliness, or depression. Despite this guidance, many families stated that the only reason they were allowed to visit with their loved ones was because the facility considered them compassionate care visits. Yet, even then, facilities were limiting the frequency and length of visits, often to only twice a week and for short periods of time.

Quotes from family members:

- *"The facility makes you feel like she's in prison and they're the wardens and not like they want you to be there with your family member at all."*
- *"Married 57 years and watching his decline thru a window. The saddest time in both our lives. Visiting at a table 6 feet apart in masks, I can't hear a word he says. Cruel!"*
- *"Visitation is only M-F from 1 to 3 pm. This means that most working family members cannot visit at all."*
- *"I usually stay about 10-15 minutes because it's uncomfortable to have a staff member sitting in the room while I'm trying to talk to my mom. My mom is in an advanced stage of disease, but I would still prefer to have a private visit with her."*
- *"We have been vaccinated, my loved one and her roommate have both been vaccinated, and yet we still cannot go in their room."*
- *"We are still told no compassionate care visits. We have read the facility guidelines on visits but the facility claims they follow the state guidelines."*

IMPACT ON RESIDENTS

Physical Decline



Like Consumer Voice's earlier family survey, 78% of respondents indicated their loved ones had experienced a decline in their physical appearance, with many of those reporting significant declines in physical ability. Families complained that loved ones had lost significant weight and the ability to lift and carry objects. Respondents continued to report that their loved ones suffered from pressure ulcers from lying in bed for so long. One family member reported that her mother developed a pressure sore on her toe that became gangrenous. As a result, her mother had to undergo a partial leg amputation.

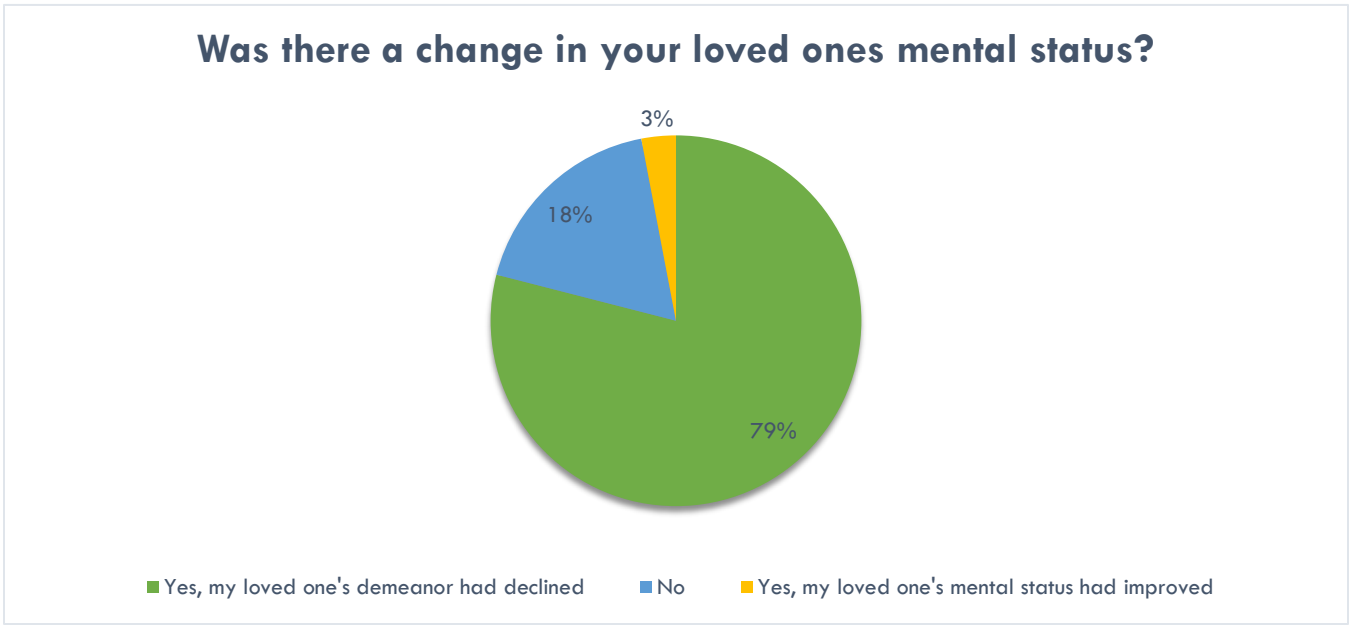
Quotes from family members:

- *"Horrible so skinny and weak near death. Deprived of food drink activities and access to loved ones."*
- *"Extreme weight loss…bedsores, extreme back pain. Kept in bed March 13 until October."*
- *"My mom doesn't stand or try to walk as she used to before. She also had a bedsore.*
- *"Declining cognitively due to severe weight loss."*

COGNITIVE AND MENTAL HEALTH DECLINE

For months, most residents spent each day shut in their own rooms with little to no interaction with family or other residents. As a result, loneliness, depression, and cognitive decline took an extreme toll on residents. 79% of families reported that their loved ones felt abandoned, seemed depressed, and in some instances, suicidal. Residents with dementia and other cognitive impairments suffered precipitous declines, often being disengaged or completely unresponsive.

Notably, these responses mirrored previous responses from Consumer Voice's earlier survey in January 2021. Almost six months after documenting such significant declines in residents, the problem persists.



CONCLUSIONS AND RECOMMENDATIONS

Much has changed since Consumer Voice issued its previous report on visitation in January 2021. COVID-19 cases and deaths are at an all-time low. Vaccination has proven to be effective and safe. CDC has eased masking and social distancing requirements. Importantly, CMS has loosened its visitation guidance.

Yet while the risk of contracting and dying from COVID-19 has significantly decreased, the risks from isolation, loneliness, and neglect continue. This is because the changes in the guidance have not translated into significant improvements for residents. Connection between residents and their families is negatively affected by arbitrary limits imposed by facilities on the length, frequency, and location of visits.

Prior to COVID-19 families played a crucial role in assisting residents by providing direct personal care, companionship and/or emotional support. This support, often provided daily, was essential to maintaining resident well-being and health. Now, restrictions, such as a 40-minute visit only two times per week, make it impossible for family members to provide the assistance necessary to prevent decline in residents. Further, compassionate care visits, designed to be the way in which residents who were declining or in distress could receive visits from their family members, have not achieved this purpose since these visits are often denied or severely restricted.

Quotations from loved ones and family members:

- *"Very subdued, not alert, sleeping in wheelchair, very short attention span, completely withdrawn."*
- *"Despondent, depressed, angry. Did not get out of bed whereas before was very physically active, cried a lot. No interest in favorite things."*
- *"Extreme depression, crying jags, extreme fatigue."*
- *"My father can no longer hold a conversation. He is depressed, angry, and refers to the facility as a prison. No longer knows me. Flat affect- no smiles or facial expressions."*
- *"Can't understand anything she says- no longer speaking in real words."*
- *"Complete disconnect. From her surroundings and me. Formerly happy and now looks sad, distant. Formerly social butterfly & telling jokes, now appears nonverbal."*

The guidance fails to address the needs of residents who require regular, ongoing visits the most. The family survey results indicate that very little has changed for far too many residents since our January 2021 report. The physical and cognitive/mental health status of residents continues to decline; residents continue to suffer from isolation and neglect; and residents continue to die.

Further revision of the guidance is not the answer since the wide latitude given to facilities regarding visitation policies and the failure to enforce the guidance would only result in the same problems.

The time has come for the visitation restrictions to be completely lifted. After more than a year of prohibitions and limitations, residents need the ongoing presence and care of family and friends that can only come with unrestricted visitation. Consumer Voice, along with other advocacy groups, is calling on CMS to restore full visitation rights to nursing home residents without delay.

In addition to the full restoration of visitation, Consumer Voice makes the following recommendations:

Visitation

- Pass federal legislation giving each nursing home resident the right to designate two essential caregivers who can visit the resident to provide care and support during any public health emergency (currently HR 3733; 117th Congress).

Staffing and workforce

- Strengthen the direct care workforce by (a) increasing compensation, including hazard pay; and (b) improving access to affordable health insurance, paid family and medical leave, paid sick leave, and affordable childcare.
- Require a minimum staffing standard of at least 4.1 hours per resident day.
- Require 24-hour registered nurse presence in all nursing homes.
- Increase required nurse aide training to a minimum of 150 hours.
- Establish a robust enforcement mechanism to ensure adequate staffing levels.

Infection Prevention and Control

- Require a full-time qualified Infection Preventionist in all facilities.
- Require enhanced training on infection control.

As we move forward, we must ensure that the tremendous suffering and loss of life residents have experienced for far too long ends, and that residents are never again without supports during a public health emergency. We must also commit to dramatically improving how nursing home care is delivered in our nation. We owe it to the thousands of residents who suffered and died during the pandemic to guarantee that those who survived, as well as future residents, receive the quality of care and quality of life they so deserve.