The Impact of Covid-19 Pandemic Policy Decisions on the Wellbeing of Nursing Home Residents in Missouri

Jera White

HRTS W3996 Human Rights Thesis Seminar- **Spring, 2022**
Institute for the Study of Human Rights
Columbia University

ABSTRACT

The Impact of Covid-19 Pandemic Policy Decisions on the Wellbeing of Nursing Home Residents in Missouri

Jera White

Residents in nursing homes have been particularly affected by the Covid-19 pandemic as their living situations and health statuses render them especially vulnerable to serious illness from the virus. Federal and state governing bodies have made policy decisions over the last two years that attempted to protect residents and staff in these facilities from Covid-19 infection. The prevailing literature argues that pre-existing issues in the nursing home sector, such as staffing shortages, oversight failures, design flaws, underinvestment, and ageism, were exacerbated by the Covid-19 pandemic, causing care quality to decline. This project argues that certain policy decisions made specifically to address the challenges of the pandemic also contributed to reductions in care quality in these spaces. While these policies were largely successful at reducing the spread of Covid-19, they inadequately accounted for the unique needs of nursing home residents, such as socialization and access to health advocates, and as a result, were the source of new deficiencies in care delivery and resident wellbeing. The thesis concludes by discussing two new policies that represent positive steps toward rectifying the mistakes made during the pandemic and building a safer future for nursing home residents.

Table of Contents

List of Figures

ACKNOWLEDGEMENTS

I am extremely grateful to my supervisors Dr. Andrew Nathan and Dr. Tracey Holland for their invaluable guidance and continued support during this project. I would also like to thank my human rights senior seminar classmates for all their advice and encouragement. Finally, I would like to express my appreciation for the time, support, and confidence my friends and family graciously gave to me throughout the completion of this work.

I. Introduction

Michelle Gralnick spoke through tears as she testified in front of the Missouri Senate Seniors, Families, Veterans, and Military Affairs Committee on March 2, 2022. Both of her parents, who had resided in long-term care facilities in Missouri for nearly a decade, had died during the Covid-19 pandemic. Herbert and Rhoda Gralnick were both artists and teachers, as well as valued members of their community. Their daughter described how their final months of life were marred by preventable infections, unanswered phone calls to an understaffed nursing facility, and isolation from those they loved most. During her testimony, she explained that while her parents did not die of Covid-19 infection, she believes they died "as a result of the pandemic and the inadequacies and failures of our nursing home system to properly care for them."[1] The Gralnicks' story is just one of many stories of neglect and mental anguish that have emerged across the U.S. as a result of changes to the conditions in nursing homes since the beginning of the pandemic in March, 2020. Accounts of dramatic weight loss, preventable infections, lack of dental and hygiene maintenance, and increased sedation only scratch the surface of what seems to be the shared experience of many patients in these facilities.[2]

For nearly two years, the Covid-19 pandemic has caused wide-spread suffering and loss of life, particularly among the most vulnerable members of society. There are many ongoing studies as to what factors increase the likelihood of virus contraction and severity of illness, with data indicating that people over the age of 65 residing in care facilities are especially at risk.[3] Given this information, many efforts have been made over the past two years to prevent or

[1] *Senate Bill 671 Hearing, Before the Missouri Senate Seniors, Families, Military, and Veterans Affairs Committee,* 101 Assembly, (2 March 2022) (statement of Michelle Gralnick).
[2] Matt Sedensky and Bernard Condon, "Not Just COVID: Nursing Home Neglects Deaths Surge in Shadows," *Associated Press,* November 19, 2020, https://ap-news.com/article/nursing-homes-neglect-death-surge-3b74a2202140c5a6b5cf05cdf0ea4f32.
[3] Bart G. Pijls et al., "Demographic risk factors for COVID-19 infection, severity, ICU admission and death: a meta-analysis of 59 studies," *BMJ Open* 11, no. 1 (2021): https://doi.org/10.1136/bmjopen-

eradicate the presence of the virus in these settings. This thesis argues that some of the policies which emerged as a part of pandemic response efforts inadvertently deprioritized or made more difficult adherence to day-to-day quality of care and life standards in nursing homes. This is especially important considering the knowledge that prior to the pandemic, nursing homes had a long history as places prone to fostering abuse and neglect.[4] To move into a future in which nursing home residents are always safe, supported, and treated with dignity, it is imperative that we examine the repercussions of every policy decision which affects them and strive to learn from both the failures and the successes.

II. Research Question and Significance

This thesis argues that some policy decisions at the state and federal levels made in response to the Covid-19 pandemic increased the potential for reduced quality of care in Missouri nursing homes. For the purposes of this research, the term "nursing home" refers to Medicaid and Medicare funded skilled nursing facilities and nursing facilities. In order to address this question, the research first reviews pandemic related measures taken by relevant governing bodies that affected numerous aspects of nursing home operation. It then evaluates the areas in which nursing home residents and their loved ones experienced challenges during the pandemic. The information regarding policy decisions and the experiences of residents is then brought together for an analysis of the appropriateness and efficacy of those decisions. Finally, the research investigates early steps being taken to ensure that nursing homes are better prepared for emergency situations in the future through a review of recent policy proposals. This project

2020-044640.

[4] David A Bohm, "Striving for Quality Care in America's Nursing Homes: Tracing the History of Nursing Homes and Noting the Effect of Recent Federal Government Initiatives to Ensure Quality Care in the Nursing Home Setting," *DePaul Journal of Health Care Law* 4, no. 2-3 (2001): 317-366.

specifically investigates these questions in regard to the state of Missouri, as it offers a representative case study due to its mixture of urban and rural environments, its relatively mid-sized population, and its varying leadership in terms of political parties.

The significance of this research is as follows. In the coming decades, the United States will harbor the largest population of elderly individuals in its history.[5] The Covid-19 pandemic has not only highlighted existing insufficiencies in the nation's healthcare systems but has also exacerbated them. The same can be expected in future health emergencies if no course corrections occur. Presently, the majority of research surrounding the pandemic and nursing homes is focused on virus transmission and virus-related illness. There is a risk that the lived experiences of nursing home residents regarding their care and the violation of their rights will be overshadowed or unaddressed if their stories are not given platforms and the conditions that culminated in these events are not investigated. It is therefore a goal of this research to promote discussion about the challenges faced by residents and analyze the role that policy decisions played in mitigating or aggravating these challenges.

III. Literature Review

Literature on the subject of changes to resident wellbeing and care quality in nursing homes over the past two years is somewhat limited due to the recent and ongoing nature of the Covid-19 pandemic. However, a handful of early studies provide important insights into the prevalence and types of changes to care provision and quality of life that occurred in nursing homes. Human Rights Watch conducted a study from October, 2020 to March, 2021 for which they interviewed and surveyed over 600 people, including nursing home residents, their relatives,

[5] Institute of Medicine (US) Committee on Nursing Home Regulation, "Improving the Quality of Care in Nursing Homes," *National Academy Press (US)* 1986. Appendix A.

staff, administrators, advocates, lawyers, experts, and ombudspersons across the United States. In their report, "U.S. Concerns of Neglect in Nursing Homes", Human Rights Watch concluded that neglect and prolonged isolation "may have caused serious harm to many people" in American nursing homes during the pandemic. The results of their study highlighted concerns regarding dehydration, inadequate hygiene, declines in mental and physical health, weight loss, and misuse of medications, among other conditions. Through interviews with ombudspersons, they also found that there was a significant increase in neglect complaints during the pandemic.[6] Although the study did not include a statistically representative sample, it remains one of the most wholistic studies to date of the prevalence and characteristics of changes that occurred in nursing homes during this time.

A study conducted by the Society for Post-Acute and Long-Term Care Medicine in March, 2021, supported the conclusions of Human Rights Watch. Using a sample of 29,097 nursing home residents in Connecticut across a span of four years, researchers found statistically significant increases in the percentage of residents with depressive symptoms, unplanned substantial weight loss, decreased cognitive function, and episodes of incontinence during the pandemic. From these findings, they concluded that the conditions of the pandemic, which included decreased provision of direct care and visitation restriction policies, contributed to "reductions in resident well-being".[7] In addition to the increased prevalence of neglect indicators found in these studies, additional research has posited that the pandemic caused a significant number of excess deaths in nursing homes. Research conducted by Professor Stephen Kay at the Institute on Health and Aging at the University of California San Francisco for the Associated

[6] "US: Concerns of Neglect in Nursing Homes," *Human Rights Watch,* (May 2021).
[7] Michael Levere et al., "The Adverse Effects of the COVID-19 Pandemic on Nursing Home Resident Well-Being." *Journal of the American Medical Directors Association* 22, no. 5 (2021): 948-52. doi:10.1016/j.jamda.2021.03.010.

Press estimated that a minimum of 40,000 excess deaths, unrelated to Covid-19, took place in American nursing facilities between March and November of 2020. He found that a positive relationship existed between the prevalence of Covid-19 and the number of non-Covid-19 related deaths in a facility. From this finding, he theorized that residents' health may have suffered in facilities where the staff and resources were primarily consumed by infection control and Covid-19 treatment.[8]

Although the literature is clear that care standards declined during the pandemic, it is less clear about the causes. Individual studies have pointed to an array of possible contributors, including staffing issues, visitation restriction policies, underinvestment in the nursing home sector, oversight problems, physical design flaws, and ageism. The most frequently postulated causes for the observed change in care quality relate to staffing. Dr. Nina Kohn, a law professor at Syracuse University who specializes in elderly rights, wrote in an essay that staffing shortages were a likely contributor to decreased care quality because "the ratio of staff to residents is a key predictor of the quality of care nursing home residents receive." She cited research which indicated severe staffing shortages became more common during the pandemic and then pointed to the lack of regulations requiring minimum staffing levels as a reason for this shortage.[9] Other scholars have proposed different causes for the staffing shortages in nursing homes. The president of the John A. Harford Association, Dr. Terry Fulmer, also commented that staffing shortages affected pandemic care quality, but he hypothesized that the staffing shortage is in part due to the fact that society has "taught nurses that to be a nursing home nurse is second-class

[8] Matt Sedensky and Bernard Condon, "Not Just COVID: Nursing Home Neglects Deaths Surge in Shadows," *Associated Press,* November 19, 2020, https://ap-news.com/article/nursing-homes-neglect-death-surge-3b74a2202140c5a6b5cf05cdf0ea4f32.
[9] Nina A. Kohn, "Nursing Homes, COVID-19, and the Consequences of Regulatory Failure," *Georgetown Law Journal* 110, (2021).

nursing." As such, nursing homes are not attractive workplaces for highly qualified and motivated nurses. He also cited the traditionally low wages and minimal benefits associated with staffing positions in nursing homes as deterrents that keep facilities in shortages. During the pandemic specifically, he saw the lack of support staff for nurses and nursing assistants as an issue which increased worker burnout and perpetuated staffing problems. In his view, the conditions of the pandemic had a unique psychological impact on staff that increased work-related stress, yet this stress was not mitigated or addressed through increased resources or decreased role responsibilities.[10] A study published in the Journal of Applied Gerontology found that poor employer communication about Covid-19 was related to increased resignations of nursing home staff and posited that the quality of communication and emergency preparedness in these facilities was correlated to their ability to staff and adequately care for residents.[11] The notion that staffing shortages increased during the pandemic is not entirely agreed upon, however. Research by professors at the Perelman School of Medicine found that staffing hours per day did not decrease in the United States during the pandemic. Using daily payroll-based staffing data from CMS and accounting for changes to patient censuses, the researchers concluded that staff hours per resident per day remained stable or increased during the pandemic. They attributed the widely perceived shortages to observed increases in work related stressors and demands upon staff members, which can also impact care quality.[12]

In addition to discussions of staffing ratios, other theories revolve around the experience of staff members and changes to their ability to provide quality care. An article in the Journal of

[10] J. Abbasi, "COVID-19 Crisis Advances Efforts to Reimagine Nursing Homes." *JAMA* 326, no. 16 (2021):1568-70. Doi:10.1001/jama.2021.13326.
[11] Verena R. Cimarolli et al., "Job Resignation in Nursing Homes During the COVID-19 Pandemic: The Role of Quality of Employer Communication." *Journal of Applied Gerontology* 41, no. 1 (2022):12-21. https://doi.org/10.1177/07334648211040509.
[12] Rachel M. Werner and Norma B. Coe, "Nursing Home Staffing Levels Did Not Change Significantly During Covid-19." *Health Affairs* 40, no. 5 (2021). https://doi.org/10.1377/hlthaff.2020.02351.

Nursing Care Quality posited that there was a "information overload" from relevant governing bodies such as the Centers for Disease Control (CDC), the Centers for Medicare and Medicare Services (CMS), the Missouri Department of Health and Senior Services (DHSS), and various nursing home associations, which hindered nursing home administrators' ability to direct their staff and adapt to pandemic conditions.[13] Others pointed to a loss of essential, but frequently unrecognized, members of the care continuum as a source of increased stress and workload upon staff.[14] When family members and volunteers were restricted from facilities, many daily tasks such as feeding and hygiene maintenance shifted to the nursing home workers who were already inundated with responsibilities. This line of thought moves into the broader discussion of visitation restrictions, which many have highlighted as a cause for the decreased well-being and care of residents. One conclusion from the Human Rights Watch study was that reduced visitation and social activities led to isolation that was detrimental to residents' health in many situations.[15] Similarly, the Connecticut study pointed to restricted visitation as a cause of physical and mental decline in residents.[16]

Departing from visitation policies, other individuals have placed blame for decreased care quality during the pandemic upon under-investment in the nursing home sector. Dr. David Grabowski at Harvard Medical School and Dr. Vincent Mor at Brown University wrote that the pandemic exacerbated pre-existing issues of insufficient Medicaid funding for nursing homes. They explained that while Medicare is a "relatively generous payer", Medicaid frequently pays

[13] Lori Popejoy et al., "A Coordinated Response to the COVID-19 Pandemic in Missouri Nursing Homes." *Journal of Nursing Care Quality* 35, no. 4 (2020): 287-292. doi: 10.1097/NCQ.0000000000000504.
[14] J. Abbasi, "COVID-19 Crisis Advances Efforts to Reimagine Nursing Homes." *JAMA* 326, no. 16 (2021):1568-70. Doi:10.1001/jama.2021.13326.
[15] "US: Concerns of Neglect in Nursing Homes," *Human Rights Watch,* (May 2021).
[16] Michael Levere et al., "The Adverse Effects of the COVID-19 Pandemic on Nursing Home Resident Well-Being." *Journal of the American Medical Directors Association* 22, no. 5 (2021): 948-52. doi:10.1016/j.jamda.2021.03.010.

below the cost of care needed for nursing home residents. As such, nursing homes rely upon a certain number of Medicare beneficiaries who typically enter facilities for short-term stays to receive post-acute care after surgeries. They theorized that because hospitals decreased elective surgeries during the pandemic to avoid virus infection and spread, nursing homes lost revenue they typically would receive from Medicare residents. The facilities which were most dependent upon Medicaid reimbursement suffered from this loss of revenue and were unable to retain staff, provide high quality care, or in some cases, keep their doors open.[17] A report by the National Academies of Sciences, Engineering, and Medicine also pointed to underinvestment as a cause of difficulties for nursing homes during the pandemic. They cited low staff salaries, inadequate support for regulatory activities, and inadequate quality measurement efforts as three ways in which the nursing home sector has suffered from "under-investment in ensuring the quality of care."[18]

Dr. Terry Fulmer hypothesized that the physical design of nursing homes was another contributory factor to care quality issues during the pandemic. He said that because a majority of nursing homes are more than fifty years old, they have outdated design features such as double rooms and shared bathrooms which are problematic for infection control. They also have long corridors with remote nursing stations, which makes care delivery difficult, especially when staff are in short supply. The lack of flexible spaces, the large number of patients housed in each facility, and the heterogeneity of conditions treated in one place were particularly problematic for care delivery during the pandemic in his view.[19]

---

[17] D.C. Grabowski and V. Mor, "Nursing Home Care in Crisis in the Wake of COVID-19." *JAMA* 324, no. 1 (2020):23-4. doi:10.1001/jama.2020.8524.

[18] "The National Imperative to Improve Nursing Home Quality: Honoring Our Commitment to Residents, Families, and Staff." *National Academies of Sciences, Engineering, and Medicine*, (Washington, DC: The National Academies Press, 2022). doi: 10.17226/26526.

[19] J. Abbasi, "COVID-19 Crisis Advances Efforts to Reimagine Nursing Homes." *JAMA* 326, no. 16 (2021):1568-70. Doi:10.1001/jama.2021.13326.

Finally, the last area which commentators have highlighted as a potential source for decreased care quality is societal ageism. Jon Rueda at the University of Granada wrote that ageism was prevalent in several risk mitigation measures taken during the pandemic. He proposed that policies which restricted socialization neglected to account for the unique needs of nursing homes residents for community and connection and that nursing home residents were deprioritized for resources in age-based rationing schemes. He pointed to media narratives as one source of ageist messaging that fueled a lack of respect for the needs of older adults during the pandemic.[20] An article in the American Journal of Public Health also pointed out that while many stories ran in the media about the bravery of hospital workers and their need for resources, nursing homes and their workers did not receive as much attention. In fact, the article claims that nursing homes were criticized for a lack of preparation while hospitals were portrayed as victims of an unfortunate situation.[21] In the view of these commentators, the result of such public indifference or negativity was detrimental to getting nursing homes the resources they need to successfully provide care.

Nursing home oversight is the only area in which both pre-existing challenges and pandemic related policy changes has been investigated. In her work, Dr. Nina Kohn discussed pre-existing oversight enforcement issues such as the classification of quality of care problems as less severe than they are by surveyors and states' failures to penalize violations and adequately correct issues. In addition, she cited pandemic-specific underenforcement of existing oversight as an issue as well, and highlighted state actions across the country that granted liability immunity

[20] Jon Rueda, "Ageism in the COVID-19 pandemic: age-based driscrimination in triage decisions and beyond." *History and Philosophy of the Life Sciences* 43, no. 3 (2021):91. doi: 10.1007/s40656-021-00441-3.
[21] R. T. Konetzka, "Improving the Fate of Nursing Homes during the COVID-19 Pandemic: The Need for Policy." *American Journal of Public Health* 111, no. 4 (2021):632-634. http://ezproxy.cul.columbia.edu/login?url=https://www.proquest.com/scholarly-journals/improving-fate-nursing-homes-during-covid-19/docview/2516302044/se-2?accountid=10226.

to nursing homes during the pandemic and made it more difficult to hold providers accountable for negligence.[22] In a similar vein, an article in the Journal of the American Geriatrics Society questioned whether decreased surveillance of facilities during the pandemic, in combination with the reduced access of family members who often serve as monitors themselves, increased the potential for suboptimal care in nursing homes. They also noted that statements from CMS were at times contradictory, as they emphasized the importance of supporting facilities as they adapt to the challenges of the pandemic, while simultaneously promising to take "aggressive enforcement action" against facilities that failed to meet infection control standards. Finally, they commented that State Survey Agencies (SSAs) were not allowed to consult with the facilities they oversee, and as such, were underutilized during the pandemic.[23] Scholarly discussions such as these begin the work of evaluating the efficacy of pandemic-related policy changes, but further investigation into a broader array of the decisions made is necessary to judge their successes and shortcomings. Most theories about the causes of the decline in nursing home care during the pandemic have pointed to the exacerbation of pre-existing issues in the nursing home sector such as staffing shortages, oversight failures, design flaws, underinvestment, and ageism. The following data will show, however, that in the state of Missouri, a range of policy decisions that were designed to mitigate pandemic challenges were the source of new, rather than pre-existing, issues for care delivery and resident wellbeing.

[22] Nina A. Kohn, "Nursing Homes, COVID-19, and the Consequences of Regulatory Failure," *Georgetown Law Journal* 110, (2021).
[23] D.G. Stevenson and A.K. Cheng, "Nursing Homes Oversight During the COVID-19 Pandemic." Journal of American Geriatric Society 69, (2021):850-60. https://doi.org/10.1111/jgs.17047.

IV. Methodology

The methodological design of this research includes mixed methods, with both qualitative and quantitative data being examined. It was necessary to establish the extent and characteristics of challenges faced by nursing home residents during the pandemic in order to understand the ways in which policy changes impacted care, as specific deficiencies may be rooted in certain policy decisions. To gather this information, a survey was created consisting of 42 multiple choice and open response questions designed to be filled out by individuals whose loved ones were residents of a Missouri nursing home during the pandemic. The survey questions centered around the residents' understanding of and response to changes they experienced in their day-to-day life as a result of the pandemic. The survey questions covered a variety of topics including experiences with visitation, recreational activities, provision of daily necessities, and emotional, mental, or physical conditions. Additionally, there were questions regarding participants' experience with reporting suboptimal care, their awareness of reporting options, their knowledge of programs involving ombudspersons and essential caregivers, and whether they were informed about temporary discontinuation of oversight through facility inspections. The survey was administered through the online platform Qualtrics and was advertised through social media, newsletters from long-term care advocacy groups and government officials, and word of mouth. The survey was not designed to comprise a random sample and therefore was not representative of loved ones of nursing home residents across Missouri. However, the data aids in investigating the prevalence of individual experiences regarding decreased quality of life and care in the state and gives insight into the kinds of deficiencies experienced.

A thematic analysis approach was used to examine the survey data. The open responses on the surveys were coded for repeated themes. The qualitative information from the surveys

provided rich detail as to the specific ways in which residents' wellbeing and care was altered, whether it be through descriptions of mental anguish from social isolation, physical ailments from absence of caretakers, or other issues that are found to be prominent through repeated expression across surveys. The analysis also gave insight into how residents and their loved ones perceive, interact with, and are informed about the interaction between policy and daily life in the nursing home. To further support the existence of increased deficiencies and decreased quality inside nursing homes during this time period, data was reviewed from CMS's Quality, Certification, and Oversight Reports (QCOR) website regarding the number of immediate jeopardy complaints investigated each year since 2012. Immediate Jeopardy complaints were the only category outside of infection control protocols to be continuously monitored since March of 2020, so they offered the best opportunity to investigate whether there had been an increase in deficiencies cited during the pandemic. Additionally, further CMS data was analyzed that had been previously compiled by the Center for Long-Term Care Quality & Innovation at Brown University regarding the yearly percentage of Missouri nursing home residents with bed sores as another indicator of decreased care quality. The research also consisted of interviews with five nursing home administrators from around the state. During the interviews, the administrators were asked to elaborate upon their experiences during the pandemic, the policies and practices they found challenging or useful, and their suggestions moving forward. The purpose of these interviews was not only to gain additional perspective on the situation outside of that of the residents, but also to begin connecting the lived experiences of nursing home residents and staff with policies, practices, and circumstances unique to the pandemic.

The survey and interview responses guided an analysis of policies and guidance administered by federal and state entities regarding nursing home operation. Based on the issues

that arose from the comments by the loved ones of nursing home residents and nursing home administrators, the policies that most closely related to complaints were discussed in the context of their adherence to previously established rights and their potential to have increased risk to resident wellbeing. To ascertain which policies might have affected various areas of care, the researcher reviewed a comprehensive list of waivers and guidance and highlighted those that directly made changes to the ways in which care is delivered or overseen. In the discussion that followed, conclusions gathered from the work of previous researchers was used to understand the potential impacts that alterations to these areas would have on resident wellbeing and care quality. This information, when combined with the recorded alterations to care from the survey and interview data, showed that certain policy changes were likely to have negatively impacted various aspects of patient care. Finally, emerging policy reform that seeks to address some of the issues uncovered by the survey data and policy critique are briefly reviewed to highlight possible corrective measures moving forward.

V. Nursing Home Standards

In order to understand the significance of the survey results and policy changes, it is necessary to construct a baseline against which to measure the quality of care and wellbeing of nursing home residents during the pandemic. Nursing home residents represent a unique group of individuals due to their living situation and health needs. As such, they have particular rights which are elaborated in international, national, and state laws. These rights provide a standard upon which the care of nursing home residents can be measured to understand if they are being treated appropriately in these environments. Internationally, the Universal Declaration of Human

Rights,[24] The International Covenant on Civil and Political Rights (ICCPR),[25] the International Covenant on Economic, Social, and Cultural Rights (ICESCR),[26] and the Convention on the Rights of Persons with Disabilities[27] all assert the universal right to the highest attainable standard of physical and mental health or the right to a standard of living adequate for health. The Convention on the Rights of Persons with Disabilities also includes the right to freedom from exploitation, violence, and abuse, as well as the rights to freedom from degrading treatment, access to information, privacy, habilitation and rehabilitation, participation in public life, recreation, accessibility, and non-discrimination among others. The United Nations has adopted Principles of Older Persons which echo the rights listed above and add additional rights such as the right to live in "environments that are safe and adaptable to personal preferences and changing capacities" and the right to family and community support. Perhaps most relevant to nursing homes, this list of principals includes the right to "enjoy human rights and fundamental freedoms when residing in any shelter, care or treatment facility, including full respect for their dignity, beliefs, needs, and privacy and for the right to make decisions about their care and the quality of their lives."[28] It should be noted that the United States signed the ICESCR and the Convention on the Rights of Persons with Disabilities but did not ratify either of them. Additionally, the Principles of Older Persons were adopted by the UN without a member vote. However, federal laws reflect an internalization of the norms laid out in these documents.

A federal law called the Nursing Home Reform Act of 1987 states that residents of nursing homes have the "right to be free from verbal, sexual, physical, and mental abuse,

[24] Universal Declaration of Human Rights, *UN General Assembly*, 10 December 1948, 217 A (III)
[25] International Covenant on Civil and Political Rights, *UN General Assembly* 999, (16 Dec 1966): 171.
[26] International Covenant on Economic, Social, and Cultural Rights, *UN General Assembly* 993, (16 Dec 1966): 3.
[27] Convention on the Rights of Persons with Disabilities, UN General Assembly, (24 Jan 2007): A/RES/61/106.
[28] "United Nations Principles for Older Persons." *General Assembly Resolution 46/91,* December 16, 1991.

corporal punishment, and involuntary seclusion." It also provides regulations and guidelines which obligate facilities to "develop and implement written policies and procedures that prohibit mistreatment, neglect, abuse, and misappropriation of resident property." The Act specifies that staff members at the facilities must be reported to a registry concerning abuse, neglect, or mistreatment when incidents occur. Additionally, the Nursing Home Reform Act established a list of rights of nursing home residents, which includes rights to privacy, active participation, freedom from physical or chemical restraints, freedom from neglect, mistreatments and other forms of abuse, dignity, communication without fear of censure, self-determination, to be informed of changes in care, and to complain without fear of consequences.[29] The Older Americans Act of 1965 dictates that the elderly are entitled to comprehensive services like nutrition and health programs[30] and the 1990 Americans with Disabilities Act bars discrimination against people with disabilities, which is relevant for many nursing home residents.[31] The 1980 Civil Rights of Institutionalized Persons Act also includes nursing home residents as a protected group which has certain rights and for which the Attorney General may intervene on their behalf when rights are repressed or violated. Other laws have established and regulated the Federal Ombudsman Program, which allows for ombudsmen to advocate for nursing home residents and resolve complaints.[32] An ombudsman is an official who investigates residents' complaints, advocates for solutions, and helps residents understand and exercise their rights. At the state level in Missouri, the Residents' Rights Statutes of the Missouri Code of State Regulations

[29] "Federal Nursing Home Reform Act from the Omnibus Budget Reconciliation Act of 1987 Summary." *The National Consumer Voice for Quality Long-Term Care*, https://theconsumervoice.org/uploads/files/family-member/Summary-History-Federal-_Nursing-Home-_Reform-Act_(3).pdf.
[30] K. Colello. "Older Americans Act: 2020 Reauthorization," *Congressional Research Service*, July 1, 2020.
[31] Americans with Disabilities Act of 1990. Public Law 101-336. 108th Congress, 2nd session (July 26, 1990).
[32] "General States Nursing Home Law." *Nursing Home Abuse Guide*. https://www.nursinghomeabuseguide.org/states/.

provides a complete list of rights prescribed to nursing home residents that echo the rights and standards elaborated in federal law.[33]

When discussing care quality in nursing homes, deficiencies in care provision often appear in the form of neglect. The Administration on Aging is a federal body that defines neglect as "the refusal or failure of a caregiver to fulfill his or her obligations or duties to an older person, including …. providing any food, clothing, medicine, shelter, supervision, and medical care and services that a prudent person would deem essential for the well-being of another."[34] Missouri Adult Protective Services defines it slightly differently as "the failure to provide services to an eligible adult by any person, firm or corporation with a legal or contractual duty to do so, when such failure presents either an imminent danger to the health, safety, or welfare of the client or a substantial probability that death or serious physical harm would result."[35] When determining if care quality has decreased, one can look for indications of neglect, as well as other situations which constitute violations to residents' rights as elaborated above.

VI. Enforcement of Nursing Home Standards

Interpretation of and adherence to the standards discussed in the previous section are conducted and measured through a complex monitoring system. Facilities that have residents on Medicare or Medicaid are evaluated for quality assurance at both the federal and state levels. The federal government sets facility performance criteria through CMS. Nursing must meet these Requirements of Participation in order to receive federal funding. Requirements of Participation

[33] Missouri Code of State Regulations, Resident's Rights Statutes, Title XII Public Health and Welfare, Div. 30, Ch 88.
[34] Catherine Hawes, "Elder Abuse in Residential Long-Term Care Settings: What is Known and What Information is Needed," *National Academies Press (US)* 14, (2003).
[35] Revised Statutes of Missouri, Title XII Public Health and Welfare, Chapter 192, 2400.

include the provision of specific rights for residents and a certain scope of services provided. States set licensing agreements, which may include additional standards for staffing, quality of care, and physical environments at the discretion of the state. Typically, nursing homes first acquire state licensure, and then federal certification after a brief period of operation.[36] The federal government delegates the responsibility of facility inspection to state governments. In Missouri, the Section for Long-Term Care Regulation within the Department of Health and Senior Services (DHSS) conducts inspections and surveys and issues state licenses. The surveys are conducted according to federal guidance in these facilities, and they also certify facilities' Medicaid eligibility. Medicare eligibility is certified at the federal level by the Health Care Finance Administration at the recommendation of state surveyors. There are two primary types of surveys completed by staff of a state's health facility licensure and certification agency - Life Safety Code Surveys and Standard Surveys. Life Safety Code Surveys deal directly with fire and building safety, while standard surveys assess compliance with residents' rights and quality of life requirements, as well as a range of quality of care services and the effectiveness of the physical environment for empowering and accommodating residents. Both of these surveys take place no more than every fifteen months at each facility and occur unannounced. State surveyors also conduct complaint investigations on behalf of CMS when residents, family members, staff, ombudsman, or facilities submit complaints about an aspect of a nursing home's operation or care provision. There are also federal surveyors under CMS who periodically evaluate state surveyors' complaint investigation process and do independent surveys of facilities at their discretion.[37]

[36] Phoenix Voorhies and Kirsten Colello, "Overview of Federally Certified Long-Term Care Facilities," *Congressional Research Service,* May 2020.
[37] "Monitoring Nursing Home Performance," in Improving the Quality of Care in Nursing Homes.(Washington (DC): National Academies Press (US), 1986). https://www.ncbi.nlm.nih.gov/books/NBK217555/.

Facilities are cited when they are out of compliance with federal standards, and they are given time to remedy the issues. Deficiency citations are assigned a scope which indicates the number of residents affected and a severity which indicates the level of harm. The scope and severity citations are assigned a letter from A to L, with J, K, and L citations indicating immediate jeopardy to residents at isolated, pattern, and widespread scopes respectively. Follow-up surveys then take place to ensure enforcement actions were properly taken. When facilities are egregiously out of compliance, they are fined or enrolled in the Special Focus Facility program for increased monitoring. Repeated failure to meet standards or address problems can result in a facility losing its license. Facilities' performance on routine surveys and complaint investigations informs the CMS's Quality Rating System.[38] This system is used to track facility performance, and its data is used on CMS's Nursing Home Compare Website which informs consumers about the quality of nursing homes. The Quality Rating System rates quality of care under three domains. The first is health inspection outcomes, which is based on number, scope, and severity of deficiencies. The second is staffing, which includes registered nurse hours per day and total nurse, including licensed practical nurses and nurse's aides, hours per resident per day. The final category is quality measures, which is based on multiple indicators such as percent of residents with pressure sores, left-in catheters, or placed in physical restraints, among others. The Quality Rating System produces a score out of five stars based on the combination of these factors, and these scores are made publicly available to inform consumers about the quality of various facilities.[39] Inspection reports are also publicly available, but they typically take several months to be posted after the initial inspection.

[38] Victoria A. Schall, "CMS Releases New Nursing Home Special Focus Facility List." *Locks Law Firm*, June 14, 2019. https://www.lockslaw.com/blog/2019/06/14/cms-releases-new-nursing-home-special-focus-facility-list.
[39] "Nursing Home Compare Five-Star Quality Rating System: Year Three Report," *Centers for Medicare & Medicaid Services*, 7 June 2013.

VII. An Overview of Missouri Nursing Homes Prior to the Pandemic

In the state of Missouri, there are 1,165 "long-term care" facilities which contain roughly 81,100 beds according to DHSS. These include skilled nursing facilities, intermediate care facilities, residential care facilities, and assisted living facilities.[40] Of these facilities, 522 are Medicare or Medicaid funded "nursing homes."[41] As was mentioned previously, for the purposes of this project, the term nursing home refers to skilled nursing facilities and nursing facilities. CMS defines skilled nursing facilities as those which primarily provide skilled inpatient care to patients requiring medical, nursing, or rehabilitative services below the level of treatment available in a hospital. Nursing facilities have a similar definition, but they include institutions which regularly provide services to individuals who "because of their mental or physical condition require care and services which can be made available to them only through institutional facilities."[42] Missouri DHSS uses the term skilled nursing facility but does not use the term nursing facility. However, the definition for intermediate care facility is near equivalent to CMS's definition of a nursing facility and therefore the two are used interchangeably in this research. This project does not investigate what Missouri DHSS defines as residential care facilities as they do not require a licensed Nursing Home Administrator and they do require a certain level of patient mobility not necessary in skilled nursing or nursing facilities. Additionally, although nursing homes are often considered long-term care facilities, they frequently house short-term residents during rehabilitation periods as well. In summary, when looking at policy decisions affecting nursing homes in the state of Missouri, this research

[40] "Nursing Home Inspections." *Missouri Department of Heath & Senior Services,* https://health.mo.gov/safety/nursinghomesinspected/.
[41] "Missouri Should Improve Its Oversight of Selected Nursing Homes' Compliance with Federal Requirements for Life Safety and Emergency Preparedness." *Department of Health and Human Services Office of the Inspector General,* A-07-18-03230, March 2020.
[42] "Glossary." *Centers for Medicare & Medicaid Services, https://www.cms.gov/glossary.*

considers policy which affect the 522 nursing homes that participate in federal Medicaid or Medicare Programs and are equivalent to CMS's definition of skilled nursing and nursing facilities.

The majority of these 522 nursing homes are for-profit facilities. Slightly over 100 of the facilities are non-profit facilities in which excess revenue is reinvested into the nursing home and a small portion are government operated. The ownership status of nursing homes is often indicative of their performance, as non-profit nursing homes typically have the fewest deficiency citations. For example, in 2014, for-profit nursing homes had the highest average number of facilities among the three ownership types, followed by government owned homes and then non-profit homes respectively. Additionally, the overwhelming majority of these facilities are dually certified to accept residents with either Medicaid or Medicare coverage. The majority of facilities have between 50 and 199 beds, with 39 facilities having fewer than 50 and 17 facilities having greater than 199 as of 2014.[43] Throughout the state, these 522 nursing homes range from having one star on CMS's quality rating system to five stars. Within nursing homes, direct care employees typically include Registered Nurses (RNs), Licensed Practical Nurses (LPNs), and Certified Nursing Assistants (CNAs) in order of decreasing training requirements. Physical Therapists, Dieticians, Administrators, and Support employees such as maintenance, human resources, accounting, and sanitation are also vital employees within nursing homes.

Missouri nursing homes exhibit great variety in terms of the number and characteristics of their recorded deficiencies. However, looking at the total number of deficiencies in all facilities across the state provides a useful baseline for understanding the status of care in

[43] "Nursing Home Data Compendium 2015 Edition." *The Centers for Medicare & Medicaid Services, https://www.cms.gov/Medicare/Provider-Enrollment-and-certification/CertificationandComplianc/Downloads/nursinghomedatacompendium_508-2015.pdf.*

Missouri nursing homes before the pandemic. In 2019, there were 5,077 citations of deficiency in complaint and standard surveys across all nursing homes in the state. Of these, only 107 were actual harm deficiencies, while an additional 53 were immediate jeopardy deficiencies.[44] As such, the overwhelming majority of deficiencies were classified as situations which posed "no actual harm" with only "potential for minimal harm."[45] The figures follow a similar pattern in the records from 2010 to 2018. This data shows that reported situations in which residents faced injurious neglect or serious risk to resident wellbeing were uncommon going into the Covid-19 pandemic.

VIII. Pandemic Related Policy Decisions Regarding Nursing Homes

As Covid-19 began to spread across the United States, federal and state governments responded with an array of policy decisions aimed at stemming the proliferation of the virus. Nursing homes became a sector of particular concern after an outbreak at the Life Care Center in Washington resulted in the deaths of 35 residents and staff in February and March of 2020. This event was followed by outbreaks in nursing homes throughout the country which exhibited high death rates relative to the general population. As a result, governments began instituting regulatory changes in the nursing home sector. These changes had a constructive goal – to allow for greater focus on infection control in the face of staffing and resource shortages. However, they also had some negative unintended consequences for facility oversight and daily care provision.

[44] "Deficiency Count Report." *Quality, Certification, & Oversight Reports,* https://qcor.cms.gov/report41snf.jsp?which=0&report=report41snf.jsp#pagetop.
[45] "Assessment Factors Use to Determine the Seriousness of Deficiencies Matrix." *Alabama Nursing Home Association,* http://anha.org/uploads/ScopeSeverity2018.pdf.

A. Policy Decisions Affecting Nursing Home Oversight

Recognizing the serious threat that Covid-19 posed to nursing home populations, one of the first actions taken by CMS was to ensure that facilities were following infectious disease containment protocols. On March 4, 2020, CMS released a memorandum to all state survey agency directors requiring them to suspend non-emergency inspections of nursing homes in order to focus on the "most serious health and safety threats like infectious disease and abuse." Under this guidance, state surveyors were to prioritize inspections for cases of immediate jeopardy complaints and infection control deficiencies. Immediate jeopardy complaints are those in which a facility's noncompliance to standards puts the residents at risk for serious injury, harm, impairment, or death. In this first guidance, certain other survey activities were still permitted, such as statutorily required recertification surveys, re-visits needed to resolve ongoing enforcement actions, initial certifications, and inspections of facilities with histories of infection control deficiencies.[46] An additional memorandum released on March 20, 2020, further restricted survey activities to only permit immediate jeopardy complaint investigations and targeted infection control surveys. This guidance also restricted surveyors from completing any in-person surveys if they were unable to meet personal protective equipment expectations produced by the CDC and encouraged information to be collected remotely in these situations. The duration of this survey prioritization period was initially intended to last three weeks.[47] However, it remained in place for slightly over ten weeks, after which CMS issued guidance allowing state

[46] Director Quality, Safety & Oversight Group, "Suspension of Survey Activities." (official memorandum, Baltimore, Maryland: Centers for Medicare & Medicaid, March 4, 2020). https://www.cms.gov/files/document/qso-20-12-all.pdf.
[47] Director Quality, Safety & Oversight Group, "Prioritization of Survey Activities." (official memorandum, Baltimore, Maryland: Centers for Medicare & Medicaid, March 20, 2020). https://www.cms.gov/files/document/qso-20-20-all.pdf.

survey agencies to re-expand survey activities for facilities once they had entered Phase 3 of Nursing Home Reopening as described by CMS guidance, or earlier at a state's discretion.[48] CMS criteria for Phase 3 Reopening included no staffing shortages in the facility, no new Covid-19 cases for at least 28 days, adequate supply of PPE and cleaning equipment, access to Covid-19 testing, and specific community case rates.[49] In the state of Missouri, DHSS left the decision to enter Phase 3 with each individual facility and closely followed CMS's Phase 3 guidelines.[50] After June, 2020, state surveyors in Missouri slowly began to complete routine inspections and inspections that had been deprioritized in the months prior. Over the following two years, survey activities were periodically re-restricted when community case rates elevated.

B. Policy Decisions Affecting Daily Nursing Home Operation

In addition to changes regarding nursing home surveillance and monitoring, state and federal governments also made policy decisions which affected aspects of daily nursing home operation on multiple levels. These decisions largely took the form of regulatory waivers. On January 31, 2020, the U.S. Secretary of Health and Human Services (HHS) declared a public health emergency for Covid-19.[51] The President followed this on March 13, 2020, by declaring a

[48] Director Quality, Safety & Oversight Group, "COVID-19 Survey Activities, CARES Act Funding, Enhanced Enforcement for Infection Control deficiencies, and Quality Improvement Activities in Nursing Homes." (official memorandum, Baltimore, Maryland: Centers for Medicare & Medicaid, June 1, 2020). https://www.cms.gov/files/document/qso-20-31-all-revised.pdf.

[49] Director Quality, Safety & Oversight Group, "Nursing Home Reopening recommendations for State and Local Officials." (official memorandum, Baltimore, Maryland: Centers for Medicare & Medicaid, May 18, 2020). https://www.cms.gov/files/document/qso-20-30-nh.pdf.

[50] "Missouri Guidance on Reopening of Long-Term Care Facilities." *Missouri Department of Health and Senior Services,* August 31, 2020. https://health.mo.gov/living/healthcondiseases/communicable/novel-coronavirus/pdf/missouri-guidance-on-reopening-of-long-term-care-facilities.pdf.

[51] Secretary Alex M. Azar II, "Determination that a Public Health Emergency Exists." *U.S. Department of Health & Human Services,* January 31, 2020. https://www.phe.gov/emergency/news/healthactions/phe/Pages/2019-nCoV.aspx.

national state of emergency.[52] These actions triggered section 1135 of the Social Security Act, which grants the Secretary of HHS the authority to authorize waivers or modifications to regulations pertaining to certain Medicare and Medicaid programs. These waivers are commonly referred to as Blanket Waivers and were enacted to "help healthcare providers contain the spread of 2019 Novel Coronavirus Disease."[53] The Governor of Missouri also declared a state of emergency in Missouri on March 13, 2020[54] and issued executive orders in response to the virus which granted state agencies authority to suspend certain statutory and regulatory provisions where "strict compliance would hinder the State's recovery from Covid-19.[55] Missouri DHSS was primarily responsible for waivers relating to the nursing home sector in the state. The full and partial waivers issued by the federal government and the state government of Missouri often coincided, and while their primary objective was to stop the spread of Covid-19, they also sought to relieve pressure from the increasingly strained healthcare system. Many of the waivers specifically aimed at addressing staffing shortages or their related challenges in recognition of the impact that staffing has on a facility's ability to control infection and provide quality care. The areas covered by the waivers were numerous, so only a selection of the more pertinent waivers is discussed here, beginning with waivers relating to staff training and working hours.

[52] President Donald J. Trump, "Proclamation on Declaring a National Emergency Concerning the Novel Coronavirus Disease (COVID-19) Outbreak." March 13, 2020. https://trumpwhitehouse.archives.gov/presidential-actions/proclamation-declaring-national-emergency-concerning-novel-coronavirus-disease-covid-19-outbreak/.
[53] "Covid-19 Emergency Declaration Blanket Waivers for Health Care Providers." *Centers for Medicare & Medicaid Services,* https://www.cms.gov/files/document/summary-covid-19-emergency-declaration-waivers.pdf.
[54] Governor Michael L. Parson, "Executive Order 20-02." https://www.sos.mo.gov/library/reference/orders/2020/eo2.
[55] Governor Michael L. Parson, "Executive Order 20-09." https://www.sos.mo.gov/library/reference/orders/2021/eo9.

i. Policy Decisions Regarding Staffing

Under the federal blanket waiver, certain tasks previously only permitted to be performed by physicians were allowed to be delegated to nurse practitioners, physician assistants, or clinical nurse specialists, including visits to patients inside nursing homes. Training requirements for various levels of staff were also significantly modified. Nursing homes were temporarily allowed to employ individuals who had not yet met training and certification requirements for a period longer than four months and clinical practice and practicum exams were allowed to be conducted outside of facilities in laboratory settings on actors as opposed to patients. They additionally postponed deadlines for in-service training and performance reviews of nurses' aides and waived the requirement that facilities must receive verification that a potential nurses' aide had met competency evaluation requirements before being allowed to begin performing nurses' aide duties.[56] Similar waivers were made by the Missouri DHSS. For example, nursing assistants were allowed to provide direct care after completion of 12 hours of supervised practical orientation specific to their duties and not through the state approved training program. Previously, they had been required to complete a 16-hour orientation module and 12 hours of supervised practical orientation from the state approved training program. Nurses no longer needed to be licensed in Missouri to work in Missouri nursing homes if they held a multistate license, and nursing personnel were allowed to perform non-nursing duties at facilities with more than twenty residents. Facilities could also have registered nurses carry out eight consecutive hour shifts at any point in the day, rather requiring it be during the day shift. Individuals who had completed a nurse education program but had not taken the nursing exam were allowed to

[56] "Covid-19 Emergency Declaration Blanket Waivers for Health Care Providers." *Centers for Medicare & Medicaid Services,* Updated May 24, 2021. https://www.cms.gov/files/document/summary-covid-19-emergency-declaration-waivers.pdf.

administer medications to residents.[57] Nursing home administrators also had certain requirements waived which allowed for required education to be completed online, extended the timeframes for successfully completing certification examinations, and allowed temporary licenses to be extended.[58] These waivers represent a sample of the waivers regarding staff training and roles that were made largely to combat shortages of staffing.

ii. Policy Decisions Regarding Visitation & Socialization

Another category of policy decisions involved visitation and socialization policies. CMS waived patients' rights to certain visitation practices under the blanket waiver. They also issued guidance in March, 2020, which said, "facilities should restrict visitation of all visitors and non-essential health care personnel, except for certain compassionate care situations, such as an end-of-life situation."[59] End of life is the only compassionate care situation explicitly mentioned in this guidance, but compassionate care situations typically include those in which a visitor provides necessary support for a resident whose wellbeing is suffering or is at risk.[60] Facilities were subsequently instructed to notify visitors of this change through signage, calls, letters, or other appropriate means. They also noted that if a state were to ban visitation more extensively, facilities would not be cited for noncompliance by CMS for following state protocol. Missouri

[57] "Important Information Regarding State Waiver Implementation for Intermediate and Skilled Nursing Care Facilities." *Missouri Department of Health and Senior Services,* April 17, 2020. https://health.mo.gov/living/healthcondiseases/communicable/novel-coronavirus/pdf/19-csr-30-85-snf-icf-waiver-implementation.pdf.
[58] "Waivers for Nursing Home Administrators and Residential Care/Assisted Living Administrators." *Missouri Department of Health and Senior Services,* April 2, 2020. https://cdn.ymaws.com/www.mohealthcare.com/resource/resmgr/covid-19/Waivers_for_Nursing_Home_Adm.pdf.
[59] Director Quality, Safety & Oversight Group, "Guidance for Infection Control Prevention of Coronavirus Disease 2019 in Nursing Homes." (official memorandum, Baltimore, Maryland: Centers for Medicare & Medicaid, March 13, 2020). https://www.cms.gov/files/document/qso-20-14-nh-revised.pdf.
[60] "Making the Case for Compassionate Care." *The National Consumer Voice for Quality Long-Term Care,* https://theconsumervoice.org/uploads/files/issues/making-the-case-for-compassionate-care.pdf.

chose to reiterate CMS's guidance[61] and required that facilities distribute notification letters to families regarding the policy change.[62] CMS's guidance also stated that decisions regarding end-of-life situations should be made on a "case by case" basis and that any signs of respiratory infection would disqualify potential visitors in these situations. If such visitations were designated allowable, facilities were to have visitors refrain from physical contact with residents. CMS guidance asked facilities to consider offering alternative means of communication between residents and their loved ones but did not require them to do so. The alternative means they suggested included phone calls and video-communication. They also recommended facilities to assign staff to monitor inbound calls and make outbound calls for the purpose of keeping families informed about visitation policies. CMS held these guidelines in place until September, 2020, at which time they once again allowed visitation in the event that visitors, residents, and staff met specific criteria with negative Covid tests, PPE, and social distancing practices.[63] At the same time, Missouri state guidance changed to allow for greater visitation. In September, DHSS gave prescriptions about how to conduct in person visitation and required that visitors be able to enter resident's private rooms if they are bedbound, as well as that visitors be accommodated according to their work or childcare barriers. Visitation restrictions then fluctuated throughout the following two years at the direction of state, local, or facility authorities when community or facility Covid-19 cases escalated.

---

[61] "Important Information Regarding State Waiver Implementation for Intermediate and Skilled Nursing Care Facilities." *Missouri Department of Health and Senior Services,* April 17, 2020. https://health.mo.gov/living/healthcondiseases/communicable/novel-coronavirus/pdf/19-csr-30-85-snf-icf-waiver-implementation.pdf.

[62] "Missouri Interim Guidance for Long Term Care Facilities with Confirmed COVID-19." *Missouri Department of Health and Senior Services,* August 31, 2020. https://health.mo.gov/living/healthcondiseases/communicable/novel-coronavirus/pdf/ltcf-guidance.pdf.

[63] Director Quality, Safety & Oversight Group, "Nursing Home Visitation – COVID-19." (official memorandum, Baltimore, Maryland: Centers for Medicare & Medicaid, September 17, 2020). https://www.cms.gov/files/document/qso-20-39-nh-revised.pdf.

In an attempt to safeguard the wellbeing of residents and reduce staff workloads, the state of Missouri issued guidance in September, 2020, for facilities wanting to establish Essential Caregiver Programs.[64] Essential caregivers are defined by DHSS as individuals who provide healthcare services or assist with activities of daily living at the consent of a resident and who are essential for their health and wellbeing. In this guidance, DHSS instructed that if a facility decided to participate, individuals could apply for essential caregiver status to "help maintain or improve the quality of care or quality of life of a facility resident." Facilities were not obligated to offer this program, however, and they were allowed to deny such status for a number of reasons. CMS does not officially recognize a difference between visitors and "essential caregivers", so facilities were still required to adhere to federal visitation guidelines within their essential caregivers programming.

In addition to visitation, there were also extensive restrictions placed on socialization within facilities. CMS guidance and federal waivers required that facilities "cancel communal dining and all group activities, such as internal and external group activities."[65] Restriction of such activities was also added as a criterion to CMS's Covid-19 focused facility surveyor questionnaire as a metric of resident care. As a part of the CMS blanket waivers, the right of residents to organize and participate in resident groups in the facility was waived. Additionally, Missouri DHSS guidance required facilities to suspend group dining and activities and stated that "residents should stay in their rooms as much as possible." If a resident needed to leave their room for "medically necessary reasons" they were to wear masks and social distance.

[64] Randall Williams, "Guidance for Long Term Care Facilities to Establish Essential Caregiver Programs and to Allow Visits." (Official memorandum, Jefferson City, MO: Department of Health and Senior Services, September 17, 2020). https://health.mo.gov/living/healthcondiseases/communicable/novel-coronavirus/pdf/visitation-guidance.pdf.

[65] Director Quality, Safety & Oversight Group, "Guidance for Infection Control Prevention of Coronavirus Disease 2019 in Nursing Homes." (Official memorandum, Baltimore, Maryland: Centers for Medicare & Medicaid, March 13, 2020). https://www.cms.gov/files/document/qso-20-14-nh-revised.pdf.

Additionally, staff were advised to "bundle" patient care activities together in order to minimize room visits.[66]

iii. Policy Decisions Regarding Transfer & Discharge

A third grouping of policy decisions affected the transfer and discharge of residents from facilities. At the federal level, the blanket waiver temporarily eliminated the requirement for residents to receive written notice of a transfer or discharge before it is completed, and instead allowed notice to be provided "as soon as practicable." It also waived the requirement for facilities to assist residents and their representatives in selecting post-acute care providers in order to expedite the discharge processes.[67] Similar waivers were released at the state level. Previously, residents were to receive 30-day prior written notice of transfer and discharge events which included the reasoning for the move, the date of the move, the location of the new destination, the process for filing an appeal, and the contact information of an ombudsman.[68]

iv. Policy Decisions Regarding Daily Life & Service Provision

The final category of waivers includes modifications to a variety of regulations which deal with daily service provision and life, including the requirements regarding the development of care plans, dispersal of information, nutrition, Medicaid payments, and physical environments. The CMS blanket waiver changed the requirement that facilities develop care plans for each

[66] "Missouri Interim Guidance for Long Term Care Facilities with Confirmed COVID-19." *Missouri Department of Health and Senior Services,* August 31, 2020. https://health.mo.gov/living/healthcondiseases/communicable/novel-coronavirus/pdf/ltcf-guidance.pdf.
[67] Director Quality, Safety & Oversight Group, "COVID-19 Survey Activities, CARES Act Funding, Enhanced Enforcement for Infection Control deficiencies, and Quality Improvement Activities in Nursing Homes." (official memorandum, Baltimore, Maryland: Centers for Medicare & Medicaid, June 1, 2020). https://www.cms.gov/files/document/qso-20-31-all-revised.pdf.
[68] "Nursing Home Residents' Rights". *Missouri Long-Term Care Ombudsman,* https://health.mo.gov/seniors/ombudsman/pdf/residents-rights-fact-sheet.pdf

resident which provide effective and person-centered care and meet professional standards of quality care within 48 hours of admission to allow them to complete such plans "as soon as practicable." Care plans typically involve periodic health assessments, descriptions of health and personal services needed, the type of staff needed to perform those services, the frequency with which services are needed, the equipment or supplies required, dietary plans, and health goals, among other items. Another change under the waiver modified the time frame to access personal and medical records in a facility from two working days to ten working days. [69] Missouri DHSS employed similar waivers, but only for residential care facilities rather than nursing homes.[70] Regarding dispersal of information, CMS guidance created a Covid-19 survey form which asked facility surveyors to ensure that residents, their representatives, and families were being frequently informed about Covid-19 cases in the facility and about actions being taken to prevent virus transmission. Facilities were required to provide cumulative updates to these stakeholders weekly under this regulation.[71] CMS waived regulatory language regarding roommate choice in residential facilities so that such institutions were no longer responsible for providing individuals with their roommate of choice or for providing notice and rationale for changing a resident's room. CMS also delayed the updating of their Nursing Home Compare website and their 5 Star

[69] Director Quality, Safety & Oversight Group, "COVID-19 Survey Activities, CARES Act Funding, Enhanced Enforcement for Infection Control deficiencies, and Quality Improvement Activities in Nursing Homes." (official memorandum, Baltimore, Maryland: Centers for Medicare & Medicaid, June 1, 2020). https://www.cms.gov/files/document/qso-20-31-all-revised.pdf.
[70] "Residential Care Facilities." *Missouri Department of Health and Senior Services*, April 16, 2020. https://health.mo.gov/living/healthcondiseases/communicable/novel-coronavirus/pdf/waiver-residential-care-facilities.pdf.
[71] Director Quality, Safety & Oversight Group, "Prioritization of Survey Activities." (Official memorandum, Baltimore, Maryland: Centers for Medicare & Medicaid, March 20, 2020). https://www.cms.gov/files/document/qso-20-20-all.pdf.

Quality Rating System, which is one of the primary ways potential residents and their loved ones evaluate the quality of nursing homes.[72]

In terms of policy changes made to food and nutritional services, CMS waived a regulation which previously required paid feeding assistants to have a minimum of eight hours of a state-approved training course before feeding residents. Under the waiver, feeding assistants needed only one hour of training to complete the task with residents.[73] The Missouri DHSS also waived requirements for training in food preparation and serving, written approval for diet plans, and pre-planned menus.[74] The CMS blanket waiver also allowed nursing home residents to use their Medicare coverage after just one midnight in the hospital as opposed to three to allow hospitals to turn over beds more quickly.[75] In terms of physical environment, both the Missouri DHSS and CMS waived certain requirements to allow for delayed maintenance of fire extinguishers, unannounced fire drills, fire alarm system inspections, and sprinkler system inspections.[76] Additionally, they both waived requirements as to allow facilities to use non-traditional spaces to house residents, such as activity rooms, conference rooms, or dining rooms as long as residents were able to be kept safe and comfortable.[77] Finally, CMS waived the

[72] Director Quality, Safety & Oversight Group, "COVID-19 Survey Activities, CARES Act Funding, Enhanced Enforcement for Infection Control deficiencies, and Quality Improvement Activities in Nursing Homes." (official memorandum, Baltimore, Maryland: Centers for Medicare & Medicaid, June 1, 2020). https://www.cms.gov/files/document/qso-20-31-all-revised.pdf.
[73] "Covid-19 Emergency Declaration Blanket Waivers for Health Care Providers." *The Centers for Medicare and Medicaid*, https://www.cms.gov/files/document/summary-covid-19-emergency-declaration-waivers.pdf.
[74] "Intermediate Care and Skilled Nursing Facilities." *Missouri Department of Health and Senior Services,* April 14, 2020. https://ltc.health.mo.gov/wp-content/uploads/sites/18/2020/04/Intermediate-Care-and-Skilled-Nursing-Facilities-4-14-20.pdf.
[75] "Medicare Shared Savings Program Skilled Nursing Facility 3-Day Rule Waiver." *The Centers for Medicare and Medicaid*, May 2021. https://www.cms.gov/medicare/medicare-fee-for-service-payment/sharedsavingsprogram/downloads/snf-waiver-guidance.pdf.
[76] "Intermediate Care and Skilled Nursing Facilities." *Missouri Department of Health and Senior Services,* April 15, 2020. https://ltc.health.mo.gov/wp-content/uploads/sites/18/2020/04/Intermediate-Care-and-Skilled-Nursing-Facilities-4-15-20.pdf.
[77] "Covid-19 Emergency Declaration Blanket Waivers for Health Care Providers." *The Centers for Medicare and Medicaid*, https://www.cms.gov/files/document/summary-covid-19-emergency-declaration-waivers.pdf

requirement that residents must be provided designated rooms for dining and activities.[78] Although the waivers discussed in this final section do not explicitly dictate about staffing, many of them do alter standards typically upheld and carried out by staff. As such, they can be thought of as, in part, reducing the work strain of staff while also aiming to make adherence to infection control protocols easier and a priority for facilities.

C. Policy Decisions Conclusion

All of the policy decisions discussed here reflect a portion of the actions taken by the federal government and the state government of Missouri in their efforts to reduce the spread of Covid-19 and its toll on human lives. The diversity of these policy decisions reflects the multiple avenues through which government agencies attempted to improve the situation for nursing homes during Covid-19. For example, training requirements for nurse's aides or feeding assistants were decreased so that more of these professionals could be in the facilities quickly, providing care to an increasingly segregated patient population facing new health challenges. Similarly, timelines for administrative tasks were expanded so that workers could focus on meeting the patient's health needs. The most obvious of the policy changes restricted visitation and socialization for residents to avoid the spread of the virus. Each of these decisions was made with the intention of providing relief to the strained system so that resources could be adequately dedicated to the containment and treatment of Covid-19. It is important to be familiar with these policy changes when discussing the impact that the Covid-19 pandemic had on nursing home residents because they offer insight into facility conditions and into the concerns and priorities of

[78] Director Quality, Safety & Oversight Group, "COVID-19 Survey Activities, CARES Act Funding, Enhanced Enforcement for Infection Control deficiencies, and Quality Improvement Activities in Nursing Homes." (Official memorandum, Baltimore, Maryland: Centers for Medicare & Medicaid, June 1, 2020). https://www.cms.gov/files/document/qso-20-31-all-revised.pdf.

facility regulators during this time. It will now be useful to evaluate the areas in which nursing home residents experienced challenges to their daily life and care during the pandemic in order to inform an analysis of these policy decisions.

IX. Changes to Wellbeing & Care During the Pandemic

A. Quantitative Data

As was discussed in the literature review, there have been increasing concerns regarding decreased quality of care inside nursing homes during the pandemic. However, the unique circumstances of this event limit the traditionally available sources of information that can be used to investigate this question, such as data collected by state surveyors for regular and complaint inspections. When survey activities were restricted, immediate jeopardy complaints were the only traditional metric that was theoretically uninterrupted. As such, a brief analysis of complaint investigations at the immediate jeopardy level throughout the reduced surveillance periods is informative both about how quality of care suffered during the pandemic and as to the likelihood that other events of lesser classifications occurred. There are three levels of Immediate Jeopardy deficiencies - J, K, and L. The definitions of these categories are listed in the table on the following page.

Figure 1: Immediate Jeopardy Deficiency Definitions[79]

Deficiency Level	Scope Definition of Deficiency
Immediate Jeopardy J	Isolated - Scope is isolated when one or a very limited number of residents or employees is/are affected and/or a very limited area or number of locations within the facility are affected.
Immediate Jeopardy K	Pattern - Scope is a pattern when more than a very limited number of residents or employees are affected, and/or the situation has occurred in more than a limited number of locations but the locations are not dispersed throughout the facility.
Immediate Jeopardy L	Widespread - - Scope is widespread when the problems causing the deficiency are pervasive (affect many locations) throughout the facility and/or represent a systemic failure that affected, or has the potential to affect, a large portion or all of the residents or employees.

In analyzing the number of such complaint investigations in recent years, one can note that between 2019 and 2020, the number of Immediate Jeopardy K and L complaints increased in Missouri. Additionally, 2021 saw a ten-year record high for J and K level complaints with 63 J complaints and 16 K complaints in the state.[80] This indicates that there was an increase in care deficiencies during the pandemic when compared to previous years. Research from the Center for Long-Term Care Quality and Innovation at Brown University supports this conclusion using data from the CMS nursing home compare repository. It recorded that from 2019 to 2020, nursing home facilities in Missouri had an increase in the percentage of low-risk long-stay residents with at least one pressure ulcer. The percentage rose from 8.33% in 2019 to 9.22% in 2020, which is also a ten-year record high for Missouri. The Institute characterized this metric as a signal of quality of care.[81] This quantitative data provides strong evidence that nursing home

[79] "Assessment Factors Use to Determine the Seriousness of Deficiencies Matrix." *Alabama Nursing Home Association*, http://anha.org/uploads/ScopeSeverity2018.pdf.
[80] "Deficiency Count Report." *Quality, Certification, & Oversight Reports*, https://qcor.cms.gov/report41snf.jsp?which=0&report=report41snf.jsp#pagetop.
[81] "Data." *Center for Long-Term Care Quality and Innovation Brown University*, https://www.brown.edu/academics/public-health/qandi/research/data

care quality declined in Missouri nursing homes during the pandemic, but more detail is needed to understand the specific areas in which challenges were presented.

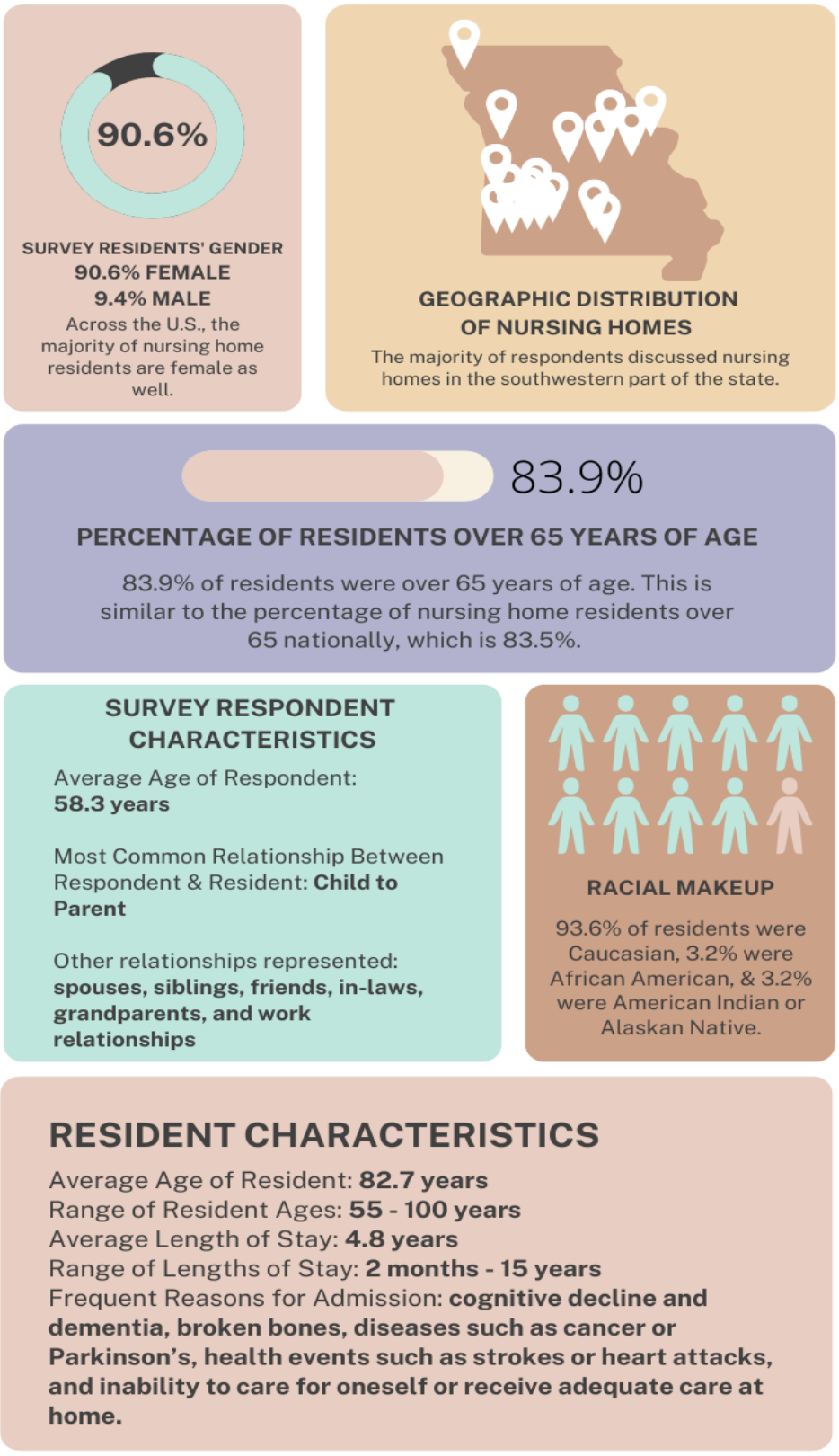
B. Survey Data

The survey of nursing home residents' loved ones conducted for this study suggests which areas of care worsened most dramatically during the pandemic. The survey showed that residents experienced negative changes in their emotional, social, mental, and physical wellbeing. Additionally, residents' loved ones underwent emotional distress as a reaction to their resident's altered mental or physical health status. The most descriptive portion of the survey was a series of three questions which asked respondents to describe changes they noticed to their residents' cognitive, emotional, and physical states.

i. Survey Demographics

Demographic information regarding the respondents and the residents with whom they have a relationship can be found in the infographic on the following page.

Figure 2: Survey Demographic Data



ii. Changes to Residents' Cognitive, Physical & Emotional States

The survey asked respondents to explain whether they noticed changes to their loved ones' cognitive state during the pandemic lockdown. The most common responses consisted of increased confusion, worsened dementia, and decreased communication abilities. However, three respondents took care to note that while they felt the cognitive status of their loved one declined, they were uncertain if such changes could be attributed to conditions of the pandemic. These comments highlight a crucial point which is relevant for all the discussion surrounding this investigation. A significant percent of nursing home residents are individuals with disabilities, comorbidities, and neurodegenerative disease diagnoses. Therefore, it would be extremely difficult to separate the typical decline that accompanies frailty and disease from the adverse health impacts of isolation or decreased care quality during a specific period of time in most cases. However, as will be discussed later in this paper, there is significant scientific data that shows a correlation between conditions, such as social isolation or fewer hours per patient of nursing care, and negative clinical health outcomes.

When asked about changes they noticed in their loved ones' physical state during the pandemic lockdown, there were several repeated themes among the answers. One of the most common responses was that respondents noticed weight loss in their loved ones. Weight loss is an important health status indicator, as well as a potential indicator of neglect. Respondents also repeatedly mentioned more frequent incidences of falling, decreased mobility, or increased muscular weakness in general. One respondent noted that after frequent falls, her loved one had bone fractures. Other respondents noted that their loved one developed pressure ulcers, some of which became infected, urinary tract infections, and dry skin. Several individuals also observed a decline in hygiene and appearance, with some describing indicators such as uncut fingernails and

toenails, tooth loss, repeated wear of the same clothing without washing, and unkept or uncut hair. Additionally, multiple respondents described situations in which they found their loved one no longer knew the location of essential items such as hearing aids or dentures. One respondent wrote that when she was allowed to visit, she noticed her mother's lower dentures were missing. After asking the staff, they were located in a drawer in the nursing office. A staff member then informed her that they had been broken for "a long time." Several individuals commented that their loved one passed away in the nursing home, some of whom directly blamed physical neglect on the part of the nursing home for their passing.

The final question in this series regarded changes to the respondent's loved one's emotional states. The most frequent response indicated that the resident had become depressed during the period of time in which pandemic restrictions were in place. Other frequent responses included feelings of anxiety, agitation, loneliness, disinterest, and hopelessness. Several of the respondents commented that their loved ones cried during their limited visits and were frequently upset. One observed that their loved one had frequent nightmares, and another said their loved one panicked because they felt trapped. A few individuals noted their loved ones were unable to communicate due to their health status, that they were not sure the changes could be attributed to the conditions of the pandemic, or that they did not notice any changes. These responses constituted a small minority.

These responses not only elaborate further on some of the emotional distress mentioned in the visitation and socialization section on the part of the residents, but they also provide insight into potential changes in care provision. Several of the noted ailments of participant's loved ones overlapped with known signs of neglect in nursing home settings. For example, pressure ulcers, broken bones, dehydration, malnutrition, new or untreated medical conditions,

personal hygiene issues, significant personality changes, and other unexplained injuries are all typical symptoms of neglect in long term care settings. This does not mean the appearance of any of these symptoms was definitively caused by neglect, but it does highlight a relationship between a lack of adequate care provision and certain ailments that may offer insight into some of the individual situations mentioned. It should also be noted that there are numerous types of neglect, including social and emotional neglect, neglect of basic living needs, neglect of personal hygiene, and medical neglect. While these responses provide evidence that the wellbeing of some residents declined during the pandemic, other portions of the survey attempted to explore factors that may have contributed to such outcomes. The survey responses primarily highlighted challenges with access to information, social isolation, and fulfillment of daily needs, each of which constitute an aspect of care deficiencies more generally.

iii. Challenges Regarding Access to Information

For the purposes of this project, access to information is considered an aspect of care quality because it is a clearly defined patient right in federal and state statutes and it has an impact on resident wellbeing. Respondents indicated that the lack of information had negative impacts on their residents' and their own emotional states - which has clinically significant implications for wellbeing. Their lack of knowledge about reporting mechanisms also limited their ability to raise concerns and address poor quality of care situations. Survey respondents were asked how informed they felt about the pandemic, policy changes, reporting mechanisms, and advocacy services. First, they were asked whether they or their loved ones felt fully informed by the nursing homes about Covid-19 during the course of the pandemic. The most common response was that neither the respondent nor their loved one felt fully informed, with 43.3% of

respondents selecting this option. The next most prevalent answer was that both parties felt fully informed, and 20% indicated that they felt fully informed, but their loved one residing in the nursing home did not. For those that indicated that they or their loved one had not felt fully informed, they were asked to describe how they or their loved one felt regarding Covid-19. The most common feelings noted were anger, confusion, uncertainty, and fear. Some said their residents felt alone or abandoned. One individual wrote that "we were both sad, heartbroken because we couldn't see each other face to face. We missed our hugs." Such negative emotional reactions are important for residents' ability to thrive within nursing homes, and as such, are important to their wellbeing. A different subsect of respondents indicated that their loved ones could not be adequately informed due to their cognitive state, frequently citing dementia or other mental impairments.

The respondents were then asked to select any policy changes of which they were aware that occurred as a result of the pandemic. The three most frequently indicated changes were the restriction of visitation, increased resident isolation/loss of scheduled activities or group socialization spaces, and the loss of excursions outside the facility, respectively. Only three respondents indicated that they were aware of policy changes which decreased requirements for staff training, and no respondents indicated they were aware of changes to patient transfer policies. One respondent selected that they were not aware of any changes, and a few respondents chose to list additional changes such as decreased access to physicians outside the facility and new inbound mail protocols. The intention of this question was primarily to gauge the extent to which the respondents were informed of policy changes and simultaneously to understand which changes went most noticed by the loved ones of residents, as the actual policy changes for nursing homes are well documented and have been discussed in detail in this project.

What these responses showed was that certain policy modifications, such as those which limited visitor access or resident socialization, were more likely to be noted by loved ones of residents than other changes. There could be numerous explanations for why this is the case, but as the responses from further questions made clear, isolation and lack of visitation was frequently the primary complaint of the survey respondents, and many saw such policy changes as sources of harm to their loved ones. Additionally, restriction of visitation is the policy change that is most likely to affect the survey respondents themselves as visitors, so it is logical that this would be the change the majority of respondents were informed about.

The survey of loved ones of nursing home residents also collected information about respondents' interactions with reporting mechanisms, as well as the extent to which they were informed of various services and policies. Respondents were asked whether they or their loved ones had concerns about their treatment in the nursing home since the beginning of the Covid-19 pandemic. Of the respondents, 84% responded with the affirmative, and 16% responded that they had not had such concerns. This result is consistent with the quantitative data that indicated decreased care quality. Of those that indicated they had concerns, 72.7% said they had reported their concerns to someone. When asked who they reported concerns to, responses varied. The most common answer was that concerns were reported to the administrator of the nursing home or to other staff members within the facility. Other contact points noted included the Centers for Medicare and Medicaid, state inspectors, the Missouri Attorney General, a long-term care advocacy group and ombudsman provider called VOYCE, social workers, the board of trustees of facilities, the Missouri Department of Health and Senior Services, ombudsman, facility compliance officers, Missouri Protection and Advocacy Services, and Missouri politicians, which will become relevant when undertaking policy critiques. When asked whether their

concerns were adequately addressed, there was once again a spectrum of responses. The most common response was that concerns were not addressed adequately, while some indicated that they were partially addressed, and one respondent replied that their concerns were addressed in totality. For those who indicated they had concerns but did not report them, they were asked to explain their decision not to submit complaints. The most common reason given was that previous expression of concerns had been ignored. Other reasons given were that respondents were unsure where to submit concerns, unable to reach resources to discuss concerns, they had personal connections to faculty inside the home, or their loved one had already passed away. Only half of the respondents indicated that they were familiar with the position of an ombudsman and the work they do. Additionally, 88.9% of respondents were not informed that state survey agencies paused recertification surveys and investigation of non-immediate jeopardy complaints in nursing homes in March, 2020, as a part of pandemic response.

Participants were asked about their knowledge of essential caregiver programs in order to understand whether or not they were offered the opportunity to participate in such a program or if they were aware that such offerings may be available. When asked if they were made aware of options to apply for essential caregiver status or to conduct compassionate care visits during the pandemic, 75.9% of respondents indicated they were unfamiliar with one or both of those terms, while 4 respondents indicated their applications were denied and two responded they were granted permission for one of those opportunities. For those that were denied, respondents were asked to relay what reasoning was given for their denial. One respondent was told her loved one did not qualify because compassionate care visits were reserved for those who are actively dying. Another attempted to get essential care giver status for her mother's partner who lived in a different part of her facility, but was denied due to policies that restricted interaction between

different segments of the facility during the pandemic. A third person was told that only employees were allowed in the facility at the time of her request. Additionally, one respondent noted that they only learned of these options through their own research, and that her requests for caregiver status were ignored or met with ignorance about the program. This respondent relayed that she was eventually allowed to make one 30-minute visit to her loved one after intervention from her state representative. However, during the visit she was not allowed to touch them or assist with their care, which had been her initial goal as she noted significant weight loss and sought to assist with meals. One respondent who indicated she was granted essential caregiver status explained that she had to fight to receive the status and she required assistance from the Missouri Department of Health and Senior Services during the process. Several respondents used this question as an opportunity to express the fact that they were not informed of these opportunities or were informed late into the pandemic, and others expressed regret at the fact that they were not made aware of them. When all of these responses are viewed together, an image is created in which facility residents and their loved ones were not satisfactorily informed about the pandemic and how it was affecting nursing home operations. Additionally, such a lack of information caused emotional and mental distress, as well as did not position individuals to be able to correct situations of subpar care quality.

iv. Challenges Regarding Social Isolation

Social isolation was the second central challenge represented by survey respondents. This primarily stemmed from reduced visitation and socialization opportunities inside and outside the facilities. In anticipation of challenges regarding restricted visitation during the pandemic, one segment of the survey was centered around visitation policies and residents' reactions to them.

All the survey respondents whose loved ones were admitted to a facility before March, 2020, indicated that prior to the pandemic their loved one received frequent in-person visitation. In fact, 51.6% of respondents replied that their loved one had received visitors daily. For the respondents of this survey, it is clear that their loved ones experienced consistent in-person connection with loved-ones prior to the pandemic. During the pandemic, however, the majority of respondents indicated that their loved one did not receive in-person visitors while restrictions were in place. One survey respondent noted that their visits were inconsistent because visitation policies changed numerous times as community Covid-19 case rates changed, and a few respondents indicated that they were able to visit in-person only when weather permitted outside visitation. The average time that respondents said they went without seeing their loved one in a traditional in-person setting was 6.7 months, but responses ranged from 5 months to over one year. Several individuals noted that their loved one had died before visitation restrictions were lifted, and that they had not been able to visit them before their death.

When asked about alternative visitation policies, the most frequent options noted were window visits, phone calls, and video conferencing. Window visits typically consist of the nursing home resident remaining inside the facility while their loved ones conducted a visit from outside through a window. Numerous respondents had complaints about these visitation methods. One repeated concern was that the residents had poor hearing or eyesight, and therefore the offered alternative visitation methods were non-productive or stressful. Others cited discomfort on the part of the resident or for themselves in cold or hot weather conditions during outside visits. When asked to describe how their loved one adjusted to these alternative forms of visitation, the responses largely indicated that residents had negative reactions to the changes. The most commonly stated reactions were those of confusion, loneliness, isolation, and

depression. Several respondents relayed that their loved one felt they were being punished or as if they were in jail. Many individuals indicated that their loved one could not understand the situation, largely due to their cognitive status. One respondent noted that the situation was not enjoyable, but that they understood the necessity of the practices. Overall, the responses highlighted the mental and emotional anguish that separation from social networks can impose upon an individual.

Interviews with nursing home administrators and directors of nursing revealed similar feelings about restricted visitation policies. Several participants commented that they noticed increased depression among their residents, which they related to a lack of visitation, outside excursions, and socialization. They commented on increased medication for depression and anxiety, as well as feelings of anger from the residents at policies which the administrators were largely unable to change as they were following guidance from institutions that rate them on their adherence to policies. One respondent noted that they believe their residents went nearly a year with no physical contact from their loved ones. Even in special situations when it was allowed, physical touch was only allowed through rubber gloves rather than skin contact. Additionally, it was noted that doctor appointments were canceled, and hospital trips were only made in cases of emergency, which would likely have an impact on resident wellbeing. Regular doctor visits are important opportunities for practitioners to review health status and catch any changes in patient wellbeing or condition. Some administrators did highlight the responsibility of nursing home directors and staff to alleviate residents' discomfort with such policies and gave examples of ways they tried to maintain socialization among them. For instance, one facility took their residents on group outings where they were isolated from the general public but were still able to have experiences like visiting local parks or viewing Christmas lights. As one

administrator put it, the staff at the facility had a responsibility to become the family that the residents were missing during this time.

Numerous studies have shown that loneliness has negative clinical impacts on health. A study conducted by researchers at the University of Chicago concluded that "the absence of positive social relationships is a significant risk factor for broad-based morbidity and mortality" and that this pattern becomes more pronounced with advanced age. Morbidity was defined within this study as a combination of depressive symptoms, functional limitations, and poor self-rated health. The study noted that loneliness has previously been found to be a risk factor for a host of health conditions, including high blood pressure and increased vascular resistance, metabolic syndrome, fragmented sleep, increased hypothalamic pituitary adrenocortical activity which is linked to diabetes, obesity, cardiovascular disease, mood disorders, declining cognition, altered gene expression indicative of decreased inflammatory control and increased glucocorticoid insensitivity, diminished immunity, and diminished impulse control.[82] Additionally, a 2020 study reported that social isolation rivals risk factors such as smoking, obesity, and physical inactivity in terms of risk of premature death[83] and a 2011 study found that social isolation was associated with a 50% risk of dementia. Another relevant aspect of this situation is that loneliness has been discovered to be "contagious" in that individuals who are around lonely individuals tend to grow lonelier across time. Researchers concluded that this pattern is one of induction rather than a tendency for lonely people to group together voluntarily, which has important ramifications on nursing home environments where residents' primary

[82] John T. Cacioppo and Stephanie Cacioppo, "Social Relationships and Health: The Toxic Effects of Perceived Social Isolation." *Social and Personality Psychology Compass* 8, no. 1 (2014):58-72. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4021390/.

[83] "Social Isolation and Loneliness in Older Adults: Opportunities for the Health Care System." *National Academics of Sciences, Engineering, and Medicine,* (Washington DC: National Academies Press, 2020). https://search-ebscohost-com.ezproxy.cul.columbia.edu/login.aspx?direct=true&AuthType=ip&db=e025xna&AN=2514627&site-ehost-live&scope-site.

socialization comes from other facility residents.[84] When viewed in totality, these responses show that restriction of socialization and visitation opportunities were frequently associated with negative mental and emotional health outcomes, which have been empirically shown to have numerous deleterious health effects.

v. Challenges Regarding Fulfillment of Daily Needs

The challenges presented by restricted visitation are not limited in scope to mental and emotional wellbeing, however. The final area of challenge that was evident through survey responses was in the fulfillment of daily needs. The survey asked respondents to select which tasks, if any, they would typically help their loved ones with during in-person visits prior to the pandemic. In order of decreasing response frequency, individuals indicated they typically assist with emotional support, communication, eating or drinking, repositioning or mobility, hobbies or recreation, and hygiene during in-person visits. Seven respondents added additional tasks such as cleaning the room, sorting mail, doing laundry, assisting with beauty routines, sexual activity, taking excursions out of the facility, and advocating for their loved one with staff and administrators. These responses highlight the vital role that some visitors play as caregivers for their loved ones, as well as the potential hazard of eliminating visitors from the daily routines of nursing home residents. It is clear from these answers that residents benefit physically, socially, emotionally, and mentally from frequent visitation with loved ones, which is an important point to note when considering the potential ramifications of decreased or discontinued visitation during emergency situations like the Covid-19 pandemic. Additionally, this observation has

[84] J. T. Cacioppo et al., "Alone in the crowd: the structure and spread of loneliness in a large social network." Journal of Personality and Social Psychology 97, 6 (2009):977-91. doi: 10.1037/a0016076. PMID: 19968414; PMCID: PMC2792572.

significant implications for the workload of nursing home staff, who were rendered without the support that caregivers typically provide for an extended period of time while visitation restrictions were in place.

In the general comments portion of the survey, there was further evidence that fulfillment of daily needs was a challenge for many residents. Nutritional needs presented a problem for many, and respondents noted that their loved ones indicated their facility had stopped providing the same type or quality of food that it had previously offered, the food was subpar, menu planning, and food service was inadequate, or that dietary needs were not being met at the facility generally. In addition to nutrition, one respondent commented that their loved one wished to get exercise but was not allowed to use the exercise room due to pandemic restrictions. In general, this open response portion of the questionnaire restated the three areas of challenges which have been highlighted here. To briefly summarize the comments, respondents noted feelings of guilt and anger at being separated from their loved ones, cited discontinuation of services like physical therapy, said that they were not informed of their loved one's health conditions in a timely manner, expressed discontent at the decrease of monitoring and oversight by state agencies, and complained of short staffing, crowding, unsatisfactory nutritional management, and general inadequate care for their loved ones.

This qualitative data collection accomplished two objectives. It provided supplementary evidence that the quality of care in Missouri nursing homes declined for some residents during the Covid-19 pandemic. To summarize the data collected, nursing home residents exhibited key indicators of care quality decline from physical attributes like pressure ulcers and weight loss to mental and emotional characteristics of depression and anxiety. The three central challenges noted by resident's loved ones to care were lack of access to information, decreased

opportunities for socialization, and inadequate fulfillment of daily needs. Recognizing the impact that policy had on nursing home operations, these observations will now be used to conduct an analysis and critique of the policy decisions made during this public health emergency.

X. The Unexpected Consequences of Regulatory Changes

The majority of the policy decisions considered within this project were made with the primary objective of stopping the proliferation of the Coronavirus, which they were successful in doing. However, the impacts introduced in the previous section necessitate and inform a discussion of the consequences and merits of such decisions and indicate that certain regulatory changes increased risk to resident health. It would be difficult and beyond the scope of this project to claim with certainty that specific policy decisions directly caused particular outcomes. However, the testimony of loved ones of nursing home residents and logical analysis support the conclusion that regulatory changes exacerbated some existing problems in the nursing home sector and therefore contributed to situations of decreased care quality. Rather than a question of whether policy decisions achieved their goal of protecting individuals from Covid-19, the following discussion debates the question of whether the particular vulnerabilities of nursing home populations were adequately accounted for in pandemic response policy. At the least, this conversation serves to open the subject to further study and debate. Considering the decline in care exhibited through quantitative and qualitative data, it is imperative that the ramifications of policy decisions are debated so that policy makers are maximally equipped to make decisions in the future that best benefit nursing home residents in times of emergency. Policy decisions regarding monitoring and surveillance, staffing, visitation and socialization, facility transfer and discharge, and care provision will be critically examined in the following paragraphs.

A. Monitoring & Surveillance

What impact did the reduction in surveillance taken as a measure against Covid-19 infection have on residents' experiences? As the survey data highlighted, many loved ones of residents had concerns about their resident's care in the nursing home, but only a portion successfully reported their concerns, and a smaller number had their concerns satisfactorily addressed. Residents and their loved ones experienced barriers to the right to raise grievances that should be straightforward to remedy through increased education about reporting mechanisms and about available services and advocates. The responses which indicated that complaints went unaddressed highlight a challenge that is more difficult to resolve, as they seem to indicate a lack of functionality in the current reporting and complaint investigation system, which may have been exacerbated by the reduced capacities of survey agencies during the pandemic.

The policy decision to limit complaint investigation surveys to only immediate jeopardy level complaints for a portion of the pandemic was arguably insufficient for protecting residents' wellbeing. The ranking system which dictates the level of jeopardy a complaint constitutes is relatively complex. There are fine lines between situations which constitute "actual harm" that is not immediate and those which constitute immediate jeopardy. Further, these distinctions are made at the discretion of surveyors, and are therefore subject to a certain level of personal judgement. For example, recently a Missouri facility was cited for failing to ensure that a resident's twice daily anti-epileptic medication had been delivered from the pharmacy for two days, which resulted in five missed doses and a host of health consequences including cognitive and sensorimotor impairments suffered by the resident. This citation was given the level of isolated actual harm but did not meet the requirement of an immediate jeopardy level complaint and therefore would not have triggered a complaint investigation while restrictions were in

place.[85] To give an example of an immediate jeopardy situation which did necessitate investigation during restrictions, one facility failed to ensure adequate cardiopulmonary resuscitation for a resident with full code status. In this situation, the LPN conducted cardiopulmonary resuscitation (CPR) until the resident regained a weak pulse and then left the resident, without checking the vital signs of the patient, in the room with a CNA who was not CPR certified. The resident subsequently died before paramedics arrived.[86] Although the second case resulted in death while the first only resulted in impairment, it is difficult to justify the discontinuation of investigations for situations that cause significant harm to residents simply by designating them as non-immediate. This is particularly salient in situations like the former in which events may reflect larger issues at a facility such as a lack of oversight regarding pharmaceutical delivery which could cause harm to a larger population of residents. Although there was a reasonable necessity for surveyors to focus on infection control inspections during the height of the pandemic, it was not in the best interest of nursing home residents to completely restrict complaint investigations at the actual harm level. The survey prioritization remained in place for over ten weeks, and some facilities went much longer before they had any complaint investigation inspections conducted. It is not reasonable to allow situations of actual harm to go without investigation for such a prolonged period, as doing so puts residents at risk of repeated care deficiencies. This assertion is further supported by the fact that immediate jeopardy complaints increased during the pandemic, and as such it can be reasonably assumed that

[85] "Statement of Deficiencies and Plan of Correction 265439." *Department of Health & Human Services,* February 24, 2021. https://www.medicare.gov/care-compare/inspections/pdf/nursing-home/265439/health/complaint?date=2021-02-24.
[86] "Statement of Deficiencies and Plan of Correction 265769." *Department of Health & Human Services,* July 2, 2021. https://www.medicare.gov/care-compare/inspections/pdf/nursing-home/265769/health/complaint?date=2020-07-02.

complaints at other levels were likely to have increased as well, yet those complaints were not investigated in a timely manner due to the policy decisions of CMS and Missouri DHSS.

Investigations are a critical component of nursing home care quality because they provide clarity into situations that resulted in harm or risk of harm, and at times, they uncover systematic issues in facilities through interviews with staff and residents. When interviewing Missouri nursing home administrators, the majority commented on their positive relationship with surveyors, and the important role that surveyors play in educating staff about how to best protect the health and safety of residents. With this in mind, it is recommended that in future instances of survey prioritization, actual harm complaint investigations are not restricted, although they may be prioritized below immediate jeopardy and infection control inspections. To discuss the survey restrictions more generally, the backlog of standard nursing home surveys created by the survey restriction period is also in need of consideration. The Office of the Inspector General (OIG) found that between February, 2020, and May, 2021, 76% of Missouri nursing homes went without a standard survey. According to the OIG, standard surveys are CMS's "main tool to ensure that nursing homes meet the minimum standards necessary for the safety and wellbeing of residents" because they "help to identify and address deficiencies."[87] The restricted surveillance activity prescribed by CMS was not intended to harm residents or have their needs go unmet, but rather sought to reduce the frequency of visitation from outside entities that could expose residents to the Covid-19 virus and to allow survey agencies to focus their resources on ensuring facilities were following infection control protocols. This is a justifiable desire on their part given the particular threat of harm Covid-19 presented to nursing home residents. However, the policy may have resulted in a quicker return to normal survey procedures if state survey agencies

[87] "States' Backlogs of Standard Surveys of Nursing Homes Grew Substantially During the COVID-19 Pandemic." *Office of Inspector General*, July 2021. https://oig.hhs.gov/oei/reports/OEI-01-20-00431.pdf.

were given more concrete criteria and deadlines by which they could resume regular survey activities, rather than being authorized to resume "as soon as they have the resources to do so".[88] Supplementary government actions granting such resources to survey agencies during this time would have also been helpful, including increased access to PPE, vaccinations, testing, and increased funding to pay surveyor staff. The majority of loved ones who participated in the survey about life in nursing homes during the pandemic were unaware that these changes to monitoring activities had even occurred. If CMS and state survey agencies took greater efforts to be transparent in their actions, there might have been greater urgency for resumption of survey activities and more resources allotted to surveyors' efforts, which could only benefit the public, nursing home residents, and surveyors in their mission to make life safe and healthy in these facilities. Overall, the general decision to limit surveillance was not ill-advised, but the specifics with which it was carried out could have been modified so that nursing home residents were not faced with unnecessary risk.

B. Staffing

The federal and state government made numerous policy decisions, primarily through waivers, with the goal of easing the strain of staffing shortages on nursing homes made worse by the pandemic. Infection control protocols necessitated additional work from already understaffed facilities. As such, combatting staffing shortages was essential for ensuring infection control was properly carried out in facilities in addition to their regular operations. However, through their decisions, regulators allowed facilities to operate with larger staff to resident ratios and with less

[88] Director Quality, Safety & Oversight Group, "Enforcement Cases Held during Prioritization Period and Revised Survey Prioritization." (Official memorandum, Baltimore, Maryland: Centers for Medicare & Medicaid, August 17, 2020). https://www.cms.gov/files/document/qso-20-35-all.pdf.

rigorously trained staff than prior to the pandemic. Additionally, it is worth nothing that there was an absence of a policy decision to increase funding for staffing given that increasing staffing was the goal of regulators. A shortage of staffing, or inadequate care from staff, was identified by both survey respondents and in interviews with nursing home administrators. In multiple portions of the survey, respondents raised concerns about staffing levels or staff actions and commented about unaddressed concerns and their inability to reach staff for communication regarding their loved ones' care. It was the comments of nursing home administrators, however, that elaborated upon the significant role that staffing plays in nursing home operation and the difficulties faced during the pandemic.

When asked to discuss some challenges they faced to nursing home administration during the pandemic, several administrators chose to talk about staffing shortages. Despite the goal of policy to bolster the workforce, staffing shortages in nursing homes have been shown to have increased from May to December, 2020, with 23 percent of nursing homes across the country reporting a shortage of one or more categories of direct care staff by the end of the year. Facilities with Covid-19 cases and personal protective equipment shortages have been shown to have experienced more severe staffing shortages than their counterparts, highlighting the fact that unique pandemic conditions contribute to the problem of inadequate staffing.[89] One interviewee began by noting that there was a staffing shortage in Missouri prior to the pandemic, and that it was only exacerbated by the recent conditions. One such condition mentioned was the inability for some nursing homes to remain competitive with other health care facilities in terms of hourly wages. The administrator attributed this to the fact that Missouri nursing homes have

[89] "Nursing Home Safety During Covid: Staff Shortages." *U.S. PIRG Education Fund*, January 2021. https://uspirg.org/sites/pirg/files/reports/StaffShortages/WEB_USP_Nursing-Home-Safety-During-COVID_Staff-Shortages.pdf.

not seen increases in Medicaid or Medicare funding for numerous years which remained true during the pandemic. As such, they did not have additional money to allocate toward paying or retaining staff, even as minimum wage increased. Other healthcare providers offered more competitive wages. The statements of nursing home administrators regarding staffing shortages and wages in Missouri are substantiated by evaluations of such positions in states across the country. For example, Missouri currently ranks 42nd in terms of Registered Nurse hourly mean wage across all types of healthcare settings.[90] This is important given that research shows increasing nursing home reimbursement, and therefore staff wages, is associated with increased RN staffing levels.[91] Research also shows that the amount which states increased Medicaid payment directly affected their improvement in resident outcomes.[92] The policy decision not to increase Medicaid funding allocation at the state level is thus inadvisable because it places Missouri nursing homes in a position where they are unable to attract and retain the quality workforce that is needed to provide skilled care to the residents in these facilities.

Missouri was ranked 51st and 50th in 2020 and 2021 respectively in the nation for average hours of direct care for each nursing home resident per day.[93] While federal recommendations suggest that each resident should receive four hours of direct care each day, [94] the average in Missouri is 2.99 hours per day. [95] It should be noted that this is an average, and as such, some

[90] Marcus Robertson, "What nurses are paid per hour in all 50 states." *Becker's ASC Review,* November 18, 2021. https://www.beckersasc.com/benchmarking/what-nurses-are-paid-per-hour-in-all-50-states.html.
[91] Dana B. Mukamel et al. "The Relationship of California's Medicaid Reimbursement System to Nurse Staffing Levels." *Medical Care* 50, no. 10 (2012):836-42. http://www.jstor.org/stable/41714583.
[92] Vincent Mor et al., "The Effect of State Policies on Nursing Home Resident Outcomes." *Journal of the American Geriatrics Society* 59, (2011):3-9. https://doi.org/10.1111/j.1532-5415.2010.03230.x
[93] "Nursing Home Staffing Q3 2021." *Long Term Care Community Coalition, https://nursinghome411.org/data/staffing/staffing-q3-2021/.*
[94] Megan Lynch "Data shows Missouri nursing homes fail to provide recommended hours of care." *NewsRadio 1120 KMOX,* August 16, 2021. https://www.audacy.com/kmox/news/local/missouri-nursing-homes-fail-recommended-hours-of-care.
[95] "Nursing Home Staffing Q3 2021." *Long Term Care Community Coalition, https://nursinghome411.org/data/staffing/staffing-q3-2021/.*

facilities exceed national recommendations, while others fall as low as two hours per resident per day. Missouri currently has no minimum requirement for direct care staff, but it does require sufficient staff, which it defines as "sufficient numbers to enable each resident to attain or maintain the highest practicable level of physical, mental, and psychosocial well-being."[96] As Marjorie Moore, director of the long-term care advocacy group VOYCE, points out, there is a strong correlation between hours per day of staff care and number of complaints to monitoring bodies or survey results.[97] In fact, the CMS 5-star quality rating system is based in part upon staffing of a facility because "there is considerable evidence of a relationship between nursing home staffing levels and resident outcomes." As such, the rating system considers two measures, registered nurse hours per resident per day and total nurse hours per resident per day including nurses' aides and licensed practical nurses.[98] Numerous other studies outside of the CMS staffing study have drawn similar conclusions.

Research conducted at Indiana University found that RN staffing has a "large and significant impact on quality of care." In this case, quality of care was measured by the count of deficiencies cited in a facility and a score measure to account for differences in scope and severity of the violations that constituted the deficiencies. The study concluded that increasing RN hours per resident per day by .3 hours increases quality of care by 16%.[99] A different study found that quality improved with increases of staffing at all levels up to certain thresholds. This

[96] Cherry Harrington, "Nursing Home Staffing Standards in State Statutes and Regulations." *Department of Social and Behavioral Sciences University of California San Francisco,* January 2008. https://www.justice.gov/sites/default/files/nursing_home_staffing_standards_in_state_statutes_and_regulations.pdf.
[97] Megan Lynch "Data shows Missouri nursing homes fail to provide recommended hours of care." *NewsRadio 1120 KMOX,* August 16, 2021. https://www.audacy.com/kmox/news/local/missouri-nursing-homes-fail-recommended-hours-of-care.
[98] "Design for Care Compare Nursing Home Five-Star Quality Rating System: Technical Users' Guide." *The Centers for Medicare & Medicaid Services,* April 2022. https://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/CertificationandComplianc/Downloads/usersguide.pdf.
[99] Lin Haizhen, "Revisiting the Relationship Between Nursing Staffing and Quality of Care in Nursing Homes." Journal of Health Economics 37, (2014):13-24. https://doi.org/10.1016/j.jhealeco.2014.04.007.

study measured quality of care through indicators such as hospital transfers for avoidable causes like urinary tract infections, sepsis, and electrolyte imbalances, and instances of quality-of-care issues such as pressure sores, skin trauma, and weight loss over periods of 90 days.[100] An additional study found a correlation between minimum direct care staffing requirements and nursing staff levels, which is relevant as Missouri does not have such a requirement at this time.[101] Finally, further research found that the highest staffed nursing homes performed better on 13 of 16 care processes performed by nursing assistants when compared to lower staffed homes. These 16 processes covered the domains of out of bed and social engagement, feeding assistance, incontinence care, and exercise and repositioning.[102]

Recognizing that staffing is a vital component of care quality in nursing homes, the lack of additional funding during the pandemic to support the nursing home workforce was not in the best interest of residents' wellbeing. Moving forward, a greater portion of state funds should be allocated to nursing homes through Medicaid. This funding should be used to increase wages across all positions in nursing homes, with a particular focus on increasing the wages of CNAs. Although this decision represents the absence of action on behalf of the government, the decision to waive certain training and staffing requirements are vulnerable to critique as well. Decisions that allowed for greater flexibility of staff scheduling, such as the waiver which allowed RNs to complete day or night shifts, are reasonable because they did not detract from the actual time nurses were required to be in the facility, nor did it alter their level of training. These waivers were generally well received by nursing home administrators because they allowed them to be

[100] "Appropriateness of Minimum Nurse Staffing Ratios in Nursing Homes." *Report to Congress,* December 2001, https://www.justice.gov/sites/default/files/elderjustice/legacy/2015/07/12/Appropriateness_of_Minimum_Nurse_Staffing_Ratios_in_Nursing_Homes.pdf.
[101] John R. Bowblis, "Staffing ratios and quality: an analysis of minimum direct care staffing requirements for nursing homes." *Health services research* 46, no.5 (2011): 1495-516. doi:10.1111/j.1475-6773.2011.01274.x
[102] John F. Schnelle et al., "Relationship of nursing home staffing to quality of care." *Health Services Research* 39, no. 2 (2004): 225-50. doi:10.1111/j.1475-6773.2004.00225.x.

creative within the confines of their staffing shortages in order to provide the most care possible to their residents. Waivers which reduced the time and type of training and certification for various levels of workers in these facilities warrant greater scrutiny. They raise important concerns about how decreased staff training and increased burden on nurses to perform additional tasks may impact care delivery and resident and staff experience in these facilities given what is known about the correlation between staffing levels, stress of workers, and quality of care for residents. This is particularly important when considering that these workers were operating during a period in which facility surveyors were not evaluating their performance on a regular basis as they would have been previously. Dramatic reductions in training time, such as the waiver which allowed for one hour of online training rather than the previously required eight hours of online training, are not advisable because the quality of the training is likely to have suffered from this change. However, these policies were primarily geared toward quickly training workers so that they could be in the facility and performing multiple roles. As such, it could be recommended that rather than diminishing training requirements in the future, such requirements could be adapted to be completed inside facilities with hands-on experience and supervision of trained professionals. Training on the job allows for new workers to join in the workflow quickly, while still operating safely under the supervision of others until they are satisfactorily prepared to deliver care services on their own.

Finally, the decision to recommend that nurses "bundle" care provision to avoid numerous room visits is counterintuitive to the constantly changing health needs of nursing home residents and the knowledge that staffing hours per day are related to patient outcomes. Once again, while this recommendation prioritizes infection control, it fails to take into account the complexity of care delivery in these facilities that is necessitated by the wide array of serious

health challenges present in nursing home populations. Rather than focusing on limiting room visitation, policy makers would do better to emphasis infection control methods that can be performed by staff between and inside patient rooms to limit virus exposure and transmission without compromising direct care delivery. In summary, the policy decision to not provide additional funding to nursing homes likely contributed to staffing shortages, and the decisions to alter training requirements increased the likelihood that underqualified staff would be delivering care. On the other hand, regulatory changes that allowed for greater workforce flexibility were considerate of the value and necessity of on-site healthcare professionals. With exception to the lack of additional funding, the decisions made were reasonable measures for reducing staffing shortages, but a handful created situations in which residents were at heightened risk of inadequate care.

C. Visitation & Socialization

Visitation and socialization were another focus of policy decisions made by state and federal governments during the pandemic. As is stated in the memorandums from CMS, the primary goal of limiting visitation and socialization was to prevent Covid-19 infection and stop the spread of the virus. The decision to limit visitors or social gatherings was logical given our current knowledge of infectious disease. However, these policies failed to sufficiently account for the considerable mental, emotional, and physical harm that can arise from social isolation and decreased time with healthcare providers. Missouri DHSS includes in their list of patient rights the "right of access to individuals, services, community members, and activities inside and outside the facility" as well as to "visitors of his or her choosing, at any time, and the right to

refuse visitors" and to "participate in social, religious, and community activities."[103] The Nursing Home Reform Act Bill of Rights also includes the right to participate in resident and family groups.[104] Therefore, the broad banning of visitation and socialization is a clear violation of the rights of residents. The ability of state or federal governing bodies to waive rights that have been elaborated for the express purpose of protecting the health and wellbeing of individuals is not consistent with the intention of the legislation which created them. At the very least, the existence of such rights should warrant careful consideration and planning as to how they can be best conserved in times of emergency, with credence given to the reasoning behind their creation.

The guidance offered by governing bodies regarding visitation and socialization was arguably insufficient for the preservation of these rights, as they offered limited practical and functional alternatives to maintain socialization of residents. Survey respondents indicated numerous difficulties with the suggested alternative visitation forms such as window visits and phone calls because they did not accommodate the disabilities of nursing home residents. For these alternatives to work in the future, creative engineering is needed to ensure that issues such as hearing loss, poor eyesight, mobility issues, or temperature sensitivity are not barriers to communication. Further, CMS only recommended that facilities offer such alternatives, which could have led to situations in which loved ones were completely cutoff from their resident. It would have been advisable for CMS to mandate the offering of alternative visitation options. Although it was necessary to limit the number of visitors into these facilities, exceptions should have been clearly made for individuals who provide vital care and support services to their loved

[103] "Nursing Home Residents' Rights." *Missouri Long-Term Care Ombudsman,* https://health.mo.gov/seniors/ombudsman/pdf/residents-rights-fact-sheet.pdf.
[104] "Omnibus Budget Reconciliation Act of 1987: subtitle C, Nursing Home Reform." Public Law 100-203, 100th Congress, (1987).

ones. Under CMS guidance, visits should have been allowed to be made in compassionate care situations, although they gave facilities the authority to approve such visits on a case-by-case basis and provided no further requirements or details about this recommendation. Compassionate care situations, as defined by CMS, should include situations in which a resident is experiencing emotional distress, exhibits decreased communication, needs encouragement with eating or drinking, is experiencing weight loss or dehydration, is struggling with a lack of physical family support or a change in environment, is grieving the death of a loved one, or is at the end of life. However, CMS chose to only list end of life situations in their recommendations, and evidence from survey respondents indicates that many facilities did not consider this broad definition when making decisions about compassionate care visitation.

Missouri's effort to encourage facilities to adopt essential caregiver programs was a move to improve the wellbeing of nursing home residents, but it was not a strong enough stance and did not produce actual policy that required facilities to offer such opportunities. It would have better served these populations if it required facilities to offer an essential caregiver program, rather than simply offering guidance for facilities that wanted to do so. Essential caregiver programs are a solution to numerous problems that arose during the pandemic. When caregivers are allowed to enter nursing homes, they provide support to nursing home staff because they help with daily care tasks. They also allow for closer monitoring of the health condition and care residents are receiving and provide important socialization for both the residents and the caregivers. The decision to limit visitation and socialization in nursing homes during this pandemic did not strike the correct balance between controlling for infectious disease and protecting against the harms of social isolation. In the future, clear policies that allow

compassionate care visits and essential caregivers should be in place which preserve residents' rights to the fullest extent possible while maintaining the health of the public.

D. Transfer & Discharge

The waivers related to transfer and discharge were reasonable for the purposes of quickly organizing for infection control and for reducing staff workload. However, waivers which eliminated requirements for written notice of transfers and discharges, or for various resources offered throughout the process, could be harmful to residents' wellbeing. Such policies could lead to situations in which residents and their loved ones are unaware of their transfer or discharge prior to it being conducted or in which residents' needs are not properly communicated or met after transfer or discharge. According to Missouri DHSS, residents traditionally have rights during discharge and transfer which require they receive 30-day prior written notice of such events that includes the reasoning for the move, the date of the move, the location of the new destination, the process for filing an appeal, and the contact information of an ombudsman. Additionally, they have a right to return to the facility after hospitalization or therapeutic leave and the right to preparation and orientation that ensures safe and orderly transfer or discharge.[105] These policy changes also impacted residents' rights to be fully informed as they temporarily removed timely notification protocols that directly impacted the resident's experience of their care. Discharge and transfer can be delicate times for residents since their environments and routines change, so ensuring that they are fully informed and prepared for these events should never be waived to the extent that it was in this health emergency. Reduced notification periods are reasonable given the urgent nature of the pandemic, but a lack of information about location

[105] "Nursing Home Residents' Rights." *Missouri Long-Term Care Ombudsman,* https://health.mo.gov/seniors/ombudsman/pdf/residents-rights-fact-sheet.pdf.

or ombudsman services could be damaging to the physical and emotional wellbeing of a resident or their loved ones.

E. Care Provision

The last category of policy decisions to be discussed includes a broad array of measures that altered daily operation of nursing homes and care provision. Policy modifications as to the level of information required to be given to residents and their families, as well as to the timeliness of such notifications were one of the most common adjustments across all of the pandemic response measures. The Nursing Home Reform Act's Bill of Rights includes the right to participate in the review of one's care plan and to be fully informed in advance about any changes in care, treatment, or change of status in the facility.[106] While advanced warning may not be possible in pandemic situations, it is not a responsible policy to completely eliminate requirements for informing residents about changes that affect the care they are receiving, particularly when resident advocates already have restricted access to facilities. This creates the potential for situations in which residents experience distress from being uninformed about their care and are unable to accurately share with those that typically advocate for them about the nature of the changes without proper information. The changes made to nutritional services and physical environment regulations have the potential to come into conflict with residents' right to privacy and to accommodation for their physical needs, as well as their right to a dignified existence which includes the right to a homelike environment.[107] Many of the physical environment measures were logical steps to take for grouping and quarantining residents for

[106]"Omnibus Budget Reconciliation Act of 1987: subtitle C, Nursing Home Reform." Public Law 100-203, 100th Congress, (1987).
[107] "Nursing Home Residents' Rights." *Missouri Long-Term Care Ombudsman,* https://health.mo.gov/seniors/ombudsman/pdf/residents-rights-fact-sheet.pdf.

infection control purposes. It could be recommended that in the future such waivers be accompanied by guidance that requires alternative versions of the services traditionally offered in those spaces to be offered in the resident's room or at a reduced capacity when those spaces are lost that are necessary for the health and flourishing of residents, such as communal gyms or activity rooms. Each of these changes to care provision were likely successful in aiding with infection control, but they also each posed some increased risk to residents' physical or mental health and would better serve nursing home populations in the future with greater consideration to their secondary effects.

.

XI. Conclusion: Emerging Policy Solutions

The purpose of this paper was not to vilify any of the stakeholders discussed within. Despite the conclusions made by survey respondents or interviewees, or the comments and policy decisions made by governing bodies and other interest groups, the intentions of the vast majority of those involved were good. This is clear to see even without reference to any scientific study or survey on the subject. As one nursing home administrator commented in their interview, those working in nursing homes don't stay because it is "glorious or well paid" but they stay because they truly care about the residents and about each other. Instances of neglect or suboptimal care provision do not represent the majority of care providers or their actions. The purpose of highlighting instances where problems do occur is to reduce their prominence further, and to improve the working conditions for staff who benefit from having team members perform to a standard. The administrators themselves all cited their motivations in their jobs as caring for their residents and improving their quality of life. The surveillance mechanisms, although imperfect, perform a useful service and individual surveyors work tirelessly to improve nursing

home conditions. Although the policy decisions made may have had unintended consequences to care provision or wellbeing, they were made with the primary goal of preventing harm in these settings. While giving informational purpose testimony on the Missouri Essential Caregivers Act, a representative of the Missouri Hospital Association took the opportunity to point out that "the vast majority of hospitals, doctors, nurses, therapists, and technicians did absolutely the best they could do to take care of people during the pandemic." He acknowledged the tragedies that came from both the pandemic itself and from the policies that had negative effects on patient welfare, applauded reform efforts, and then closed with a reminder that emphasized that healthcare workers do their job because they want to see people healthy and safe.[108] Implicit in his comments is a pertinent reminder to all readers of research on this topic. The events that unfolded during the pandemic as a result of pandemic policies were not the product of battling malicious entities, but rather were the result of a rapid response to an unfolding and terrifying public health threat. They provide guidance as to where improvement is needed, and as such, discussion of the shortcomings at all levels is necessary. Honest analysis of the failings and successes of policy in situations like these is one way to ensure that the rights of those most vulnerable are protected and that nursing homes residents are always safe, supported, and treated with dignity.

The policy decisions made by the state and federal government were logical and reasonable responses to the pandemic if one only considers the goal of reducing the spread of Covid-19. They fall short, however, in their failure to anticipate and address the side-effects that their policy decisions would have on aspects of resident wellbeing outside of Covid-19 illness.

[108] *Senate Bill 671 Hearing, Before the Missouri Senate Seniors, Families, Military, and Veterans Affairs Committee,* 101 Assembly, (2 March 2022).

These side-effects can be grouped together and generalized as a decrease in care quality experienced by residents, which led to unnecessary harm on the part of residents and their loved ones. As more time has passed since the beginning of the pandemic in early 2020, it has been increasingly recognized that the pandemic both highlighted pre-existing inadequacies in the nursing home sector and saw new challenges emerge as a result of policy decisions. With this recognition has come early attempts at reforming nursing home operation, regulations, and policies in order to ensure quality care provision and to protect against similar situations in future health emergencies. Two such efforts, President Biden's nursing home reform agenda and the proposed Missouri Essential Caregivers Act serve as examples of ways in which concerns stemming from issues related to nursing home life during the pandemic are being addressed. A brief analysis of the goals of these efforts, as well as the arguments of relevant interest groups surrounding them, provides insight into potential solutions to some of the issues uncovered in this research, as well as reflects the importance of advocacy for those who are most vulnerable.

On February 28, 2022, President Joe Biden released a statement entitled "Protecting Seniors By Improving Safety and Quality of Care in the Nation's Nursing Homes." In this statement, he announced a set of reforms to be implemented through the Department of Health and Human Services aimed at improving multiple sectors of care provision in the nation's nursing homes. These reforms seek to hold poorly performing nursing homes accountable for improper care, to ensure nursing homes provide sufficient numbers of staff with adequate training, and to better inform the public about nursing home conditions[109]. These three directives align remarkably with the issues raised in the analysis above regarding staffing, surveillance,

[109] "Fact Sheet: Protecting Seniors by Improving Safety and Quality of Care in the Nation's Nursing Homes." *White House Statements and Releases*, February 28, 2022. https://www.whitehouse.gov/briefing-room/statements-releases/2022/02/28/fact-sheet-protecting-seniors-and-people-with-disabilities-by-improving-safety-and-quality-of-care-in-the-nations-nursing-homes/.

lack of information, and poor care quality. As such, this policy seems to be appropriately reacting to the experiences of nursing home residents, their loved ones, and staff during the pandemic. The statement describes some of the actions that will be taken to accomplish the goals it has set forth, including the establishment of a minimum nursing home staffing requirement. Additional actions include phasing out nursing home rooms with three or more occupants and promoting single occupancy spaces, as well as reinforcing safeguards against unnecessary medications and treatments. To hold facilities accountable for substandard care, the reform sets out to provide adequate funding for inspection activities by calling on Congress to increase CMS's budget by twenty-five percent. It also seeks to increase scrutiny on poor performing facilities by overhauling the current Special Focus Facility Program to be more rigorous and to evaluate more facilities. Expanding financial penalties and other enforcement actions is included in these reforms, as well as providing technical assistance to nursing homes to help them improve their quality of care. To increase transparency, CMS is being directed to make changes to its Nursing Home Care Compare website so that the ratings more closely reflect verifiable data and so that individuals have easier access to accurate information regarding nursing home performance. CMS's website is directed to include whether a facility meets the minimum staffing requirement when that is decided upon and put into effect, and they have already added weekend staffing and staff turnover measures to their ratings as of January 2022 as a part of this effort to increase transparency and data accuracy. Finally, to address staffing issues, the reforms aim to ensure nurse aide training is affordable, to support state efforts to improve staffing and workforce sustainability, and to launch a national nursing career pathways campaign.

While these reforms have received support from nursing home advocacy groups such as the Center for Medicare Advocacy, they have also received backlash from organizations which

advocate for skilled nursing facilities. The American Health Care Association president rebuked President Biden's statement because he found the implication that nursing home quality had declined to be factually incorrect. In fact, he was displeased that blame was placed on nursing home caregivers when, in his view, the poor outcomes in nursing homes were the result of "a series of horrible public health policy decisions" which did not prioritize long-term care adequately. He added that the federal direction to isolate residents in their rooms was to blame for predictable declines in their conditions and that it is demoralizing to make such accusations when nursing home staff are underpaid and do their jobs out of love for their residents.[110] The debate surrounding this reform is as informative as the reform itself. It reveals a tension between government regulations and their practical application in nursing home settings. This trend was commented upon by one of the nursing home administrators interviewed for this project. They said that there was a fundamental disconnect between the rules and regulations concocted by those in government and the actual needs and operation of a facility. Both sides are correct in this situation. President Biden's reforms are necessary, and early data and advocacy do indicate that some nursing homes failed to provide adequate care during the pandemic. As such, it is more than reasonable that the reforms should highlight the failings of such facilities and make changes to policy so that they can be addressed in the future. At the same time, the American Health Care Association is correct to point out that some of the guidance passed by the federal government created or exacerbated situations in which care quality would inevitably decrease, so there is responsibility to be shared in both arenas. Understanding this issue from diverse perspectives

[110] Dave Muoio, "Long-term care group pushes back on 'factually incorrect' quality claims in Biden's nursing home pitch." *Fierce Healthcare,* March 9, 2022. https://www.fiercehealthcare.com/providers/ahcancal-biden-nursing-home-long-term-care-group-pushes-back-factually-incorrect-quality.

such as these is the only way to position society to make reform that holistically addresses the issues experienced by residents during this public health crisis.

The second example of policy that seeks to address concerns uniquely created for nursing homes by the pandemic is the proposed Essential Caregiver Program Act in Missouri.[111] This is a piece of state legislation which aims to require long-term care facilities to allow residents or their guardians to designate an essential caregiver for in-person contact during governor-declared states of emergency. This is different from the guidance issued by Missouri DHSS during the pandemic because it makes it mandatory for facilities to offer this program, rather than leaving the decision with each facility. The bill defines the parameters of an essential caregiver and then requires that DHSS and the Department of Mental Health develop program standards and guidelines that allow a resident to designate at least two caregivers, require facilities to establish in-person contact schedules that allow for at least four hours each day, and establish procedures for enabling physical contact between residents and caregivers. In the event of an infection control scenario, the bill specifies that contact protocols can be no more stringent than those in place for facility employees. The bill also places limitations on the duration of time that in-person visitation with essential caregivers may be restricted. This bill had its first committee hearing in March, 2022, and the testimony during this hearing was insightful. A representative of the Missouri College of Emergency Physicians and the Missouri Assisted Living Association testified in opposition to the bill, in part due to concerns over conflicting federal and state requirements. He expressed that facilities may be subjected to penalties for allowing essential caregivers into a facility if doing so violated visitation restrictions passed down by the federal government. In response to this concern, the bill sponsor noted the possibility of adding a

[111] Senate Bill 671, 101st Missouri General Assembly, (2022).

requirement in which the passage of such restrictive mandates by federal regulators would trigger an immediate injunction by the Missouri Attorney General. The testifying representative also raised concerns about liability for actions taken by the caregivers while in the facility and was directed to a section of the bill which elaborated upon immunity for facilities regarding the acts of essential caregivers. This interaction is encouraging because it shows that state government policy is anticipating interaction with federal policy, as well as practical application issues, and attempting to adjust for them before the bill is perfected. A representative with the Missouri Healthcare Association also testified in opposition to the bill and raised concerns about the limited duration specified in the bill that facilities could restrict essential caregiver access, saying that DHSS may not have the resources to react quickly in these scenarios.

Those who testified in support of the bill largely based their testimony on personal experiences during which restricted visitation caused harm to either themselves or their loved one who was a resident in a facility. Mrs. Gralnik was mentioned at the opening of this project, and her story was just one of several. Another woman testified that she was uninformed about her mother's condition while the visitation restriction was in place, and that she found out her mother had a bedsore "too late." She died as a result 17 days later. She commented that she was always her mom's eyes and ears, yet in this situation she wasn't able to see what was going on. The director of Missouri AARP also testified in favor of the bill saying that their agency received hundreds of phone calls from upset family caregivers during the lockdown. She noted that when people weren't able to see their loved ones, care quality declined and issues of neglect became more prominent. The policy and advocacy director for VOYCE also testified, and she read testimony from others who could not be there that day regarding their experiences. She read the words of individuals who, upon finally being able to visit their loved ones in person again,

encountered tremendous evidence of neglect. She spoke about finding hearing aids with dead batteries or that were missing entirely, uncut toenails, broken thermostats leading to no heat in the middle of winter, a missing shower curtain with the implication that showers had not been taking place, unattended accidents, and empty hand sanitizer stations. One individual came in to find their mother drinking out of a Gatorade bottle that had a razor blade in it. She ended her testimony by saying that "it's not just about their mental health, it is their physical health and their wellbeing and their life."[112]

Reviewing the testimony both for and against this bill allows one to observe the power that advocacy and having outlets to voice your experiences can have on changing conditions for the future, as well as the importance of creating policy that won't create incidental burdens for those it affects. This bill recognizes the vital role that family members and other loved ones play as essential members of a resident's care team, which was shown in the survey data collected for this project and in the testimony at the hearing that day. It is heartening to see an example of policy that acknowledges and reacts to issues which arose from other policies, as it shows a capacity and desire to progress together toward improving conditions in nursing homes, especially during public health emergencies.

XII. Project Limitations

The primary limitation of this study is the incomplete nature of the CMS data. The state of Missouri is currently in the process of conducting investigations and recertifications that were put off during the height of the pandemic and the resurgence in the summer of 2021. With this in

[112] *Senate Bill 671 Hearing, Before the Missouri Senate Seniors, Families, Military, and Veterans Affairs Committee,* 101 Assembly, (2 March 2022).

mind, complaints filed during the time of interest to this study may still be pending investigation and therefore not all the relevant information regarding the complaint, nor corrective measures, is available for analysis. This limits quantitative data analysis to primarily immediate jeopardy complaints. Another limitation which was briefly addressed previously is the lack of statistical rigor in the conduction of the surveys and interviews. Participation was voluntary and a random sample was not obtained, making population generalizations impossible. The size of the survey and interview participant pool is relatively small, and therefore inherently less representative. In addition, the survey and interviews were distributed and conducted in English, which limits participation, as does the sources through which the survey and interview were advertised. Given that the survey was distributed through an online platform and required internet connectivity, participants were limited if those resources were not available. This is especially pertinent given that there are numerous rural areas of Missouri that do not yet have access to broadband. Additionally, due to the location of the researcher and their contacts, the majority of the survey responses were obtained from the southwestern region of the state, whereas ideally there would have been greater geographic diversity. The scope and design of the study also does not allow for causation to be determined between any of the policies discussed and the reported impacts to nursing home life and care. Instead, the research is able to consider the challenges faced by nursing home residents and discuss how certain policies may have aggravated or mitigated these circumstances. Finally, this research was completed before the conclusion of the pandemic, which leaves it vulnerable to becoming outdated as new information is discovered and events continue to unfold.

Bibliography

Abbasi, J. "COVID-19 Crisis Advances Efforts to Reimagine Nursing Homes." *JAMA* 326, no. 16 (2021):1568-70. Doi:10.1001/jama.2021.13326.

Americans with Disabilities Act of 1990. Public Law 101-336. 108th Congress, 2nd session (July 26, 1990).

"Appropriateness of Minimum Nurse Staffing Ratios in Nursing Homes." *Report to Congress,* December 2001, https://www.justice.gov/sites/default/files/elderjustice/legacy/2015/07/12/Appropriateness_of_Minimum_Nurse_Staffing_Ratios_in_Nursing_Homes.pdf.

"Assessment Factors Use to Determine the Seriousness of Deficiencies Matrix." *Alabama Nursing Home Association,* http://anha.org/uploads/ScopeSeverity2018.pdf.

Azar II, Alex M. "Determination that a Public Health Emergency Exists." *U.S. Department of Health & Human Services,* January 31, 2020. https://www.phe.gov/emergency/news/healthactions/phe/Pages/2019-nCoV.aspx.

Bohm, David A. "Striving for Quality Care in America's Nursing Homes: Tracing the History of Nursing Homes

and Noting the Effect of Recent Federal Government Initiatives to Ensure Quality Care in the Nursing Home

Setting," *DePaul Journal of Health Care Law* 4, no. 2-3 (2001): 317-366.

Bowblis, John R."Staffing ratios and quality: an analysis of minimum direct care staffing requirements for nursing homes." *Health services research* 46, no.5 (2011): 1495-516. doi:10.1111/j.1475-6773.2011.01274.x

Cacioppo, J. T. et al. "Alone in the crowd: the structure and spread of loneliness in a large social network." Journal of Personality and Social Psychology 97, 6 (2009):977-91. doi: 10.1037/a0016076. PMID: 19968414; PMCID: PMC2792572.

Cacioppo. John T. and Stephanie Cacioppo. "Social Relationships and Health: The Toxic Effects of Perceived Social Isolation." *Social and Personality Psychology Compass* 8, no. 1 (2014):58-72. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4021390/.

Cimarolli, Verena R. et al. "Job Resignation in Nursing Homes During the COVID-19 Pandemic: The Role of Quality of Employer Communication." *Journal of Applied Gerontology* 41, no. 1 (2022):12-21. https://doi.org/10.1177/07334648211040509.

Colello, K. "Older Americans Act: 2020 Reauthorization," *Congressional Research Service,* July 1, 2020.

Convention on the Rights of Persons with Disabilities, UN General Assembly, (24 Jan 2007): A/RES/61/106.

"Covid-19 Emergency Declaration Blanket Waivers for Health Care Providers." *Centers for Medicare & Medicaid Services,* Updated May 24, 2021. https://www.cms.gov/files/document/summary-covid-19-emergency-declaration-waivers.pdf.

"Data." *Center for Long-Term Care Quality and Innovation Brown University,* https://www.brown.edu/academics/public-health/qandi/research/data.

"Deficiency Count Report." *Quality, Certification, & Oversight Reports,* https://qcor.cms.gov/report41snf.jsp?which=0&report=report41snf.jsp#pagetop.

"Design for Care Compare Nursing Home Five-Star Quality Rating System: Technical Users' Guide." *The Centers for Medicare & Medicaid Services,* April 2022. https://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/CertificationandComplianc/Downloads/usersguide.pdf.

Director Quality, Safety & Oversight Group, "COVID-19 Survey Activities, CARES Act Funding, Enhanced Enforcement for Infection Control deficiencies, and Quality Improvement Activities in Nursing Homes." (Official memorandum, Baltimore, Maryland: Centers for Medicare & Medicaid, June 1, 2020). https://www.cms.gov/files/document/qso-20-31-all-revised.pdf.

Director Quality, Safety & Oversight Group, "Enforcement Cases Held during Prioritization Period and Revised Survey Prioritization." (Official memorandum, Baltimore, Maryland: Centers for Medicare & Medicaid, August 17, 2020). https://www.cms.gov/files/document/qso-20-35-all.pdf.

Director Quality, Safety & Oversight Group, "Guidance for Infection Control Prevention of Coronavirus Disease 2019 in Nursing Homes." (Official memorandum, Baltimore, Maryland: Centers for Medicare & Medicaid, March 13, 2020). https://www.cms.gov/files/document/qso-20-14-nh-revised.pdf.

Director Quality, Safety & Oversight Group, "Nursing Home Reopening Recommendations for State and Local Officials." (Official memorandum, Baltimore, Maryland: Centers for Medicare & Medicaid, May 18, 2020). https://www.cms.gov/files/document/qso-20-30-nh.pdf.

Director Quality, Safety & Oversight Group, "Nursing Home Visitation – COVID-19." (Official memorandum, Baltimore, Maryland: Centers for Medicare & Medicaid, September 17, 2020). https://www.cms.gov/files/document/qso-20-39-nh-revised.pdf.

Director Quality, Safety & Oversight Group, "Prioritization of Survey Activities." (Official memorandum, Baltimore, Maryland: Centers for Medicare & Medicaid, March 20, 2020). https://www.cms.gov/files/document/qso-20-20-all.pdf.

Director Quality, Safety & Oversight Group, "Suspension of Survey Activities." (Official memorandum, Baltimore, Maryland: Centers for Medicare & Medicaid, March 4, 2020). https://www.cms.gov/files/document/qso-20-12-all.pdf.

"Fact Sheet: Protecting Seniors by Improving Safety and Quality of Care in the Nation's Nursing Homes." *White House Statements and Releases,* February 28, 2022. https://www.whitehouse.gov/briefing-room/statements-releases/2022/02/28/fact-sheet-protecting-seniors-and-people-with-disabilities-by-improving-safety-and-quality-of-care-in-the-nations-nursing-homes/.

"Federal Nursing Home Reform Act from the Omnibus Budget Reconciliation Act of 1987 Summary." *The National Consumer Voice for Quality Long-Term Care,* https://theconsumervoice.org/uploads/files/family-member/Summary-History-Federal-_Nursing-Home-_Reform-Act_(3).pdf.

"General States Nursing Home Law." *Nursing Home Abuse Guide*. https://www.nursinghomeabuseguide.org/states/.

"Glossary." *Centers for Medicare & Medicaid Services, https://www.cms.gov/glossary.*

Governor Michael L. Parson, "Executive Order 20-02." https://www.sos.mo.gov/library/reference/orders/2020/eo2.

Governor Michael L. Parson, "Executive Order 20-09." https://www.sos.mo.gov/library/reference/orders/2021/eo9.

Grabowski, D.C. and V. Mor. "Nursing Home Care in Crisis in the Wake of COVID-19." *JAMA* 324, no. 1 (2020):23-4. doi:10.1001/jama.2020.8524.

Haizhen, Lin. "Revisiting the Relationship Between Nursing Staffing and Quality of Care in Nursing Homes." Journal of Health Economics 37, (2014):13-24. https://doi.org/10.1016/j.jhealeco.2014.04.007.

Harrington, Cherry. "Nursing Home Staffing Standards in State Statutes and Regulations." *Department of Social and Behavioral Sciences University of California San Francisco,* January 2008. https://www.justice.gov/sites/default/files/nursing_home_staffing_standards_in_state_statutes_and_regulations.pdf.

Hawes, Catherine. "Elder Abuse in Residential Long-Term Care Settings: What is Known and What Information is Needed," *National Academies Press (US)* 14, (2003).

"Important Information Regarding State Waiver Implementation for Intermediate and Skilled Nursing Care Facilities." *Missouri Department of Health and Senior Services,* April 17, 2020. https://health.mo.gov/living/healthcondiseases/communicable/novel-coronavirus/pdf/19-csr-30-85-snf-icf-waiver-implementation.pdf.

"Intermediate Care and Skilled Nursing Facilities." *Missouri Department of Health and Senior Services,* April 14, 2020. https://ltc.health.mo.gov/wp-content/uploads/sites/18/2020/04/Intermediate-Care-and-Skilled-Nursing-Facilities-4-14-20.pdf.

"Intermediate Care and Skilled Nursing Facilities." *Missouri Department of Health and Senior Services,* April 15, 2020. https://ltc.health.mo.gov/wp-content/uploads/sites/18/2020/04/Intermediate-Care-and-Skilled-Nursing-Facilities-4-15-20.pdf.

International Covenant on Civil and Political Rights, *UN General Assembly* 999, (16 Dec 1966): 171.

International Covenant on Economic, Social, and Cultural Rights, *UN General Assembly* 993, (16 Dec 1966): 3.

Institute of Medicine (US) Committee on Nursing Home Regulation, "Improving the Quality of Care in Nursing Homes," *National Academy Press (US)* 1986. Appendix A.

Kohn, Nina A. "Nursing Homes, COVID-19, and the Consequences of Regulatory Failure," *Georgetown Law Journal* 110, (2021).

Konetzka, R.T. "Improving the Fate of Nursing Homes during the COVID-19 Pandemic: The Need for Policy." *American Journal of Public Health* 111, no. 4 (2021):632-634. http://ezproxy.cul.columbia.edu/login?url=https://www.proquest.com/scholarly-journals/improving-fate-nursing-homes-during-covid-19/docview/2516302044/se-2?accountid=10226.

Levere, Michael et al. "The Adverse Effects of the COVID-19 Pandemic on Nursing Home Resident Well-Being." *Journal of the American Medical Directors Association* 22, no. 5 (2021): 948-52. doi:10.1016/j.jamda.2021.03.010.

Lynch, Megan. "Data shows Missouri nursing homes fail to provide recommended hours of care." *NewsRadio 1120 KMOX,* August 16, 2021. https://www.audacy.com/kmox/news/local/missouri-nursing-homes-fail-recommended-hours-of-care.

"Making the Case for Compassionate Care." *The National Consumer Voice for Quality Long-Term Care,* https://theconsumervoice.org/uploads/files/issues/making-the-case-for-compassionate-care.pdf.

"Medicare Shared Savings Program Skilled Nursing Facility 3-Day Rule Waiver." *The Centers for Medicare and Medicaid,* May 2021. https://www.cms.gov/medicare/medicare-fee-for-service-payment/sharedsavingsprogram/downloads/snf-waiver-guidance.pdf.

Missouri Code of State Regulations, Resident's Rights Statutes, Title XII Public Health and Welfare, Div. 30, Ch 88.

"Missouri Guidance on Reopening of Long-Term Care Facilities." *Missouri Department of Health and Senior Services,* August 31, 2020. https://health.mo.gov/living/healthcondiseases/communicable/novel-coronavirus/pdf/missouri-guidance-on-reopening-of-long-term-care-facilities.pdf.

"Missouri Interim Guidance for Long Term Care Facilities with Confirmed COVID-19." *Missouri Department of Health and Senior Services,* August 31, 2020. https://health.mo.gov/living/healthcondiseases/communicable/novel-coronavirus/pdf/ltcf-guidance.pdf.

"Missouri Should Improve Its Oversight of Selected Nursing Homes' Compliance with Federal Requirements for Life Safety and Emergency Preparedness." *Department of Health and Human Services Office of the Inspector General,* A-07-18-03230, March 2020.

"Monitoring Nursing Home Performance," in Improving the Quality of Care in Nursing Homes.(Washington (DC): National Academies Press (US), 1986). https://www.ncbi.nlm.nih.gov/books/NBK217555/.

Mor, Vincent et al, "The Effect of State Policies on Nursing Home Resident Outcomes." *Journal of the American Geriatrics Society* 59, (2011):3-9. https://doi.org/10.1111/j.1532-5415.2010.03230.x

Mukamel, Dana B. et al. "The Relationship of California's Medicaid Reimbursement System to Nurse Staffing Levels." *Medical Care* 50, no. 10 (2012):836-42. http://www.jstor.org/stable/41714583.

Muoio, Dave. "Long-term care group pushes back on 'factually incorrect' quality claims in Biden's nursing home pitch." *Fierce Healthcare,* March 9, 2022. https://www.fiercehealthcare.com/providers/ahcancal-biden-nursing-home-long-term-care-group-pushes-back-factually-incorrect-quality.

"Nursing Home Compare Five-Star Quality Rating System: Year Three Report," *Centers for Medicare & Medicaid Services,* 7 June 2013.

"Nursing Home Data Compendium 2015 Edition." *The Centers for Medicare & Medicaid Services, https://www.cms.gov/Medicare/Provider-Enrollment-and-certification/CertificationandComplianc/Downloads/nursinghomedatacompendium_508-2015.pdf.*

"Nursing Home Inspections." *Missouri Department of Health & Senior Services,* https://health.mo.gov/safety/nursinghomesinspected/.

"Nursing Home Residents' Rights". *Missouri Long-Term Care Ombudsman,* https://health.mo.gov/seniors/ombudsman/pdf/residents-rights-fact-sheet.pdf

"Nursing Home Safety During Covid: Staff Shortages." *U.S. PIRG Education Fund,* January 2021. https://uspirg.org/sites/pirg/files/reports/StaffShortages/WEB_USP_Nursing-Home-Safety-During-COVID_Staff-Shortages.pdf.

"Nursing Home Staffing Q3 2021." *Long Term Care Community Coalition, https://nursinghome411.org/data/staffing/staffing-q3-2021/.*

"Omnibus Budget Reconciliation Act of 1987: subtitle C, Nursing Home Reform." Public Law 100-203, 100th Congress, (1987).

Pijls, Bart G. et al. "Demographic risk factors for COVID-19 infection, severity, ICU

admission and death: a meta-analysis of 59 studies," *BMJ Open* 11, no. 1 (2021): https://doi.org/10.1136/bmjopen-2020-044640.

Popejoy, Lori et al. "A Coordinated Response to the COVID-19 Pandemic in Missouri Nursing Homes." *Journal of Nursing Care Quality* 35, no. 4 (2020): 287-292. doi: 10.1097/NCQ.0000000000000504.

President Donald J. Trump, "Proclamation on Declaring a National Emergency Concerning the Novel Coronavirus Disease (COVID-19) Outbreak." March 13, 2020. https://trumpwhitehouse.archives.gov/presidential-actions/proclamation-declaring-national-emergency-concerning-novel-coronavirus-disease-covid-19-outbreak/.

"Residential Care Facilities." *Missouri Department of Health and Senior Services,* April 16, 2020. https://health.mo.gov/living/healthcondiseases/communicable/novel-coronavirus/pdf/waiver-residential-care-facilities.pdf.

Revised Statutes of Missouri, Title XII Public Health and Welfare, Chapter 192, 2400.

Robertson, Marcus. "What nurses are paid per hour in all 50 states." *Becker's ASC Review,* November 18, 2021. https://www.beckersasc.com/benchmarking/what-nurses-are-paid-per-hour-in-all-50-states.html.

Rueda, Jon. "Ageism in the COVID-19 pandemic: age-based driscrimination in triage decisions and beyond." *History and Philosophy of the Life Sciences* 43, no. 3 (2021):91. doi: 10.1007/s40656-021-00441-3.

Schall, Victoria A. "CMS Releases New Nursing Home Special Focus Facility List." *Locks Law Firm,* June 14, 2019. https://www.lockslaw.com/blog/2019/06/14/cms-releases-new-nursing-home-special-focus-facility-list.

Schnelle, John F. et al. "Relationship of nursing home staffing to quality of care." *Health Services Research* 39, no. 2 (2004): 225-50. doi:10.1111/j.1475-6773.2004.00225.x.

Sedensky, Matt and Bernard Condon. "Not Just COVID: Nursing Home Neglects Deaths Surge in Shadows,"

Associated Press, November 19, 2020, https://ap-news.com/article/nursing-homes-neglect-death-surge-3b74a2202140c5a6b5cf05cdf0ea4f32.

Senate Bill 671, 101st Missouri General Assembly, (2022).

Senate Bill 671 Hearing, Before the Missouri Senate Seniors, Families, Military, and Veterans Affairs Committee, 101 Assembly, (2 March 2022).

"Social Isolation and Loneliness in Older Adults: Opportunities for the Health Care System." *National Academies of Sciences, Engineering, and Medicine,* (Washington DC: National Academies Press, 2020). https://search-ebscohost-com.ezproxy.cul.columbia.edu/login.aspx?direct=true&AuthType=ip&db=e025xna&AN=2514627&site-ehost-live&scope-site.

"Statement of Deficiencies and Plan of Correction 265439." *Department of Health & Human Services,* February 24, 2021. https://www.medicare.gov/care-compare/inspections/pdf/nursing-home/265439/health/complaint?date=2021-02-24.

"Statement of Deficiencies and Plan of Correction 265769." *Department of Health & Human Services,* July 2, 2021. https://www.medicare.gov/care-compare/inspections/pdf/nursing-home/265769/health/complaint?date=2020-07-02.

"States' Backlogs of Standard Surveys of Nursing Homes Grew Substantially During the COVID-19 Pandemic." *Office of Inspector General,* July 2021. https://oig.hhs.gov/oei/reports/OEI-01-20-00431.pdf.

Stevenson, D.G. and A.K. Cheng, "Nursing Homes Oversight During the COVID-19 Pandemic." Journal of American Geriatric Society 69, (2021):850-60. https://doi.org/10.1111/jgs.17047.

"The National Imperative to Improve Nursing Home Quality: Honoring Our Commitment to Residents, Families, and Staff." *National Academies of Sciences, Engineering, and Medicine,* (Washington, DC: The National Academies Press, 2022). doi: 10.17226/26526.

"United Nations Principles for Older Persons." *General Assembly Resolution 46/91,* December 16, 1991.

Universal Declaration of Human Rights, *UN General Assembly,* 10 December 1948, 217 A (III)

"US: Concerns of Neglect in Nursing Homes," *Human Rights Watch,* (May 2021). https://www.hrw.org/news/2021/03/25/us-concerns-neglect-nursing-homes.

Voorhies, Phoenix and Kirsten Colello. "Overview of Federally Certified Long-Term Care Facilities," *Congressional Research Service,* May 2020.

"Waivers for Nursing Home Administrators and Residential Care/Assisted Living Administrators." *Missouri Department of Health and Senior Services,* April 2, 2020. https://cdn.ymaws.com/www.mohealthcare.com/resource/resmgr/covid-19/Waivers_for_Nursing_Home_Adm.pdf.

Werner, Rachel M. and Norma B. Coe. "Nursing Home Staffing Levels Did Not Change Significantly During Covid-19." *Health Affairs* 40, no. 5 (2021). https://doi.org/10.1377/hlthaff.2020.02351.

Williams, Randall. "Guidance for Long Term Care Facilities to Establish Essential Caregiver Programs and to Allow Visits." (Official memorandum, Jefferson City, MO: Department of Health and Senior Services, September 17, 2020). https://health.mo.gov/living/healthcondiseases/communicable/novel-coronavirus/pdf/visitation-guidance.pdf.