

Annex

Human Rights Watch Communications

I. HRW Exchange with LeadingAge

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December 11, 2020

Katie Smith Sloan
President & CEO
LeadingAge
2519 Connecticut Avenue NW
Washington, DC 20008



HRW.org

Dear Ms. Sloan:

I am the Acting Director of the Disability Rights Division at Human Rights Watch. I am writing to share with you findings from our research in the United States on human rights issues affecting older people in skilled nursing facilities (SNF) and nursing facilities (NF) and their families during the Covid-19 pandemic.

Human Rights Watch is the largest US-based international human rights research and advocacy organization. We document human rights violations in 90 countries around the world, including the US. We use our research to draw attention to important human rights issues and to offer concrete recommendations on how to improve protections of people's rights.

We have conducted 51 interviews with nursing home residents, family members, staff, long-term care ombudsmen, and advocates in several states. We also conducted an online survey of people who have relatives in nursing homes, which received 564 responses from 45 states. While the survey was conducted via convenience sampling and therefore cannot be used to draw conclusions about all nursing home residents, it provides evidence of the commonality of these experiences as well as their broad geographic scope.

We plan to write a report documenting our findings in the coming months. We do not anticipate identifying any specific nursing facilities in our report. We would welcome LeadingAge's response to our preliminary findings and questions outlined below.

Preliminary Findings:

Neglect

Many interviewees and survey respondents who had a relative in a nursing home reported that after widespread visitor bans were imposed in nursing homes in response to Covid-19, their loved ones showed severe weight loss, dehydration, untreated bedsores or wounds, and inadequate hygiene. Interviewees also reported that many residents experienced concerning declines in their physical, mental, and emotional states during this time. For some residents, depression, anxiety, and hallucinations became more common.

Alternatives to in-person visitation, such as communication by phone or computer, did not always provide the emotional support residents required, particularly for people with dementia who found video calls or visits through a closed window or door confusing or upsetting.

Increases in Use of Medication

Some relatives whom we interviewed or who responded to our survey expressed serious concerns about increases in psychotropic medications administered to their loved ones during the pandemic. One in three survey respondents said staff had increased or initiated psychotropic drugs for their loved one at this time. Antidepressants and anti-anxiety medication were most common, and a smaller but still notable number of interviewees reported increases in the use of antipsychotic drugs, the dangers of which have been highlighted in our previous reporting.¹ In some cases, these medications were prescribed without the informed consent of the resident or their medical proxy. Family members reported seeing changes in their loved one's behavior following medication changes, including lethargy or excessive sleeping. Non-medical interventions to treat anxiety, depression, and other conditions were not typically offered.

Staffing Shortages

Independent analyses of CMS's payroll-based staffing data found that facilities were critically understaffed during the pandemic.² Staff whom we interviewed said that low wages, no or low hazard pay, no sick leave or health benefits led to many quitting their nursing home jobs during the pandemic. Staff also reported that insufficient staffing undermined their ability to provide quality care to residents.

¹ Human Rights Watch, *They Want Docile: How Nursing Homes in the United States Overmedicate People with Dementia*, February 2018, <https://www.hrw.org/report/2018/02/05/they-want-docile/how-nursing-homes-united-states-overmedicate-people-dementia>

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Inadequate Communication

In March, in response to Covid-19, CMS made recommendations encouraging facilities to facilitate phone calls or virtual visits for residents and their loved ones in lieu of in-person visits.

Interviewees told Human Rights Watch that facility staff arranged video and phone calls sporadically, if at all, making it difficult for relatives to monitor their loved one's care and sustain emotional connection. When these calls did take place, staff did not always provide meaningful support to residents who could not independently manage a phone or other device to facilitate these conversations.

Confusing and Inconsistent Visitation Policies

It is significant that in its September 2020 guidelines, CMS explicitly reasserts residents' rights to visitation. However, our research found that some facilities appeared to cite a variety of official guidance—including from state, county, or other health authorities—to justify denying visitation even when CMS criteria would have allowed for it, creating confusion among relatives, residents, and even staff about visitation policies. When visitation was allowed, it was often infrequent and short in duration and therefore did not provide meaningful support to residents. Some said that staff monitored visits so closely that it undermined their privacy.

CMS's earlier March 2020 guidance allowed compassionate care visits, which were described as visits for residents at end-of-life, to continue during the pandemic. The CMS September guidance expands the definition of "compassionate care" beyond these cases, to include cases in which a person has suffered weight loss, needs assistance or encouragement to eat, or is showing signs of depression. However, Human Rights Watch found that some nursing homes denied compassionate care visits to relatives who had identified serious weight loss, emotional decline, and other relevant concerns.

Response to Residents and Family Members' Complaints

Interviewees and survey respondents reported that when they raised concerns about the decline in their loved one's physical or mental health, they were often dismissed or ignored by staff. Some expressed fear that staff could take away the already limited access they had to their loved one if they complained too much. Human Rights Watch spoke to several people who said the facility had retaliated against them, denying or limiting access to their loved one in response to concerns expressed about quality of care or transparency, or for minor violations of visitation protocols.

Failure to Protect Residents and Staff from Covid-19

While the purpose of our investigation was not to do an in-depth assessment of facilities' response to the pandemic, we nonetheless documented several cases in which infection control protocols clearly fell short of what was needed to protect residents and staff from Covid-19. Independent analyses of federal data show insufficient supplies of personal protective equipment (PPE) and slow turnaround of testing in nursing facilities.

As part of our research and to ensure thorough and objective reporting, we would welcome your response to the questions below. In addition to these responses, we would also welcome your any other information you would like to share on the issues highlighted above.

Questions about nursing facilities:

1. As you know, long-term care facilities have been linked to approximately 40 percent of Covid-19 deaths, despite making up less than one percent of the population. This rate has remained fairly consistent throughout the pandemic. What do you believe are the key reasons that rates of Covid-19 in nursing facilities remain so high?
2. Are you monitoring or collecting information about severe weight loss, dehydration, untreated bedsores or other wounds, as well as physical, mental, and emotional decline among residents during the Covid-19 pandemic? Do you have any concerns about these issues, and if so, what steps have you taken or do you believe are needed to address those concerns?
3. What impact has the suspension of data reporting requirements, such as the suspension of reporting the Minimum Data Set for the duration of the federal State of Emergency and the temporary suspension of payroll-based reporting data from March to May, had on nursing homes?
4. What impact have restrictions on relatives' visits to nursing homes had on the care and support provided to residents in nursing homes? What steps have you taken to address any of these issues?
5. What impact have limits on the access of long-term care ombudsmen to facilities had on nursing homes? What steps, if any, are you taking to address transparency issues at this time?
6. What impact has the Covid-19 pandemic had on psychotropic drug use in nursing facilities? What steps are you taking to ensure that the prescribing of psychotropic drugs during this time is done appropriately, in response to a specific clinical diagnosis, and that residents have access to alternatives such as behavioral interventions?

7. What guidance do you provide to your members regarding responding to concerns and complaints raised by residents or their family members? What steps have you taken to ensure that nursing homes give timely, transparent, and meaningful responses to complaints raised by residents and relatives, during the Covid-19 pandemic?
8. What has the impact of CMS's September 2020 revised guidance, which expanded access to visitation with some restrictions, been on nursing homes? Are you monitoring or collecting information about how this guidance is being implemented?
9. What steps have you taken to ensure that nursing homes are compliant with visitation guidance in ways that are meaningful to residents and their families?
10. When CMS and state or county guidance on visitation differ, which guidance do you recommend that nursing homes follow?
11. In the September 2020 guidelines on visitation, CMS says nursing homes can use civil monetary penalty (CMP) funds to buy equipment that would facilitate visitation. Have members used these funds to facilitate visitation; and if yes, how? What steps has LeadingAge taken to facilitate members taking advantage of these funds, and are you collecting any data on usage of these funds? If so, please share this data.
12. Have your members expressed concerns about quality and sufficiency of staff during the Covid-19 pandemic? What steps are you taking to address these issues?
13. A federal advisory committee recently voted to prioritize residents and staff of long-term care facilities for vaccination against the novel coronavirus. What steps should be taken to ensure effective distribution of the vaccine to nursing facilities?

We respectfully request that you respond to these queries by January 15, 2021, so we can incorporate your response into our report and into public comments Human Rights Watch issues on this topic. We will be certain to acknowledge publicly your responses to these queries if they are provided. Please feel free to reach out to me at [REDACTED] or by phone at [REDACTED].

Sincerely,
Jane Buchanan
Acting Director
Disability Rights Division
Human Rights Watch

January 15, 2021



Jane Buchanan
Human Rights Watch
350 Fifth Avenue, 34th Floor
New York, NY 10118-3299

Dear Ms. Buchanan:

We appreciate the opportunity to share information with Human Rights Watch about the critical role of long-term care in America's health care system, and how our system can better support and improve how care is provided at nursing homes—especially in times of crisis like the current COVID-19 pandemic.

LeadingAge represents more than 5,000 nonprofit aging services providers, many of which have been deeply embedded in their communities for more than a century. Our members, including providers of skilled nursing and long-term care, and the entire field of aging and disability services, have long played a special and critical role in communities across the U.S. We represent mission-driven organizations that are guided by common values, including multiple faith-based traditions, to offer meaningful care and support so that all our neighbors can reach their potential regardless of age, race, religion, or background.

As your research acknowledges, the COVID-19 pandemic created an unprecedented crisis for these nursing homes—and highlighted some of the long-term systemic problems in how nursing homes are staffed and funded. These new and ongoing challenges led to problems throughout the crisis, and even the most diligent of nursing homes were no match for rampant community spread. As the virus surges in the community around them, older adults and the people caring for them suffer disproportionately—and nursing home residents, who are older and have higher levels of chronic illness than the general public, are particularly vulnerable. ["Trying to protect nursing home residents without controlling community spread is a losing battle,"](#) said Tamara Konetzka, a University of Chicago researcher on long-term care. But brave and dedicated workers scrambled to provide care to older Americans, at great risk to their own health and safety.

Our nation has undervalued and under-invested in older adults and their care providers for decades. The needs and very lives of older Americans are too often ignored. The result? Older adults and those who care for them suffer. In fighting the pandemic, they have been left to battle largely on their own. As one LeadingAge nursing home member explains, "We're in the fight of our lives." Without the tools to combat the virus quickly, nursing home residents faced devastating isolation while providers worked overtime to deliver quality, person-centered care while also fighting the pandemic.

LeadingAge's nursing home members have never faced such urgent challenges as they have in the past year. We implored federal leaders to immediately deliver the leadership, resources, and support needed to ensure the health and wellbeing of millions of people in long-term care. Our leaders did not listen. We are incredibly grateful that long-term care workers and older adults have finally been placed at the front of the line with hospitals for vaccine prioritization. But the tragic first 10 months of the pandemic left their destructive and deadly mark. We continue to work with members to share information and best practices, to understand their challenges,

connect them to national experts, and work with them to advocate for the support they need to fulfill their missions of quality care despite the ongoing emergency.

Since our founding in 1961, LeadingAge has stood for quality nursing home care. We've taken leadership roles in the creation of policy and regulatory initiatives (like the Nursing Home Reform Act) and efforts within our field (like Quality First and Advancing Excellence in America's Nursing Homes); and have been a partner with the Centers for Medicare and Medicaid Services on myriad initiatives (including the [National Partnership to Improve Dementia Care in Nursing Homes](#)). Our vision is a future in which nursing homes are places any of us would be willing to live if we needed the level of care provided.

To make this vision a reality, our society and its leaders must make a commitment to bring nursing homes into the future and deliver the resources needed to back that transformation. One of many elements to this evolution is professionalizing the direct care workforce. The longstanding and systemic challenges of frontline workers have been exacerbated throughout the COVID crisis, while the value of these workers has never been clearer. Now is the time to work together on a new approach to investing in this essential workforce.

For example, research [released by the LeadingAge LTSS Center @UMass Boston in September](#) shows that wage increases for this critical workforce would actually pay for themselves and save money in the long run—benefiting workers, communities, employers, and the older adults who rely on their work. Another workforce research initiative, "[COVID-19 in Nursing Homes: Who is Leaving the Job?](#)," will help us address the direct care workers' stresses and challenges throughout COVID-19 in order to improve their workplace experience.

We thank you for your attention to the terrible impact of the pandemic on nursing homes and the millions of people they serve. LeadingAge and our members are committed to resolving the short and long-term challenges illuminated by this crisis, and we hope you will work with us to help reimagine the future for these critical care providers for older Americans and their families.

Best,

A handwritten signature in black ink that reads "Katie Smith Sloan". The signature is written in a cursive, flowing style.

Katie Smith Sloan
President & CEO
LeadingAge

II. HRW Exchange with American Health Care Association and National Center for Assisted Living (AHCA/NCAL)

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December 11, 2020

Mark Parkinson
President and CEO

American Health Care Association and National
Center for Assisted Living (AHCA/NCAL)
1201 L Street NW
Washington, DC 20005



HRW.org

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We plan to write a report documenting our findings in the coming months. We do not anticipate identifying any specific nursing facilities in our report. We would welcome AHCA-NCAL's response to our preliminary findings and questions outlined below.

Preliminary Findings:

Neglect

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Response to Residents and Family Members' Complaints

Interviewees and survey respondents reported that when they raised concerns about the decline in their loved one's physical or mental health, they were often dismissed or ignored by staff. Some expressed fear that staff could take away the already limited access they had to their loved one if they complained too much. Human Rights Watch spoke to several people who said the facility had retaliated against them, denying or limiting access to their loved one in response to concerns expressed about quality of care or transparency, or for minor violations of visitation protocols.

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While the purpose of our investigation was not to do an in-depth assessment of facilities' response to the pandemic, we nonetheless documented several cases in which infection control protocols clearly fell short of what was needed to protect residents and staff from Covid-19. Independent analyses of federal data show insufficient supplies of personal protective equipment (PPE) and slow turnaround of testing in nursing facilities.

As part of our research and to ensure thorough and objective reporting, we would welcome your response to the questions below. In addition to these responses, we would also welcome your any other information you would like to share on the issues highlighted above. While the main focus of our report and most of our interviews pertained to nursing homes, one in four respondents to the survey had a loved one in an assisted living facility. Questions pertaining to assisted living facilities are addressed separately below.

Questions about nursing facilities:

1. As you know, long-term care facilities have been linked to approximately 40 percent of Covid-19 deaths, even though their residents make up less than one percent of the population. This rate has remained fairly consistent throughout the pandemic. What do you believe are the key reasons that rates of Covid-19 in nursing facilities remain so high?
2. Are you monitoring or collecting information about severe weight loss, dehydration, untreated bedsores or other wounds, as well as physical, mental, and emotional decline among residents during the Covid-19 pandemic? Do you have any concerns about these issues, and if so, what steps have you taken or do you believe are needed to address those concerns?
3. What impact has the suspension of data reporting requirements, such as the suspension of reporting the Minimum Data Set for the duration of the federal State of Emergency and the temporary suspension of payroll-based reporting data from March to May, had on nursing homes?
4. What impact have restrictions on relatives' visits to nursing homes had on the care and support provided to residents in nursing homes? What steps have you taken to address any of these issues?
5. What impact have limits on the access of long-term care ombudsmen to facilities had on nursing homes? What steps, if any, are you taking to address transparency issues at this time?
6. What impact has the Covid-19 pandemic had on psychotropic drug use in nursing facilities? What steps are you taking to ensure that the prescribing of psychotropic

drugs during this time is done appropriately, in response to a specific clinical diagnosis, and that residents have access to alternatives such as behavioral interventions?

7. What guidance do you provide to your members regarding responding to concerns and complaints raised by residents or their family members? What steps have you taken to ensure that nursing homes give timely, transparent, and meaningful responses to complaints raised by residents and relatives, during the Covid-19 pandemic?
8. What has the impact of CMS's September 2020 revised guidance, which expanded access to visitation with some restrictions, been on nursing homes? Are you monitoring or collecting information about how this guidance is being implemented?
9. What steps have you taken to ensure that nursing homes are compliant with visitation guidance in ways that are meaningful to residents and their families?
10. When CMS and state or county guidance on visitation differ, which guidance do you recommend nursing homes to follow?
11. In the September 2020 guidelines on visitation, CMS says nursing homes can use civil monetary penalty (CMP) funds to buy equipment that would facilitate visitation. Have members used these funds to facilitate visitation; if yes, how? What steps has ACHA taken to facilitate members taking advantage of these funds, and are you collecting any data on usage of these funds? If so, please share this data.
12. Have your members expressed concerns about quality and sufficiency of staff during the Covid-19 pandemic? What steps are you taking to address these issues?
13. A federal advisory committee recently voted to prioritize residents and staff of long-term care facilities for vaccination against the novel coronavirus. What steps should be taken to ensure effective distribution of the vaccine to nursing facilities?

Questions on assisted living facilities:

1. Are you monitoring or collecting information about severe weight loss, dehydration, untreated bedsores or other wounds, as well as physical, mental, and emotional decline in assisted living facilities during the Covid-19 pandemic? Do you have any concerns about these issues, and if so, what steps have you taken or do you believe are needed to address those concerns?
2. What impact have restrictions on relatives' visits to assisted living facilities had on the care and support provided to residents in these facilities? What steps have you taken to address any of these issues?

3. What impact have limits on the access of long-term care ombudsmen to facilities had on assisted living facilities? What steps, if any, are you taking to address transparency issues at this time?
4. What guidance do you provide to assisted living facilities regarding responding to concerns and complaints raised by residents or their family members? What steps have you taken to ensure that they give timely, transparent, and meaningful responses to complaints raised by residents and relatives, during the Covid-19 pandemic?

We respectfully request that you respond to these queries by January 15, 2021, so we can incorporate your response into our report and into public comments Human Rights Watch issues on this topic. We will be certain to acknowledge publicly your responses to these queries if they are provided. Please feel free to reach out to me at [REDACTED] or by phone at [REDACTED]

Sincerely,
Jane Buchanan
Acting Director
Disability Rights Division
Human Rights Watch

Response from AHCA/NCAL:

Questions about nursing facilities:

- 1. As you know, long-term care facilities have been linked to approximately 40 percent of Covid-19 deaths, even though their residents make up less than one percent of the population. This rate has remained fairly consistent throughout the pandemic. What do you believe are the key reasons that rates of Covid-19 in nursing facilities remain so high?**

According to CDC data, the risk of mortality in this age group is 630 times higher than those 18-29 years old. The average age of residents in long term care facilities is 85 and almost every one of them has an underlying health condition, and some have multiple chronic conditions.

The other rate that has remained fairly consistent is the low number of cases attributed to long term care (approximately 6%). To have only 6% of the nation's cases, yet 40% of its deaths demonstrates the vicious nature of the virus on our resident population.

- 2. Are you monitoring or collecting information about severe weight loss, dehydration, untreated bedsores or other wounds, as well as physical, mental, and emotional decline among residents during the Covid-19 pandemic? Do you have any concerns about these issues, and if so, what steps have you taken or do you believe are needed to address those concerns?**

Providers track this information about their residents to monitor their health and wellbeing.

We are deeply concerned about the prolonged isolation of our residents, which is bad for their health and wellbeing. No one could wish for a swifter end to this pandemic than those who live and work in long term care. Public health officials were put between a rock and a hard place on how to best protect those in long term care, and due to the vicious nature of the virus on our resident population, it was determined best to restrict visitors and social interactions. Had they not, perhaps thousands more would have succumbed to COVID.

The sad truth is that we're likely to see that many Americans experienced declining physical, mental and emotional health due to this pandemic; long term care residents are not the exception. While this is a serious concern, let's not diminish the extraordinary efforts of our health care heroes who put their lives on the lines to fight the virus, provide more one-on-one care, and help fill the void of loved ones by treating residents like family.

The best way we can address concerns of deteriorating health is to end the pandemic as soon as possible. This is why we've been calling on members of the public to help slow the spread, as well as public health officials to prioritize long term care residents and staff, including with vaccine distribution. We also need to address the workforce shortage crisis in long term care, to ensure there are enough caregivers to help residents have the best quality of life.

- 3. What impact has the suspension of data reporting requirements, such as the suspension of reporting the Minimum Data Set for the duration of the federal State of Emergency and the temporary suspension of payroll-based reporting data from March to May, had on nursing homes?**

It allowed frontline caregivers to keep their focus on fighting the virus and dedicate precious resources to protecting their residents and staff during this pandemic.

- 4. What impact have restrictions on relatives' visits to nursing homes had on the care and support provided to residents in nursing homes? What steps have you taken to address any of these issues?**

Nothing can replace seeing loved ones, and for those who have family members, they play an important role in helping caregivers understand the care needs and individual preferences of residents. Long term care facilities adapted to the new environment by regularly connecting residents with loved ones via video calls, or by setting up safe visitation areas in accordance with government guidance (e.g., outdoor visitations).

AHCA/NCAL assisted in this effort by developing [guidance](#) for providers to help facilitate connections between residents and family members while maintaining strong infection control best practices. We also shared [communication strategies](#) providers could employ to help keep family members up-to-date on their loved one as well as the situation within their facility.

- 5. What impact have limits on the access of long-term care ombudsmen to facilities had on nursing homes? What steps, if any, are you taking to address transparency issues at this time?**

Our priority has to be stopping the spread of this virus, and that requires limiting as many individuals as possible from entering our buildings. We have worked with the Ombudsman program to examine when it is critical to enter the building and when they can do their work remotely, which is what CMS guidance outlines. Due to the well-known amount of community spread, this is the safest course of action.

- 6. What impact has the Covid-19 pandemic had on psychotropic drug use in nursing facilities? What steps are you taking to ensure that the prescribing of psychotropic drugs during this time is done appropriately, in response to a specific clinical diagnosis, and that residents have access to alternatives such as behavioral interventions?**

AHCA/NCAL and our members have been an active partner in an effort to reduce the unnecessary use of antipsychotic medications. In the past decade, the use of antipsychotics in nursing homes has decreased by 40 percent nationwide.

It's important to remember that these medications are often prescribed by physicians not directly affiliated with the long term care facility and prior to the admittance of a resident to a facility. Even family members can sometimes urge their use or be reluctant to stop using them. According to the medical literature, there are still situations where these medications may be necessary and beneficial to certain patients. But we believe in increasing education about the proper use of antipsychotics and have asked CMS and others to expand its outreach to hospitals, community settings, families and physicians.

During COVID-19, AHCA/NCAL collaborated with the Alzheimer's Association to share [resources](#) with providers related to caring for individuals with dementia during the pandemic. This includes strategies on how to engage residents with non-pharmacological interventions.

- 7. What guidance do you provide to your members regarding responding to concerns and complaints raised by residents or their family members? What steps have you taken to ensure that nursing homes give timely, transparent, and meaningful responses to complaints raised by residents and relatives, during the Covid-19 pandemic?**

Since the beginning of the pandemic, long term care facilities have recognized that communication with residents, families, staff and others is so important. AHCA/NCAL issued guidance early-on to our members regarding open and transparent communication.

We must also remember that nursing homes may only communicate specific details about a resident with their emergency contact or designated representative. Families need to work together and with facilities to identify a single point of contact who can be responsible for information dissemination within families, especially during a crisis.

If residents' designated representatives have contacted the facility and received no response, or they are concerned about abuse or neglect of a resident, then these individuals should contact their state's LTC Ombudsman office. We support and respect the role of the LTC Ombudsman and work with them frequently to ensure the safety and wellbeing of our residents.

- 8. What has the impact of CMS's September 2020 revised guidance, which expanded access to visitation with some restrictions, been on nursing homes? Are you monitoring or collecting information about how this guidance is being implemented?**

We appreciated CMS looking for ways to safely facilitate more indoor visits for residents, especially as we headed into colder months. Providers are eager to welcome back family and friends to our facilities, and this guidance helped many do so while still maintaining strong infection control practices.

- 9. What steps have you taken to ensure that nursing homes are compliant with visitation guidance in ways that are meaningful to residents and their families?**

We have been in constant communication with our member providers about changes in guidance to help them comply with federal regulations, but we also share innovative ideas to keep residents engaged during this challenging time. We also appreciate the work of our state affiliates in helping providers understand any additional visitation guidance that was stipulated by their state government officials as well.

This has been a rapidly changing situation as we continue to learn more about the virus, and government guidance was changing sometimes on a daily basis, making it extremely difficult for providers to care for their residents and keep up with constant, new government rules. We aimed to help providers stay on the top of the changes and learn how to practically implement as much as possible.

[\(See our related resource on this topic.\)](#)

- 10. When CMS and state or county guidance on visitation differ, which guidance do you recommend nursing homes to follow?**

CMS or federal guidance is the minimum. States or counties may go further than the federal government, but they cannot be weaker. If guidance differs, providers must follow the stricter guidance.

- 11. In the September 2020 guidelines on visitation, CMS says nursing homes can use civil monetary penalty (CMP) funds to buy equipment that would facilitate visitation. Have**

members used these funds to facilitate visitation; if yes, how? What steps has AHCA taken to facilitate members taking advantage of these funds, and are you collecting any data on usage of these funds? If so, please share this data.

We welcomed the opportunity for facilities to use CMP funds to help nursing homes adapt their facilities to offer indoor visits between residents and families. Please reach out to CMS for data requests on usage of these funds.

12. Have your members expressed concerns about quality and sufficiency of staff during the Covid-19 pandemic? What steps are you taking to address these issues?

This pandemic has been an all-hands-on deck emergency. We've been calling for help since the beginning. Long term care was already dealing with a workforce shortage prior to COVID, and this has only exacerbated the crisis due to staff members getting sick, having to isolate, or a lack of childcare options. At the same time, we're asking them to provide patients more one-on-one care to help prevent spread.

AHCA/NCAL urged governors to help address the workforce shortage by outlining strategies in a [roadmap for states](#) back in May 2020. We also developed free online courses to help train temporary caregivers (nurse aides and feeding assistants) to help fill the gap the pandemic created.

Additionally, AHCA/NCAL urged Congress and the Administration to direct financial aid to long term care facilities, so that providers could use those resources to respond to the crisis, including by hiring more staff and offer hero pay. In a [survey](#) of nursing home providers conducted in November 2020, 70 percent of nursing homes had hired additional staff and nine out of 10 asked staff to work overtime and provided hero pay.

We need ongoing staff support during the pandemic, but we also need a more long term solution when we get through this. We have been highlighting this workforce crisis for years, including testifying to Congress twice in 2019. It's time we addressed it. We need a comprehensive strategy to recruit more health care heroes to serve in long term care.

13. A federal advisory committee recently voted to prioritize residents and staff of long-term care facilities for vaccination against the novel coronavirus. What steps should be taken to ensure effective distribution of the vaccine to nursing facilities?

As soon as the recommendation was issued by the Advisory Committee on Immunization Practices (ACIP), AHCA/NCAL immediately [called on governors](#) to ensure their distribution plans put long term care residents and staff at the highest priority. We're pleased to see that all governors and states followed this recommendation, and that vaccination in long term care is well underway.

You can see our recent thoughts on the vaccine rollout here: <https://www.ahcancal.org/News-and-Communications/Press-Releases/Pages/AHCA-NCAL-Issues-Statement-Regarding-COVID-19-Vaccine-Rollout-In-Long-Term-Care.aspx>

Questions on assisted living facilities:

1. Are you monitoring or collecting information about severe weight loss, dehydration, untreated bedsores or other wounds, as well as physical, mental, and emotional decline in assisted living facilities during the Covid-19 pandemic? Do you have any concerns about these

issues, and if so, what steps have you taken or do you believe are needed to address those concerns?

See answer to #2 in the nursing home section regarding our concerns about this issue.

2. What impact have restrictions on relatives' visits to assisted living facilities had on the care and support provided to residents in these facilities? What steps have you taken to address any of these issues?

See answer to #4 in the nursing home section.

3. What impact have limits on the access of long-term care ombudsmen to facilities had on assisted living facilities? What steps, if any, are you taking to address transparency issues at this time?

See answer to #5 in the nursing home section.

4. What guidance do you provide to assisted living facilities regarding responding to concerns and complaints raised by residents or their family members? What steps have you taken to ensure that they give timely, transparent, and meaningful responses to complaints raised by residents and relatives, during the Covid-19 pandemic?

See answer to #7 in the nursing home section.

III. HRW Letter to Seema Verma, Centers for Medicare & Medicaid Services

350 Fifth Avenue, 34th Floor
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December 11, 2020

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Hassan Elmasry, *Co-Chair*
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Seema Verma
Administrator
Centers for Medicare & Medicaid Services
7500 Security Boulevard
Baltimore, MD 21244



HRW.org

Dear Ms. Verma:

I am the Acting Director of the Disability Rights Division at Human Rights Watch. I am writing to share with you findings from our research in the United States on human rights issues affecting older people in skilled nursing facilities (SNF) and nursing facilities (NF) and their families during the Covid-19 pandemic.

Human Rights Watch is the largest US-based international human rights research and advocacy organization. We document human rights violations in 90 countries around the world, including the US. We use our research to draw attention to important human rights issues and to offer concrete recommendations on how to improve protections of people's rights.

We have conducted 51 interviews with nursing home residents, family members, staff, long-term care ombudsmen, and advocates in several states. We also conducted an online survey of people who have relatives in nursing homes, which received 564 responses from 45 states. While the survey was conducted via convenience sampling and therefore cannot be used to draw conclusions about all nursing home residents, it provides evidence of the commonality of these experiences as well as their broad geographic scope.

We plan to write a report documenting our findings in the coming months. We do not anticipate identifying any specific nursing facilities in our report. We would welcome CMS's response to our preliminary findings and questions outlined below.

Preliminary Findings:

Neglect

Many interviewees and survey respondents who had a relative in a nursing home reported that after widespread visitor bans were imposed in nursing homes in response to Covid-19, their loved ones showed severe weight loss, dehydration, untreated bedsores or wounds, and inadequate hygiene. Interviewees also reported that many residents experienced concerning declines in their physical, mental, and emotional states during this time. For some residents, depression, anxiety, and hallucinations became more common.

Alternatives to in-person visitation, such as communication by phone or computer, did not always provide the emotional support residents required, particularly for people with dementia who found video calls or visits through a closed window or door confusing or upsetting.

Increases in Use of Medication

Some relatives whom we interviewed or who responded to our survey expressed serious concerns about increases in psychotropic medications administered to their loved ones during the pandemic. One in three survey respondents said staff had increased or initiated psychotropic drugs for their loved one at this time. Antidepressants and anti-anxiety medication were most common, and a smaller but still notable number of interviewees reported increases in the use of antipsychotic drugs, the dangers of which have been highlighted in our previous reporting.¹ In some cases, these medications were prescribed without the informed consent of the resident or their medical proxy. Family members reported seeing changes in their loved one's behavior following medication changes, including lethargy or excessive sleeping. Non-medical interventions to treat anxiety, depression, and other conditions were not typically offered.

Staffing Shortages

Independent analyses of CMS's payroll-based staffing data found that facilities were critically understaffed during the pandemic.² Staff whom we interviewed said that low wages, no or low hazard pay, no sick leave or health benefits led to many quitting their nursing home jobs during the pandemic. Staff also reported that insufficient staffing undermined their ability to provide quality care to residents.

¹ Human Rights Watch, *They Want Docile: How Nursing Homes in the United States Overmedicate People with Dementia*, February 2018, <https://www.hrw.org/report/2018/02/05/they-want-docile/how-nursing-homes-united-states-overmedicate-people-dementia>

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Inadequate Communication

In March, in response to Covid-19, CMS made recommendations encouraging facilities to facilitate phone calls or virtual visits for residents and their loved ones in lieu of in-person visits.

Interviewees told Human Rights Watch that facility staff arranged video and phone calls sporadically, if at all, making it difficult for relatives to monitor their loved one's care and sustain emotional connection. When these calls did take place, staff did not always provide meaningful support to residents who could not independently manage a phone or other device to facilitate these conversations.

Confusing and Inconsistent Visitation Policies

It is significant that in its September 2020 guidelines, CMS explicitly reasserts residents' rights to visitation. However, our research found that some facilities appeared to cite a variety of official guidance—including from state, county, or other health authorities—to justify denying visitation even when CMS criteria would have allowed for it, creating confusion among relatives, residents, and even staff about visitation policies. When visitation was allowed, it was often infrequent and short in duration and therefore did not provide meaningful support to residents. Some said that staff monitored visits so closely that it undermined their privacy.

CMS's earlier March 2020 guidance allowed compassionate care visits, which were described as visits for residents at end-of-life, to continue during the pandemic. The CMS September guidance expands the definition of "compassionate care" beyond these cases, to include cases in which a person has suffered weight loss, needs assistance or encouragement to eat, or is showing signs of depression. However, Human Rights Watch found that some nursing homes denied compassionate care visits to relatives who had identified serious weight loss, emotional decline, and other relevant concerns.

Response to Residents and Family Members' Complaints

Interviewees and survey respondents reported that when they raised concerns about the decline in their loved one's physical or mental health, they were often dismissed or ignored by staff. Some expressed fear that staff could take away the already limited access they had to their loved one if they complained too much. Human Rights Watch spoke to several people who said the facility had retaliated against them, denying or limiting access to their loved one in response to concerns expressed about quality of care or transparency, or for minor violations of visitation protocols.

Failure to Protect Residents and Staff from Covid-19

While the purpose of our investigation was not to do an in-depth assessment of facilities' response to the pandemic, we nonetheless documented several cases in which infection control protocols clearly fell short of what was needed to protect residents and staff from Covid-19. Independent analyses of federal data show insufficient supplies of personal protective equipment (PPE) and slow turnaround of testing in nursing facilities.

As part of our research and to ensure thorough and objective reporting, we would welcome your response to the questions below. In addition to these responses, we would also welcome any other information you would like to share on the issues highlighted above.

Questions on Monitoring and Enforcement:

1. Is CMS collecting information on neglect, including weight loss and untreated bedsores or other wounds, increased use of medications, or the decline of nursing home residents' physical, mental, and emotional conditions during the Covid-19 pandemic, beyond what is required by the annual survey that is conducted by state authorities and is part of the certification process for nursing homes? Please share the information if so.
2. What was the rationale for suspending reporting requirements for the Minimum Data Set for the duration of the State of Emergency? How does CMS plan to monitor and hold nursing facilities accountable for neglect, decline, or the increased use of psychotropic drugs during the Covid-19 pandemic without collecting this information? Will facilities be required to submit this information, including for the months starting from March 2020, once the State of Emergency ends?
3. Given credible reports of neglect and decline among nursing home residents during the Covid-19 pandemic, has CMS expanded, or do you plan to expand your monitoring capacity so as to ensure residents' rights are fully respected? How so?
4. Since September, when standard annual surveys resumed, are there states or localities where surveyors, due to virus spread or other factors, were unable to conduct surveys of nursing homes where needed?
5. What, if any, information has CMS collected on rates of prescribing of psychotropic medication for nursing home residents during the Covid-19 pandemic?
6. What has CMS done to ensure that prescribing of psychotropic drugs during the pandemic is appropriate and in response to a specific clinical diagnosis? What actions has CMS taken to bolster facilities' capacity to provide alternative, non-medical/behavioral interventions to growing rates of depression, anxiety, etc.?

Questions on Visitation:

7. CMS's memos on visitation are described as "guidance," and yet CMS says that facilities will be penalized for non-compliance. As you know, many states have issued guidance on visitation that differs from that of CMS, leading to confusion among residents, their families, and staff about which guidance takes precedence. Can you please clarify CMS's position as to whether federally-regulated nursing facilities are legally obligated to follow CMS guidance on visitation, even where state guidance differs?
8. How often since issuing its September guidance has CMS cited facilities for violation of visitation guidance, and have any facilities faced any monetary penalties as a result? What was the average fine?
9. Is CMS collecting data on facilities that are and are not allowing visitation, the frequency and duration of visitation allowed, and whether or not facilities are conducting virtual or alternative visits in ways that are meaningful to residents and their caregivers?
10. The September 2020 CMS guidance allows nursing facilities to use civil monetary penalty funds to facilitate virtual and in-person visitation. How many facilities have applied for the use of these funds, and how does CMS monitor how this money is spent?

Questions on Staffing:

11. Given particularly acute staffing shortages during the pandemic, as confirmed by independent analyses of CMS's payroll-based staffing data, and increased responsibilities of staff (including observing additional infection control protocols, organizing phone and virtual visits, monitoring in-person visits, and increased care responsibilities), how does CMS plan to ensure that nursing homes have sufficient quantity, training, and consistency of staff during and beyond the pandemic?
12. What is CMS's stance on hazard pay, sick leave, or health benefits for nursing home workers working during an infectious disease outbreak, both during the Covid-19 pandemic and beyond?

Questions on Covid-19 infection control measures:

13. What is CMS doing to respond to slow turnaround times in testing and ongoing shortages in PPE in nursing facilities?
14. How has CMS been monitoring compliance with wearing of PPE and other infection control protocols during the pandemic? How many facilities have faced monetary penalization for violations of these protocols, and what has the average fine been?

15. Given the ongoing pandemic, what plans does CMS have to better ensure protection of nursing home residents, including from neglect, physical, mental, and emotional decline, and staff?
16. What plans does CMS have to ensure that vaccines are distributed efficiently and effectively to nursing homes? What issues do you foresee in effective distribution of a vaccine?

We respectfully request that you respond to these queries by January 15, 2021, so we can incorporate your response into our report and into public comments Human Rights Watch issues on this topic. We will be certain to acknowledge publicly your responses to these queries if they are provided. Please feel free to reach out to me at [REDACTED] or by phone at [REDACTED]

Sincerely,
Jane Buchanan
Acting Director
Disability Rights Division
Human Rights Watch

Human Rights Watch did not receive a response from Ms. Seema Verma.

IV. HRW Letter to Jeffrey Bossert Clark, U.S. Department of Justice

350 Fifth Avenue, 34th Floor
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December 22, 2020

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Emma Daly, *Chief Communications Officer (Acting)*
Jim Ross, *Head of Legal and Policy*
James Powell, *Chief Technology Officer*
Alan Feldstein, *General Counsel*



HRW.org

Jeffrey Bossert Clark
Acting Assistant Attorney General of the Civil Division
Civil Division
U.S. Department of Justice
950 Pennsylvania Avenue, N.W.
Washington, DC 20530

Dear Mr. Clark:

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As part of our research and to ensure thorough and objective reporting, we would welcome your response to the questions below. In addition to these responses, we would also welcome any other information you would like to share on the issues highlighted above.

Questions:

- Has the Department of Justice launched any investigations into credible reports of neglect in nursing homes during the pandemic, including extreme weight loss, dehydration, untreated bedsores and other wounds, particularly in cases where these events resulted in the death of a resident? If not, is DOJ considering launching any such investigations in the future?
- In August, DOJ requested information from four states (New York, New Jersey, Pennsylvania, and Michigan) about their response to Covid-19 in nursing homes.
 - Why did DOJ select these four states?
 - Has DOJ requested this information from other states?
 - Have officials in those states shared the requested data?
 - Has DOJ done an analysis or does it have any findings based on the data received?
 - What action has DOJ taken against authorities or nursing homes in these states?
- In early March, DOJ announced the creation of a national nursing home initiative to “coordinate and enhance civil and criminal efforts to pursue nursing homes that provide grossly substandard care to their residents.” Has this initiative resulted in any action in response to credible allegations of neglect in nursing homes during the Covid-19 pandemic? What has the outcome of those actions been?
- Has DOJ taken any actions in response to credible reports of the inappropriate and non-consensual use of psychotropic drugs by nursing homes during the pandemic? If so, what has the outcome of these actions been?

We respectfully request that you respond to these queries by January 22, 2021, so we can incorporate your response into our report and into public comments Human Rights Watch issues on this topic. We will be certain to acknowledge publicly your responses to these queries if they are provided. Please feel free to reach out to me at [REDACTED] or by phone at [REDACTED].

Sincerely,
Jane Buchanan
Acting Director
Disability Rights Division
Human Rights Watch

Human Rights Watch did not receive a response from Mr. Jeffrey Bossert Clark.

V. HRW Exchange with Liz Richter, Centers for Medicare & Medicaid Services

350 Fifth Avenue, 34th Floor
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January 28, 2021

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Hassan Elmasry, *Co-Chair*
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Liz Richter
Acting Administrator
Centers for Medicare & Medicaid Services
7500 Security Boulevard
Baltimore, MD 21244



HRW.org

Dear Ms. Richter:

I am the Acting Director of the Disability Rights Division at Human Rights Watch.

On December 11, 2020 our organization sent Ms. Seema Verma a letter regarding preliminary findings from our research on human rights issues affecting older people in nursing homes during the Covid-19 pandemic.

Given the change in presidential administrations and related changes in CMS, we are writing to again share our preliminary findings and request CMS's response to questions regarding its policies. We would also welcome the opportunity to meet with you or members of your staff virtually to discuss these questions.

Human Rights Watch is the largest US-based international human rights research and advocacy organization. We document human rights violations in more than 100 countries around the world, including the United States. We use our research to draw attention to important human rights issues and to offer concrete recommendations on how to improve protections of people's rights.

We have conducted 54 interviews with nursing home residents, family members, staff, long-term care ombudsmen, and advocates in fifteen states. We also spoke to experts in long-term care, including medical professionals. We also conducted an online survey of people who have relatives in nursing homes, which received 564 responses from 45 states. While the survey was conducted via convenience sampling and therefore cannot be used to draw conclusions about all nursing home residents, it provides evidence of the respondents' experiences as well as their broad geographic scope.

We plan to publish a report documenting our findings in the coming months. We do not anticipate identifying any specific nursing facilities in our report. We would welcome CMS's response to our preliminary findings and questions outlined below.

Preliminary Findings:

Neglect

Many interviewees and survey respondents who had a relative in a nursing home reported that visitor bans imposed in nursing homes in response to Covid-19 made it difficult or impossible to remain in contact with their relatives, advocate on their behalf, and provide practical and emotional support that they had previously. Many reported that loved ones experienced severe weight loss, dehydration, untreated bedsores or wounds, and inadequate hygiene. Interviewees also reported that many residents experienced concerning declines in their physical, mental, and emotional states during this time. For some residents, depression, anxiety, and hallucinations became more common.

Alternatives to in-person visitation, such as communication by phone or computer, did not always provide the emotional support residents required, particularly for people with dementia who found video calls or visits through a closed window or door confusing or upsetting.

Increases in Use of Medication

Some relatives whom we interviewed or who responded to our survey expressed serious concerns about increases in psychotropic medications administered to their loved ones during the pandemic. Very many survey respondents said staff had increased or initiated psychotropic drugs for their loved one at this time. Antidepressants and anti-anxiety medication were most common, and a smaller but still notable number of interviewees reported increases in the use of antipsychotic drugs, the dangers of which have been highlighted in our previous reporting.¹ In some cases, these medications were prescribed without the informed consent of the resident or their medical proxy. Family members reported seeing changes in their loved one's behavior following medication changes, including lethargy or excessive sleeping. Non-medical interventions to treat anxiety, depression, and other conditions were not typically offered.

¹ Human Rights Watch, *They Want Docile: How Nursing Homes in the United States Overmedicate People with Dementia*, February 2018, <https://www.hrw.org/report/2018/02/05/they-want-docile/how-nursing-homes-united-states-overmedicate-people-dementia>

Staffing Shortages

Independent analyses of CMS's payroll-based staffing data found that facilities were critically understaffed during the early days of the pandemic.² Staff whom we interviewed said that low wages, no or low hazard pay, no sick leave or health benefits led to many quitting their nursing home jobs during this time. Staff also reported that insufficient staffing undermined their ability to provide quality care to residents.

Inadequate Communication

In March, in response to Covid-19, CMS made recommendations encouraging facilities to facilitate phone calls or virtual visits for residents and their loved ones in lieu of in-person visits.

Interviewees told Human Rights Watch that facility staff arranged video and phone calls sporadically, if at all, making it difficult for relatives to monitor their loved one's care and sustain emotional connection. When these calls did take place, staff did not always provide meaningful support to residents who could not independently manage a phone or other device to facilitate these conversations.

Confusing and Inconsistent Visitation Policies

It is significant that in its September 2020 guidelines, CMS explicitly reasserts residents' rights to visitation. However, our research found that some facilities appeared to cite a variety of official guidance—including from state, county, or other health authorities—to justify denying visitation even when CMS criteria would have allowed for it, creating confusion among relatives, residents, and even staff about visitation policies. When visitation was allowed, it was often infrequent and short in duration and therefore did not provide meaningful support to residents. Some said that staff monitored visits so closely that it undermined their privacy.

CMS's earlier March 2020 guidance allowed compassionate care visits, which were described as visits for residents at end-of-life, to continue during the pandemic. The CMS September guidance expands the definition of "compassionate care" beyond these cases, to include cases in which a person has suffered weight loss, needs assistance or encouragement to eat, or is showing signs of depression. However, Human Rights Watch found that some nursing homes denied compassionate care visits to relatives who had identified serious weight loss, emotional decline, and other relevant concerns.

² Christopher Weaver et al., "Staffing at Some Nursing Homes Plummeted During Early Covid-19 Outbreaks," November 1, 2020, <https://www.wsj.com/articles/staffing-at-some-nursing-homes-plummeted-during-early-covid-19-outbreaks-11604242040>

Response to Residents and Family Members' Complaints

Interviewees and survey respondents reported that when they raised concerns about the decline in their loved one's physical or mental health, they were often dismissed or ignored by staff. Some expressed fear that staff could take away the already limited access they had to their loved one if they complained too much. Human Rights Watch spoke to several people who said the facility had retaliated against them, denying or limiting access to their loved one in response to concerns expressed about quality of care or transparency, or for minor violations of visitation protocols.

Failure to Protect Residents and Staff from Covid-19

While the purpose of our investigation was not to do an in-depth assessment of facilities' response to the pandemic, we nonetheless documented several cases in which infection control protocols clearly fell short of what was needed to protect residents and staff from Covid-19. Independent analyses of federal data show insufficient supplies of personal protective equipment (PPE) and slow turnaround of testing in nursing facilities.

As part of our research and to ensure thorough and objective reporting, we would welcome your response to the questions below. In addition to these responses, we would also welcome any other information you would like to share on the issues highlighted above.

Questions:

1. Given credible reports of neglect and decline among nursing home residents during the Covid-19 pandemic, what plans does CMS have to ensure effective, timely, and thorough monitoring and enforcement to protect residents' health and ensure their rights are fully respected?
2. How do you plan to address long-standing concerns of insufficient staffing, which appears to have been particularly acute during the pandemic? What plans does CMS have to implement a mandatory minimum for staffing per resident or other measures to ensure adequate and professional staffing? How do you see low wages and the lack of sick leave or health benefits affect workers and do you plan on addressing this concern?
3. What plans does CMS have to reinstate data reporting requirements for nursing homes that were waived by CMS in March 2020 in response to the Covid-19 pandemic?

We welcome responses to these questions, as well as responses to any of the questions posted in our December 11, 2020 letter. We respectfully request that you respond **by February 12, 2021**, so we may incorporate your response into our report and into public

comments Human Rights Watch issues on this topic. We will be certain to acknowledge publicly your responses to these queries if they are provided. We would also welcome the opportunity to meet with you virtually in February, at a mutually agreed upon time to discuss our findings and these questions.

You may contact me at [REDACTED] or by phone at [REDACTED] to arrange such a meeting and for any further questions.

Sincerely,
Jane Buchanan
Acting Director
Disability Rights Division
Human Rights Watch



Center for Clinical Standards and Quality (CCSQ)

February 9, 2021

Ms. Jane Buchanan
Acting Director, Disability Rights Division, Human Rights Watch
350 Fifth Avenue, 34th floor
New York, NY 10118-3299

Dear Ms. Buchanan:

Thank you for your letters regarding your upcoming report on human rights issues affecting nursing home residents, and their families, during the Coronavirus disease 2019 (COVID-19) Public Health Emergency (PHE). The Centers for Medicare & Medicaid Services (CMS) has worked to make sure America's healthcare facilities and clinical laboratories have the tools and flexibilities they need to respond to COVID-19 PHE. This is especially true for nursing homes, where residents who are often medically frail and suffer from multiple comorbidities are especially susceptible to complications from this virus. I appreciate the opportunity to share with you the important work that CMS is doing to protect this vulnerable population.

CMS's commitment to improving and protecting nursing home residents' health and safety has never been stronger, and this focus is not new. In 2019, the agency announced a five-part strategy for ensuring safety and quality in Medicare and Medicaid participating nursing homes.¹ This strategy outlined the steps the agency has taken and plans to take to keep nursing home residents safe: strengthening oversight, enhancing enforcement, increasing transparency, improving quality, and putting patients over paperwork. This framework serves as a guide to making enhancements and improvements in ensuring nursing home safety and quality.

CMS has remained focused on holding nursing homes accountable for safety and quality of care during the COVID-19 PHE. On March 23, 2020, CMS instructed State Survey Agencies (SSAs) to prioritize and focus their work to (1) respond to Immediate Jeopardy situations (cases that represent a situation in which the provider's noncompliance with federal requirements has caused or is likely to cause the health and safety of recipients in its care serious injury, serious harm, serious impairment or death); (2) conduct targeted infection control surveys with a streamlined tool based on longstanding requirements and enhanced practices that facilities should be implementing to prevent the spread of COVID-19.

CMS staff worked with the Centers for Disease Control (CDC) to identify areas at risk of COVID-19 spread where surveyors would use the new focused survey tool to ensure providers comply with federal infection control requirements.

¹ Available at: <https://www.cms.gov/blog/ensuring-safety-and-quality-americas-nursing-homes>

We also urged nursing homes to use the focused survey as a voluntary self-assessment tool, so facilities can review their own compliance with federal infection control requirements.²

As outlined above, CMS suspended certain routine inspections in order to prioritize infection control and immediate jeopardy situations and to give health care providers and suppliers time needed to respond to the spread of COVID-19. However, on August 17, 2020, CMS instructed SSAs to resume all surveys as soon as they have the resources (e.g., staff and/or Personal Protective Equipment) to do so,³ stressing the importance of having surveyors in facilities conducting routine oversight activities in order to monitor the health and safety of nursing home residents during the PHE.

While the COVID-19 public health emergency has hindered States' ability to completely resume all inspections, many states have been able to conduct additional surveys. For example, all states have conducted focused infection control surveys in all of the nursing homes in their state. CMS and SSAs have conducted approximately 40,000 focused infection control surveys, representing nearly all (99.9 percent) of Medicare and Medicaid certified nursing homes nationwide as of September 2020. CMS believes it is important for stakeholders to be aware of nursing homes' performance on the focused infection control inspections, and the results of those surveys are publically available on our CMS Care Compare website.⁴ Furthermore, findings from the focused infection control inspections will be used to calculate each nursing home's inspection rating. These findings will be included the same way findings from complaint inspections are used in the Five Star Quality Rating System.⁵ These actions affirm our commitment to oversight, accountability, and transparency.

CMS is aware that decreased oversight in facilities during the PHE due to restrictions on visitation as well as limited survey activities has led to some concerns of increased instances of neglect or decline amongst nursing home residents. CMS is also concerned by these reports, and is taking action to address these issues. We revised the criteria requiring states to conduct focused infection control surveys due to the increased availability of testing of residents and staff and factors related to the quality of care in nursing homes. Surveyors were previously instructed to perform on-site focused infection control surveys of nursing homes that had reported 3 or more new COVID-19 confirmed cases or 1 confirmed resident case in a facility that was previously COVID-free. CMS is now including additional factors that may place residents' health and safety at risk. These factors include:

- Multiple weeks with COVID-19 cases;
- Low staffing;
- Selection as a special focus facility
- Concerns related to conducting outbreak testing per CMS requirements; or
- Allegations or complaints which pose a risk for harm or Immediate Jeopardy to the health or safety of residents which are related to certain areas, such as abuse or quality of care (e.g., pressure ulcers, weight loss, depression, and decline in function).

² <https://www.cms.gov/files/document/qso-20-20-all.pdf>

³ <https://www.cms.gov/files/document/qso-20-35-all.pdf>

⁴ <https://www.cms.gov/files/document/summary-covid-19-emergency-declaration-waivers.pdf>

⁵ <https://www.cms.gov/files/document/summary-covid-19-emergency-declaration-waivers.pdf>

CMS believes that these revisions will enable surveys to be more focused on facilities with a higher likelihood of noncompliance and other resident care issues. This revised guidance also instructs surveyors to investigate any concerns related to residents who have had a significant decline in their condition (e.g., weight loss, mobility, etc.) during the PHE.

In your letter, you ask if CMS plans to expand our monitoring capacity to ensure that residents' rights are fully respected. The primary responsibility for the health and safety of residents belongs to nursing homes themselves, but there is a shared responsibility that includes certification, operation, regulation, licensing, and funding spread among the states, CMS, and nursing homes. CMS sets and oversees minimum health and safety requirements that nursing homes must meet to participate in the Medicare and Medicaid programs, including requirements for infection control and prevention. SSAs, under agreements with the Secretary, conduct surveys to observe and certify a facility's compliance with these requirements. Additionally, under state laws and authorities, States license nursing homes to operate, enforce life safety codes, and can establish additional requirements for facilities that exceed federal participation requirements. States also oversee other types of facilities for which CMS does not have oversight authority, such as assisted living facilities.

It is important to recognize the resource constraints CMS and states face, which hinder efforts to strengthen enforcement against health care facilities. Complaint-based surveys have increased by 20 percent since 2013, but the survey and certification budget has remained flat since 2015 with the exception of a pandemic-related, one-time addition of funds in the Coronavirus Aid, Relief and Economic Security (CARES) Act. The President's FY 2020 Budget requested \$442 million for survey and certification, a \$45 million increase from the previous year. Increased funding would enable CMS to continue to meet statutory survey requirements while dealing with the increase in volume and severity of complaints and rising survey costs. Through the President's Budget, CMS has asked Congress to provide the Agency with statutory authority to adjust the frequency of mandatory nursing home surveys so that more time and resources can be focused on nursing homes with records of poor performance while continuing efforts to respond to complaints.

In response to the COVID-19 PHE, CMS has issued several blanket waivers to address barriers that healthcare providers might otherwise face when trying to provide adequate care during an emergency.⁶ In your letter, you ask what the rationale was for suspending reporting requirements for the Minimum Data (MDS) set during the COVID-19 PHE. We note that CMS did not suspend reporting requirements. Rather, we waived the timeframes for submitting resident assessment information through the MDS, and nursing homes have still been submitting the required data. Since nursing homes have continued to submit MDS data, the data can be used to update quality measures without any issues. As a result, the quality measures posted on the Nursing Home Compare website and used in the Five Star Quality Rating System will also be updated on January 27, 2021.⁷ This action will not only inform residents and families of the current status of residents in nursing homes, but will also incentivize nursing homes to improve performance.

⁶ Available at: <https://www.cms.gov/files/document/summary-covid-19-emergency-declaration-waivers.pdf>

⁷ Available at: <https://www.cms.gov/files/document/qso-21-06-nh.pdf>

CMS also recognizes that addressing chronic understaffing at nursing homes, while simultaneously ensuring that the workforce is adequately trained is paramount to alleviate the burden placed on these facilities during the COVID-19 pandemic. One example of the flexibilities CMS has allowed is the waiver of the requirement that a nursing home not employ anyone for longer than four months unless they have met certain training and certification requirements. While CMS waived part of the training requirements, we did not waive the regulation that requires facilities to ensure that nurse aides are able to demonstrate competency in skills and techniques necessary to care for residents' needs. As we have seen nursing homes lag behind the rest of the healthcare sector in recovering jobs lost early in the pandemic, waivers like this can assist in potential staffing shortages during the PHE, while still ensuring the staff have the requisite skills to care for residents. These blanket waivers are only in effect through the end of the emergency declaration.

Your letter asks what CMS is doing to ensure that prescribing of psychotropic drugs during the pandemic is appropriate. Caring for residents living with dementia has become more challenging during the COVID-19 PHE as nursing homes try to prevent the spread of COVID-19 among their residents and staff. Residents living with dementia may find new practices related to COVID-19 confusing or even frightening. While infection control practices such as transmission-based precautions and cohorting may be distressing for residents, these practices are necessary to prevent transmission of this life-threatening virus. Facility staff can generally explain the new practices such as wearing masks or face coverings and social distancing to residents without cognitive impairment. However, residents living with dementia may have difficulty understanding these changes. This means that facilities will need to take the time to explain the new practices to resident families and resident representatives, as well as take extra time to work with residents living with dementia.

Despite these challenges, facilities are expected to comply with the requirements related to physical and chemical restraints while adhering to infection control standards and practice. We recognize that adhering to infection control practices and current guidance during this public health emergency may cause feelings of anxiety, distress, isolation, and depression among residents. When performing procedures, which may cause indications of distress, ensure that staff are compliant with the resident's right to be free from physical and chemical restraints. For example, facilities should not initiate a chemical restraint to sedate the resident and keep him or her from walking into another resident's room or getting too close to other residents.

CMS expects facilities to continue to implement gradual dose reductions and non-pharmacological interventions, unless contraindicated, prior to initiating or instead of continuing psychotropic medications. We want to ensure that even during a time of crisis appropriate person-centered resident care continues for each resident and that the risk of adverse consequences related to medication use is minimized.

Additionally, as part of all medication management, especially with the use of psychotropic medications, it is especially important for an interdisciplinary team to implement non-pharmacological approaches designed to meet the individual need of each resident.

Educating facility staff and providers about the importance of implementing individualized, non-pharmacological approaches to care prior to the use of medications may minimize the need for medications or reduce the dose and duration of these medications.

Deficient practices related to the prescribing of psychotropic drugs are identified by surveyors through the Long-Term Care Survey Process (LTCSP). As mentioned previously, CMS directed SSAs to resume routine surveys back in August, or as soon as they have the resources to do so. Surveyors investigate for compliance with federal regulations at 42 CFR §483.45(e), F758, psychotropic drugs, and review whether the resident is receiving any medications without an indication for use, in excessive dose or duration, with inadequate monitoring, or in the presence of any adverse consequences. Additionally, specific to psychotropic drugs, surveyors determine compliance with gradual dose reductions, the use of behavioral interventions, and the prescription of PRN (as needed) psychotropics. The LTCSP also proactively guides surveyors to more specifically audit the MDS assessments for accuracy (42 CFR §483.20(g), F641). For example, when they see an outcome, such as an adverse event, or other issues, with a resident, our pathways guide the surveyor to verify that it is also captured in their MDS as being appropriate.

CMS hosted a Medicare Learning Network event on September 22, 2020, to discuss these challenges, the call transcript and slides are available on the CMS.gov website.⁸ CMS also posts quality measures showing the percent of long-stay and short-stay residents that received an antipsychotic medication on the CMS Care Compare website; this information is available for download on the data.cms.gov website.⁹ CMS plans to post new rates of antipsychotic usage per facility in the next few weeks. These will include rates through calendar quarter 2, 2020.

In your letter, you also ask a series of questions regarding CMS guidance on visitation during the COVID-19 PHE. While CMS guidance has focused on protecting nursing home residents from COVID-19, CMS recognizes that physical separation from family and other loved ones has taken a significant toll on nursing home residents. In light of these concerns, CMS issued revised visitation guidance on September 17, 2020, that described ways in which nursing homes can safely facilitate in-person visitation during the PHE in a safe manner.¹⁰ This includes both indoor and outdoor settings and in compassionate care situations. The guidance also outlines certain core principles and best practices to reduce the risk of COVID-19 transmission to adhere to during visitations.

We believe the guidance detailed in the revised visitation memo describes reasonable ways a nursing home can facilitate in person visitation. Except for on-going use of virtual visits, facilities may still restrict visitation due to the COVID-19 county positivity rate, the facility's COVID-19 status, a resident's COVID-19 status, visitor symptoms, lack of adherence to proper infection control practices, or other relevant factor related to the COVID-19 PHE.

However, facilities may not restrict visitation without a reasonable clinical or safety cause, consistent with §483.10(f)(4)(v).

⁸ Available at: <https://www.cms.gov/files/document/2020-09-22-dementia-care-transcript.pdf>

⁹ Available at: <https://data.cms.gov/provider-data/dataset/djen-97ju>

¹⁰ Available at: <https://www.cms.gov/files/document/qso-20-39-nh.pdf>

For example, if a facility has had no COVID-19 cases in the last 14 days and its county positivity rate is low or medium, a nursing home must facilitate in-person visitation consistent with the regulations, which can be done by applying the guidance stated above. Failure to facilitate visitation, without adequate reason related to clinical necessity or resident safety, would constitute a potential violation of 42 CFR 483.10(f)(4), and the facility would be subject to citation and enforcement actions.

That being said, CMS has taken a collaborative approach to understanding the unique challenges that individual states may have in relation to visitation. CMS has engaged with various states to address their questions or concerns with implementing and complying with our visitation guidance. On these calls, CMS has noted that if facilities were to follow a state's guidance that is at odds with CMS guidance and there is an increase in COVID-19 transmission within a nursing home, surveyors would be compelled to conduct surveys and appropriately cite any noncompliance with infection prevention and control protocols that may have occurred. CMS will continue to work with states to help navigate the best way to facilitate visitation while also protecting residents, families, and staff from COVID-19. Separate from calls with individual states, throughout the PHE, CMS has also facilitated regular calls with nursing home associations, providers, and other stakeholder groups to answer questions and ensure that our guidance and other policies are clearly communicated.

CMS has also made Civil Monetary Penalty (CMP) funds available to assist nursing homes with facilitating virtual visitation through the purchasing of communicative technology.¹¹ We also provided funding to facilitate more in-person visits through the use of physical barriers or outdoor structures.¹² To date, 11,034 facilities received CMP funds to facilitate virtual and in-person visitations. CMS has applied a limit on the use of the CMP funds per facility and has a mechanism in place to track the number of facilities along with the amount of funds spent per facility. CMS also monitors the spending of these funds on an ongoing basis as states provide information on approvals. Additionally, CMS requires an end of calendar year report of funds spent on CMP projects for each state. CMS publishes information about CMP funded projects annually,¹³ and information on 2020 funded projects will be available on the CMS website in early 2021.

In your letter, you ask if CMS is tracking how many facilities are allowing for visitation, and information on the frequency and duration of those visits. This type of information not available, but CMS expects facilities to follow our guidance and requirements when it comes to conducting visitation in long-term care facilities during the COVID-19 PHE.

¹¹ Available at: <https://www.cms.gov/files/document/covid-visitation-nursing-home-residents.pdf>

¹² Available at: <https://www.cms.gov/files/document/qso-20-39-nh.pdf>

¹³ Available at: <https://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/SurveyCertificationGenInfo/LTC-CMP-Reinvestment>

The memo also provides information on regulations, which surveyors may need to investigate in relation to visitation:

Survey Considerations

- *For concerns related to resident communication with and access to persons and services inside and outside the facility, surveyors should investigate for non-compliance at 42 CFR 483.10(b), F550.*
- *For concerns related to a facility limiting visitors without a reasonable clinical and safety cause, surveyors should investigate for non-compliance at 42 CFR 483.10(f)(4), F563.*
- *For concerns related to ombudsman access to the resident and the resident's medical record, surveyors should investigate for non-compliance at 42 CFR 483.10(f)(4)(i)(C), F562 and 483.10(h)(3)(ii), F583.*
- *For concerns related to lack of adherence to infection control practices, surveyors should investigate for non-compliance at 42 CFR 483.80(a), F880.*

You also asked if CMS is tracking the number of citations related to COVID-19 visitation. To view citations for violations with federal requirements, including visitation (F-tag 550), please visit CMS' Quality, Certification and Oversight Reports website¹⁴. Note, because the regulations and - tags can be broad, the citation alone does not mean there was a citation related to COVID-19 visitation. The write-up of the citation would explain the details of the cited non-compliance.

CMS has also reminded facilities and families to leverage the Long-Term Care Ombudsman Program to help families stay connected with their loved ones and also alert them to any potential resident rights violations.¹⁵

In addition to working with states and long-term care facilities to assist with safe visitation strategies during the PHE, CMS has also taken proactive steps to enhance infection control policies, including practices that limit potential transmission, and prevent outbreaks within these facilities to protect residents. Nursing homes are currently required to establish and maintain an infection prevention and control program designed to provide a safe, sanitary, and comfortable environment and to help prevent the development and transmission of communicable diseases and infections. This includes a system of surveillance designed to identify possible communicable diseases or infections before they can spread to other persons in the facility. Further, nursing homes are required to know when and to whom possible incidents of communicable disease or infections should be reported.¹⁶

Beginning in April 2020, CMS announced a new requirement for facilities to report data to the CDC about COVID-19 cases, deaths, and supply levels, among other things.¹⁷ As of mid-September, 99.3 percent of facilities are currently submitting these reports.

¹⁴ S&C's Quality, Certification and Oversight Reports website: <https://qcor.cms.gov/main.jsp>

¹⁵ Available at: <https://www.cms.gov/files/document/covid-visitation-nursing-home-residents.pdf>

¹⁶ Available at: <https://www.cms.gov/files/document/qso-20-26-nh.pdf>

¹⁷ <https://www.cms.gov/files/document/covid-ifc-3-8-25-20.pdf>

This data is used as a coordinated effort between CMS and CDC to provide detailed information to state and local health departments, and nursing homes to inform national infection prevention and control policies and strategies to further support nursing home residents.

CMS shares data with the SSAs so they know which nursing homes may have potential problems with preventing or controlling the spread of COVID-19 cases in order to target their surveys appropriately. The findings from these surveys are available on the CMS Care Compare website.

On August 25, 2020, CMS published an interim final rule with comment period, establishing long-term care facility testing requirements for staff and residents. Specifically, this rule required facilities to begin testing residents and staff for COVID-19 based on parameters set forth by the Secretary of Health and Human Services.¹⁸ Following this announcement, CMS released a memorandum on August 26, 2020, that provided guidance for facilities to meet the new testing and reporting requirements.¹⁹

CMS is currently working through operational challenges that facilities may have with meeting these testing requirements through phone outreach to individual facilities and by holding regular calls with the Nursing Home associations. CMS is aware that some states continue to face challenges of testing supply shortages or limited access or inability of laboratories to turn around tests in 48 hours. However, we do expect facilities to take actions to mitigate any resource shortages and show they are taking all appropriate steps to obtain the necessary supplies as soon as possible. In such instances, as discussed in the August 26, 2020, guidance, the facility should document their efforts to obtain timely test results with the identified laboratory or laboratories and their contact with state and local health departments.

The focused infection control survey tool, described earlier in this letter, also includes an assessment of whether a facility has adequate supplies of Personal Protective Equipment (PPE). CMS has worked with the CDC to communicate with nursing homes about what they should do in the event they experience shortages of PPE. This included an April 2, 2020, call to action that urged state and local leaders to work with nursing homes to determine and help address their needs for PPE.²⁰ To further assist with this effort, in an April 24 memorandum, CMS published facility-reported information that shows the average number of staff a facility has onsite each day that states could use to target PPE supplies.²¹ CMS provided this data to states and to Federal Emergency Management Agency to aid in their efforts to target and prioritize shipments of PPE supplies.

CMS has also released guidance regarding proper use of PPE based on CDC recommendations and provided training to nursing home staff on PPE; however, addressing issues of allocation of PPE and staffing is outside of CMS's authority, as these are largely state prioritization decisions, in some cases with assistance from other Federal agencies. CMS has taken efforts to support states where feasible. For example, CMS sent a letter to governors in May 2020 encouraging them to allocate PPE resources to state surveyors.

¹⁸ Available at: <https://www.cms.gov/files/document/covid-ifc-3-8-25-20.pdf>

¹⁹ Available at: <https://www.cms.gov/files/document/qso-20-38-nh.pdf>

²⁰ Available at: <https://www.cms.gov/files/document/4220-covid-19-long-term-care-facility-guidance.pdf>

²¹ Available at: <https://www.cms.gov/files/document/qso-20-28-nh.pdf>

In addition, in some cases when states were unable to secure PPE, CMS stepped in to conduct surveys, surveying hundreds of facilities in the early months of the public health emergency.

CMS compiled best practices in infection control in skilled nursing facilities and is currently sharing these strategies with the nursing home community. On May 13, CMS released a new toolkit developed to aid nursing homes, governors, states, departments of health, and other agencies who provide oversight and assistance to these facilities, with additional resources to aid in the fight against the COVID-19 pandemic within nursing homes. These best practices include solutions on actions to improve access to PPE and actions to improve utilization of PPE. This toolkit is being updated regularly (most recently in November).²²

The CARES Act allocated \$100 million in supplemental funds for survey and certification efforts with a focus on areas where there is community spread of 2019 COVID-19. Of this amount, CMS is providing states approximately \$81 million which will be available for spending through September 30, 2023. With this funding, states will be able to purchase additional PPE (for example, N-95 facemasks, surgical gowns, goggles, gloves, and thermometers) for surveyors to ensure worker safety and hire or contract for additional staff.

On December 11, 2020, the Food and Drug Administration issued an Emergency Use Authorization to Pfizer for its COVID-19 vaccine, the first authorization for a COVID-19 vaccine in the United States. CMS will continue to work with the Department of Health and Human Services to ensure rapid distribution of the COVID-19 vaccine. However, our primary involvement is related to reimbursement for the vaccine. CMS released a set of toolkits for providers, states and issuers to help the health care system prepare to swiftly administer the vaccine. These resources apply to all vaccine administrators, including CVS and Walgreens, and are designed to increase the number of providers that can administer the vaccine and ensure adequate reimbursement for administering the vaccine in Medicare. This toolkit includes the following information and can be found at <https://www.cms.gov/covidvax-provider>:

- How health care providers can enroll in Medicare to bill for administering COVID-19 vaccines when available
- The COVID-19 Vaccine Medicare coding structure
- The Medicare reimbursement strategy for COVID-19 vaccine administration
- How health care providers can bill correctly for administering vaccines, including roster and centralized billing

CMS also distributed material developed by the CDC to nursing homes related to the CVS and Walgreens program, and provided an opportunity for CDC to describe the program on our bi-weekly Nursing Home Stakeholder calls.

²² Available at: <https://www.cms.gov/files/document/covid-toolkit-states-mitigate-covid-19-nursing-homes.pdf>

We appreciate the work that your organization does to draw attention to these important issues. CMS will continue to hold nursing homes accountable and work with our state and local partners to protect nursing home residents from the ongoing threat of COVID-19.

Sincerely,

A handwritten signature in black ink, appearing to read "Lee A. Fleisher". The signature is fluid and cursive, with a large, stylized "L" and "F".

Lee A. Fleisher, MD
Chief Medical Officer and Director
Center for Clinical Standards and Quality
Centers for Medicare & Medicaid Services