



Human Rights Watch Submission to the United States House of Representatives Ways and Means Committee Hearing on Caring for Aging Americans, November 14, 2019

In the United States, Human Rights Watch has documented widespread inappropriate use of antipsychotic drugs given to older people in nursing facilities, often without informed consent, which arises from inadequate enforcement of existing laws and regulations. We have also expressed serious concerns about recent US government removal of prohibitions meant to protect access to courts for nursing home residents.

Human Rights Watch's 2018 report, "[*They Want Docile: How Nursing Homes in the United States Overmedicate People with Dementia*](#)", is based on visits to 109 nursing facilities, mostly with above-average rates of antipsychotic medication use, in six states.¹ The report documented that every week, more than 179,000 people in nursing homes in the US are given antipsychotic drugs even though they have not been diagnosed with any condition for which their use is approved. Often, facilities administer the drugs without making any effort to seek informed consent. Many nursing homes use these drugs not to treat a specific medical condition—such as psychosis or a neurological disorder—but because of their sedative effect. Antipsychotic drugs make nursing home residents easier to control by pacifying and sedating them.

While symptoms of dementia can be distressing for the people who experience them, their families, and nursing facility staff, evidence of the benefits of treating these symptoms with antipsychotic drugs is weak.² More importantly, studies find that on average, antipsychotic drugs increase the risk of stroke, falls, pneumonia and death in older people with dementia.³

In 2012, the government regulator for nursing facilities in the US, the Centers for Medicare and Medicaid Services (CMS), created an initiative in recognition of the unacceptably high prevalence of antipsychotic drug use.⁴ While the initiative may have contributed to reductions in the use of antipsychotic medications, many nursing home residents are still routinely given these drugs. Effective regulation and oversight of nursing homes, including meaningful sanctions for noncompliance with mandatory standards, is essential.

Our research found several significant shortcomings in enforcement of federal regulations to protect nursing home residents, from the underestimation of harm cited to the inadequate deterrent effect of

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>.

² *Ibid.*, p. 1.

³ Martin Steinberg and Constantine G. Lyketsos, "Atypical Antipsychotic Use in Patients with Dementia: Managing Safety Concerns," *American Journal of Psychiatry*, vol. 169(9) (2012), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3516138/pdf/nihms421959.pdf> (accessed October 10, 2017); American Psychiatric Association (APA), *The American Psychiatric Association Practice Guideline on the Use of Antipsychotics to Treat Agitation or Psychosis in Patients with Dementia*, (Arlington, Virginia: APA, 2016), <http://psychiatryonline.org/doi/pdf/10.1176/appi.books.9780890426807> (accessed September 8, 2017).

⁴ "National Partnership to Improve Dementia Care in Nursing Homes," Centers for Medicare and Medicaid Services (CMS), last updated July 27, 2017, <https://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/SurveyCertificationGenInfo/National-Partnership-to-Improve-Dementia-Care-in-Nursing-Homes.html>.

finances around these drugs' use.⁵ We found that penalties for noncompliance were often limited to monetary fines that may not be significant enough to deter malfeasance. Our quantitative analysis of fines assessed in all states between 2014 and 2016 found that 80 percent were less than \$10,000 and 20 percent between \$10,000 and \$100,000.

Human Rights Watch also has serious concerns about the CMS regulation removing prohibitions on limitations for access to justice through courts of law for individuals alleging harm in nursing facilities.

In 2016, CMS had banned the use of pre-dispute arbitration clauses, describing them as “fundamentally unfair” because “it is almost impossible for residents or their decision-makers to give fully informed and voluntary consent to arbitration before a dispute has arisen.”⁶ It concluded that “residents should have a right to access the court system if a dispute with a facility arises.”⁷

CMS noted “there is significant evidence that pre-dispute arbitration agreements have a deleterious impact on the quality of care for Medicare and Medicaid patients” in nursing facilities.⁸ It also emphasized that while arbitration proceedings are widespread in health care, the “significant differential in bargaining power” between residents and nursing facilities—the former depends on the latter for almost all their needs—make it “unconscionable” for such facilities to demand, as an admission condition, that residents sign a pre-dispute agreement for binding arbitration.⁹

However, in 2017, CMS did a complete about-face and issued a new proposed rule that not only would eliminate the 2016 rule's provisions prohibiting pre-dispute arbitration, but would allow facilities to deny admission to a resident who refuses to sign the arbitration agreement.¹⁰ In 2019, CMS finalized this rule and put it into effect, replacing the 2016 regulation protecting residents' right to access courts in the event of abuse or mistreatment in a nursing home, with a rule removing prohibitions on pre-dispute arbitration.¹¹ Under the new rule, nursing homes can add pre-dispute arbitration clauses to their contracts for new residents to forgo the option of filing a case in court.¹²

With this new rule, residents who accept these new conditions will only have access to an arbitration proceeding, despite serious concerns about whether arbitration offers a fair and impartial hearing and a realistic chance at a remedy.

⁵ The most recent Office of Inspector General analysis is from 2005, but it found that less than half of the civil money penalties imposed at that time were paid and that 70 percent of penalties received a reduction. Office of Inspector General, “Nursing Home Enforcement: The Use of Civil Money Penalties,” April 2005, <https://oig.hhs.gov/oei/reports/oei-06-02-00720.pdf>. A facility automatically obtains a 35 percent reduction in the civil money penalty imposed if it waives its right to a hearing. The opportunities to challenge a citation and its attached penalty are numerous as well. Centers for Medicare and Medicaid Services (CMS), “Mandatory Immediate Imposition of Federal Remedies and Assessment Factors Used to Determine the Seriousness of Deficiencies for Nursing Homes,” July 29, 2016, <https://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/SurveyCertificationGenInfo/Downloads/Survey-and-Cert-Letter-16-31.pdf>.

⁶ “Section 483.70(n), Binding Arbitration Agreements,” in CMS, “Medicare and Medicaid Programs; Reform of Requirements for Long-Term Care Facilities,” *Federal Register*, Vol. 81, No. 192, October 4, 2016, <https://www.gpo.gov/fdsys/pkg/FR-2016-10-04/pdf/2016-23503.pdf>, p. 68792.

⁷ *Ibid.*

⁸ *Ibid.*, p. 68791.

⁹ *Ibid.*, p. 68792.

¹⁰ CMS, “Medicare and Medicaid Programs; Reform of Requirements for Long-Term Care Facilities: Arbitration Agreements,” *Federal Register*, vol. 82(109) (2017), <https://www.gpo.gov/fdsys/pkg/FR-2017-06-08/pdf/2017-11883.pdf> (accessed September 10, 2017).

¹¹ “Medicare and Medicaid Programs; Revision of Requirements for Long-Term Care Facilities: Arbitration Agreements” *Federal Register*, (84 FR 34718), 2019, <https://www.federalregister.gov/documents/2019/07/18/2019-14945/medicare-and-medicaid-programs-revision-of-requirements-for-long-term-care-facilities-arbitration>.

¹² *Ibid.*

Limiting the right of nursing home residents to an effective remedy for alleged abuses introduces the possibility that they can be barred from bringing lawsuits for such abuse. Systemic problems or repeated offenses will go undetected.

Without access to the courts, the potential for harm for hundreds of thousands of older people living in nursing facilities across the US is clear. A resident signing away their right to sue not only hurts individuals, it also forecloses the courts' ability to improve the system for everyone.