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1. **Living Independently in the Community:**

In 2018, Human Rights Watch documented that older people in England are at risk of not getting adequate assistance to live independent, dignified lives due to uneven assessments for social services. This in turn interferes with their right to live independently in the community under the United Nations Convention on the Rights of Persons with Disabilities (CRPD) to which the United Kingdom is party.

For the report, “[Unmet Needs: Improper Social Care Assessments for Older People in England](https://www.hrw.org/sites/default/files/report_pdf/uk0119_web3.pdf),” Human Rights Watch spoke with older people and their relatives in 12 cities and towns across England. Some said that officials responsible for carryout out needs assessments to allocate social care appeared not to understand their disabilities and support needs. In other cases we documented, , older people said that officials announced before beginning an assessment that services would be cut regardless of an individual’s actual need. And in some cases, services were denied or cut significantly, affecting older people’s health and wellbeing.

Day-to-day responsibility for providing social care services in England rests primarily with local authorities, which are under severe financial constraints. Since social care assessments determine the level of support that older people receive, they can have a significant impact on older people’s rights to health and living independently. But our research found that no central government agency in the UK monitors the assessments. Similar concerns were also noted in the UN Committee on the Rights of Persons with Disabilities’ October 2017 review of the UK.[[1]](#footnote-1)

Human Rights Watch recommends that the UK government ensure that older people have access to the services they need to realize their rights to live independently in their communities with their rights to health and private and family life protected; and establish a mechanism to monitor and evaluate social care needs assessments and the staff who conduct them to ensure consistency and equality nationally.

1. **Freedom from Chemical Restraints:**

In the United States, in 2018, Human Rights Watch documented widespread inappropriate use of antipsychotic drugs in older people in nursing facilities, often without informed consent, both of which arise primarily from inadequate enforcement of existing laws and regulations. The report is: “[They Want Docile](https://www.hrw.org/report/2018/02/05/they-want-docile/how-nursing-homes-united-states-overmedicate-people-dementia): How Nursing Homes in the United States Overmedicate People with Dementia.”

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 because of their sedative effect. Antipsychotic drugs make nursing home residents easier to control by pacifying and sedating them.

Medical studies find that on average, antipsychotic drugs almost double the risk of death in older people with dementia.[[2]](#footnote-2)

In 2013, Juan Mendez, then the UN special rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, stated that the use of a “prolonged restraint” may constitute torture and ill-treatment; when used against people with mental disabilities, “even a short period of time may constitute torture and ill-treatment.”[[3]](#footnote-3)

Our research found several significant shortcomings in enforcement of federal regulations to protect nursing home residents, from the underestimation of harm of violations in citations by regulators to the inadequate deterrent effect of fines around these drugs’ use.[[4]](#footnote-4) We found that penalties for noncompliance were often limited to monetary fines that may not be significant enough to deter malfeasance.

1. **Access to Justice for Long-Term Care Users:**

There are also concerns about access to justice through courts of law for individuals harmed in nursing facilities: “[They Want Docile](https://www.hrw.org/report/2018/02/05/they-want-docile/how-nursing-homes-united-states-overmedicate-people-dementia): How Nursing Homes in the United States Overmedicate People with Dementia” also documented how in 2016, the US’ regulatory agency, the Centers for Medicare and Medicaid Services (CMS), banned the use of pre-dispute arbitration agreements between nursing homes and residents, 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.”[[5]](#footnote-5) It concluded that “residents should have a right to access the court system if a dispute with a facility arises.”[[6]](#footnote-6)

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.[[7]](#footnote-7) It also emphasized the “significant differential in bargaining power” between residents and nursing facilities—the former depends on the latter for almost all their needs—makes it “unconscionable” for such facilities to demand, as an admission condition, that residents sign a pre-dispute agreement for binding arbitration.

However, in June 2017, the government did a complete about-face, issuing a new proposed rule that eliminates provisions prohibiting pre-dispute arbitration and allows facilities to deny admission to a resident who refuses to sign the arbitration agreement.[[8]](#footnote-8)

1. Concluding Observations on the initial report of the United Kingdom of Great Britain and Northern Ireland to the United Nations Committee on the Rights of Persons With Disabilities, October 3, 2017, para 44, <http://docstore.ohchr.org/SelfServices/FilesHandler.ashx?enc=6QkG1d%2fPPRiCAqhKb7yhspCUnZhK1jU66fLQJyHIkqMIT3RDaLiqzhH8tVNxhro6S657eVNwuqlzu0xvsQUehREyYEQD%2bldQaLP31QDpRclCKZKktydtAkeqhq77NLo1>. [↑](#footnote-ref-1)
2. See, e.g., LS Schneider et al., “Effectiveness of Atypical Antipsychotic Drugs in Patients with Alzheimer’s Disease,” New England Journal of Medicine, vol. 355(15) (2006), https://www.ncbi.nlm.nih.gov/pubmed/17035647 (accessed September 8, 2017); Philip S. Wang et al., “Risk of Death in Elderly Users of Conventional vs. Atypical Antipsychotic Medications,” New England Journal of Medicine, vol. 353 (2005), http://www.nejm.org/doi/full/10.1056/NEJMoa052827#t=article (accessed September 8, 2017); “Public Health Advisory: Deaths with Antipsychotics in Elderly Patients with Behavioral Disturbances,” US Food and Drug Administration, April 11, 2005, https://www.fda.gov/Drugs/DrugSafety/PostmarketDrugSafetyInformationforPatientsandProviders/ucm053171.htm (accessed September 8, 2017); Office of Inspector General, “Medicare Atypical Antipsychotic Drug Claims for Elderly Nursing Home Residents,” https://oig.hhs.gov/oei/reports/oei-07-08-00150.pdf p. 3; “Information for Healthcare Professionals: Conventional Antipsychotics,” U.S. Food and Drug Administration, June 16, 2008, https://www.fda.gov/Drugs/DrugSafety/PostmarketDrugSafetyInformationforPatientsandProviders/ucm124830.htm (accessed September 8, 2017). [↑](#footnote-ref-2)
3. Human Rights Council, Report of the special rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, Juan E. Méndez, A/HRC/22/53, February 1, 2013, <http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53_English.pdf> para 32. [↑](#footnote-ref-3)
4. The most recent Office of Inspector General analysis is from many years ago, but it found that less than half of the civil money penalties imposed at that time were paid and that seventy 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. Facilities automatically obtain 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. 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. [↑](#footnote-ref-4)
5. Ibid., p. 68792. [↑](#footnote-ref-5)
6. Ibid. [list from p. 68793]. See also, Tripp, Lisa, ‘‘A Senior Moment: The Executive Branch Solution to the Problem of Binding Arbitration Agreements in LTC facilities Admission Contracts’’, *Campbell Law Review Symposium*, vol. 31(2) (2009); Tripp, Lisa, ‘‘Arbitration Agreements Used by LTC facilities: An Empirical Study and Critique of AT&T Mobility v. Concepcion’’, *American Journal of Trial Advocacy*, vol. 35(87) (2011); and Bagby, K. and Souza, S., ‘‘Ending Unfair Arbitration: Fighting Against the Enforcement of Arbitration Agreements in Long-Term Care Contracts’’, *Journal of Contemporary Health Law & Policy*, vol. 29 (2013). [↑](#footnote-ref-6)
7. Ibid. [↑](#footnote-ref-7)
8. 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). [↑](#footnote-ref-8)