**Questionnaire on the rights of older persons with disabilities (English)**

The following answers are taken from a February, 2018, Human Rights Watch report, “’They Want Docile:’ How Nursing Homes in the United States Overmedicate People with Dementia,” available at: <https://www.hrw.org/report/2018/02/05/they-want-docile/how-nursing-homes-united-states-overmedicate-people-dementia>

This report finds that in an average week, nursing facilities in the United States administer antipsychotic drugs to over 179,000 people who do not have diagnoses for which the drugs are approved. The drugs are often given without free and informed consent, which requires a decision based on a discussion of the purpose, risks, benefits, and alternatives to the medical intervention as well as the absence of pressure or coercion in making the decision. Most of these individuals—like most people in nursing homes—have Alzheimer’s disease or another form of dementia. Facilities often use these drugs to control symptoms of these conditions. The US Food and Drug Administration (FDA) never approved them for this use and has issued its strongest warning against use for these symptoms. Studies find that on average, antipsychotic drugs almost double the risk of death in older people with dementia. When the drugs are administered without informed consent, people are not making the choice to take such a risk.

The inappropriate use of antipsychotic drugs on people with dementia in nursing facilities raises two principal human rights concerns. First, antipsychotic drugs are often administered without a medical purpose—as a last resort to treat psychosis in dementia, although they have not been found to be effective to this end—and for the convenience of facility staff. Such medically unnecessary use of medication may amount to torture or ill-treatment under international law. It may also amount to a prohibited “unnecessary drug” or a chemical restraint—a form of abuse—under US law. Second, these medications are frequently administered without free and informed consent. This practice constitutes forced medication under international law.

Our answers in this questionnaire pertain solely to our findings in this report, in the specific context of nursing facilities in the US.

***Please provide information on the legislative and policy framework in place in your country to ensure the realization of the rights of older persons with disabilities, including both persons with disabilities who are ageing and older persons who acquire a disability.***

US federal and state laws protect against abuse and neglect in skilled nursing facilities, primarily through the Nursing Home Reform Act of 1987 and associated regulations.

Based on the admission criteria for skilled nursing facilities and nursing facilities, almost all nursing facility residents are protected by the Americans with Disabilities Act (ADA) of 1990.[[1]](#footnote-1)

The US Attorney General has jurisdiction to enforce the ADA: to prosecute the violation of the rights of people with disabilities articulated under it. However, it does not have exclusive jurisdiction; private individuals may sue as well. Anyone who has been “subjected to discrimination on the basis of disability … may institute a civil action for preventive relief, including an application for a permanent or temporary injunction, restraining order, or other order.”[[2]](#footnote-2)

US regulations establish that antipsychotic drugs cannot be administered to nursing facility residents without a medical need based on a comprehensive assessment conducted by the nursing facility.[[3]](#footnote-3) However, Human Rights Watch found in some facilities, medical need is often not the primary reason antipsychotic drugs are prescribed and comprehensive assessments are not routinely conducted to determine whether a medical basis exists.

***Please provide information and statistical data (including surveys, censuses, administrative data, literature, reports, and studies) related to the realization of the rights of older persons with disabilities in general, as well as with particular focus in the following areas:***

* ***Exercise of legal capacity;***

The Nursing Home Reform Act governing nursing facilities certified by Medicare and Medicaid does not require nursing facilities to obtain free and informed consent, written or otherwise, from any residents prior to administering antipsychotic or other psychotropic medications. It does provide for the right to be fully informed of one’s health status; the right to participate in treatment planning; the “right to be informed in advance, by the physician or other practitioner or professional, of the risks and benefits of proposed care, of treatment and treatment alternatives or treatment options and to choose the alternative or option he or she prefers”; and the right to refuse treatment.[[4]](#footnote-4)

Many people in nursing facilities do not make their own decisions about their treatment. In some cases, people are formally stripped of legal capacity through legal processes that vary from state to state, but result in another person being given authority to make decisions instead of the individual.[[5]](#footnote-5) Under US regulations, the rights to be fully informed in advance about treatment and to refuse treatment apply only to residents that have not been formally “adjudged incompetent,” or stripped of their legal capacity, and who do not have a surrogate authorized to stand in on these subjects.[[6]](#footnote-6)

More commonly, doctors either informally determine that people are not competent to make decisions about their care, or doctors and staff discuss care issue with relatives or health proxies by default, regardless of the resident’s cognitive abilities and the scope and activation of the proxy. The formal loss of legal capacity and excessive or premature use of proxies can completely exclude people from decisions.

* ***Older persons with disabilities living in institutions;***

Nursing facilities in the US use antipsychotic medications on a massive scale. According to CMS reports in 2017, every week, facilities administer antipsychotic drugs to over 179,000 long-stay residents (residing in the facility for more than 100 days) who do not have an exclusionary diagnosis—of schizophrenia, Huntington’s disease, or Tourette syndrome, psychiatric and neurological diseases for which the drugs are approved—and most of whom have dementia.[[7]](#footnote-7) At the end of 2016, CMS’s official measure was that 16 percent of long-stay nursing home residents were receiving an antipsychotic medication without one of these three exclusionary diagnoses.[[8]](#footnote-8)

Human Rights Watch research on older people’s experiences in six states in 2016 and 2017, for the report, “They Want Docile,” found that antipsychotic medications not only have adverse medical consequences, but also have social and emotional effects on nursing facility residents and their families. To capture these consequences of forced and inappropriate antipsychotic drug administration, Human Rights Watch interviewed people living in nursing facilities who had dementia and were currently on antipsychotic medications or had been on them previously, as well as their family members. We spoke with 74 residents and 36 family members in all six states. Residents described the trauma of losing their ability to communicate, to think, and to remain awake.

Such medically unnecessary use of medication may amount to torture or ill-treatment under international law. It may also amount to a prohibited “unnecessary drug” or a chemical restraint—a form of abuse—under US law. When administered without free and informed consent, this practice constitutes forced medication under international law.

* ***Access to support to live independently in the community;***

In the US, of the 6 million older people receiving long-term care, about 4 million receive care from a home health agency at home.[[9]](#footnote-9) About 1.2 million people aged 65 and over lived in 15,600 nursing facilities in 2014, and almost 780,000 people lived in other residential care communities.[[10]](#footnote-10)

Medicare is the primary provider of health insurance to people aged 65 and older in the United States. Medicaid, which is the primary public health insurance program for people with low income in the US and is jointly administered by the federal government and the states, is the primary payer for long-term care, accounting for 51 percent of the nursing home industry’s expenditures.[[11]](#footnote-11) Consequently, to receive institutional long-term care outside of a nursing facility, such as in assisted living facilities and communities, requires significant private resources, estimated at over US$3,000 per month.[[12]](#footnote-12) According to CMS and Medicare Payment Advisory Committee, Medicare and Medicaid do not pay for assisted living facilities (a form of institutional long-term care regulated only at the state level that does not provide medical services or as intensive support for activities of daily living compared to those provided by nursing homes) in most cases.[[13]](#footnote-13)

In 2015, the median annual cost of living in a nursing facility was over $90,000 per year, roughly twice the cost of having a home health aide and five times the cost of an adult day health care program (almost $18,000).[[14]](#footnote-14)

***Please describe how is access to justice guaranteed for older persons with disabilities. Please provide information on jurisprudence, complaints or investigations in relation to violence, abuse and neglect against older persons with disabilities.***

In the context of nursing facilities, the Centers for Medicare and Medicaid Services (CMS) is the main US government regulatory agency. However, other government agencies have overarching enforcement authority across sectors, such as the US Department of Justice.[[250]](https://www.hrw.org/report/2018/02/05/they-want-docile/how-nursing-homes-united-states-overmedicate-people-dementia%22%20%5Cl%20%22_ftn250%22%20%5Co%20%22)

In many contexts, individuals use civil tort lawsuits to secure accountability and redress for abuses the law does not otherwise prevent or punish. Approximately half of the country’s nursing facilities ask residents (or their proxies) to sign binding arbitration agreements upon admission; some make it a condition of admission.[[15]](#footnote-15) Under these contract clauses, disputes between the facility and resident must be resolved outside of the court system. In other words, the resident “waiv[es] his or her right to judicial relief for any potential cause of action covered by the agreement.”[[16]](#footnote-16) Instead, disputes that may arise are resolved through arbitration proceedings. As is true in many other contexts, these agreements raise concerns about whether arbitration offers a fair and impartial hearing and a realistic chance at remedy.

In 2016, CMS 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.”[[17]](#footnote-17) Instead of limiting avenues for relief in cases of violations “residents should have a right to access the court system if a dispute with a facility arises.”[[18]](#footnote-18) CMS noted that “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.[[19]](#footnote-19)

In June 2017, however, CMS reversed its position, issuing a new proposed rule that not only would eliminate provisions prohibiting pre-dispute arbitration, but also would allow facilities to deny admission to a resident who refuses to sign the arbitration agreement.[[20]](#footnote-20)

Human Rights Watch research found that CMS has failed to use the tools at its disposal to ensure adequate protection for residents’ rights. Specifically:

* **Failure to adequately enforce the right to be fully informed and to refuse treatment or to require free and informed consent requirement.** The Nursing Home Reform Act of 1987 grants residents the right “to be fully informed in advance about care and treatment,” to participate in care planning, and to refuse treatment without penalty. If it were enforced fully, these protections would not differ substantially from the right to free and informed consent. However, without adequate enforcement, current practice falls far short of this protection.
* **Weak enforcement of federal regulations specifically banning chemical restraints and unnecessary drugs.** Federal regulations prohibit chemical restraints—drugs used for the convenience of staff or to discipline residents without a medical purpose—and unnecessary drugs: a technical term meaning drugs used without adequate clinical indication, monitoring, or tapering. The regulations also provide for the right to refuse treatment. However, federal and state enforcement of these regulations is so weak that the drugs are routinely misused without significant penalty. Almost all antipsychotic drug-related deficiency citations in recent years have been determined to be at the level of causing “no actual harm,” curtailing the applicability and severity of financial sanctions.
1. Americans with Disabilities Act of 1990, as Amended, US Congress, Title 42, cap. 126, https://www.ada.gov/pubs/adastatute08.htm (accessed September 10, 2017). [↑](#footnote-ref-1)
2. Private Suits, Code of Federal Regulations, Title 28, part 36, https://www.ada.gov/reachingout/t3regl9.html (accessed September 10, 2017) sec. 36.501. [↑](#footnote-ref-2)
3. CMS, “Revision to State Operations Manual (SOM) Appendix PP – Incorporate Revised Requirements of Participation for Medicare and Medicaid Certified Nursing Facilities,” <https://www.cms.gov/Regulations-and-Guidance/Guidance/Transmittals/2017Downloads/R168SOMA.pdf>, referencing 42 CFR 483.20 F272. [↑](#footnote-ref-3)
4. Resident Rights, Code of Federal Regulations, Title 42, https://www.law.cornell.edu/cfr/text/42/483.10 sec. 483.10(c). [↑](#footnote-ref-4)
5. Legal capacity is a critical element of autonomy: It is the authority to make decisions or otherwise act on one’s own behalf. Capacity is presumed in adults; it is lost as to particular subjects, such as contracting, driving a car, consenting to medical care, or signing a will, for example. Normally, outside of temporary emergencies, one or two physicians must establish that a person lacks the ability to understand, to reason, or to communicate as a basis of a capacity determination; loss of legal capacity is not based on a status, such as having dementia. Thaddeus Mason Pope, “Unbefriended and Unrepresented: Better Medical Decision Making for Incapacitated Patients Without Healthcare Surrogates,” *Georgia State University Law Review*, vol. 33(4) (2017), http://thaddeuspope.com/images/Unbefriended\_And\_Unrepresented-\_Better\_Medical\_Decision\_Making\_For\_Incapacitated\_Patients\_Without\_Healthcare\_Surrogates.pdf (accessed on September 23, 2017); Raphael J. Leo, “Competency and the Capacity to Make Treatment Decisions: A Primer for Primary Care Physicians,” *Primary Care Companion Journal of Clinical Psychiatry*, vol. 1(5) (1999), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC181079/> (accessed on September 23, 2017). See also, American Bar Association Commission on Law and Aging and American Psychological Association, “Assessment of Older Adults with Diminished Capacity: A Handbook for Psychologists,” 2008, <https://www.apa.org/pi/aging/programs/assessment/capacity-psychologist-handbook.pdf> p. 53. [↑](#footnote-ref-5)
6. Legal capacity is a critical element of autonomy: It is the authority to make decisions or otherwise act on one’s own behalf. Capacity is presumed in adults; it is lost as to particular subjects, such as contracting, driving a car, consenting to medical care, or signing a will, for example. Normally, outside of temporary emergencies, one or two physicians must establish that a person lacks the ability to understand, to reason, or to communicate as a basis of a capacity determination; loss of legal capacity is not based on a status, such as having dementia. Thaddeus Mason Pope, “Unbefriended and Unrepresented: Better Medical Decision Making for Incapacitated Patients Without Healthcare Surrogates,” *Georgia State University Law Review*, vol. 33(4) (2017), http://thaddeuspope.com/images/Unbefriended\_And\_Unrepresented-\_Better\_Medical\_Decision\_Making\_For\_Incapacitated\_Patients\_Without\_Healthcare\_Surrogates.pdf (accessed on September 23, 2017); Raphael J. Leo, “Competency and the Capacity to Make Treatment Decisions: A Primer for Primary Care Physicians,” *Primary Care Companion Journal of Clinical Psychiatry*, vol. 1(5) (1999), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC181079/> (accessed on September 23, 2017). See also, American Bar Association Commission on Law and Aging and American Psychological Association, “Assessment of Older Adults with Diminished Capacity: A Handbook for Psychologists,” 2008, <https://www.apa.org/pi/aging/programs/assessment/capacity-psychologist-handbook.pdf> p. 53. [↑](#footnote-ref-6)
7. CMS, “New Quality Measures on Nursing Home Compare,” April 27, 2016, https://www.cms.gov/Newsroom/MediaReleaseDatabase/Fact-sheets/2016-Fact-sheets-items/2016-04-27.html (accessed September 8, 2017). See also, CMS “MDS 3.0 Quality Measures User’s Manual,” effective April 1, 2017, https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/NursingHomeQualityInits/Downloads/ MDS-30-QM-Users-Manual-V11-Final.pdf (accessed September 8, 2017) p. 34. [↑](#footnote-ref-7)
8. National Partnership to Improve Dementia Care in Nursing Homes, “National Partnership to Improve Dementia Care in Nursing Homes: Antipsychotic Medication Use Data Report (March 2017),” https://www.nhqualitycampaign.org/files/AP\_package\_20170413.pdf. [↑](#footnote-ref-8)
9. Federal Interagency Forum on Aging-Related Statistics, “Older Americans: Key Indicators of Well-Being, 2016,” August 2016, https://agingstats.gov/docs/LatestReport/Older-Americans-2016-Key-Indicators-of-WellBeing.pdf (accessed September 8, 2017). [↑](#footnote-ref-9)
10. Just under 20 percent of residents are ages 65 to 74, over a quarter are ages 75 to 84, and over 30 percent are ages 85 to 95. “MDS 3.0 Frequency Report: First Quarter 2017 Report,” Centers for Medicare & Medicaid Services (CMS), https://www.cms.gov/research-statistics-data-and-systems/computer-data-and-systems/minimum-data-set-3-0-public-reports/minimum-data-set-3-0-frequency-report.html (accessed September 8, 2017); “Nursing Home Care,” Centers for Disease Control and Prevention, last modified May 3, 2017, https://www.cdc.gov/nchs/fastats/nursing-home-care.htm. [↑](#footnote-ref-10)
11. See generally, Richard J. Mollot, et al., “Informed Consent Rights in U.S. Nursing Homes: An Overview of State & Federal Requirements,” 2013, http://www.ltccc.org/publications/documents/ltccc-rpt-informed-consent-laws-sept2013\_001.pdf. [↑](#footnote-ref-11)
12. Texas Health & Safety Code, Texas State Legislature, http://www.statutes.legis.state.tx.us/Docs/HS/htm/HS.242.htm (accessed September 10, 2017) secs. 242.501(a)(23) and 242.505. [↑](#footnote-ref-12)
13. Medicare Payment Advisory Committee (MedPAC), “Skilled Nursing Facility Services,” in *Report to Congress, Medicare Payment Policy*, (Washington, DC: MedPAC, 2017), http://www.medpac.gov/docs/default-source/reports/mar17\_medpac\_ch8.pdf?sfvrsn=0 (accessed September 8, 2017); Barbara S. Klees, Christian J. Wolfe, and Catherine A. Curtis, “Brief Summaries of Medicare & Medicaid,” CMS, Office of the Actuary, November 2016, https://www.cms.gov/Research-Statistics-Data-and-Systems/Statistics-Trends-and-Reports/MedicareProgramRatesStats/Downloads/MedicareMedicaidSummaries2016.pdf (accessed September 8, 2017). [↑](#footnote-ref-13)
14. Reaves and Musumeci, “Medicaid and Long-Term Services and Supports: A Primer,” *Kaiser Family Foundation,*http://www.kff.org/medicaid/report/medicaid-and-long-term-services-and-supports-a-primer; Matthew Craft, “Cost of Long-Term Care Beyond Reach for Middle-Class Elderly,” *Press Herald*, July 21, 2015, http://www.pressherald.com/2015/07/21/cost-of-long-term-care-beyond-reach-for-middle-class-elderly/ (accessed September 8, 2017). [↑](#footnote-ref-14)
15. Stephanie Francis Ward, “Judge Blocks Federal Rule that Would Ban Arbitration in Nursing Home Disputes,” *ABA Journal*, November 7, 2016, http://www.abajournal.com/news/article/jusge\_blocks\_federal\_rule\_which\_would\_ban\_arbitration\_in\_nursing\_home\_dispu. “[Attorney Joseph L. Bianculli] estimates that 50 percent of nursing homes have pre-dispute arbitration agreements with residents.” [↑](#footnote-ref-15)
16. “Section 483.70(n), Binding Arbitration Agreements,” in CMS, “Medicare and Medicaid Programs; Reform of Requirements for Long-Term Care Facilities,” *Federal Register*, https://www.gpo.gov/fdsys/pkg/FR-2016-10-04/pdf/2016-23503.pdf p. 68790. [↑](#footnote-ref-16)
17. Ibid., p. 68792. [↑](#footnote-ref-17)
18. 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-18)
19. Ibid. [↑](#footnote-ref-19)
20. 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-20)