Human Rights Watch Statement

Australian Joint Parliamentary Committee on Human Rights

August 20, 2019 Hearing on F2019L00511, the Quality of Care Amendment (Minimising the Use of Restraints) Principles 2019

Human Rights Watch is an independent, nongovernmental, human rights organization that conducts research and advocacy in over 90 countries on a range of human rights issues, including on the <u>rights of older people</u> and the rights of people with disabilities.

Through extensive research on <u>overmedication of older people living in nursing homes in the United States</u>, we have documented how nursing facilities give antipsychotic drugs to residents with dementia to control their behavior out of convenience, despite rules against the misuse of drugs as chemical restraints. The use of antipsychotic drugs on older people with dementia is associated <u>with a nearly doubled risk of death</u> and other adverse reactions including stroke, falls and the inability to stake awake long enough to eat or spend time with loved ones.

Based on our experience documenting these harmful practices, we have written to this Committee to share our concerns regarding F2019L00511, the <u>Quality of Care Amendment (Minimising the Use of Restraints)</u>

<u>Principles 2019</u>, registered on April 2, 2019. We have urged this Committee to recommend the disallowance of this regulation.

This legislation, which aims to regulate the use of restraints in aged care facilities, is inconsistent with Australia's obligations under several core human rights treaties that Australia has ratified, including the International Covenant on Civil and Political Rights,¹ the International Covenant on Economic, Social and Cultural Rights,² and the Convention on the Rights of Persons with Disabilities.³

The use of physical or chemical restraints for control, punishment, retaliation, or as a measure of convenience for nursing facility staff should be prohibited. This regulation does not prohibit such measures. Medicines should only ever be used for therapeutic purposes and with the free and informed consent of the person receiving them.

Informed Consent

The regulation does not require informed consent for chemical restraint, although it is required for physical restraint.

In its 2013 Concluding Observations on Australia, the United Nations Committee on the Rights of Persons with Disabilities (CRPD Committee) expressed concern that "under Australian law a person can be subjected to medical intervention against his or her will, if the person is deemed to be incapable of making or communicating a decision about treatment." The committee called on Australia to repeal all

¹ Implicates Article 6, the right to life; Article 7, the right to be free from torture and cruel, inhuman or degrading treatment or punishment; Article 26, equality before the law and to the equal protection of the law.

² Implicates Article 12, the highest attainable standard of physical and mental health.

³ Implicates Article 12, Equal Recognition Before the Law; Article 14, Liberty and Security of Person; Article 15, Freedom from Torture, or Cruel, Inhuman or Degrading Treatment or Punishment; Article 16, Freedom from Violence, Exploitation and Abuse; Article 17, Protecting the Integrity of the Person; Article 25, Health.

legislation that authorizes medical intervention without the free and informed consent of the persons with disabilities concerned.⁴

Similarly, the UN special rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health has stated that informed consent "is a core element of the right to health, both as a freedom and an integral safeguard to its enjoyment."⁵

For persons who may require support in making decisions and giving their informed consent for medical treatment, support should be provided and can take different forms. These can include:

- accessibility measures and reasonable accommodation in understanding medical interventions, their consequences and side effects, as well as alternatives;
- advance directives; and
- the appointment of one or more support persons chosen by the person concerned.

The CRPD Committee has acknowledged that in some cases, even after serious and sustainable efforts have been made, it may not be possible to determine a person's will and preferences, due to communication barriers or for other reasons. This may be the case with some people with dementia. In such situations, every effort should be made to make the best interpretation of an individual's will and preferences. ⁶ Consideration should be given to all forms of verbal or nonverbal communication, as well as a person's relevant previously manifested preferences, values, attitudes, and actions.

Prohibition on restraints in social care institutions

In a 2013 report, the UN special rapporteur on torture stated that "it is essential that an absolute ban on all coercive and non-consensual measures, including restraint and solitary confinement of people with psychosocial or intellectual disabilities, should apply in all places of deprivation of liberty, including in psychiatric and social care institutions."

The CRPD Committee has stated in numerous concluding observations that laws that condone the practice of restraining persons with disabilities or using other coercive measures to control them should be repealed.⁸ It criticized the use of restraints in its 2013 review of Australia, expressing serious concern that persons with disabilities are "subjected to unregulated behaviour modification or restrictive practices such as chemical, mechanical and physical restraints and seclusion, in various environments, including schools, mental health facilities and hospitals." The Committee called on Australia to take immediate steps to end such practices.

⁴ Committee on the Rights of People with Disabilities (CRPD Committee), Concluding observations on the initial report of Australia, adopted by the Committee at its tenth session (2-13 September 2013), 21 October 2013, CRPD/C/AUS/CO/1, https://tbinternet.ohchr.org/layouts/15/treatybodyexternal/Download.aspx?symbolno=CRPD/C/AUS/CO/1&Lang=En, para. 33.

⁵ Human Rights Council, Report of the special rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, Dainius Puras, A/HRC/35/21, March 28, 2017, https://documents-dds-ny.un.org/doc/UNDOC/GEN/G17/076/04/PDF/G1707604.pdf?OpenElement, para. 63.

⁶ CRPD Committee, General Comment 1, para. 21.

⁷ Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, Juan E. Méndez A/HRC/22/53, para 63. February 2013. http://www.ohchr.org

⁸ See, for example, CRPD New Zealand, Concluding Observations CRPD/C/NZL/CO/1 http://docstore.ohchr.org/SelfServices/FilesHandler.ashx?enc=6QkG1d%2fPPRiCAqhKb7yhsl0TAZAFn%2fysap%2b9nlo7rkvRmN J6uyxoc44CPcdshSIzpSxW%2bwhPoD0WnpuECahTAQtdCX5Yjd%2btcuc1aJHm%2fCQBiz4qXZd2vaDYn8RQsT7v, para. 32, "The Committee recommends that immediate steps be taken to eliminate the use of seclusion and restraints in medical facilities."

The Joint Parliamentary Human Rights Committee itself stated in a December 2018 report on the National Disability Insurance Scheme, which sought to regulate restraint in National Disability Insurance Scheme-funded services, that "Australia's obligations in relation to the prohibition on torture, cruel, inhuman and degrading treatment or punishment are absolute and therefore cannot be limited." And, "[t]o that extent, a nationally consistent approach which prohibits restrictive practices that could amount to torture, cruel, inhuman and degrading treatment or punishment would be desirable from a human rights perspective." 11

Australia should be working to end the use of all forms of restraints, including physical restraints, sedatives (chemical restraints), forced isolation, and forced psychiatric treatment as a means of managing or disciplining older people in aged care. They should develop support and interventions for persons experiencing crises and emotional distress, including in nursing homes, that do not involve restraints. Any new law should also ensure informed consent for all treatment or interventions and ensure independent monitoring and effective, accessible, independent complaints mechanisms, including for individuals in aged care and their families.

In the United States, the US Code of Federal Regulations, Title 42, Section 483.13 (a) states that, "The resident has the right to be free from any physical or chemical restraints imposed for purposes of discipline or convenience, and not required to treat the resident's medical symptoms." ¹²

In closing, Human Rights Watch urges you to recommend disallowance of this legislation that seeks to regulate practices that are incompatible with Australia's international human rights obligations. This regulation should be repealed and replaced with a robust prohibition on such practices, and requirements for:

- supportive interventions, including training for aged care facility staff;
- informed consent for all interventions;
- independent, immediate, external review of complaints;
- rights of access for advocates and inspectors to investigate potential restraint to ensure drugs are being used for therapeutic purposes only;
- meaningful, regular monitoring by health practitioners;
- sanctions for health practitioners found to be engaging in restraint;
- clear lines of enforcement from inspectors for facilities found to be in breach; and
- increased scrutiny of affiliated facilities with repeated violations.

Thank you for your consideration.

⁹ Restrictive Practice and Behaviour Support Rules 2018 [F2018L00632]

¹⁰ Joint Parliamentary Human Rights Committee, Human Rights Scrutiny Report 13 of 2018, 4 December 2018 <a href="https://www.aph.gov.au/~/media/Committees/Senate/committee/humanrights_ctte/reports/2018/Report%2013/Report

¹¹ Ibid.

¹² United States, *42 CFR 483.13 - Resident behavior and facility practices*. https://www.govinfo.gov/app/details/CFR-2013-title42-vol5/CFR-2013-title42-vol5-sec483-13 (accessed August 7, 2019).