**Submission to Special Rapporteur on the Rights of Persons with Disabilities**

**on Informed Consent**

Human Rights Watch has found in research on Iran, Brazil, Australia, Serbia, and India that people with disabilities are being subjected to ostensible medical treatment without their free and informed consent. This can be, but is not exclusively, linked to laws and regulations that allow for the deprivation of legal capacity of people with disabilities, in which they are denied the opportunity to make decisions for themselves. Even in situations where people with disabilities are not deprived of their legal capacity, they can be given medical treatment without their informed consent.

**Iran**

Iran allows for people with disabilities to be stripped of their legal capacity.[[1]](#footnote-1) Human Rights Watch research on Iran in 2017 and 2018 documented cases in which doctors and other healthcare professionals did not seek or obtain informed consent of patients with disabilities before administering medical treatment or medications. Doctors also did not provide individuals with comprehensive information about the treatment and potential side-effects in a fully accessible and understandable format. In many cases, parents or other family members consented for their children or relatives to receive medical treatment, with such consent typically obtained as part of the paperwork required for the treatment to start, also often without full information about the treatment. Human Rights Watch documented that some people received Electroconvulsive Therapy (ECT) without their informed consent. Health professionals in Iran told Human Rights Watch that ECT is often carried out unnecessarily, or for conditions in which ECT is not likely to be helpful.[[2]](#footnote-2)

**Brazil**

Human Rights Watch conducted research in 2017 and 2018 in 19 institutions for people with disabilities in Brazil. In all institutions visited, directors or staff members told Human Rights Watch that nearly all people living there had been stripped of their legal capacity, or the right to make decisions for themselves, and were under the guardianship of another person, either the institution director or a relative. Most people in institutions had been placed there by guardians and cannot leave, even for a short period, without the consent of the guardian. [[3]](#footnote-3)

Staff in most institutions said that they regularly gave medicines to adults without consent. Staff at several institutions confirmed that they put residents on psychoactive medications without seeking their consent so that they could control residents’ behavior for staff convenience or as a punishment.[[4]](#footnote-4)

**Australia**

Human Rights Watch research between September 2016 and January 2018 on people with disabilities in 14 prisons across Western Australia, Queensland, New South Wales, and Victoria found that prison staff, including mental health professionals, often fail to discuss with prisoners the nature, purpose, risks, and benefits of different types of treatment so that the prisoner is not in a position to make informed decisions as to whether or not to consent to the treatment.[[5]](#footnote-5)

Sterilization is another form of irreversible medical procedure that has been repeatedly performed on people with disabilities without appropriate regard for their free and informed consent. Under Australian law, sterilization of persons with disabilities without their free and informed consent is not a crime “if a family court or a guardianship tribunal determines that they ‘lack capacity’ and the procedure is in their ‘best interests.’”[[6]](#footnote-6)

A 2013 Australian Senate inquiry into involuntary or coerced sterilization of people with disabilities in Australia revealed that 59 requests for sterilization of women and girls with disabilities were approved by state and territory tribunals between 1992 and 2013 but noted that the data was incomplete due to variations across states and territories.[[7]](#footnote-7)

Several UN bodies including Human Rights Council, the Committee on the Elimination of Discrimination against Women, the Committee on the Rights of the Child, and the Committee on the Rights of Persons with Disabilities have repeatedly condemned Australia for the practice of forced sterilizations of children and adults with disabilities without their free and informed consent.[[8]](#footnote-8) However, the practice continues as evidenced by a 2016 Family Court case where medical treatment was carried out without adequate evidence nor independent oversight.[[9]](#footnote-9)

**Serbia**

Under Serbia’s Law on the Rights of Patients, healthcare providers do not need to obtain consent for medical treatment or interventions of a person who has been deprived of legal capacity and placed under guardianship.[[10]](#footnote-10) The guardian’s consent alone is enough to carry out medical procedures. Most women and girls with intellectual disabilities are deprived of their legal capacity and placed under guardianship, which means that they cannot decide on their medical interventions, parenting, or reproductive rights.

In 2015, Human Rights Watch conducted 118 in-depth interviews with children and adults with disabilities, disability advocates, staff of institutions, and government officials, and visits to five institutions for people with disabilities. Human Rights Watch documented that some women living in institutions were subjected to invasive medical interventions without their consent.[[11]](#footnote-11)

In its 2016 review of Serbia, the Committee on the Rights of Persons with Disabilities (CRPD Committee) recommended that Serbia investigate and prohibit “all medical interventions without the prior consent of persons with disabilities and provide sufficient remedies and compensation to those subjected to such procedures.”[[12]](#footnote-12) The CRPD Committee also expressed concern that persons with disabilities were being subjected to contraceptive treatments, abortions and sterilization against their will,[[13]](#footnote-13) and urged Serbia to “take all necessary measures to ensure their right to free, prior and informed consent for any kind of treatment that may affect a person with a disability, regardless of her/his legal capacity.”[[14]](#footnote-14)

Human Rights Watch interviews with three local nongovernmental organizations in 2018 and 2019 found that these coercive practices continue in institutions across Serbia.[[15]](#footnote-15) Human Rights Watch found that women with disabilities are deprived of legal capacity and that contraceptives are administered at times even without consent from guardians.[[16]](#footnote-16)

**India**

Women and girls with intellectual disabilities continue to be sterilized without their consent in India. Sterilization often occurs for the purpose of ending menstruation or because of fear of sexual assault or exploitation resulting in unwanted pregnancies. The government does not provide adequate health and social services for women and girls with psychosocial or intellectual disabilities primarily due to stigma, social exclusion and discrimination. In addition, the government does not recognize that women and girls with disabilities have legal capacity, or the right to make decisions for themselves, on an equal basis with others. In these cases, individuals may consent to medical treatment including sterilization on women’s behalf.[[17]](#footnote-17)

1. “‘I Am Equally Human’: Discrimination and Lack of Accessibility for People with Disabilities in Iran,” Human Rights Watch, June 26, 2018, www.hrw.org/report/2018/06/26/i-am-equally-human/discrimination-and-lack-accessibility-people-disabilities-iran. [↑](#footnote-ref-1)
2. Ibid., p. 60. [↑](#footnote-ref-2)
3. “‘They Stay until They Die’: A Lifetime of Isolation and Neglect in Institutions for People with Disabilities in Brazil,” Human Rights Watch, May, 23, 2018, www.hrw.org/report/2018/05/23/they-stay-until-they-die/lifetime-isolation-and-neglect-institutions-people. [↑](#footnote-ref-3)
4. Ibid. [↑](#footnote-ref-4)
5. “‘I Needed Help, Instead I Was Punished’: Abuse and Neglect of Prisoners with Disabilities in Australia,” Human Rights Watch, February 6, 2018, www.hrw.org/report/2018/02/06/i-needed-help-instead-i-was-punished/abuse-and-neglect-prisoners-disabilities. [↑](#footnote-ref-5)
6. Guardianship Act 1987 (NSW), ss. 33–34; Adult Guardianship Act (NT), s.21; Guardianship and Administration Act 2000 (QLD), s. 70; Guardianship and Administration Act 1995 (Tas); Guardianship and Administration Act 1986 (VIC), s. 36, s. 39. [↑](#footnote-ref-6)
7. Senate Community Affairs References Committee, “Involuntary or coerced sterilization of people with disabilities in Australia,” July 2013, http://www.aph.gov.au/Parliamentary\_Business/Committees/Senate/Community\_Affairs/Involuntary\_Sterilisation/First\_Report [↑](#footnote-ref-7)
8. Committee on Civil and Political Rights, Concluding observations on the sixth periodic report of Australia, CCPR/C/AUS/CO/6 December 1, 2017; Committee on the Elimination of All Forms of Discrimination Against Women, Concluding observations on the eighth periodic report of Australia, CEDAW/C/AUS/CO/8 July 25, 2018; Committee on the Rights of the Child, Concluding observations on the combined fifth and sixth periodic reports of Australia CRC/C/AUS/CO/5-6, September 31, 2019; and Committee on the Rights of Persons with Disabilities, Concluding observations on the initial report of Australia, adopted by the Committee at its tenth session (2 – 13 September 2013), CRPD/C/AUS/CO/1, October 21, 2013. [↑](#footnote-ref-8)
9. Re Carla (Medical procedure) [2016] FamCA 7. See also: Morgan Carpenter, The Family Court case Re: Carla (Medical procedure) [2016] FamCA 7, OII Australia, 2016, https://oii.org.au/31036/re-carla-family-court/ [↑](#footnote-ref-9)
10. Human Rights Watch interview with medical doctor in Stamnica Home for children and adults with disabilities, October 21, 2015; Human Rights Watch interview with medical doctor in the Institution for children and adults with disabilities in Veternik, October 20, 2015, Human Rights Watch interview with a medical doctor, Sremčica Home for children and adults with disabilities, November 16, 2015. The staff in all three institutions did not provide Human Rights Watch with the exact number of young women who were subjected to these treatments. [↑](#footnote-ref-10)
11. These included forced insertion of intrauterine devices (IUDs), uninformed administration of contraceptive pills, forced or coerced termination of pregnancy, and non-consensual administration of pap smear tests (Papanicolaou test - a screening procedure for cervical cancer). “’It is My Dream to Leave This Place’: Children with Disabilities in Serbian Institutions,” Human Rights Watch, June 8, 2016, https://www.hrw.org/report/2016/06/08/it-my-dream-leave-place/children-disabilities-serbian-institutions. [↑](#footnote-ref-11)
12. Committee on the Rights of Persons with Disabilities, Concluding observation on the initial report of Serbia, CRPD/C/SRB/CO/1, April 21, 2016, para. 34. https://tbinternet.ohchr.org/\_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD/C/SRB/CO/1&Lang=En. [↑](#footnote-ref-12)
13. Ibid., para. 37. [↑](#footnote-ref-13)
14. Ibid., para. 38. [↑](#footnote-ref-14)
15. Vikic, Elida. “Time for Serbia to Uphold Rights of Women with Disabilities.” Human Rights Watch, April 24, 2019, www.hrw.org/news/2019/04/23/time-serbia-uphold-rights-women-disabilities. [↑](#footnote-ref-15)
16. “Disability Rights International, Human Rights Watch, and Women Enabled International Submission to the United Nations Committee on the Elimination of Discrimination Against Women,” Human Rights Watch, February 14, 2019, www.hrw.org/news/2019/01/28/disability-rights-international-human-rights-watch-and-women-enabled-international. [↑](#footnote-ref-16)
17. CEDAW Committee, General Recommendation No. 35 on gender-based violence against women, updating general recommendation No. 19, para. 31(c), U.N. Doc. CEDAW/C/GC/35 (2017). [↑](#footnote-ref-17)