A Castle in the Sky?

The Icelandic Ban on Non-Therapeutic, Non-Consensual Interventions on Intersex Children in Context

Daniela Alaattinoğlu and Kári Hólmar Ragnarsson*

Abstract

Framing non-consensual, medically unnecessary interventions as human rights violations has become a priority for global intersex movements in recent years. However, establishing binding legal norms in this area remains challenging. Few countries have prohibited such interventions and scholarly discussions on these bans are still in their early stages. This article offers a contextual case study of Iceland's 2020 ban, as one of the few countries to outlaw non-consensual, non-therapeutic interventions on children with variations in sex characteristics. Drawing parallels with similar bans in other European countries, the article argues that framing the issue in terms of rights has been effective in mobilising action, building consensus and driving legislation. Yet, the broad and ambiguous framework underlying these laws appears to result in ineffective implementation, making such legislative bans at risk of becoming symbolic achievements for states, offering limited protection and few remedies for intersex people.

Keywords: intersex, children, consent, non-therapeutic interventions, Iceland, legislative ban

* Dr Alaattinoğlu is an Assistant Professor at the Faculty of Law, University of Turku. Dr Ragnarsson is an Associate Professor at the Faculty of Law, University of Iceland. Contact: daniela.alaattinoglu@utu.fi; khr@hi.is. The research for this article has been supported by the Icelandic Research Fund (grant number 206677-053) and the finalisation of the article has been supported by the Faculty of Law at the University of Turku. We would like to thank our colleagues for commenting earlier versions of this article and the anonymous reviewers for their helpful remarks.

Introduction

Globally, children with variations in sex characteristics, whose bodies do not fall neatly within medical categories of "male" and "female", are subject to surgeries and other medical interventions, such as hormonal treatments.[1] Such interventions are often carried out to make intersex children's bodies conform to gendered social corporeal norms.[2] In most cases, variations in sex characteristics do not pose a threat to the health or life of the child in question.[3] As opposed to medical emergencies, medical interventions – which can be both invasive and irreversible – performed under such circumstances are mainly based on social norms or aesthetic grounds.[4] As such, these interventions can be considered non-therapeutic. Many interventions are carried out when the children in question are very young, often under 24 months, which gives them no opportunity to form or express their own views on the matter.[5] In response to intersex activism,[6] some countries have recently established national bans on non-therapeutic, non-consensual interventions on intersex children.[7] In Europe, these countries are Malta (2015),[8] Portugal (2018),[9] Iceland (2020),[10] Germany (2021),[11] Greece (2022),[12] and Spain (2023).[13] Facing political and medical opposition, such bans may often be politically

1 This is a broad definition of "intersex". For an extensive study of intersex interventions, see K. Karkazis, *Fixing Sex: Intersex, Medical Authority, and Lived Experience* (Durham: Duke University Press, 2008), particularly Chapter 2.

2 Ibid.

3 S. Witchel, "Disorders of Sex Development" (2018) 48 *Best Pract Res Clin Obstet Gynaecol* 90, 98. The most commonly-noted exception is severe forms of Congenital Adrenal Hyperplasia (CAH), which pose fatal risks. Notably, the medical risks linked to CAH are not treated by surgically modifying genitalia. See H. Claahsen-van der Grinten et al. "Congenital Adrenal Hyperplasia - Current Insights in Pathophysiology, Diagnostics, and Management" (2022) 43 *Endocr Revi* 91.

4 See, for example, B. Dickens, "Management of Intersex Newborns: Legal and Ethical Developments" (2018) 143 *Int J Gynaecol Obstet* 255.

5 These interventions are sometimes referred to as "Intersex Genital Mutilations", particularly if they involve genital surgeries. See M. Jones, "Intersex Genital Mutilations – a Western Form of FGM" (2017) 25 *Int J Child Rights* 396. The name of a prominent NGO in the field is also StopIGM.org.

6 Scholarly contributions regarding intersex activism are, for example, L. Pereira, "Intersex Legal Activism. United Nations on the Human Rights of Intersex People" (2022) *AHRJ* 181; M. Bauer et al, "Intersex Human Rights" (2019) 24 *IJHR* 724; M. Sudai, "Revisiting the Limits of Professional Autonomy: The Intersex Rights Movement's Path to De-medicalisation" (2018) 41 *HJLG* 1.

7 A recent example of one such ban is the Australian Capital Territory's Variation in Sex Characteristics (Restricted Medical Treatment) Act 2023.

8 Act No. XI of 2015.

9 Decreto da Assembleia da República 203/XIII.

10 Lög nr. 154 29. desember 2020.

11 Gesetz zum Schutz von Kindern mit Varianten der Geschlechtsentwicklung Vom 12. Mai 2021.

12 Νόμος 4958/2022 - ΦΕΚ 142/A/21-7-2022.

13 Ley 4/2023, de 28 de febrero, para la igualdad real y efectiva de las personas trans y para la garantía de los derechos de las personas LGTBI, Article 19.

difficult to establish, which has been the case in many European countries.[14] Moreover, once established, doubts linger concerning their actual enforcement.[15]

This article originally analyses the establishment, text, implementation and context of the Icelandic ban of 2020 and related legislation. Iceland is a small Nordic state which has a comparatively strong track record with respect to human rights and gender equality in general,[16] and, in recent years, on rights pertaining to sexual orientation, gender identity and sex characteristics in particular.[17] As a small country which was able to gather the most important national experts and stakeholders in one working group and one room, and where there is a legislative imperative to register all interventions on intersex children, Iceland is a suitable case study to qualitatively, contextually and comprehensively analyse a legislative ban of non-consensual, non-therapeutic interventions on children with variations in sex characteristics. The analysis is representative of Iceland, but some parallels can be drawn to other national bans, even though contextual studies of other jurisdictions are likely to demonstrate both unique national features and common, transnational themes, such as tensions between medical doctors and civil society, problems for policy-makers to conceptualise sex characteristics, or the use of human rights instruments in advocacy.[18]

Since few countries have established similar bans, the scholarly discussion on this type of regulation is at present in its infancy.[19] Studies on Malta, the first country to introduce a ban

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14 Indeed, most European countries have no such bans. See, for example, ILGA World, "Legal Frameworks: Restrictions on interventions on intersex minors", https://database.ilga.org/interventions-intersex-minors.

15 See, for example, Committee on the Rights of the Child, "Concluding observations on the combined third to sixth periodic reports of Malta", 26 June 2019, CRC/C/MLT/CO/3-6, para. 28–29; Committee on the Rights of the Child, "Concluding observations on the combined fifth and sixth periodic reports of Portugal", 9 December 2019, CRC/C/PRT/CO/5-6 at para 28(b); Human Rights Committee, "Concluding observations on the fifth periodic report of Portugal", 28 April 2020, CCPR/C/PRT/CO/5, para. 16–17.

16 See e.g. Human Rights Committee, "Concluding observations on the fifth periodic report of Iceland", 31 August 2012, CCPR/C/ISL/CO/5. Iceland has also topped the World Economic Forum's Global Gender Gap Index for several years.

17 See, for example, ILGA Europe, "Rainbow Map 2024", https://rainbowmap.ilga-europe.org/.

18 Common themes appear, for example, in N. Pikramenou, "From Intersex Activism to Law-Making – The Legal Ban of Intersex Genital Mutilation (IGM) in Greece" (2024) 13 *Soc Sci* 221; F. Garland and M. Travis, "Legislating Intersex Equality: Building the Resilience of Intersex People through Law" (2018) 38 *Leg Stud* 587; F. Garland and M. Travis, *Intersex Embodiment: Legal Frameworks beyond Identity and Disorder* (Bristol: Bristol University Press, 2022).

19 See, for example, T. Mhuirthile, "Malta" in *The Legal Status of Intersex Persons* (Brussels: Intersentia, 2018) pp. 357–368; L. Platero and S. Solntseva, "Analysing intersex rights narratives in Spain" (2024) *Sexualities* 1; D. Alaattinoğlu, "Intersex Rights in the Icelandic Gender Autonomy Act" (SSRN, 2022), https://papers.ssrn.com/sol3/papers.cfm?abstract_id=4252270; D. Alaattinoğlu, "Líkamleg friðhelgi intersex fólks: Blindur blettur í mannréttindabaráttu á Norðurlöndum og íslenska undantekningin [The Icelandic Exception: The Bodily Integrity of Intersex People, A Nordic Human Rights Blind Spot]" in *Fléttur VII: Hinsegin Ísland í alþjóðlegu samhengi [Fléttur VII: Queer Iceland in an International Context]* (Reykjavík: Háskólaútgáfan, 2024), pp. 15–38. For a discussion on the compliance gap in Europe,

on non-therapeutic, non-consensual medical interventions on intersex children, point out the ground-breaking nature of the legislation,[20] but have also suggested that its societal impact remains limited.[21] In an article from 2024, Tabone, Garland and Travis recommend Malta to "undertake an extensive education program in order to tackle hermeneutic injustice",[22] since "law, alone, is insufficient" to change the present conditions of injustice faced by intersex people.[23] There are also studies on the introduction of the bans in Greece and Spain, which focus on the emergence of national intersex movements and how the mobilisation of such movements has been the main driving force behind recent legislation.[24] Drawing on empirical evidence from the Icelandic context, which has been covered to a limited extent in scholarly discussions to date, the present study originally seeks to develop the emerging discussions on bans of non-therapeutic, non-consensual interventions on intersex children and, more specifically, the role of human rights in shaping such bans, investigating the mobilisation by crucial actors to introduce legislation, the responses by public institutions, the formulation of the eventual legislation and its implementation in medical practice.

Rooted in the Icelandic example, drawing parallels with other comparative examples in Europe, the main argument of the article is that the human right framework has provided an effective framework to mobilise, find (a sense of) consensus and establish the 2020 Icelandic ban. Yet, under this broad and ambiguous framework, it simultaneously seems to be difficult to secure effective national implementation of current human rights standards. Such difficulties increase the risks that bans on non-therapeutic, non-consensual interventions remain symbolic achievements for the states, since they offer limited remedies for intersex people.

The article is structured as follows: Next section explains the terminology used and the methodology of the study. The following section, in turn, analyses the developing, supranational human rights principles regarding non-consensual, non-therapeutic intersex interventions, particularly focusing on the European context, demonstrating the developing normative standards in the field. Subsequently, the article contextually illustrates the

see N. Pikramenou, *Intersex Rights: Living between Sexes* (Berlin: Springer, 2019); J. Garland and S. Slokenberga, "Protecting the Rights of Children with Intersex Conditions from Nonconsensual Gender-Conforming Medical Interventions: The View from Europe" (2019) 27 *Med Law Rev* 482.

20 See Mhuirthile,"Malta"; Garland and Travis, "Legislating Intersex Equality".

21 Garland and Travis, *Intersex Embodiment*, 109–137; C. Tabone et al, "Cultural Awareness of Intersex in Malta: Invisibility, Stigma and Epistemic Injustice" (2024) 13 *Soc Sci* 150.

22 Tabone et al, "Cultural Awareness of Intersex in Malta", 167.

23 Ibid, 168.

24 Pikramenou, "From Intersex Activism to Law-Making – The Legal Ban of Intersex Genital Mutilation (IGM) in Greece"; Platero and Solntseva, "Analysing Intersex Rights Narratives in Spain".

establishment and content of the 2020 Icelandic ban, showing how the drafting process of the Icelandic legislation was initiated by prominent civil society representatives, and how a compromise on the formulation of the law was achieved owing to common ground of human rights principles. Thereafter, the implementation of the Icelandic law is discussed in a comparative context, highlighting the lingering gap between human rights standards, on the one hand, and implementation, medical practices and lack of remedies for intersex people, on the other. The concluding section of the article brings the insights together to emphasise the need for an empirically-informed scholarly discussion on the effectiveness of bans on non-consensual, non-therapeutic intersex interventions.

Terminology and Methodology

At the outset of the article, some terminological choices should be explained. The word "intersex" is used as an umbrella term to refer to people whose bodies have variations in sex characteristics, as often used by civil society and human rights organisations.[25] When referring to variations in bodily sex characteristics, the article alternates between the terms "variations" and "atypical" – generally preferring the former, but also using the latter in the context of the Icelandic law since it linguistically better corresponds to the term used in the original language *(ódæmigert).* Furthermore, the term "non-therapeutic" is used to refer to medical interventions which are not motivated by strictly medical reasons, in other words, in situations where the patient's physical health or life is not at risk.

Centring on the 2020 Icelandic law in the light of developing human rights law and standards – with a focus on the European rights framework –, the article draws on multidisciplinary literature and is the result of an interdisciplinary research project. To provide a contextually rich account, analysing not only the legal developments on paper but also the environment in which they took place and in which the law is also implemented, the article combines doctrinal legal scholarship with comparative law and socio-legal scholarship, including social movement scholarship.

To understand more about the motivations behind the law, its formulation and implementation, the article includes in-depth interviews with eight key informants: civil society

[25] Medical professionals rather tend to use the term "Disorders of Sex Development (DSD)". This term stems from the Chicago Consensus Meeting among medical experts in 2005. It defines DSD as "congenital conditions in which development of chromosomal, gonadal, or anatomical sex is atypical". Hughes et al. "Consensus Statement on Management of Intersex Disorders" (2006) 91 *ADC* 554, 554.

representatives, a politician, a civil servant, a medical doctor and legal experts who have been involved in the process to introduce the Icelandic general prohibition of 2020. The number of interviewees is limited, but so is the number of people who have been involved in the introduction, drafting and implementation of the 2020 ban, making the sample representative for the Icelandic context. The interviewees were identified based on a review of the most important relevant official documents, such as state reports and official comments on the draft law, and through snowballing. The interviewees were initially approached by one of the authors, Daniela Alaattinoğlu, through e-mail, and were sent the most important questions a couple of days before the interview.[26]

The other author, Kári Hólmar Ragnarsson, has acted as a human rights expert in the working group which drafted the legal provisions in question. This participation has provided the authors with embedded, contextual knowledge about the law drafting process which cannot be gained merely from analysing written documents, for example regarding which topics were subject to much internal debate and which ones did not stir debate. Finally, the authors have obtained empirical data on the implementation of the legislation directly from the relevant national authorities. The methodology ensures that from the law's conception, through the drafting process and to implementation, the article provides a full account of the context and the law's real-world impact.

Human Rights Framing and Developing Supranational Standards

Framing non-consensual, medically unnecessary interventions as human rights violations has been a central tenet of the global intersex movement in recent years, generally formulating political demands in terms of rights. "Framing" is, in this context, borrowed from social movement studies and refers to the formulation, creation, maintenance and reformulation of significance by social movements[27] – identifying a problem, prognosis and motivation for how to address the problem.[28] In the context of intersex embodiment, human rights and medicine have long presented competing frameworks of interpretation, with different understandings of

[26] Unfortunately, not all relevant actors could be reached for an interview. The names of the interviewees are not published in this article. The University Ethics Committee on Scientific Research at the University of Iceland has decided that the study does not go against the Guidelines for Research Ethics and, therefore, that there is no occasion to oppose the research (issue SHV2022-019).

[27] See, for example, R. Snow and D. Benford, "Framing Processes and Social Movements: An Overview and Assessment" (2000) 26 *Ann Rev Soc* 611, 613.

[28] A-M. Marshall, *Confronting Sexual Harassment: The Law and Politics of Everyday Life* (Farnham: Ashgate, 2005), 60–61.

central questions, such as who is intersex, or what medical treatment intersex people want or need.[29] Here, human rights have been a way of challenging and displacing dominating medical frameworks.[30]

At the First International Intersex Organising Forum in Brussels, 2011, the "[p]athologisation of intersex individuals" was considered the root cause of "gross human rights violations" of "bodily integrity and personal dignity".[31] The first among the published demands was to "put an end to mutilating and 'normalising' practices such as genital surgeries, psychological and other medical treatments".[32] These principles have later been confirmed and further developed in global and regional activist statements such as the Malta Declaration (2013),[33] the Darlington Statement (2017),[34] a Public Statement by the African Intersex Movement (2017),[35] the San José de Costa Rica Statement (2018),[36] and a Public Statement by the Asian Intersex Movement (2018).[37]

The human rights framing seems to have been successful. More specifically, intersex activists have gained institutional response at the United Nations (UN) level when framing the question of non-consensual, medically unnecessary interventions as a human rights violation.[38] The interventions have been conceptualised as violating principles of various UN policy documents, among others, the security of the person, bodily and mental integrity, personal dignity, the right to non-discrimination, the right to freedom from torture and ill-treatment, the right to health and the right of children to be free from violence, torture and ill treatment.[39]

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29 D. Rubin, *Intersex Matters: Biomedical Embodiment, Gender Regulation, and Transnational Activism* (Albany: SUNY Press, 2017); Garland and Travis, *Intersex Embodiment.*

30 See M. Carpenter, "The Human Rights of Intersex People: Addressing Harmful Practices and Rhetoric of Change" (2016) *RHM* 74.

31 Interaction, "Media Release" (2011), https://interaction.org.au/14340/first-international-intersex-forum/.

32 Ibid.

33 Third International Intersex Forum, "Public Statement by the Third International Intersex Forum" (2013), https://www.oiieurope.org/public-statement-by-the-third-international-intersex-forum/.

34 Interaction, "Darlington Statement: Joint Consensus Statement from the intersex Community Retreat in Darlington" (2017), https://interaction.org.au/darlington-statement/.

35 Intersex Day, "Public Statement by the African Intersex Movement" (2017), https://intersexday.org/en/statement-african-forum-2017/.

36 Brújula Intersexual, "San José de Costa Rica Statement" (2018), https://brujulaintersexual.org/2018/04/13/san-jose-de-costa-rica-statement/.

37 Astrea Foundation, "Media Statement" (2018), https://astraeafoundation.org/stories/first-asian-intersex-forum/. Forced medical procedures were also declared contrary to the right to recognition before the law in the Yogyakarta Principles of 2006 (Principle 3). The Yogyakarta Principles moreover contain a specific right to protection from medical abuses (Principle 18).

38 See, for example, E. Zelayandia-Gonzalez, "The Growing Visibility of Intersex Demands at the United Nations: A Review of the Treaty Bodies' Concluding Observations" (2023) 12 *Soc Sci* 73.

39 For a comprehensive overview, see OHCHR, "Background Note on Human Rights Violations against Intersex People" (2019), https://www.ohchr.org/Documents/Issues/Discrimination/LGBT/BackgroundNoteHumanRightsViolationsagainstIntersexPeople.pdf.

Such documents have been issued by a range of UN bodies and special procedures, such as the United Nations High Commissioner for Human Rights,[40] the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment,[41] the Human Rights Council,[42] the Human Rights Committee,[43] the Committee on Economic, Social and Cultural Rights,[44] the Committee on the Rights of the Child,[45] the Committee on the Rights of Persons with Disabilities,[46] the Committee on the Elimination of Discrimination against Women,[47] and the Committee against Torture.[48]

In 2016, a certain mainstreaming of the topic took place within the UN machinery, as the widely signed interagency statement "End Violence and Harmful Medical Practices on Intersex Children and Adults" was launched in anticipation of the Intersex Awareness Day (26 October).[49] This statement reiterated the principle that interventions without the "full, free and informed consent of the person concerned" amount to "violations of fundamental human rights".[50] Nevertheless, even though the message from these UN institutions appears clear, the

40 OHCHR, "Discriminatory laws and practices and acts of violence against individuals based on their sexual orientation and gender identity", A/HRC/19/41, 17 November 2011, para. 57.

41 See General Assembly, "Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment", A/HRC/22/53, 12 March 2013, para. 77; General Assembly, "Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment", A/HRC/31/57, 5 January 2016, para. 50.

42 See General Assembly, "Resolution adopted by the Human Rights Council on 4 April 2024, 55/14. Combating discrimination, violence and harmful practices against intersex persons", A/HRC/RES/55/12, 8 April 2024.

43 See Human Rights Committee, "Concluding observations on the sixth periodic report of Australia", 1 December 2017, CCPR/C/AUS/CO/6, para. 25–26; Human Rights Committee, "Concluding observations on the fourth periodic report of Switzerland", 22 August 2017, CCPR/C/CHE/CO/4, para. 24–25.

44 See Committee on Economic, Social and Cultural Rights, "General Comment No. 22 on the right to sexual and reproductive health", E/C.12/GC/22, 2 May 2016, para. 59.

45 See Committee on the Rights of the Child, "Concluding observations on the combined fifth and sixth periodic reports of Spain", 5 March 2018, CRC/C/ESP/CO/5-6, para. 24; Committee on the Rights of the Child, "General Comment No. 20 on the implementation of the rights of the child during adolescence", CRC/C/GC/20, 6 December 2016, para. 34.

46 See Committee on the Rights of Persons with Disabilities, "General Comment No. 3 on women and girls with disabilities", CRPD/C/GC/3, 25 November 2016, para. 32 and 44.

47 See Committee on the Elimination of Discrimination against Women, "Concluding observations on the seventh periodic report of Chile", 9 March 2018, CEDAW/C/CHL/CO/7, para. 22–23.

48 See Committee against Torture, "Concluding observations on the seventh periodic report of France", 10 June 2016, CAT/C/FRA/CO/7, para. 34–35; Committee against Torture, "Concluding observations on the seventh periodic report of Switzerland", 7 September 2015, CAT/C/CHE/CO/7, para. 20; Committee against Torture, "Concluding observations of the Committee against Torture: Germany", 12 December 2011, CAT/C/DEU/CO/5, para. 20.

49 OHCHR et al., "Intersex Awareness Day" (2016), https://www.ohchr.org/en/press-releases/2016/10/intersex-awareness-day-wednesday-26-october.

50 Ibid.

developed soft law has been criticised for its lack of enforcement and being easily avoided by states.[51]

Moving on to the European regional level, the European Union (EU) has also picked up on the topic of intersex rights over the last few years. Following expert reports detailing various forms of discrimination and human rights violations,[52] the European Parliament took a more concrete step in 2019 by issuing a resolution on the rights of intersex people.[53] The resolution "strongly condemns sex-normalising treatments and surgery", and "welcomes laws that prohibit such surgery, as in Malta and Portugal".[54] Moreover, it "encourages other Member States to *adopt similar legislation as soon as possible*" (emphasis added).[55] While this resolution, akin to the UN policy documents, takes an explicit and normatively strong stance, the implementation of the norms laid down is left to national authorities.

The Council of Europe (CoE), too, has been an active agent in challenging medically unnecessary non-consensual interventions on intersex children in terms of human rights. Already in 2013, the Parliamentary Assembly of the Council of Europe (PACE) issued a resolution on children's right to physical integrity, in which it expressed particular worry concerning "early childhood medical interventions in the case of intersex children".[56] In the resolution, PACE recommended states to "ensure that no-one is subjected to unnecessary medical or surgical treatment that is cosmetic rather than vital for health during infancy or childhood" and to "guarantee bodily integrity, autonomy and self-determination to persons concerned, and provide families with intersex children with adequate counselling and support".[57]

The focus on intersex issues has been developed further within CoE institutions, including in a comprehensive 2015 report by the CoE Commissioner for Human Rights.[58] Among other things, the report refers to interventions of intersex bodies as sex

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51 F. Garland et al., "Intersex Activism, Medical Power/Knowledge and the Scalar Limitations of the United Nations" (2022) 22(3) *HRLR* 1.

52 Such as European Parliament, "Report on the EU Roadmap against homophobia and discrimination on grounds of sexual orientation and gender identity" (2013/2183(INI)), 7 January 2014; European Union Agency for Fundamental Rights, *The Fundamental Rights Situation of Intersex People*, (Vienna: FRA Publications, 2015); van den Brink et al., *Trans and intersex equality rights in Europe – a comparative analysis* (Brussels: European Commission Directorate-General for Justice and Consumers, 2018).

53 European Parliament resolution of 14 February 2019 on the rights of intersex people (2018/2878(RSP)).

54 Ibid, Section 2.

55 Ibid.

56 PACE Resolution 1952 (2013), Section 2.

57 Ibid, at Section 7.5.3.

58 Council of Europe Commissioner for Human Rights, *Human rights and intersex people* (Strasbourg: Council of Europe Publications, 2015).

"reassignments".[59] PACE issued a second resolution in 2017,[60] recognising that non-consensual treatments of intersex people which are not medically necessary constitute "serious breaches of physical integrity".[61] Among other recommendations, the resolution calls on Member States to "prohibit medically unnecessary sex-'normalising' surgery, sterilisation and other treatments practised on intersex children without their informed consent".[62]

When the Icelandic legislation central to this article was passed in 2020, the European Court of Human Rights had not yet dealt with the question of non-consensual intersex interventions. In 2022, however, the Court delivered its decision on the admissibility of *M v France*[63] where the applicant, having been born with variations in sexual characteristics, had been subjected to medically unwarranted "feminising" treatment which included bilateral castration at an early age.[64] While the case was ruled inadmissible based on the failure to exhaust domestic remedies, the Court indicated that a medical intervention which is not therapeutically necessary, and which is carried out without the informed consent of the patient, is liable to constitute ill-treatment under Article 3.[65] If the patient is a legal minor, such informed consent must be obtained of their legal guardian.[66] The Court emphasised that sterilisation or genital mutilation of people without therapeutic purpose and informed consent is in principle incompatible with the respect for human freedom and dignity under Article 3, especially when carried out on a child.[67]

The human rights framing utilised by intersex human rights defenders has gained an institutional response from the three supranational organisations UN, EU and CoE, resulting in the establishment of a policy-based framework which considers non-consensual, non-

59 Ibid, Chapter 2.
60 PACE Resolution 2191 (2017).
61 Ibid, Section 2.
62 Ibid., Section 7.1.1. Other Council of Europe institutions have addressed the issue as well, see ECRI, "Report on Switzerland (sixth monitoring cycle)", adopted on 10 December 2019, para. 23; ECRI, "Report on Austria (sixth monitoring cycle)", adopted on 7 April 2020, para. 31; ECRI, "Report on Germany (sixth monitoring cycle)", adopted on 10 December 2019, para. 34. There are also plans to establish a new Committee of Ministers Recommendation on equality of rights of intersex people. See Council of Europe, "Human rights of intersex people: work launched on new Council of Europe recommendation" (2023), https://www.coe.int/en/web/portal/-/human-rights-of-intersex-people-work-launched-on-new-council-of-europe-recommendation.
63 Application No 42821/18, Admissibility, 26 April 2022.
64 Ibid., at para. [1–15].
65 Ibid., at para. [61].
66 Ibid.
67 Para. [62]. At this point, the Court made a reference to its decision in *Sow v Belgium*, Application No 27081/13, Merits and Just Satisfaction, 19 January 2016, para. [64]. See D. Alaattinoğlu, "Intersex Interventions as Human Rights Violations: The European Court of Human Rights Sets Out Guiding Principles in *M v France*" (2023) 86 *MLR* 1265.

therapeutic interventions on intersex children as human rights violations, particularly of bodily integrity. Interestingly, by framing non-consensual, medically unnecessary interventions as a legal problem – violations of human rights, particularly of bodily integrity – intersex rights defenders and human rights institutions have also welcomed legal solutions: outlawing such medical practices, embracing national prohibitions. Typically, the human rights framing has also challenged pathologisation and other typical explanation models within the medical framework.

The Icelandic Road to Legislation

Breaking the Silence

The issue of children born with variations in sex characteristics long attracted very limited attention in Icelandic politics and public discourse. Framed primarily as a medical question, which could only be understood by medical professionals, the topic was not one of public debate. This changed when the civil society organisation *Intersex Ísland* was founded in 2014 by the prominent intersex human rights defender Kitty Anderson. The organisation, run by a few activists, has been the primary force behind putting intersex issues on the Icelandic political agenda ever since. In their activism, the organisation has typically framed intersex matters – most prominently non-therapeutic, non-consensual interventions on intersex children –, as pressing human rights questions.

In the years following the establishment of *Intersex Ísland*, interviews detailing the personal stories of intersex persons and their close relatives began to appear in Icelandic mass media outlets.[68] A mother who had given birth to an intersex child in the early 1980s depicted the parental choice as limited and characterised by incomprehensive and misleading information:

> "The doctor told me that my daughter had a chromosomal defect and her gender was unknown. I was told that she needed an operation in which the gonads would

[68] See e.g. K. Guðbrandsdóttir, "Við vorum einar í heiminum [We Were Alone in the World]", (Vísir, 23 May 2015), https://www.visir.is/g/2015705239975; E. Karlsdóttir, "Ég er bara intersex [I am Just Intersex]", (DV, 8 August 2014), 12-13; B. Finnsdóttir, "Ég er líka til [I Exist, Too]", (Vísir, 3 March 2017), https://www.visir.is/g/20171643659d; U. Kristjönudóttir Jónsdóttir and K. Anderson, "Trans fólk, intersex fólk og heilbrigðiskerfið sem mismunar þeim [Trans People, Intersex People and the Health System that Discriminates Against Them]", (Vísir, 14 October 2015), https://www.visir.is/g/20151044254d.

be removed. He recommended getting it over with as soon as possible, preferably before the age of two so she would not remember it. In my memory, there was no choice. This had to be done."[69]

The effort to publicise stories by and about intersex people in the mid-2010s was successful in raising awareness of the issue in the small country. The lack of informed consent was problematised as a human rights question, particularly among more generalist national human rights actors, which had not engaged in intersex matters prior to the foundation of *Intersex Ísland*. In an interview, a legal advisor at the Icelandic Ombudsman for Children at the time described how the Ombudsman had largely been unaware of the issue before the establishment of the intersex-specific organisation:

> "And we decided that this is a huge children's rights issue, so the Ombudsman for Children would need to discuss it, and we were surprised to hear that the other Nordic countries… the other Ombudsmen for Children, had not been discussing this topic. So this shows how hidden this issue has been. So the thing is that the office has been interested in the bodily integrity and the rights of children… and then this organisation [*Intersex Ísland*] comes to light here in Iceland around a similar time… and we decided to look into that issue […]."[70]

Law Drafting and Rights Mobilisation

The effort to bring the personal stories to the public was paired with input from other human rights actors, who also aligned with a human rights framework, typically advocating for legal solutions to the problem of non-therapeutic, non-consensual interventions. The Icelandic Ombudsman for Children issued a statement in 2015, in which the Office lamented medically unnecessary interventions on children born with variations in sex characteristics, applying a human rights framework.[71] The same year, key civil society representatives took the matter of law revision into their own hands on account of the shortcomings recognised in the national

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69 Translated from Icelandic by the authors. Guðbrandsdóttir, "Við vorum einar í heiminum [We Were Alone in the World]".

70 Interview with legal expert, 11 January 2022.

71 The statement includes references to documents by the World Health Organization, the Council of Europe Commissioner for Human Rights and the United Nations Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment. Direct references were also made to the Convention on the Rights of the Child and the Constitution of the Republic of Iceland. Translated from Icelandic by the authors. The Icelandic Ombudsman for Children, "Aðgerðir á intersex börnum [Interventions on Intersex Children]" (8 May 2015), https://www.barn.is/frettir/adgerdir-a-intersex-bornum.

laws at the time,[72] joining forces with a supportive opposition MP to collaborate with politicians across party lines, experts and other members of civil society on preparing new legislative efforts.[73] In 2017, a new coalition government headed by the Left-Green Movement was formed and included an emphasis on the rights of LGBT+ persons in its joint political statement.[74] This statement included a promise to establish "ambitious legislation on gender autonomy in line with the Council of Europe's new recommendations on the human rights of intersex persons".[75]

The promise was partially broken in the passing of a new Act on Gender Autonomy 80/2019 (the "2019 Act", the "Gender Autonomy Act" in the following), which, while representing significant progress from the point of view of trans and non-binary people's rights, failed to address any issues regarding children under the age of sixteen with variations in sex characteristics. This decision was motivated by the political divisiveness of the question in the drafting process and due to concerns raised by the medical community.[76] As a result, the bodily integrity of intersex children was a topic excluded from the Bill,[77] over the objections of various civil society actors and a minority of the relevant standing committee of the Icelandic Parliament.[78] Instead, the 2019 Act provided that a new working group should be established to propose amendments to the law relating to children under sixteen.

In the same year, as the divisiveness of the issue was coming to the fore in public debate – particularly formulated as a division between medical professionals and intersex rights activists –, Amnesty International published a detailed report on the status of children born

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72 Such shortcomings were, for example, a pathologised definition of trans people and a rigid binary view of gender. See Act no. 57/2012, Lög um réttarstöðu einstaklinga með kynáttunarvanda [Act on the Legal Status of Persons with Gender Identity Disorders]; Icelandic Directorate of Equality, "Umsögn um frv. til laga um réttarstöðu einstaklinga með kynáttunarvanda, 736. Mál [Commentary on Bill to Establish Act on the Legal Status of Persons with Gender Identity Disorder, Case 736]", 25 May 2012.

73 Icelandic Government Bill 1184/149 (2019).

74 The Icelandic Government, "Sáttmáli Framsóknarflokks, Sjálfstæðisflokks og Vinstrihreyfingarinnar – græns framboðs um ríkisstjórnarsamstarf og eflingu Alþingis [Coalition Agreement between the Progressive Party, the Independence Party and the Left-Green Movement on Forming a Government and Empowering the Icelandic Parliament]", https://www.stjornarradid.is/library/05-Rikisstjorn/sattmali-rikisstjornarsamstarf.pdf.

75 Ibid at 29, translated from Icelandic by the authors.

76 Interviews with a political decision-maker and a civil society representative, 4 March 2022 and 17 December 2021 respectively.

77 Icelandic Government Bill 1184/149 (2019).

78 See Nefndarálit með breytingartillögu um frumvarp til laga um kynrænt sjálfræði. Frá minni hluta allsherjar- og menntamálanefndar [Opinion of the Minority of the Icelandic Parliamentary Standing Committee on Judicial and Educational Affairs], 149th legislative session 2018–2019, doc. no. 1825, issue no. 752. The report explained that, among others, Amnesty International, *Intersex Ísland*, the Icelandic Centre for Human Rights and the Icelandic Ombudsman for Children had urged the Icelandic Parliament to include protections for children under sixteen in the bill and proposed an amendment to that effect.

with variations in sex characteristics in Iceland, which included interviews with intersex persons, their families and medical professionals.[79] The report was critical of the lack of clear protocols and multidisciplinary care in the medical setting, and the prevalence of non-consensual, non-therapeutic surgeries and treatment.[80] As such, the report clearly framed these issues as violations of the human rights of intersex people and as a politically important issue in the Icelandic context.

According to a human rights defender at Amnesty International, the report was the first thematic report regarding Iceland authored by the organisation. Owing to the broad international and national recognition of Amnesty International, it was expected that the report would have a national impact:

> "We thought [that] we want to team up with the organisations that are the specialists within the area and make their voices, or all our voices, heard. And their voices were definitely heard among politicians, but we know that when Amnesty comes out with a report… it is usually quite, at least in Iceland […] it is well-respected here."[81]

The report recommended that the Icelandic Prime Minister's Office "[a]lign laws, policies, and practices to comply with s.7.1.1 of Resolution 2191 of the Parliamentary Assembly of the Council of Europe to 'prohibit medically unnecessary sex-"normalising" surgery, sterilisation and other treatments practised on intersex children without their informed consent'".[82]

Compromises and Finding Common Ground in Human Rights

In order to address the legislative void pertaining to interventions on children with variations in sex characteristics, which had been framed by human rights defenders as a major problem, a working group was appointed in 2020. As required by the 2019 Act, it comprised a variety of experts: a paediatric surgeon, a paediatric endocrinologist, a child psychologist, a representative of *Intersex Ísland*, a representative of the National Queer Association of Iceland *Samtökin '78*, an expert on gender studies, an ethicist, a lawyer with expert knowledge of

79 Amnesty International, "No Shame in Diversity: The Right to Health for People with Variations of Sex Characteristics in Iceland" (2019), https://www.amnesty.org/en/documents/eur28/9498/2019/en/.
80 Ibid.
81 Interview with human rights defender, 15 December 2021.
82 Amnesty International, "No Shame In Diversity", 56.

children's rights issues, a lawyer with expert knowledge of human rights, and a chairperson.[83] The working group delivered its final report in September 2020,[84] formulating proposals which formed the basis of a legislative bill presented to Parliament in October 2020.[85] In the course of its operation, the working group looked to Council of Europe[86] and European Parliament[87] resolutions, international human rights standards,[88] and national legislation, considering developments in Malta,[89] Portugal[90] and California in detail,[91] as these were viewed as the most prominent attempts to regulate medical interventions on intersex children at the time.[92] Moreover, the working group paid attention to that the Maltese and Portuguese laws had been favourably referred to by the European Parliament,[93] providing examples of definitions of key concepts and decision-making procedures.

In the internal discussions of the working group, clear divisions re-emerged between the medical professionals and the civil society representatives. Regardless of these divisions, however, the group was able to find common ground in that the legal framework should be based on human rights principles and be in line with developing human rights norms. More specifically, a general agreement was reached that most interventions for solely aesthetic or social purposes were unacceptable. Moreover, based on the working group's mandate and the 2017 coalition agreement,[94] the working group considered its task as being to establish Iceland as a global leader in the legal protection of intersex persons. In sum, the importance attached

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83 Temporary Provision I of the Lög um kynrænt sjálfræði [Act on Gender Autonomy] no. 80/2019.

84 Icelandic Prime Minister's Office, "Tillögur starfshóps um málefni barna sem fæðast með ódæmigerð kyneinkenni [Proposals of the Working Group on the Issue of Children Born with Atypical Sex Characteristics]", September 2020, in this article also referred to as the "Working Group Report".

85 Icelandic Government Bill 154/2020.

86 PACE Resolution 2191 (2017).

87 European Parliament resolution of 14 February 2019 on the rights of intersex people (2018/2878(RSP))

88 Important documents were, for example, Committee on Economic, Social and Cultural Rights, "Concluding observations on the sixth periodic report of Denmark", 12 November 2019, E/C.12/DNK/CO/6, paras. 64-65; Committee on the Rights of the Child, "Concluding observations on the combined fifth and sixth periodic reports of Spain", 5 March 2018, CRC/C/ESP/CO/5-6, para. 24; Committee on the Rights of the Child, "Concluding observations on the combined fifth and sixth periodic reports of Italy", 28 February 2019, CRC/C/ITA/CO/5-6, para. 23; Committee on the Rights of the Child "Concluding observations on the combined fifth and sixth periodic reports of Belgium", 28 February 2019, CRC/C/BEL/CO/5-6, para. 26; OHCHR et al., "Intersex Awareness Day"; OHCHR, "Born Free and Equal," HR/PUB/12/06/Rev.1 (2nd ed. 2019). The activist statements *The Yogyakarta Principles* and *The Yogyakarta Principles +10* were influential as well. The principles are available at: https://yogyakartaprinciples.org/.

89 Act No. XI of 2015.

90 Decreto da Assembleia da República 203/XIII.

91 California Senate Bill No. 201, 31 January 2019. The bill did not pass into law.

92 The group also considered practice in the other Nordic states, as well as scholarly literature and national inquiries in several European states. Icelandic Prime Minister's Office, Working Group Report, 6–16.

93 European Parliament resolution of 14 February 2019 on the rights of intersex people (2018/2878(RSP)), Section 2.

94 The Icelandic Government, "Working Group Report".

to international human rights standards and the protection of the human rights of intersex children helped to place intersex interventions on the political agenda, on the one hand, and aided the establishment of the law as a common ground for compromise, on the other.[95]

The 2020 Act

The human rights framing persisted, as the working group proposals were transformed into law as Act no. 154/2020 amending the Act on Gender Autonomy (the "2020 Act"). The 2020 Act introduced substantive and procedural rules on contemplated medical interventions concerning intersex children under sixteen years old. The 2020 Act brought many important changes.

Firstly, bodily integrity, self-determination and children's right to the best available health care are explicitly stated as the Act's general, overarching principles.[96] The core of the Act is that interventions for the purpose of "sex-normalising" children's bodies are unacceptable. Social, psychosocial or aesthetic reasons, which include normative ideas about how sex characteristics "should" look or function to count as "normal", as well as projections about the future psychological or emotional state of the children concerned, are thereby excluded from the assessment of whether medical interventions are necessary.[97]

Secondly, "atypical sex characteristics" are defined very broadly as sex characteristics which do not conform to standard definitions as male or female including as regards functionality or appearance.[98] The broad definition also makes the group of individuals covered by the law relatively vast.[99]

Thirdly, the 2020 Act introduced a general rule that no permanent interventions[100] can be performed regarding the sex characteristics of children under sixteen who are born with variations, unless in conformity with the will of the child. When the child is unable to give such consent, due to young age or other circumstances, medical interventions are only allowed when required by "health reasons", explicitly excluding "social, psychosocial and aesthetic

95 These findings are based on first-hand observations by Ragnarsson.

96 Article 4(1), becoming Article 11a(1) of the 2019 Act as amended by the 2020 Act. In what follows, references will solely be made to the provisions of the 2019 Act as amended.

97 Icelandic Prime Minister's Office, "Working Group Report", 20–21.

98 Lög um kynrænt sjálfræði [Act on Gender Autonomy] no. 80/2019, Article 2(1)(6). The 2019 Act already contained a definition of "sex characteristics" in Article 2(1)(2).

99 It is possible that some individuals included in the legal definition may not identify as intersex.

100 The rule was defined to include, among other things, surgery, medication, and other permanent medical interventions.

reasons".[101] When therapeutic interventions are carried out based on this exception a detailed, legislated decision-making procedure applies, where parents or legal guardians are to be advised by an interdisciplinary team of experts.[102] A reasoned view shall be given as to whether permanent interventions can be postponed until the child is old enough to give their full consent.[103] Parents moreover have a right to an external second expert opinion, free of charge.[104]

Fourthly, in cases of non-therapeutic medical interventions, any permanent modifications of sex characteristics shall conform with the will of the child and the development of their gender identity.[105] Such non-therapeutic interventions must be approved by parents as well as an expert committee, which shall base its decision on an inquiry into the child's views.[106]

Fifthly, the law contains an obligation to register all relevant interventions on children with variations in sex characteristics and an obligation to inform the Directorate of Health about the interventions and the age of the children who undergo them.[107] The deliberations for the decision shall be included in the patient's health record, to which they should be given access.[108] The law furthermore contains an obligation for the child's legal guardians to explain any interventions performed on them as soon as they are mature enough to understand.[109] These provisions are important to monitor the implementation of the law and secure the right to truth and freedom of information.[110] In an international comparison, they are uniquely pronounced in the Icelandic law and can also be considered international best practice.[111]

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101 Lög um kynrænt sjálfræði [Act on Gender Autonomy] no. 80/2019, Article 11a(2).
102 Ibid., Article 11a(3).
103 Ibid.
104 Ibid.
105 Ibid., Article 11a(6).
106 Ibid. One type of intervention – hormonal treatment to induce puberty – irrespectively does not require the approval of the expert committee.
107 Ibid., Article 11a(7).
108 Ibid., Article 11a(4).
109 Ibid.
110 On the freedom of information and intersex interventions in the UK context, see F. Garland et al, "Management of 'Disorders of Sex Development'/Intersex Variations in Children: Results from a Freedom of Information Exercise" (2021) 21 *Med Law Int* 116.
111 OHCHR, "Technical note on the human rights of intersex people: Human rights standards and good practices" (2023), https://www.ohchr.org/sites/default/files/2023-11/ohchr-technical-note-rights-intersex-people.pdf, 16, listing the 2020 Act's provision on record keeping as an example of good practice. The right to truth is also included in the The Yogyakarta Principles +10, as Principle 37.

Sixthly, two specific, non-therapeutic medical interventions are subject to special rules and exempted from the requirement of "health reasons".[112] The interventions are: (i) surgery to alter hypospadias,[113] and (ii) medication to alter micropenis.[114] While these two procedures are subject to the same heightened procedural safeguards as other interventions covered by the law, social, psychosocial or aesthetic reasons are not excluded from the assessment of the necessity of the treatment.[115] The short- and long-term risks and benefits must be assessed in detail, including the consequences of delaying medical interventions until the child is old enough to be able to provide their informed consent.[116]

The exemptions of micropenis and hypospadias were the most disputed topics within the working group. Both exemptions are based on purported negative experiences of living with penile variations, and are mostly concerned with social norms.[117] The exemptions were included at the insistence of the medical doctors in the group, who did not consider hypospadias and micropenis to belong to the intersex category, since medical treatments for these variations did not involve any gender "assignment", consequently not giving rise to the same ethical concerns as other intersex interventions.[118]

Regarding hypospadias, the Working Group report summarised certain arguments for distinguishing the variation from other variations of sex characteristics. It stated that while hypospadias was covered by the Icelandic law's broad definition of atypical sex characteristics, other definitions may exclude hypospadias. The report further claimed that performing surgical interventions early may be beneficial, stating that people who do not have a recollection of the surgery are more likely to have a positive body image.[119] It additionally pointed out that early interventions may have fewer complications, that the domestic experiences of such surgeries was generally positive and that health reasons may be closely intertwined with (psycho)social

112 Lög um kynrænt sjálfræði [Act on Gender Autonomy] no. 80/2019, Article 11a(5).

113 "Hypospadias" refers to when the opening of the urethra is not located at the tip of the penis. Hypospadias comes in many variations as the opening can be anywhere from just below the tip to the scrotum. WHO, International Classification of Diseases ICD-11 (2019), "LB53 Hypospadias".

114 As the word suggests, "micropenis' is a diagnosis based on the smallness of a child's penis, below a certain threshold. Ibid, "LB50 Micropenis".

115 Lög um kynrænt sjálfræði [Act on Gender Autonomy] no. 80/2019, Article 11a(5).

116 Ibid.

117 Icelandic Prime Minister's Office, "Working Group Report", 26. The working group's arguments on hypospadias and micropenis are reiterated in Icelandic Government Bill 154/2020, 16-17.

118 Whether hypospadias should fall within the legislative definition of intersex has also been discussed in the Maltese context. See Garland and Travis (2022), *Intersex Embodiment*, 129.

119 Icelandic Prime Minister's Office, "Working Group Report", 26. This notion can be traced back to the Johns Hopkins protocols, see A. Redick, "What Happened at Hopkins: The Creation of the Intersex Management Protocols" (2005) 12 *CJLG* 289.

and aesthetic factors.[120] Conversely, the most important arguments against exempting hypospadias surgery were also included. The most prominent among these was that the exemption, by legitimising the aesthetic, social and psychosocial reasons, ran contrary to the main idea of the legislative ban.[121] It was also pointed out that surgery always involves potential risks and that, in the absence of long-term studies demonstrating clear benefits, non-therapeutic surgeries should be avoided as a general principle.[122]

When it comes to micropenis, a variation which the report considers to a lesser extent, the exemption for hormonal treatment was mainly motivated by that treatment was considered effective only if performed on infants, and ineffective if postponed until the child can consent.[123] Moreover, the report pointed to few known risks or side effects, positive domestic medical experiences and that negative social and psychosocial impacts for the child are foreseeable in untreated cases.[124]

The more permissive regulation of the two medical interventions was the result of a compromise. A condition of the compromise was that the 2020 Act, and these exemptions in particular, was to be reconsidered within three years.[125] In public consultation on the legislative bill, several civil society organisations (including Human Rights Watch,[126] *Intersex Ísland*,[127] *Samtökin 78*[128] and Amnesty International[129]) expressed a positive view regarding the core of the law, but were very critical of the exceptions. In its written comments on the bill, the Icelandic Medical Association also expressed a positive view but stressed the importance of the treatments having been exempted.[130] The 2020 Act, largely framed as an important

120 Icelandic Prime Minister's Office, "Working Group Report", 26.
121 Ibid. Indeed, if surgery was medically necessary, it would be allowed under the main rule in any event.
122 Ibid, 27.
123 Ibid.
124 Ibid.
125 Lög um kynrænt sjálfræði [Act on Gender Autonomy] no. 80/2019, Temporary Provision as amended by the 2020 Act.
126 Human Rights Watch, "RE: Protecting the Rights of Children with Variations in Their Sex Characteristics" (2020), https://www.althingi.is/altext/erindi/151/151-284.pdf.
127 Intersex Ísland, "Comments to the Standing Committee on Judicial and Educational Affairs" (2020), available at: https://www.althingi.is/altext/erindi/151/151-156.pdf.
128 Samtökin 78, "Umsögn: Frumvarp til Laga um breytingu á Lögum um kynrænt sjálfræði, nr. 80/2019 (ódæmigerð kyneinkenni) [Commentary: Bill Amending the Act on Gender Autonomy No. 80/2019 (atypical sex characteristics)]" (2020), https://www.althingi.is/altext/erindi/151/151-215.pdf.
129 Amnesty International, "Efni: Umsögn íslandsdeildar Amnesty International um frumvarp um breytingu á lögum um kynrænt sjálfræði, nr. 80/2019. Þskj. 22, 22. Mál á 151. Löggj.þ. 2020-2021 [Topic: Amnesty International's Icelandic Department's Comments on the Bill to amend the Act on Gender Autonomy, no. 80/2019, case 22 of Law 151 2020-2021]" (2020), https://www.althingi.is/altext/erindi/151/151-213.pdf.
130 Icelandic Medical Association, "Frumvarp til laga um breytingu á lögum um kynrænt sjálfræði, nr. 80/2019 (ódæmigptö kyneinkenni), 22. mál, stjómarfrumvarp [Bill for the Amendment of the Act on Gender Autonomy, no. 80/2019 (Atypical Sex Characteristics), case 22, legislative draft] (2020), https://www.althingi.is/altext/erindi/151/151-1059.pdf.

advancement of the human rights of intersex people, passed with an overwhelming majority in Parliament.[131]

In this context, the clash between the competing frameworks of human rights and medicine clearly came to the fore. Icelandic legislation was inspired by supranational human rights frameworks, but supranational human rights standards tend to address the issue of children born with variations in sex characteristics at the level of principles, as opposed to analysing individual diagnoses and considering whether each diagnosis warrants similar treatment, which would be a more typical medical perspective. As such, the human rights framework has shunned questions of whether distinctions between cases are acceptable: a non-engagement which may be read as a signal that distinctions or exceptions are unacceptable. Yet, the silence on the issue can also be interpreted to the detriment of intersex children, demonstrated by the formulation of the Icelandic law.

Notwithstanding the practical reasons for needing to reach a compromise between different stakeholders to be able to establish a law, the exemptions in the 2020 Icelandic Act can be considered highly problematic.[132] The exceptions allow for different treatment of intersex individuals, depending on their type of variations in sex characteristics. Thereby, the bodily integrity of individuals with some intersex variations is more rigorously protected through law than that of those with the specific penile variations of micropenis and hypospadias, raising questions of whether the motivations for the difference in treatment are justifiable and in line with the prohibition of discrimination.[133]

Another issue is that the law neither introduces any sanctions on violation of the ban,[134] nor address non-consensual, non-therapeutic interventions carried out before the Act's

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131 51 votes in favour, 9 against. One opposition party strongly and publicly opposed the Act. The leader of said party, Sigmundur Gunnlaugsson, referred to the 2020 bill as "probably the most frightening parliamentary proposal I can recall in recent times" (translated from Icelandic by the authors). S. Gunnlaugsson, address to Parliament, 1 October 2022, transcription available at: https://www.althingi.is/altext/raeda/151/rad20201001T194913.html; S. Gunnlaugsson, "Þegar öfgar taka völdin [When Radicals Take Over]" (*Morgunblaðið*, 17 December 2020).

132 Some criticism has already been voiced by the Human Rights Committee, "Concluding observations on the sixth periodic report of Iceland", 26 November 2024, CCPR/C/ISL/CO/6, para. 13–14.

133 Non-discrimination norms in human rights law generally require, *inter alia,* that relevantly similar situations are treated alike, unless objective and reasonable justifications for a difference in treatment are present. Non-discrimination may also require that different situations are treated differently. See e.g. Human Rights Committee, "General Comment 18, Non-discrimination" (Thirty-seventh session, 1989), para. 7, 13; European Court of Human Rights, *Oršuš and Others v. Croatia* Application No 15766/03, 16 March 2010, at para. [149]–[150]. See also Alaattinoğlu, "Líkamleg friðhelgi intersex fólks: Blindur blettur í mannréttindabaráttu á Norðurlöndum og íslenska undantekningin [The Icelandic Exception: The Bodily Integrity of Intersex People, A Nordic Human Rights Blind Spot]".

134 Such sanctions are included in the Maltese and Greek legislation.

establishment. Moreover, it has failed to introduce any extraordinary remedies for victims of such violations, such as providing assistance in seeking access to justice.[135] Victims may claim damages based on existing rules on medical malpractice,[136] but accessing remedies through claiming legal liability for damages before courts may involve long, costly and psychologically difficult processes for victims. The silence on extraordinary remedies in the Gender Autonomy Act begs the question of whether the bodily integrity of people with variations in sex characteristics is duly protected by Iceland.[137]

The Implementation Gap: Who Benefits from Legal Bans?

At the time of writing, the Icelandic law has been in effect for four years. Therefore, experience of its implementation is limited, especially on account of the fairly rare occurrences of children born with variations in sex characteristics in a small country in this short timeframe. Nonetheless, the implementation of the 2020 Act is worth analysing to the extent possible. As a general conclusion, the empirical data gathered by the authors suggest that the 2020 Act is not implemented in the way in which it was intended by its drafters.

When it comes to accessing the right to truth, the authors found that the implementation of data collection in accordance with the 2020 Act has been slow to initialise. In an effort to ensure correct and transparent data on the medical interventions in question, the 2020 Act stipulated that medical professionals are to annually report the number and nature of performed interventions within the scope of the legislation to the Directorate of Health.[138] This specific duty of registration was intended to assist in the planned revision of the legislation.[139] Yet, in a response to a query on the status of the registry envisioned by the 2020 Act, the Directorate of Health revealed that the identification of diagnosis and procedure codes did not take place until November 2023, almost three years after the 2020 Act entered into force.[140] It seems that this reporting duty has been burdensome to implement with respect to the contrast and

135 See GA Res 60/147, 15 December 2005, A/RES/60/147 (2005), Article VIII.

136 These rules are set out in Act No. 111/2000, Lög um sjúklingatryggingar [Act on Patient Insurance] and the unwritten rules of Icelandic rules on liability and compensation.

137 In this context, see, for example, Committee on the Rights of the Child, "Concluding observations on the fifth periodic report of Denmark", 26 October 2017, CRC/C/DNK/CO/5, para. 24; Committee on the Rights of the Child, "Concluding observations on the combined sixth and seventh periodic reports of Sweden", 7 March 2023, CRC/C/SWE/CO/6-7, para. 27.

138 Lög um kynrænt sjálfræði [Act on Gender Autonomy] no. 80/2019, Article 11a(7).

139 Icelandic Government Bill 154/2020, 19.

140 E-mail from A. Harðardóttir, project manager at the Directorate of Health, 12 March 2024.

translation difficulties between the existing medical recordkeeping infrastructure, designed around medical terminology, and the 2020 Act, building on a more socially constructed view of gender and sex and human rights.[141]

Based on the diagnoses and interventions defined as relevant, the authors obtained confirmation that in the three year period from January 2021, when the 2020 Act entered into effect, until end of year 2023, a total of 30 hypospadias surgeries of children under sixteen were performed at Iceland's public hospitals, as well as one additional relevant surgery (unilateral oophorectomy).[142] These figures reveal that the 2020 Act has not limited the number of hypospadias surgeries, since they appear to have been performed at similar rates as in the years immediately prior to the 2020 Act.[143]

Disconcertingly, the elaborate decision-making procedure envisaged by the 2020 Act in the case of all interventions, including hypospadias surgery,[144] has not been followed. More specifically, the 2020 Act provided that a standing multidisciplinary team on children born with variations in sex characteristics, comprised of members with relevant expertise and experience, was to be appointed by the Minister of Health. The Bill[145] and the Working Group Report[146] both state that, while the law does not stipulate the categories of relevant expertise, these may be expected to include not only medical specialists, but also psychologists, social workers and/or experts in gender studies. Yet, this team was not appointed until 21 October 2022; Once appointed, it included only medical experts – of endocrinology and surgery –,[147] in direct contrast to the original intention of the drafters.[148]

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141 The difference between human rights and medical language when it comes to intersex has been discussed in other contexts, for example, by M. Carpenter, "The 'Normalization' of Intersex Bodies and 'Othering' of Intersex Identities in Australia" (2018) 15 *JBI* 487; F. Garland and M. Travis, "Making the State Responsible: Intersex Embodiment, Medical Jurisdiction and State Responsibility" (2020) 47 *Journal of Law and Society* 298.

142 Data processed on 20 March 2024 by A. Harðardóttir, project manager at the Directorate of Health. On file with authors.

143 The breakdown of annual number of hypospadias surgeries is as follows: 2023: 13, 2022: 10, 2021: 7, 2020: 8, 2019: 6, 2018: 6, 2017: 19, 2016: 22. Data processed on 20 March 2024 by A. Harðardóttir.

144 Lög um kynrænt sjálfræði [Act on Gender Autonomy] no. 80/2019, Article 11a(5), stating that paragraph 3 of the Article, outlining the decision-making procedure, applies to these surgeries.

145 Icelandic Government Bill 154/2020, 20.

146 Icelandic Prime Minister's Office, "Working Group Report", 23.

147 The Icelandic Government, "Teymi sérfræðinga um börn sem fæðast með ódæmigerð kyneinkenni [A team of experts on children born with atypical gender characteristics]" (2022), https://www.stjornarradid.is/raduneyti/nefndir/nanar-um-nefnd/?itemid=e980c237-539e-11ed-9bb1-005056bc4727.

148 The failure to create truly multidisciplinary teams in this context has been criticised by other authors. See, for example, F. Garland et al, "Management of 'Disorders of Sex Development'/Intersex Variations in Children: Results from a Freedom of Information Exercise", 138–141.

At least as late as April 2024, the team had never convened.[149] Decisions regarding the hypospadias surgeries carried out did thus not follow the procedure prescribed by the 2020 Act. The reason appears to be a misunderstanding regarding the obligations created by the law. In other words, the view within the Icelandic National University Hospital (*Landspítali*) seems to have been that hypospadias surgeries were entirely exempted from the 2020 Act.

Strikingly, the law does not seem to have changed medical practices in Iceland much.[150] In an interview for the purpose of this study, a medical expert pointed out that:

> "The law just was in line with what we were already doing. It did not change our practice, because the need for change, this big push for the law, was based on misconceptions on how we were working. So basically, we have been working like that for almost decades."[151]

The above observations demonstrate that the implementation of the Icelandic 2020 Act, which was intended to change previous practice, at least to some extent, has failed to integrate in medical practice. While a compromise was reached between opposing views in the design of the 2020 Act by continuing to allow certain interventions if the decision is made following a rigorous process involving interdisciplinary expertise, this compromise has been undermined by the lack of adherence to the new regulation.

Concerns about non-implementation have also been voiced by the UN Committee on the Rights of the Child in 2022, which has recommended that Iceland "ensure that the performance of unnecessary medical or surgical treatment on intersex children is safely deferred until children are able to provide their informed consent, in line with the prohibition of such procedures under the Act on Gender Autonomy".[152] Moreover, the Committee recommended that the country provides "reparations for children who received unnecessary treatment",

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149 E-mail from R. Bjarnason, physician-in-chief at the Children's Hospital at the National University Hospital of Iceland, 2 April 2024. It should be noted, however, that the individuals appointed to the team routinely collaborate and consult each other with respect to individual cases.

150 In addition to this, the expert commission under Article 9 of the Gender Autonomy Act, tasked with, among other things, approving permanent modifications of sex characteristics of children old enough to express their own views, has not received any requests within the scope of the relevant provision. There are however no indications that medical interventions falling within the scope of this particular provision have been performed in Iceland during the period. Rather, it appears that such situations have not come up since the 2020 Act was passed. Lög um kynrænt sjálfræði [Act on Gender Autonomy] no. 80/2019, Article 11a(6); e-mail from the Prime Minister's Office, 25 January 2024.

151 Interview with medical expert, 14 December 2021.

152 Committee on the Rights of the Child, "Concluding observations on the combined fifth and sixth periodic reports of Iceland", 23 June 2022, CRC/C/ISL/CO/5-6, para 26(b).

emphasising the need for access to remedies.[153] In a similar vein, the UN Human Rights Committee has expressed concerns regarding the exceptions included in the 2020 Act and recommended that the Act is reconsidered.[154] Indeed, a part of the compromise behind the 2020 Act was that revision was planned in three years,[155] and that compromise has been undermined as the Government has thus far failed to initiate the revision process.[156]

While these findings are concerning in and of themselves, of import in the international legal and scholarly discussion is that Iceland is not the only country in which bans on non-consensual, non-therapeutic interventions may be primarily, or even merely, symbolic. Worries regarding the non-implementation of prohibitions of non-consensual, non-therapeutic interventions have also surfaced in the other European countries which have established similar legislative bans. In 2019, for example, the UN Committee on the Rights of the Child expressed its concern that despite the much-discussed legislation in Malta, the first country to establish a ban, non-consensual, medically unnecessary surgeries and other procedures continued to be reported.[157] This is confirmed by civil society reporting, with the NGO StopIGM.org asserting that such procedures are "widespread and ongoing" and continue to be endorsed and facilitated by the healthcare system, and that Maltese children are sent for surgeries in other jurisdictions.[158] Similar observations have also been made, for example, regarding the Portuguese law.[159]

In their study of the Maltese law and context, Garland and Travis have concluded that "medical practice remains the same as pre-Act".[160] Further, Tabone, Garland and Travis consider the limited implementation of the Maltese law to stem from fundamental

153 Ibid.

154 Human Rights Committee, "Concluding observations on the sixth periodic report of Iceland", para. 13–14.

155 Lög um kynrænt sjálfræði [Act on Gender Autonomy] no. 80/2019, Temporary provision I.

156 E-mail from R. Ingvarsdóttir, legal advisor at the Ministry of Social Affairs and Labour, 12 December 2024, confirmed that the revision working group envisioned in the 2020 Act has not been appointed.

157 Committee on the Rights of the Child, "Concluding observations on the combined third to sixth periodic reports of Malta" para. 28(b).

158 StopIGM.org, "Intersex genital Mutilations. Human Rights Violations of Children with Variations of Reproductive Anatomy NGO Report to the 3rd to 6th Report of Malta on the Convention on the Rights of the Child (CRC)" (2019), https://intersex.shadowreport.org/public/2019-CRC-Malta-NGO-Zwischengeschlecht-Intersex-IGM.pdf, 7.

159 StopIGM.org, "Intersex genital Mutilations. Human Rights Violations of Children with Variations of Reproductive Anatomy NGO Report (for Session) to the 5th Periodic Report of Portugal on the International Covenant on Civil and Political Rights (CCPR)" (2020), https://intersex.shadowreport.org/public/2020-CCPR-Portugal-NGO-Zwischengeschlecht-Intersex-IGM.pdf; Human Rights Committee, "Concluding observations on the fifth periodic report of Portugal", para. 16–17.

170 Garland and Travis, *Intersex Embodiment*, 131.

disagreements about the definition and terminology between human rights experts and medical experts.[161] In the Maltese context, prominent discussions have centred on similar questions as debated by the Icelandic working group, such as whether people with hypospadias should be included in the national law.[162] Building on the Maltese example, Garland and Travis have also pointed out that "even comprehensive legal challenges informed by intersex experiences struggle to change the conceptualisation of intersex embodiment as disordered".[163] In general, the Maltese example – which served as a model for the Icelandic legislation – has many similarities to the Icelandic when it comes to a lack of implementation.

The prevalence of difficulties regarding the implementation of other European bans may be the result of different factors in each jurisdiction and generalisations carry risks.[164] Yet, a common element complicating the implementation is likely the clash between human rights and medical frameworks,[165] comprehensively illustrated by the Icelandic case. The Icelandic compromise illustrates how the competing frameworks of medicine and human rights have become enmeshed – seemingly through a broadening of the human rights framework and the co-optation of human rights language by medical professionals. At the same time, this alignment has led to a reinterpretation of human rights standards, as changes in the framework alone have not sufficed to alter medical practice. The Icelandic case demonstrates the volatility of the human rights framework, particularly in the face of soft and non-specific supranational standards, which appear to have facilitated the creation of illusory legislation at the national level.

In the mobilisation for the Icelandic 2020 Act and its subsequent establishment, a ban was framed by human rights defenders and state institutions as a way to redress a legal problem: the failure to regulate medical interventions on intersex children. Furthermore, the establishment of the law was an effort to place Iceland on the international forefront of the protection of intersex rights. While the law may have bolstered Iceland's international reputation as an LGBTIQ+ champion, a closer examination of its formulation and implementation reveals that it may have done less to protect intersex people's bodily integrity

161 Tabone et al, "Cultural Awareness of Intersex in Malta", 158.

162 Ibid.

163 Garland and Travis, *Intersex Embodiment*, 111.

164 Some examples of implementation problems in a range of countries which have some form of regulation on intersex interventions are recollected in E. Rubashkyn and I. Savelev, *Intersex Legal Mapping Report: Global Survey on Legal Protections for People Born with Variations in Sex Characteristics* (Geneva: ILGA World, December 2023), 26–42.

165 See Carpenter, "The 'Normalization' of Intersex Bodies and 'Othering' of Intersex Identities in Australia"; Garland and Travis, "Making the State Responsible".

or ensure access to justice and remedies. Iceland is not unique in this regard, as other internationally praised bans appear to share similar shortcomings in practice.[166] In our view, the problems discussed in this article are not solely indicative of medical resistance to legal regulation. [167] Rather, the Icelandic experience also highlights the inherent weakness of supranational soft law and the volatility of the human rights framework. The findings of this article align with earlier legal scholarship suggesting that legislative bans are not straightforward "solutions" to the issue of non-consensual, non-therapeutic medical interventions on intersex children but can serve as starting points. [168] Given this, the international community must critically scrutinize the provisions of national bans and monitor their implementation to avoid focusing solely on their text—an approach that risks overemphasizing their symbolic achievements.

Only Symbolic Bans?

As shown in this article, considerable work has been done by various international and regional human rights defenders and institutions to develop the intersex-specific application of human rights norms. Through the advocacy of civil society representatives, the work of experts and the expressed views of state representatives, the human rights community has established that non-consensual, non-therapeutic interventions violate several human rights norms. Largely motivated by these developments and an active use of the human rights framework by involved actors, a few countries have in recent years taken legislative action to ban such interventions on children with variations in sex characteristics. Globally, these bans have been welcomed by human rights defenders and institutions as effective ways of protecting the bodily integrity of intersex children.[169]

This article has revealed that a position firmly based on human rights, rather than medical principles, was an important factor behind the establishment of the Icelandic ban from 2020. As such, the human rights framing proved successful to gain institutional response and resonance.[170] Yet, the Icelandic case has also demonstrated that, while broad principles are

166 See Garland and Travis, *Intersex Embodiment*; Tabone et al, "Cultural Awareness of Intersex in Malta".
167 See, for example, Garland and Travis, *Intersex Embodiment*, 136.
168 Ibid.
169 See, for example, Rubashkyn and Savelev, *Intersex Legal Mapping Repor*t, 18–21.
170 On the institutional validation of grievances formulated as human rights claims (in a different context than the topic of this article), see D. Alaattinoğlu, *Grievance Formation, Rights and Remedies: Involuntary Sterilisation and Castration in the Nordics, 1930s–2020s* (Cambridge: Cambridge University Press, 2023), 204–207.

important and human rights law has identified "red lines" in terms of clear violations of rights, considerable work is necessary, particularly at the level of implementation, to give meaning to and strengthen human rights principles in practice, particularly regarding how these principles translate into medical practice. An important insight based on our analysis of the Icelandic case is that more emphasis should particularly be placed on reaching the medical community.

Consider that, even though the working group which worked out the precise wording of the Icelandic ban was from the start unanimous on that non-therapeutic – so-called "normalising" – interventions were not to be performed and that Iceland was to become a global leader in terms of intersex rights, it turned out that the members' understanding of the rights framework and the interventions which ought to be included in the ban was much less uniform. While a blurring of the competing frameworks, eventually reaching a compromise, made the Icelandic ban possible, the conflict between different conceptualisations of central issues in the law appears to only have been superficially solved during the drafting process, and continues in the limited implementation of the law.

This article has demonstrated the danger of overemphasising symbolic legislation in the case of the 2020 Icelandic ban of non-therapeutic, non-consensual interventions on children with variations in sex characteristics. The most central problems discussed in the Icelandic context appear not to be unique, but indicative of a transnational, European trend inherent in similar bans – also because such laws tend to become models for other countries seeking to establish legislation. Importantly, the conclusion of this article is not that states and human rights defenders should abandon prohibitions of non-therapeutic, non-consensual intersex interventions. Rather, the article suggests that a more binding and detailed supranational rights framework is needed, together with more empirical data and discussion on the precise provisions and implementation of national bans, as well as more efforts to reach medical professionals.[171] Only then can we hope to strengthen intersex people's bodily integrity, access to justice and remedies, rather than building castles in the sky.

[171] See also K. Roen, C. Breen and A. Yee, "Human Rights-Based Intersex Healthcare: Using Hospital Data to Quantify Genital and Reproductive Surgery on Children in Aotearoa New Zealand" (2023) 12 *Soc Sci* 660.