D5.2 eReport on Law, Ethics and Human Rights

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Junta de Andalucía
Consejería de Salud y Consumo
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ULB Université Libre de Bruxelles

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D5.2.1 Intersex Framings Within International Human Rights Law

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Intersex Framings Within International Human Rights Law

Introduction

Over the last decade, intersex human rights issues have received increasing attention at the international level. Largely thanks to the work of intersex human rights defenders, there is greater understanding by international human rights mechanisms as to the harms facing intersex people performed or condoned by states and other actors. As a consequence, there has been an increased amount of work undertaken to acknowledge how international human rights law relates to the rights of intersex people, including via public awareness campaigns and targeted recommendations directed at states to change practices that violate the rights of intersex people. This paper seeks to outline how international human rights law addresses the rights of intersex people. It further considers how intersex issues are framed by the human rights system.

As part of this research, the author undertook a review of all UN treaty body concluding observations on intersex issues in order to analyse which intersex issues were raised and how they were discussed. How intersex issues are framed in terms of the language used, the aspects of intersex that are considered relevant, and the human rights issues that intersex issues are associated with, can have implications for how states (including Ireland, which is examined as a case study in Section III) understand and respond to intersex issues. The review found that intersex-related recommendations were mostly discussed as 'harmful practices', although different treaty bodies take different approaches, and when discussing substantive intersex issues, intersex was rarely included within broader LGBTI frameworks. The findings from the review are discussed further in Section III. At the international level, how United Nations (UN) mechanisms frame intersex issues can impact what degree of responsibility a state may consider it has to guarantee the human rights of intersex people and can further impact what action a state takes on intersex issues. This question of framing can also present opportunities for civil society to demand action from states, in order to ensure the adequate protection of intersex people.

Section I: Understanding intersex human rights

The term 'intersex' and the issues intersex people can face are often misunderstood. While often conflated with gender and identity, intersex instead refers to innate physical characteristics of the body: specifically, variations in sex characteristics that people may be born with, and which may only become apparent later in life. These can include genitals, gonads or chromosome patterns that may be different to what is considered typical for male and female bodies.[1] Based on descriptions of intersex from the UN and advocacy groups, a simple definition of intersex used in this paper is that intersex people have innate sex characteristics that do not fit medical and social norms for female or male bodies, and that create risks or experiences of stigma, discrimination and harm.[2]

Intersex may be referred to by other names: for example, differences or disorders of sex development (DSD), variations of sex characteristics, or by variation-specific terminology tied to a medical diagnosis.[3] International human rights mechanisms have adopted the language of 'intersex' to describe this population as well as 'sex characteristics' to describe the physical

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[1] Office of the United Nations High Commissioner for Human Rights, 'UN Intersex Fact Sheet: Free and Equal Campaign' (September 2015) <https://www.unfe.org/intersex-awareness/> accessed 27 September 2017.

[2] Intersex Human Rights Australia, 'What Is Intersex? – Intersex Human Rights Australia' (2 August 2013) <https://ihra.org.au/18106/what-is-intersex/> accessed 21 June 2021.

[3] Tove Lundberg, Peter Hegarty and Katrina Roen, 'Making Sense of "Intersex" and "DSD": How Laypeople Understand and Use Terminology' (2018) 9 *Psychology & Sexuality* 161; Morgan Carpenter, 'The Human Rights of Intersex People: Addressing Harmful Practices and Rhetoric of Change' (2016) 24 *Reproductive Health Matters* 74; Georgiann Davis, '"DSD Is a Perfectly Fine Term": Reasserting Medical Authority through a Shift in Intersex Terminology' in PJ McGann and David J Hutson (eds), *Advances in Medical Sociology*, vol 12 (Emerald Group Publishing Limited 2011).

characteristics relating to sex that all people have. 'Sex characteristics' is defined in the Yogyakarta Principles plus 10 as 'each person's physical features relating to sex, including genitalia and other sexual and reproductive anatomy, chromosomes, hormones, and secondary physical features emerging from puberty'.[4] It is estimated that at least 0.05% of the population are intersex but that the figure may be up to 1.7%,[5] the broad range indicating the lack of research in this area, as well as competing claims as to which intersex traits should be classified as intersex at all. There are also over 40 different intersex variations.[6] The existence of so many different variations highlights the diversity of intersex bodies. While intersex bodies can look very different from one another and intersex people do not hold a singular identity, intersex people face common risks to their human rights.

Foremost among them is the risk of non-consensual medical interventions to change an individual's sex characteristics without their informed consent. These surgical and hormonal interventions are often rooted in stigma, discriminatory attitudes, and homophobic fears that people with bodies that are different may live as the 'wrong sex' and be involved in same-sex relations, as well as transphobic fears of transcending binary notions of sex.[7] While for centuries intersex people have been subjected to these fears by medical practitioners and by wider society, it was in the 1940s when this began to be translated to medical interventions on intersex people's bodies, with the development of medical techniques that would allow these kinds of

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[4] International Commission of Jurists, 'Yogyakarta Principles plus 10: Additional Principles and State Obligation on the Application of International Human Rights Law in Relation to Sexual Orientation, Gender Identity, Gender Expression and Sex Characteristics to Complement the Yogyakarta Principles' (2017) preamble. The Yogyakarta Principles clarify how international human rights law relates to sexual orientation and gender identity and are further discussed in Section II.

[5] Office of the United Nations High Commissioner for Human Rights, 'UN Intersex Fact Sheet: Free and Equal Campaign' (n 1); Intersex Human Rights Australia, 'Intersex Population Figures' (28 September 2013) <https://ihra.org.au/16601/intersex-numbers/> accessed 18 March 2021.

[6] Tiffany Jones et al, *Intersex: Stories and Statistics from Australia* (Open Book Publishers 2016) 82.

[7] Elizabeth Reis, *Bodies In Doubt: An American History of Intersex* (The John Hopkins University Press 2009).

interventions to take place.[8] It was during the 1950s and 1960s when psychologist Dr John Money's 'optimum gender of rearing model' was at its most influential. This theory supported medical interventions on intersex infants and children to align them with the sex most surgically feasible (typically, female) and supported hiding from the individual the truth of what had happened, based on the belief that this would help maintain a consistent gender identity in line with their (reformed) bodily anatomy.[9] Decades of this practice has meant that many intersex people may not know they have an intersex variation, may not know what medical interventions they have been subjected to, and can also face difficulties in accessing their medical records.[10] While medical practitioners may claim that practices have changed, for example, by providing more information to patients (or, at least, their parents) or point towards improvements in surgical techniques,[11] the human rights risks surrounding these treatments remain just as great today. With little transparency by doctors and hospitals over what practices do occur, intersex people in different regions of the world are subject to non-consensual and unnecessary medical interventions which can result in sterilisation, removal of tissue and sensation, life-long reliance on hormone replacement therapy, ongoing medical complications and the need for surgical revisions, and barriers to accessing appropriate health care over the course of their life.[12] The psychological impacts of these interventions and the secrecy and shame associated with having intersex traits are significant, and many intersex people may not be aware that there are other

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[8] Elizabeth Reis, 'Impossible Hermaphrodites: Intersex in America, 1620–1960' (2005) *The Journal of American History* 411, ch 5.

[9] ibid.

[10] Council of Europe Commissioner for Human Rights, 'Human Rights and Intersex People: Issue Paper' (2015) 14; Tiffany Jones et al, *Intersex: Stories and Statistics from Australia* (Open Book Publishers 2016) 105-106.

[11] Peter A Lee et al, 'Global Disorders of Sex Development Update since 2006: Perceptions, Approach and Care' (2016) 85 *Hormone Research in Paediatrics* 158.

[12] Human Rights Watch and InterACT, *'I Want to Be like Nature Made Me': Medically Unnecessary Surgeries on Intersex Children in the US* (25 July 2017) <https://www.hrw.org/report/2017/07/25/i-want-be-nature-made-me/medically-unnecessary-surgeries-intersex-children-us> accessed 7 November 2020.

intersex people and groups that they can reach out to, or conversely, that it may be dangerous to do so if there is a risk of being identified.[13]

Key human rights concerns

Current medical practices towards intersex people may contravene a wide range of human rights. Non-consensual interventions which are not medically necessary may contravene the right to bodily integrity in article 17 of the UNCRPD; the right to liberty and security of person in article 3 of the UDHR, article 9 of the ICCPR and article 14 of the UNCRPD; and also the non-derogable prohibition on torture or cruel, inhuman or degrading treatment or punishment as outlined in article 5 of the UDHR, article 7 of the ICCPR, article 37(a) of the UNCRC, article 15 of the UNCRPD, and articles 2 and 16(1) of the UNCAT.[14] These interventions may be consented to by parents, albeit often with limited information and lack of awareness of other options.[15] The UN has made it clear that in relation to these kinds of medical interventions, only the consent of the intersex individual themselves is appropriate.[16] There is limited understanding of the long-term outcomes of these interventions, and what is known is largely through personal testimonies.[17] Where there

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[13] Bonnie Hart and Jane Shakespeare-Finch, 'Intersex Lived Experience: Trauma and Posttraumatic Growth in Narratives' (2021) *Psychology & Sexuality* 14; Katrina Roen and Vickie Pasterski, 'Psychological Research and Intersex/DSD: Recent Developments and Future Directions' (2014) 5 *Psychology & Sexuality* 102.

[14] UNHRC, 'General Comment No. 35: Article 9 (Liberty and Security of Person)' (2014) CCPR/C/GC/35 at 3 and 9; UN Human Rights Council, 'Report of the Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, Juan E Mendez' (2013) A/HRC/22/53 at 32 and 39.

[15] Hart and Shakespeare-Finch (n 13); Halley P Crissman et al, 'Children with Disorders of Sex Development: A Qualitative Study of Early Parental Experience' (2011) *International Journal of Pediatric Endocrinology* 10.

[16] Office of the United Nations High Commissioner for Human Rights, 'Intersex Awareness Day – Wednesday 26 October' (24 October 2016) <https://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=20739&LangID=E%20viewed%2024> accessed 30 September 2017.

[17] OII Europe and Janik Bastien-Charlebois, '#MyIntersexStory' (2019) <https://oiieurope.org/wp-content/uploads/2019/11/testimonial_broch_21-21cm_for_web.pdf> accessed 7 October 2020.

is a lack of data on the ongoing health outcomes of these interventions,[18] these may also be classified in some instances as medical experimentation and without the consent of the individual may contravene the right to freedom from medical experimentation in article 7 of the ICCPR and article 15 of the UNCRPD.[19] As one of the key issues faced by intersex people, UN statements on intersex regularly raise non-consensual medical interventions,[20] although so far it has led to little change at a national level. In many national laws, parents have a right to make medical decisions on behalf of their child at least up until a certain age or maturity level.[21] Oftentimes, the right of children to bodily autonomy and the need for the child's informed consent in this context is perceived to amount to a conflict between the rights of the child and the rights of parents; or, alternatively, children's rights are considered to be synonymous with parental rights (so that informed consent means informed consent of the parent).[22]

Intersex people also face other barriers in accessing appropriate health care, including in appropriate transition from paediatric to adult health care, a general lack of knowledge of intersex variations by medical practitioners, and a history of medical trauma making it difficult to seek out

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[18] Amnesty International, 'First, Do No Harm: Ensuring the Rights of Children with Variations of Sex Characteristics in Denmark and Germany' (2017) 39–41; Lee et al (n 11) 170; Sarah M Creighton et al, 'Childhood Surgery for Ambiguous Genitalia: Glimpses of Practice Changes or More of the Same?' (2014) 5 *Psychology & Sexuality* 34.

[19] Tanya Ni Mhuirthile, 'Recent reforms in law on LGBT rights in Ireland: Tightening the tourniquet in the rights of vulnerable intersex people' in James Gallen & Tanya Ni Mhuirthile (eds), Law, Responsibility and Vulnerability: State Accountability and Responsiveness (Routledge forthcoming 2021).

[20] See, for example, Office of the United Nations High Commissioner for Human Rights, 'UN Intersex Fact Sheet: Free and Equal Campaign' (n 1); Office of the United Nations High Commissioner, 'Opening Statement by UN High Commissioner for Human Rights Zeid Ra'ad Al Hussein at the 30th Session of the Human Rights Council' (16 September 2015) <https://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=16431&LangID=E> accessed 20 September 2018.

[21] In Ireland, section 23 of the Non-Fatal Offences Against the Person Act 1997 specifies that children aged 16 or over can give consent to surgical, medical or dental procedures without requiring consent from a parent or guardian. Under the age of 16, children who have sufficient understanding and intelligence to understand the proposed medical treatment ('Gillick competence') may consent to or refuse their own treatment, however determining the Gillick competency of a child must be done on a case-by-case basis (see *Gillick v West Norfolk and Wisbech Area Health Authority* [1985] UKHL 7).

[22] In Ireland, the Irish Constitution enshrines the rights of the family and education of children in articles 41 and 42.

medical care.[23] This results in difficulties in accessing appropriate and affordable expertise. A lack of studies on intersex variations has also resulted in little understanding of how to manage intersex people's health needs, whether related to their intersex variation or not. These issues in accessing appropriate health care contravene the right in article 12 of the ICESCR to the enjoyment of the highest attainable standard of physical and mental health.

Intersex people can face discrimination in education, employment and sport.[24] This is protected against in articles 2 and 7 of the UDHR, articles 2(1) and 26 of the ICCPR, article 2 of the ICESCR and article 2 of the UNCRC. Such discrimination can be direct, due to obvious physical differences and bullying and mistreatment, or indirect, due to environments which are not accommodating for individuals who may need to take extended periods of time away for medical treatments or may require reasonable adjustments. Within sporting contexts, intersex issues have been highly profiled with the contentious regulations imposed by international sporting organisations on elite intersex women athletes.[25] On 18 February 2021, Caster Semenya, a South African athlete singled out by these regulations for having naturally elevated levels of testosterone, lodged an application with the European Court of Human Rights in order to challenge the regulations that prevent her from competing by World Athletics, on the grounds of violation of her right to respect for private life, prohibition of discrimination, and prohibition of inhuman or degrading treatment.[26]

Access to accurate legal documentation can also be problematic for some intersex people. While many intersex people's gender aligns with their legal gender documentation, some do not identify

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[23] Amy Rosenwohl-Mack et al, 'A National Study on the Physical and Mental Health of Intersex Adults in the US' (2020) 15 PLOS ONE <https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0240088>; Jones et al (n 6).

[24] European Union Agency for Fundamental Rights, *A Long Way to Go for LGBTI Equality* (Publications Office 2020) <https://data.europa.eu/doi/10.2811/582502> accessed 26 February 2021.

[25] Human Rights Watch, '"They're Chasing Us Away from Sport"' (2020) <https://www.hrw.org/report/2020/12/04/theyre-chasing-us-away-sport/human-rights-violations-sex-testing-elite-women> accessed 5 January 2021.

[26] *Semenya v Switzerland* App no 10934/21(ECtHR, 18 February 2021).

with an assignment they were socially or medically forced into, and often face barriers in changing their legal gender.[27] Article 7 of the UNCRC, article 24 of the ICCPR and article 18(2) of the UNCRPD recognise a right to be registered immediately after birth with a name and right to a nationality, but do not require that a sex or gender be recorded.[28] Requirements by many states to register a sex or gender at or shortly after birth, as well as barriers to change documentation, can therefore limit access to accurate documentation.

Intersex people also have a history of being subject to medical photography and may lack privacy in medical spaces, in institutions and during travel.[29] Under article 16 of the UNCRC, all people have the right to privacy, including the right to private life, freedom from arbitrary or unlawful interference with privacy, and a right to the development and preservation of identity. Stigma, shame and superstition regarding intersex variations can result, in some regions, in intersex people being at risk of infanticide,[30] violating the right to life as protected under article 3 of the UDHR, article 6 of the ICCPR, article 10 of the UNCRPD and article 6(1) of the UNCRC. Intersex people also struggle to access justice, including due to statutes of limitations barring claims,[31] and lack access to redress and compensation for harms suffered, as protected in article 14 of the UNCAT.

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[27] European Commission Directorate General for Justice and Consumers, 'Trans and Intersex Equality Rights in Europe: A Comparative Analysis' (*Publications Office* 2018) ch 3 <https://data.europa.eu/doi/10.2838/75428> accessed 8 February 2021.

[28] Office of the United Nations High Commissioner, 'Background Note Human Rights Violations against Intersex People' (2019).

[29] Alice Dreger, *Hermaphrodites and the medical invention of sex* (Harvard University Press 1998).

[30] UN Human Rights Council, 'Report of the Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment' (2016) A/HRC/31/57 at 50.

[31] *M v France (communicated case)* App No 42821/18 (ECtHR, October 2020).

Section II: The international human rights system

International human rights mechanisms have increasingly considered intersex rights. While none of the international human rights treaties explicitly mention intersex, they have since been interpreted to apply to intersex experiences. The following section outlines how intersex issues raised in the previous section have been considered and framed in the international human rights system, by examining the Yogyakarta Principles and UN human rights mechanisms.

Yogyakarta Principles

The Yogyakarta Principles, published in 2007, are guiding principles that outline how international human rights law relates to sexual orientation and gender identity.[32] As stated by the Co-Chairpersons of the drafting committee, they are designed 'to be a coherent and comprehensive articulation of the obligations of states and non-state actors to respect, protect, and fulfil the human rights of all persons regardless of sexual orientation and gender identity'.[33] Unlike the international human rights treaties which states sign and agree to be bound by, the Yogyakarta Principles have not been agreed to by states per se. They are not designed to set out new rights, but rather to clarify rights that are already held. Furthermore, in recognition of the universality of rights, the drafters chose to use the neutral, universal language of 'sexual orientation' and 'gender identity' which applies to all people.[34]

Ten years later, the 'Yogyakarta Principles plus 10' were developed to supplement the original Yogyakarta Principles.[35] This document outlines the developments from the preceding ten years since original publication, establishes additional principles and state obligations, and, importantly,

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[32] 'Yogyakarta Principles on the Application of International Human Rights Law in relation to Sexual Orientation and Gender Identity' (2007) <http://yogyakartaprinciples.org/wp-content/uploads/2016/08/principles_en.pdf> accessed 29 January 2021.

[33] 'An Activist's Guide to the Yogyakarta Principles' (2010) <http://yogyakartaprinciples.org/wp-content/uploads/2016/10/Activists_Guide_English_nov_14_2010.pdf> accessed 16 March 2021.

[34] Michael O'Flaherty, 'The Yogyakarta Principles at Ten' (2015) 33 *Nordic Journal of Human Rights* 280, 284.

[35] International Commission of Jurists (n 4).

gives recognition to how international human rights law impacts people on the distinct and intersectional grounds of 'gender expression' and 'sex characteristics'.[36]

The addition of sex characteristics reflects a shift in understanding in the last decade of how sexual orientation and gender identity grounds alone are not enough to adequately cover the experience of intersex. As Morgan Carpenter (drafter to the Yogyakarta Principles plus 10 and intersex advocate) writes, the original Yogyakarta Principles were not suitable to cover diverse bodies rather than just diverse identities.[37] Discussions of sexual orientation and gender identity often presume the agency of individuals to express those identities, whereas young intersex people may not be old enough to express their gender or sexual orientation or preferences for what their body might look like before they are at risk of irreversible medical intervention. This shift to include sex characteristics reflects the commentary from the interim ten years from international bodies to the effect that intersex concerns are intended to be covered under international human rights law.

The Yogyakarta Principles plus 10 introduce a number of additional principles and state obligations directly relevant to intersex issues, including: the right to bodily and mental integrity (principle 32); the right to legal recognition (principle 31); the right to the highest attainable standard of health (principle 17); the right to truth (principle 37); as well as rights relating to equality and non-discrimination (principle 2); privacy (principle 6); and freedom from torture and cruel, inhuman or degrading treatment (principle 10). Considering these rights in relation to sex characteristics extends our interpretation of international human rights law to intersex experiences.

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[36] ibid.

[37] Morgan Carpenter, 'Intersex Human Rights, Sexual Orientation, Gender Identity, Sex Characteristics and the Yogyakarta Principles plus 10' (2020) *Culture, Health & Sexuality* 1 at 4.

Office of the High Commissioner of Human Rights

The Office of the High Commissioner of Human Rights (OHCHR) is the department of the UN that works on promoting human rights and supports the UN Human Rights Council and treaty monitoring bodies. Over the past decade, the OHCHR has become increasingly vocal about intersex human rights issues. In a report in 2011 on 'Discriminatory laws and practices and acts of violence against individuals based on their sexual orientation and gender identity', non-consensual interventions on intersex children were briefly mentioned.[38] This was then expanded upon in a 2014 UN interagency statement lead by the World Health Organization, of which OHCHR was a co-author, on eliminating forced, coercive, and otherwise involuntary sterilization.[39] Former President of Ireland and former UN High Commissioner for Human Rights, Mary Robinson, was one of the signatories to the Yogyakarta Principles.

Since 2015, OHCHR has been more actively engaged with intersex issues. In his opening statement to the 30th session of the Human Rights Council, the UN High Commissioner for Human Rights, Zeid Ra'ad Al Hussein, declared that intersex children and adults are 'frequently subjected to forced sterilization and other unnecessary and irreversible surgery, and suffer discrimination in schools, workplaces and other settings.'[40] In September 2015, the OHCHR convened an expert meeting on ending human rights violations against intersex persons, marking the first time the

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[38] UN General Assembly, 'Discriminatory Laws and Practices and Acts of Violence against Individuals Based on Their Sexual Orientation and Gender Identity' (2011) A/HRC/19/41 at 57.

[39] Office of the United Nations High Commissioner for Human Rights et al, 'UN Interagency Statement - Eliminating Forced, Coercive and Otherwise Involuntary Sterilization' (2014) <https://www.who.int/reproductivehealth/publications/gender_rights/eliminating-forced-sterilization/en/> accessed 7 October 2017.

[40] Office of the United Nations High Commissioner, 'Opening Statement by UN High Commissioner for Human Rights Zeid Ra'ad Al Hussein at the 30th Session of the Human Rights Council' (16 September 2015) <https://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=16431&LangID=E> accessed 21 January 2021.

UN had convened a discussion to solely address intersex human rights issues.[41] In the same month, OHCHR included intersex in its public awareness 'Free and Equal' campaign on the rights of LGBTI people which included a fact sheet and video.[42] In 2016, in advance of Intersex Awareness Day, a group of UN and regional human rights experts made a joint statement speaking out against intersex human rights violations and called on states to prohibit unnecessary medical practices on intersex children without their informed consent.[43] In 2016, OHCHR published 'Living Free and Equal' which outlined a number of harms faced by intersex people on the basis of sex characteristics,[44] and in 2019, OHCHR published a second edition of its report, 'Born Free and Equal: Sexual Orientation, Gender Identity and Sex Characteristics in International Human Rights law', which includes recommendations directed at the rights of intersex people,[45] a development from the 2012 version which solely focused on LGBT issues. In 2019 also, the UN published a background note on human rights violations against intersex people, detailing the human rights issues facing intersex people and the work undertaken by the UN and intersex human rights defenders.[46]

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[41] Office of the United Nations High Commissioner for Human Rights, 'Opening Remarks by Zeid Ra'ad Al Hussein, United Nations High Commissioner for Human Rights at the Expert Meeting on Ending Human Rights Violations against Intersex Persons' <http://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=16431&LangID=E> accessed 21 January 2021.

[42] United Nations Free & Equal, 'Intersex Babies Are Perfect Just as They Are!' (*UN Free & Equal*) <https://www.unfe.org/intersex-awareness/> accessed 23 March 2021.

[43] Office of the United Nations High Commissioner for Human Rights, 'Intersex Awareness Day – Wednesday 26 October' (n 16).

[44] UN OHCHR, 'Living Free and Equal' (2016) <https://www.ohchr.org/Documents/Publications/LivingFreeAndEqual.pdf> accessed 29 April 2021.

[45] Office of the United Nations High Commissioner for Human Rights, 'Born Free and Equal: Sexual Orientation, Gender Identity and Sex Characteristics in International Human Rights Law' (2019) <https://www.ohchr.org/Documents/Publications/Born_Free_and_Equal_WEB.pdf> accessed 29 April 2021.

[46] Office of the United Nations High Commissioner, 'Background Note Human Rights Violations against Intersex People' (2019) <https://www.ohchr.org/Documents/Issues/Discrimination/LGBT/BackgroundNoteHumanRightsViolationsagainstIntersexPeople.pdf> accessed 29 April 2021.

These developments reflect the UN's increased engagement and growing understanding of the importance of highlighting intersex issues. While the work of the OHCHR is not law, the visibility the OHCHR gives to intersex issues and its highlighting of the human rights violations towards intersex provides an educative function and reflects a growing awareness within the UN system of these issues.

UN Human Rights Council and Special Procedures

The UN Human Rights Council is an inter-governmental body made up of 47 Member States elected by the UN General Assembly and responsible for promoting and protecting human rights. One way it does this is through its reports and recommendations to states. In a 2019 resolution on the elimination of discrimination against women and girls in sport, the UN Human Rights Council expressed concern at the discriminatory regulations that impact women and girls with differences of sex development.[47] In the report that followed, the terminology shifted to variations in sex characteristics, and it outlined how female eligibility regulations contravened the rights of people with variations in sex characteristics to a number of human rights as outlined previously, and also the right to work and to the enjoyment of just and favourable conditions of work.[48]

Another way that the UN Human Rights Council seeks to protect human rights is through its Special Procedures mechanism. The Special Procedures of the Human Rights Council are experts who are independent of governments or organisations. Their role includes reporting and advising on human rights that relate to their thematic or country-specific mandate. As part of their functions, they can send communications to States and organisations in relation to human rights concerns.

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[47] UN Human Rights Council, 'Elimination of Discrimination against Women and Girls in Sport' (2019) A/HRC/40/L.10/Rev.1.

[48] Office of the United Nations High Commissioner for Human Rights, 'Intersection of Race and Gender Discrimination in Sport' (2020) A/HRC/44/26 at 34.

A number of Special Procedures have mandates that impact on issues affecting intersex people. In February 2013, the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, Juan E Méndez, commenting on LGBTI persons, called upon states to repeal any law allowing intrusive and irreversible treatments, including forced genital-normalizing surgery, involuntary sterilization, unethical experimentation, medical display, 'reparative therapies' or 'conversion therapies', when enforced or administered without the free and informed consent of the person concerned.[49] In 2016, the same Special Rapporteur, reporting on torture towards women, girls and LGBTI persons, focused on the harms caused to intersex people in health care settings, noting that 'discrimination against women, girls, and persons on the basis of sex, gender, real or perceived sexual orientation or gender identity and sex characteristics often underpins their torture and ill-treatment in health-care settings,'[50] and called on states to 'repeal laws that allow intrusive and irreversible treatments of lesbian, gay, bisexual, transgender and intersex persons including, *inter alia*, genital-normalizing surgeries and "reparative" or "conversion" therapies, whenever they are enforced or administered without the free and informed consent of the person concerned'.[51]

In 2009, the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, Anand Grover, outlined that 'health-care providers should strive to postpone non-emergency invasive and irreversible interventions until the child is sufficiently mature to provide informed consent', and highlighted this was particularly so in relation to intersex surgeries.[52] In July 2015, the subsequent Special Rapporteur, Dainius Puras, made recommendations to states in relation to the health of children, in which he recommended:

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[49] UN Human Rights Council, 'Report of the Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, Juan E Mendez' (2013) A/HRC/22/53 at 88.

[50] ibid at 42.

[51] ibid at 72(i).

[52] United Nations General Assembly, 'Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health, Anand Grover' (2009) A/64/272 at 49.

> To prohibit discrimination against intersex people, including by banning unnecessary medical or surgical treatment, and adopt measures to overcome discriminatory attitudes and practices through awareness-raising, training for public officials and medical professionals and the elaboration of ethical and professional standards that respect the rights of intersex persons, in consultation with intersex people and their organizations. [53]

As noted above, intersex health issues are not solely related to just non-consensual medical interventions. In 2016, the same Special Rapporteur, reporting on sport and healthy lifestyles, made recommendations to:

> Protect the physical integrity and dignity of all athletes, including intersex and transgender women athletes, and immediately remove any laws, policies and programmes that restrict their participation or otherwise discriminate or require them to undergo intrusive, unnecessary medical examinations, testing and/or procedures in order to participate in sport.[54]

The Special Rapporteurs on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, Dainius Puras, and on torture and other cruel, inhuman or degrading treatment or punishment, Nils Melzer, also sent joint communications to medical and sporting bodies, calling for the better protection of rights for intersex persons. Two communications were sent in February 2018, one to the American Academy of Pediatrics and the other to the American Medical Association, calling for, *inter alia*, a prohibition on medically unnecessary surgeries and procedures on intersex children and training for health professionals

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[53] UN General Assembly, 'Report of the Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health' (2015) at 112(m).

[54] UN General Assembly, 'Report of the Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health' (2016) A/HRC/32/33 at 101(i).

in line with human rights standards.[55] In September 2018, a third communication was sent, jointly also with the Working Group on the issue of discrimination against women in law and practice, to the president of the International Association of Athletics Federations (now World Athletics), calling for the removal of guidelines that unfairly discriminate against intersex athletes.[56] These actions show a willingness to engage non-state actors in the treatment of intersex people. Ultimately however this mechanism has no ability to enforce compliance and it does not appear that these communications have received a response.[57]

The Special Rapporteur on the right to privacy, Joseph A Cannataci, has also recently commented on the human rights issues impacting intersex people as they relate to privacy, noting that birth certificates can create challenges for attainting 'dignity, identity, privacy and development for transgender and intersex children',[58] and further that children with variations in sex characteristics can be subject to violence, discrimination, harassment, pathologisation of their body, and unnecessary medical treatment, as well as publication of details about their genitalia, stigmatisation and withholding of specific health services.[59]

Conversely, the previous Independent Expert on Sexual Orientation and Gender Identity, Vitit Muntarbhorn, whose mandate began in 2016, has also commented on the treatment of intersex

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[55] 'Communication to Dr Agliano, Chair of American Medical Association Council on Ethical and Judicial Affairs' (1 February 2018) <https://spcommreports.ohchr.org/TMResultsBase/DownLoadPublicCommunicationFile?gId=23617> accessed 22 February 2021; 'Communication to Dr Kraft, American Academy of Pediatrics' (1 February 2018) <https://spcommreports.ohchr.org/TMResultsBase/DownLoadPublicCommunicationFile?gId=23618> accessed 22 February 2021.

[56] 'Communication to Mr Coe, President International Association of Athletics Federations' (18 September 2018) <https://spcommreports.ohchr.org/TMResultsBase/DownLoadPublicCommunicationFile?gId=24087> accessed 21 February 2021.

[57] Replies to communications sent by special procedures are available on the OHCHR public database at https://spcommreports.ohchr.org/. No response is listed for these communications.

[58] UN Human Rights Council, 'Artificial Intelligence and Privacy, and Children's Privacy: Report of the Special Rapporteur on the Right to Privacy, Joseph A Cannataci' (2021) A/HRC/46/37 at 103.

[59] ibid at 98(c).

people but has been cautious on the extent of the mandate to cover intersex issues. In his inaugural report to the UN General Assembly and to the UN Human Rights Council, he recognised that intersex people face distinct issues,[60] and clarified that the mandate will cover intersex only where there 'is a link with sexual orientation and gender identity'.[61] Similarly his successor, Victor Madrigal-Borloz, has also been careful not to confuse the issues together and has limited intersex inclusion in his reports, although he has been vocal in his support for intersex issues elsewhere.[62]

Section III: Framing of intersex human rights

Framing of human rights and treaty body mechanisms

The framing of intersex human rights can have implications for how the state understands intersex issues and how it responds to them. The role of treaty body mechanisms is particularly important in this regard. This section considers how treaty body mechanisms have framed intersex human rights issues and recommendations to Ireland, as well as how Ireland has responded to intersex concerns.

States that have signed and ratified UN treaties are subject to review by the UN treaty body committee that is responsible for its oversight (known as treaty body mechanisms). While the process varies amongst treaty bodies, typically states provide periodic reports to the relevant UN treaty body mechanism and on the basis of this report, the committee prepares a list of issues in advance of the session where the treaty body will consider the state report in order to help frame the dialogue with the state. The treaty body then provides a report of concluding observations

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[60] UN General Assembly, 'Protection against Violence and Discrimination Based on Sexual Orientation and Gender Identity' (2017) A/72/172 at 7.

[61] UN Human Rights Council, 'Report of the Independent Expert on Protection against Violence and Discrimination Based on Sexual Orientation and Gender Identity, Vitit Muntarbhorn' (2017) A/HRC/35/36 at 6.

[62] See, for example, ILGA World, 'International Intersex Virtual Forum: How to Be a Good Intersex Ally' (*ILGA*, 13 October 2020) <https://ilga.org/intersex-forum-webinar-allyship> accessed 25 March 2021.

and recommendations after considering the State party's report.[63] Many treaty bodies also require states to report back to the treaty body on their progress on implementing the recommendations in 'follow-up procedures'.[64]

Intersex issues were first raised in concluding observations by the Committee on the Elimination of Discrimination Against Women (CEDAW) to Germany in 2009, which recommended that Germany engage further with non-government intersex organisations to further understand their claims and to better protect intersex human rights.[65] The rest of this section considers the concluding observations by UN treaty body mechanisms directed at intersex human rights concerns.

In order to have a comprehensive understanding of how UN treaty bodies discussed intersex issues, the author undertook a review of all treaty body concluding observations across all states that mention 'intersex' and 'sex characteristics' in a substantive way since this first observation in 2009. References to 'intersex' or 'sex characteristics' included within references to lesbian, gay, bisexual, transgender and intersex were not considered, given these references typically do not consider how the issues specifically impact intersex people. Instead, this review focused on intersex specific references and recommendations. The review was conducted by searching the UN 'Universal Human Rights Index' database and cross-checking it against the ILGA World treaty body annual reports (available since 2014) and OII Europe's International Intersex Human Rights Movement resource list.[66] This review captures treaty body concluding observations from 12 December 2011 to 12 February 2021.

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[63] See, for example, the report of the UN Committee on the Rights of the Child, 'Concluding observations on the combined third and fourth periodic reports of Ireland' (2016) CRC/C/IRL/CO/3-4.

[64] Office of the United Nations High Commissioner, 'The United Nations Human Rights Treaty System Fact Sheet No 30/Rev 1' 29 <https://www.ohchr.org/Documents/Publications/FactSheet30Rev1.pdf> accessed 22 July 2021.

[65] UN Committee on the Elimination of Discrimination Against Women, 'Concluding Observations of the Committee on the Elimination of Discrimination against Women' (2009) CEDAW/C/DEU/CO/6 at 62.

[66] The database is available at https://uhri.ohchr.org/en/. The search parameters used were: 'all countries'; 'all mechanisms'; 'all human rights themes'; 'all concerned persons/groups'; the text search of 'intersex' and then

Overall, there were 66 reports directed at 32 different states and across six committees that included at least one substantive intersex specific reference. The count is determined by each report to a state that makes at least one intersex reference. For example, if a country made multiple intersex references in the same report, it would be counted as one. It was found that most of the substantive references used ‘intersex’. ‘Sex characteristics’ was not commonly used in these reports and when it was, it was rarely in a substantive way but included alongside sexual orientation and gender identity.[67] The Committee on the Rights of the Child (CRC) had 19 reports with an intersex recommendation (including one directed at Ireland in 2016),[68] and one report in relation to the Optional Protocol on Sale of Children; CEDAW had 18 reports (including one directed at Ireland in 2017);[69] the Committee Against Torture (CAT) had eight reports; the Committee on the Rights of Persons with Disabilities had eight reports; the Human Rights Committee had seven reports; and the Committee on the Economic, Social and Cultural Rights (CESCR) had six reports. Germany is the only country that has twice received recommendations from the same body in relation to intersex concerns, specifically from CEDAW in 2009 (the first recommendation) and again in 2017 recommending, *inter alia*, that the state adopt legislation to prohibit unnecessary surgeries on intersex children until they can provide informed consent.[70] Collectively, the recommendations from the committees were spread geographically with 17 reports directed at states in Europe, six in Asia, four in South America, three in Africa and two in Oceania.

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separately ‘sex characteristics’. Document type was limited to ‘concluding observations’, and the date range was from 12 December 2011 (the first UN treaty body recommendation on intersex) to 12 February 2021 (when the review was undertaken).

[67] With the exception of the UN Committee on the Rights of Persons with Disabilities, ‘Concluding observations on the sixth periodic report of Australia’ (2017) CCPR/C/AUS/CO/6 at 26 which refers to ‘infants and children born with variations in sex characteristics’.

[68] UN Committee on the Rights of the Child, ‘Concluding observations on the combined third and fourth periodic reports of Ireland’ (2016) CRC/C/IRL/CO/3-4.

[69] UN Committee on the Elimination of Discrimination Against Women, ‘Concluding observations on the combined sixth and seventh periodic reports of Ireland’ (2017) CEDAW/C/IRL/CO/6-7.

[70] UN Committee on the Elimination of Discrimination Against Women, ‘Concluding Observations on the combined seventh and eighth periodic reports of Germany’ (2017) CEDAW/C/DEU/CO/7-8 at 23 and 24.

The treaty bodies framed issues impacting intersex people, in order of frequency, under the headings of ‘harmful practices’, ‘intersex persons’, ‘health’, ‘sexual orientation, gender identity and intersex’ and at times by other specific convention rights.

Framing of intersex human rights concerns as ‘harmful practices’

The review found that intersex human rights concerns are commonly framed as ‘harmful practices’ by the CRC and CEDAW and less commonly as ‘stereotypes and harmful practices’ or ‘discriminatory stereotypes and harmful practices’. This has been a largely consistent framing since the CRC first began commenting on intersex issues in 2015. It has also been the majority of framings for CEDAW since 2016. In their concluding observations, these committees also consistently refer to their joint general recommendation on harmful practices,[71] and intend for intersex to be categorised similarly.

Some of the main recommendations from the CRC and CEDAW under ‘harmful practices’ have been to: prohibit children being subject to unnecessary surgeries;[72] provide families with intersex children with adequate counselling and support;[73] protect the physical and mental integrity, autonomy and self-determination of intersex people;[74] and ensure effective remedy for victims,

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[71] UN Committee on the Elimination of Discrimination Against Women and UN Committee on the Rights of the Child (n 70).

[72] See, for example, UN Committee on the Rights of the Child, ‘Concluding observations on the combined fifth and sixth periodic reports to Austria (2020) CRC/C/AUT/CO/5-6 at 27(a); ‘Concluding observations on the combined fifth and sixth periodic reports of Australia’ (2019) CRC/C/AUS/CO/5-6 at 31(b); ‘Concluding observations on the combined third to fifth periodic reports of Nepal’ (2016) CRC/C/NPL/CO/3-5 at 42(c); UN Committee on the Elimination of Discrimination Against Women, ‘Concluding observations on the seventh periodic report of Chile’ (2018) CEDAW/C/CHL/CO/7 at 22(a).

[73] See, for example, UN Committee on the Rights of the Child, ‘Concluding observations on the fifth periodic report of Denmark’ (2017) CRC/C/DNK/CO/5 at 24(a); UN Committee on the Elimination of Discrimination Against Women, ‘Concluding observations on the ninth periodic report of Mexico’ (2018) CEDAW/C/MEX/CO/9 at 22.

[74] See, for example, UN Committee on the Rights of the Child, ‘Concluding observations on the combined third and fourth periodic reports of Ireland’ (2016) CRC/C/IRL/CO/3-4 at 40(a).

including redress and compensation.[75] Other recommendations have included investigating incidents of treatments on intersex children without informed consent;[76] the need to develop a rights-based health care protocol;[77] and the need to educate and train medical and psychological professionals on diversity and the consequences of unnecessary surgery.[78]

Framing of 'intersex persons' as a category distinct from other human rights issues

Some committees have chosen to frame intersex issues under its own distinct category of 'intersex persons' or 'intersex children', most notably CAT and CESCR but also one instance from the Human Rights Committee.

Under this framing, committees have recommended that: all necessary measures need to be undertaken to ensure no child undergoes unnecessary surgery;[79] there is a need to guarantee impartial counselling services for all intersex children and their parents;[80] and there is a need to guarantee that full, free and informed consent is ensured and that a child is sufficiently mature to participate in decision-making and give effective consent.[81]

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[75] See, for example, UN Committee on the Rights of the Child, 'Concluding observations on the combined third to sixth reports of Malta' (2019) CRC/C/MLT/CO/3-6 at 29(e); UN Committee on the Elimination of Discrimination Against Women, 'Concluding observations on the eighth period report of New Zealand' (2018) CEDAW/C/NZL/CO/8 at 24(c).

[76] See, for example, UN Committee on the Rights of the Child, 'Concluding observations on the combined third to sixth reports of Malta' (2019) CRC/C/MLT/CO/3-6 at 29(e).

[77] See, for example, UN Committee on the Elimination of Discrimination Against Women, 'Concluding observations on the sixth periodic report of the Netherlands' (2016) CEDAW/C/NLD/CO/6 at 22(f).

[78] See, for example, UN Committee on the Elimination of Discrimination Against Women, 'Concluding observations on the eighth period report of New Zealand' (2018) CEDAW/C/NZL/CO/8 at 25(d).

[79] See, for example, UN Human Rights Committee, 'Concluding observations on the fourth periodic report of Switzerland' (2017) CCPR/C/CHE/CO/4 at 25(a).

[80] See, for example, UN Committee Against Torture, 'Concluding observations on the sixth periodic report of the United Kingdom of Great Britain and Northern Ireland' (2019) CAT/C/GBR/CO/6 at 65(a).

[81] See, for example, UN Committee Against Torture, 'Concluding observations on the sixth periodic report of Austria' (2016) CAT/C/AUT/CO/6 at 45(c).

Framing of intersex issues as health issues

CEDAW has mostly framed intersex human rights issues under harmful practices, but has also framed it under 'health' in concluding observations directed at Austria, Bulgaria, Italy, Liechtenstein and the Republic of Korea.

Under this framing, CEDAW has recommended: that states develop and implement a rights-based health-care protocol for intersex people;[82] that no person be subjected to surgery or treatment without their free, informed and prior consent;[83] and that children are involved to the greatest extent possible in decision making about medical interventions and their choices are respected.[84]

Framing of intersex issues in the category of 'sexual orientation, gender identity, and intersex'

The Human Rights Committee typically frames intersex issues under 'sexual orientation, gender identity and intersex status',[85] 'sexual orientation, gender identity and intersex status and persons with HIV',[86] 'sexual orientation, gender identity and intersexuality'[87] or, in concluding observations to Mexico, under 'discrimination and violence based on sexual orientation and

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[82] UN Committee on the Elimination of Discrimination Against Women, 'Concluding observations on the eighth periodic report of Bulgaria' (2020) CEDAW/C/BGR/CO/8 at 34(e); 'Concluding observations on the fifth periodic report of Liechtenstein' (2018) CEDAW/C/LIE/CO/5 at 36(c); 'Concluding observations on the seventh periodic report of Italy' (2017) CEDAW/C/ITA/CO/7 at 42(e).

[83] UN Committee on the Elimination of Discrimination Against Women, 'Concluding observations on the ninth periodic report of Austria' (2019) CEDAW/C/AUT/CO/9 at 35(e); 'Concluding observations on the eighth periodic report of Bulgaria' (2020) CEDAW/C/BGR/CO/8 at 34(d).

[84] UN Committee on the Elimination of Discrimination Against Women, 'Concluding observations on the seventh periodic report of Italy' (2017) CEDAW/C/ITA/CO/7 at 42(e).

[85] UN Human Rights Committee, 'Concluding observations on the sixth periodic report of Australia' (2017) CCPR/C/AUS/CO/6.

[86] UN Human Rights Committee, 'Concluding observations on the third periodic report of Viet Nam' (2019) CCPR/C/VNM/CO/3.

[87] UN Human Rights Committee, 'Concluding observations on the fifth periodic report of Portugal' (2020) CCPR/C/PRT/CO/5; 'Concluding observations on the sixth periodic report of Belgium' (2019) CCPR/C/BEL/CO/6.

gender identity'.[88] CAT also has one report to Hong Kong of intersex considered under 'transgender and intersex persons'[89] and CESCR has one report to Germany with 'intersex children and transgender persons'.[90] There was also one instance of framing by CEDAW to Slovakia in 2015 under the heading of 'disadvantaged and marginalized groups of women' where intersex was substantively discussed alongside issues facing transgender women.[91]

As outlined, this review only considered references that were intersex-specific. In many concluding observations there are references to LGBTI, with the I meaning intersex. This is often done however without considering how the issues impact intersex people or the issue discussed may not be relevant for intersex people. For example, there are numerous recommendations to decriminalise same-sex relations and this is considered an 'LGBTI issue' even though those discussions are about gay, lesbian or bisexual relationships.[92] Where intersex-specific issues are being considered, interestingly across the board there are few instances of intersex being discussed alongside LGBT or sexual orientation and gender identity.

Under this framing, the Human Rights Committee recommended strengthening measures to end the performance of irreversible medical acts, especially surgical operations, on intersex children who are not yet capable of giving their free and informed consent; except in cases where such

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[88] UN Human Rights Committee, 'Concluding observations on the sixth periodic report of Mexico' (2019) CCPR/C/MEX/CO/6.

[89] UN Committee Against Torture, 'Concluding observations on the fifth periodic report of China with respect to Hong Kong, China' (2016) CAT/C/CHN-HKG/CO/5.

[90] UN Committee on Economic, Social and Cultural Rights, 'Concluding observations on the sixth periodic report of Germany' (2018) E/C.12/DEU/CO/6.

[91] UN Committee on the Elimination of Discrimination Against Women, 'Concluding observations on the combined fifth and sixth periodic reports of Slovakia' (2015) CEDAW/C/SVK/CO/5-6 at 37(c).

[92] See, for example, UN Human Rights Committee, 'Concluding observations on the sixth periodic report of Tunisia' (2020) CCPR/C/TUN/CO/6 at 19-20 and UN Committee Against Torture, 'Concluding observations on the sixth periodic report of the Russian Federation' (2018) CAT/C/RUS/CO/6 at 32-33.

interventions are absolutely necessary for medical reasons.[93] CAT recommended Hong Kong take legislative, administrative and other measures necessary to respect the physical integrity and autonomy of intersex persons and to ensure that no one is subjected during infancy or childhood to non-urgent medical or surgical procedures intended to decide the sex of the child; guarantee impartial counselling services for all intersex children and their parents; guarantee full, free and informed consent and that non-urgent, irreversible medical treatments are postponed until a child is sufficiently mature to participate in decision-making and give effective consent; and provide adequate redress to intersex persons.[94] CESCR recommended Germany prohibit medically unnecessary surgery on intersex infants and children and provide an enabling environment in which intersex infants and children can develop and in which their preferred gender identity can be respected. It also recommends that the State party revise its gender laws in accordance with international human rights standards and best practice.[95]

Framing of intersex issues alongside particular rights

The Committee on the Rights of Persons with Disabilities has favoured discussing intersex issues with reference to particular rights. In six instances it has framed intersex issues under protecting

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[93] UN Human Rights Committee, 'Concluding observations on the fifth periodic report of Portugal' (2020) CCPR/C/PRT/CO/5 at 17; 'Concluding observations on the sixth periodic report of Belgium' (2019) CCPR/C/BEL/CO/6 at 22; 'Concluding observations on the sixth periodic report of Mexico' (2019) CCPR/C/MEX/CO/6 at 13.

[94] UN Committee Against Torture, 'Concluding observations on the fifth periodic report of China with respect to Hong Kong, China' (2016) CAT/C/CHN-HKG/CO/5 at 29.

[95] UN Committee on Economic, Social and Cultural Rights, 'Concluding observations on the sixth periodic report of Germany' (2018) E/C.12/DEU/CO/6 at 24 and 25.

the integrity of the person (art 17),[96] one framing to India under the right to life (art 10),[97] one to India on liberty of movement and nationality (art 18),[98] and one to the United Kingdom of Great Britain and Northern Ireland under freedom from exploitation, violence and abuse (art 16).[99]

The CRC also considered intersex issues under 'birth registration and nationality' in relation to Kenya,[100] the Human Rights Committee considered 'non-discrimination' in relation to Pakistan,[101] and CESCR considered 'sexual and reproductive rights' in relation to Argentina.[102] The CRC also gave concluding observations in one instance to India in 2014 regarding the optional protocol to the CRC on the sale of children, child prostitution and child pornography. Under article 9(1) and (2) of the optional protocol, the CRC commented on 'the inadequate protection of boys and intersex children from sexual abuse and exploitation' and recommended that 'prevention strategies incorporate key actions to address protection of boys and intersex children from sexual abuse'.[103]

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[96] UN Committee on the Rights of Persons with Disabilities, 'Concluding observations on the initial report of India' (2019) CRPD/C/IND/CO/1 at 36-37; 'Concluding observations on the combined second and third reports of Australia' (2019) CRPD/C/AUS/CO/2-3 at 33-34; 'Concluding observations on the initial report of Morocco' (2017) CRPD/C/MAR/CO/1 at 36-37; 'Concluding observations on the initial report of the United Kingdom of Great Britain and Northern Ireland' (2017) CRPD/C/GBR/CO/1 at 40-41; 'Concluding observations on the initial report of Italy' (2016) CRPD/C/ITA/CO/1 at 45-46; 'Concluding observations on the initial report of Germany' (2015) CRPD/C/DEU/CO/1 at 37-38.

[97] UN Committee on the Rights of Persons with Disabilities, 'Concluding observations on the initial report of India' (2019) CRPD/C/IND/CO/1 at 22-23.

[98] UN Committee on the Rights of Persons with Disabilities, 'Concluding observations on the initial report of India' (2019) CRPD/C/IND/CO/1 at 38-39.

[99] UN Committee on the Rights of Persons with Disabilities, 'Concluding observations on the initial report of the United Kingdom of Great Britain and Northern Ireland' (2017) CRPD/C/GBR/CO/1 at 38-39.

[100] UN Committee on the Rights of the Child, 'Concluding observations on the combined third to fifth periodic reports of Kenya' (2016) CRC/C/KEN/CO/3-5 at 29.

[101] UN Human Rights Committee, 'Concluding observations on the initial report of Pakistan' (2017) CCPR/C/PAK/CO/1 at 11.

[102] UN Committee on Economic, Social and Cultural Rights, 'Concluding observations on the fourth periodic report of Argentina' (2018) E/C.12/ARG/CO/4 at 55-56.

[103] UN Committee on the Rights of the Child, 'Concluding observations on the report submitted by India under article 12, paragraph 1, of the Optional Protocol to the Convention on the Rights of the Child on the sale of children, child prostitution and child pornography' (2014) at 21(d) and 22(d).

Many of the recommendations from the committees cover numerous and similar issues, regardless of the committee making the recommendation or the heading under which is it considered. Nevertheless, these recommendations reflect the breadth of concerns that overlap with a number of human rights issues and are directed at many countries from different regions of the world. That so many committees, which consider the rights outlined in different human rights treaties, have all made substantively similar comments and recommendations in relation to intersex issues reflects the degree to which intersex issues intersect with so many fundamental human rights issues and other populations. Further, while the substance of those concerns may be similar, how intersex human rights issues are framed still has important implications for how states might consider intersex concerns, and in turn which national departments and bodies they consider as relevant in this space and what actions they may subsequently take. Where intersex issues are framed under harmful practices, there may be a greater obligation for states to enact protections to prevent harm. Particularly when it comes to harmful practices directed at children, CEDAW and CRC recommend a greater role for states to intervene to protect the intersex child and the child's future ability to consent to interventions on their body. There is arguably no place for parental consent in cases of harm towards children. This is seen in other examples of state intervention to protect against harmful practices towards children even if a parent or guardian consents to the practice, like female genital mutilation or child abuse.[104] Concluding observations by the CAT have also caused particularly emotive reactions by perpetrators, who understand themselves as providing health care rather than being associated with torture or cruel, inhuman or degrading practices, reflecting that the language of human rights can itself be a barrier to change.[105] While this framing risks making discussions regarding these issues more divisive, it may lead the state to recognise the gravity of the practices. Bauer, Truffer and Crocetti see this framing

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[104] In Ireland, for example, section 2(3) of the Criminal Justice (Female Genital Mutilation) Act 2012 provides that it is not a defence for an offence of female genital mutilation that it was consented to by the parents or guardian of the girl concerned.

[105] Daniela Crocetti et al, '"You're Basically Calling Doctors Torturers": Stakeholder Framing Issues around Naming Intersex Rights Claims as Human Rights Abuses' (2020) 42 *Sociology of Health & Illness* 943, 953-954.

as more likely to guarantee legal repercussions by states and redress for intersex people.[106] Conversely, framing intersex issues under health requires a state to work progressively towards achieving the highest attainable standard of physical and mental health to the maximum of the state's available resources, and may result in greater work by medical professionals to work towards particular health outcomes for intersex people and include parents of intersex children within decision-making processes. Framings under LGBTI or sexual orientation, gender identity, and sex characteristics also have certain implications at a national level for which departments or local groups are considered relevant to be working on intersex issues and can potentially be problematic in some countries where intersex is confused with and considered the same as LGBT, or where being LGBT may be illegal and/or dangerous.

Quite consistently, the UN has adopted the language of 'intersex' to describe the population, even though terminology in this area is highly contested, following the language of intersex human rights defenders who have raised these issues at the international level. Different terminology may be suitable for different contexts, while some framings like 'disorders of sex development' or 'DSD' seek to shift definitions to exclude particular intersex traits and legitimise the medicalisation of intersex bodies. By arguing that people with DSDs are men or women with disorders, and choosing to frame intersex as an identity that is neither male or female, this conceptual shifting allows for the jurisdiction of the medical profession to continue 'treating' disordered men and women,[107] as well as legitimising the state to defer its jurisdiction over protecting the rights of intersex people to the medical profession.[108] This lack of medicalised language in UN documentation reflects a recognition at the international level that having an

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[106] Markus Bauer, Daniela Truffer and Daniela Crocetti, 'Intersex Human Rights' (2020) 24 *The International Journal of Human Rights* 724, 742.

[107] Morgan Carpenter, 'The "normalisation" of Intersex Bodies and "Othering" of Intersex Identities: The Experience in Australia' in Jens M Scherpe, Anatol Dutta and Tobias Helms (eds), *The Legal Status of Intersex Persons* (Intersentia 2018).

[108] Fae Garland and Mitchell Travis, 'Making the State Responsible: Intersex Embodiment, Medical Jurisdiction, and State Responsibility' (2020) 47(2) *Journal of Law and Society* 298, 307-309.

intersex variation is not solely a medical concern but that intersex people are a distinct group in need of human rights protection. It removes responsibility for the treatment of intersex people solely out of the medical jurisdiction and demands that states play a greater role in recognising and addressing the social, legal and medical issues that arise for intersex people.

Framing of intersex issues in Ireland

Ireland has signed and ratified numerous human rights treaties, agreeing to obligations to protect the human rights of all people, including intersex people.[109] However, there is currently little movement in Ireland to consider intersex issues as human rights concerns. The sparse work undertaken on intersex issues to date has framed intersex alongside gender issues and more broadly within LGBTI frameworks. The 2018 review of the Gender Recognition Act 2015 recommended that 'all measures taken to improve access to gender recognition […] should also provide access for intersex individuals/people with VSCs.'[110] While important for some intersex people, this is far from the more pressing concerns faced by the intersex population. Intersex has also been included within broader government LGBTI frameworks, as reflected in the LGBTI+ National Youth Strategy (2018-2020),[111] the National LGBTI Inclusion Strategy 2019-2021,[112] and the LGBTI+ Youth in Ireland and across Europe analysis.[113] In these government strategies and

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[109] Ireland has signed and ratified the International Covenant on Civil and Political Rights (ICCPR; International Covenant on Economic, Social and Cultural Rights (ICESCR); International Convention on the Elimination of All Forms of Racial Discrimination (IHREC); Convention Against Torture (UNCAT; Convention on the Elimination of Discrimination Against Women (CEDAW); Convention on the Rights of the Child (UNCRC); and the Convention on the Rights of Persons with Disabilities (UNCRPD).

[110] Department of Social Protection, 'Review of the Gender Recognition Act 2015 - Report to the Minister for Employment Affairs and Social Protection' (2018) s 6.8.

[111] Department of Children and Youth Affairs, 'LGBTI+ National Youth Strategy 2018-2020 LGBTI+ Young People: Visible, Valued and Included' (2018) <https://assets.gov.ie/24459/9355b474de34447cb9a55261542a39cf.pdf> accessed 18 March 2021.

[112] Department of Justice, 'National LGBTI+ Inclusion Strategy 2019-2021' (2019) <http://www.justice.ie/en/JELR/LGBTI+Inclusion_Strategy_2019-2021.pdf/Files/LGBTI+Inclusion_Strategy_2019-2021.pdf> accessed 24 November 2020.

[113] Department of Children, Equality, Disability, Integration and Health, NUI Galway and Health Promotion Research Centre, 'LGBTI+ Youth in Ireland and across Europe: A Two-Phased Landscape and Research Gap Analysis' (2021)

reports, it has been repeatedly noted that little is known or understood about intersex,[114] that there needs to be further data collection,[115] and that there is a need to improve understanding of and response to the physical and mental health needs of intersex young people.[116] The work to understand these issues further and collect adequate data is yet to be done. Legal understanding of intersex is also currently limited. There is no explicit inclusion in any domestic legislation or case law and, with the exception of the work of legal scholar Ni Mhuirthile,[117] there has been limited intellectual consideration of how the law may impact intersex people in Ireland. Intersex invisibility in the law again reflects the lack of understanding of intersex issues by government as well as a readiness to consider intersex as a medical issue and outside the scope of state responsibility.

Within the international system, intersex is also framed as a medical responsibility by Irish government representatives. During the CRC review of Ireland in 2016, the Head of Delegation Minister Dr James Reilly, then Minister for Children and Youth Affairs and former Minister for Health, stated that intersex surgeries were a 'clinical decision', and 'very often we are talking about very young babies here, very very young children, who have a serious anatomical, physiological difficulty to be sorted out, and that's the basis on which these procedures might be carried out.'[118] This rhetoric reflects the state's position, whereby intersex is framed as a medical issue and not within the jurisdiction of the state to intervene. Intersex issues are thereby

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<https://www.gov.ie/pdf/?file=https://assets.gov.ie/135654/4d466c48-34d9-403a-b48e-fdcfb7931320.pdf#page=null> accessed 21 June 2021.

[114] Department of Children and Youth Affairs (n 111) 4; Department of Children, Equality, Disability, Integration and Health, NUI Galway and Health Promotion Research Centre (n 113) 129.

[115] Department of Justice (n 112), action 20.

[116] Department of Children and Youth Affairs (n 111) 29.

[117] See, for example, Tanya Ni Mhuirthile, 'Building Bodies: A Legal History of Intersex in Ireland', *Sexual Politics in Modern Ireland* (2015); Tanya Ni Mhuirthile, 'Gender Identity, Intersex and Law in Ireland: Critique and Reform' in Lynsey Black and Peter Dunne (eds), *Law and Gender in Modern Ireland* (1st edn, Hart Publishing 2019). An 'Intersex Mapping Project' is currently being undertaken through Dublin City University to collect data on the experiences of intersex people in Ireland, see: https://www.dcu.ie/intersex.

[118] Gavan Coleman, Markus Bauer and Daniela Truffer, 'NGO Report to the Second Report of Ireland on the Convention Against Torture' (2017) 8.

considered anatomical problems which need to be fixed, and it is the clinicians who are determining what is problematic and in need of fixing. Following Ireland's review, the CRC made recommendations to Ireland to prohibit harmful practices to intersex people. It recommended that Ireland:

> (a) Ensure that no one is subjected to unnecessary medical or surgical treatment during infancy or childhood, guarantee bodily integrity, autonomy and self-determination to children concerned, and provide families with intersex children with adequate counselling and support;
>
> (b) Undertake investigation of incidents of surgical and other medical treatment of intersex children without informed consent and adopt legal provisions in order to provide redress to the victims of such treatment, including adequate compensation;
>
> (c) Educate and train medical and psychological professionals on the range of sexual, and related biological and physical, diversity and on the consequences of unnecessary surgical and other medical interventions for intersex children.[119]

Similarly, in CEDAW's review of Ireland in 2017, Department of Health Principal Officer Kieran Smyth stated that intersex surgeries took place 'after a unanimous decision of the consultants and of the parents.'[120] No consideration is given to the informed consent of the intersex person, the future ability of an intersex child to consent, or other human rights considerations involved in these interventions. In its concluding observations, CEDAW noted under 'harmful practices' its concern that 'medically irreversible and unnecessary sex assignment surgery and other treatments are reportedly performed on intersex children'. It recommended that Ireland:

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[119] UN Committee on the Rights of the Child, 'Concluding observations on the combined third and fourth periodic reports of Ireland' (2016) CRC/C/IRL/CO/3-4 at 40.

[120] Coleman, Bauer and Truffer (n 118) 8.

> Develop and implement an appropriate rights-based health-care protocol for intersex children, which ensures that children and their parents are properly informed of all options and that children are, to the greatest extent possible, involved in decision-making about medical interventions and that their choices are fully respected.[121]

Evidently Ireland's framing of intersex issues and action to date does not align with how the UN presents intersex human rights. In Ireland, any work directed at intersex issues has so far been considered alongside trans and more broadly LGBTI issues. While government documents and reports show some understanding that intersex is a distinct population, the limited understanding of the issues facing intersex people in Ireland has so far meant that little work is being undertaken to address intersex specific harms and human rights issues. UN treaty bodies have made recommendations to Ireland under a framing of 'harmful practices' and have directed attention to non-consensual intersex surgeries, however Ireland continues to assert at the UN that intersex issues are medical health issues and in other spaces domestically considers intersex issues within broader LGBTI frameworks.

While consideration of intersex within LGBTI is not necessarily a good or a bad approach within the Irish context, similar constructions within the UN show that the ready inclusion of intersex within LGBTI may result in a lack of direct attention being brought on intersex issues and can risk misunderstanding what the key intersex concerns are. Furthermore, while there is an understanding within Ireland that more knowledge and data on intersex issues is required (as acknowledged in the aforementioned government strategies and reports), collecting this data should not come at the expense of guaranteeing the human rights of intersex people in the interim. The framing of intersex issues at the UN has not yet had much impact on how Ireland understands intersex issues as Ireland continues to deny responsibility towards intersex and considers the treatment of intersex people to be a medical health care issue rather than a human

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[121] UN Committee on the Elimination of Discrimination Against Women, 'Concluding observations on the sixth and seventh periodic report of Ireland' (2017) CEDAW/C/IRL/CO/6-7 at 25(b).

rights concern. Nevertheless, if Ireland shifts to accepting its responsibility over the human rights of intersex people, this framing by the UN offers ways in which it can act. In the meantime, UN statements can help legitimise the concerns of intersex civil society and assist them to pressure Ireland to change its practices.

Conclusion

The UN has increasingly become aware of and condemned intersex human rights abuses over the last decade. Increasing attention has been given to intersex human rights issues at the UN by the OHCHR, special procedures and treaty bodies. While it is common in treaty body concluding observations and in other UN literature for intersex to be included within LGBTI framings, when considering substantive intersex human rights concerns it is notable that intersex is more often distinctly and relevantly separated out and considered under other framings of 'harmful practices', 'intersex persons' or 'health'. Indeed, the first Independent Expert on Sexual Orientation and Gender Identity clarified that intersex persons face distinct issues not specifically covered under his mandate.

It is clear that international human rights law extends to protect intersex people and the UN is working on articulating how intersex people are impacted and increasingly putting pressure on states to respond to address intersex human rights concerns. How intersex issues are framed and presented to states can have implications for how states understand and work towards addressing these issues, though it is first necessary for states to acknowledge their responsibility in guaranteeing the rights of intersex people. Ireland, where it does consider intersex issues, typically considers it within LGBTI frameworks and has acknowledged the lack of data and understanding on the needs of intersex people domestically. However, while there is some commitment to collect more data on intersex in Ireland, this has not yet extending to committing to address human rights concerns. Internationally there is still a denial by Ireland of any wrongdoing or harm towards intersex people, and Ireland continues to defer to medicine for the treatment of intersex people rather than engage with intersex human rights. The increasing moves at the international level to raise intersex concerns with states, as well as work by civil society organisations to leverage those UN statements and remind states of their international obligations, may ultimately help shift how states understand and respond to intersex issues domestically.

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D5.2.2 Report on Review of Methodologies and Ethical Frameworks in Recent Studies Related to Intersex Issues

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REPORT ON REVIEW OF METHODOLOGIES AND ETHICAL FRAMEWORKS IN RECENT STUDIES RELATED TO INTERSEX ISSUES

1. INTRODUCTION AND KEY FRAMEWORK

The definition of ethics is a process that requires the consideration of many factors since it is constantly changing under different frameworks.[i] It is possible to find meanings of “relational ethics, interactional ethics, reflexive ethics, reflexive, research ethics, contextual bioethics, critical bioethics, goodness-of-fit ethics, supported consent, individualized communication and consent, relational autonomy, everyday ethics, evidence-based research ethics, patient-oriented research, participant-centered research, person-centered research, person-oriented research and related terms”,[ii] all valid to identify ethical practices. In the context of research, ethics means “the balance between our own ethics and those of the people we are studying.”[iii] The need of this balance and the further evaluation of its accomplishment in research had its origin in medical research, as a result of harmful practices executed during and after the Second World War.[iv] To prevent those types of human rights violations from happening again, the international community created instruments such as the Nuremberg Code in 1947 and time after the Declaration of Helsinki in 1964 to mainly establish the importance of the well-being of research participants above any other interest.[v]

When it comes to research a particular population group that tends to be more vulnerable to acts of discrimination and abuse, the application of ethical guidelines designed since the last century to protect the participants’ rights during research has been a challenging process with different concerns such as “advancing academic careers at the expense of communities, neglecting to share results, over-researching certain communities, failing to give back to communities, and stigmatizing communities by releasing results out of context."[vi] Nevertheless, the Belmont Report in 1979 was a starting point in this subject to determine the pertinence and execution of the research project and evaluating research under the principles of respect for persons, beneficence, and justice.[vii] The consequence of applying these principles is the emergence of the requirements of informed consent, risk/benefit assessment, and the selection of research subjects.[viii] From this moment, the application of these requirements in specific population groups has been a constant learning process to interpret them in a correct manner but also to respect the internal dynamics of every community.[ix]

Each population has their own history and therefore concerns that are clearly distinguishable from others. Therefore, the application of specific guidelines to research a certain population is a recommended ethical practice to obtain the best results in research, without creating scenarios that may affect the communities, such as stigmatization, or disclosure of identities.[x] For the intersex community, the research context is accompanied by a history of medicalization,[xi] imposition of gender roles,[xii] pathologizing language,[xiii] epistemic injustice,[xiv] and misrepresentation.[xv] These features have jointly created massive human rights violations and the development of harmful practices during research.

When it comes to medicalization, there are deep wounds inflicted on intersex people. Particularly since the last century the new medical understandings of intersexuality, and the clinical desire for intervention with policies such as the "optimum gender of rearing" created in the 1950s under the leadership of psychologist John Money had irreparable consequences.[xvi] This policy appeals to the earliest gender assignment (before eighteen months of age) for intersex babies to either female or male, so the child can develop 'correctly', which synonymizes what is 'good' with what can be pigeonholed in a binary gender identity and body.[xvii]

Since the practice of this policy got popular within the medical field, the birth of intersex babies meant a process of objectivization of the bodies through gender assignment, reconstruction, and "adequation" of the person into society.[xviii] The obligation to impose a gender role led to the performance of surgeries for cosmetic reasons, and the misuse of patients' personal information for medical research purposes.[xix] Thus, the environment around the medicalized model of treatment towards the intersex population was characterized by the idea of a defective body which implies a circle of pathologizing language, associating body diversity as something that needs to be fixed.[xx]

In this sense, the narrative of `repairing´ the human biology brings other two important concepts to contextualize the problematic behind the research on intersex issues: epistemic injustice, and misrepresentation.[xxi] Due to the ownership and treatment that medicine made on intersex bodies, the health professionals acquired a position of power under the name of science.[xxii] This umbrella of entitlement implies a decision-making process of what is better for intersex people without them to actively participate. Producing an atmosphere where only the medical knowledge and experiences are taken into consideration, disregarding the experiences and knowledge that the community itself can propose for its own well-being is a violation to their self-determination, and constitution of epistemic injustice.[xxiii] This epistemic injustice frames the community in a powerless stereotype where the people "variously involve an association with some attribute inversely related to competence or sincerity or both: over-emotionality, illogicality, inferior intelligence, evolutionary inferiority, incontinence, lack of 'breeding', lack of moral fibre, being on the make, etc."[xxiv]

Thus, these stereotypes can be applied to the intersex people "bringing to light the institutional mechanisms that permeate their experience, both in terms of the modes of production and circulation of knowledge guiding the actions that target them and in terms of their ability to stock."[xxv] In the process of framing these concepts within research of intersex people´s issues, it is key to comprehend better the struggles of knowledge production, and the privilege of access to knowledge that may occur in this field.[xxvi]

The objective of this report is to present an analysis of qualitative and quantitative academic studies on intersex issues and determine which methodological and ethical aspects are accomplished or missing within the reviewed papers.

2. METHODOLOGY

The narrative literature review in which this report is based on aims to identify the human rights violations in research on intersex issues across both quantitative and qualitative research. Also, it analyzes the different methodologies and ethical frameworks in research related to intersex issues. In this sense, relevant literature was analyzed to determine what are the most common ethical aspects mentioned by researchers in the development of qualitative and quantitative studies on intersex people's issues, and what could be possible ethical conflicts or human rights violations that occur within research. The selection process of the academic articles was determined by the methodology used: either qualitative or quantitative research on intersex people´s issues. Papers were selected that have been published after August 2006, year when the Chicago Consensus[xxvii] was released until August 2022.

In total 24 papers were analyzed: twelve papers based on qualitative studies and twelve on quantitative studies.[xxviii] Within the analysis, two main categories were established: methodological aspects and ethical aspects. The methodological aspects were divided in three subcategories: sample and access, research techniques, and methods of analysis. The ethical aspects were divided in four subcategories: research ethics boards, informed consent, data management, and ethical frameworks and practices. The purpose of these categories was to determine if the academic papers studied had in consideration these fundamental aspects during the research development.

3. REVIEW OF SELECTED QUALITATIVE / QUANTITATIVE STUDIES

The following chart enlist the 24 papers studied to get a better overview:

TITLE	YEAR	RESEARCH DESIGN	AUTHORS	DOI
Intersex individuals' religiosity and their journey to wellbeing	2009	Qualitative	Kerry.	doi.org/10.1080/09589230903057092
Screening of Genital Anomalies in Newborns and Infants in Two Egyptian Governorates	2010	Quantitative	Mazen et al.	doi:10.1159/000313588
Sexual function and surgical outcome in women with congenital adrenal hyperplasia due to CYP21A2 deficiency: clinical perspective and the patients' perception	2010	Quantitative	Nordenström et al.	doi:10.1210/jc.2009-2639
Satisfaction with Genital Surgery and Sexual Life of Adults with XY Disorders of Sex Development: Results from the German Clinical Evaluation Study	2012	Quantitative	Köhler et al.	doi:10.1210/jc.2011-1441
DSD and Professionalism from a Multilateral View: Supplementing the Consensus Statement on the Basis of a Qualitative Survey	2012	Qualitative	Streuli et al.	doi:10.1155/2012/185787
Syndrome-Related Stigma in the General Social Environment as Reported by Women with Classical Congenital Adrenal Hyperplasia	2016	Qualitative	Meyer-Bahlburg et al.	doi:10.1007/s10508-016-0862-8
Deferring surgical treatment of ambiguous genitalia into adolescence in girls with 21-hydroxylase deficiency: afeasibility study	2017	Quantitative	Bougnères, Bouvattier, and Cartigny.	doi.org/10.1186/s13633-016-0040-8
Evaluation and treatment for ovotesticular disorder of sex development (OT-DSD) - experience based on a Chinese series	2017	Quantitative	Mao et al.	doi.org/10.1186/s12894-017-0212-8
Analysis of Presentations and Outcomes of Care of Children with Disorders of Sexual Development in a Nigerian Hospital	2018	Quantitative	Mieszczak, Houk, and Lee.	doi.org/10.1016/j.jpag.2018.08.005
Disorders of sex development: timing of diagnosis and management in a single large tertiary center	2018	Quantitative	Kohva et al.	doi:10.1530/EC-18-0070
Shaping parents, shaping penises: How medical teams frame parents' decisions in response to hypospadias	2018	Qualitative	Roen, and Hegarty.	doi.org/10.1111/bjhp.12333

Legislating intersex equality: building the resilience of intersex people through law	2018	Qualitative	Garland, and Travis.	doi.org/10.1017/lst.2018.17
Does Patient-centered Care Change Genital Surgery Decisions? The Strategic Use of Clinical Uncertainty in Disorders of Sex Development Clinics	2018	Qualitative	Timmermans et al.	doi:10.1177/0022146518802460
Briefing Paper: What do intersex people want from the law?	2018	Qualitative	Garland, and Travis.	
Special Parents for "Special" Children? The Narratives of Health Care Providers and Parents of Intersex Children	2019	Qualitative	De Clercq, and Streuli.	doi: 10.1353/nib.2019.0026
The Modified McIndoe Technique: A Scar-free Surgical Approach for Vaginoplasty With an Autologous Micromucosa Graft	2019	Quantitative	Teng et al.	doi:10.1016/j.urology.2019.05.020
Drawing the Line Between Essential and Nonessential Interventions on Intersex Characteristics With European Health Care Professionals	2020	Qualitative	Hegarty et al.	doi.org/10.1177/1089268020963622.
Inside the doctor's office. Talking about intersex with Italian health professionals	2020	Qualitative	Prandelli, and Testoni.	doi:10.1080/13691058.2020.1805641
'You're basically calling doctors torturers': stakeholder framing issues around naming intersex rights claims as human rights abuses	2020	Qualitative	Crocetti et al.	doi.org/10.1111/1467-9566.13072
Intersex lived experience: trauma and posttraumatic growth in narratives	2021	Qualitative	Hart, and Shakespeare-Finch.	doi.org/10.1080/19419899.2021.1938189
Recommendations of patients and families of girls with 46XX congenital adrenal hyperplasia in the United Kingdom regarding the timing of surgery	2021	Quantitative	Shalaby et al.	doi: 10.1007/s00383-020-04780-3
Staged transverse preputial island flap urethroplasty for some proximal hypospadias with moderate-to-severe chordee	2021	Quantitative	Lin et al.	doi:10.1186/s12894-021-00948-8
Quantitative proteomics reveals specific protein regulation of severe hypospadias	2022	Quantitative	Zhu et al.	doi:10.21037/tau-22-155
One-stage tubularized urethroplasty using the free inner plate of the foreskin in the treatment of proximal hypospadias	2022	Quantitative	Shi et al.	doi:10.1186/s12887-022-03464-2

3.1. Methodological Aspects

3.1.1 Sample and access

Most of the reviewed papers indicate a defined target group within the intersex community. In the quantitative papers, the selection criteria are very specific, and mostly refer to health conditions that the intersex person may have, or medical procedures that an intersex person went through, also some papers consider the range of age to classify as a participant in the quantitative research. In the case of the qualitative papers, some of the criteria are the activist profile of the people, belonging to a particular group or living in a specific country.

Regarding the access of the sample, within the twelve reviewed quantitative studies, four papers did not clarify how the researchers approached the participants. In the other eight, the access was given through support groups of particular health conditions, or through the hospital databases where participants had some medical procedure. This last form of access is also used in the reviewed qualitative studies. Besides, in the qualitative papers, the vast majority explain the access to the sample through other methods such a snowball recruitment, or directly contacting the participants via e-mail.

3.1.2 Research techniques

The strategies to collect the data constantly vary in each research, particularly in the quantitative papers. Here, there are papers where data was collected by reviewing the medical records of the participants, through surveys, or through the observation of the participants after a medical procedure. In the analyzed qualitative papers, the research techniques are more homogeneous. The majority of authors conducted interviews with different type of questions like semi-structured or open-ended questions, some of them used audio recordings, or implemented follow-up interviews.

3.1.3 Methods of analysis

The methods of analysis of the information gathered are diverse in both types of research. In the quantitative studies, the majority of the authors implemented different scores and values, some used statistical methods such as the Kruskal–Wallis test, Whitney U test, or Chi-square test. In the reviewed qualitative studies, many of the authors used thematic analysis, interpretative phenomenological analysis, or deductive content analysis. A small minority of both types of studies does not mention their method of analysis.

3.2. Ethical Aspects

3.2.1 Research ethics boards

Within the 24 consulted papers, the approval of the project by a research ethics board is included in the text of 14 papers. Five of them quantitative studies and nine qualitative studies. The remaining 10 papers do not specify whether or not there was a previous approval of a research ethics board.

3.2.2 Informed consent

From the 24 reviewed papers, 15 papers do mention the participants' informed consent, 9 quantitative studies and 6 qualitative studies. Out of these 15 papers, 5 did not mention anything related to ethical approval, 4 in quantitative studies and 1 in qualitative studies.

3.2.3 Data management

In the case of the reviewed quantitative studies, some of the authors clarify that the data described in the papers are available to use with prior consent of the authors, making statements like: "all data and materials can be obtained by mail of the corresponding author."[xxix] For the qualitative studies, the vast majority of the authors audiotaped and transcribed the gathered information, some of them use particular software or certified companies to manage the data.

3.2.4 Ethical frameworks and practices

Within the analyzed 24 papers, the most common ethical framework is the declaration of no conflict of interests by the authors. In the case of quantitative studies, two of twelve papers mention ethical practices like: "the assessment of the individuals with DSD was conducted by trained psychologists during personal encounters,"[xxx] or "ethical statement: the authors are accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved."[xxxi]

In the case of qualitative studies, four papers mention ethical frameworks. Some state the use of ethical guidelines: "given the sensitive nature of this topic, the authors ensured that the study complied with the SLSA's ethical guidelines."[xxxii] Other ones highlight the preparation needed for the research to conduct the interviews: "due to the sensitive research topic, interviewers were trained to use a dialogical approach, since this allows the researcher and interviewees to explore multiple meanings, narratives, implicit frames of reference and practices."[xxxiii] Furthermore, some ethical practices can be observed to protect the identity of the participants (for example "for ethical reasons, the interviewer emphasized the importance of not disclosing identifying details about patients, and any potentially identifying details were removed from transcripts prior to analysis")[xxxiv] and to make sure the questions were appropriate (for example "the authors also asked individuals from two independent intersex organisations (one UK-based, the other USA-based) to scrutinize the interview schedule and information sheets.")[xxxv]

4. DISCUSSION AND CONCLUSIONS

Research grounded in a human rights-based approach and ethical frameworks is critical for ensuring that a community that has suffered violations of their human rights does not go through possible scenarios that create them any harm within the research process.
The literature review made it possible to distinguish different features in the reviewed qualitative and quantitative papers. While in the quantitative studies, the sample is more specific in most of the studies, the access was in the majority given to the researcher through a certain link that the participant had with a medical institution, such as: “from September 2011 to December 2015, 16 patients with OT-DSD were evaluated and treated in our hospital."[xxxvi] This shows that in some academic papers, the researcher is at the same time the doctor that performs a medical intervention to the patient/participant.

For the case of the reviewed qualitative studies, the sample is broader in most of the studies, but the access seems to require a more direct connection to the participant, for instance: “suitable participants were identified and contacted through organizational websites and also by snowballing. The sample includes individuals from non-responsive states like the UK, Denmark, USA and Sweden; status-based states like Australia and Germany; and holistic states such as Malta and Iceland."[xxxvii] Thus, through the analysis of these two dynamics it is possible to observe previous relationships between researchers and participants in some of the papers, raising the question how this may influence the research process.[xxxviii]

Besides the review of the research methodology, one of the purposes of the literature review was to analyze the ethical frameworks present in both types of research. In 22 of the 24 papers, the main aspects such as the informed consent and data management were exposed in general terms, or not clearly exposed at all in some of them. Also, there are particularities in a few manuscripts that raised attention, for example in some of the quantitative studies, there was a presence of pathologizing language with the use of words such as “the other patient had a normal looking vagina”[xxxix] or “as the appearance of bisexual phenotype and continuous anxiety of parents call for the management, it is rational and, in a degree, mandatory to initiate the evaluation at an early age.”[xl] The presence of images is also very controversial because although it is not possible to recognize the participant, it may bring a sensation of discomfort and pain to watch these pictures, and raise the question: How does the participant feel regarding the public character of these images and their right to privacy? Was clear in the informed consent form the kind of pictures that would be published?

Significant reflections on pathologizing language and image use within intersex studies have been made to point out the importance of “using and promoting respectful, affirmative and non-pathologizing conceptualizations and terminologies”[xli] and “[a]bstaining from a use of pathologizing images in publications or presentations.”[xlii] The idea of these practices is to promote an ”ethics of depathologization”, understanding it as “a research practice based on the depathologization and human rights perspective, developed in the field of trans and intersex studies, but applicable to different research topics, knowledge fields and situations of structural violence and epistemic injustice.”[xliii]

Continuing with the reviewing of ethical frameworks, it was interesting to observe that out of 24 papers, only one (a qualitative study) mentions a specific training that was provided to the researchers to be able to perform better research practice. The document states: “the interviews were conducted by three Caucasian students (1 woman and 2 men) for a final year project in social psychology, after receiving specific training on the research topic and methodology.”[xliv] Acknowledging the internal dynamics of a vulnerable population and understanding their history, struggles and claims is a crucial aspect within research ethics,[xlv] in both qualitative and quantitative research, the responsibility of knowledge production towards the community and the results of the research should go in the same line. Otherwise, there could be a risk of problematic practices and therefore re-traumatization of the participants in the research context.[xlvi]

As it was mentioned in the introduction, the idea of ethics can include many different meanings. Although the viewpoints can be diverse, there must be certain unbreakable standards to protect the participants' rights. Still, there is a long way to go to the application of ethical frameworks. Although within this literature review it was possible to determine some common ethical grounds in both types of research, such as the informed consent, it is important to go further when it comes to safeguard the participants´ identity, beliefs or needs. Being aware of the big responsibility of the researchers in the production of ethical knowledge is an ongoing task, particularly when the research involves a community that have possibly been exposed to human rights violations.

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[i] M. Ariel Cascio, and Eric Racine, "Person-Oriented Research Ethics: Integrating Relational and Everyday Ethics in Research," *Accountability in Research* 25, no. 3 (February 2018): 170-197, https://doi.org/10.1080/08989621.2018.1442218.

[ii] Cascio, and Racine, "Person-Oriented Research Ethics," 170-197.

[iii] Cascio, and Racine, "Person-Oriented Research Ethics," 170-197.

[iv] European Commission, Directorate-General for Research and Innovation, *Ethics for researchers*: *facilitating research excellence in FP7* (Luxembourg: Publications Office of the European Union, 2013), https://data.europa.eu/doi/10.2777/7491.

[v] European Commission, *Ethics for researchers.*

[vi] Greta Bauer et al., *CPATH Ethical Guidelines for Research Involving Transgender People* (Canada: CPATH, Canadian Professional Association for Transgender Health, 2019), https://cpath.ca/wp-content/uploads/2019/08/CPATH-Ethical-Guidelines-EN.pdf.

[vii] The National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. *Belmont Report: Ethical Principles and Guidelines for the Protection of Human Subjects of Research* (Washington D.C.: Department of Health, Education, and Welfare, United States, 1979), https://www.hhs.gov/ohrp/sites/default/files/the-belmont-report-508c_FINAL.pdf

[viii] The National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, *Belmont Report.*

[ix] Dearbhail Bracken-Roche et al., "The Concept of 'Vulnerability' in Research Ethics: An in-Depth Analysis of Policies and Guidelines," *Health Research Policy and Systems* 15, no. 1 (July 2017), https://doi.org/10.1186/s12961-016-0164-6.

[x] Bauer et al., *CPATH Ethical Guidelines for Research Involving Transgender People*.

[xi] "What's Wrong with the Way Intersex Has Traditionally Been Treated?," Intersex Society of North America, accessed September 16, 2022, https://isna.org/faq/concealment/.

[xii] Alice Domurat Dreger, *Hermaphrodites and the Medical Invention of Sex* (Cambridge, Mass, London: Harvard University Press, 2003).

[xiii] Amnesty International, *First, Do No Harm: Ensuring the Rights of Children with Variations of Sex Characteristics in Denmark and Germany* (London: Amnesty International, 2017), https://www.amnesty.org/en/documents/eur01/6086/2017/en/.

[xiv] Miranda Fricker, *Epistemic Injustice Power and the Ethics of Knowing* (Oxford: Oxford University Press, 2007).

[xv] Janik Bastien Charlebois, "How Medical Discourse Dehumanizes Intersex People," Intersex Day, October 18, 2017, accessed September 16, 2022, https://intersexday.org/en/medical-discourse-bastien-charlebois/.

[xvi] Intersex Society of North America, "What's Wrong with the Way Intersex Has Traditionally Been Treated."

[xvii] Intersex Society of North America, “What’s Wrong with the Way Intersex Has Traditionally Been Treated.”

[xviii] Dreger, *Hermaphrodites and the Medical Invention of Sex*.

[xix] Dreger, *Hermaphrodites and the Medical Invention of Sex.*

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D5.2.3 Report providing results of the review of existing ethical principles in intersex studies and related fields

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1. INTRODUCTION AND KEY FRAMEWORK

Within the last decades there has been an increasing interest from international organizations, governmental bodies, and academia to produce quality research, understanding this as research that is able to create an impact within the society and not only aims to knowledge production; the result has been the questioning of traditional techniques for developing research, and the desire to implement new methodologies and interpretations to obtain better outcomes.[i] Within the tools to promote change, the community participatory approaches in social research have been a guided framework especially for the research of populations who throughout their history have suffered marginalization, and violations of their human rights.[ii]

The study about and with vulnerable populations has led to the development of research projects to access these communities and understand their issues, which has raised complex ethical considerations regarding research practices.[iii] On many occasions, participants from vulnerable communities have stated that they have been victims of violence and re-traumatization performed by the researchers, feeling that they are being treated as objects of research instead of people with rights.[iv] From this point a range of ethical concerns appeared; such as the tendency to try to `correct´ with the research a condition or way of living,[v] the disregard of people’s knowledge on their personal experiences,[vi] the relationship of power between participant and researcher,[vii] the settlement of unrealistic expectations,[viii] the lack of true understanding of the informed consent,[ix] and the misuse of sensitive participant data.[x]

The lack of preparation for the researcher to avoid the above issues, and consequent violations of human rights can lead to the creation of more harm for the communities involved and lose of trust to research practices.[xi] With the idea of protecting the participants against harm and misrepresentation, institutional ethical guidelines have been created to align the research with the internal contexts of the studied groups, and their cultural, socioeconomical, and political system.[xii] Guidelines such as the Tri-Council Policy Statement - Ethical Conduct for Research Involving Humans in Canada,[xiii] the AIATSIS Code of Ethics for Aboriginal and Torres Strait Islander Research,[xiv] Guidelines for researchers and stakeholders in Australia,[xv] or the SAMHSA Concept of Trauma and Guidance for a Trauma-Informed Approach of the United States,[xvi] among others, have the purpose to build research practices with awareness, trusting relationships, prioritizing community members knowledge and the wellbeing of all the people involved in the research project.

This report is intended to briefly explain the current ethical frameworks implemented in three population groups who have suffered violations of their human rights during research; the first one will be intersex people, the second one indigenous people, and the third one victims of armed conflicts, victims of domestic violence, victims of forced displacement, victims of human trafficking and victims of sexual violence.

The report aims at describing the common key resources in terms of research practices within these three groups and highlight the recommended tools that can be implemented in all of them.

2. METHODOLOGY

The following report is based on a narrative literature review with the aim of analyzing existing ethical principles in intersex studies and related fields and review key resources regarding the practice of ethical research within three different population groups which have been exposed to human rights violations and social vulnerabilities.

The first selected group were intersex people since the protection of their human rights during research is the focus of my project, understanding intersex person as somebody "born with sex characteristics that do not fit typical definitions for male or female bodies, including sexual anatomy, reproductive organs, hormonal patterns, and/or chromosome patterns."[xvii] In terms of research, the intersex community has suffered from a history of medicalization,[xviii] misrepresentation,[xix] and epistemic injustice,[xx] that have jointly created scenarios of harmful practices during research.

The second group were indigenous people. Acknowledging that there are different terminologies to denominate this population, such as 'aboriginals' and 'native', for this report, the term indigenous will be used, understanding the concept recognize and respect their pre-colonial history.[xxi] Due to the social vulnerabilities that indigenous people have historically passed and made a profound impact in their life experiences, considerable research have been done to understand their issues and respect their beliefs,[xxii] which makes pertinent the analysis of their research practices.

Regarding the third group, the initial idea was to focus on people who have suffered sexual violence, nevertheless, the literature review showed a tendency to frame the research practices and key resources for these people within a larger category of people who have gone through traumatizing life experiences of violence, and consequently the framework of trauma-informed[1] research will used to analyze this third part with guidelines from research. The group is composed of people who have gone through traumatizing life experiences of violence, this group gathered trauma-based research practices from victims of armed conflicts, victims of domestic violence, victims of forced displacement, victims of human trafficking and victims of sexual violence. This section of study was selected because of the severe human rights abuses these populations groups have suffered and the importance given to not aggravate the participants' pain, to promote their recovery and also to consider the researchers' wellbeing during the research project.

The narrative literature review established as selection criteria documents related to research practices, ethical principles, and human rights-based research within the three mentioned groups. In this sense, 47 documents were analyzed, which includes 33 academic papers, 21 activist documents and NGO reports, 9 book chapters, and 5 national laws. The paper is divided in two main parts, one dedicated to each population group mentioned and the research frameworks used in the reviewed bibliography, lastly the report has a discussion part where some common understandings of the frameworks are highlighted and concepts are mentioned that can potentially be complemented in research practices of other population groups.

3. REVIEWED RESEARCH FRAMEWORKS

Over the years, the development of general research practices have been useful for the development of knowledge in some aspects of people´s life.[xxiii] However, there are cases where the research benefits have been questioned, in this sense the establishment of ethical frameworks to lead the research processes and make them meaningful has become a

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[1] In the reviewed literature, the terms trauma-informed and trauma-based were used by different authors as synonyms. Thus, the terms will be used according to the preferences of each author.

responsibility for different national and international organizations with the aim of respecting the values and life experiences of the communities studied.[xxiv] In this sense, the following section will introduce three research frameworks and ethical understandings regarding intersex population, indigenous population, and people who have gone trough traumatizing life experiences of violence.

3.1 Intersex People

Throughout their history, the intersex community have suffered violations of their human rights during research.[xxv] The need to categorize the bodies in either female or male has brought pathologizing associations to what is good and bad with their bodies, and therefore some research has tried to stigmatize and misrepresent the community towards the need to be fixed, so the intersex person will adequate 'properly' to society.[xxvi] In this sense, the deconstruction of these ideas requires the implementation of different research approaches and techniques where the community can feel represented and their voices be centered. The following approaches are the recompilation of different research practices in the field of intersex studies that could improve the projects development and findings, respecting the intersex community voices.

- Study of the population: The reviewed authors highlight that before starting the research or present a proposal, it is pertinent to study the history of the intersex population and their current agenda.[xxvii] IHRA affirms that learning about the general context will not be sufficient to develop proper research, it is necessary to acknowledge the background, main actors, and different scenarios where intersex people have been subjected to discrimination and stigma.[xxviii] According to Karkasis, getting comfortable with the terminology that intersex people have, the correct language use, and particular circumstances that distinguish them from other population groups could help to remove false assumptions and biases from the researcher and avoid the misrepresentation of the intersex people's needs with other communities.[xxix]

- Positionality: Lundberg indicates that the reflexivity about the researcher's motivation is an important step within the research process. [xxx] Making an analysis as early as possible of personal expectations, struggles, biases, and beliefs could impact considerably the research development because it can create an awareness through the possible discomforts and emotions that the research may bring for the researcher and how to navigate through it.[xxxi]
- Personal training: As Berry and Monro state, many intersex people have endured violence to their bodies and violations of their sexual and reproductive rights throughout their life.[xxxii] According to the reviewed literature, it is recommendable for the researcher to be trauma-informed and prepared to give support to the participants after the interviews if needed.[xxxiii]
- Designing a research proposal: The Darlington Statement suggests different research priorities[xxxiv] which are beneficial for the researcher to know beforehand since it could help her/him/them to know the areas where the intersex community would rather have more research development. Once that the researcher has a defined project idea, it is suggested to consult the community regarding the pertinence of the research topic and their advice about the benefits and impact that the research could bring to the population.[xxxv] The reviewed authors mentioned that engaging with the community from the beginning will allow the researcher to start building a relationship of trust, diminishing the risk of harm and ensuring the research projects have meaningful grounds.[xxxvi]
- Preparation of fieldwork: RéFRI suggests that during the preparation of the interviews or survey, the researcher have in consideration how the participants identify, which means not to make assumptions regarding the gender identity or sexual orientation. [xxxvii] They also recommend that the questions are phrased in a consensual language to avoid any type of pathologizing, retraumatizing or stigmatizing terms.[xxxviii]
- Acknowledging life experiences: Understanding that intersex people are the experts of their narratives, Bastien Charlebois comments that intersex people's opinions should not be disregarded during the research, which means, giving them within the research the

place that their knowledge deserves.[xxxix] Handing to intersex people the same knowledge authority that has been given to the people who have studied them as experts, according to Koyama, will minimize considerably harmful discourses, and start centering intersex people's voices.[xl]

- Appropriate use of images: The reviewed authors highlight that due to the history of bodily integrity violations that the intersex people have endured, the use of images becomes a very sensible matter since it has been attached to the idea of pathologization, reconstruction of bodies[xli] and recreation of stigmatizing narratives,[xlii] which makes the respect of the people's privacy and their images is a key area within the research of intersex people's issues. Therefore, a relevant recommendation is that the researcher use images only when it is pertinent for the analyses, always with respect and having a critical view of the context of the images.[xliii]
- Informed Consent: According to the reviewed literature, the ethics of informed consent within the study of intersex people's research is a sensitive matter since the population has come with a history of lack of agency in their bodies, and consequently the performing of medical treatment without their free and informed consent.[xliv] In this sense, Henrickson et al. emphasize that the procedure of informed consent in research should be prioritized and presented in an age-appropriate way, particularly when researching intersex children so there will be totally understanding of the research aim.[xlv] IHRA recommends that the researcher seeks to provide and explain the information related to the research, including information of contacts for peer support, advocacy organizations and ethical norms.[xlvi]

3.2 Indigenous People

The indigenous population or first nation people come with a long history of values, and traditions that are not generally practiced in the world.[xlvii] The following ethical frameworks are a compilation of different documents, academic papers, reports and guidelines, whose purpose is to present an overview of recommendations for ethical research practices with indigenous communities.

- Analyze if the research topic will benefit the indigenous community: The reviewed authors highlight that every community has different priorities, therefore it is recommended that the research is aligned with those; this idea is based on the principle of indigenous-led research.[xlviii] If the researcher does not find enough public data to determine the community's main priorities, authors like Pirjo suggest advisory mechanisms to get more information from the local communities and identify the specific community needs and how the research idea can impact the community.[xlix]
- Cultural awareness: According to Hale, it is expected that the researcher possesses deep knowledge in the specific indigenous history, dynamics, and traditions that will be researched.[l] Recognizing indigenous narratives is considered as a way of decolonizing knowledge production and creating more ethical research which does not problematize the communities' lives under western values.[li] AIATSIS considers that this recognition is culturally based and values the ancestral wisdom by giving it the importance it deserves.[lii]
- Positionality and self-reflection: AIATSIS argues that unconsciously or not, every researcher has their own bias, reason why, before the research starts, there should be an internal reflection about the motivations for doing the research, the strengths and weaknesses the researcher may face when she/he/they get immersed in the cultural context of the community, and the researcher's capabilities to adapt the research according to the community needs.[liii]
- Consultation: The Māori ethical guidelines emphasizes that the details of the research project and development should involve the community.[liv] They imply that this participation can reduce risks of harm, give validity to the research proposal, and open the space for constructive advice regarding the possible outcomes and how that can benefit the community.[lv]

- Respectful engagement: It is recommended that the researcher is willing to demonstrate her/his/their interest to work for the wellbeing of the community.[lvi] Sometimes the research aspirations may not align with the development of the research, however, ethical guidelines of aboriginal communities highlight the researcher's responsibility to value the community knowledge and give priority to the experiences shared and the relationship of trust over the research aims.[lvii]
- Negotiation of the research relationship: Guidelines for the research of indigenous people manifest that from the beginning there should be a clarification of mutual expectations depending on the characteristics of the research and the community values, the scope of the research in topics such as intellectual property and data interpretation, the participants' right to dissent from the project, the procedures in case of disagreements, the establishment of possible mechanisms to guarantee the respect of the participants' rights such as the set-up of a research review board.[lviii]
- Flexibility in the research protocol: when the research is actively involving the community, using a participatory approach, according to Jamieson et al. there are occasions where the researcher could experience unexpected outcomes or feedbacks from the community during the course of the research, which means that there should be a preparation and further willingness to adjust the development of the research while maintaining scientific rigor.[lix]
- Ensure fully informed consent: the reviewed authors recommend that the communication of the research funding, aims, protocol and scope are as clear as possible and using a terminology that can be easily understood for all community members.[lx] Ensuring that participants fully comprehend the risks of the research is considered a measure for the protection of their rights.[lxi] To facilitate the correct understanding of the research, Fitzpatrick recommends to have a method to communicate the information during the consent process, this method can embrace cultural protocols and ancestral values through different ways like storytelling.[lxii] According to the author, the implementation of these

methods will reduce the risk of coercion and diminish the feeling of power imbalance between researcher and participant.[lxiii]

- Community control and ownership: according to Schnarch, the materialization of the effective community involvement and respect for their knowledge is given through control and ownership of the research.[lxiv] The research is being developed inside the community and the results will affect them in some way, therefore the author stresses that based on the right of self-determination and a human rights-based research approach, the community members are the ones who should have the control over the findings, data, and physical possession of the data to guarantee all the time the integrity of the research.[lxv]
- Sharing of data: Researchers recommend to share the obtained data for working with and within the community in an easy language and accesible material.[lxvi] Making the research as accessible as possible for the community is a way of honoring them; the data can be shared through informal reports, copies of the academic papers, co-authorship, in community events, and other opportunities where the research outputs can be shared.[lxvii]

3.3 Groups Who Have Gone Through Severe Traumatic Life Experiences

Although in this third part of the report there is not only one specific sector of the population as were the two previous population groups, it is also pertinent to analyze experiences of this third group from the perspective of massive human rights violations that a person has endured through a prolonged period, generating considerable traumas. For the purpose of the analysis, it is important to define trauma as the actual or perceived threat that a human being can experience over their psychological or physical integrity and that due to its impactful consequences, it can overwhelm the person´s responses to deal with it, and the result will be the presence of side effects in the person´s life and how she/he/they can perceive the world.[lxviii]

Even though the impact of an event and further trauma can vary depending on the person´s individual response, there are certain events that will considerably create long-term impact and require a previous training for the researcher who wants to be involved in these topics.[lxix] In this sense, the following recommendations come from a variety of sources created for population groups such as: victims of armed conflicts, victims of domestic violence, victims of forced displacement, victims of human trafficking and victims of sexual violence.

- Debriefing and support: According to Smith, the researcher should receive previous "training about countertransference and the importance of debriefing and seeking support to offset the vicarious trauma, secondary stress, and compassion fatigue."[lxx] During the research of population groups which are survivors of massive human rights violations, according to Barrington and Shakespeare-Finch there will be positive and negative effects that will have a considerable emotional impact on the researcher, in this sense it is recommended that the researcher seeks for support groups that help her/him/them to assimilate the emotional reactions of their work, and the implementation of effective coping strategies for soothing and taking care of the mental health.[lxxi]
- Study design: Due to the sensitive topics that most of these project developments have, Newman et al. recommend the research plan to consider meticulously every possible risk and solutions, also the different ways the data collection will be gathered throughout the research.[lxxii] The reviewed authors imply that the researcher should have an open mind regarding the ways of getting data, there are different methods to acquire knowledge; the authors suggest to perform interviews about sensitive matters when it is the only method to achieve the project aims.[lxxiii] In case of developing interviews, it is considered advisable that the study design is trauma-based and have a revision from review boards or ethical committees.[lxxiv]
- Relationship of trust: According to the reviewed literature, one important element within the building of a relationship of trust with a person who have gone through severe trauma

is confidentiality.[lxxv] The reviewed authors highlight that most of these people are victims of severe harm, some of them were involved in illegal activities, and don't want their identities to be recognized for these events, particularly if they are still under any type of risk, and that is why it is recommended that the researcher is careful with the disclosure of the information received during the project development because it may lead to re-traumatization or endanger the participants wellbeing.[lxxvi] Seedat et al. recommend researchers to seek for the creation of a relationship that does not finish with the fieldwork but involves a continuous dialogue during the whole project development, including asking the participants' opinion in the analysis of data, techniques used, and ideas for publication.[lxxvii]

- Transparency in the research aim: According to the reviewed authors, some of the participants from these different groups could be going through a delicate condition of vulnerability.[lxxviii] It is considered advisable that the researcher is clear about the project purposes and if it will improve in some way the wellbeing of the participants or not.[lxxix] The authors argued that the researcher should not take advantage of their positionality to mislead the participants' expectations with the research project.[lxxx]
- Informed Consent: Particularly with the groups that have going through severe trauma, the informed consent is considered more as a constant process rather than as a simple act.[lxxxi] The reviewed authors stress that many of the victims of severe trauma are still going through difficult emotional situations at the time that the research is being carried out, which makes the informed consent a very careful process where the participants should be reminded throughout the project process about their rights, research aims, researcher position, and possible risks to avoid further misunderstandings.[lxxxii] Mackenzie et al. recommend researchers to acknowledge the possible perception of power dynamics for the people being researched, and making sure that there is true "moral agency" and autonomy in the approval of consent and not only for the hope of assistance to the participants.[lxxxiii]

- Preparation of participants for the interviews: According to WHO it is up to each researcher the amount of information that is given to the participants regarding the questions of the interview, however, it is recommendable that the researcher prepares their participants informing them of possible violence-specific questions and how they could be uncomfortable and if that is the case, the interview can stop at any moment.[lxxxiv]
- Preparation of the researcher for the interviews: With the purpose to maximize as possible the participants´ wellbeing, the reviewed authors recommend the researcher to carefully prepare the interviews or survey.[lxxxv] It is considered advisable that the interview questions have a meticulous wording, in this sense, the authors said that there should be a preparation around the proper time and space to introduce the type of questions related with trauma exposure.[lxxxvi] Also, it is recommended for the researcher to acquire proper training skills to detect symptoms of distress in the participants and be able to identify when it is pertinent to suspend or terminate the interview without discouraging the participant.[lxxxvii]
- Referring to a mental health professional: Seedat et al. highlight that ideally, the research project should have the possibility to offer the participants a mental health assistance in the case that during the research any distress occurs.[lxxxviii] If there is no possibility to include an additional health care professional within the research team, it is suggested that the researcher have previously received trained to "gather traumatic or symptomatic material and to distinguish normative from pathologic responses to trauma"[lxxxix] to support the participants efficiently and avoid re-traumatization.
- Sharing the findings: According to Faulkener, research that at some extend involves the human suffering of other person requires an extensive accountability from the researcher in the way that the information will be presented to respect the people´s life experiences that have been shared, and safeguard their rights and wellbeing.[xc] It is expected that the findings of these type of research will also be used to improve or benefit in some way the different groups studied.[xci] Hence, Faulkener argues that the publication of findings should

be culturally sensitive and always from a respectful position, where the people are seen and perceived as participants and not as mere source of data.[xcii]

4. DISCUSSION AND CONCLUSIONS

During the review of the different population groups analyzed in the report, there was possible to observe a past trend of research being designed and developed to research on the community and not with the community, generating violations of participants' rights during the process. According to the three groups studied, there are common good practices that can be implemented to improve not only the research development, but also to take care of the wellbeing of the participants and researchers during and after the project.

According to the literature review, taking awareness of the own positionality becomes a first step before starting to dig into research ideas. Determining the personal why and what for starting that research is key to understand what drives the self-motivation during the project development, and if those interests will align with the research aims or community priorities. Bastien Charlebois highlights that selecting emotionally demanding research only for career development purposes can be very damaging for the participants because the establishment of a relationship of trust will not have strong basis, and situations such as dismissal of knowledge, dominant power dynamics, and dehumanization can bring serious long-term consequences for the participants.[xciii]

Regardless of the positionality, deciding to work with a community requires a deeper understanding of their context. The different population groups mentioned the need to study their history, values, beliefs, current struggles, and population goals. For the case of the third group (people who have gone through severe life experiences), the priority is on the understanding of the participants' culture, and the context in which their traumatic experiences were created. Accepting that no matter the previous studies done about the community and their experiences, the researcher will not achieve the level of knowing better/more the narratives than the participants is a way of showing respect for their life experiences and stopping the cycle of epistemic injustice[xciv] through which the three groups have passed in previous research.

Once that the researcher has conducted the internal (personal) and external (community) preparation, it may be easier that the creation of a study design helps to conduct a more respectful and ethical research. The documents analyzed[xcv] from the intersex and indigenous population suggest that the study design should always be consulted by members of the community to avoid or diminish any possible harm for the participants, in the same line of action, the third group with a trauma-based approach goes towards finding the best research methodology which does not necessarily has to imply interviewing the community. The authors reviewed[xcvi] advise to analyze if effectively it is necessary to perform interviews to accomplish the project aims, the researcher should acquire special training to cope with the emotional impact that this process can trigger in the participant and in herself/himself/themselves. Through the literature review it was possible to observe that the documents related to trauma-informed research methodology aims to center the wellbeing of the participants but also to consider the researchers' emotional welfare during the process, which may be left out sometimes.[xcvii]

Regarding qualitative interviews, trauma-informed research approaches propose different frameworks oriented to minimize any possible risk of re-traumatization of the participants.[xcviii] Among these frameworks, the informed consent takes a protagonist role because the participants should be totally aware of the risks, rights, and project aims. The documents from the three populations[xcix] agree on the fact that the informed consent should be taken as a continuous process and not as a singular act, which means that participants should be reminded all the time about the research process and what it implies. This is very important especially if the group studied has gone or is still going through traumatic experiences, the existence of these experiences can deeply distress the participant during the interview, and it is under this scenario that the supporting groups from participants and researchers can be a fundamental help to provide assistance if needed.

Lastly, the three population groups highlight the importance of sharing findings in a respectful way to the community's knowledge and life experiences, having in mind that the findings should help them in some ways with their struggles.[c] For the particular case of intersex people, the lack of data control has been a considerable source of human rights violations within the research of intersex people,[ci] which brings a responsibility for the researcher to comply with strict standards of data management to acknowledge the expertise of intersex people´s life experiences, considering them as the only ones entitled to share their narratives, same as with the other two groups. It is recommendable by the reviewed authors to co-conduct data collection with intersex scholars and organizations, and that their expertise is remunerated.[cii]

Also, it is considered advisable to share the findings with the community in the most accessible formats for them.[ciii] In this sense, the literature review recognizes that the creation, execution, and culmination of a research project implies many different frameworks which may vary depending on the population, but in general terms, research with communities that have suffered from marginalization and trauma requires an in-depth analysis and training to prevent any of the parties from getting hurt in the process.[civ] There are several tools available such as the guidelines and recommendations previously quoted in this report, however, it depends on the researcher and her/his/their level of commitment to carry out an investigation that protects the participants and herself/himself/themselves in the best possible way.

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D5.2.4 Report on systematic explorative review of documents contributed by the international intersex movement, international and regional human rights bodies and recent scientific bibliography

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Report on systematic explorative review of documents contributed by the international intersex movement, international and regional human rights bodies and recent scientific bibliography

1. INTRODUCTION

Intersex is a term used as an umbrella term to encompass people born with innate differences of sex traits such as genital, gonadal, hormonal, or chromosomal characteristics that seemingly challenge binary medical and social conceptions of what the male and female body are expected to look like.

The United Nations Office of the High Commissioner of Human Rights (OHCHR) considers that the term intersex describes: "a wide range of innate bodily variations in sex characteristics. Intersex people are born with sex characteristics that do not fit typical definitions for male or female bodies, including sexual anatomy, reproductive organs, hormonal patterns, and/or chromosome patterns". (1)

In 2006, however, a group of medical practitioners challenged this conceptualization of the term and proposed a shift from "intersex" to the newly created term "Disorders of sex development" (DSD) which has since been used in medical settings to encompass over 40 variations of sex characteristics. The term DSD is defined by "congenital conditions in which development of chromosomal, gonadal, or anatomic sex is atypical." (2)

Intersex activism is fairly ‘young’ compared to other forms of activism, for example feminism, or LGBT activism. While people with different variations in their sex characteristics have always existed, research suggests that it wasn’t until the late 80’s and early 90’s that people who identified themselves as ‘intersex’ started to come together to advocate for political goals. (3–7)

Also, while patient associations, support groups or what I will call here ‘patient groups’ have also been present for a long time, even before intersex activists, a recent study suggests that these groups often characterized themselves by limiting their scope of actions to a specific diagnosis or set of diagnosis, providing peer support, and advocating for better health care access or treatments. (8) While these can be seen by some as political and human rights claims, this study observes that patient groups often are not particularly interested in engaging politically or ‘critically’ for systematic or legislative change and tend to reject the label of ‘activist.’ (8)

A lot of the existing literature on intersex activism and (human) rights claims is focused on the United States, this has to do, perhaps, with the long and well documented history of US trans and intersex activism; the well documented efforts of the Intersex Society of North America, one of the first public and visible organizations in the country, and the published memoirs of its founder Chery Chase, (3) but undeniably it has to do also with the hegemony of the United States, the power and importance of American academia and access to dissemination resources, as well as the privilege that is to have and produce information in English, considered fairly accessible to foreign English speakers and researchers around the globe. (9) This does not mean however that ‘intersex activism’ was not happening elsewhere or at least one shouldn’t assume so. In Europe different political groups started to take on the label of ‘intersex activists’ as well, with some of the most visible countries being France, Germany and the UK. Intersex activism has also a long history in Australia, New Zealand, and Argentina. (10–12)

2. METHODOLOGY

The report consists of three document and literature reviews:

In the first review, I looked for and analyzed the main demands coming from different intersex activist groups present in international and regional declarations and how human rights framings are included in them.

In the second part of the report, I reviewed international and regional declarations or statements and recommendations coming from international human rights monitoring bodies (IHRMBs) and observe how they resonate with the demands from activists, particularly from their region.

In the third part, using a scoping review methodology, I review how scholarship considers human rights regarding intersex people.

In all three reviews I analyzed also how the topic of 'reparations' or access to justice mechanisms is considered within the main demands coming from intersex activists' documents, recommendations from IHRMBs and intersex studies scholarship, this is because in a previous work I encountered that this issue is often less visible as a matter of human rights priorities in literature and activist documents but has been gaining visibility in other fields, for example amongst UN treaty bodies. (13) Each of the subchapters below include a more detailed methodology.

3. RESULTS

3.1. Review of intersex activists' demands

3.1.1. Methodology

As stated above, for the first review I looked for and analyzed the main demands coming from different intersex activist groups present in international and regional declarations and other statements. The review includes a summary of the most relevant themes of each recommendation without reproducing the complete content and order.

I decided to focus on these grand statements because there are plenty of different position statements, public statements or research documents such as reports, factsheets or guides coming from different groups, to the point that is extremely difficult to gather them all. The documents that were selected, were so because they: a) gather different positions from regional or international activists and organizations; b) they present demands summarized in order to make sense to lay people and often law and policy makers and c) they can be understood as the culmination of internal negotiations regarding prioritization of political goals and demands and framing of issues. A total of 7 activist documents were included in the review. The Yogyakarta Principles and Yogyakarta Principles plus 10 were also included as they are relevant pieces of literature inclusive of matters relevant to intersex persons (amongst other groups) and speak directly about international human rights law perspectives.

3.1.2. Summary of activist documents review

3.1.2.1. International documents

3.1.2.1.1. The Malta Declaration

In December 2013, following the Third International Intersex Forum, an event that brought together 34 activists representing 30 intersex organizations from all continents, intersex activists published the Malta Declaration. (14) The Malta Declaration is a document that puts together a list of priority demands in which intersex activists from different places could find common ground.

The main demand of the Malta Declaration is “to put an end to mutilating and ‘normalising’ [sic] practices such as genital surgeries, psychological and other medical treatments through legislative and other means”, as well as to empower intersex people to “make their own decisions affecting own bodily integrity, physical autonomy and self-determination.” (14)

Other demands can be classified as: those having to do with stopping other abusive and harmful practices, including medical practices, access to medical records and professional training, those having to do with sex registration and gender recognition; those having to do with cultural awareness, and building safe spaces for intersex people; those having to do with ending discriminatory practices, particularly with regards to family life and sports inclusion and other more specific claims, for instance putting an end to infanticide and killings of intersex people. Of course, all of these claims intertwined often with one another.

There is also one specific claim about reparations.

- To provide adequate acknowledgement of the suffering and injustice caused to intersex people in the past, and provide adequate redress, reparation, access to justice and the right to truth. (14)

3.1.2.1.2. The Yogyakarta Principles and Yogyakarta Principles plus 10

The Yogyakarta Principles (15) and the Yogyakarta Principles +10 (16) reflect the doctrines of the most competent publicists, i.e. experts, in both international human rights law and sexual, gender and bodily diversity issues, and so they can be viewed in line with art. 38 of the International Court of Justice Statutes (17) as a source of interpretation of international law. While these principles are not an international instrument of a binding nature, they expand the understanding of States' obligations already enshrined in binding international treaties, in light of the principle of non-discrimination, with respect to sexual orientation, gender identity, gender expression or sex characteristics. The first set of 29 Principles were developed by human rights experts from all fields, following a meeting in Yogyakarta, Indonesia, in 2006. (15,18,19) More than ten years later in 2017, an additional set of principles known as 'The Yogyakarta Principles plus 10' (YP +10), included the ground of 'sex characteristics' and recognized the rights to bodily integrity, truth and legal recognition. (16,19) According to Morgan Carpenter "The attribute of sex characteristics was identified early as a key development to reflect within the YP plus 10, to address human rights violations based on physical features relating to sex, irrespective of age or agency." (19) Carpenter further affirms that the YP+10 "drew upon developments in domestic law in Malta, other European states and institutions, and the work of the Asia Pacific Forum of National Human Rights Institutions." (19)

The YP+10 include nine new principles, namely the rights to bodily and mental integrity, the right to truth, legal recognition, state protection, freedom from criminalization, protection from poverty, the right to sanitation, enjoyment of information and communication technologies, and cultural diversity.

In terms of reparations, principle 37 of the YP+10, the right to truth, states that:

> Every victim of a human rights violation on the basis of sexual orientation, gender identity, gender expression or sex characteristics has the right to know the truth about the facts, circumstances and **reasons why the violation occurred.** The **right to truth includes effective, independent and impartial investigation to establish the facts, and includes all forms of reparation recognised by international law.** The right to truth is not **subject to statute of limitations** and its application must bear in mind its dual nature as an individual right and the right of the society at large to know the truth about past events. (16)[1]

To guarantee this right the Yogyakarta Principles plus 10 encompass 9 action points or recommendations, amongst them, to adopt legal provisions to provide redress to victims of violations, to ensure access to remedies that include psychological support and restorative treatments; to ensure people's right to access their medical histories, and medical records; to adopt and implement truth-seeking mechanisms and procedures oriented towards knowing the truth about violations based on sexual orientation, gender identity, gender expression and/or sex characteristics (SOGIESC); to document human rights violations and ensuring communities and society at large are aware and have access to archival information of past human rights violations; to include themes related to rights violations in educational curricula and to recognize the suffering of victims by commemorating rights violations via cultural events. (16)

Also, the Yogyakarta Principles already included the right to effective remedies and redress in principle number 28. The principle considers that States shall ensure that:

> Every victim of a human rights violation, including of a violation based on sexual orientation or gender identity, has the right to effective, adequate and appropriate remedies. Measures taken for the purpose of providing reparation to, or securing adequate advancement of, persons of diverse sexual orientations and gender identities are integral to the right to effective remedies and redress. (15)

In order to secure the above rights, the Yogyakarta Principles recommend States to establish necessary legal procedures; ensure remedies are implemented in a timely manner; ensure people have access to information about the redress procedures and that

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[1] Bold added.

personal enforcing them are sensitized regarding SOGIESC issues; and that financial aid is provided where needed, amongst other things. (15)

3.1.2.2. *European documents*

3.1.2.2.1. The Statement of Riga

On October, 8th, 2014 after a meeting that took place in Riga, European organizations working for human rights adopted a statement to “identify objectives and strategies to advocate for the full implementation of human rights and bodily integrity and self-determination for intersex individuals in Europe.” (20) Four objectives were established, namely to: challenge the binary definition of sex; antidiscrimination protections for intersex people; to ensure that different stakeholders are instructed on intersex issues from a human rights perspective; and to work towards making non-consensual medical and psychological treatment unlawful. No specific reparation claims or objective were identified. (20)

3.1.2.2.2. The Vienna Statement

In 2017 following the first OII Europe community event in Vienna that gathered 28 intersex persons from 16 Council of Europe member states, the European intersex activist movement issued the Vienna statement with 26 action points oriented towards different stakeholders, for example governments, stakeholders in the field of health care and education, and the media and endosex allies. Amongst the demands there are calls for the ban of IGM and stopping medical treatments to the purpose of modifying the sex characteristics of intersex people until the affected person can consent to them; to protect intersex people from discrimination; to include intersex realities in education efforts, for example school curricula and trainings for public servants and other relevant stakeholders; counselling support, including peer counselling, for intersex people and counselling for their families that is human rights affirming and depathologizing; positive cultural representations of intersex people in the media; claims related to sex and gender registration; and calls for allies to support intersex movements and not to instrumentalize their claims, amongst other aspects. (21)

There is one explicit reference to reparations:

- Provide intersex people who endured medically unnecessary or degrading treatment with reparations. (21)

3.1.2.3. Aotearoa/New Zealand and Australian documents

3.1.2.3.1. The Darlington Statement

In 2017, members from the Australia and Aotearoa/New Zealand intersex community organizations and independent advocates, including the Androgen Insensitivity Syndrome Support Group Australia (AISSGA), Intersex Trust Aotearoa New Zealand (ITANZ), Organisation Intersex International Australia (OIIAU, now IHRA, Intersex Human Rights Australia), and individual activists, issued a joint consensus statement. (22) The document sets out the priorities and calls for action under six headings which the document classifies as: a preamble; we acknowledge; human rights and legal reform; health and wellbeing; peer support; allies; and education, awareness and employment. Overall, the document sets out more than 50 demands. Within the above headings calls for action could also be classified as: demand for the prohibition of deferrable medical interventions; legal gender and sex registration claims; nondiscrimination claims; reparation and justice claims; health care and wellbeing claims; claims related to psychosocial and peer support; claims related to ally movements and persons; and claims related to awareness raising and sensitization, particularly in the ambits of education, employment and media. There is one explicit call for government institutions regarding reparations:

- We call on governments and institutions to **acknowledge** and **apologise** for the treatment of people born with variations of sex characteristics, and provide **redress and reparation** for people born with variations of sex characteristics who have experienced involuntary or coercive medical interventions. There must be no time limit on access to redress and reparation. (22)

3.1.2.4. *African documents*

3.1.2.4.1. Public Statement by the African Intersex Movement

On November 2017, a number of 22 intersex activists from at least 7 African countries gathered in Johannesburg, South Africa and issued a public statement with 16 demands and 6 action points. Aside from the demand to end intersex normalizing surgeries, the top demands call for the prevention of violence against intersex people, for example infanticide; for change in medical practice including the depathologization of intersex variations, access to medical records, trainings for health providers and ending sterilization practices; other demands include those for sex and legal gender registration; awareness raising and education for society at large, for medical professionals involved in health care and for parents as part of antenatal support; antidiscrimination protections including in the field of sports; demands for recognition of harm and for psycho-social and peer support for intersex persons and their families. (23)

No specific claim for reparations was found except as mentioned above claims for recognition of harm.

- To **acknowledge** the suffering and injustice caused to intersex people.
- To **recognise** that medicalization and stigmatisation of intersex people result in significant trauma and mental health concerns. (23)[2]

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[2] Bold added.

3.1.2.5. Asian documents

3.1.2.5.1. Statement of the First Asian Intersex Forum

In 2018 intersex activists from the Asia region convened during the First Asian Intersex Forum in Bangkok. The forum brought together intersex activists from at least 10 countries and served as the foundation for Intersex Asia, the first regional network of Asian human rights-based organizations and intersex activists. Following the meeting Intersex Asia published a statement containing 36 demands and 7 calls for action. (24)

Aside from the demand to stop genital surgeries, demands from Asian intersex activists could be categorized as demands for recognition, destigmatization and demedicalization; to end abusive medical practices and to provide confidential access to their medical data; demands related to nondiscrimination in all ambits but highlighting employment, family, and sports; demands for psychosocial and peer support; demands for education and awareness raising not just for key stakeholders in the provision of public services but for society at large and human rights education for intersex persons so they can be aware of their rights; sex and legal gender registration claims. There are also some very specific claims related to inheritance; claims related to other different intersectionalities for example intersex people with disabilities and intersex refugees; and demands to protect intersex people from specific forms of violence for example sexual violence, honor killings or infanticide. (24)

In terms of reparations two demands were coded in this area.

- To provide adequate acknowledgement of the suffering and injustice caused to intersex people in the past, and provide adequate redress, reparation, access to justice and the right to truth.
- To acknowledge the suffering and injustice caused to intersex people. (24)

3.1.2.6. Latin American documents

3.1.2.6.1. Statement of San José de Costa Rica

The Statement of San José is a document containing a series of 36 demands, that came out after the first Latin American meeting of intersex people that happened in 2018 in San José de Costa Rica. The prologue of the statement calls out historical practices of colonization not just of people's land but bodies as well. The statement also calls for respect of how different intersex groups decide to call themselves in Spanish, Portuguese and other native tongues. While asking for the recognition of the political history of intersex movements in the Latin American region and recognition of geopolitical contexts it also subscribes to the demands of international activists made in the Malta Declaration. (25)

The Statement of San José makes differentiated demands on the basis of political stakeholders, for example, the State, human rights institutions, funders, allied movements, the media, health institutions, family members, and other intersex persons. Aside from the main demand to prohibit unnecessary medical practices carried out without the consent of the of the main person affected, the rest of demands include those concerning health care treatments and intersex medical care practice; those related to sex registration and legal gender identity recognition; claims related to reparations and access to justice. (25) Contrary to the Malta Declaration, the Statement of San José is framed more in the line of petitions rather than demands. Three of the petitions made in the Statement of San José seem to directly speak to reparations and recognition of harm.

5. Guarantee the right of all persons subjected to any practice aimed to modify their sex characteristics to learn the truth about their birth, sex assignment, diagnosis, practices performed on their body and their rationale, as well as the names of those involved in such practices and their follow-up.
6. Recognize that pathologizing our bodies has deeply negative implications for our access to education and employment, and implement specific and effective reparation policies. (…)
8. Investigate all systematic violations against our human rights that have been widely recognized and exposed by different international bodies and to produce reports that specifically address these violations while also following-up on the reports submitted by Intersex movements.
9. Provide spaces (such as Human Rights Tribunals) where those suffering such violations and their consequences on our physical and mental health and integrity can make them public. (25)

3.2. Review of human rights recommendations

3.2.1. Methodology

For this second review documents that come from international regional institutions or regional human rights monitoring bodies were included. Only documents that can be understood as "soft law", meaning recommendations or declarations were selected. Documents pertaining to the universal human rights system were left out as a similar analysis has been done elsewhere. (13,26) The review includes a summary of the most relevant themes of each recommendation without reproducing the complete content and order.

3.2.2. Summary of human rights recommendations review

3.2.2.1. Europe

In the EU, intersex persons are mentioned in the European Parliament Resolution of 14 February 2019 on the rights of intersex people (27); the European Commission LGBTIQ Equality Strategy 2020-2025 (28); the European Commission EU strategy on the rights of the child of 2021 (29); and in terms of research there is a focus paper from the European Union Agency for Fundamental Rights on the Fundamental Rights Situation of Intersex People of 2015 (30); intersex issues were also included in the 2019 FRA survey and analysis of results. (31)

On its end, the Council of Europe has also increased visibility of intersex issues through the years. Intersex issues were first mentioned in the Parliamentary Assembly of the Council of Europe Resolution 1952 on "Children's Right to Physical Integrity" in 2013 (32); two years later in 2015 the Commissioner for Human Rights of the Council of Europe issued a report titled: "Human Rights and Intersex People" (33); then the Parliamentary Assembly of the Council of Europe in 2017 issued Resolution 2191 on the "Promoting the human rights of and eliminating discrimination against intersex people." (34) Currently the Committee of Ministers of the CoE is working on a new resolution to address the rights of intersex people. (35)

There are a number of explicit mentions and recognition for the need of redress mechanisms and reparations in the European region recommendations and statements, for instance, the Parliamentary Assembly of the Council of Europe Resolution 2191 (2017) recommends member States to:

> 7.5.1. **conduct an inquiry** into the harm caused by past invasive and/or irreversible sex-"normalising" treatments practised on individuals without their consent and **consider granting compensation, possibly through a specific fund, to individuals having suffered as a result of such treatment carried out on them.** (34)[3]

The EU LGBTI Strategy 2020-2025 addresses harmful practices such as non-vital surgery and medical intervention on intersex persons. (28,36) The action points recognizing the rights of victims of crimes and their access to justice programs do not refer explicitly to intersex people, but could give room to maneuver special recognition for intersex people

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[3] Bold added.

who have been victims of IGM, or at least in those EU countries where this has been recognized as an unlawful practice.

The strategy recognizes that:

> Harmful practices such as non-vital surgery and medical intervention on intersex infants and adolescents without their personal and fully informed consent (**intersex genital mutilation**), forced medicalisation on of trans people and conversion practices targeting LGBTIQ people **may have serious bodily and mental health repercussions**. The Commission will foster Member States' exchange of good practice on ending these practices. Forced abortion and forced sterilisation on and other harmful practices against women and girls are forms of gender-based violence and serious violations of women's and children's rights. The Commission will also include an intersectional perspective in the Recommendation on harmful practices against women and girls announced in the Gender equality strategy 2020-2025. (28)[4]

Within the action points to be taken, amongst other things, the LGBTI Strategy aims at

> - present an initiative in 2021 to extend the list of 'EU crimes' (Article 83 TFEU) to cover hate crime and hate speech, including when targeted at LGBTIQ people;
> - provide funding opportunities for initiatives that aim to combat hate crime, hate speech, violence and harmful practices against LGBTIQ people ('Citizens, Equality, Rights and Values' programme) and **promote the rights of victims of crime, including LGBTIQ people ('Justice' programme)**. (28)[5]

3.2.2.2. Africa

In 2023 the African Commission on Human and Peoples' Rights (ACHPR) issued Resolution Res.552 (LXXIV) 2023 on the Promotion and Protection of the Rights of Intersex Persons in Africa. The resolution recognizes the existence of people with variations of sex characteristics in Africa and recalls different regional legal frameworks relevant for the protection of their rights. Among other things, the resolution recognizes

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[4] Bold added.

[5] Bold added.

the harms that non-consensual and unnecessary surgical and other procedures carried out to achieve "genital normalization" on intersex persons have and call State parties of the African Charter of Human and Peoples' rights to:

1. Stop non-consensual genital normalization practices on intersex persons, such as surgical, hormonal and sterilization procedures that alter the sexual characteristics of intersex persons and ensure respect for their rights to make their own decisions regarding their bodily integrity, physical autonomy and self-determination. (37)

The resolution also provides recommendations to State parties concerning the promotion and protection of the rights of intersex persons, to guarantee the best interests of the child concerning medical treatments, the protection of children's rights including protection from abandonment and infanticide; to prohibit discrimination based on "intersex traits and characteristics or intersex status"; to provide counselling and sensitization to families of intersex children; to protect the work of intersex human rights defenders; to allow intersex persons to change their gender registration on legal documents; to guarantee intersex people's access to their medical records; to raise awareness of intersex issues and their rights in society; and to ensure that public officials and public servants are sensitized to the respect and equal treatment of intersex persons, amongst other things. (37)

Regarding access to justice mechanism and reparations, the resolution calls on State parties to:

10. Ensure that human rights violations against intersex people are investigated, perpetrators are prosecuted, and victims have access to effective remedies, including redress and compensation. (37)

3.2.2.3. The Americas[6]

The Inter-American system of human rights is composed of two main monitoring bodies as per the American Convention of Human Rights (ACHR), the Inter-American Court of Human Rights (IACtHR) and the Inter-American Commission on Human Rights (IACHR). (38) While the Court has not dealt with a case related to an intersex person, intersex issues have been considered by the Inter-American Commission on Human Rights.

In 2015 the IACHR and its LGBTI Rapporteur included a specific section about intersex 'medical violence' on its first ever thematic report focused on violence against LGBTI persons. (39) In the report the IACHR recognizes the different forms of human rights violations experienced by intersex people because "their bodies do not physically conform to socially accepted standards for 'female' and 'male' bodies". (39) The IACHR also noted intersex activist claims that "have indicated that human rights violations suffered by intersex persons are different from the human rights violations which lesbians, gays, bisexuals and trans persons typically suffer."(39) The Commission raised its concerns about the fact that "sex assignment" and genital surgeries that are carried out without the informed consent of intersex children are standard practice in countries across the American continent. (39) Likewise, the Commission expressed concerns about the fact that these surgeries cause intersex children great harm, are irreversible, have consequences that extend into adulthood including: "chronic pain, life-long trauma, sterilization, genital insensitivity, and diminished or lost capacity for sexual pleasure." (39) In its report the IACHR highlighted that the principle of free, prior and informed consent should guide the decisions concerning a person's body and medical treatments. The Commission recommended the member states of the Organization of American States to "make necessary amendments to policy and law to prohibit medically unnecessary procedures on intersex persons, when it is administered without the free informed consent of the intersex person." (39)

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[6] Also included in the eBrief: Ní Mhuirthile T, Dixit S, Zelayandía González E, Lum S, Mestre Martínez YM, Aegerter A, Suess Schwend A. Human Rights eBrief. INIA: Intersex New Interdisciplinary Approaches, DCU; 2022.

In line with its mandate the Inter-American Commission also issued a series of recommendations to OAS member states. The IACHR urged states to: “(i) conduct trainings of medical personnel and medical community in order to provide adequate treatment and support to intersex persons and their families; (ii) create multidisciplinary groups to provide support and counselling to parents and relatives of intersex children and infants and to provide care and support to intersex persons from childhood into adolescence and adulthood; (iii) conduct awareness-raising and sensitization campaigns at the national level on the short term and long-term effects of ‘normalising’ interventions on intersex children; and (iv) carry out educational campaigns in conjunction with the ministries of education in order to bring down stereotypes, stigma and invisibility surrounding intersex persons.” (39)

Another Inter-American body that has given visibility to intersex issues ever since 2008 is the General Assembly of the Organization of American States (OAS-GA) which is the highest-ranking body of the OAS and is formed by the delegations of all the member states. The OAS-GA has included issues concerning sexual orientation and gender identity in its annual resolution calling for the promotion and protection of human rights. (40) In 2012, following the creation of the LGBTI thematic unit at the IACHR, the OAS-GA for the first time ever included in its annual resolution entitled ‘Human rights, sexual orientation, and gender identity’ references to intersex people as part of the LGBTI umbrella group. (41) In the resolution the OAS GA called on member states to: “eliminate, where they exist, barriers faced by lesbians, gays, and bisexual, transsexual, and intersex (LGBTI) persons in access to political participation and in other areas of public life, as well as to avoid interferences with their private life.” (41) Progressively, in 2013, the OAS-GA finally included a recommendation to all OAS member states pertaining intersex genital surgeries and urged members States to “afford appropriate protection to intersex people and to implement policies and procedures, as appropriate, to ensure medical practices that are consistent with applicable human rights standards.”(42) In its 2019 resolution the OAS GA, for the first time ever made references not only to intersex people and the harmful medical practices that affects them, but also embraced ‘sex characteristics’ as a human rights-based term and as a ground for protection and called out member states to condemn violence and discrimination based on such ground. (43) To date there are still no specific references to reparations made by the OAS GA.

3.3. Review of academic literature

3.3.1. Introduction

For the academic part of this review, I conducted an explorative systematic review or scoping review. I aim at painting a picture of the landscape of intersex human rights claims and demands present in literature. As Arksey et al. (44) state, scoping reviews are often carried out in order to examine the extent, range and nature of a particular research topic. Scoping reviews are also used to explore research gaps in current literature and determine whether a broader systematic review is called for or if this already exists. Additionally, one of the main reasons one would choose to conduct a scoping review is to summarize and disseminate findings from existing literature and possibly identifying research gaps or policy needs, this falls within the aims of the INIA project.

3.3.2. Methodology

For this scoping review, I followed the different stages of scoping reviews present in the works of Arksey and O'Malley (44) as well as the Joanna Briggs Institute manual for evidence synthesis chapter on scoping reviews. (45)

Stage one in scoping reviews refers to identifying a research question that is better suited to be addressed by a scoping review. In this sense the question guiding this scoping review is to explore the different human rights framings or frameworks intersex activists use to transmit knowledge, explain their needs and gain support for the demands of intersex people as observed in academic literature.

Stage two refers to identifying relevant literature that addresses the research question. In order to explore the different framings intersex activists and movements have used to mobilize their political goals, I looked at scholarship on that topic from the last 23 years. I limited the search to academic works published between the years 2000 and 2022 in order to gain a perspective of the most recent literature. I limited the search to peer-reviewed journal articles and excluded other works such as books, chapters or thesis. Only publications in English were included.

To identify relevant material, I conducted an advanced search looking for social sciences articles with keywords in their title and abstract: 'intersex,' 'DSD,' 'sex characteristics,' 'sex development,' and 'human rights.' The search was conducted in the Web of Science, Scopus, and PubMed databases, because these are three of the most renown and reliable databases with comprehensive and interdisciplinary resources.

The search results showed 272 records, after scanning for duplicates 121 records were eliminated and 151 records were selected to move forward to the inclusion/exclusion stage by reading the title and abstract in order to determine the relevance of the articles.

Stage three refers to study selection. The inclusion criteria during the title/abstract read was set as the following: a record was included for full text review if it explicitly mentioned in the title or abstract 'intersex,' 'intersexuality,' 'DSD,' or any of the other variant keywords and also made references to 'rights,' or 'human rights' or it was very clear that these themes were present in the main text. Records were excluded if they failed to mention 'intersex' or if it was clear that the focus was not even partly about intersex. Records that did not explicitly mention activism or human rights were only included for full text review if activism, advocacy or related political activities were implied in the abstract or if there was a strong indication that the article's subject was closely related to this review's topic. Records that did not include an abstract were included by default in the review.

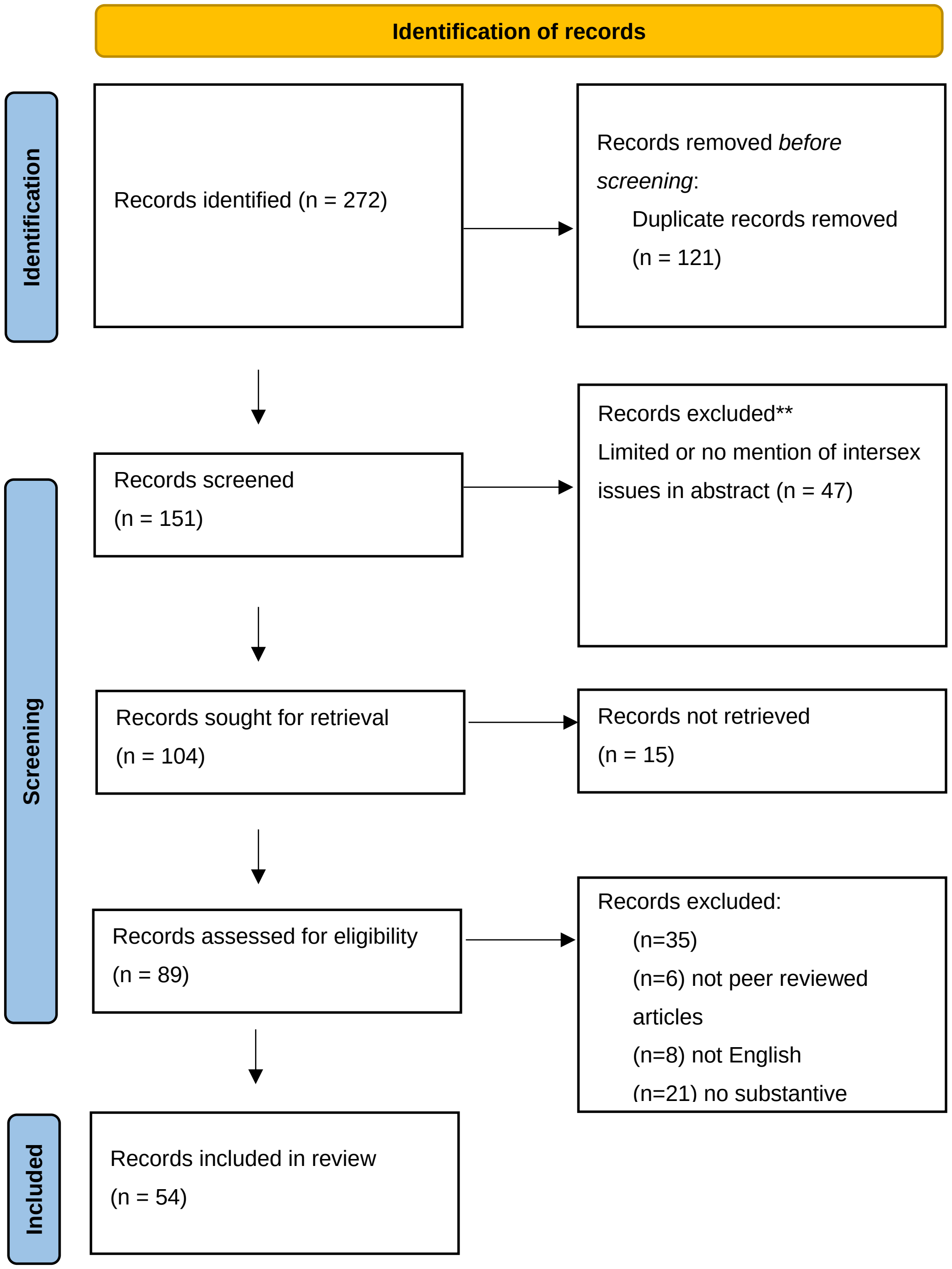
After reading the titles and abstracts of 151 records and following the inclusion criteria, 104 articles were included for full text review. After full text read 50 articles were excluded and 54 records were included in this report. (6–8,19,46–95)

A total of 15 article were excluded because I had no access to them, 6 pieces were excluded because they were not peer reviewed articles and 8 were not written in English; 21 records were excluded because they had no or limited mentions of 'intersex' issues in the main text, the majority used it only as part of the LGBTI acronym without expanding further on any substantive information about the topic through its text.

Stage 4 refers to the charting of data. For this review, I included the following information: Author(s), title, publication year, data base source, main themes observed and main human rights referred.

Stage 5: collating, summarizing and reporting the results.

For the analysis of information, a thematic approach (96) was taken, for this part my leading questions were: what themes or issues were present in the documents? If human rights discourses were present, what specific rights are invoked? Which ones had more visibility? Finally, because I wanted to explore literature on reparations I highlight if any references to reparations was present in the literature and if so, how is it framed? What ideas or rights it conveys?



Template from: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. Doi: 10.1136/bmj.n71

3.3.3. Results

3.3.3.1. Overarching themes

Following this approach, I analyzed three overarching themes present in the reviewed documents and grouped as “streams”:

1. Human rights international legal frameworks. (6–8,19,46,48,49,51–54,58–61,63,64,68,70,73,78,79,81,82,85,89,94)
2. Intersex medical practice and management. (47,51,56,59,62,63,65–68,70,73–75,77,84–86,88–93,95)
3. Intersex inclusion in sports. (50,57,69,76,83,87)

These themes often intertwined and cannot be neatly divided. In this exercise I tried to locate the articles in the stream that seemed closer to the centered theme discussed. Subthemes were present in each of these streams.

In the first stream, references to international human rights law (IHRL) were common; they often presented a review of legal or policy frameworks pertaining the rights of intersex persons, for examples those coming from the Council of Europe (CoE), the European Union, or the UN and its special procedures. (6–8,19,46,48,51–53,58,59,61,64,73,78,79,81,89,94)

This stream also included references to intersex activism, particularly its engagement with international human rights institutions and international human rights monitoring bodies (IHMB) and framing of claims as human rights issues. There were also some discussions about domestic legal frameworks, for example the case of Australia, Germany, the United States, Switzerland, and Belgium stand out. (7,19,46,48,53–55,60,61,64,78,79,81,89,94)

Human rights references spoke about bodily integrity, autonomy (6,19,46,48,53,58–60,78,79,81,89) and torture or ill treatment claims, (48,58,60,61,64,68,78,79,81) also references to discrimination, (19,48,53,54,59,60,64,78,81) claims concerning the right to health, (7,19,48,51,54,61,64,89) and the right to life and private life. (19,48,64,78) Other human rights framings present were that of sexual and reproductive rights and harmful practices. (48,53,58,60,61,64,78,81)

Children rights claims were present in many ways, for example concerning children's agency, the principle of the best interest of the child, their right to identity, development, and their right to be heard. (48,51,59,61,63,64,70,78,81,89) There were also mentions of parents' rights, often noticing possible conflicts between the rights/views of parents and those of children. (51,59,61,63,70)

Concerning the second stream, articles centered in medical practice also included to some degree discussions on human rights, often without going into details concerning legal implications or state or individual responsibility for human rights violations. Other subthemes include the history of medical practice, current medical protocols, matters that are seen as improvements or progress regarding medical treatments, specific variations, diagnosis and specific lines of treatments. (47,56,65,67,68,73–75,88–93,95) Critical perspectives of current and past medical protocols were also present and so were activists' and human rights concerns, but were not always centered to the discussion. (59,62,66,68,73,75,84,88–90,92,93,95) Articles in this stream also included both intersex and DSD terminology as well as some mentions of variations of sex characteristics.

As a matter of explicit rights mentions, many referred to personal or bodily integrity and autonomy as the main human rights concerns. (59,62,65,68,70,84,89) Other articles mentioned children's autonomy, right to an identity, right to development, right to be heard, and right to be protected from abuse and violence. (51,59,68,75,86,89) Interesting discussions about children's rights *vis a vis* parental rights were also observed. (59,70,75,84,86,93) There was limited mention of any rights or human rights in some articles in this stream. (62,66,67,84,88,91,93,95)

Concerning the third stream about sports the main human rights concern expressed was discrimination. (50,57,76,83,87) Other themes relate to fair play and sports rules regarding sex/gender, and sex-testing in sports, and the medicalization and pathologization of intersex variations. (50,57,69,76,83,87) Another issue present as well was the specific case of Caster Semenya. (50,57,76,87) The comparison of terminologies preferred show that the DSD frame is more common in sports related literature than 'intersex'.

Overall, in all streams there was a limited mention or references to social, economic and cultural rights, other than the right to health. Mentions to a disability rights approach also continue to be marginal.

3.3.3.2. Reparations and access to justice

The issue of reparations, redress or access to justice mechanisms was not particularly a main topic addressed in human rights literature, only 5 records were coded as mentioning any idea or referring to any form of reparations or justice claims or redress. (19,48,53,64,78) In two pieces of this review pertaining to Morgan Carpenter, the author makes references to this topic. In a 2020 piece Carpenter recalls how access to justice and remedies have been limited to intersex persons; this, in view of the author, is greatly due to stigma, the effect of limited disclosure of clinical records and unnecessary statutes of limitation which hamper the capacity of individuals to seek redress. (53) In another piece the author expands on what the inclusion of the right to truth in the Yogyakarta Principles plus 10 would mean for people with diverse sex characteristics. (19)

Bauer et al. also address the topic of reparations, in their 2020 article, the authors highlight international human rights frameworks, for example that of the Committee against torture, referring to "the right to access to redress and justice for victims of torture, including to fair and adequate compensation and the means for as full rehabilitation." (48) The authors also show concern over the barriers intersex persons have to access ordinary justice mechanisms, they note that "Statutes of Limitations render redress and access to justice for childhood IGM difficult or impossible in many nations". (48)

In a 2019 piece, talking about access to redress and reparations, Garland and Slokenberga state that "several national medical-ethics organizations have warned that protection for intersex children requires enhanced remedies, including criminal penalties and additional time to seek redress, where clinicians physically harm children through violations of their right to refuse any gender-conforming procedures." (64)

In an analysis of the ECHR jurisprudence and standards, Mestre argues that current medical practice that does not consider the agency of the person might be in violation of the prohibition against ill treatment and torture, likewise, she argues that the ECHR has emphasized that "states have a positive obligation to prevent the commission of ill-treatment and investigate the possible violation of human rights that covers itself with the redress of the damage, according to Article 13 of the Convention." (78)

4. DISCUSSION

4.1. Human rights framings

The three reviews carried out here show that human rights discourses are commonly evoked by intersex activists and social movements to portray their claims. The main demand highlighted by intersex activists is to put a stop to medically unnecessary surgery or treatments that are not consented by the affected person, however this claim is not alone. As mentioned in the gray literature[7] review there are many other demands directly connected to this issue and other human rights violations experienced by intersex persons, for example stigma, discrimination, lack of access to health care, including lack of psychosocial and peer support.

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[7] Consistent of activist declarations and international recommendations.

4.2. Access to justice and reparations

Intersex people suffer multiple forms of direct and indirect discrimination, and this also applies to accessing redress mechanism and reparations. As Bauer et al. (48) highlight, because surgeries and other invasive unnecessary medically approved treatments have been normalized they often go unquestioned. In some jurisdictions such as Canada, intersex genital normalizing surgeries are barred from criminal liability. (97) In 2021 Human Rights Watch started documenting efforts in the United States to shield from criminal responsibility these forms of medical abuse. (98)

Another issue is the aspect of statute of limitations, usually people have a period of time to present a claim before the criminal justice system, statutes of limitation are intended to be a procedural guarantee so people do not have to 'fear' criminal responsibility for the rest of their lives, a common classroom example would be someone who committed theft in their teens do not have to worry about been prosecuted into their old age.

In the case of intersex persons, however, as highlighted by the OHCHR, "intersex organizations have suggested that statutes of limitations unnecessarily limit access to redress for intersex individuals who have suffered unnecessary or inappropriate medical interventions without their consent during childhood or adolescence." (1) Bauer et al. point out that "statutes of limitation render redress and access to justice for childhood IGM difficult or impossible in many nations." (48) This is because violations committed against them, for example surgery or unwanted medical treatments, are carried out during childhood and it takes time for people to grow up and be legally able to bring a claim of their own to the courts. On the second hand because these human rights abuses have been normalized in medical practice and common culture, it takes extra time for the person to decide if they want to bring a claim to action or not. An additional barrier exists in those cases where people are unaware of surgery or treatments forced upon them because of medical secrecy, or in cases where they know, but the medical records do not exist or are not available. Precedents exists however when in cases of child abuse, statutes of limitation are extended or suspended until the person is old enough to carry out a claim. (1)

4.2.1. The right to truth and a proper investigation

Regarding specific forms of reparations, what stands out in the review is the right of intersex people to know the truth about what happened to them. The OHCHR has highlight that "[e]xperts recommended capacity building for judicial systems to ensure that intersex people have effective access to justice. Victims of human rights violations are entitled to truth, justice, reparation, rehabilitation and other remedies. In some cases, access to treatment may be reparative." (1) This was also considered in the YP+10. (16)

Regarding the right to truth, the standard of the Inter-American system of human rights is quite helpful. The IACHR has considered that the right to truth is closely linked to the person (or family members) to know what happened. The right to truth is not necessarily an individual right, meaning it is not necessarily exhausted by the production of a private report, but also can be a collective form of reparations. (99)

4.2.2. Recognition of harm

Many of the activist claims in the gray literature review spoke of the need for a recognition of harm. Both the Darlington Statement and the Yogyakarta Principles plus 10 also highlight the need for a public apology. The Yogyakarta Principles plus 10 for example speak about social dissemination of findings about past human rights violations, through commemorative dates, acts of public recognition and apology, museum and cultural exhibits and inclusion in educational curricula. (16)

4.2.3. Individual redress and compensation

Other forms of reparations observed in this review were specific rehabilitation measures for people who have suffered from abusive medical treatments and surgeries. As noted by the Vienna Statement intersex persons who have gone through these treatments can have health needs because of the surgeries and treatments, States and health policies should consider this. (21) Activist statements also highlight the need of psychosocial care and peer support, especially for victims of human rights abuses. (22,24) Redress as a form of financial compensation was also highlighted, for example the Parliamentary Assembly of the Council of Europe Resolution 2191 speaks about the creation of a specific fund.

5. CONCLUSIONS

A review of the above documents confirms that the demand for bodily integrity and to end medically unnecessary and non-consented surgeries and medical treatments is present in activists' and human rights documents in different regions.

The review also suggests that access to redress procedures and mechanisms, and the right to effective remedies and reparations are demands that are already present in different activist groups' documents. In this review the most extensive interpretation was found in the Yogyakarta Principles plus 10, this might be in due to the fact that they consider already existing interpretations of IHRL, which in itself already has extensive literature and jurisprudence on the topic of redress and reparations. (100,101)

Except for the Yogyakarta Principles and YP+10, most activist documents reviewed here do not go into details of what reparations and redress would look like, but there are two elements that stand out when it comes to access to justice and reparations, one is the acknowledgement of harm and the other one is redress. The Darlington Statement, for example, includes a demand for a public apology as a form of recognition. Other measures suggested by the Yogyakarta Principles plus 10 is publicity of past rights violations for example by commemorating dates, museums, events, or inclusion in human rights education curricula.

More research is necessary on the topic of redress and reparations from a human rights perspective. While this topic is addressed in most of the activists' declarations and statements examined in this report, only a limited number of international recommendations have called for redress and reparations. In terms of intersex studies and human rights scholarship, this topic is mostly left unaddressed, only marginal mentions were found in this review. In this sense it is not only recommended that researchers put more attention to the issues of redress and reparations but also that policy makers and human rights monitoring bodies start to include them in their recommendations.

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D5.2.5 Report on systematic explorative review of European national legislations related to the human rights protection of intersex people and their implementation

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Report on systematic explorative review of European national legislations related to the human rights protection of intersex people and their implementation

1. INTRODUCTION

“Intersex” is a term adopted by human rights defenders and human rights monitoring bodies to refer to people whose bodies do not fit the typical male or female medical and cultural binary standards. According to the Organisation Intersex International Europe (OII Europe), one of the main intersex activists’ organizations in the European continent:

> Intersex individuals are born with sex characteristics (sexual anatomy, reproductive organs, hormonal structure and/or levels and/or chromosomal patterns) that do not fit the typical definition of male or female. The term “intersex” is an umbrella term for the spectrum of variations of sex characteristics that naturally occur within the human species. The term intersex acknowledges the fact that physically, sex is a spectrum and that people with variations of sex characteristics other than male or female exist.[1]

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[1] Dan Christian Ghattas, *Protecting Intersex People in Europe: A Toolkit for Law and Policymakers* (ILGA Europe, OII Europe 2019) 9.

While most intersex people are capable of living perfectly healthy lives, with only a few experiencing medical conditions that put their health at risk,[2] intersex people's bodies have been traditionally and systematically stigmatized, mythologized, othered and pathologized.[3] Despite attempts to change and update medical standards of treatment, intersex people, particularly young children and newborns, continue to be subjected to sex 'normalizing' surgeries or treatments that in most circumstances have no medical necessity, urgency nor benefit, yet are carried out purely for body-altering cosmetic reasons and with the main purpose of 'normalizing' or 'defining' the sex traits of the infant to accommodate medical and cultural standards of what a male or female body should look like.[4]

These surgeries constitute a problem when they are carried out without the consent of the patient, often a child, and as they can have severe long-lasting consequences such as chronic pain, life-long trauma, sterilization, genital insensitivity and or diminished or lost capacity for sexual pleasure.[5] Moreover, under current human rights standards they represent a violation to the right of respect for one's private life, bodily autonomy and integrity, the right to consent to medical treatments, to be free from medical experimentation and ill-treatment, and they hamper the right to the highest attainable standard of health.[6] An important issue to keep in mind as well is that intersex activist groups and human rights monitoring bodies alike have called for a children's rights perspective to be respected and taken into consideration when dealing with medical treatments, especially children's rights to

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[2] Parliamentary Assembly of the Council of Europe, Resolution 2191 (2017). Promoting the Human Rights of and Eliminating Discrimination against Intersex People (2017).

[3] Council of Europe Commisioner for Human Rights (CoE), *Human Rights and Intersex People. Issue Paper* (CoE 2015); United Nations and Office of the High Commissioner for Human Rights (OHCHR), *Background Note on Human Rights Violations against Intersex People* (OHCHR 2019); Robert Hupf, 'Allyship to the Intersex Community on Cosmetic, Non-Consensual Genital "Normalizing" Surgery' (2015) 22 William & Mary Journal of Race, Gender and Social Justice 73.

[4] CoE (n 3); OHCHR (n 3); Inter-American Commission on Human Rights (IACHR), *Violence against Lesbian, Gay, Bisexual, Trans and Intersex Persons in the Americas* (IACHR 2015).

[5] IACHR (n 4), para 186.

[6] Markus Bauer, Daniela Truffer and Daniela Crocetti, (2020) 'Intersex Human Rights' 24 International Journal of Human Rights 724.

development, to be free from violence, and their right to be heard regarding decisions that affect their lives according to their age and maturity to be respected, which means that simply the consent of parents or those with custody rights to invasive treatments is not always enough.[7]

While there are a number of other issues that hamper the rights of intersex people, the prohibition of intersex genital normalizing surgery and treatments (IGS) continues to be the main demand of intersex activist groups and human rights monitoring bodies that echo these demands and ask of governments to prohibit that these types of surgeries are carried out without control.[8] According to the European Union Agency for Fundamental Rights (FRA), 'normalization' surgeries are carried out on intersex children in at least 21 Member States of the European Union (EU)[9] and this is a situation reflected throughout the world.[10]Among the member states of the EU and the Council of Europe (CoE), only four countries have legislation that provides protections against these types of interventions during early childhood at the time of writing.[11]

This report examines the legal nuances in the way the legal schemes in Malta, Portugal, Iceland and Germany have regulated and prohibited the performance of medically unnecessary and non-urgent intersex 'normalizing' surgeries (IGS) and other medical treatments. Special emphasis is put in the way the different legislative bodies seem to

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[7] IGLYO, OII Europe and EPA, *Supporting your intersex child* (IGLYO, et al. 2018); Kavot Zillén, Jameson Garland and Santa Slokenberga, *The Rights of Children in Biomedicine: Challenges posed by scientific advances and uncertainties* (CoE 2017).

[8] Ernesto Zelayandia-Gonzalez, 'The Growing Visibility of Intersex Demands at the United Nations: A Review of the Treaty Bodies Concluding Observations' (2023) 12 Social Sciences 73.

[9] EU Agency for Fundamental Rights (FRA), *The Fundamental Rights Situation of Intersex People* (FRA 2015).

[10] CoE (n 3); OHCHR (n 3); IACHR (n 4).

[11] See: The law of Malta 2015 "on gender identity, gender expression, and sex characteristics" [The Gender Identity, Gender Expression and Sex Characteristics Act]; the gender identity law of Portugal (2018) [Lei n.º 38/2018, de 7 de agosto. Direito à autodeterminação da identidade de género e expressão de género e à proteção das características sexuais de cada pessoa]; the Icelandic Gender Autonomy Act 2019 [Kynrænt sjálfræði] and the German law "for the protection of children with variants of sex development" 2021 [Gesetz zum Schutz von Kindern mit Varianten der Geschlechtsentwicklung].

understand the underlying ‘problem’ with these surgeries and treatments as it provides for a more comprehensive analysis of the measures or ‘solutions’ that are put forward to stop such problem.[12] The main goal of this report is to compile the best practice elements present in the four legislations under analysis.

This report looks at specific sections or provisions in the laws under review to better understand how they aim to tackle challenges presented by activists and literature. This also means that legal schemes are not ‘ranked’ against each other even in the comparison section. It needs to be said that this report should be considered as a theoretical exercise, one that acknowledges the different nuances, context realities and difficulties of law and policy making processes across Europe and does not aim to provide a ‘one size fits all’ solution or essentialize the demands of intersex activists across the continent but rather to identify positive elements (and challenges) to consider in the law and policy making process.

For the writing of this report, the legislative schemes of Malta, Portugal, Iceland and Germany were selected for review as these constituted at the time of writing the only four jurisdictions where intersex genital surgeries are prohibited at the national level, since the writing of this report Greece and Spain[13] have introduced similar legislations. In the first part of this report, the elements pertaining to the rights of intersex people present in the four laws are highlighted followed by a commentary on the interesting, positive or problematic elements with the laws. A second part of this report provides a comparison of how these four different countries have decided to deal with similar issues and aims at putting the different legal drafting styles in conversation with one another.

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[12] Carol Bacchi and Susan Goodwin, *Poststructural Policy Analysis. A Guide to Practice* (Springer 2016).

[13] See: Greek Law No. 4958/2022 Government Gazette 142/A/21-7-2022 Reforms in medically assisted reproduction and other urgent regulations Articles 17 -20. [ΝΟΜΟΣ ΥΠ' ΑΡΙΘΜ. 4958/2022 ΦΕΚ 142/Α/21-7-2022 Μεταρρυθμίσεις στην ιατρικώς υποβοηθούμενη αναπαραγωγή και άλλες επείγουσες ρυθμίσεις.] and for Spain Law 4/2023, of 28 February [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].

As a limitation I would like to point out the difficulties in accessing information regarding the legal schemes themselves and their implementation practices. Legal scholarship on this field seems to be limited still. Likewise, I faced some limitations regarding language and legal jurisdiction knowledge. While the Maltese and the Icelandic law have official English translations, this is not the case for the German and Portuguese ones, so some matters may have a different translation or meaning in the local language. Similarly, some of the laws refer to other broader aspects of the domestic legal landscape, for example provision regarding the statutes of limitations, civil or family codes. In order to avoid falling into a rabbit's hole I decided not to pursue all the questions concerning references to other laws. Despite the limitations, the report aims at providing a review of the legal landscape regarding intersex human rights in Europe.

2. LEGISLATION HIGHLIGHTS

2.1 Malta

Malta was the first country in the world to prohibit intersex genital 'normalizing' surgeries and treatments. The Maltese "Gender Identity, Gender Expression and Sex Characteristics Act"[14] was approved by the Maltese Parliament unanimously in April 2015 to make intersex genital surgeries that can be deferred and are carried out without the patient's consent mainly for social reasons unlawful. It was also the first one to extend nondiscrimination protections on the basis of one's sex characteristics.[15] While the law mainly deals with the procedures to recognize trans people's right to their gender identity and rectification of

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[14] Malta, Gender Identity, Gender Expression and Sex Characteristics Act. To provide for the recognition and registration of the gender of a person and to regulate the effects of such a change, as well as the recognition and protection of the sex characteristics of a person. ACT XI of 2015, as amended by Acts XX of 2015 and LVI of 2016 and XIII of 2018. <https://legislation.mt/eli/cap/540/eng/pdf> accessed September 15, 2022.

[15] ibid art 2.

identification documents, some provisions also speak to the rights of intersex people. Some of the elements included in the Maltese law to highlight are: The legal recognition of sex characteristics as a protected ground under the law, the right to bodily integrity and the prohibition of IGS, provision regarding health care treatments and the inclusion of monitoring mechanisms to follow up on the implementation of the law.

2.1.1 The legal recognition of one's sex characteristics and non-discrimination protections

The Maltese Gender Identity, Gender Expression and Sex Characteristics Act was probably the first in the world to provide a legal definition for the term "sex characteristics" and to include it as a protected ground against discrimination.[16] As per section 2 the term sex characteristics refers to: "the chromosomal, gonadal and anatomical features of a person, which include primary characteristics such as reproductive organs and genitalia and/or in chromosomal structures and hormones; and secondary characteristics such as muscle mass, hair distribution, breasts and, or structure". This terminology is much like the one included later in the Yogyakarta Principles +10.[17]

Sex characteristics are also recognized in the Maltese law as a protected ground against unlawful discrimination. Article 13 mandates the public service to ensure that unlawful discrimination and harassment, including those incidents that happen because of, or are driven by a person's sex characteristics are eliminated, and to ensure that its services must promote equality of opportunity to all, irrespective of sexual orientation, gender identity, gender expression **and sex characteristics.**[18] Likewise, Article 19 amends the existing

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[16] ibid art 2 and art 19.

[17] The Yogyakarta Principles Plus 10 - Additional Principles and State Obligation on the Application of International Human Rights Law in Relation to Sexual Orientation, Gender Expression and Sex Characteristics to Complement the Yogyakarta Principles (YP plus 10), 10 November 2017 <https://www.refworld.org/docid/5c5d4e2e4.html> accessed September 15, 2022.

[18] Malta (n 14), art 13.

Maltese Equality for Men and Women Act to include sex characteristics as a protected ground against discrimination along the lines of other grounds such as family responsibilities, sexual orientation, age, religion or belief, racial or ethnic origin, or gender identity and gender expression.[19]

2.1.2 The right to bodily integrity and prohibition of IGS

The Maltese law recognizes the right to bodily integrity and physical autonomy in article 3(1d), albeit it does not define them.[20] The law prohibits medical treatments and/or surgical interventions on the sex characteristics of minors unable to consent in circumstances where: a) these interventions lead to "sex assignment" and b) these interventions can be deferred until the person to be treated can provide informed consent.[21]

There are some circumstances that have been added to the law, which would make some of these surgeries and treatments legal if: a) "the minor gives informed consent through the person exercising parental authority or the tutor of the minor"[22] or b) ***if in exceptional circumstances****:* the minor does not, or cannot, give consent and the medical intervention is not driven by social factors, then interventions may be permissible where an agreement is reached between (i) the interdisciplinary team of experts and (ii) the persons exercising parental authority or the tutor of a minor who is still unable to consent.

A 2018 reform introduced sanctions within the body of the law. Article 14(2) established that medical practitioners or other professionals who breach the prohibition of IGS, if

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[19] ibid Article 19; ACT I of 2003, To promote equality for men and women, as amended by Legal Notice 427 of 2007; and Acts IV of 2009, IX of 2012, XVIII of 2014, and VII and XI of 2015, 9th December 2003, art 2.
[20] ibid art 3(1d).
[21] Malta (n 14), art 14(1).
[22] Malta (n 14), art 14(1), para 2.

convicted, can be liable to the punishment of imprisonment not exceeding five years, or to a fine between five thousand and twenty thousand euro.

2.1.3 Health services and intersex medical management

Section 14(4) mandates the creation of an interdisciplinary team appointed by the Minister responsible for equality for a period of three years. Under section 14(5), the composition of the team is left at the discretion of the Minister. Section 14(6) indicates that, when a minor expresses the decision for treatment with the consent of their parents and/or tutor, the medical professionals should: (a) ensure that the best interests of the child be the paramount consideration; and (b) give weight to the views of the minor having regard to the minor's age and maturity.[23]

Article 15 considers the right to psychosocial services and counselling, including peer counselling. The law states that: "All persons seeking psychosocial counselling, support and medical interventions relating to sex or gender should be given expert sensitive and individually tailored support by psychologists and medical practitioners or peer counselling. Such support should extend from the date of diagnosis or self-referral for as long as necessary."[24]

2.1.4 Monitoring mechanisms regarding implementation of the law

In terms of monitoring mechanisms, Article 16 considers the creation of a "working group" that shall be appointed by the Minister of equalities after consulting the Minister responsible for health to: "review the current medical treatment protocols in line with current medical best practices and human rights standards and shall, within one year from the date of their appointment, issue a report with recommendations for revision of the current medical

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[23] ibid art 14.

[24] ibid art 15.

treatment protocols."[25] The working group should be formed by nine experts, amongst them, three experts in human rights issues, three psychosocial professionals and three medical experts. The Chairperson shall be a medical doctor with at least twelve years of experience.

2.1.5 Commentary

While the Maltese law has been praised by many and is considered as a golden standard in law and policy making processes in terms of legal protections based in sexual orientation, gender identity and expression and sex characteristics,[26] particularly for being the first one to ever recognize sex characteristics as a ground for protection, there are some fronts where the law seems to fall short. Regarding the prohibition of IGS, for example, while the addition of some of the driving factors behind IGS used to justify these surgeries, namely 'sex assignment',[27] is a welcomed development as it raises visibility to one of the main underlying influences behind these interventions,[28] there are also some legally ambiguous terms

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[25] ibid art 16.

[26] Fae Garland and Mitchell Travis, 'Legislating Intersex Equality: Building the Resilience of Intersex People through Law' (2018) 38 Legal Studies 587; OII Europe, 'OII-Europe applauds Malta's Gender Identity, Gender Expression and Sex Characteristics Act' (April 1, 2015) <https://www.oiieurope.org/press-release-oii-europe-applauds-maltas-gender-identity-gender-expression-and-sex-characteristics-act/> accessed September 15, 2022; TGEU, 'Malta Adopts Ground-breaking Trans and Intersex Law - TGEU Press Release' (April 1, 2015) <https://tgeu.org/malta-adopts-ground-breaking-trans-intersex-law/> accessed September 15, 2022.

[27] Sylvan Fraser, 'Constructing the Female Body: Using Female Genital Mutilation Law to Address Genital-Normalizing Surgery on Intersex Children in the United States' (2016) 9 International Journal of Human Rights in Healthcare 62; Markus Bauer, Daniela Truffer and Daniela Crocetti, 'Intersex Human Rights' (2020) 24 International Journal of Human Rights 724; Daniela Crocetti and others, '"You're Basically Calling Doctors Torturers": Stakeholder Framing Issues around Naming Intersex Rights Claims as Human Rights Abuses' (2020) 42 Sociology of Health & Illness 943; Elizabeth Reis, 'Divergence or Disorder?: The Politics of Naming Intersex' (2007) 50 Perspectives in Biology and Medicine 535; Francesca Romana Ammaturo, 'Intersexuality and the "Right to Bodily Integrity"' (2016) 25 Social & Legal Studies 591.

[28] In its press release on the law, OII Europe praised the law claiming "For the first time in history intersex individuals will no longer be forced to endure arbitrary surgical sex assignment based on sociological factors." For more information visit: OII Europe, 'Press Release: OII-Europe applauds Malta's Gender Identity, Gender Expression and Sex Characteristics Act' (April 1, 2015) <https://www.oiieurope.org/press-release-oii-europe-applauds-maltas-gender-identity-gender-expression-and-sex-characteristics-act/> accessed September 15, 2022; The Maltese Human Rights Directorate website similarly mentions prohibiting normalising surgeries. More information: Human Rights Directorate, 'Legal Gender Recognition and Bodily Integrity' (Government of

present in the law that open a window for very important questions as to how the law should be interpreted. For example, the Maltese law fails to define what it means in Article 14(3) when it refers to the "exceptional circumstances" that allow for medical treatment, including surgery, to be carried out without the consent of the minor.[29] A better definition or at least a protocol to better identify these "exceptional circumstances" would provide extra protections to intersex minor's bodily integrity. Similarly, the law prohibits unlawful medical interventions driven by "social factors", but falls short at providing a definition of what those social factors are, making this also a legally ambiguous term. Seemingly the goal of both framings is to provide an open ended list of circumstances in order to better protect children from medically unnecessary interventions, however, by not providing a clear definition or any other criteria as to how one would identify what should be considered as an exceptional circumstance or how to distinguish 'social factors' from '*not* social factors,' these aspects of the law are left in a gray undefined area. Ambiguity is such that for instance, Tanya Ní Mhuirthile has questioned whether "The wording of Article 14(1) of the legislation is such that it might be read such as to prohibit circumcision of neo-natal males."[30] Perhaps this is not a pressing problem or a relevant matter when it comes to the applicability of the Maltese law, after all circumcision does not have a sex assignment motivation behind it, and there are no reports that this practice is forbidden or even questioned in Malta, for now however, and by the way it stands, the legal ambiguity in the Maltese law could be interpreted by some to prohibit this religious practice, therefore clarifying both aspects can only make the provision stronger and more accurate. Moreover, scholars, particularly those involved in critical disability movements, mad studies and social diagnosis theory have pointed out that the whole process behind creating a diagnosis is full of sociological factors and structures

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Malta 2020) <https://humanrights.gov.mt/en/Pages/LGBTIQ%20Equality/Legal%20Provisions/Legal-Gender-Recognition-and-Bodily-Integrity.aspx>, accessed September 15, 2022.

[29] Art 14(3) reads: "In exceptional circumstances treatment may be effected once agreement is reached between the interdisciplinary team and the persons exercising parental authority or tutor of the minor who is still unable to provide consent: Provided that medical intervention which is driven by social factors without the consent of the minor, will be in violation of this Act."

[30] Tanya Ní Mhuirthile, 'Malta' in Jens M. Scherpe, Anatol Dutta and Tobias Helms (eds), *The Legal Status of Intersex Persons* (Intersentia 2018) 361.

that frame such diagnosis.[31] As it will be addressed below, other legislations have not only included ways to identify troubling social and cultural factors that motivate unnecessary surgeries but also have added safeguards to medical procedures to better define and address concerns about medical necessity.

Another aspect that is unclear from the text of the law is the composition of the interdisciplinary team mentioned in article 14 and most of their functions. The law leaves its composition to the discretion of the Minister and does not define if this team should be understood as a medical team, a legal team, a psychosocial team, or if it is a true interdisciplinary team with a mixture of all the above.

The text of the law is also confusing regarding the functions and distinct responsibilities of the interdisciplinary team (article 14) and the working group (article 16). From the text of article 16 it can be inferred that when talking about the 'working group' the law talks about a national team of experts with the mandate of reviewing current medical practices and policies at the macro level. But the full role of the interdisciplinary team in article 14 is not clear as the text of the law only highlights that medical professionals are to make sure the best interests of the child as per human rights standards are secured "when the decision for treatment is being expressed by a minor with the consent of the persons exercising parental authority or the tutor" and to give weight to the child views according to their age and maturity.

While Article 16 states that the working group should have been appointed 3 months after entry into force of the act, yet it is unclear if such working group has been formed. The report

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[31] Tania M. Jenkins and Susan E. Short, 'Negotiating Intersex: A Case for Revising the Theory of Social Diagnosis' (2017) 175 Social Science and Medicine 91; Phil Brown and Stephen Zavestoski, 'Social Movements in Health: An Introduction' (2004) 26 Sociology of Health and Illness 679; Carol Thomas, 'How is disability understood? An examination of sociological approaches' (2004) 19 Disability & Society 569; Hannah Morgan, 'Mad Studies and disability studies' in Peter Beresford and Jasna Russo (eds), *The Routledge International Handbook of Mad Studies* (Routledge 2022).

mandated in article 16.6 that was supposed to "review the current medical treatment protocols in line with current medical best practices and human rights standards" was also not found in the course of this research.

Another point to highlight is that while the inclusion of peer counselling services in article 15 is a welcomed development, as it resonates with some of the demands of intersex activists,[32] the fact that the Maltese law fails to mention what kind of peer counselling intersex people can expect and who will provide such services is a missed opportunity. From the text of the law, it seems that the government relies on the existence of a strong network of intersex people's associations to provide such services. However, if peer services are to be provided by non-governmental associations the law fails to mention any form of support, funds, or compensation for their work. The state of the implementation of such services could not be found during the drafting of this report.

Most issues problematized in this section can be solved via secondary pieces of regulation, for example directives or protocols that regulate the composition of teams and working groups established in the law, and that provide for legal definitions for legally ambiguous terms. These set of issues do not necessarily need to be included in the law or need a legislative reform. However, when compared to other more recent pieces of legislations there are other issues that have not been included in the Maltese law and would make it stronger should a review or reform were to come. Other issues identified by activists, for example, periodical monitoring procedures of implementation, and procedural guarantees against statutes of limitation to access courts and litigation[33] would make it enough to call for a new the reform of the Maltese law.

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[32] Third International Intersex Forum, 'Malta Declaration. Public Statement by the Third International Intersex Forum' (2013).

[33] OHCHR (n 3); Morgan Carpenter, 'The OHCHR Background Note on Human Rights Violations against Intersex People' (2020) 28 Sexual and Reproductive Health Matters 1.

2.2 Portugal

In August 2018 Portugal became the second country in the world to approve a state-wide law aiming at protecting the sex characteristics of people. Commonly known as the Gender Identity law or *Lei da Identidade de Género*, Law n.º 38/2018 has amongst its aims protecting the "right to the protection of the sex characteristics of each person."[34] The proposal approved by the Portuguese Council of Ministers recalled in its motivation the Yogyakarta Principles[35] as source of inspiration and considered that the main aim of the law was to "make Portugal more respectful of the human rights of transexual and transgender people, as well as intersex people, establishing procedures that guarantee a better quality of life and greater inclusion of a social group that is often the target of discrimination, stigma and violence."[36] The law applies to both public and private institutions and public entities have also the mandate not only to implement the law and to refrain from unlawful actions but also to promote the right to the protection of one's sex characteristics.

2.2.1 The right to protection and non-discrimination based on one's sex characteristics

While the law does not provide a legal definition of the term "sex characteristics" the exposition of motives from the Portuguese Council of Ministers took inspiration from the terminology present in the Yogyakarta Principles[37] and the Yogyakarta Principles +10.[38]

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[34] Portugal, Lei n.º 38/2018, de 7 de Agosto. Direito à autodeterminação da identidade de género e expressão de género e à proteção das características sexuais de cada pessoa, Article 1. Own translation. <https://dre.pt/dre/detalhe/lei/38-2018-115933863> accessed September 15, 2022.

[35] The Yogyakarta Principles. Principles on the Application of International Human Rights Law in Relation to Sexual Orientation and Gender Identity (YP) 2007. <https://www.refworld.org/pdfid/48244e602.pdf> accessed September 15, 2022.

[36] Presidência do Conselho de Ministros. Proposta de Lei n.º 75/XIII. Exposição de Motivos. Own translation. <https://app.parlamento.pt/webutils/docs/doc.pdf?path=6148523063484d364c793968636d356c6443397a6158526c6379395953556c4a5447566e4c305276593356745a57353062334e4a626d6c6a6157463061585a684c7a526b597a5a684d7a42694c544931597a51744e445a6d4d5330344d5455774c546b784f545931597a4d344e54426b5969356b62324d3d&fich=4dc6a30b-25c4-46f1-8150-91965c3850db.doc&Inline=true> accessed September 15, 2022.

[37] YP (n 35).

[38] YP plus 10 (n 17).

Article 1 of the Portuguese law establishes the "right to the protection of the sex characteristics of each person."[39] and Article 4 considers that everyone "has the right to *maintain their primary and secondary sex characteristics.* [40] The law also includes nondiscrimination measures in Article 2 which prohibits any form of direct or indirect discrimination based on gender identity, gender expression or the *exercise* of one´s right to the protection of their sex characteristics.

2.2.2 Prohibition of IGS

Article 5 of the Portuguese law contains a prohibition on "treatments and surgical or pharmaceutical interventions or those of another nature that entail modifications at the level of the body and the sex characteristics of an intersex minor," and until the moment in which their gender identity manifests.[41] The only exceptions to this rule are: "situations of proven risk for the person's health."[42] The law also highlights the importance of allowing the free development of a person's gender identity.[43]

2.2.3 Teaching and education

The Portuguese law also considers educational policy measures oriented towards the protection of intersex pupils which serve as awareness raising tools to promote intersex people's rights. Article 12 states that "The State must guarantee the adoption of measures in the educational system, at all levels of education and study cycles, that **promote the exercise of the right to self-determination of gender identity and gender expression and the right to the protection of people's sex characteristics**, (…)."[44] To achieve this goal, the law recommends the government turns to: Measures to prevent and combat

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[39] Portugal (n 34), art 1. Own translation.
[40] ibid art 4. Own translation, emphasis added.
[41] ibid art 5. Own translation.
[42] ibid art. 5. Own translation.
[43] ibid art 2.
[44] ibid art 12. Own translation, emphasis added.

discrimination based on gender identity, gender expression and sex characteristics; mechanisms to detect and intervene in situations of risk that endanger the healthy development of children; creating the adequate conditions for the protection of gender identity, gender expression and sex characteristics against all forms of social exclusion and violence within the school context, ensuring respect for children's autonomy, privacy and self-determination; and appropriate training aimed at teachers and other professionals in the education system in the context of issues related to the issue of gender identity, gender expression and the diversity of the sex characteristics of children and young people.[45] Finally, all educational establishments, regardless of their public or private status, must guarantee the necessary conditions for children and young people to feel respected according to their gender identity and gender expression and their sex characteristics.[46]

2.2.4 Treatments and medical management

While the law does not specifically address health services pertaining intersex people, Article 11(2) mandates the Directorate-General for Health to draft an intervention model, guidelines and technical standards, to be implemented by health practitioners on issues related to gender identity, gender expression and people's sex characteristics within a maximum period of 270 days from the entry into force of the law.[47] No information was found however if such model exists.

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[45] ibid Summary of the law text, own translation.

[46] ibid.

[47] ibid art 11.

2.2.5 NGO procedural rights

Article 16 recognizes the right of associations and NGOs that exist with the main goal to defend and promote the rights of trans and intersex people to legal standing and procedural legitimacy for the defense of such rights either in collective or individual procedures.

2.2.6 Commentary

Regarding protections against IGS, while Article 2 of the Portuguese law does not explicitly speak about bodily integrity, it does recognize people's right to have their sex characteristics protected. This framing could give sufficient protections for people with variations of sex characteristics but the fact that the law does not legally defines sex characteristics means this is left open to interpretation. Likewise, the reference and inclusion to the person's gender identity and *not* to their bodily autonomy and/or integrity in Article 5, where the main protection against IGS relies, seems to give primacy to the former making the latter rather invisible.[48] In this sense, it seems that the way IGS is problematized by the Portuguese lawmaker relies on the concern of conducting the 'wrong' type of surgery in the 'wrong' person or body, rather than conducting a surgery without the person's consent (prioritizing autonomy and bodily integrity). In fact, Article 5 makes no mention to the person's consent at all. The legislature *does* mention that treatments and interventions cannot be carried out until the person manifests their gender identity. This framing again implies that the legislature seems worried that surgeries will have the unwanted effect of assigning a wrong physiology or 'sex' on someone that will cause a disconnection with their gender identity, when it could give equal importance to the fact that this person might not want any kind of

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[48] Article 5 states that: "Except in situations of proven risk to their health, treatments and surgical or pharmaceutical interventions or those of another nature that entail modifications at the level of the body and the sex characteristics of an intersex minor, should not be performed until the moment in which their gender identity manifests." (Own translation) ["Salvo em situações de comprovado risco para a sua saúde, os tratamentos e as intervenções cirúrgicas, farmacológicas ou de outra natureza que impliquem modificações ao nível do corpo e das características sexuais da pessoa menor intersexo não devem ser realizados até ao momento em que se manifeste a sua identidade de género."]

surgery in the first place, regardless if their gender identity matches or not their physiology. OII Europe has spoken about risks of doctors and/or parents considering the gender identity of a child "manifested" already in order to green light surgeries as a situation of concern.[49]

The Portuguese law makes no reference to the underlying factors that often serve as a justification for IGS, other than factors that risks the person's health, this, I believe, is a missed opportunity. While it is perhaps not legally possible to list all the causes or justifications doctors or parents use to carry out IGS, a reference to the leading factors highlighted by activists,[50] with a '*numerus apertus*' that includes identified social factors, could provide possible victims of IGS with more elements to prove the damage made to them. For doctors, parents and others involved in decision making processes this would provide them with more elements to identify unnecessary treatments and surgical interventions.

Portugal includes nondiscrimination protections based on the right to the *protection* of one's sex characteristics. Because the law does not provide a definition on sex characteristics nor does it legally define what intersex means, the aspect of who is protected by the law falls into a large margin of interpretation which could either benefit people with variations of sex characteristics by including most variations or could limit the number of who is counted as an intersex person or what counts as a sex characteristic.

Finally, as stated above, the fact that article 16 recognizes procedural rights to associations and NGO can be seen as a positive element that resonates with intersex activists claims, as it gives associations the capacity to act on behalf of individuals.[51]

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[49] See: OII Europe, 'Portugal has taken an important step towards protecting intersex people's bodily integrity – but will it be enough?' (July 12, 2018) <https://www.facebook.com/480416118685282/posts/portugal-has-taken-an-important-step-towards-protecting-intersex-peoples-bodily-/2038977029495842/> accessed September 15, 2022.

[50] Ghattas (n 1).

[51] Third International Intersex Forum (n 32).

2.3 Iceland

In 2019 Iceland approved "The Gender Autonomy Act" (Kynrænt sjálfræði)[52] to give legal recognition to a series of rights of trans and intersex people. Despite initial reports that the law would include protections for intersex people, specifically a prohibition against IGS, this was not included in the version of the law that was ultimately approved which dealt primarily with trans gender identity recognition issues.[53] In December 2020, however, the Icelandic parliament approved a series of reforms to the gender autonomy act and a provision to prohibit IGS was finally codified in the law.[54]

2.3.1 Protecting physical integrity and sex characteristics

One of the main objectives of the Icelandic law as stated in Article 1 is to guard people's right to their physical integrity as well as their right to self-define their gender and guarantee the legal recognition of people's gender identity. Ever since the originally approved version of the law (2019), Article 2 provides a legal definition of "sex characteristics" and "physical integrity" that is much like the one used by activist groups and present in the Yogyakarta Principles plus 10.[55] As per article 2 physical integrity is defined as: "The absolute right to autonomy over one's body and entitlement to respect for one's right to life, security, freedom and human dignity."[56] About sex characteristics, the same article considers these are:

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[52] Iceland, Act on Gender Autonomy No. 80/2019 as Adopted by Althingi on 18 June 2019 <https://www.government.is/library/04-Legislation/U%C3%9EM2019080051%20-%20L%C3%B6g%20um%20kynr%C3%A6nt%20sj%C3%A1lfr%C3%A6%C3%B0i%20(002)%20_loka.pdf> accessed September 15, 2022.

[53] Rachel Savage, 'Iceland's intersex children at risk as without new protection, activist says' (Reuters, February 19, 2019); Ugla Stafanía Kristjönudóttir Jónsdóttir, 'Making life better for trans people and intersex people in Iceland' (Gay Iceland, January 6, 2021).

[54] Iceland, Act on Gender Autonomy No. 80/2019 as Amended by Act No. 159/2019, No. 152/2020 and No. 154/2020 <https://www.government.is/library/04-Legislation/Act%20on%20Gender%20Autonomy%20No%2080_2019.pdf> accessed September 15, 2022.

[55] YP plus 10 (n 17).

[56] Iceland (n 52), art 2.

"Biological traits related to gender, such as sex chromosomes, hormone function, gonads and genitals."[57]

After the 2020 reform to the law the term "*atypical* sex characteristics" was also included. These 'atypical' characteristics are defined as "sex characteristics that fall outside traditional definitions of sex characteristics as male or female, e.g. as regards functionality or appearance".[58] Article 3 recognizes the unrestricted right to physical integrity and autonomy concerning changes in one's sex characteristics and Article 11a extensively considers the dimensions and protection to the right to physical integrity and changes regarding atypical sex characteristics.

2.3.2 Prohibition of IGS

The 2020 reform saw the introduction of new protections to the *atypical* sex characteristics of children under the age of 16 and prohibits *permanent* changes to their sex characteristics. When speaking of permanent changes the Icelandic law includes surgical operations, medication, and other irreversible medical interventions.[59] Exceptions are included in the prohibition, and permanent changes to the sex characteristics of children under the age of 16 born with atypical sex characteristics may be considered lawful if these are: a) required for health reasons and b) are followed by a detailed assessment concerning the need and short and long term consequences of the proposed interventions.[60] When considering medical interventions, the law requires that the child is consulted to the extent possible according to their age, level of maturity and in all cases once the child has reached the age of 12.[61] The Icelandic law also considers that "[s]ocial, psychosocial and appearance related

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[57] Iceland (n 52), art 2. Icelandic language makes no difference between the concepts of sex/gender.

[58] Iceland (n 54), art 2(6).

[59] ibid art 11, para 2.

[60] ibid art 11, paras 2-3.

[61] ibid art 11a, para 3.

reasons"[62] shall not be regarded as health reasons. Treatments, including surgery, are exempted from the application of this law in the case of hypospadias as per article 11a paragraph 5 of the law, as well as "medication for micropenis". There's is no reasoning as to why this exclusion is present, albeit there is the compromise in Article 18 to review whether to maintain it or not.

2.3.3 Treatment management, health care services and multidisciplinary teams

Article 9 seeks the creation of a "committee of experts on changes to the gender registration of children and permanent changes to atypical sex characteristics of children." This committee of experts is given the responsibility to provide a decision pursuant to the change of the gender registration of a child[63] and permanent changes to the sex characteristics of a child.[64] The Prime Minister's office is entitled with the responsibility to appoint this committee of experts to serve for a term of four years. Article 9 states that the committee shall be comprised of three members: a pediatrician, appointed by the Directorate of Health; a psychologist expert in the field of child psychology, appointed by the Icelandic Psychological Association, and a lawyer "with special knowledge in the field of children's rights, appointed by the Minister responsible for human rights issues." In providing an assessment on a case, the committee may obtain the opinion of other specialists as well. If an application for treatment entailing a change to sex characteristics is rejected by the Committee of experts, the right to appeal this decision is guaranteed as per article 14a. The appeal shall be directed towards the Directorate of Health.

A second "team of experts" is established in Article 12(1). Given that services for intersex people seem to be concentrated in Landspítali hospital in Reykjavík, Article 12(1) of the Icelandic law considers the formation of a group of experts in the field of "changes to sex

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[62] ibid art 11a, para 2.
[63] ibid art 5(3).
[64] ibid art 11a(6).

characteristics" who shall be appointed by the director or Chief Executive Officer (CEO) of that hospital. The law further considers that "the team shall be interdisciplinary and composed of professionals with relevant knowledge and experience. The team may call on other experts for consultations and collaboration in order, among other things, to secure knowledge of the social aspects of gender identity."[65] The main responsibility of this team is to "provide its clients, *18 years and older*, with information, counselling and treatment in accordance with the needs of each and every one. The team should also provide the relatives of clients with information and counselling."[66] The team of interdisciplinary experts at Landspítali hospital may adopt its own rules of procedure and the Minister responsible for health care services may lay more detailed provisions on the tasks for the team.

The 2020 reform to the Icelandic law saws the introduction of article 13a which also calls for a third team on issues concerning "atypical sex characteristics" to be created. This team shall also be appointed by the Landspítali hospital director or CEO. This team shall also be interdisciplinary and members can request the opinion of outside members as matters of consultation. The law further stipulates that the team provides children under the age of 16 born with *atypical* sex characteristics and their families with information, counselling and treatment in conformity with individual needs.[67] Likewise, the interdisciplinary team is expected to "guide its clients to appropriate peer-to-peer counselling of people with atypical sex characteristics and their representative associations."[68] The law also clarifies that the team provides services to intersex patients regardless if their sex characteristics have been permanently changed, or if no changes have taken place or have been postponed.

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[65] ibid art 12, para 1.
[66] ibid art 12, para 1. Emphasis added.
[67] ibid art 13a, para 2.
[68] ibid art 13a.

2.3.4 Recording and disclosure of health data

All the steps taken during the decision-making process concerning surgery and any other permanent changes to one's sex characteristics shall be recorded as per Article 11a paragraph 4. The law also encourages parents and legal guardians to disclose to their children any permanent changes made regarding their sex characteristics, albeit no sanctions are present in the law shall the parents or guardians fail to complain.[69]

2.3.5 Statute of limitation

Article 15 of the Icelandic law suspends the statute of limitations for IGS carried out before the age of 18 and considers that the limitation period for claims for damages shall start at this age, and allows for claims to be pursued via criminal sanctions and fines in accordance to Icelandic criminal law.

2.3.6 Monitoring and evaluation

A transitional provision was added to the law in order to establish a working group, which within the first three years of entry into force of the protections against IGS is expected to review its practical experience and develop research and knowledge and best practices in the field of human rights. The group is also expected to review whether hypospadias surgeries and medical treatments for micropenis cases should remain excluded from the ambit of the IGS prohibition or not.[70] This reviewing group "shall be comprised of a pediatric surgeon, a pediatric endocrinologist, a child psychologist, appointed by the Minister of Health, a representative of Intersex Iceland, a representative of Samtökin '78, the National Queer Association of Iceland, a sexologist appointed by the University Level Collaboration

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[69] ibid arts 14(4) and 15(3).
[70] ibid art 18.

Committee, an ethicist appointed by University of Iceland‘s Center for Ethics and two lawyers, one with expert knowledge of children's rights issues and the other with expert knowledge of human rights". [71] The group is due in 2023 but no information was found about its formation.

2.3.7 Commentary

Some of the most positive aspects of the Icelandic way of protecting intersex people's rights is that the law aims to protect both physical integrity, people's sex characteristics as well as their gender identity differentiating these aspects from each other, giving it a great intersectional perspective and equal standing. It is also positive that when naming medical reasons as a justification for carrying out these surgeries, the Icelandic law excludes "psychosocial and appearance related reasons."[72] Likewise, another welcomed development is that, as stated above, the Icelandic law mandates that intersex children and their guardians are provided with counselling and support from a team of experts on the issue of children born with *atypical* sex characteristics concerning the decision of carrying out surgeries. The team of experts is also encouraged to guide its clients to receive appropriate peer counselling from intersex persons. [73] Regarding intersex medical management provisions, both the interdisciplinary team of Article 9 and the team of experts of Article 13a seem to aim to have balanced views with perspectives that go beyond the clinical.

On the other hand, regarding the prohibition of IGS an important limitation in its ambit of protection comes from the fact that that hypospadias surgery and micropenis treatments are excluded from the scope of the law, albeit, there is a commitment to review this position in the future. This is a major limitation of the law.

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[71] ibid art 18.
[72] ibid art 11a, para 2, last sentence.
[73] ibid arts 11a(3) and 13a.

Also, the difference between the terms sex characteristics and '*atypical'* sex characteristics in the text of the Icelandic law is not fully clear. While the 2019 version of the "Gender Autonomy Act"[74] already included and defined the term "sex characteristics" in its text, using a definition not far from that of activist groups,[75] the updated version sees the inclusion of the term "atypical sex characteristics."[76] This inclusion seems troubling in different aspects, for one it adds nothing in terms of providing an actual definition but rather seems fixed in binary definitions of what is a typical or atypical male of female body. In this sense, the new definition leaves more questions than answers. Another aspect is that, classifying these other set of characteristics as *atypical* can also be perceived to have an 'othering,' if not pathologizing effect.

2.4 Germany

In 2021 the German Bundestag entered discussions of the law "on the protection of children with variants of sex development,"[77] The law was approved by the Bundestag in March 2021 and came into effect in May 2021. The German law contains a series of reforms to different pieces of legislation and is aimed at protecting intersex children, or as the German law calls them "*children with variants of sex development"* from unnecessary surgery and medical treatments. The most relevant change in terms of prohibiting IGS is present in Article 1 which modifies the German civil code.

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[74] Iceland (n 52), art 2.

[75] Ghattas (n 1) 9.

[76] Iceland (n 54), art 2.

[77] Germany, Gesetz zum Schutz von Kindern mit Varianten der Geschlechtsentwicklung, Vom 12. Mai 2021 <https://www.bmj.de/SharedDocs/Gesetzgebungsverfahren/Dokumente/Bgbl_Varianten_der_Geschlechtsentwicklung.pdf;jsessionid=94CCC259C0936B2B4D88B6A643B28E50.1_cid334?__blob=publicationFile&v=3> accessed September 15, 2022.

2.4.1 Prohibition of IGS

Article 1(1) restricts parental and guardian custody rights to consent to or perform surgery and treatments to be carried out in a child with variants of sex development solely with the intention that their physical appearance fits that of the male of female bodily appearance. Article 1(2) indicates that parents only can give consent in cases where such intervention cannot be postponed until the child can make a self-determined decision. Article 1(3) indicates that the parental consent according to Art 1(2) requires the approval of the family court, unless the surgical intervention is deemed as necessary to avert a danger to the life or health of the child and cannot be postponed until the granting of the approval. This approval must be granted upon application of the parents if the planned intervention is in the best interest of the child. Art 1(3) also indicates that if the parents submit to the family court a supportive statement of an interdisciplinary commission, it should be presumed that the planned intervention is in the best interest of the child.

2.4.2 Health care services and interdisciplinary teams

Article 1, paragraph 4 articulates the composition of the interdisciplinary commission. The team must be comprised of at least the professional treating the child, at least another doctor, a mental health professional with qualifications in the treatment of children and adolescents and one person trained in ethics. The medical members of the interdisciplinary commission must have different specializations in the field of pediatrics, amongst them there must be a specialist in pediatrics and adolescent medicine with a focus on pediatric endocrinology. The second doctor in the commission must not be employed by the medical facility where the intervention is planned to be carried out. All committee members must have experience of dealing with children with variants of sex development and at the request of the parents, the commission should involve an advisor with a variant of sex development.

According to Art 1(5), the interdisciplinary commission has the mandate of providing a position statement on the necessity of surgery in the case established in Art 1(2).[78] This statement is required to have the following elements: "1. the designation of the members of the commission and information on their qualifications, 2. the age of the child and whether and what variant of sex development they have, 3. the planned intervention and which indication exists for it, 4. a reasoning as to why the commission supports the intervention taking into account the best interest of the child, and to what extent the intervention corresponds to the best interest of the child, in particular which risks are related to the intervention, another treatment or refraining from intervention until a self-determined decision of the child, 5. whether and which members of the commission have conducted a conversation with the parents and the child and if and by which members of the commission the parents and the child have been informed and advised on how to deal with variants of sex development, 6. if a counselling of the parents and the child has been conducted by an advisor with a variant of sex development, 7. the extent to which the child is capable of forming and expressing an opinion and whether the planned intervention corresponds to their will, and 8. if the advisor with a variant of sex development involved supports the favorable position statement."[79] Finally, Art 1(6) requires the medical records of a person who has received treatment because of their sex characteristics to be kept until that person turns 48 years old.

2.4.3 Monitoring and evaluation

Article 6 orders the federal government to monitor the effectiveness of articles 1 and 3 of the German law, concerning the limitations to parental rights and family court procedures. After five years from the time the law enters into force, the Federal Government is to submit a report to the German Bundestag. The Federal Government should also review if an extension

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[78] Surgical intervention on the sex characteristics of the child that cannot be postponed until the child can take a self-determined decision.

[79] ibid art 1(5). Own translation.

of the regulations is recommended regarding: "1. Extension of the family court approval procedure to other types of treatment or to other groups of children, 2. Introduction of a procedure to verify the child's capacity to give consent, 3. Introduction of prerequisites for the treatment of children with variants of sex development capable of giving consent, 4. Introduction of an obligation to seek independent counselling on dealing with variants of sex development and 5. Introduction of a regulation on the costs of the position statement of the interdisciplinary commission."[80]

2.4.5 Commentary

According to a review of the draft law contributed by OII Europe, the German law makes unlawful surgeries that are solely performed for the reason of altering the child's body into a more normative appearance without fully informed consent. In this sense "The law provides a first, yet non-comprehensive, framework to protect intersex children from non-vital, non-emergency medical interventions."[81] Only two exceptions are made to the general prohibition in the German law: parents can give consent in name of the child, upon the required approval of a family court, if the surgical intervention "cannot be postponed until the child has made a self-determined decision", however the family court approval is not required if "the surgical intervention is necessary to avert a danger to the life or health of the child and cannot be postponed until approval has been granted."[82] It is not quite clear what reasons other than preserving the life or health of the child could be understand as reasons that "cannot be postponed".

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[80] ibid art 6. Own translation.

[81] OII Europe, 'A good first step: Germany adopts law banning IGM. But there is still room for improvement' <https://oiieurope.org/a-good-first-step-germany-adopts-law-banning-igm/> accessed September 15, 2022.

[82] Germany (n 77), arts 1(2) and 1(3). Own translation.

As a positive development the changes to the German legal framework aiming to protect children's sex characteristics and development reiterate the importance of keeping the principle of the best interest of the child centred at all times.

Regarding medical management, some questions remain. For one, the German law does not specify the function of the interdisciplinary committee other than providing a position statement on why the Commission supports the intervention, and whether, in its view, it corresponds with the best interests of the child. The law does not mention what kind of periodic health services are provided to intersex people or who is in charge of providing them. Finally, the law requires the medical records of a person who has received treatment because of their sex characteristics to be kept until that person turns 48 years old. While this period of time could be expanded further, this is a good development that will give more people the possibility of accessing their records for a longer period of time.

3. LEGAL SCHEMES IN DIALOGUE

3.1 Definitions and scope of protections

There are some interesting findings regarding the definitions used in the laws under review and how these definitions are given a legal meaning in order to grant or recognize protection of rights. The one that stands out perhaps is the emergence of the term 'sex characteristics' as a legal ground for protections much similar to race, gender, age, sexual orientation amongst others. The Maltese law, for example, includes a definition of sex characteristics and recognizes protections on this protected ground, including nondiscrimination via the reform of their equality act. Likewise, it recognizes the right to bodily integrity albeit it does not provide a definition.[83] Portugal does not provide a legal definition of what sex characteristics

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[83] Malta (n 14).

are, however, the term is included in the law as it does recognize the "right to the protection of the sex characteristics of each person."[84]

Iceland defines sex characteristics and 'atypical' sex characteristics, grants protections based on sex characteristics and recognizes the right to physical integrity as well.[85] The Icelandic framing of sex characteristics stands out because it makes a differentiation between sex characteristics that are considered typical and those that are viewed as *atypical.* If sex characteristics emerged as a term that is supposed to be relatable to everyone or universal, meaning that 'all human beings have sex characteristics,'[86] the differentiation made in the Icelandic law seems unnecessary. The German law does not provide a definition of either sex characteristics or bodily integrity, consequently it says nothing regarding the right to bodily integrity nor explicit protections to one's sex characteristics. While the German law uses the term "variants of sex development" to refer to intersex variations, it falls short to give legal meaning to this ambiguous term, the law therefore further creates a gray area making its ambit of protection unclear. This critique was also made by OII Europe to an earlier version of the law. [87]

A common potential problem with the legislative schemes examined in this report is the repeated use of legally ambiguous language. In the absence of precise definitions of terms such as 'intersex', 'sex characteristics' and 'sex development' it is unclear who can come within the ambit of the legislative protections and who is excluded therefrom. Therefore, the line in the sand of who is and who is not protected remains unclear. Iceland, for example, does try to give legal meaning to the terms sex characteristics and atypical sex characteristics, but as stated before the terms continue to be confusing. The Maltese

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[84] Portugal (n 34), art 1. Own translation.
[85] Iceland (n 54), art 1.
[86] Ghattas (n 1) 21; Morgan Carpenter, 'Intersex Human Rights, Sexual Orientation, Gender Identity, Sex Characteristics and the Yogyakarta Principles plus 10' (2020) 23 Culture, Health and Sexuality 516.
[87] OII Europe (n 81).

provision focuses on the purpose and effects of interventions ("sex assignment treatment and/or surgical intervention on the sex characteristics") rather than the people subjected to the interventions. Therefore, the Maltese provision is applicable to all children who are unable to consent. It also provides a clear legal definition of "sex characteristics."[88]

A common fear found in literature points to the fact that a badly designed provision to protect intersex children from IGS could have the unwanted effect of limiting gender affirming treatments for trans youth.[89] This did not seem to be an issue in the laws examined. All of the laws, with the exception of Germany, extensively consider trans rights. And more importantly, by keeping the child's capacity to consent and self-determine decision concerning their bodies centered, the Maltese, Portuguese and Icelandic legal schemes keep the right of both intersex children and trans children and youth safe from forced procedures.

Because terms such as 'intersex', 'sex characteristics', 'sex development' and even 'bodily integrity' are still open to interpretation, it seems to constitute a good legal practice to include a definition in the law, this helps better define the scope of its application and to define what is the matter that the law primarily aims to target. If left undefined ambiguous terms might serve to exclude a number of people from legal protections. On the other hand, there are also explicit yet unreasoned exclusions such as the case of hypospadias or micropenis cases being left out of the scope of protection of the Icelandic law.

3.2 Ban on surgery, scope of protection and exceptions

Regarding the ban on abusive medical treatments and surgical interventions, all the laws under review ban the performance of medical treatments and surgical interventions, where

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[88] Malta (n 14), art 2.

[89] Marijke Naezer and others, '"We Just Want the Best for This Child": Contestations of Intersex/DSD and Transgender Healthcare Interventions' (2021) 30 Journal of Gender Studies 830.

a child cannot consent, and interventions are not deemed as urgent to preserve the child's life or health.

Three of the laws also make reference to the socio-cultural underlying factors that may drive doctors' and/or parents' decisions to carry out or allow for such interventions. Iceland for example prohibits IGS on the basis of "[s]ocial, psychosocial and appearance-related reasons."[90] Similarly, Germany limits them if they have the intention or effect of modifying the bodily appearance of the child[91] so it becomes in accordance with the male or female physiology. As mentioned before Malta makes "any sex assigning treatment and, or surgical intervention on the sex characteristics of a minor"[92] unlawful in cases where the treated person cannot provide consent and the intervention can be deferred.[93]

All laws examined consider exceptional circumstances where IGS is deemed as legal. Portugal, Iceland and Germany consider health related reasons as valid motives for allowing IGS. Malta also considers exceptions, however Malta stands out in that it does not mention the health or life of the child as factors to decide on the necessity of surgery or treatments but rather bans under all circumstances interventions driven by social factors without the consent of the child.[94] The Maltese law considers that "(3) In exceptional circumstances treatment may be effected once agreement is reached between the interdisciplinary team and the persons exercising parental authority or tutor of the minor who is still unable to provide consent."[95] However, it fails to mention what these exceptional circumstances are or what criteria to use to determine that. What it is clear however is that interventions driven by social factors without the consent of the child will be in violation of the law.

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[90] Iceland (n 54), art 11a, para 2.
[91] Germany (n 77), art 1(2) ("das körperliche Erscheinungsbild des Kindes").
[92] Malta (n 14), art 14(1).
[93] ibid art 14(1).
[94] ibid art 14(2).
[95] ibid art 14(3).

In terms of scope of limitations, the Icelandic law has the effect of being limited to children *born with atypical sex characteristics* until the age of 16,[96] and as previously stated, the case of hypospadias or micropenis cases being left out of the scope of protection of the Icelandic law. Portugal does not admit an age requirement but rather limits its scope of application to "intersex minors" until the moment "they manifest their gender identity."[97] Germany limits its scope of protection to *children with variants of sex development* until they are able to consent, no specific age is mentioned.[98]

3.3 Nondiscrimination protections and affirmative action measures

Both Malta and Portugal include nondiscrimination protections based on one's sex characteristics.[99] While the Maltese law reforms the Maltese Equality for Men and Women Act and brings sex characteristics to the same standing as other protected grounds such as race or gender; the Portuguese law includes nondiscrimination protections based on the right to *the protection* of one's sex characteristics. This framing is unusual as it suggests that the person needs to exercise or invoke their right to *protection* first (and prove it) in order to claim antidiscrimination protections. Nonetheless regardless of how implementation works, the inclusion of antidiscrimination protections based on sex characteristics seems like an important step in the right direction. Only the Portuguese law includes explicitly affirmative measures, in this case, in the form of educational policy reforms oriented towards awareness raising of intersex people's rights.[100] Both the Icelandic law and the German law fall short in terms of nondiscrimination protections as they do not include any provisions to protect intersex people and people with variations of sex characteristics from discrimination.

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[96] Iceland (n 54), art 11a.
[97] Portugal (n 34), art 5.
[98] Germany (n 77), art 1.
[99] Malta (n 14) art 13; Portugal (n 34), art 2.
[100] Portugal (n 34), art 12.

3.4 Provision of health services

Malta, Portugal and Iceland recognize the right to health or health care services for intersex people. Germany fails to address this issue in any explicit way, however this should not be surprising as the law mainly focuses on reforms to the civil code.[101] While Malta and Portugal mention the right to health of intersex children, these laws do not go into details as to how this right is to be secured. The language in the Maltese law refers to psychosocial counselling, support and medical interventions relating to sex or gender,[102] however also falls short to assign responsibilities as to who or what institution is mainly responsible for intersex health services, with further online research I was not able to determine this. Likewise, the Portuguese law limits itself to ordering the Directorate-General for Health to define an intervention model through guidelines and according to technical standards, to be implemented by the health professionals in relation to issues about gender identity, gender expression and sex characteristics. This was supposed to happen within a maximum of 270 days after the entry into force of the law, however no information was found about these guidelines or their implementation.[103]

The Icelandic law extensively refers to different forms of treatment and care that it aims to secure, and makes references to explicitly satisfying the health care needs of intersex people. The law considers the formation of two specialized teams at Landspítali hospital in Reykjavík for intersex people's care. The first one, the Landspítali Team "on Gender Identity and Changes to Sex Characteristics," is charge of providing clients, 18 years and older, with information, counselling and treatment in accordance with the needs of each and every one. There is also a second team "on the issue of children born with atypical sex characteristics" which is to provide children under the age of 16 born with "atypical sex characteristics" and

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[101] Needs to be noted that the fact health care services are not explicitly included in the German law does not mean these services are none existent or not provided to people with variations of sex characteristics.
[102] Malta (n 14), art 15.
[103] Portugal (n 34), art 11(2).

their families with information, counselling and treatment in conformity with their individual needs.[104] It is unclear why is there a gap between 16 and 18 years of age.

The Maltese law also considers the creation of a specialized team to be involved in the provision of health care services for intersex persons. As stated before, art. 14 considers the creation of an "interdisciplinary team" appointed by the Minister responsible for equality, however most of its functions are not addressed in the text of the law.

In the recent bibliography, the functions of multidisciplinary, interdisciplinary, and transdisciplinary teams in intersex-related health care are discussed.[105] A scoping review that looked into the work of 12 specialized teams involved in health treatments for intersex people found that the prevalent approach in most teams seems to be of a multidisciplinary rather than interdisciplinary nature, meaning "collaboration in which different care providers work simultaneously but separately."[106] The authors of the scoping review also criticize that there is a dominance of endocrinologists, urologists and surgeons over other health care experts, including psychological care in the teams examined. This is something to watch for in the process of law and policy making, if the goal is the true inclusion of interdisciplinary approaches to intersex health care services.

Peer counselling services are only explicitly mentioned in the cases of Malta and Iceland.[107] Both laws however could be further developed as to how and who will be providing such counselling services. For instance, if intersex people's organizations are to be involved, a role with decision making powers and designing such policies should be guaranteed. Also matters of compensation for such services and funds or grants would need to be secured.

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[104] Iceland (n 54), arts 12 and 13a.

[105] Sarah M Creighton and others, 'Childhood Surgery for Ambiguous Genitalia: Glimpses of Practice Changes or More of the Same?' (2014) 5 Psychology and Sexuality 34; Martine Cools and others, 'Caring for Individuals with a Difference of Sex Development (DSD): A Consensus Statement' (2018) 14 Nature Reviews Endocrinology 7 415; Martin Gramc, Jürg Streuli and Eva De Clercq, 'Original Research: Multidisciplinary Teams Caring for People with Variations of Sex Characteristics: A Scoping Review' (2021) 5 BMJ Paediatrics Open.

[106] Gramc, Streuli and De Clercq (n 105) 8.

[107] Malta (n 14), art 15(1); Iceland (n 54), art 13a.

3.5 Safeguards against unlawful treatments

All the laws under review, except for Portugal, explicitly state ways to monitor and make sure that only lawful, urgent and necessary surgeries and treatments are carried out. While some go into more details than others, the addition of safeguards in the form of detailed reports for example and independent reviewing bodies can be seen as a positive development.

The Maltese law, for instance, considers the creation of an interdisciplinary team appointed by the Minister responsible for equality to overview medical treatments of intersex children and to make sure the best interests of the child are respected and that the child's views are taken into consideration considering their age and maturity.[108] Furthermore a 2018 reform introduced criminal sanctions for those that break the law and perform unlawful treatments or surgeries.[109]

The Icelandic law establishes the creation of a "committee of experts on changes to the gender registration of children and permanent changes to atypical sex characteristics of children."[110] The committee is given the responsibility to provide a decision pursuant to the change of the gender registration of a child[111] and permanent changes to the sex characteristics of a child.[112] The fact that the committee shall be comprised of three members: a pediatrician, a psychologist with child psychology as a field of expertise and a children rights lawyer can be seen as a positive development as it provides a more balanced view on the issue, however this needs to be monitored closely. The fact that this team is an independent team from the one that carries out direct health care services (the team on "atypical sex characteristics") might bring a more 'independent' and comprehensive view.

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[108] Malta (n 14), art 16.
[109] ibid art 14(2).
[110] Iceland (n 54), art 9.
[111] ibid art 5(3).
[112] ibid art 11a(6).

The inclusion of a child rights lawyer can be seen as a step towards having a sort of *ad litem* advocate for the child who considers views other than the ones from doctors. Likewise, this could be useful in the case parents appeal the decision to not carry out surgeries in terms of article 14(a).

The German model considers safeguards in a different way. Considering parental rights are limited regarding IGS, the parents can only consent to a surgical intervention on the sex characteristics of the child if this intervention cannot be postponed until the child can make a self-determined decision, and this consent requires the approval of the family court. This approval of the family court, however, is not necessary where surgical intervention is deemed as necessary to avert a danger to the life or health of the child. The German law also requires the formation of an interdisciplinary commission that has the role of elaborating a supporting statement for a surgical intervention in the case this intervention cannot be postponed until the child can make a self-determined decision, to be presented to the family court. As stated before it is not quite clear what reasons other than preserving the life or health of the child could be understood as reasons that "cannot be postponed," giving room for the family court decision to be necessary. The text of the law is not clear regarding who is the ultimate authority which decides on the aspect of medical necessity, this is a problem if it could be used to circumvent the ordinary procedure before the family court. Lastly, the composition of the interdisciplinary commission in Germany seems to provide a balanced view of medical, social and ethical perspectives as it requires the team to be comprised of at least the professional treating the child, at least another doctor, a mental health professional with qualifications in the treatment of children and adolescents and one person trained in ethics,[113] and if requested, an advisor with a variant of sex development.[114]

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[113] Germany (n 77), art 1(4).

[114] ibid art 1(4).

Both Iceland and Germany also set into place a system that requires detail reports before invasive treatments can be allowed.[115] These reports include information on the opportunity of parents and guardians of intersex children to ask questions and receive counselling services, including peer counselling. This overall can be seen as a positive development that is oriented towards families to be part of an informed consent process in cases where it is considered that a medical intervention is necessary for health reasons[116] or cannot be postponed until the child can make a self-determined decision.[117] This is not explicit in other laws.

All of the legal schemes examined make references to the best interest of the child principle. In particular, the Icelandic and the German legal frameworks also reiterate the importance of keeping the principle of the best interest of the child centred at all times. Germany, for example, demands a reasoned decision as to why surgical interventions that cannot be postponed are approved for intersex children, and that this decision takes into account the best interests of the child.[118] Iceland's law states in Article 11a that "[p]ermanent changes to the sex characteristics of a child under the age of 16 born with atypical sex characteristics shall only be made in conformity with the will of the child and its level of gender identity, and always with the best interests of the child in mind."[119]

On this point one needs to be mindful, however, that the best interest of the child can be an ambiguous term subjected to culturally biased interpretations of what is best for children.[120] In the case of intersex children, scholars have pointed out that "[i]n intersex/DSD care, those who defend early interventions often consider intersex bodies as problematic, while those

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[115] Iceland (n 54), art 11a; Germany (n 77), art. 1(5).
[116] Iceland (n 54), art 11a, para 2.
[117] Germany (n 77), art 1(2).
[118] Germany (n 77), art 1(5.4).
[119] Iceland (n 54), art 11a.
[120] Bruce Macdougall, 'The Legally Queer Child' (2004) 49 McGill Law Journal 1057–91; Pieter Cannoot, 'Do Parents Really Know Best? Informed Consent to Sex Assigning and "Normalising" Treatment of Minors with Variations of Sex Characteristics' (2020) 23 Culture, Health and Sexuality 564.

who challenge these interventions often consider intersex bodies as 'natural variations' that deserve protection against health care interventions".[121] This paradox perhaps highlights why children's rights, like all human rights, need to be understood as linked and interconnected. In the case of the German law, the lawmaker makes sure to add different safeguards to protect the rights of children that go beyond the "best interest of the child" that is centered in an adult / third party perspective. In this sense, the German law also demands that the extent to which the child is capable of forming and expressing an opinion, and whether the planned intervention corresponds to the child's will to be included in the report decision concerning surgeries that cannot be postponed,[122] which adds another layer of safeguards for the effective protection of the child's rights.

Only the Portuguese law fails to specify any safeguards that guarantee the ban on unconsented treatments is respected. The Portuguese law considers that IGS is allowed in "situations of proven risk for their health."[123] However there is no mention of who carries out this evaluation or what kind of criteria they are to use. There is no elaboration on how the reviewing process for the exceptions to the general ban would work.

3.6 Procedural rights for justice and restitution

Out of the laws under review, only the Portuguese law explicitly recognizes procedural rights to associations and NGOs invested in securing the rights of intersex people.[124] This is an interesting aspect that is not present in the other laws reviewed in this report and a positive element as some jurisdictions do not provide organizations but rather individuals with legal standing to rights claims. Likewise in many jurisdictions, collective actions are not legally possible. The Portuguese law considers and gives green light to both situations. It would be

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[121] Naezer and others (n 89) 9.
[122] Germany (n 77), art 1(5.7).
[123] Portugal (n 34), art 5. Own translation.
[124] Portugal (n 34), art 16.

interesting to analize how this provision interacts with the rest of the legal system in Portugal.

Regarding other procedural aspects, only the Icelandic law considers the extension of the general statute of limitations for cases of IGS,[125] this is something innovative that is not present in other legislations under this review and seems like a positive approach as it would provide people with the opportunity to submit criminal claims, starting at the age of 18. Intersex activists have highlighted that statutes of limitation when bringing criminal or civil lawsuits represent an important barrier when seeking justice for intersex people.[126] There is a caveat however with the Icelandic provision in that usually, legal systems do not allow for the law to work in retrospect, as per due process limitations, so while this provision is beneficial to intersex people born after the entry into force of the Icelandic law or whose medical procedures happen after that date, it does little to provide justice or redress to those who have suffered from IGS already.

3.7 Monitoring and evaluation on the functioning of the law

The Maltese, Icelandic and German laws consider mechanisms of supervision regarding very specific aspects of their legal schemes. The Icelandic law explicitly considers a monitoring mechanism to supervise its own functioning by ordering the creation of a working group to review practical experiences and develop research, knowledge and best practices in the field of human rights.[127] The group is also to review whether hypospadias surgeries and medical treatments for micropenis cases should remain excluded from the ambit of the IGS prohibition or not. It also can be seen as a positive development that the reviewing group includes experts from civil society with lived experience, academia and human rights perspectives as well as medical perspectives. The Maltese law considers the creation of a

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[125] Iceland (n 54), art 15(3).

[126] Ghattas (n 1).

[127] Iceland (n 54), art 18, para 1.

'working group' to review that medical treatment protocols are in line with human rights standards. However, there is no wording that the law itself will be subjected to review or for verification of its implementation and functioning.[128] Likewise, the German law also orders the Federal government to monitor the implementation of certain aspects of the law.[129] In general terms it would be useful to have monitoring and review mechanisms in all of the laws as it would facilitate follow up on implementation and possibly suggesting changes to adapt with implementation challenges. In Ireland for example reviewing processes have been included in both the Gender Recognition Act and the Abortion Act.[130]

4. CONCLUSIONS

With this document I intended to show the main legal schemes four EU member states have adopted in order to guarantee and protect the rights of intersex people. Malta having been the first country in the world to recognize legal protections for people with variations of sex characteristics had the very difficult task of starting from cero and its legislation while not flawless can be seen a pioneer in intersex law and policy making. The legal recognition of sex characteristics as a ground of protection, the expansion of nondiscrimination protections on that ground and of course the legal restrictions on IGS are some of the most important elements that the Maltese legislature prioritized in its legal framework.

After Malta other states had the opportunity to follow its footprint, however the examination of the intersex laws carried out here, seems to indicate that while other legal schemes may have had inspiration by the Maltese experience, the result of the processes in other countries are different enough and seem to have been designed and developed following local needs and priorities. All the provisions examined here are different enough to reach this

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[128] Malta (n 14), art 16.

[129] Germany (n 77), art 6.

[130] Ireland, Gender Recognition Act 2015 (Act 25 of 2015), s 7; Ireland, Health (Regulation of Termination of Pregnancy) Act 2018 (Act 31 of 2018), s 7.

conclusion. While they all had the same goal, restrict IGS, all took different, yet similar paths to achieve this goal.

The passing of time, development of ideas, visibility of main concerns and better understandings of intersex people's demands and the issues they face is notable when reviewing more recent laws. The Icelandic model seems to be the most comprehensive model so far including legal definitions, limitations on IGS, safeguards to verify the lawfulness of intersex treatments, developing the firsts steps towards health services and recognizing the possibility of starting criminal claims and a moratorium on statutes of limitation. A great flaw however is regarding the scope of protection as if explicitly excludes hypospadias and micropenis cases, this is a major flaw in the reach and impact of the law. As stated above the German model while intended to produce similar results as the other laws is framed as a restriction on parental rights rather than a protection for the rights of bodily autonomy and bodily integrity which is an interested deviation from the other legal schemes, perhaps influenced by cultural or legal traditions.

Regarding the implementation of these laws, it is still early to review how the most recent ones at the time of writing the report, Iceland and Germany, have functioned, however both laws include some kind of monitoring mechanism, and it would be valuable to keep an eye on them in the future. In the cases of Malta and Portugal, no information was found on how the laws have functioned since entering into force, which makes an opportunity for research in the future or perhaps reporting mechanisms to be included in future reforms to these laws.

As a general conclusion this report wants to highlight how important it is for law and policy makers to look at other examples of intersex legal design when drafting law and policy, however paramount importance needs to be given to the demands of local activists and so that they address the specific needs of the people the laws will impact the most. In order to achieve this, it is recommended that intersex activists, human rights defenders and civil society organizations have an active role in the design of law and policy.

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