INTERSEX STUDIES

A MULTIDISCIPLINARY EXPLORATION

EDITED BY

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Intersex Studies:
A Multidisciplinary Exploration

Edited by Marisela Montenegro, Joan Pujol,Lucas Platero, Amets Suess Schwend, and Surya Monro.

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Introduction

Marisela Montenegro, Joan Pujol, Lucas Platero, Amets Suess Schwend, and Surya Monro

Intersex studies constitute a vibrant and relatively young discipline promoted by both activists and academics who are challenging the traditional medical practices that often subject intersex individuals, especially infants and children, to unnecessary and irreversible surgeries and life-long treatments (Chase, 1998; Fausto-Sterling, 2000; Davis, 2015; Jones, 2018). Broadly speaking, intersex studies also seek to represent the voices and experiences of the wide diversity of intersex people and people with variations of sex characteristics across different arenas such as family, education, healthcare, sport, religion, and culture. For some people, “The emerging field of interdisciplinary intersex studies, therefore, can be characterised by the co-constitution of knowledge with the individuals and communities it seeks to study, as Intersex activists (both academics and non-academics) are important authors in the field” (Monro et al., 2021: p. 431). The emergence of a community consisting of scholars, activists, healthcare practitioners, and researchers with academic-activist backgrounds characterises not only intersex studies (Wolf et al., 2022) but also this edited book, which includes early-stage researchers and senior researchers. Indeed, intersex studies as an emerging discipline is capturing the moment in which intersex individuals and their lived experiences are shifting from a traditional research subject position to that of active agents who actively shape and contribute to the production of knowledge within academic discourse, becoming what professor Ana Cristina Santos names as “scholar activism” (2013).

While issues related to intersexuality and the experiences of intersex individuals have always existed, the academic study of intersex issues as a distinct field with its own body of research and scholarship is a relatively recent development. The emergence of intersex studies as an academic discipline gained momentum in the late 20th and early 21st centuries, primarily as a critical response to the medicalisation and pathologisation of intersex people that continues nowadays (Chase, 1998; Fausto Sterling, 2000; Grabham, 2007; Cabral Grinspan, 2009; Cabral Grinspan & Benzur, 2013; Malatino, 2019). It is only in the last three decades that there has been a small but growing literature in critical intersex studies that established that intersex people face marginalisation, discrimination, and potential malpractice, as well as the need for appropriate healthcare (Wolff et al., 2022, p. 44; Davis, 2015; Crocetti, Monro, Vecchietti and Yeadon-Lee, 2020).

Intersex studies can be described as an interdisciplinary field of academic inquiry that examines the experiences, identities, and rights of intersex individuals, as well as the social, medical, and cultural aspects of intersexuality. Intersex refers to a range of variations in sex characteristics that do not align with typical binary definitions of male or female, referring to individuals born with chromosomal, hormonal, or genital variations in sex characteristics (Garland & Travis, 2020, p. 165; Davis, 2015). The term ‘Variations of Sex Characteristics’ can also describe these variations.

In 2017, some leading activists of the international intersex community released the Darlington Statement, in which intersex was defined as:

> Intersex people are born with physical or biological sex characteristics (such as sexual anatomy, reproductive organs, hormonal patterns, and/or chromosomal patterns) that are more diverse than stereotypical definitions for male or female bodies. For some people, these traits are apparent prenatally or at birth, while for others, they emerge later in life, often in puberty (…) We recognise our diverse histories and use the word intersex inclusively, and acknowledging our rights to self-determination (Australia and Aotearoa/New Zealand intersex community organisations and independent advocates. Darlington Statement 2017, para A).

Organisation Intersex International defines intersex individuals as those “born with sex characteristics that do not fit typical binary notions of male or female bodies” (OII, 2023, para. 2). Each variation of the many intersex experiences highlights the interaction between chromosomal, hormonal, reproductive, and genital conceptions of sex and their influence in the understanding of gender (Garland & Travis, 2023, p. 5). However, the term 'intersex' is also a cultural category shaped by the perspectives of numerous stakeholders, including healthcare professionals, politicians, lawyers, activists, media, and scholars, among others (Amato, 2016; Monro et al., 2021). Therefore, intersexuality does not have a single fixed definition; instead, its understanding varies depending on the context and the individuals involved. These interpretations encompass not only biological dimensions but also a spectrum of social and political implications (Dreger & Herndon, 2009, p. 201).

Intersex studies seek to challenge the historical medicalisation and pathologisation of intersex variations, advocating for the human rights of intersex individuals. This de-pathologisation and human rights framework frames the interventions on intersex people as harmful practices and violations of rights to bodily integrity, non-discrimination, equality before the law, privacy, and freedom from torture, ill-treatment, and experimentation (Carpenter, 2018; Bauer et al., 2019; Crocetti et al., 2020). Therefore, intersex studies explore the complex intersections of biology, gender, sexuality, culture, and society as they relate to intersex people. In accordance, this emerging field incorporates research and scholarship from diverse disciplines, including sociology, anthropology, gender studies, ethics, history, medicine, law, disability studies, critical race studies, trans studies, anticolonial studies, and more, to better understand and address the issues faced by intersex individuals.

Intersex activism and scholarly endeavours are linked to the accomplishments and insights generated in feminist, disability and racial justice movements, as well as the broader LGBTIQ+ activism, among others (Griffiths, 2023). However, despite having some shared struggles with these social movements, the legislative actions and activisms that they have promoted to date have been unable to address the particular needs of intersex people (Carpenter, 2023, p. 179; Garland & Travis, 2020, 2021).

One of the pivotal aspects within the field of intersex studies is that it not only addresses criticisms of medical and pathologising concepts of intersexuality but also establishes its unique domain for knowledge production, in which intersex lives and experiences take centre stage (Malatino, 2019). It is precisely the lack of knowledge about the first-hand experiences of intersex individuals in various disciplines and social domains that contributes to perpetuating misconceptions about them. This edited collection provides a range of chapters, some of which centre on the experiences and voices of intersex people.

The chapters aim to make a substantial and meaningful contribution to intersex studies. Through the exploration and analysis of various aspects related to intersexuality, these chapters collectively seek to advance our understanding and knowledge within this important academic discipline. In the book, authors use affirmative language regarding intersex people, critically acknowledging other terms used in different fields of research (Carpenter, 2023; Griffiths, 2023, 2018; OII, 2023; Monro et al., 2021; Garland & Travis, 2020). The authors are ethically committed to advocating for the rights of intersex individuals, genuinely listening to intersex people's needs, and contributing to the production of knowledge in this field while disseminating it within society. By shedding light on the complexities and challenges faced by intersex individuals, as well as addressing the social, medical, and legal issues surrounding intersexuality, this compendium strives to enrich the existing body of scholarship in this field.

This book presents the results of the fieldwork and knowledge produced by early-stage researchers who are part of the INIA Innovative Training Network, Intersex - New Interdisciplinary Approaches (2020-2024). This work was undertaken as part of INIA's Innovative Training Network project, supported by a grant from the European Commission's Marie Skłodowska-Curie Actions program under grant number 859869. This edited collection reflects only the views of the authors, and the agency is not responsible for any use that may be made of the information it contains. The book is a result of the research produced within the INIA project, which was intended to support the well-being and rights of intersex people and those who are born with some variations of sex characteristics but do not identify as intersex by using a human rights perspective. The objectives of the INIA project are to:

- Generate knowledge that supports the well-being and social/economic contributions of intersex people/people with variations of sex characteristics.
- Use innovative interdisciplinary academic resources to push forward understandings of intersex and inform academic fields.
- Produce excellent research and evidence to help address societal challenges associated with intersex.

The INIA project started on 1 March 2020 with a 48-month brief, training a cohort of ten early-stage researchers working collaboratively to develop knowledge that informs policy-making and practice across various key sectors. This INIA consortium has been established by the University of Huddersfield, the Université Libre de Bruxelles, Dublin City University, the University of Zurich, the Escuela Andaluza de Salud Pública / Andalusian School of Public Health, and the Universitat Autònoma de Barcelona in collaboration with academic and activist organisations, intersex activists and advocates, clinicians, and other specialists. The INIA project enables 21 organisations from more than ten countries to work together on issues relating to intersex people and people with variations of sex characteristics in a unique multidisciplinary and trans-sectoral network. The project includes international experts from a wide range of countries across the globe.INIA's research topics are shared across its partners and INIA projects and include the experience of older intersex people; intersex policy-making; intersex activism; legislative and policy reform; awareness about intersex issues in education; psychosocial support to parents and factors related to decision-making; multidisciplinary teams in intersex healthcare; intersex subjectivities and lived experiences; research ethics in intersex studies; and demands and strategies of international and regional intersex activist networks and human rights bodies.

Doing intersex studies

The book comprises nine chapters, including theoretical, experiential and activist perspectives, studies on the healthcare provision to intersex people, and chapters about the rights of intersex people in several localities. The initial chapter, authored by Sean Saifa Wall and entitled "Reconceptualising Intersex Embodiment", poses the question: How do we envision intersex embodiment beyond medicalisation? To answer this question, Wall explores critical intersex studies. He suggests that where there have been discussions of embodiment, they tend to centre intersex medicalisation and the role of medical practitioners. Whilst that critique helps interrupt practices that continue to harm intersex children and adults, Wall argues that there is a gap in thinking about intersex embodiment outside of medical practice. Drawing on Nietzsche's concept of morality, Wall highlights the role of doctors in contributing to intersex erasure but also envisions a concept of intersex embodiment that moves beyond pathologisation and medicalisation. Wall incorporates Sara Ahmed's concept of strange bodies to discuss how bodies do not exist outside of colonisation, and he engages with Carol Bacchi's concepts of gendering and social flesh to envision intersex embodiment in society and policy.

The second chapter develops a critical review of the studies on older intersex people written by Adeline W. Berry. In their work, Berry informs the readers that little is known about the life experiences of older intersex people, including those subjected to genital surgeries in infancy. Since at least the 1960s, it has been common medical practice to operate on the genitalia of intersex children born with ambiguous genitalia in an effort to align their bodies with expectations typically associated with the sex the child was assigned at birth. While these intersex children are subjected to perhaps unwanted medical attention performed without consent, others, such as those with Klinefelter Syndrome, have often been neglected, going without testing and appropriate medical care. Berry examines literature published between 2000 and 2023 to explore issues that may be faced by this almost invisible population using grey literature, as well as LGBT literature where necessary, in the absence of research on older intersex people. Their findings suggest that older intersex people may face disadvantages in many areas of life, such as healthcare, employment, housing, social support, financial stability, disability, and the law.

Audrey Aegerter authors the third chapter, "'I do not want to have my parents as my enemy': intersex activism and breaking the veil of silence", using a more personal voice in her analysis. Discovering the term 'intersex' and the subsequent process of identifying with it is a pivotal aspect of the intersex experience that Aegerter refers to as “becoming intersex”. Becoming intersex is the beginning of a transformative journey that involves the de-pathologisation and destigmatisation of one's own body, Aegerter reasons, accompanied by a significant shift in personal narrative. In this chapter, Aegerter delves into how the intersex identity influences family dynamics and relationships. The act of coming out as intersex breaks decades of silence, opening up a new and often challenging topic of discussion for both the intersex individual and their parents. Sometimes, parents may struggle to comprehend their child's anger and feelings of injustice.

Conversely, there are cases where parents provide information and experience a sense of relief in addressing the intersex variation with their child, even opting to engage in intersex activism. Aegerter recalls that many intersex individuals go through a phase where they blame their parents for what has been done to them, seeing parents as doctors' accomplices. Other times, intersex people view their parents as victims of the medical professionals. The perception of the parents' reality, as accomplice or victim, can change with time and impacts the relationship between the intersex person and their parents.

In line with the analysis introduced by Aegerter, the next chapter presents a narrative production that departs from a conversation between Camino Baró and Lucas Platero, focusing on the emergence of a new form of intersex activism in Spain. Co-authored with Joan Pujol and Marisela Montenegro, the chapter is titled “A Glimpse of the Intersex Spring”, capturing the sense of progress and emergence felt by intersex activists in Spain. The conversation with Baró explores the needs of Spanish intersex individuals and the evolution of intersex activism over the past decade. This evolution has shifted from patient support groups to activism that collaborates with the LGBTQIA+ movement in advocating for new legislation and social change. This discussion is situated within the context of the current social debate and political shifting scenario in Spain, particularly regarding new legislation, Law 4/2023, which consolidates the rights of both the LGBTQIA+ and intersex communities, often intertwining trans and intersex rights[1]. As Baró contends, the law aims to address the lack of intersex rights without a thorough understanding of this intricate reality, leading to significant discomfort among many intersex activists. The portrayal of intersex individuals in cultural production is a crucial aspect of the conversation, emphasising the importance of positive representations for the intersex community. Lastly, the discussion encompasses two additional topics: the public exposure of intersex activists—something Baró has experienced—and her aspiration to transform society to meet the needs of intersex individuals better.

The fifth text is Martin Gramc’s chapter, “The trouble with DSD-Life studies”. Gramc starts by discussing the Chicago Consensus Statement, which, according to his analysis, introduced new guidelines for the treatment of intersex people and support for their families, as the evidence for the old treatment protocols was lacking or did not provide the results that would support these protocols. As Gramc describes, the statement and its update advocated for multidisciplinary teams (MDT), patient-centred care, psychosocial support that would accommodate parental concerns and wishes, and peer support based on open communication to provide space for true shared decision-making and less medicalised care for intersex people. However, it has been only recently that the implementation of medical treatment of Chicago consensus policies has been examined in extensive sample international studies such as DSD-Life. Gramc assesses the studies that came out of the DSD-Life project, focusing on the methodological segment of the studies. On the one hand, the research in the DSD-Life studies lacks engagement with the intersex community, Gramc argues. On the other hand, he highlights the insufficient provision of historical context in the DSD-Life studies, which provides skewed results, as the paradigm and related medical treatment have shifted in the last 20 years.

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[1] Law 4/2023, February 28th, for the real and effective equality of trans people and the guarantee of the rights of LGBTI people. State’s Official Bulletin 51, 01/03/2023.

The following chapter is co-authored by Daria Abrosimova, Martin Gramc, Surya Monro, John Stephenson, and Jürg Streuli, addressing healthcare provision to infants, children, and young people with variations of sex characteristics using a pan-European survey of the perceptions of multidisciplinary teams and peer support organisation members. This chapter presents the findings from a survey of healthcare professionals from various professional backgrounds and peer supporters. It addresses European healthcare practice, focusing on the role of psychosocial support for minors with variations of sex characteristics and their families, peer support, and several other key issues, such as terminology and healthcare professionals' perceptions of surgical interventions. A convenience sample was used because of the small number of professionals working directly with families who have a child with variations of sex characteristics and the difficulty accessing them. Key findings were that more psychosocial support that centres appropriate care for the child is needed, including peer support, that amongst some healthcare professionals, support for surgical interventions for non-vital variations persists, and that there are barriers to improved care such as a lack of suitably trained professionals. The findings were indicative, and more research is required.

The last three chapters are devoted to analysing intersex rights in different spaces and latitudes, such as Malta, Europe, and Latin America, but also in international bodies, for example, the United Nations. In the seventh chapter, Yessica Mestre analyses the human rights situation of intersex people in Europe and Latin America, who are often subjected to different degrees of invisibility and discrimination, some of which have been addressed as violations of intersex human rights. Mestre studies the experiences of violence suffered by intersex people, the role of states in promoting justice, and the possibilities offered by a human rights framework to guarantee a dignified life for bodily-diverse communities. This research also illustrates that, although regional, cultural and social landscapes differ in both continents, intersex groups are subject to constant violations of their human rights, and they struggle for recognition and for their bodies to be respected outside the binary categories of sex and gender. Furthermore, Mestre argues that European and Latin American states have made proven legislative advances that have led to the greater visibility of intersex people but also face remaining difficulties and gaps.

The specific situation of intersex human rights and their lived experience in Malta is analysed by Somya Dixit, Tanya Ní Mhuirthile, and Mel Duffy. In 2015, Malta became the first country worldwide to enact legislation, known as the Gender Identity, Gender Expression, and Sex Characteristics Act, which protects the right to bodily integrity, physical autonomy, and self-determination of intersex people. This groundbreaking reform was followed by amendments in various Maltese legislations and the development of new policies to ensure the rights of the intersex community in Malta. Nevertheless, there is a scarcity of available data regarding the realities of intersex people and how the law has impacted the community. Interviews were conducted with academics, biomedical scientists, intersex activists, policymakers, and government officers. Using Heidegger's hermeneutic phenomenological approach, Dixit, Ní Mhuirthile, and Duffy focus on uncovering what it really means "to be a person in the world". In this research, hermeneutic phenomenological research enabled this team to uncover and understand what it is to be intersex in Malta and the meaning of their experiences at present. It also sheds light on how the legal reform in intersex rights has affected their experiences.

Lastly, Ernesto Zelayandía-González studies the growing visibility of intersex demands at the United Nations, conducting a review of the treaty bodies. There has been an increasing visibility of intersex people's issues and experiences of human rights violations amongst international human rights institutions and monitoring bodies, according to Zelayandía-González. At the United Nations, to date, there are more than 500 treaty bodies with concluding observations, taking notice of human rights abuses against intersex persons, and calling member states to fulfil their human rights obligations. This chapter follows the inclusion and visibility of intersex issues in the text of the United Nations treaty bodies' concluding observations. Zelayandía-González looks for explicit mentions of the word "intersex" in treaty bodies' report documents and reviews how the concluding observations and recommendations of these bodies resonate with demands coming from intersex activist groups. The main issues included in the treaty bodies' reports concern intersex genital surgeries (IGS), autonomy claims, and demands for redress and support mechanisms, and while these issues have gained visibility, there are also a number of demands by intersex activists that remain less visible, if not invisible altogether. In this chapter, Zelayandía-González provides evidence of the increasing visibility and awareness of human rights monitoring bodies over intersex people's rights.

References

Amato, V. (2016). *Intersex Narratives: Shifts in the Representation of Intersex Lives in North American Literature and Popular Culture.* Transcript Verlag.

Australia and Aotearoa/New Zealand intersex community organisations and independent advocates. (2017). *Darlington Statement.* https://ihra.org.au/darlington-statement/

Bauer, M., Truffer, D., and Crocetti, D. (2019). Intersex human rights*. The International Journal of Human Rights, 24*(6), 724-749. doi:10.1080/13642987.2019.1671354

Cabral Grinspan, M., and G. Benzur (2013). Cuando Digo Intersex. Un Diálogo Introductorio a la Intersexualidad. *Debate Feminista, 47*, 31–47.

Cabral Grinspan, M. (Ed.). (2009). *Interdicciones*. Anarrés Editorial.

Carpenter, M. (2023). Intersex Human Rights in a Time of Instrumentalization and Blacklash. In A. Tirado Chase, P. Mahdavi, H. Banai, and S. Gruskin (Eds.), *Human Rights at the Intersections* (pp.169-179). Bloomsbury Academic.

Carpenter, M. (2018). Intersex Variations, Human Rights, and the International Classification of Diseases. *Health Hum Rights, 20*(2), 205-214. PMID: 30568414; PMCID: PMC6293350.

Chase, C. (1998). Hermaphrodites with Attitude: Mapping the Emergence of Intersex Political Activism. *GLQ, 4*(2), 189–211.

Crocetti, D., Afini, E.A.G., Monro, S., and Yeadon-Lee, T. (2020). You're basically calling doctors torturers': stakeholder framing issues around naming intersex rights claims as human rights abuses. *Sociology of Health and Illness, 42*(4). 943-948 doi: 10.1111/1467-9566.13072

Crocetti, D., Monro, S., Vecchietti, V. and Yeadon-Lee, T. (2020) Towards an Agency-Based Model of Intersex, Variations of Sex Characteristics (VSC) and DSD/dsd Health. *Culture, Health and Sexuality*, 23(4), 500-515. https://doi.org/10.1080/13691058.2020.1825815

Davis, G. (2015). *Contesting Intersex*: *The Dubious Diagnosis*. New York University Press.

Dreger, A.D., and Herndon, A.M. (2009). Progress and politics in the intersex rights movement feminist theory in action. GLQ. *A Journal of Lesbian and Gay Studies*, 15(2), 199–200.

Fausto Sterling, A. (2000). *Sexing the Body: Gender Politics and the Construction of Sexuality.* Basic.

Garland, F., and Travis, M. (2020). Queering the Queer/Non-Queer Binary: Problematizing the "I" in the LGBTI+. In S. Raj, and P. Dunne (Eds.), *The Queer Outside in Law, Recognising LGBTIQ People in the United Kingdom* (pp.165-185). Palgrave McMillan.

Grabham, E. (2007). Citizen Bodies, Intersex Citizenship. *Sexualities, 10*(1), 29–48.

Griffiths, D.A. (2023). Georgina Sommerset, British Intersex history, and the I in LGBTQI. *Journal of Homosexuality.* doi: 10.1080/00918369.2022.2164234

Griffiths, D.A. (2018). Diagnosing sex: Intersex surgery and ‘sex change’ in Britain 1930-1955. *Sexualities*, 21(3), 476-495. doi: 10.1177/1363460717740339

Jones, T. (2018). Intersex Studies: A Systematic Review of International Health Literature. *SAGE Open*, *8*(2). doi: 10.1177/2158244017745577

Malatino, H. (2019)*. Queer Embodiment: Monstrosity, Medical Violence, and Intersex Experience.* University of Nebraska Press. Monro, S., Carpenter, M., Crocetti, D., Davis, G., Garland, F., Griffiths, D., Hegarty, P., Travis, M., Cabral Grinspan, M., and Aggleton, P. (2021). Intersex: Cultural and Social Perspectives. *Culture, Health & Sexuality, 23*(4). 431-440.

OII, Organization Intersex International. (2023). *Website.* https://oiiinternational.com/

Santos, A.C. (2013). *Social Movements and Sexual Citizenship in Southern Europe*. Palgrave McMillan.

Wolff, M., Rubin, D.A. and Lock Swarr, A. (2022). The Intersex Issue. An Introduction. Transgender Studies Quarterly, 9(2), 143-159. DOI 10.1215/23289252-9612767.

1.Reconceptualising Intersex Embodiment

Sean Saifa Wall

How do you conceptualise intersex embodiment when intersex has been erased from the social imagination? I define intersex erasure as a historical, social, and political process through which intersex identity and experiences were gradually removed from social consciousness and legal protection. When considering the harm of erasure, I am interested in how embodiment[2] as a concept can challenge intersex erasure. Like the subject of erasure within critical intersex studies, intersex embodiment has been discussed but primarily in the context of the intersex body as it relates to the impact of pathology and challenging medicalisation (Garland & Travis, 2018; Garland & Travis, 2023; Malatino, 2019; Roen, 2004; Shildrick, 2008). Furthermore, embodiment discourse within critical intersex studies has pertained to what Malatino (2019) refers to as 'sexed embodiment', where intersex bodies are forced into dimorphic categories of male and female. Other approaches to intersex embodiment include legal perspectives (Garland & Travis, 2023; Ní Mhuirthile, 2015) that highlight how medical intervention supersedes natural law and legal apparatuses. Discussions of embodiment by other scholars (Garland & Travis, 2018; Roen, 2004; Shildrick, 2008) critique medical practice and violence instead of inquiring about how intersex people experience their actual bodies. As a result of these discussions occurring outside of the body, disembodiment occurs within discourses of embodiment in critical intersex studies.

In this chapter, I will engage with Nietzsche's concept of morality to conceptualise a discourse of embodiment that considers the intersex body and its possibilities beyond medicalisation. Except for Feder (2014), Nietzsche has not been applied to intersex studies. Feder (2014) adapted Nietzsche's concept of 'ressentiment' to illustrate the antipathy that doctors have toward intersex embodiment, which facilitates surgical intervention. Although ressentiment as a concept is useful to illustrate the aversion that doctors have toward intersex children, I feel that the application did not accurately capture Nietzsche's idea of ressentiment when considering the power that doctors have over intersex embodiment. Nietzsche (1887/2007) describes ressentiment as the contempt that those belonging to the lower classes (i.e., those without power), also referred to as the slave morality, have toward those in the master morality (i.e., those with power and influence) who are the rulers and more privileged classes in society. Aside from Feder (2014), this is an original contribution adapting Nietzschean thought to intersex embodiment.

While I value Nietzsche's contribution to embodiment, I also recognise the limitations of a white German philosopher working during the late 19th century and how his theory overlooked race, gender, and sexuality. To develop a complex understanding of intersex embodiment as it relates to race and colonisation, I will engage with Sara Ahmed's (2000) concept of strange bodies to show how bodies are rendered as strange within a dominant paradigm. This idea of intersex bodies as strange lends to erasure through gender normalisation, pornotroping (Spillers, 1987) and surgery. However, to envision a new form of intersex embodiment beyond medicalisation, I revisit Nietzsche's (1887/2007) concept of morality to flesh out embodiment. I will then use Nietzsche's concept of embodiment along with Carol Bacchi and Joan Eveline's concept of *gendering* (Eveline & Bacchi, 2010) with *social flesh* by Chris Beasley and Carol Bacchi (Beasley & Bacchi, 2012) to challenge current gender practices that limit possibilities for intersex children.

This chapter also contributes to developing race theorisation within critical intersex studies. Scholars in critical intersex studies, such as Swarr (2023), Orr (2022), Malatino (2019), and Rubin (2017), have incorporated discussions of race as it pertains to intersex. Nevertheless, the subject of race and colonisation within critical intersex studies is still underdeveloped. Because intersex erasure also sits within a context of colonisation, the intersections between race and intersex

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[2] Garland and Travis (2023) define embodiment as the ways in which bodies are constructed through material, discursive, and institutional frameworks.

embodiment will also be explored in this chapter. However, an in-depth analysis of race, intersex and colonisation is outside the scope of this chapter.

This chapter aims to conceptualise embodiment using Nietzsche's concept of morality, define intersex embodiment, and expand the concept of intersex embodiment beyond medicalisation.

Nietzsche's Morality and Strange Bodies

Although Nietzsche wanted to move beyond binary thinking (i.e., good/evil, master/slave, moral/immoral), he still contended with another binary throughout his writings: master morality and slave morality (Nietzsche, 1887/2007). According to Nietzsche, Christianity contributed to this dichotomy by ascribing values to 'master' and 'slave', 'good' and 'evil', which limited human beings and their potential (Nietzsche, 1886/1907). Nietzsche (1887/2007) describes those belonging to the slave morality as the downtrodden and oppressed. For Nietzsche, slave morality can be represented by those who are subordinated by the master class as well as those who subscribe to Christianity. As mentioned in the introduction to this chapter, those who are part of the slave morality belong to the 'inferior classes of society' and, over time, develop 'ressentiment' toward those in the master morality (Nietzsche, 1886/1907). Nietzsche (1887/2007) eschews the anarchist, who belongs to the slave morality and, in their contempt of the master class, embodies ressentiment. Although Nietzsche condemns ressentiment as a moment of 'imaginary revenge', he also represents this as an opportunity for those belonging to the slave morality to push back against the moral system.

On the other hand, Nietzsche (1882/2001) depicts master morality as those in power who consider themselves to be good and noble. He states that 'it was from this pathos of distance that they first claimed the right to create values and give these values names' (Nietzsche, 1887/2007, p. 11). Although the noble and aristocratic classes are regarded as 'good' and may engage in charitable acts, there is something lacking inside them as well. Those who are invested in master morality become rigid and are unable to be creative or 'envisage new ideals' (Nietzsche, 1882/2001 p. 188).

Nietzsche envisioned master morality as the aristocratic class composed of rulers, priests, jurists, and doctors who created value systems and laws that helped order society (Nietzsche, 1887/2007; see also Nietzsche, 1882/2001). Those belonging to the master morality positioned themselves as authority figures and experts who obeyed and upheld the moral system (Nietzsche & Zimmern 1907). Master morality is a useful concept to describe the paternalism that exists in medicine, which both stigmatises and pathologises intersex bodies. Garland and Travis (2018) argue that 'paternalism, stigmatisation, surveillance and regulation have been the hallmarks of medical approaches to intersex embodiment' (p. 81). Since jurists and doctors belong to the master morality, jurists conferred power to doctors over intersex bodies (Fausto-Sterling, 2000/2020; Nietzsche, 1887/2007). Within this system, doctors operate within binaries of healthy and sick, normal and abnormal, male and female. Coupled with the power the state and citizens conferred to them, doctors were granted powers 'to command severely' (Nietzsche, 1882/2001, p. 206) in attaining their vision toward gender conformity in children.Nietzsche initially recognised doctors as having authority conferred to them by society, but Foucault expanded Nietzsche's critique of doctors to reflect the power they exert over bodies (Foucault, 1988; Lash, 1984). Some scholars within critical intersex studies have often turned to Foucault to explain medical power over intersex embodiment (Germon, 2009; Malatino, 2019; Rubin, 2017). Foucault uses hospitals and asylums as examples of how institutions consolidate power, which allows them to define and ascribe value to certain bodies (i.e., mental health diagnoses) as well as control other bodies (i.e., prisons) (Foucault, 1995; see also Foucault, 1963/2010). The regulation of bodies by systems of power is where Foucault expounded upon Nietzsche's concept of morality (Lash, 1984). Although Foucault discusses the body in relationship to power, Turner (1984/2008) argues that Foucault leaves the actual body unexplored in his discourse. Defining intersex embodiment requires more than just applications of governance and control to the body, as evidenced by Foucault (1988, 1995); it also needs the body itself. Nietzsche (1887/2007) developed genealogy as a method to question the values that exist in society. The genealogical method seeks to understand an1231 d examine how morals and value systems exercise control over human behaviour (Nietzsche, 1882/2001; 1887/2007). Furthermore, Nietzsche asked that people interrogate the conditions that gave birth to those values. He stated that 'we need a critique of moral values, the value of these values should itself, for once be examined—and so we need to know about the conditions and circumstances under which the values grew up, developed and changed' (Nietzsche, 1887/2007, pp. 7-8). Foucault (1977), in his adaptation of genealogy, recognised that historical processes have shaped, controlled, and, at times, destroyed the body. The application of Nietzsche's genealogy to this research study begins with an interrogation, which commenced in the literature review, of how intersex bodies were assigned value and subsequently erased from society by doctors.

Strange Bodies

Nietzsche's concept of morality is useful for understanding how master morality threatens intersex embodiment. This section will introduce Sara Ahmed's (2000) concept of strange bodies to highlight how intersex erasure occurs within this moral system. Sara Ahmed is a feminist writer and independent scholar whose work encapsulates topics related to feminism, queerness, and race (Ahmed, n.d.). While her work draws from feminist theory, queer theory, and postcolonial theory, her concept of strange bodies sits within postcolonialism[3] (Ahmed, 2000). Ahmed's (2000) concept of strange bodies will be used to show how encounters between medical practitioners and intersex children result in intersex bodies becoming a pathology.

Ahmed (2000) explains how bodies that deviate from a white, masculine norm are considered strange bodies. Ahmed mentions the encounter between white and Black or brown bodies that determine proximity and value. In this encounter, subjectivity is determined by how people are touched (Ahmed, 2000; Beasley & Bacchi, 2000). Although she positions white masculinity as the norm, Ahmed (2000) also recognises that whiteness as an institution regulates bodies and imposes restrictions on Black, indigenous and queer bodies. Often, bodies that are Black and indigenous are stopped or policed to reinforce the boundaries between bodies that are perceived as strange and the white masculine body (Ahmed, 2006). These limitations are designed to prevent these bodies deemed as strange from extending into dominant spaces (Ahmed, 2006). Within this framework of strange bodies, I argue that atypical, intersex bodies are stopped from extending into normative, binaried space through surgical intervention. This limiting of intersex variations contributes to disembodiment and erasure.

The Colonised Body

Ahmed's concept of strange bodies exists in a history of colonisation marked by forced displacement, labour and resource exploitation, and genocide. The Western context, which includes the United States and Europe, has been imprinted by the Transatlantic enslavement of Africans, a brutal campaign of settler colonialism and attempted genocide of indigenous people (Lugones, 2016; see also Hawkesworth, 2016; Snorton, 2017). As a result, bodies do not exist outside of colonisation. Bodies are more than just 'inert brute matter' (Bacchi & Beasley, 2002, p. 345) but carry our histories, traumas, and lineages and are shaped by the contexts in which they exist (Ahmed, 2000). Shilling (1993/2003) adds that while bodies occupy different societal positions, they 'remain material, physical, and biological entities' (p. 10). In the context of intersex medicalisation, Orr and Magnet (2022) assert that racism and colonisation underpin medical practices that control and regulate intersex bodies. Furthermore, Grosz (1994) states that 'the

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[3] Bhambra (2007) states that postcolonialism examines the historical conditions of conquest and enslavement by colonial powers, providing context for contemporary inequalities encountered in former colonised contexts. Ahmed's (2000) work draws inspiration from postcolonial scholars such as Gayatri Spivak, Franz Fanon, Edward Said, Anne McClintock and Aijaz Ahmad. In Strange Encounters, Ahmed (2000) critiques postcolonialism and instead asserts postcoloniality, which insists that countries in the Global South are still impacted by colonialism via globalisation, migration, and transnationalism. Sandoval (2000) contends that postcoloniality recognises the strategies developed in response to colonisation and how they spur continued resistance to new forms of colonisation and exploitation.

body has thus far remained colonised through the discursive practices of the natural sciences, particularly the discourses of biology and medicine' (p. x). Bodies that are not white, cisgender, straight, male, and able-bodied face obstacles in accessing care and are subject to pathology based on their difference (Sharman, 2021; Tosh, 2019). In addition, bodies outside that dominant paradigm are viewed as 'abnormal' or 'strange' and subject to surveillance and discrimination (Ahmed, 2000; see also Clare, 2017; Eckert, 2017).

Before European colonisation, indigenous people had understandings of intersex bodies that were not confined to a sex/gender binary and did not view intersex bodies as a pathology (Lugones, 2016). Concerning different cultures and customs, Lugones (2016) acknowledges that pre-colonial societies in the Americas recognised intersex people without pressure for them to conform to a sex/gender binary. With the colonial project, Europeans introduced the gender binary and patriarchy, which undermined relationships in indigenous communities and controlled who had access to land, education, and other resources (Costello, 2021; Hawkesworth, 2016). Furthermore, patriarchy subverted the leadership of indigenous women in matriarchal societies (Lugones, 2016). Oyěwùmí (1997) discusses how British colonisation in Nigeria imposed the category of woman onto Yoruba society, which undermined female governance:

The very process by which females were categorised and reduced to "women" made them ineligible for leadership roles. The basis for this exclusion was their biology, a process that was a new development in Yoruba society. The emergence of women as an identifiable category, defined by their anatomy and subordinated to men in all situations, resulted, in part, from the imposition of a patriarchal colonial state. For females, colonisation was a twofold process of racial inferiorization and gender subordination (p. 124).

Hawkesworth (2016) states that 'through sexual violence, exploitation, and systems of concubinage, the colonisers used gender to break the will of Indigenous men and women, imposing new hierarchies that were institutionalised with colonialism' (p. 22). In the encounter with white European bodies, Black and indigenous bodies became strange or othered (Ahmed, 2006). Colonisation also facilitated medical exploration via the anthropological taxonomy and exploitation of indigenous people (Eckert, 2017). Colonisation and medicine not only commanded the subordination of Black and indigenous bodies but reinforced male and female as fixed, stable categories (Eckert, 2017; see also Magubane, 2014; Swarr, 2023).

Pornotroping and the hospital

While Nietzsche recognised how doctors wielded power as part of the master morality, Foucault developed Nietzsche's idea of medical power to show how medical institutions discipline and control the body (Foucault, 1977; see also Foucault, 1995). Foucault (1988) acknowledges that the function of the hospital was to 'sever or to correct' (p. 159). In this 'living laboratory' of the hospital, as described by Spillers (1987), intersex children and adults become experiments in gender compliance. Given the historical context of hospitals, they are not objective spaces and have served as containers that project racist, ableist, misogynist, and homophobic narratives onto bodies that are considered deviant (Eckert, 2017; see also Sharman, 2021; Snorton, 2017). Hospital settings privilege the sex/gender binary and maintain biological essentialism (Malatino, 2019). In this setting, intersex bodies are not only strange bodies but are pathologies that require medical intervention (Ehrenreich & Barr 2005; Garland & Travis 2023; Orr 2022).

As part of the master morality, doctors are not separate from the legacy of colonisation. In other words, the Western medical gaze is not separate from the racialised, colonialist gaze that objectified African and indigenous bodies (Reis, 2021; see also Eckert, 2017). Spillers (1987) introduced the concept of pornotroping to describe how enslaved Africans were dehumanised and, at the same time, objects of sexual predation. In this subjugated state, enslaved Africans became a living laboratory (Spillers, 1987, pp. 67-68) where they were subject to a myriad of violence that included endless toil, forced miscegenation, and medical experimentation. In the medical model, Black bodies are positioned 'at the very margins of the human' (Eckert, 2017, p. 3). Black women, like intersex and disabled people, have been exploited to advance medicine or have been subject to medical techniques designed to ‘cure’ them (Orr, 2022; see also Clare, 2017). In the context of the American South, the bodies of enslaved Black women were brutalised and violently intervened upon by white male doctors to advance medical knowledge in the field of gynaecology (Cooper Owens, 2017). Snorton (2017) and Cooper Owens (2017) reference one of those doctors, J. Marion Sims, who owned and experimented on three enslaved Black women, Anarcha, Betsey, and Lucy, on whom he conducted multiple vaginal surgeries without anaesthesia in his makeshift hospital. Snorton states that the hospital operated as a laboratory where flesh was acted upon by ‘medico-scientific discourses, techniques of examination, and objectification’ (p. 40).

Medical photography is a form of pornotroping that takes place in the hospital. Medical photography documented anatomical differences, trying to prove inferiority among marginalised groups, and was particularly weaponised against Black, indigenous, intersex, and disabled communities (Orr & Magnet, 2022). In the context of intersex medicalisation, Malatino (2019) states that a black bar was used to cover the faces of intersex children and adults who were photographed to document intersex variations. In addition to photography, doctors often used degrading language to describe and refer to patients’ bodies (Ehrenreich & Barr, 2005; see also Blumberg, 1994). The black bar created distance between the physician and patient, allowing the doctor to objectify the patient while simultaneously absolving the doctor of harm. Moreover, the black bar further contributed to intersex erasure, where ‘the visible intersex body must remain secret, covered, socially and politically invisible’ (Malatino, 2019, p. 91).

As mentioned earlier, pornotroping and medical photography have been weaponised against marginalised communities in medicine. When discussing medical power over marginalised bodies, a disability framework provides a lens to critique medical authority. Charlton (2000) states that the disability rights movement grew out of a ‘consciousness’ developed by disabled people that ‘transforms the notion and concept of disability from a medical condition to a political and social condition’ (p. 17). Disability studies are an outgrowth of the disability rights movement and recognise that structural conditions such as poverty, inadequate medical care, racism, and other forms of oppression disable people (Orr 2022; see also Morland 2006). Contemporary voices from the disability justice movement contribute analyses of race, gender identity, class, and sexual orientation to disability studies (Bailey & Mobley, 2019; Clare, 2017; Mingus, n.d.; Piepzna-Samarasinha, 2018; Schalk, 2022). Schalk (2022) states that ‘disability justice builds on and extends the work of the early disability rights movement, which was often very white and focused on the single issue of disability rights’ (p. 7).

Intersex bodies, like disabled bodies, are pathologised and ‘corrected’ to make them legible in a world that ignores sex variation and disability (Clare 2017; see also Koyama 2006; Orr 2022). Blumberg (1994) states that ‘society’s prejudices against disabled people are enacted in medical settings in many virulent ways, ranging from indiscriminate surgery to unnecessary hospitalisation to the denial of basic health care’ (p. 76). Although Blumberg is referring to the treatment of disabled people, intersex people also contend with disparaging and condescending attitudes from medical professionals in addition to unnecessary medical interventions and inadequate healthcare. Orr (2022) provides a bridge between intersex medicalisation and disability in her concept of ‘cripping intersex’, which applies disability theory to intersex studies. Orr argues that the concept of cripping intersex ‘requires us to contend with the fact that medical interventions are often disabling. Interphobic curative violence is a disability issue’ (p. 65). The following section on intersex surgery illustrates how doctors, as part of the master morality, bring strange bodies into alignment through gender normalisation surgery.

Intersex Surgery

Morland (2005) states that the purpose of surgery is to ‘make intersexed bodies more easily understood by non-intersexed’ (p. 335). Morland adds that while the medical establishment has deemed atypical intersex genitals as abnormal, it continually exalts idealised, arbitrary versions of male and female genitals as the basis of ‘normal’ human development. Ehrenreich and Barr

(2005) emphasise that the sexual function of genitals in people assigned male and female often trumps sexual satisfaction. As a result, there is an emphasis on fashioning genitals that can engage in penile-vaginal sex, even if the attainment of that goal harms the patient in the process (Ehrenreich & Barr, 2005; see also Davis & Murphy, 2013). As part of intersex medicalisation in a hospital setting, there is an assumption that non-consensual touching does not take place. Because of this assumption, intersex people who describe their medical experiences as non-consensual or even sexual abuse are not believed or dismissed (Tosh, 2013; see also Koyama, n.d.). Tosh (2013) states that 'the potentially painful, unwanted, or non-consensual genital examinations and surgery experienced by intersex children are not framed as sexual abuse because the individual's motivation is seen as medically warranted and therefore non-sexualised' (p. 79). Morland (2012) provides a personal account to illustrate the impact of genital surgery. When referring to the surgeries that were done on his body, Morland (2012) expresses that 'scars and genitals grow together, shaping each other, registering a past intervention' (p. 25). The touch that occurs between the surgeon and intersex patient is a type of touch which alters and sometimes harms intersex children (Grabham, 2007). Furthermore, the encounter between the surgeon and intersex child results in 'practices and techniques of differentiation' (Ahmed, 2000) that not only estrange and invisibilise intersex bodies but reinforce normative, binary notions of gender and sexuality.

Compulsory Heterosexuality

The goal of surgery on intersex children is not only about gender legibility in a heteronormative culture but also pacifies society's anxieties about gender nonconformity and presumed homosexuality (Kessler, 1998; see also Koyama, 2006, para 33). Here, Ahmed's reference to heterosexuality as a straightening device is useful to consider how intersex children, for example, with curvature in their penises, are surgically altered to facilitate penetration (Ahmed, 2006: see also Ehrenreich & Barr, 2005; Mak, 2012). Dreger (1998) argues that the treatment of intersex people, long before the advent of medical interventions in childhood, has always been predicated on denying intersex embodiment and maintaining heterosexuality. The fear and hatred of homosexuality, but particularly 'lesbianism' in children with atypical genitals assigned as female, has warranted clitorectomies and other forms of violent medical interventions (Roen, 2006; see also Gill-Peterson, 2018; Kessler, 1998). The violence that intersex children are subjected to aligns with feminist author Adrienne Rich's concept of compulsory heterosexuality (Rich, 1980). Rich (1980) explains that heterosexuality as an institution assumes that women are subservient while objectifying their bodies and ignoring their sexualities and desires. Within this institution of heterosexuality, lesbian identity and desires are erased. Rich also argues that this system of domination created by men is 'maintained by a variety of forces, including both physical violence and false consciousness' (p. 648). In rejecting the presumed discourse of heterosexuality, Rich (1980) advocates for women to question not only their sexuality but the institution that restricts and limits them as people.

In this section, I applied Ahmed's concept of strange bodies to explain how intersex children are erased by the medical establishment. Nietzsche (1882/2001) named doctors as part of the master morality. However, according to Eckert (2017), doctors are not separate from the colonial project—medicine functions as part of the master morality, which is also rooted in colonisation. Colonisation and medical power have rendered intersex bodies strange in juxtaposition to an arbitrary idea of what constitutes normal bodies. The legacy of colonisation was continued through pornotroping (Spillers, 1987) in the form of medical photography and situated the hospital as a site of experimentation. The hospital has become a laboratory (Snorton, 2017) where the life trajectories of intersex children and young adults are altered by surgery and compulsory heterosexuality (Rich, 1980) to align their bodies with expectations of normative gender and sexuality. These practices work together to further erasure. In the next section, I will define embodiment using Nietzsche's (1887/2007) concept of morality in addition to gendering (Eveline & Bacchi, 2010) and social flesh (Bacchi & Beasley, 2002). These concepts will explore how harm towards intersex children can be interrupted in society and policy.

Morality and intersex embodiment

Because of prevailing notions that privilege sex binarism and heterosexuality, intersex embodiment is precluded from existing. Intersex erasure is facilitated by gender normalisation and surgery to make intersex bodies align with typical notions of male and female. In this section, I will delve further into Nietzsche's concept of morality to define embodiment.

As a philosophy, Nietzsche's concept of morality evolved over a decade in several texts that include The Gay Science (Nietzsche, 1882/2001), Beyond Good and Evil (Nietzsche, 1886/1907) and On the Genealogy of Morality (Nietzsche, 1887/2007). According to Nietzsche (1887/2007), morality arose from the need for structure as humans evolved from tribal structures to form complex societies. As these societies developed, particularly in Europe, they embraced Christianity, which imposed moral values and norms on society (Nietzsche, 1886/1907). In these texts, Nietzsche explores the saturation of religious influence across social institutions that establishes a default sense of order and structure. Hanna (1985) argues that while Nietzsche recognised Christianity as an organising force contributing to structure and order in society, Christianity also tamed human beings' unhinged, animalistic nature. Hanna explains that this ungovernable characteristic of human beings is foundational to an awareness of the body or somatic awareness. Nietzsche described this dulling of our sensations and impulses as 'taming', which at an earlier time in human history was vital to the survival of the group (Nietzsche, 1886/1907). Although it is no longer necessary, human beings existing within the moral system have clung to this taming, which Nietzsche (1882/2001) argues is 'herd-instinct in the individual' (p. 115). The lasting impact of morality is that it perpetuates conformity, which benefits most of society.

Realising how Christianity limited full human potential, Nietzsche was committed to deconstructing the relationship between personal growth, societal values, and the influence of Christianity (Nietzsche, 1882/2001; 1886/1907). Nietzsche (1886/1907) said, 'This system of morals helps its author to forget, that system makes him, or something of him, forgotten' (p. 106). To challenge the moral structure, Nietzsche (1887/2007) thought that people needed to question what he perceived as social conformity taking root. When deciding to challenge morality, Nietzsche (1882/2001) states that 'one emerges from such dangerous exercises in self-mastery as a different person, with a few more question marks, above all with the will henceforth to question further, more deeply, severely, harshly, evilly, and quietly than one had previously questioned' (p. 7).

Challenging the established value system liberates the body. For Nietzsche, the acquisition of knowledge and power was a direct result of people connecting to their bodies (Grosz, 1994). Nietzsche (1887/2007) believed that people maintain morality by not questioning and suppressing their thoughts and feelings. He thought that through questioning and cultivating a drive for knowledge, people could transcend the constraint of morality and connect to their embodiment (Nietzsche, 1901/1968; see also Lash, 1984; Nietzsche, 1887/2007). Foucault (1977) acknowledges that Nietzsche's genealogical method is not separate from the body and that it 'attaches itself to the body. It inscribes itself in the nervous system, temperament, and digestive apparatus' (p. 147). Nietzsche's interest in the body as a source of knowledge and power is compelling; he shows that challenging a moral system requires the body's participation. While Nietzsche implored his audience to critically examine the structures that confined them through his genealogical method, he also asserted a material, fleshly perspective of the body:

> We are no thinking frogs, no objectifying and registering devices with frozen innards – we must constantly give birth to our thoughts out of our pain and maternally endow them with all that we have of blood, heart, fire, pleasure, passion, agony, conscience, fate and disaster (Nietzsche, 1882/2001, p. 6)

At that time, his articulation of the body challenged Cartesian dualism that encouraged a mind-body split (Grosz, 1994; see also Nietzsche, 1887/2007). In response to Descartes, Nietzsche (1882/2001) argued that 'philosophy has been no more than an interpretation of the body and a misunderstanding of the body' (p. 5). To further develop his concept of embodiment, Nietzsche

(1901/1968) asserted that ‘thinking, feeling, and willing’ were inherent to all human beings (p. 347). This raw definition of embodiment is integral to intersex embodiment because it asserts a universal understanding of the body outside a positivist medical perspective.

Within Nietzsche’s framework of morality, he conceptualised the body as a way to challenge the established order. While he recognises the power of religion, particularly Christianity, in dictating societal norms and values, he criticises how the inability to question these values does not allow people to cultivate a deeper awareness and expansion of self. According to Nietzsche (1901/1968), the willingness to seek knowledge beyond the constructs of morality connects people to their bodies. When doctors, as part of the master morality, connect to their bodies, they can envision bodies beyond the scripted norms of male and female. Allowing intersex bodies to exist challenges the confines of morality. However, what is intersex embodiment beyond medicalisation? The following section will look at intersex embodiment by defining flesh and extending beyond the flesh to globalise the intersex body using the concepts of social flesh (Bacchi & Beasley, 2012) and gendering (Eveline & Bacchi, 2010).

Defining Flesh

While Nietzsche provides a rudimentary framework to understand the body (Nietzsche, 1882/2001; see also Nietzsche 1886/1907), his definition of embodiment assumed a cisgender, European male body. His portrayal of the 'superman' or übermensch was Nietzsche’s ideal European man whose genetic selection allowed him to overcome nature and the confines of morality (Young, 2010). Eventually, Nietzsche’s idea of the übermensch was picked up by proponents of eugenics, such as Hitler and the Nazi Party, to prove the superiority of the white race (Nietzsche, 1901/1968; Young, 2010). In addition, Nietzsche did not consider Africans to be his equals. Nietzsche refers to Africans as the 'primaeval man' (Nietzsche, 1887/2007, pp. 43-44), arguing that their pain tolerance is greater than that of Europeans, a belief that has continually contributed to the dehumanisation of Black people in medicine (Cooper Owens, 2017). While I recognise that Nietzsche can be problematic regarding race and gender, I find value in his concept of embodiment, which I will use first to define flesh and then intersex flesh.

As women of colour, Moraga and Anzaldúa (1983) describe the importance of theorising from the flesh to not only account for the material realities of people’s lives but also factor in the relationships that people have with their race and cultural background, sexuality, desires as well as the land from which they originate. To begin defining intersex embodiment, I will start by reconstituting flesh. I define flesh as the raw material that encapsulates our physical, emotional, and spiritual embodiment (Grosz, 1994; Aquilina, 2016). Snorton (2017) states that flesh is a ‘thing that produces relations—real and imagined, metaphysical and material’ (p. 40). Snorton complicates his definition of flesh by invoking Spillers' (1987) concept of 'captive flesh', which references the enslavement of Africans who were subjected to captivity and objectification during the colonial period. Spillers' concept of captive flesh, like pornotroping, can also be applied to intersex children and adults whose bodies have been on display for medical professionals.

Intersex Flesh

Intersex bodies have been historically defined by genitals, but genitals are flesh. Eckert (2017) asserts that medicine ‘creates sexual dimorphism out of intersex flesh to bring healthy but culturally unacceptable flesh into line with the signifiers of ‘boy’ and ‘girl” (p. 97). Chase (2013) speaks to how intersex flesh is cut to limit sexual possibilities and satisfy demands for heterosexuality and gender normativity. From a historical and medical perspective, intersex genitals have been viewed as ambiguous, abnormal, and disordered (Davis & Murphy, 2013; Ehrenreich & Barr, 2005; Germon, 2009; Grabham, 2007; Morland, 2005). By referring to intersex flesh as genitals and gonads, doctors are obfuscating the process by which healthy tissue is altered or removed, and reproductive potential is reduced to sterility (Holmes, 2009; see also Eckert, 2017; Germon, 2009; Morland, 2011). By defining intersex flesh beyond the abstracted notion of genitals, I am reclaiming what Ahmed (2000) refers to as a ‘border that feels’ (p. 45).Nietzsche’s conceptualisation of the body is important to move the body beyond an objectified version of itself. Nietzsche’s body has feelings, emotions and processes but is conceived in a way that centres whiteness and maleness. By ‘theorising from the flesh' (Moraga & Anzaldúa, 1983), embodiment is recognised as flesh with a new meaning that accounts for race, gender and cultural history. By asserting the primacy of flesh, intersex flesh has meaning. In the next section, I will examine the concepts of social flesh and gendering that globalise the idea of flesh beyond medical spaces.

Social Flesh and Gendering

Social flesh and gendering were developed by Carol Bacchi in collaboration with Joan Eveline and Chris Beasley as policy concepts to reintroduce the body and gender into policy discourse (Bacchi, 2017; Beasley & Bacchi, 2007). Bacchi is a feminist and policy scholar who developed social flesh in collaboration with Chris Beasley as part of corporeal feminism (Beasley & Bacchi, 2007). Corporeal feminism is a feminist theory that views the body beyond societal inscriptions of the body as male or female and looks at how bodies are located biologically, historically, culturally, and politically (Grosz, 1994). Bray and Colebrook (1998) assert that corporeal feminism was introduced by feminist scholars such as Luce Irigaray, Moira Gatens and Judith Butler, who rejected a masculinist construction of the body that devalued femininity. Furthermore, corporeal feminism challenged Cartesian dualism by privileging knowledge that is generated from the body (Bray & Colebrook, 1998).

In addition to social flesh, Bacchi offers another concept, which is gendering. Bacchi (2017) situates gendering within poststructuralism and asserts that gender is not fixed, especially in the context of policy practices. Poststructuralism as a discipline emerged during the 1960s and was dominated by French philosophers such as Jacques Derrida, Gilles Deleuze, and Michel Foucault (Williams, 2005). Williams (2005) asserts that poststructuralism challenges established truths such as gender and sexuality and 'guards against the sometimes overt, sometimes hidden, violence of established values such as an established morality, an artistic cannon or a fixed legal framework' (p. 4).

Applying social flesh to intersex

Social flesh expands the possibility of intersex flesh by situating the body as a priority in policy spaces. Bacchi and Beasley (2002) assert that policy spaces are disembodied—prioritising the mind over the body, particularly in decision-making about the body. Furthermore, social flesh responds to neoliberal practices and policies that reinforce heterosexism, racism, and patriarchy (Beasley & Bacchi, 2012). Social flesh critiques the problematisations of certain populations in 'need of care' and asserts that a model of care that denies embodiment or rights to bodily autonomy is inherently flawed. Beasley and Bacchi (2012) view social flesh as an intervention that reinforces the interconnectedness of bodily experiences and challenges frameworks, spaces, and institutions that render bodies as ‘strange’ or ‘other’. Beasley and Bacchi (2007) conceived of social flesh as a policy concept that insists on the 'embodied interdependence' of people, which globalises the notion of flesh and the body beyond the private medical sphere (p. 280).

Except for Grabham (2007), scholars have not applied the concept of social flesh to intersex. Grabham applied social flesh to intersex in the context of citizenship studies to argue that intersex children are subject to an 'unusual level of intervention by medical practitioners and family' (p. 43). These interventions deny intersex embodiment and impact their rights as citizens. Applying social flesh to this discussion of intersex embodiment challenges the authority of medical practice and decision-making over intersex bodies, therefore rejecting the management of intersex variations in the private medical sphere. Although Beasley and Bacchi (2012) recognise this concept as a ‘utopian ideal’ (p. 107), by considering intersex bodies and experiences in social policy using the concept of social flesh, intersex bodies move from the margins of being strange bodies toward being a part of the collective body.

Applying gendering to intersex

In using the term gendering, Eveline and Bacchi (2010) problematise gender, historically understood as a characteristic of a person instead of a process 'that is ongoing, contested and incomplete' (p. 87). Bacchi et al. (2010) argue that gender is less about biology and more about the policies, practices, and institutions that ‘produce gendered people’ (p. 62). Bacchi (2017) envisioned gendering as a way of interrogating policy practices that discursively create ‘men’ and ‘women’. Gendering practices are rooted in European colonisation and gave birth to racial and gender hierarchies that were premised on ‘biological dimorphism’ and ‘heterosexual patriarchy’ (Lugones, 2016, p. 2). The racialisation of indigenous people prescribed race based on biological characteristics, which determined value and access (Hawkesworth, 2016; Lugones, 2016). Hawkesworth (2016) adds that ‘racialisation and gendering simultaneously create the dominant and the subordinate by means of laws, norms, policies, and practices that categorise, separate, [and] assign places in the social order’ (p. 11). Bacchi (2017) argues that because gendering is intersectional, it opens possibilities to question how policies and practices are disabling, heterosexist, classist, and racist.

As a poststructural concept, gendering is similar to Nietzsche’s (1901/1968) idea of becoming. Nietzsche questioned the idea that identity is fixed since the world is in a constant state of flux (Turner, 1984/2008). To challenge this notion of fixed identities, Nietzsche proposed the idea of becoming to reflect that in a world of constant change, people’s identities cannot be fully materialised. Turner (1984/2008) adds that the idea of becoming, according to Nietzsche, acknowledges that ‘we can only know that part of being which we have constructed’ (p. 204). For intersex children, the idea of becoming is also a valuable concept, especially when decisions about gender are finite and fixed. In an intersex context, Malatino (2019) mentions how gender should be viewed as a process of becoming that encapsulates 'embodiment beyond sexual dimorphism' (p. 136). Concepts such as gendering and becoming can act as interventions that allow more space for children in general, but especially intersex children, to develop outside of societal constraints of male and female.

Conclusion

While discussions of embodiment within critical intersex studies have been able to critique oversight of legal protections for intersex people and call attention to the medical exploitation of intersex children and young adults, these conversations have not considered the intersex body outside of a legal or medical context. I engaged with Nietzsche’s concept of morality to critique how this value system erases intersex people via sex binarism and heterosexuality. As part of his critique of morality, Nietzsche (1887/2007) developed a genealogical method to understand how societal values were created and imposed. By using Nietzsche’s genealogical approach to intersex erasure, I am uncovering how doctors, as part of the master morality, assigned value to intersex bodies. To illustrate intersex erasure, I brought in Ahmed’s (2000) concept of strange bodies to illuminate how intersex bodies are regarded as strange by medical practitioners, which facilitates interventions in the form of pornotroping and surgery. Within morality, Nietzsche (1887/2007) offers embodiment as a way forward. Considering that doctors are part of the master morality, embodiment not only liberates them but also allows them to think creatively about intersex embodiment. Conceptually, embodiment is not only important for doctors to think differently about intersex embodiment but also for lawyers and policymakers who can create safeguards for intersex citizens. Although Nietzsche’s model of embodiment is compelling, I found that his concept of embodiment centred on white, able-bodied, cisgender men as exemplified by his übermensch concept. As an intervention toward intersex embodiment, I incorporated social flesh and gendering. Social flesh, a concept by Bacchi and Beasley (2012), challenges the idea of intersex bodies as strange by centring marginalised bodies in policy spaces. Social flesh, in addition to gendering (Eveline & Bacchi, 2010), establishes the interconnectedness of people’s bodies on both interpersonal and policy levels. Gendering is another intervention that forces people to question the policies and practices that create ‘gendered people’ (Bacchi et al., 2010, p. 62).

References

Ahmed, S. (n.d.). Bio. https://www.saranahmed.com/bio-cv

Ahmed, S. (2000). Strange encounters: Embodied others in post-coloniality. Routledge.

Ahmed, S. (2006). Queer Phenomenology: Orientations, Objects, Others. Duke University Press. http://doi.org/10.2307/j.ctv125jk6w

Aquilina, E. (2016). EMBODYING AUTHENTICITY: A somatic path to transforming self, team & organisation. LIVE IT Publishing.

Bacchi, C. (2017). Policies as Gendering Practices: Re-Viewing Categorical Distinctions. Journal of Women, Politics & Policy, 38(1), 20-41. https://doi.org/10.1080/1554477X.2016.1198207

Bacchi, C. L., & Beasley, C. (2002). Citizen bodies: is embodied citizenship a contradiction in terms? Critical Social Policy, 22(2), 324–352. https://doi.org/10.1177/026101830202200201

Bacchi, C., Eveline, J., Binns, J., MacKenzie, C., & Harwood, S. (2010). Gender analysis and social change: Testing the water. In C. BACCHI & J. EVELINE (Eds.), Mainstreaming Politics: Gendering Practices and Feminist Theory (pp. 61–86). University of Adelaide Press. http://www.jstor.org/stable/10.20851/j.ctt1t30564.11

Bailey, M., & Mobley, I. A. (2019). Work in the Intersections: A Black Feminist Disability Framework. Gender & Society, 33(1), 19–40. https://doi.org/10.1177/0891243218801523

Beasley, C., & Bacchi, C. (2000). Citizen bodies: Embodying citizens - a feminist analysis. International Feminist Journal of Politics, 2(3), 337-358. https://doi.org/10.1080/14616740050201931

Beasley, C., & Bacchi, C. (2007). Envisaging a new politics for an ethical future: Beyond trust, care and generosity—towards an ethic of `social flesh'. Feminist Theory, 8(3), 279-298. https://doi.org/10.1177/1464700107082366

Beasley, C., & Bacchi, C. (2012). Making politics fleshly: The ethic of social flesh. In A. Bletsas & C. Beasley (Eds.), Engaging with Carol Bacchi: Strategic Interventions and Exchanges (pp. 99-120). The University of Adelaide Press. http://www.jstor.org/stable/10.20851/j.ctt1sq5x83

Bhambra G. K. (2007). Rethinking modernity: postcolonialism and the sociological imagination. Palgrave.

Blumberg, L. (1994). Public Stripping. In B. Shaw (Ed.), The ragged edge: the disability experience from the pages of the first fifteen years of The disability rag (pp. 73-77). Advocado Press.

Bray, A., & Colebrook, C. (1998). The Haunted Flesh: Corporeal Feminism and the Politics of (Dis) Embodiment. Signs, 24(1), 35–67. http://www.jstor.org/stable/3175671

Charlton, J. I. (2000). Nothing about us without us: Disability oppression and empowerment. Univ. of California Press.

Chase, C. (2013). Hermaphrodites with attitude: Mapping the emergence of intersex political activism. In S. Stryker & S. Whittle (Eds.), The transgender studies reader (pp. 300-314). Routledge.

Clare, E. (2017). Brilliant imperfection: Grappling with Cure. Duke University Press.

Cooper Owens, D. (2017). Medical bondage: Race, gender, and the origins of American gynecology. University of Georgia Press.

Costello, C. (2021). Beyond Binary Sex and Gender Ideology. In N. Boero, & K. Mason (Eds.), The Oxford Handbook of the Sociology of Body and Embodiment (pp. 199-220). Oxford University Press.

Davis, G., & Murphy, E. (2013). Intersex Bodies as States of Exception: An Empirical Explanation for Unnecessary Surgical Modification. Feminist Formations, 25(2), 129-152. http://www.jstor.org/stable/43860689

Dreger, A. D. (1998). Hermaphrodites and the medical invention of sex. Harvard University Press.

Eckert, L. (2017). Intersexualization: The clinic and the colony. Routledge/Taylor & Francis Group.

Ehrenreich, N., & Barr, M. (2005). Intersex surgery, female genital cutting, and the selective condemnation of "cultural practices". Harvard Civil Rights-Civil Liberties Law Review, 40(1), 71-140.

Eveline, J., & Bacchi, C. (2010). What are we mainstreaming when we mainstream gender? In J. Eveline & C. Bacchi (Eds.), Mainstreaming Politics: Gendering Practices and Feminist Theory (pp. 87–110). University of Adelaide Press. http://www.jstor.org/stable/10.20851/j.ctt1t30564.12

Fausto-Sterling A. (2020). Sexing the body: gender politics and the construction of sexuality (Second). Basic Books.

Feder, E. K. (2014). Making sense of intersex: Changing ethical perspectives in biomedicine. Indiana University Press.

Foucault, M. (1977). “Nietzsche, Genealogy, History.” In D.F. Bouchard (Ed.), Language, Counter-Memory, Practice: Selected Essays and Interviews. Cornell University Press.

Foucault, M. (1988). Madness and Civilization. Vintage Books.

Foucault, M. (1995). Discipline and punish: The birth of the prison (2nd Vintage Books ed). Vintage Books.

Foucault, M. (2010). The birth of the clinic: An archaeology of medical perception (A.M. Sheridan, Trans.; 1. publ., reprinted). Routledge. (Original work published 1963)

Garland, F., & Travis, M. (2018). Legislating intersex equality: Building the resilience of intersex people through law. Legal Studies, 38(4), 587-606. https://doi.org/10.1017/lst.2018.17

Garland, F., & Travis, M. (2023). Intersex embodiment: Legal frameworks beyond identity and disorder. Bristol University Press.

Germon, J. (2009). Gender: A genealogy of an idea (1st ed). Palgrave Macmillan.

Gill-Peterson, J. (2018). Histories of the Transgender Child. University of Minnesota Press. https://doi.org/10.5749/j.ctv75d87g

Grabham, E. (2007). Citizen Bodies, Intersex Citizenship. Sexualities, 10(1), 29–48. https://doi.org/10.1177/1363460707072951

Grosz, E. A. (1994). Volatile bodies: Toward a corporeal feminism. Allen & Unwin.

Hanna, T. (1985). Bodies in revolt: A primer in somatic thinking (2nd ed). Freeperson Press.

Hawkesworth, M. E. (2016). Embodied power: Demystifying disembodied politics. Routledge, Taylor & Francis Group.

Holmes, M. (Ed.). (2009). Critical intersex. Ashgate.

Kessler, S. J. (1998). Lessons from the intersexed. Rutgers University Press.

Koyama, E. (n.d.). Intersex Initiative: Medical Abuse of Intersex Children. Intersex Initiative. http://www.ipdx.org/articles/medicalabuse.html

Koyama, E. (2006). Intersex Initiative: From “Intersex” to “DSD.” Intersex Initiative. http://www.intersexinitiative.org/articles/intersextodsd.html

Lash, S. (1984). Genealogy and the Body: Foucault/Deleuze/Nietzsche. Theory, Culture & Society, 2(2), 1–17. https://doi.org/10.1177/0263276484002002003

Lugones, M. (2016). The Coloniality of Gender. In W, Harcourt (Ed.), The Palgrave Handbook of Gender and Development (pp. 13-33). Palgrave Macmillan. https://doi.org/10.1007/978-1-137-38273-3_2

Magubane, Z. (2014). Spectacles and Scholarship: Caster Semenya, Intersex Studies, and the Problem of Race in Feminist Theory. Signs, 39(3), 761-785. http://doi.org/10.1086/674301

Mak, G. (2012). Doubting Sex: Inscriptions, bodies and selves in nineteenth-century hermaphrodite case histories. Manchester University Press.

Malatino, H. (2019). Queer embodiment: Monstrosity, medical violence, and intersex experience. University of Nebraska Press.

Mingus, M. (n.d.). Leaving Evidence. https://leavingevidence.wordpress.com/

Moraga, C., & Anzaldúa, G. (1983). This Bridge Called My Back: Writings by Radical Women of color (2nd ed.). Kitchen table.

Morland, I. (2005). ‘The Glans Opens Like a Book’: Writing and Reading the Intersexed Body. Continuum, 19(3), 335-348. https://doi.org/10.1080/10304310500176586

Morland I. (2006) Postmodern Intersex. In S. Sytsma (Ed.), Ethics and Intersex. International Library of Ethics, Law and the New Medicine, vol 29. Springer. https://doi.org/10.1007/1-4220-4314-7_20

Morland, I. (2011). Intersex Treatment and the Promise of Trauma. In J. Fisher (ed)., Gender and the Science of Difference. Rutgers University Press. https://doi.org/10.36019/9780813550794-009

Morland, I. (2012). The Injured World: Intersex and the Phenomenology of Feeling. Differences, 23 (2), 20-41. https://doi.org/10.1215/10407391-1629803

Ní Mhuirthile, T. (2015). Building bodies: a legal history of intersex in Ireland. In J. Redmond, S. Tiernan, S. McAvoy, and McAuliffe, M. McAuliffe (Eds.), Sexual Politics in Modern Ireland (pp. 154-172). Irish Academic Press.

Nietzsche, F. W. (2007). On the genealogy of morality (C. Diethe, Trans.; student edition). Cambridge University Press. (Original work published 1887)

Nietzsche, F. W. (1968). The will to power (W. Kaufmann, W. & R.J. Hollingdale, Trans.). Vintage Books. (Original work published 1901)

Nietzsche, F. W. (2001). The gay science: With a prelude in German rhymes and an appendix of songs (J. Nauckhoff, Trans). Cambridge University Press. (Original work published 1882)

Nietzsche F. W. (1907). Beyond good and evil prelude to a philosophy of the future (H. Zimmern, Trans). http://catalog.hathitrust.org/api/volumes/oclc/1925555.html (Original work published 1886)

Orr, C. E. (2022). Cripping Intersex. UBC Press.

Orr, C. E., & Magnet, S. (2022). Feminist surveillance studies and the institutionalization of interphobia. Surveillance & Society, 20(4), 420-433.

Oyěwùmí, Oyèrónkẹ́. (1997). The invention of women: Making an African sense of Western gender discourses. University of Minnesota Press.

Piepzna-Samarasinha, L. L. (2018). Care work: Dreaming Disability Justice. Arsenal Pulp Press.

Reis, E. (2021). Bodies in doubt: An American history of intersex (Second edition). Johns Hopkins University Press.

Rich, A. (1980). Compulsory Heterosexuality and Lesbian Existence. Signs, 5(4), 631–660. http://www.jstor.org/stable/3173834

Roen K. (2004). Intersex embodiment: when health care means maintaining binary sexes. Sexual health, 1(3), 127–130. https://doi.org/10.1071/sh04007

Roen, K. (2006). Queer kids: Towards ethical clinical interactions with intersex people. In M. Shildrick & R. Mykitiuk (Eds.), Ethics of the body: Postconventional challenges. MIT Press.

Rubin, D. A. (2017). Intersex matters: Biomedical embodiment, gender regulation, and transnational activism. State University of New York Press.

Sandoval, C. (2000). Methodology of the oppressed. University of Minnesota Press.

Schalk, S. (2022). Black Disability Politics. Duke University Press. https://doi.org/10.1515/9781478027003

Sharman, Z. (Ed.). (2021). The care we dream of: Liberatory & transformative approaches to LGBTQ+ health. Arsenal Pulp Press.

Shildrick, M. (2008). Corporeal Cuts: Surgery and the Psycho-social. Body & Society, 14(1), 31–46. https://doi.org/10.1177/1357034X07087529

Shilling, C. (2003). The body and social theory. SAGE Publications Ltd. https://dx.doi.org/10.4135/9781446215470

Snorton, C. R. (2017). Black on both sides: A racial history of trans identity. University of Minnesota Press. https://doi.org/10.5749/j.ctt1pwt7dz

Spillers, H. (1987). Mama's baby, papa's maybe: An American grammar book. Diacritics, 17(2), 65-81.

Swarr, A. L. (2023). Envisioning African intersex: Challenging colonial and racist legacies in South African medicine. Duke University Press.

Tosh, J. (2013). The (In)Visibility of Childhood Sexual Abuse: Psychiatric Theorizing of Transgenderism and Intersexuality. Intersectionalities: A Global Journal Of Social Work Analysis, Research, Polity, And Practice, 2(1), 71-87. https://journals.library.mun.ca/ojs/index.php/IJ/article/view/739

Tosh, J. (2019). The Body and Consent in Psychology, Psychiatry, and Medicine: A Therapeutic Rape Culture (1st ed.). Routledge. https://doi.org/10.4324/9781315114484

Turner, B. S. (2008). The body & society: Explorations in social theory (3rd ed). SAGE.

Williams, J. (2005). Understanding poststructuralism. Acumen Pub.

Young, J. (2010). Friedrich Nietzsche: A philosophical biography. Cambridge University Press.

2. Older Intersex People: A Critical Literature Review[4]

Adeline W. Berry

Introduction

This chapter explores concerns faced by older intersex people headed into old age, providing an overview of existing literature and highlighting the urgent need for more research in this area. Little is understood about the needs of the intersex person throughout the remainder of their life into old age (Rosenwohl-Mack et al., 2020), as intersex variations are often associated with and considered only in relation to paediatric care. There is a dearth of research on intersex and ageing, and what exists often includes very few intersex participants (Hughes, 2016, 2018; Latham & Holmes, 2017). This paucity (Griffiths, 2018) illuminates how intersex variations are too often relegated in medical settings to paediatric urology and endocrinology, with little regard shown for what follows (Crocetti, Berry & Monro, 2023). As intersex people often have their medical histories hidden from them, many struggle along with carers to understand their needs as they age (Latham & Holmes, 2017). This chapter highlights where, if anywhere, literature on older people is focused, asking what is missing and the implications of these foci and paucities. Older people will be defined here as those aged 50 and above (Age UK, 2019).Methods used are detailed before presenting findings grouped into the following sections: intersex medical interventions; healthcare for older intersex people; older intersex people and disability; older intersex people and psychosocial well-being; older intersex people and social support; older intersex people and financial stability; older intersex people and the law; older intersex people and social support; and intersex identity. Future research directions are suggested, followed by a discussion and conclusion.

Methods

The author is an older transgender and intersex person of European descent. A literature search used library databases, Google, and Google Scholar. The dates covered were 2000–2023, and the following keywords were employed to identify potentially valuable articles: intersex, DSD, differences of sex development, disorders of sex development, ageing, disability, community, healthcare, housing, and discrimination. Because of the lack of literature on ageing and intersex, the search was broadened to include LGBT and transgender research. Books, articles, and chapters published since 2000 that had the potential to illuminate issues facing older intersex people were considered for inclusion. Only publications available in the English language were chosen. This review included 137 publications. Some grey and LGBT literature were included where necessary in the absence of available literature on older intersex people. A thematic approach was used to identify key issues.

Findings

Intersex medical interventions and older intersex people

Since the 1960s, many intersex people have been subjected to binary-affirming surgical and hormonal procedures based on the theories of Dr John Money (Money, Hampson & Hampson, 1957). However, there is little literature on the lifelong effects of early medical interventions apart from the considerable amount of literature relating to hypospadias 'repairs' (Barbagli et al., 2006, 2010, 2012; Snodgrass & Bush, 2017). Hypospadias is an intersex variation that sees the urethral opening, or meatus, located on the underside of the phallus rather than on the tip. Hypospadias

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[4] This chapter was based on the literature review for my PhD research project. Some of the work in this chapter was included previously in a 2022 paper co-authored with Professor Surya Monro entitled: Ageing in obscurity: a critical literature review regarding older intersex people, published by Sexual and Reproductive Health Matters: https://www.tandfonline.com/doi/pdf/10.1080/26410397.2022.2136027

may manifest alone or with other variations. Hypospadias 'repairs' surgically relocate the urethral opening to the tip of the phallus. These procedures, performed for social rather than medical reasons, have been justified as necessary by one surgeon as they "...give the young person an opportunity to, you know, particularly as a boy to, you know, be continent to not least stand up at the urinal with his pals and pee in the pot at the same time" (Hegarty et al., 2021, p.107). Sometimes, surgeries are required to resolve issues stemming from previous 'repairs', and the risk of complications may increase with each subsequent surgery (Snodgrass & Bush, 2017). Surgical outcomes not requiring further surgeries cannot be guaranteed, "In adults with complications after failed hypospadias repair, all urethroplasty procedures, despite meticulous technique, have the potential to fail, and any substitute material can deteriorate over time" (Barbagli et al., 2006, p.893). Common complications with surgical hypospadias alterations include scarring, strictures, recurrent fistulas, and wound dehiscences (Snodgrass & Bush, 2019; Verla et al., 2020). Those who have undergone multiple failed attempted hypospadias repairs may be given the distressing label of "hypospadias cripple" (Badawy et al., 2019; Badawy et al., 2019; Horton & Devine, 1970; Stecker Jr et al., 1981) with “limited options for reconstruction” (Neheman et al., 2020, 163.e2). Bracka suggests:

> for meaningful interpretation of the results of hypospadias repair, we should follow patients through to maturity. Early discharge is but an easy way to ‘sweep our shortcomings under the carpet’, allowing us to work to those priorities which we find most convenient (1989, p.254).

Hypospadias literature provides some valuable insight into the psychosocial effects of early intersex medical interventions in childhood. Individuals subjected to hypospadias ‘repairs’ reported higher rates of relationship avoidance, lower numbers of lovers, higher rates of erectile dysfunction and ejaculatory problems, and were significantly less satisfied with their sexual lives than controls (Bubanj et al., 2004; Rynja et al., 2011; Tourchi & Hoebeke, 2013).

Often, intersex babies were assigned as female because those surgeries were considered easier to perform (Hegarty, 2000; Woodhouse, 2004). Geneticist and endocrinologist Eric Vilain has confirmed that the phrase “it’s easier to dig a hole than build a pole” (Reardon, 2016, p.160) was commonly uttered by doctors tasked with determining the futures of intersex infants. Feminising interventions involve the creation of genitalia that appear typically feminine to the satisfaction of surgeons to replace what they determine to be masculinised female genitalia or masculine genitalia which they feel is inadequate (de Maria Arana, 2005; Kipnis & Diamond, 1998). Children born with what doctors call “micropenis” were often assigned female at birth, followed by irreversible surgery to cement that decision (Wisniewski et al., 2001). Surgery often involves the removal of healthy testes, rendering the child infertile, followed by the crafting of a functional vagina for future sexual penetration (Holmes, 2002).

Dr Money (1968), whose theories popularised the performance of binary-affirming surgeries on intersex infants around the world, seconded the Freudian belief (1962) that women derived sexual pleasure mostly from vaginal penetration. As a result, surgical reduction and removal of clitorises were popularised and justified by Money's belief (1968) that the clitoris serves no purpose, and removal reduced the possibility of future homosexuality (Reis & Kessler, 2010). Minto et al. (2003) found that participants subjected to clitoral reduction surgery experienced higher rates of non-sensuality and inability to orgasm than controls who had not been subjected to clitoral reduction surgery. While complete removal of the clitoris has fallen out of favour, surgical reduction of the clitoris is still commonly practised as part of the medical model of intersex management (Weidler et al., 2020). The genitalia of intersex infants continue to be restructured in order to facilitate future penetrative, heteronormative sex, with little thought given until recently (Ernst et al., 2020) to the intersex person's sexuality or gender identity. Medical procedures of this nature position the facilitation of the penis of an imagined future partner above the sexual sensation and satisfaction of the intersex person.

Like hypospadias 'repairs', vaginoplasties performed on intersex infants often require repeated surgical revisions (Ehrenreich & Barr, 2005). Dilation is often necessary to maintain neovaginal openings, which medical professionals direct the child's parent or caretaker to perform until the child is old enough to do this themselves. This act has been reported as sexual assault and even rape by intersex individuals and their parents (Reis & McCarthy, 2016; Tosh, 2013). Intersex adults subjected to binary-affirming medical interventions in childhood report dissatisfaction with appearance, scarring, pain, and sexual function that is diminished or absent (de Maria Arana, 2005). In a study of adults subjected to clitoral reduction surgery in infancy, most experienced sexual difficulties later in life and more than one-third reported inability to reach orgasm (Minto et al., 2003).

In 2020, services at the Tavistock and Portman Gender Identity Development Service, a clinic for transgender youth in the United Kingdom, were brought to a halt following a case brought against them by 23-year-old Keira Bell over regret related to irreversible aspects of their medical transition (Tobin et al., 2020). Twenty-nine per cent of intersex adults and adolescents in a recent study (Rapp et al., 2020) stated that medical interventions had negatively impacted their lives. Considering that regret by one de-transitioning transgender person was sufficient to persuade England's High Court to intervene in healthcare for transgender youth, it should follow that irreversible interventions to address "social emergencies" (Committee, 2000, p.138), children born with ambiguous genitalia, be halted until more is known about how intersex people experience them.

Older intersex people and healthcare

COVID-19 exposed shortcomings in the care of ageing people worldwide. Older people are at increased risk of infection due to pre-existing illnesses, in addition to isolation and mobility issues. Ageing LGBT communities commonly subjected to discrimination and intersectional inequalities, such as racism and classism, are particularly vulnerable (Daley et al., 2020; Haghighat et al., 2023). Findings from recent reviews of healthcare inequalities faced by ageing LGBTI (LGBT plus I for intersex) people, as well as barriers to care provision by healthcare professionals (Zeeman et al., 2019), show insufficient specialised treatment is mainly responsible for inadequate care and because LGBTI individuals often avoid medical treatment for fear of discrimination (Zirngast, 2002; Haghighat et al., 2023). Rosenwohl-Mack et al. (2020), in the first national study of intersex adults in the United States, discovered that more than 43 per cent of 198 participants surveyed rated their physical health as fair or poor, with significant differences by age. Almost one third reported difficulty with everyday tasks. Arthritis and hypertension were prevalent, with more than 20 per cent reporting serious difficulties when walking or climbing stairs (Rosenwohl-Mack et al., 2020).

Ageing intersex people entering retirement facilities may harbour fears about carers, and residents may be less accepting and tolerant of those they perceive as deviant (McPhail & Fulop, 2016). Fear of reprisal, discrimination and violence is to be expected when much elder care is provided by organisations with religious affiliations (Latham & Barrett, 2015). Some older intersex people may be distressed at returning to a world which they may have long fought to escape from (Crameri et al., 2015). As there is a paucity of research on ageing intersex bodies, medical staff may fail to predict the needs of older intersex people (Barrett & Crameri, 2015). Ageing intersex people might also fear the loss of community, respect, and networks they might have relied on for support (McPhail & Fulop, 2016). Bodies of intersex patients might not fit the expectations of carers (Crameri et al., 2015). Policies of care facilities that profess to treat everyone the same risk failing to respect the unique histories and culture of LGBTI people (Barrett & Crameri, 2015). Older intersex patients with onset dementia might fear jeopardising their safety by accidentally revealing guarded aspects of themselves following previous negative experiences in medical settings (McPhail & Fulop, 2016). While home care may provide an alternative for those apprehensive about entering a care facility, older intersex people may fear suffering abuse from carers at home (Waling et al., 2019). Frameworks that include community engagement, education, and training have been developed to address mistrust by older LGBT linked to previous experiences of discrimination in healthcare settings (Daley et al., 2020; Hafford-Letchfield et al., 2018). There is a dearth of research on how older intersex people have navigated medical environments that have been instrumental in their erasure. It is imperative that the needs of ageing intersex people are understood and addressed both for their benefit and to avoid contributing to overburdened future healthcare systems.

Older intersex people and disability

Little is known about ageing intersex people with disabilities. Under the American Disabilities Act (EEOC, 2008), disability is a physical or mental impairment that substantially limits one or more major life functions, including, but not restricted to, reproductive functions. Intersex people rendered infertile or left with sexual difficulties following medical interventions designed to remedy what the American Association of Paediatrics have referred to as "social emergencies" (Committee, 2000, p.138) may then qualify as disabled in this researcher's opinion. Stigma and secrecy associated with intersex may negatively impact psychosocial well-being for intersex individuals, perhaps exacerbating pre-existing mental health problems in some instances.

The literature, though sparse, indicates that older intersex people may suffer from higher levels of disability than the general population. Crameri et al. (2015) found higher rates of disability among LGBTI people. However, not all intersex people are LGBT+. The paucity of literature on older intersex people and disability makes it worth considering adjacent literature, including literature on LGBT and ageing. Skarin Nordenvall et al. (2017) found that Swedish men subjected to hypospadias interventions were more likely to receive disability pensions. Twenty-seven per cent of a sample of 272 Australian intersex survey respondents (T. Jones, 2017) reported having disabilities, and 12 per cent reported receiving disability pensions. Seven were told their variation could be considered a disability, while others considered the outcome of their binary-affirming intervention a disability or a directly contributing factor to their disability (T. Jones, 2017). Half of the disabilities were physical, including legal blindness or colour blindness, being a wheelchair user, motor skill development delays, and movement impairments. Some with osteoporosis and bone degeneration suspected binary-affirming hormonal interventions were to blame for their ailments (T. Jones, 2017). Rosenwohl-Mack et al. (2020) found that more than 15 per cent of intersex adults interviewed had a disability or were unable to work. Participants were more likely to report having a disability if they were older, suffering from poor physical or mental health, or were non-white (Rosenwohl-Mack et al., 2020). There is little literature, if any, on the intersections of secrecy, stigma, medical interventions, and disability for older intersex people. Research is needed to examine connections between intersex and disability and to determine supports for intersex people with disabilities.

Older intersex people and psychosocial well-being

Several factors combine to determine an individual's quality of life and health. A difficult childhood, for example, can influence and sometimes predetermine an individual's future health and well-being (Zeeman et al., 2019). Many aspects of early medical interventions, such as the procedures themselves, dilation, and scrutiny by medical professionals, can be experienced as traumatic for an intersex person (Ehrenreich & Barr, 2005; Haghighat et al., 2023; Morland, 2011; Preves, 2003). Childhood trauma can have long lasting repercussions for an individual (Dye, 2018). The American Psychological Association defines trauma as:

> Any disturbing experience that results in significant fear, helplessness, dissociation, confusion, or other disruptive feelings intense enough to have a long-lasting negative effect on a person’s attitudes, behaviour, and other aspects of functioning. Traumatic events include those caused by human behaviour (e.g., rape, war, industrial accidents) as well as by nature (e.g., earthquakes) and often challenge an individual’s view of the world as a just, safe, and predictable place. (2020)

As early trauma affects individuals later in life, and binary-affirming procedures can be experienced as traumatic (Ehrenreich & Barr, 2005; Haghighat et al., 2023), the health of older intersex people may differ significantly from that of older non-intersex people. In a study of more than 1,000 intersex adolescents older than 16 years from six European countries, anxiety and depression were reported as higher than for the general population (de Vries et al., 2019). Rosenwohl-Mack et al. (2020) found that 53 per cent of intersex participants reported their mental health as fair or poor, with little variation according to age group. Depression and anxiety were common, with more than half reporting serious difficulties with cognitive tasks. Almost one-third of participants had previously attempted suicide compared to 0.5 per cent of the population, which would include intersex people (CDC, 2023; Rosenwohl-Mack et al., 2020). More than 60 per cent of intersex participants reported suffering from life-long depression and anxiety, with anxiety significantly higher amongst younger participants.

Additionally, younger intersex participants reported worse memory, concentration, and decision-making skills. Schützmann et al. (2009) found suicidal tendencies and self-harming behaviour amongst intersex people comparable to endosex women who had suffered both physical and sexual abuse. Adams and Bracka (2016) found that those left unaware of their variations and medical histories experienced higher levels of shame and social embarrassment (Adams & Bracka, 2016).

Some intersex medical interventions have been acknowledged by the UN special rapporteur to be a form of torture (Méndez, 2013). Furthermore, the forced sterilisation of intersex people during childhood medical procedures was highlighted in the UN report on torture (Méndez, 2013). Torture has been shown to have profound effects on emotional brain functioning (Liddell et al., 2021), in addition to consequences such as post-traumatic stress disorder, depression, and anxiety (Campbell, 2007). It might be expected that some intersex people suffer from effects associated with torture that stem from early medical interventions. Intersex invisibility may make finding therapists adequately capable of addressing the specific needs of intersex patients, including needs associated with traumatic early procedures, more challenging (Witten, 2004).

Literature from paediatric endocrinologists and urologists (Cools et al., 2018; Gürbüz et al., 2020; Lee et al., 2020) underscores difficulties in assigning binary sexes to some intersex infants. Rates of transgender identities and gender dysphoria are higher among intersex people than the general population (Cools et al., 2018). More than a quarter of intersex participants in one study were unsure about their original sex assignment or expressed a non-binary identity, while 14 per cent scored as transgender on an identity questionnaire (Schweizer et al., 2014). When an intersex child's sex is assigned incorrectly at birth, this may place them at risk for poor outcomes and abuse in adulthood (Ryan et al., 2009, 2010; Rothman et al., 2012; Robinson, 2018; Carter et al., 2019). For example, that child may develop gender dysphoria, a marked incongruence between one's experienced or expressed gender and the sex one has been assigned (American Psychiatric Association, 2013). Gender dysphoria has been associated with significant levels of distress, anxiety, depressive disorders, disruptive behaviour, poor impulse control, and impairment in school, work, and social settings (American Psychiatric Association, 2013). In extreme circumstances, gender dysphoria can lead to suicidal ideation, suicide attempts, and death by suicide. Considering that early medical interventions are purported to increase acceptance (Timmermans et al., 2019), much is risked for an intersex child mistakenly allocated by medical professionals to a transgender existence (Cools et al., 2018; Ernst et al., 2020), especially considering disproportionately high rates of discrimination and violence faced by transgender people (Stroumsa et al., 2019; Veldhuis et al., 2018; Waite, 2020). There is little literature exploring the experiences of older intersex people assigned an incongruent sex at birth. However, recent literature suggests that even cisgender intersex adults face difficulties navigating healthcare systems with bodies that defy societal binary expectations (Haghighat et al., 2023).

> Intersex childhood medical interventions and subsequent treatments can lead to stress, stigma, confusion, anger, resentment, and a sense of violation for the intersex person (Baqutayan, 2014; Ehrenreich & Barr, 2005; Haghighat et al., 2023; Hart, B., & Shakespeare-Finch, 2022; T. Jones, 2017). Stigma may discourage intersex individuals from speaking out about their experiences. Not fitting in or holding internalised beliefs that one is different from others may lead to mental health problems (Kothgassner et al., 2020), exacerbating any alienation and feelings of exclusion (Ren et al., 2020). Early experiences of stigma and discrimination may influence the ability to form satisfying future relationships (Zeeman et al., 2019) and predict lower self-efficacy and substance use disorders (Luoma et al., 2014). Respondents in a survey of 272 Australian intersex individuals aged 16 years and over reported school experiences of being bullied and discriminated against leading to thoughts of self-harm and suicide, with many dropping out of school early (T. Jones, 2016).

> Some reported that the lack of intersex-inclusive sex education contributed to feelings of alienation:I always knew I had a penis and a vagina, but I didn't find out that it was abnormal until I saw a diagram of the penis at school when I was eight… I did not consider it a bad thing, I was mostly just amazed that not everyone was like that… I knew I'd have to hide it from the other kids to avoid being bullied (Shannon, young intersex person with ovotestis, in T. Jones, 2016, p.11).

Intersex adults subjected to binary-affirming interventions in childhood have reported poor body image, depression, sexual dysfunction, dissociation, social anxiety, substance abuse, suicidal ideation, shame, self-loathing, post-traumatic stress disorder, issues with trust and intimacy (de Maria Arana, 2005), ADHD, anxiety, autism, bipolar disorder, borderline personality disorder, depression, gender dysphoria, PTSD, reactive detachment disorder, and learning disorders (T. Jones, 2016).

Some intersex people subjected to binary-affirming procedures report having "emotional scars akin to those of a sexual abuse survivor" (de Maria Arana, 2005, p.29) but say finding other intersex people provided comfort. Shame and stigma exacerbated negative health conditions for some intersex adolescents and adults from Europe and the United States and increased reluctance to discuss their variation with others (de Vries et al., 2019; Haghighat et al., 2023). De Vries et al. (2019) found that providing informed consent for medical interventions, memories of receiving high-quality care and obtaining comprehensive information about their variations indicated better mental health. Recent literature suggests an urgent need for intersex mental health support (Haghighat et al., 2023; Magritte et al., 2023). Discrepancies in reported mental health between older and younger intersex individuals (Rosenwohl-Mack et al., 2020) may be attributed to resilience and coping strategies (Domajnko & Pahor, 2015). Although there is little literature if any on positive experiences of being intersex, there may be older people who reflect positively on an intersex life and the perspectives it brings, but research would be needed to verify this. Older intersex people and financial stabilitySeveral factors potentially contribute to diminished solvency for intersex people in later life. Access to quality care and housing often depends on financial stability (Pillay-van Wyk & Bradshaw, 2017). Coming out as intersex may jeopardise employment, relationships, and financial stability for some older intersex people. Rosenwohl-Mack et al. (2020) reported that 77.6 per cent of a sample of 179 adults aged 18 to 78 reported worrying about meeting expenses with current income (Rosenwohl-Mack et al., 2020). Many factors can negatively impact financial security for intersex people in old age, but more research is needed to support this.

While not all intersex people are transgender, it is worth considering how transgender people are discriminated against in the workplace (Kattari et al., 2016) due to the paucity of literature exploring intersex employment discrimination. Transgender people face high rates of underemployment and inordinate levels of workplace harassment (Irving, 2017). These issues may affect intersex adults perceived as transgender or gender non-conforming. Family rejection and school bullying can undermine academic achievement, social supports, and networking opportunities (Blosnich et al., 2017; Mizock & Mauser, 2014; Robinson, 2018). Employment discrimination can lead some transgender people to engage in survival sex work where they may be targeted by law enforcement (Easterbrook-Smith, 2019), which may also affect intersex people impacted by employment discrimination. Criminal records for sex work can exacerbate housing and employment issues, increasing dependency on sex work (Smith & Broege, 2020). Research into intersex financial stability in later life is needed.

Older intersex people and the law

Intersex people can be denied explicit legal protections commonly afforded others (Gomes, 2019; Hanssen, 2017). Older intersex people may have encountered marriage, adoption, and surrogacy issues, as legal protections have only become law in recent years in few countries (Travis 2015). For those whose gender identities are incongruent with the sex they were assigned at birth (Cools et al., 2018; Ernst et al., 2020), legal protections against discrimination in employment or healthcare may vary depending on geographic location (Reisner et al., 2015). LGBT and gender non-conforming people face discrimination related to inheritances, housing, and pensions (Cahill & South, 2002), so some older intersex people may have also encountered discrimination in these areas. Spousal recognition may be denied to some, while hostile family may be able to take advantage of some older intersex people in the absence of protections (McPhail & Fulop, 2016; Witten, 2004). Couples where either or both are intersex may face visitation, decision making, and inheritance issues in later life (Barrett & Crameri, 2015; Latham & Holmes, 2017). Research is needed to examine legal invisibility for older intersex people.

Older intersex people and social support

Intersex people face several potential disadvantages concerning social support in later life. Older LGBTI people in one study report limited contact with biological family, relying instead on friends and intimate partners as they age (Barrett & Crameri, 2015). Early medical interventions result in infertility for many intersex people (Council of Europe Commissioner for Human Rights, 2015; Méndez, 2013; Rowlands & Amy, 2018), decreasing the likelihood of being surrounded by children and, therefore, grandchildren in old age. Hughes (2016, 2018) found an increased risk of loneliness amongst older LGBTI people because of family estrangement and diminished social networks. Recent literature suggests intersex adults experience heightened isolation and loneliness for a plethora of reasons, including having bodies that do not fit binary-gendered societal expectations as well as othering treatment in medical settings (Hart & Shakespeare-Finch, 2022). As mentioned, intersex invisibility and stigma may especially impact older transgender intersex people (Bame, 2017; Blair & Hoskin, 2019; Fernandez & Birnholtz, 2019; Monro et al., 2021; Witten, 2004). One study (Vincent et al., 2016) exploring AIDS-related stigma and aggression toward gay men and lesbians may hold some relevance for intersex people who, because of fear of stigma by association, find themselves shunned by colleagues and neighbours. Research on adult intersex women in the United Kingdom supports this (Alderson et al., 2004). Older intersex people may have experienced rejection and isolation from former places of worship, and ageism may contribute to discrimination in otherwise more welcoming LGBTI spaces.

Divisions in intersex terminology may have deprived some older intersex people of community. While intersex activists have embraced the term intersex since the 1990s, others identify with the name of their particular variation. Efforts by the medical establishment in 2005 to install 'DSD', or 'Disorders of Sex Development', as universal may contribute to divisions amongst intersex people (Reis, 2007; Cools et al., 2016). Contact with other intersex people through internet-based and in-person support groups has been reported to promote feelings of 'normalcy' and empowerment and to alleviate social isolation (Alderson et al., 2004; Carpenter, 2016; Davis & Preves, 2019; DSD families, 2019; Haghighat et al., 2023; MacKenzie et al., 2009).

Intersex and identity

Social constructionists argue historical era and social context play pivotal roles in shaping identity (Clarke & Turner, 2007). Symbolic interactionism suggests that how we are excluded, included, and allowed to interact with society shapes the self (Adler-Nissen, 2016). Negative portrayals influence how a majority views marginalised minorities and how minority individuals see themselves (Cort, 1987). Before social media, unless an intersex child knowingly had access to other intersex people, they were likely left to navigate their world without a map. Media has been shown to shape how people see themselves, their relationships, and the world in which they exist, for better and for worse (Kivel & Johnson, 2009; Leavitt et al., 2015). Until recently, however, media representation for intersex people has been almost non-existent. On 22 April 2014, MTV launched the television show 'Faking It,' (Covington et al., 2014-2016), starring endosex (non-intersex) actress Bailey De Young as Lauren, a young intersex woman. On 5 April 2016, Bailey was joined by 21-year-old intersex InterACT youth member Amanda Saenz, playing the character Raven, making her the first intersex person to play an intersex character on television. In December of the same year, Amanda Saenz and Bailey De Young appeared in a YouTube video entitled '9 things you need to know about being intersex' (MTV, 2014). The following year, Buzzfeed released 'What's it like to be intersex,' a viral video featuring young intersex activists Sean Saifa Wall, Pidgeon Pagonis, Alice Alvarez, and Emily Saenz (Buzzfeed, 2015). Amongst the people to see the video was a young Russian woman, Irene Kuzemko, leading her to realise she too was intersex, which in turn resulted in her founding Russia's first support group for intersex people (Strudwick, 2019). The documentary Every Body (Cohen, 2023) told the stories of intersex artists and activists River Gallo, Alicia Roth Weigel and Sean Saifa Wall. For many older intersex people, however, this explosion of information and connection may have come too late. There is little literature on how intersex identities are formed in a world where most evidence of intersex existence has been hidden or erased (Bauer, 2019; Latham & Holmes, 2017). Just as intersex people are deprived of cultural representation, so are endosex people, including medical professionals, politicians, and policymakers, who know little about intersex people and what they need. The cycle of erasure, beginning with the surgical and irreversible assignment of binary sex to an intersex infant with ambiguous genitalia, has created and maintained the lack of specialist intersex care and research to inform it.

Directions for future research

This critical review demonstrates there is an urgent need for research into the needs and experiences of older intersex people. That there is vast medical literature on early intersex surgeries but little on healthcare throughout the remainder of the life course (Crocetti et al., 2023; Haghighat et al., 2023) might give the impression that intersex adults suffer few health issues. However, recent research (Rosenwohl-Mack et al., 2020) suggests this is far from true. There is an urgent need to determine and support the health needs of older intersex people and prevent or minimise harm to younger intersex people.

Literature shows there are high rates of disability amongst intersex adults. Research is needed to examine connections between intersex and disability to establish supports and determine causes. There is a necessity for research into intersex mental health to determine support and improved intersex outcomes (Haghighat et al., 2023). There is a need for research into intersex LGBT experiences, especially considering the rise and rapid spread of anti-LGBT rhetoric in media and amongst some politicians (SPLC, 2023). Literature demonstrates that connection with other intersex people promotes feelings of normalcy and empowerment for intersex people suggesting a requirement for research to support connection and determine barriers to intersex connection. Literature is scarce on intersex later life financial stability, requiring research to determine what supports may be needed, if any. There is a necessity for research into intersex navigation of legal erasure. Investigation is required on how older intersex identities are formed and maintained in the absence of cultural representation and the face of intersex erasure.

Conclusions

Sparse literature on outcomes for intersex people in adulthood paints a disturbing picture. Medical professionals refer to advances in medical treatment in response to criticism from intersex human rights activists (Cools et al., 2016); however, protests from activists are not solely related to the quality of surgical technique but rather whether those procedures should have been performed in the first place (Council of Europe Commissioner for Human Rights, 2015). Intersex adults report poor physical and mental health (Rosenwohl-Mack et al., 2020), although some older intersex people report better mental health than younger participants. This difference may be due to resilience or perhaps because intersex people with better mental health live longer (Lawrence et al., 2015). More research is needed in this area.

Intersex people assigned incongruent sex at birth may face lives filled with discrimination as well as long waiting lists for gender-affirming medical care. Not all intersex people identify as LGBT, however many do. Intersex inclusion amongst LGBT communities has been protested by medical professionals (Cools et al., 2016). However, cisgender, heterosexual intersex people also share LGBT battles for bodily autonomy, cultural representation, as well as access to adequate and appropriate healthcare. While not all intersex people are transgender, increasingly, medical professionals admit the impossibility of guaranteeing accurate sex assignment to intersex infants (Cools et al., 2018; Gürbüz et al., 2020; Lee et al., 2020).

There is a paucity of literature regarding the needs of older intersex people with disabilities. Köhler et al. (2012) reported high levels of sexual dissatisfaction and dysfunction amongst intersex adults subjected to binary-affirming medical interventions in childhood. Adults with Androgen Insensitivity Syndrome (AIS) have reported poor treatment by medical professionals as damaging (Alderson et al., 2004). Adults with Congenital Adrenal Hyperplasia (CAH) have reported relationship difficulties and sexual difficulties (Ogilvie et al., 2006; Woodhouse, 2004). Nermoen et al. (2010) found reduced fertility amongst Norwegian adults with CAH as well as impaired subjective health, with significantly higher numbers receiving disability benefits than amongst the general population. Intersex voices calling for change receive pushback from medical professionals (Cools et al., 2016). Ageing intersex people may have been denied adequate healthcare through medical histories and diagnoses being hidden from them. Medical knowledge of intersex has been relegated almost entirely to the management of sexual variations in early childhood, contributing to a dearth of adequate and appropriate healthcare for intersex people (Haghighat et al., 2023). To address concerns of older intersex people faced with admittance to care facilities or requiring care at home (Barrett & Crameri, 2015; Crameri et al., 2015; Latham & Barrett, 2015; McPhail & Fulop, 2016), adequate training should be provided for care professionals. Training should include awareness as to how intersex lives and bodies might diverge from those of non-intersex or endosex people, and research is needed to inform this training.

For the most part, intersex people have not been afforded legal protections taken for granted by others. Intersex people may be less financially secure in old age due to several factors, including having incongruent sex assigned at birth, family rejection, diminished legal protections and networking abilities. Stigma, invisibility, medical sterilisation, poor health, and disability may combine to impair social support for many intersex people in old age. Medical secrecy around intersex, while purportedly well-intentioned, has effectively served to erase intersex people, leaving them to grow up without intersex role models or intersex cultural representation. Non-consensual intersex medical interventions continue unabated worldwide, but little is known about what happens to intersex people afterwards. In addition to the financial cost of these medical interventions, there are indications that these procedures add unnecessarily to the cost of mental healthcare and disability payments, as well as to the suffering of intersex people themselves.

References

Adams, J., & Bracka, A. (2016). Reconstructive surgery for hypospadias: A systematic review of long-term patient satisfaction with cosmetic outcomes. *Indian Journal of Urology*, *32*(2), 93–102.

Adler-Nissen, R. (2016). The social self in international relations: Identity, power, and the symbolic interactionist roots of constructivism. *European Review of International Studies, 3*(3), 27-39.

Age UK. (2019). Estimating need in older people: Findings for England. *Age UK*. https://www.ageuk.org.uk/globalassets/age-uk/documents/reports-and-publications/reports-and-briefings/active-communities/id204303-estimating-needs-report.pdf

Council of Europe Commissioner for Human Rights. (2015). *Human rights and intersex people.* Council of Europe Commissioner for Human Rights. https://book.coe.int/en/commissioner-for-human-rights/6683-pdf-human-rights-and-intersex-people.html

Alderson, J., Madill, A., & Balen, A. (2004). Fear of devaluation: Understanding the experience of intersexed women with androgen insensitivity syndrome. *British Journal of Health Psychology*, *9*(1), 81-100.

American Psychiatric Association. (2013). *Diagnostic and Statistical Manual of Mental Disorders: DSM-5* (Fifth ed.). Arlington, VA: American Psychiatric Association.

American Psychological Association (APA). (2020). *Trauma.* APA. https://dictionary.apa.org/trauma

Badawy, H., Soliman, A., Moussa, A., Youssef, M., Fahmy, A., Dawood, W., ... & Orabi, S. (2019). Staged repair of redo and crippled hypospadias: analysis of outcomes and complications. *Journal of Paediatric Urology*, *15*(2), 151-e1.

Bame, Y. (2017, May 17). *21% of Americans believe that being transgender is a mental illness.* YouGov. https://today.yougov.com/topics/relationships/articles-reports/2017/05/17/21-americans-believe-identifying-transgender-menta

Baqutayan, S. M. S. (2014). The psychological distress and coping mechanisms among intersexed individuals. *Annual Research & Review in Biology*, 2910-2919.

Barbagli, G., De Angelis, M., Palminteri, E., & Lazzeri, M. (2006). Failed hypospadias repair presenting in adults. *European Urology, 49*(5), 887-895.

Barbagli, G., Perovic, S., Djinovic, R., Sansalone, S., & Lazzeri, M. (2010). Retrospective descriptive analysis of 1,176 patients with failed hypospadias repair. *The Journal of Urology, 183*(1), 207-211.

Barbagli, G., Sansalone, S., Djinovic, R., & Lazzeri, M. (2012). Surgical repair of late complications in patients having undergone primary hypospadias repair during childhood: a new perspective. *Advances in Urology*, *2012*, 705212-5

Barrett, C., & Crameri, P. (2015). *An extra degree of difficulty. An evidence-based guide to the experiences and needs of older LGBTI carers and the carers of older LGBTI people.* Australian Research Centre in Sex, Health and Society, La Trobe University.

Bauer, J. E. (2019). On Behalf of Hermaphrodites and Mongrels: Refocusing the Reception of Magnus Hirschfeld's Critical Thought on Sexuality and Race. *Journal of Homosexuality*, 1-25.

Blair, K. L., & Hoskin, R. A. (2019). Transgender exclusion from the world of dating: Patterns of acceptance and rejection of hypothetical trans dating partners as a function of sexual and gender identity. *Journal of Social and Personal Relationships, 36*(7), 2074-2095. doi:10.1177/0265407518779139

Blosnich, J. R., Marsiglio, M. C., Dichter, M. E., Gao, S., Gordon, A. J., Shipherd, J. C., ... & Fine, M. J. (2017). Impact of social determinants of health on medical conditions among transgender veterans. *American Journal of Preventive Medicine, 52*(4), 491-498.

Bracka, A. (1989). A long-term view of hypospadias. *British Journal of Plastic Surgery*, *42*(3), 251-255.

Bubanj, T. B., Perovic, S. V., Milicevic, R. M., Jovcic, S. B., Marjanovic, Z. O., & Djordjevic, M. M. (2004). Sexual behaviour and sexual function of adults after hypospadias surgery: a comparative study. *The Journal of Urology*, *171*(5), 1876-1879.

Buzzfeed. (2015, March 28). *What it's like to be intersex* [Video file]. YouTube. https://youtu.be/cAUDKEI4QKI

Cahill, S., & South, K. (2002). Policy issues affecting lesbian, gay, bisexual, and transgender people in retirement. *Generations: Journal of the American Society on Aging, 26*(2), 49-54.

Campbell, T. A. (2007). Psychological assessment, diagnosis, and treatment of torture survivors: a review. *Clinical Psychology Review*, *27*(5), 628-641.

Carpenter, M. (2016). The human rights of intersex people: addressing harmful practices and rhetoric of change. *Reproductive Health Matters, 24*(47), 74-84.

Carter, S. P., Montgomery, A. E., Henderson, E. R., Ketterer, B., Dichter, M., Gordon, A. J., … & Blosnich, J. R. (2019). Housing Instability Characteristics Among Transgender Veterans Cared for in the Veterans Health Administration, 2013–2016. *American Journal of Public Health, 109*(10), 1413-1418.

Centers for Disease Control and Prevention (CDC). (2023). *Suicide Prevention*. https://www.cdc.gov/suicide/pdf/NCIPC-Suicide-FactSheet-508_FINAL.pdf

Clarke, V., & Turner, K. (2007). V. Clothes maketh the queer? Dress, appearance and the construction of lesbian, gay and bisexual identities. *Feminism & Psychology, 17*(2), 267-276. doi:10.1177/0959353507076561

Cohen, J. (Director). (2023). *Every Body* [Film]. Focus Features.

Committee on Genetics: Section on Endocrinology and Section on Urology. (2000). Evaluation of the newborn with developmental anomalies of the external. *Paediatrics,* 106, 138–142.

Cools, M., Simmonds, M., Elford, S., Gorter, J., Ahmed, S. F., D'Alberton, F., … & Hiort, O. (2016). Response to the council of Europe human rights commissioner's issue paper on human rights and intersex people. *European Urology, 70*(3), 407-409.

Cools, M., Nordenström, A., Robeva, R., Hall, J., Westerveld, P., Flück, C., … & Pasterski, V. (2018). Caring for individuals with a difference of sex development (DSD): a consensus statement. *Nature Reviews Endocrinology*, *14*(7), 415-429.

Cort, C. (1987). A Long Way to Go: Minorities and the Media. *Media & Values, 38.* http://www.medialit.org/reading-room/long-way-go-minorities-and-media

Covington, C., Nugiel, N., & Goldman, W. (Executive Producers). (2014–2016). *Faking it* [TV series]. MTV.

Crameri, P., Barrett, C., Latham, J. R., & Whyte, C. (2015). It is more than sex and clothes: Culturally safe services for older lesbian, gay, bisexual, transgender and intersex people. *Australasian Journal on Ageing, 34*, 21-25.

Crocetti, D., Berry, A., & Monro, S. (2023). Navigating the complexities of adult healthcare for individuals with variations of sex characteristics: from paediatric emergencies to a sense of abandonment. *Culture, Health & Sexuality*, 1-14.

Daley, A., Brotman, S., MacDonnell, J. A., & St Pierre, M. (2020). A Framework for Enhancing Access to Equitable Home Care for 2SLGBTQ+ Communities. *International Journal of Environmental Research and Public Health*, *17*(20), 7533.

Davis, G., & Preves, S. (2019). Reflecting on intersex: 25 years of activism, mobilization and change. In C.G. Valentine, M.N. Trautner & J.Z. Spade (Eds.) *The Kaleidoscope of Gender: Prisms, Patterns, and Possibilities* (pp.30-43). Sage Publications.

de Maria Arana, M. (2005). *A human rights investigation into the medical "normalization" of intersex people. A Report of a Public Hearing by the Human Rights Commission of the City & County of San Francisco*.

de Vries, A. L., Roehle, R., Marshall, L., Frisén, L., van de Grift, T. C., Kreukels, B. P., … & Cohen-Kettenis, P. T. (2019). Mental health of a large group of adults with disorders of sex development in six European countries. *Psychosomatic Medicine*, *81*(7), 629.

Domajnko, B., & Pahor, M. (2015). Health within limitations: Qualitative study of the social aspects of resilience in old age. *Ageing International, 40*(2), 187-200.

DSD families. (2019). *'Listen to us': Consultations with children, young people and families living with different sex development.* DSD Families. https://www.dsdfamilies.org/application/files/8015/5447/3715/reportdsdf-2019.pdf

Dye, H. (2018). The impact and long-term effects of childhood trauma. *Journal of Human Behavior in the Social Environment*, *28*(3), 381-392.

Easterbrook-Smith, G. L. (2019). "Not on the Street Where We Live": walking while trans under a model of sex work decriminalisation. *Feminist Media Studies*, 1-16.

EEOC, Equal Employment Opportunity Commission. (2008). *ADA Amendments Act of 2008, PL 110-325 (S 3406).* https://www.eeoc.gov/statutes/ada-amendments-act-2008

Ehrenreich, N., & Barr, M. (2005). Intersex surgery, female genital cutting, and the selective condemnation of cultural practices. *Harvard Civil Rights – Civil Liberties Law Review, 40*, 71.

Ernst, M. M., Kogan, B. A., & Lee, P. A. (2020). Gender identity: A psychosocial primer for providing care to patients with a disorder/difference of sex development and their families [individualized care for patients with intersex (Disorders/differences of sex development): Part 2]. *Journal of Paediatric Urology*, *16*(5), 606-611.

Fam, M. M., & Hanna, M. K. (2017). Resurfacing the penis of complex hypospadias repair ("Hypospadias Cripples"). *The Journal of Urology*, *197*(3 Part 2), 859-864.

Fernandez, J., & Birnholtz, J. (2019). "I don't want them to not know": Investigating decisions to disclose transgender identity on dating platforms. *Proceedings of the ACM on Human-Computer Interaction, 3*(CSCW), 1-21. doi:10.1145/3359328

Freud, Sigmund (1962). *Three Essays on the Theory of Sexuality*, trans. James Strachey. New York: Basic Books.

George, M. A. (2006). The modern mulatto: A comparative analysis of the social and legal positions of mulattoes in the antebellum south and the intersex in contemporary America. *Colum. J. Gender & L.*, *15*, 665.

Gomes, I. E. (2019). *Queering European Union Law: sex and gender beyond the binary and cisnormativity*. Europa Kolleg Hamburg, Institute for European Integration. https://epub.sub.uni-hamburg.de/epub/volltexte/2019/93055/pdf/4_19Study_Paper_Ines.pdf

Griffiths, D. A. (2018). Diagnosing sex: Intersex surgery and 'sex change' in Britain 1930–1955. *Sexualities, 21*(3), 476-495.

Gürbüz, F., Alkan, M., Çelik, G., Bişgin, A., Çekin, N., Ünal, İ., ... & Yüksel, B. (2020). Gender identity and assignment recommendations in disorders of sex development patients: 20 years' experience and challenges. *Journal of Clinical Research in Paediatric Endocrinology*, *12*(4), 347.

Hafford-Letchfield, T., Simpson, P., Willis, P. B., & Almack, K. (2018). Developing inclusive residential care for older lesbian, gay, bisexual and trans (LGBT) people: An evaluation of the Care Home Challenge action research project. *Health & Social Care in the Community*, *26*(2), e312-e320.

Haghighat, D., Berro, T., Sosa, L. T., Horowitz, K., Brown-King, B., & Zayhowski, K. (2023). Intersex People's perspectives on affirming healthcare practices: A qualitative study. *Social Science & Medicine*, 116047.

Hanssen, S. (2017). Beyond male or female: Using nonbinary gender identity to confront outdated notions of sex and gender in the law. *Or. L. Rev.*, *96*, 283.

Hart, B., & Shakespeare-Finch, J. (2022). Intersex lived experience: trauma and posttraumatic growth in narratives. *Psychology & Sexuality*, *13*(4), 912-930.

Hegarty, P. (2000). Intersex activism, feminism and psychology: opening a dialogue on theory, research and clinical practice. *Feminism & Psychology*, *10*(1), 117-132.

Hegarty, P., Prandelli, M., Lundberg, T., Liao, L. M., Creighton, S., & Roen, K. (2021). Drawing the line between essential and nonessential interventions on intersex characteristics with European health care professionals. *Review of General Psychology*, *25*(1), 101-114.

Henningham, M., & Jones, T. (2021). Intersex students, sex-based relational learning & isolation. *Sex Education*, 1-14.

Holmes, M. (2002). Rethinking the meaning and management of intersexuality. *Sexualities*, *5*(2), 159-180.

Horton, C. E., & Devine Jr., C. J. (1970). A one-stage repair for hypospadias cripples. *Plastic and Reconstructive Surgery*, *45*(5), 425-430.

Hughes, M. (2016). Loneliness and social support among lesbian, gay, bisexual, transgender and intersex people aged 50 and over. *Ageing and Society, 36*(9), 1961.

Hughes, M. (2018). Health and well-being of lesbian, gay, bisexual, transgender and intersex people aged 50 years and over. *Australian Health Review, 42*(2), 146-151.

Irving, D. (2017). Gender transition and job in/security: Trans* un/der/employment experiences and labour anxieties in post-Fordist society. *Atlantis: Critical Studies in Gender, Culture & Social Justice*, *38*(1), 168-178.

Jones, T. (2016). The needs of students with intersex variations. *Sex Education*, *16*(6), 602-618.

Jones, M. (2017). Intersex genital mutilation - A western version of IGM. *The International Journal of Children's Rights, 25;2017;*(2), 396-411. doi:10.1163/15718182-02502008

Kattari, S. K., Whitfield, D. L., Walls, N. E., Langenderfer-Magruder, L., & Ramos, D. (2016). Policing gender through housing and employment discrimination: comparison of discrimination experiences of transgender and cisgender LGBQ individuals. *Journal of the Society for Social Work and Research, 7*(3), 427-447.

Kipnis, K., & Diamond, M. (1998). Paediatric ethics and the surgical assignment of sex. *Journal of Clinical Ethics*, *9*, 398-410.

Kivel, B. D., & Johnson, C. W. (2009). Consuming media, making men: Using collective memory work to understand leisure and the construction of masculinity. *Journal of Leisure Research, 41*(1), 110-134.

Köhler, B., Kleinemeier, E., Lux, A., Hiort, O., Grüters, A., Thyen, U., & DSD Network Working Group. (2012). Satisfaction with genital surgery and sexual life of adults with XY disorders of sex development: results from the German clinical evaluation study. *The Journal of Clinical Endocrinology & Metabolism*, *97*(2), 577-588.

Kothgassner, O. D., Goreis, A., Glenk, L. M., Kafka, J. X., Beutl, L., Kryspin-Exner, I., ... & Felnhofer, A. (2020). Virtual and real-life ostracism and its impact on a subsequent acute stressor. *Physiology & Behaviour*, *228*, 113205.

Latham, J. R., & Barrett, C. (2015). Appropriate bodies and other damn lies: Intersex ageing and aged care. *Australasian Journal on Ageing, 34*, 19-20.

Latham, J. R., & Holmes, M. M. (2017). Intersex ageing and (sexual) rights. In C. Barrett & S. Hinchliff (Eds.). *Addressing the Sexual Rights of Older People. Theory, Policy and Practice* (pp. 104-116). Routledge.

Lawrence, E. M., Rogers, R. G., & Wadsworth, T. (2015). Happiness and longevity in the United States. *Social Science & Medicine*, *145*, 115-119.

Leavitt, P. A., Covarrubias, R., Perez, Y. A., & Fryberg, S. A. (2015). “Frozen in time”: The impact of Native American media representations on identity and self-understanding. *Journal of Social Issues, 71*(1), 39-53.

Lee, P. A., Fuqua, J. S., Houk, C. P., Kogan, B. A., Mazur, T., & Caldamone, A. (2020). Individualized care for patients with intersex (disorders/differences of sex development): part I. *Journal of Paediatric Urology*, *16*(2), 230-237.

Liddell, B., Malhi, G. S., Felmingham, K. L., Cheung, J., Outhred, T., Das, P., ... & Bryant, R. A. (2021). The impact of torture on interpersonal threat and reward neurocircuitry. *Australian & New Zealand Journal of Psychiatry*, *55*(2), 153-166.

Luoma, J. B., Kulesza, M., Hayes, S. C., Kohlenberg, B., & Larimer, M. (2014). Stigma predicts residential treatment length for substance use disorder. *The American Journal of Drug and Alcohol Abuse*, *40*(3), 206-212.

MacKenzie, D., Huntington, A., & Gilmour, J. A. (2009). The experiences of people with an intersex condition: A journey from silence to voice. *Journal of Clinical Nursing, 18*(12), 1775-1783.

Magritte, E., Williams, J., Amyot, E., Usipuik, M., & Sanders, C. (2023). Listening to individuals with differences in sex development or intersex and their families: “Not doing surgery does not mean doing nothing”. *Hormone Research in Paediatrics*, *96*(2), 228-237.

Magubane, Z. (2014). Spectacles and scholarship: Caster Semenya, intersex studies, and the problem of race in feminist theory. *Signs: Journal of Women in Culture and Society*, *39*(3), 761-785.

McPhail, R., & Fulop, L. (2016). Champions’ perspectives on implementing the National Lesbian, Gay, Bisexual, Transgender and Intersex Ageing and Aged Care Strategy in Queensland. *Australian Health Review, 40*(6), 633-640.

Méndez, J. E. (2013). *Report of the Special Rapporteur on torture and other cruel, inhuman, or degrading treatment or punishment.* United Nations, Human Rights Council. https://www.ohchr.org/sites/default/files/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53_English.pdf

Minto, C. L., Liao, L. M., Woodhouse, C. R., Ransley, P. G., & Creighton, S. M. (2003). The effect of clitoral surgery on sexual outcome in individuals who have intersex conditions with ambiguous genitalia: a cross-sectional study. *The Lancet*, *361*(9365), 1252-1257.

Mizock, L., & Mauser, K. T. (2014). Employment, mental health, internalized stigma, and coping with transphobia among transgender individuals. *Psychology of Sexual Orientation and Gender Diversity, 1*(2), 146.

Money, J., Hampson, J. G., & Hampson, J. L. (1957). Imprinting and the establishment of gender role. *AMA archives of neurology & psychiatry*, *77*(3), 333-336.

Money, J. (1968). *Sex errors of the body: Dilemmas, education, counseling.* Johns Hopkins Press.

Monro, S., Carpenter, M., Crocetti, D., Davis, G., Garland, F., Griffiths, D., ... & Aggleton, P. (2021). Intersex: cultural and social perspectives. *Culture, Health & Sexuality, 23*(4), 431-440.

Morland, I. (2011). Intersex treatment and the promise of trauma. In J.A. Fisher (Ed.) *Gender and the science of difference: Cultural politics of contemporary science and medicine* (pp. 147-63). Rutgers University Press.

MTV (2014, December 9). *Faking It, 9 Things You Need to Know About Being Intersex* [Video file]. YouTube. https://youtu.be/CTYIjXSdZxA

Neheman, A., Rappaport, Y. H., Verhovsky, G., Bush, N., Snodgrass, W., Lang, E., ... & Efrati, S. (2020). Hyperbaric oxygen therapy for paediatric "hypospadias cripple" evaluating the advantages regarding graft take. *Journal of Paediatric Urology*, *16*(2), 163.e1-163.e7. https://doi.org/10.1016/j.jpurol.2020.01.002

Nermoen, I., Husebye, E. S., Svartberg, J., & Løvås, K. (2010). Subjective health status in men and women with congenital adrenal hyperplasia: a population-based survey in Norway. *European Journal of Endocrinology*, *163*(3), 453.

Ogilvie, C. M., Crouch, N. S., Rumsby, G., Creighton, S. M., Liao, L. M., & Con Way, G. S. (2006). Congenital adrenal hyperplasia in adults: a review of medical, surgical and psychological issues. *Clinical Endocrinology*, *64*(1), 2-11.

Pillay-van Wyk, V., & Bradshaw, D. (2017). Mortality and socioeconomic status: the vicious cycle between poverty and ill health. *The Lancet Global Health, 5*(9), e851-e852.

Preves, S. E. (2003). *Intersex and identity: The contested self*. Rutgers University Press.

Randall, J., McCaskill, M., & Hinson, H. (2020). Interactions of Mood Disorders and Episodic Event Frequency in Transgender Patients. *Neurology, 94*(15 Supplement) 2052.

Rapp, M., Duranteau, L., van de Grift, T. C., Schober, J., Hirschberg, A. L., Krege, S., ... & Szarras-Czapnik, M. (2020). Self-and proxy-reported outcomes after surgery in people with disorders/ differences of sex development (DSD) in Europe (dsd-LIFE). *Journal of Paediatric Urology*, *17*(3), 353-365. https://doi.org/10.1016/j.jpurol.2020.12.007

Reardon, S. (2016). The spectrum of sex development: Eric Vilain and the intersex controversy. *Nature News*, *533*(7602), 160-163. 160

Reis, E. (2007). Divergence or disorder?: The politics of naming intersex. *Perspectives in Biology and Medicine*, *50*(4), 535-543.

Reis, E. (2009). *Bodies in doubt: An American history of intersex*. JHU Press.

Reis, E., & Kessler, S. (2010). Why history matters: Fetal dex and intersex. *The American Journal of Bioethics*, *10*(9), 58-59.

Reis, E., & McCarthy, M. W. (2016). What Hospitalists Should Know About Intersex Adults. *Perspectives in Biology and Medicine*, *59*(3), 391-398.

Reisner, S. L., Hughto, J. M. W., Dunham, E. E., Heflin, K. J., Begenyi, J. B. G., Coffey-Esquivel, J., & Cahill, S. (2015). Legal protections in public accommodations settings: A critical public health issue for transgender and gender-nonconforming people. *The Milbank Quarterly*, *93*(3), 484-515.

Ren, D., Wesselmann, E. D., & van Beest, I. (2020). Seeking Solitude After Being Ostracized: A Replication and Beyond. *Personality and Social Psychology Bulletin*, *47*(3), 426-440. https://doi.org/10.1177/0146167220928238

Robinson, B. A. (2018). Conditional families and lesbian, gay, bisexual, transgender, and queer youth homelessness: Gender, sexuality, family instability, and rejection. *Journal of Marriage and Family, 80*(2), 383-396.

Rosenwohl-Mack A, Tamar-Mattis S, Baratz AB, Dalke KB, Ittelson A, Zieselman K, et al., (2020) A national study on the physical and mental health of intersex adults in the U.S.. *PLoS ONE 15*(10): e0240088.

Rothman, E. F., Sullivan, M., Keyes, S., & Boehmer, U. (2012). Parents' supportive reactions to sexual orientation disclosure associated with better health: Results from a population-based survey of LGB adults in Massachusetts. *Journal of Homosexuality, 59*(2), 186-200.

Rowlands, S., & Amy, J. J. (2018). Preserving the reproductive potential of transgender and intersex people. *The European Journal of Contraception & Reproductive Health Care, 23*(1), 58-63.

Ryan, C., Huebner, D., Diaz, R. M., & Sanchez, J. (2009). Family rejection as a predictor of negative health outcomes in white and Latino lesbian, gay, and bisexual young adults. *Paediatrics, 123*(1), 346-352.

Ryan, C., Russell, S. T., Huebner, D., Diaz, R., & Sanchez, J. (2010). Family acceptance in adolescence and the health of LGBT young adults. *Journal of Child and Adolescent Psychiatric Nursing, 23*(4), 205-213.

Rynja, S. P., De Jong, T. P. V. M., Bosch, J. L. H. R., & De Kort, L. M. O. (2011). Functional, cosmetic, and psychosexual results in adult men who underwent hypospadias correction in childhood. *Journal of Paediatric Urology, 7*(5), 504-515.

Schützmann, K., Brinkmann, L., Schacht, M., & Richter-Appelt, H. (2009). Psychological distress, self-harming behaviour, and suicidal tendencies in adults with disorders of sex development. *Archives of Sexual Behaviour*, *38*(1), 16-33.

Schweizer, K., Brunner, F., Handford, C., & Richter-Appelt, H. (2014). Gender experience and satisfaction with gender allocation in adults with diverse intersex conditions (divergences of sex development, DSD). *Psychology & Sexuality*, *5*(1), 56-82.

Skarin Nordenvall, A., Norrby, C., Butwicka, A., Frisén, L., Nordenström, A., Almqvist, C., & Nordenskjöld, A. (2017). Psychosocial outcomes in adult men born with hypospadias: A register-based study. *Plos ONE*, *12*(4), e0174923.

Smith, S. S., & Broege, N. C. (2020). Searching for Work with a Criminal Record. *Social Problems, 67*(2), 208-232.

Snodgrass, W., & Bush, N. C. (2017). Re-operative urethroplasty after failed hypospadias repair: how prior surgery impacts risk for additional complications. *Journal of Paediatric Urology, 13*(3), 289-e1.

Snodgrass, W., & Bush, N. C. (2019). Persistent or recurrent ventral curvature after failed proximal hypospadias repair. *Journal of Paediatric Urology*, *15*(4), 344-e1.

Southern Poverty Law Center (SPLC). (2023). *Anti-LGBTQ.* https://www.splcenter.org/fighting-hate/extremist-files/ideology/anti-lgbtq

Stecker Jr, J. F., Horton, C. E., Devine Jr, C. J., & McCraw, J. B. (1981). Hypospadias cripples. *The Urologic Clinics of North America*, *8*(3), 539-544.

Stroumsa, D., Shires, D. A., Richardson, C. R., Jaffee, K. D., & Woodford, M. R. (2019). Transphobia rather than education predicts provider knowledge of transgender health care. *Medical Education*, *53*(4), 398-407.

Strudwick., P. (2019, Jan 1). *This Woman Only Discovered She Was Intersex After Watching a Viral Video About It.* Buzzfeed*.* https://www.buzzfeed.com/patrickstrudwick/this-woman-only-discovered-she-was-intersex-after-watching

Timmermans, S., Yang, A., Gardner, M., Keegan, C. E., Yashar, B. M., Fechner, P. Y., ... & Sandberg, D. E. (2019). Gender destinies: assigning gender in Disorders of Sex Development-Intersex clinics. *Sociology of Health & Illness*, *41*(8), 1520-1534.

Tobin, S., Glass, J., & Zayed, A. (2020, December 1). Cambridge woman who took puberty blockers wins High Court ruling. *Cambridge News.* https://www.cambridge-news.co.uk/news/local-news/keira-bell-court-puberty-cambridge-19380062

Tosh, J. (2013). The (in) visibility of childhood sexual abuse: Psychiatric theorizing of transgenderism and intersexuality. *Intersectionalities: A Global Journal of Social Work Analysis, Research, Polity, and Practice*, *2*(1), 71-87.

Tourchi, A., & Hoebeke, P. (2013). Long-term outcome of male genital reconstruction in childhood. *Journal of Paediatric Urology*, *9*(6), 980-989.

Travis, M. (2015). Accommodating Intersexuality in European Union Anti-Discrimination Law. *European Law Journal*, *21*(2), 180-199.

Veldhuis, C. B., Drabble, L., Riggle, E. D., Wootton, A. R., & Hughes, T. L. (2018). “I fear for my safety but want to show bravery for others”: Violence and discrimination concerns among transgender and gender-nonconforming individuals after the 2016 presidential election. *Violence and Gender*, *5*(1), 26-36.

Verla, W., Van Nieuwenhuyse, F., Hoebeke, P., Oosterlinck, W., Sinatti, C., Spinoit, A. F., ... & Lumen, N. (2020). Urethroplasty for failed hypospadias repair related strictures in adults: a retrospective analysis with long-term follow-up. *Urology*, *143*, 248-254.

Vincent, W., Peterson, J. L., & Parrott, D. J. (2016). The association between AIDS-related stigma and aggression toward gay men and lesbians. *Aggressive Behaviour, 42*(6), 542-554. doi:10.1002/ab.21649

Waite, S. (2020). Should I stay or should I go? Employment discrimination and workplace harassment against transgender and other minority employees in Canada’s federal public service. *Journal of Homosexuality*, 1-27.

Waling, A., Lyons, A., Alba, B., Minichiello, V., Barrett, C., Hughes, M., ... & Edmonds, S. (2019). Experiences and perceptions of residential and home care services among older lesbian women and gay men in Australia. *Health & Social Care in the Community*, *27*(5), 1251-1259.

Weidler, E. M., Grimsby, G., Garvey, E. M., Zwayne, N., Chawla, R., Hernandez, J., ... & van Leeuwen, K. (2020). Evolving indications for surgical intervention in patients with differences/

disorders of sex development: Implications of deferred reconstruction. In *Seminars in Paediatric Surgery* (Vol. 29, No. 3, p. 150929). WB Saunders.

Wisniewski, A. B., Migeon, C. J., Gearhart, J. P., Rock, J. A., Berkovitz, G. D., Plotnick, L. P., ... & Money, J. (2001). Congenital micropenis: long-term medical, surgical and psychosexual follow-up of individuals raised male or female. *Hormone Research in Paediatrics*, *56*(1-2), 3-11.

Witten, T. M. (2004). Life course analysis—The courage to search for something more: Middle adulthood issues in the transgender and intersex community. *Journal of Human Behaviour in the Social Environment, 8*(2-3), 189-224.

Witten, T. M., & Eyler, A. E. (1999). Hate crimes and violence against the transgendered. *Peace Review*, *11*(3), 461-468.

Woodhouse, C. R. J. (2004). Intersex surgery in the adult. *BJU international, 93*, 57-65.

Zeeman, L., Sherriff, N., Browne, K., McGlynn, N., Mirandola, M., Gios, L., ... & Farinella, F. (2019). A review of lesbian, gay, bisexual, trans and intersex (LGBTI) health and healthcare inequalities. *European journal of public health, 29*(

3.“I do not want to have my parents as my enemy”: intersex activism and breaking the veil of silence

Audrey Aegerter

Introduction

In 2008, the French journal Nouvelles Questions Féministes marked a pivotal moment in the evolution of intersex studies in the French language by releasing a special edition. This milestone may be considered pioneering, for it represented the first instance within the Francophonie that non-medical intersex research was given prominence. Furthermore, it was the first time intersex activists received a platform and voice. Among them, Sarita Vincent Guillot contributed with an article titled “Intersex: Not having the right to say what we were not told we were” (Guillot, 2008). With this title, Guillot (2008) highlighted the profound impact of medicalisation, especially the politics of secrecy, that surround intersex variations and their healthcare.

The title of Guillot’s (2008) article brings to the fore two categories of secrecy commonly encountered by intersex individuals and their families. First, an implicit or explicit injunction exists against discussing one’s corporeal reality or personal experiences. Guillot contends that intersex individuals are denied the right to disclose their identities to others, a mandate that extends to parents who are often encouraged to keep their child’s bodily variation concealed (Medoded-Danon & Yanay, 2016). The rationale behind this directive lies in the belief that if others were aware of the child’s intersex status, they would treat them differently, potentially compromising the development of their gender identity (Kessler, 1990, 1998). The initial model of care emphasised the nurture of gender identity (Money, Ehrhard, 1972).

Moreover, fear-mongering tactics were employed, with doctors positing an unsubstantiated risk of bullying and stigmatisation (Hampson, Money, Hampson, 1955; Kessler, 1990). Consequently, it was deemed in the child’s best interest for their condition to remain undisclosed. However, what exactly is undisclosed? This question lies at the heart of the second part of Guillot’s title: what we were not told we were. A multitude of intersex testimonials attest to the fact that individuals either did not know they were intersex while growing up or were unable to comprehend their condition. Some received diagnostic terms, while others recount being subjected to lies, sometimes to explain the frequency of hospital visits, other times about the biological features of their bodies.

Consequently, many grew up with the belief that they suffered from a grave medical condition. Others suspected that they were being deceived but were unable to fathom the true nature of their situation. Either way, they developed an identity as a patient, or at least only knew pathological words to talk about their body. These beliefs can be explained by the recommendation not to disclose to parents or the child that the child is “half-half”, but instead imposing the concept of ‘unfinished genitalia’ (Hampson, Money, Hampson, 1955). The framing of the genitals as unfinished is in line with the practice of the medical professionals Suzan Kessler (1990) interviewed, who claim that the genitals of the child are underdeveloped, maldeveloped, or unfinished, making the sex assignment more complicated.

After 2006, the medical recommendations changed, due to increasing criticism of the previous medical management of intersex children by intersex activists, scholars, and some human rights institutions. The Consensus statement adopted them based on the decisions taken during an international medical conference in Chicago (Hughes et al., 2006). There was some advancement in an intersex child’s care. Homosexuality or a gender non-conforming identity was not to be considered a failure; some “normalising” surgeries should be delayed until the child could consent or at least voice their opinion; photographs of the child’s genitals, if necessary for educational purposes or record keeping, should be taken when the child is under anaesthesia and with appropriate consent as they “may be experienced as deeply shaming” (Hughes, et al, 2006); and information about the child’s variation and possible medical solutions should be given to parents and child. However, the change in medical nomenclature stands out the most in the Consensus statement. Instead of intersex, medical professionals would now use the term Disorders of Sex Development (DSD) because the previous terms were “perceived as potentially pejorative by patients and can be confusing to practitioners and parents alike” (Hughes et al., 2006, p. 556). The new DSD language has, however, participated in the medicalisation of intersex people and bodies. Medicalisation can be understood as “a process by which non-medical problems become defined and treated as medical problems, usually in terms of illness and disorders” (Conrad, 2007, p. 4). The Consensus statement and the replacement of intersex by the DSD nomenclature is a perfect example of medicalisation. Davis’ (2015) research presents the medicalisation of intersex people and shows that for many intersex activists, especially outside the United States, the switch to DSD language was not considered an improvement.

On the contrary, they claimed this would further pathologise their bodies (Davis, 2015), as the word “disorder” assumes that these bodies should be ordered. As such, intersex children are now considered as girls or as boys with a disorder that is labelled a syndrome. The language that both parents and children access is, for the most part, medical.

In most families with an intersex child, the condition is rarely discussed with the child or the extended family (Medoded-Danon & Yanay, 2016). The research for this essay, which aims to understand how intersex people become intersex activists, looked at how people with an intersex variation become intersex. Becoming intersex consists of a process where a person with a variation in sex characteristics discovers the term intersex for themselves and learns a new language in which to talk about and experience their body outside of the medical realm. It can include a reinterpretation of their medical history. Most intersex people become intersex in their adulthood, often in their thirties. However, it must be stressed that for younger generations, meaning people who grew up with or had access to the internet as young adults, the process of becoming intersex happened earlier than for the older generations. Indeed, the internet has been a mean for intersex people to access information, that were otherwise inaccessible to them, and meet other people, as has been shown in the work of, amongst others, Still (2008), Zehnder (2010), and Gosselin (2011). This generational difference can also be explained by the general increase in awareness of intersex issues in society and the scaling down on secrecy in medical recommendations since 2006.

While not all intersex people decide to engage in intersex activism, this paper explores the impact of the new intersex and activist identities on families of intersex people. When going public, intersex activists break the silence and secrecy around their bodily variation, which can affect families in many ways. Sometimes, this can result in exclusion from the family; other times, it surfaces in parents, who might share their regrets and even engage in activism, and there may also be an implicit agreement not to talk about the subject.

The subsequent sections encompass a brief methodological part, followed by three primary segments: the first delves into the process through which individuals with sex characteristic variations come to identify as intersex and the implications of this newfound identity; the second scrutinises the decision-making process surrounding the revelation of the family secret and its repercussions on family dynamics, and the third section investigates the perceptions held by family members regarding the public and political engagement of the intersex individual. Additionally, distinctions are drawn between younger and older generations of intersex individuals based on the data gathered from interviews and participant observations.

Investigating intersex identity and family dynamics

As part of this research project, I carried out 31 interviews with intersex rights activists aged 27 to 72 who are or were engaged in intersex activism in Belgium and Germany. Some interviewees have been active for a few months, others for over twenty years, and some have retired from their activist careers. The countries were chosen because of differences in each movement’s historical development. However, the findings showed that these historical development differences did not play a significant role in understanding how intersex people in these countries became activists.

Other characteristics have, however, played a more critical role in this process: the variation and age at which the intersex variation was detected, the information people received or accessed, and the environment in which they were raised. Each interview lasted anywhere from 45 minutes to almost four hours. My interviews were semi-structured, meaning there were predetermined themes to address in each interview, but the questions were asked in a different order or with a changed phrasing. The objective was to work with the participants' answers and adapt the questions to fit their experience best. The defined interview themes related to each person's intersex activism journey. For this paper, the themes that are the most relevant are the relationship with family members (especially parents), secrecy, and going public as an intersex person.

Furthermore, participants were observed at events such as peer support groups, community events, or a demonstration in front of a children's hospital in Brussels in November 2021. Content retrieved from forums and blogs was also analysed. Data retrieved online was essential to understand the overall situation of intersex people, especially for the first generation of intersex people plus activists who were uncontactable or unavailable due to health concerns. Participant observation and online data analysis also provided information regarding family relationships and activism.

Becoming intersex in the family

Intersex, whether it is being an intersex person or having an intersex child (or sibling or relative), is generally a family secret. The intersex person does not usually have the knowledge to address their situation. Previously, parents were often advised not to talk about it. In some cases, other family members, such as siblings or other relatives, may have some information but also participate in keeping the variation unaddressed (Medoded-Danon & Yanay, 2016). This chapter addresses how intersex people access information about their intersex variation and the transformative role this discovery has on their identity.

Furthermore, empirical data brings understanding about how breaking the family silence and openly addressing the intersex trait can change family dynamics. Sometimes, this can go as far as breaking the ties to parents. In other cases, parents feel remorse and start engaging in intersex activism. In contrast, some intersex people find ways to balance their desire to be openly intersex and their parents' difficulties in speaking or hearing about it.

Epistemic injustice and becoming intersex

The silence and secrecy surrounding intersex variations, both in society and within families, hinder the trajectory of people with variations in sex characteristics toward an intersex identity and an activist career. Some scholars have applied the concept of 'epistemic injustice' to discuss the experiences of intersex people (Fricker, 2007). Epistemic injustice is "a kind of injustice in which someone is wronged specifically in [their] capacity as a knower" (Fricker, 2007, p. 20). Accordingly, Miranda Fricker (2007) identifies two types of epistemic injustices: testimonial injustice and hermeneutical injustice.

The first, testimonial injustice, occurs when a person is accorded credibility in excess or deficit due to some social feature such as race, gender, or ability, meaning that the credibility accorded to a person's discourse is based on stereotypes and pre-judgment. For example, testimonial injustice has been mobilised by Janik Bastien-Charlebois (2017) and Terri Merrick (2019). Both examined differences in the excess credibility afforded to the medical claims of doctors in charge of intersex children when compared to the lesser status accorded to the testimonies of intersex activists, despite supporting evidence. The second type of epistemic injustice, hermeneutical injustice, is defined as a situation in which "a gap in collective interpretive resources puts someone at an unfair advantage when it comes to making sense of their social experience" (Fricker, 2007, p. 1). Jose Medina (2017) defines it as when a person encounters unfair obstacles in making sense of their own story. These obstacles occur in different forms, as Fricker (2017) explains.

Furthermore, she writes that feminists had to break the silence to speak out about the “this” that had no name. In the process of sharing, a collective narrative can be created, and a person might gain access to keys of knowledge. However, the lack of access to information affects groups differently, sometimes to the point of hermeneutical death. Because of the protocolised silence around the intersex variation, most, if not all, intersex people face a situation of hermeneutic injustice. Except for two interviewees, most never heard anything other than medical terminologies to describe their bodies. They grew up believing they had a disorder, a malformation, and in some cases, that they were cancer survivors, a common explanation given to intersex women, or at least people who were assigned female at birth, by their doctors to justify a gonadectomy. This justification comes from the higher risk of testicular cancer when testes are in a warm environment. However, these people were told that they had ovarian cancer, not a risk of testicular cancer.

The medical language and treatment created what Bonnie Hart and Jane Shakespeare-Finch (2021) call embodiment, which entails the emergence of a negative self-conception and the internalisation of an erroneous state of being, characterised by being labelled as deviant, abnormal, or disordered. Consequently, it erodes the agency and capacity of individuals to challenge the medical norm. Discovering the term intersex and managing to identify with it plays a pivotal role in the experience of intersex people. This is what I call “becoming intersex”. It relates to a process of de-pathologisation and destigmatisation of one’s own body and corresponds with a change in narrative. A perfect example of this change in narrative with becoming intersex is the text Coralie Smeers (2020) added to her fifth autobiographical manga. She writes:

> “I write this first page to let you know that two years ago, I discovered what intersex was. After much research, I understand now that my medical journey, sadly, is not unique. It relates to the journey of intersex people, and that in addition to medical error and mistreatment, I am also a victim of genital mutilations [...]. Since discovering my intersex variation, I do not consider myself a malformed woman (what the doctors always told me I was), and I feel better in my skin. (I will not change my previous tomes, as a proof of my psychological evolution).” (Smeers, 2020, translated by the author).

Furthermore, it is essential to note that a child’s intersex variation is often very taboo within the family. It is rarely discussed in most, if not all, families. Sometimes, some extended family members know about the intersex variation but also participate in keeping it a secret (Medoded-Danon & Yanay, 2016). Some interview participants also explained that they had developed coping strategies, particularly regarding hormonal treatment management when staying with family members, to prevent family from seeing or understanding why they took these pills. In this context of extreme secrecy and taboo, many intersex people took advantage of geographical distance, for example, when studying abroad for a year or moving to another part of the country to begin the process of becoming intersex. One person started the process once their parents passed away.

When becoming intersex, hermeneutical injustice decreases. People gain access to de-pathologising language about their bodies, understand their biology and functioning, meet other intersex people, and create a collective narrative. For some intersex people, the process of becoming intersex is gut-wrenching; it can foster anger and a strong feeling of injustice. At the same time, becoming intersex is a healing process. All the interviewees explained how healing it was for them to meet other intersex people and finally accessing non-pathological words to tell their experiences. Meeting other people also gave them the strength to engage in intersex activism, whether in an organised collective, with friends, or individually, in institutions, picketing in front of hospitals, or by creating art. Engaging in activist activities often became a necessity and therapeutic for the interview participants. For many, it served as an outlet for their rage. For example, one person stated: “In fact, I started to engage without really knowing it. I did it for myself with a therapeutic goal” (Interview 6, translated by the author, 2022). Other interview participants explained that activism is a “necessity” for them. Several interviewees had attempted suicide before they knew they were intersex, and one ended their teenage years in a psychiatric unit because of severe trauma. All interviewees explained that activism and meeting the intersex community saved their lives. One person recounted that they had no relationship with their parents, family, or childhood friends due to their activism. On the one hand, their family and friends could not accept their intersex status or activisim. On the other hand, it was because they fully committed to the movement and never looked back. They say:

> "I dived in and swam and swam and swam. It's only in the last year or two... one year... that I've recovered from the shock of being told I was intersex. For 20 years, I lived in a parallel world, and I went headlong, headlong, headlong without looking back. You know what I mean? I didn't expect it. I didn't see the consequences. [...]. I just went for it, went for it, went for it. It was a question of survival. It's a question of survival. It was either that or die. And I absolutely had to meet—and this is hyperbolic—all the inter people in the world. And I had to get them together and see each other and travel, etc..." (Interview 3, translated by the author, 2022).

Breaking the veil of silence: 'coming out' to parents and seeking information

The previous section dealt briefly with the process of becoming intersex and how hermeneutical injustice and the taboo or secrecy within the family can hinder this process. Also mentioned was how geographical distance from family and friends can contribute to the initiation of this process. What follows is a discussion on how intersex people "come out" to their families and the implications. However, the term "coming out", especially to parents, is widely debated within the intersex community. Indeed, usually, parents already know about their offspring's intersex variation and medical procedures. Parents are often the gatekeepers of this information, and sometimes, the intersex person relies on them to access information. This "coming out" experience is unlike that of LGBT+ people, where the individual first discovers information about their sexual orientation or gender identity and then decides to inform others around them. In two cases from the interviews, parents informed their minor children about their intersex variation, using not only medical terminology but also words such as intersex or hermaphrodite, at the ages of 12 and 14. The latter explained:

> "So, I learned at 14 from my family, from my father, that I am intersex. However, with a completely different designation. The word hermaphrodite was used in this context [...] I heard that, but I can say, in retrospect, that information did not reach me from the outside... but inside, I could not take it up, [...] because there was an absolute lack of understanding of the topic and in general about the idea that there is something else than this binarity of man and woman and... I was also socialised as a man." (Interview 26, translated by the author, 2022)

After that, this person did not discuss their intersex variation with their parents until the early 2000s when they heard the word "intersex" and began identifying with it. Fourteen years after the initial disclosure, this now 28-year-old person asked their parents for further information about their intersex variation, medicalisation, and information about them from their doctors. However, this was challenging because, for the parents, this was a closed chapter, and they could not understand why their now adult child wanted to reopen it.

The person who found out about their intersex variation at the age of 12 also did not talk about it with anyone for a long time. They explained that:

> "I could only have talked with my parents about it... And I ruled that out for the first time for various reasons... Amongst other things, because for me, it looked as if they hadn't told me the truth for 12 years. And this also messed up our relationship..." (Interview 2, translated by the author, 2022)

Other people stumbled across the word intersex variation and the nature of their "condition" by discovering medical papers; for instance, in their childhood home or in a sealed medical letter they got handed after a medical appointment. In these cases, the person usually confronted the parents, generally the mother, and asked for more information.

> "I actually always knew it. Because I always looked down at myself, around the genital area. I always had a sense of shame about my body, and I somehow couldn't explain it to myself. And when I found medical documents, actually in my parent's house, then I had a conversation with my mother, and she told me everything, based on these documents, for which I am also very grateful to her. But she hadn't told me about it before." (Interview 12, translated by the author, 2022).

> "I faced my mother, who broke down in tears, and she told me: 'I couldn't talk about it. The doctors told me never to talk about it'." (Interview 9, translated by the author, 2022)

Most of the participants discovered they were intersex "by chance" when watching a movie, reading a book, in class, for example in biology classes or during sex education, or talking with someone. For instance, an interviewee's friend told them about an ad they saw in the newspaper from a hermaphrodite looking to talk with open-minded people. Another person told their friend about their body and medical treatment, and the friend suggested they may be intersex.

After discovering the word intersex, the interview participants usually took their time, from a couple of weeks to several years, before breaking the silence in their family and talking. For instance, one person explained to me that they went "pregnant with it for quite a while" (Interview 11, translated by the author, 2022). Figuratively, the pregnancy represents the gestation time between discovering the intersex variation and identifying with it. It represents the time of becoming intersex, as described previously.

> "I went pregnant with it for quite a while. I wasn't sure... Because the taboo was so strong, I really felt I couldn't talk about it with someone. Talking wasn't possible at all, like that. And at the same time, it was so obvious that I couldn't push it away. Then it was clear, and I thought, 'Now I'm lying to myself'. I've been lied to, but now I'm lying to myself." (Interview 11, translated by the author, 2022)

It is also important to mention that for many people, discussing their intersex variation with their parents is exceptionally complicated for several reasons, such as years of secrecy; sex, gender, and sexuality being unspoken topics in the family or culture; shame surrounding the body and a lack of words to describe it; feelings of blame, anger, and resentment toward the parents who participated in the medicalisation of the child; and guilt and regret felt by the parents. People whose parents were still alive when the interviews took place mostly had positive initial discussions, while others were rejected. For instance, one person claimed that his parents were "in denial" and that "it is an undiscussable topic for his parents" (Interview 10, translated by the author, 2022). Another said: "We couldn't really talk. I tried to bring it up, but my father totally blocked. I was also very angry. I didn't feel... I didn't understand why they didn't tell me." (Interview 25, translated by the author, 2022).

"I don't want to have my parents as my enemy": family relationships and coming out

When engaging in intersex activism, intersex people are not only breaking the silence within their family but also with the world in general. While breaking the silence inside the family is already challenging for most people, it is even harder to have this exposed publicly. An intersex person going public may face questions from family, friends, neighbours, or their parents' colleagues, as may that intersex person's parents and family members. My interviews demonstrated that there were drastically different parental reactions to their child being publicly intersex.

Overall, the interviews showed that the older the intersex person, the less supportive the parent. Some reasons for this could be the lack of access to information, negative representations of LGBT+ people, and trouble understanding why this topic resurfaces decades after the medical treatments happened. Not receiving parental support can weaken the relationship, especially if the parents do not accept any criticism of their choices. For example, one interviewee said: "My dad still doesn't get it, and my mum is still… She still thinks they did everything right, and I don't think this is a justifiable position of how they should have acted, looking back at the situation. Therefore, we don't talk anymore." (Interview 25, translated by the author, 2022).

Other people tried to talk to me about their activism or their childhood medical experiences with their parents. However, many of these discussion attempts failed, and some intersex people found ways to hide their engagement from their parents or family members to maintain good relationships. For instance, one person told me their family knows they created an organisation but "don't know what it is about. I was just being secretive" after some discussion about their intersex variation and experience with their parents. This secrecy can be to protect the relationship with the parents. One person explained that when they started activism, it was complicated for their parents because of their guilt (Interview 27, 2022). Another person said:

> "In my family, it is still a taboo topic. […] My mother cries when I bring up the subject. I don't know… When I was 13, the doctor talked to her about it. I don't know what he told her then. To this day, she is unable to say what the doctor told her. Then she cries because she feels guilty. […] My parents are old. I don't want my parents to be my enemy. I was very angry with them for many years and was very hurt that they can't accept me as I am, and they don't recognise my achievement, and funny enough, I got that."

Because of her parents' reaction, this person decided to stop talking about her activism or variation with her parents. The parents know what she is doing, but there was an implicit agreement to not talk about it, except when something important is happening. In that case, the parents join their intersex child and celebrate the achievement with pride.

> "I got some National Awards. Human rights awards. It was always very important to me that my parents were there and that they sat in the audience. They always sat in the front row." (Interview 8, translated by the author, 2022)

With the sentence "I don't want my parents to be my enemy", the person hinted at strategies she had implemented to conceal her activism to avoid frustrating or angering her parents. Other people, especially those within the younger generation of intersex individuals who were born in the mid-80s, have the support of their parents and family. This support can extend to the point where the parents become involved in activism. For example, one person explained that she managed to repair her relationship with her parents. They now support her and actively participate in various activities within the organisation she currently chairs.

> "I can now talk openly with my parents about my activism. They also support me fully in this. My sister [too]… Actually, my entire family supports me with everything and points their friends to documentaries on the topic, and so, yes, they all do this. They are also activists for [intersex] without being [intersex] themselves." (Interview 2, 2022)

Another interviewee, whose intersex variation was detected at the age of 15, felt the support of her mother was incredibly important.

> Audrey Aegerter: "Is it important for you to have the support of your family?"
>
> Interviewee: "Yes. Especially my mum's. I'm quite close to my mum. I wasn't afraid because I know she's always been by my side and listened to me. She's always supported me in everything I've done, so I don't have any problems there.' " (Interview 6, translated by the author, 2022)

The age of discovery of the intersex variation may be necessary to acknowledge here. Indeed, the person was 15 when "diagnosed" and operated on about half a year later. The operation did not go as planned, and she underwent ultimately unsuccessful operations. Both the intersex person and their mother claim to have been lied to and not taken seriously. The patient was also old enough to state her discomfort and pain and realise that she had been lied to by the medical professionals who were taking care of her. A year after the initial surgery, they both sued the hospital for medical errors and fought for over a decade until they won damages in court.

New family relations: becoming intersex and managing emotions

Discovering one's intersex variation in non-pathological or less pathologised terms and connecting with others who share similar experiences can be the beginning of a transformative journey. This transformation involves the process of becoming intersex, which entails de-pathologising and destigmatising one's own body, leading to a shift in narrative. As individuals embark on this journey, they often experience emotions such as injustice, anger, and resentment. These emotions can serve as catalysts for their activism, as noted by Benjamin Flammand (2021), who highlights that political engagement is intimately intertwined with personal experiences.

On an individual level, initial involvement in a social movement can be influenced by emotions like anger, frustration, hope, or empathy, often rooted in personal experiences of discrimination, injustice, or oppression or through identification with the struggles of fellow group members. Emotions can play a crucial role in motivating individuals to commit to and act for social change.

As discussed in the previous section, when intersex individuals fully embrace their identity, they often develop strong feelings of anger, particularly directed towards the medical establishment and their families. Connecting with others, accessing information, and gaining a new vocabulary to discuss their bodies and experiences empower them to raise their voices with the aim of challenging the existing status quo. This process is emotionally charged and deeply personal.

Furthermore, these emotions, the potential for intersex activism, and the newfound intersex identity can compel individuals to "come out" to their parents. Disclosing their intersex identity to parents, who are usually already aware of the bodily variation, often shatters a longstanding family taboo. Medical protocols frequently recommended to doctors not to discuss intersex variations with parents and intersex child. Parents were also discouraged to tell the information they have to their child, other family members, or . For intersex individuals, coming out serves as a means to access more information and gain a better understanding of what happened to them, including the details of surgeries, treatments, and the reasons behind them. In some cases, parents provide this information, while in others, they may refuse to discuss or reconsider their stance. Some parents do not believe they did anything wrong and may struggle to comprehend why their child, years later, wishes to broach this topic. In other instances, parents acknowledge the intersex variation and offer some information but are unable to engage in ongoing discussions. To preserve family relationships, some intersex individuals, once they have obtained the necessary information, choose to return to a state of silence, only discussing intersex when something significant arises. Conversely, some parents may develop feelings of anger, guilt, or regret upon hearing their grown-up child's stories, prompting them to embark on their own activist journeys. Some parents become actively involved in organisations, while others connect with fellow parents, online or offline, or engage in awareness-raising activities whenever possible.

The experiences of intersex activists suggest that secrecy, taboo, and the lack of accurate or complete information are the primary factors contributing to their feelings of distrust and anger towards their parents. Some individuals now view their parents, like themselves, as victims of medical protocols. Others hold their parents responsible for not providing better protection and the tools to help them accept their bodies as they are. Many intersex people perceive the silence imposed by medical protocols as a form of deception. Engaging in activism and initiating a dialogue on these topics with their parents can be both helpful and divisive. For my interview participants, turning to activism has been a way to break the silence. However, not all intersex people are activists as well, and there are other ways for people to live openly as intersex individuals without engaging in intersex activism.

References

Charlebois, J. B. (2017). Can intersex subjects reflect (upon themselves)? The encroachment of epistemic injustice on the political subjectification of intersex people. *Socio*, 9, 143–162. https://doi.org/10.4000/socio.2945

Conrad, P. (2007). *The medicalization of society: on the transformation of human conditions into treatable disorders.* Baltimore: Johns Hopkins University.

Flammand, P. (2021). Se sentir politiquement engagé. *Lien social et politiques.* https://doi.org/10.7202/1079496ar

Fricker, M. (2007). *Epistemic injustice: Power and the ethics of knowing.* Oxford: Oxford University Press.

Gosselin, L. (2011). Internet et l'émergence du mouvement intersexe : Une expérience singulière, celle de l'organisation internationale des intersexué·e·s (OII). Dans : Lévy, JDJJ., Ryan, B., Thoër, C. (eds) Minorité sexuelles, internet et santé, pp. 199-209. Montréal : Presses de l'Université de Québec.

Guillot, V. (2008). Intersexes : ne pas avoir le droit de dire ce que l'on ne nous a pas dit que nous étions. *Nouvelles Questions Feministes, 27*(1), 37-48. https://doi.org/10.3917/nqf.271.0037

Hampson, JG., Money, J., Hampson, JL. (1955). Hermaphroditism: recommendations concerning assignment of sex, change of sex and psychologic management. *Bulletin of the Johns Hopkins Hospital, 97*(4), 284–300.

Hughes, I. A., Houk, C., Ahmed, S. F., Lee, P. A., & Lawson Wilkins Pediatric Endocrine Society/European Society for Paediatric Endocrinology Consensus Group. (2006). Consensus statement on management of intersex disorders. *Journal of pediatric urology, 2*(3), 148–162. https://doi.org/10.1016/j.jpurol.2006.03.004

Kessler, S. J. (1990). The medical construction of gender: case management of intersexed infants. *Journal of Women in Culture and Society, 16*(1), 3-26. https://doi.org/10.1086/494643

Kessler, S. J. (1998). *Lessons from the intersexed.* New Brunswick: Rutgers University Press.

Medina, J. L. V. (2017). Varieties of hermeneutical injustice 1. Dans Kidd, J.I., Medina, J., Pohlhaus, G (Eds.), *The routledge handbook of epistemic injustice* (p. 41-52). New York: Routledge.

Meoded-Danon, L., Yanay, N. (2016) Intersexuality: On secret bodies and secrecy. *Studies in gender and sexuality, 17*(1), 57-72, https://doi.org/10.1080/15240657.2016.1135684

Merrick, T. (2019). From 'Intersex' to 'DSD': a case of epistemic injustice. *Synthese, 196*, 4429–4447. https://doi.org/10.1007/s11229-017-1327-x

Money, J., Ehrhardt, A. (1972). *Man and woman, boy and girl : the differentiation and dimorphism of gender identity from conception to maturity.* Baltimore: Johns Hopkins University Press.

Still, B. (2008). *Online intersex communities: Virtual neighborhoods of support and activism.* Amherst: Cambria Press.

Zehnder, K. (2010). *Zwitter beim namen nennen: Intersexualität zwischen pathologisierung, selbstbestimmung und leiblicher erfahrung.* Bielfeld: Transcript.

4. Glimpsing an Intersex Spring: A Conversation with Camino Baró San Frutos[5]

Camino Baró, Lucas Platero, Joan Pujol, and Marisela Montenegro

Introduction

The following conversation has been transformed into a narrative format for ease of reading and to produce a more coherent argument. Additionally, the text was thoroughly revised to connect its themes and considerations with various theoretical and conceptual frameworks found in the social sciences. This process emphasises how our lived experiences involve profound theoretical reflections about our environment, and how it is imperative that these be made visible in a compelling textual format. In accordance with Haraway's 'situated knowledges' (Haraway, 1991), all knowledge emerges within a specific material and semiotic context, evolving within a particular life trajectory. Knowledge is also inherently partial (Haraway, 1992), emerging from a standpoint with a particular objective. The narrative presented below constructs a fragment of experience aimed at transforming our understandings of the intersex field. It offers a partial perspective that seeks to engage with other experiences and knowledge presented in this book, a dialogue between the various works that demonstrates the heteroglossic nature of every phenomenon (Bakhtin, 1979).

On a political note, it is common to encounter works that represent and incorporate the voices of others based on specific interests. Discussions often revolve around the thoughts and desires of intersex individuals, justified through questionnaire methodologies or interviews, with the argument of 'giving voice' to these positions. However, social movements have become particularly suspicious of these methodologies, as participants typically lack agency over how their voices are represented (Scharenberg, 2023). In this work, Camino speaks with her own voice, contemplating the reflections and experiences that arose during a conversation with Lucas Platero, —a conversation that we have transformed into narrative. We have created the narrative following the methodological procedure of Narrative Productions (Pujol-Tarrés, 2023). To create the narrative, the transcript of the interview is rewritten into a coherent text that blends Lucas Platero's interpellations and comments with Camino's reflections. Subsequently, the text has been reviewed and transformed by both participants and finally validated by Camino, following the usual procedures of narrative productions (Montenegro-Martínez et al., 2023).

Over the course of the last decade, several regional laws have been passed in Spain's autonomous communities that ban unnecessary medical interventions on intersex children and stipulate that such surgeries not be performed until the person is old enough to provide informed consent (Fernández-Garrido and Medina-Domenech 2020). However, this legislation is not specific to the intersex population, but is built around antidiscrimination policies for LGBTI+ individuals or specific policies for trans persons that include intersex individuals (Suess-Schwend, 2018; Platero, 2020). In 2023, the national LGBTI Law 4/2023 was passed – after a debate that included a discussion of the rights of intersex persons – providing continuity and expanding the regional proposals (depathologizing healthcare, banning unnecessary genital surgery, establishing informed consent, training professionals, protecting the right to privacy, ensuring access to comprehensive care, setting a moratorium of one year to register sex on documents, amongst other provisions) (Government of Spain 2023). This regional and national legislation brought an end to the legal vacuum around intersex individuals, who required specific protection from invasive medical

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[5] While the term 'Intersex Spring' is not widespread, Laura Vila Kremer uses it to refer to the optimistic sense of progress experienced by intersex Spanish activists in the last few years. Also, Mer Gómez uses the expression 'Intersex Spring' in her dissertation (2023, p. 16). This phrase, which is also reminiscent of the familiar concepts of the 'Arab Spring', 'Springtime of Nations' and 'Prague Spring', is particularly characteristic of intersex Spaniards in the Spring of 2023 (see https://shangay.com/2023/10/26/dia-internacional-de-la-visibilidad-intersexual/).

practices often shrouded in silence, shame and taboo. Notwithstanding these laws, which protect the rights of intersex persons, there is a lack of information and follow up on the medical practices that include protocols and operations done at an early age, often for purely cosmetic purposes, that can lead to lifelong health problems and with results that may not even be satisfactory for the intersex person (Gregori, 2016).

For quite some time now, intersex individuals and their families in Spain have organised to have their needs met and to face the challenge of a culture of silence, which is fuelled by the lack of testimonies from intersex people themselves. Often, these people have established themselves around patient associations like GrApSIA (the Spanish branch of the Androgen Insensitivity Syndrome Support Group, founded in the United Kingdom in 1988 and in Spain in 2000) and more recently, in intersex organizations with a more activist profile (examples include Kaleidos, i de intersex, KRISOL Pro Derechos Humanos Intersex, Adriano Antinoo and Caminar Intersex). Kaleidos, the intersex organization for body diversity, was founded in late 2018 by, amongst others, Chantal Navarro as president, Nuria Gregori and Dau García Dauder. Kaleidos is more political in nature – than, for example, GrApSIA, which is oriented towards mutual support – and works at national level, forming part of the change related to how to frame intersex needs and demands beyond the medical framework (Kaleidos 2020; Gregori et al., 2018).One notable and highly visible figure in intersex activism in Spain is the psychologist Camino Baró San Frutos. Baró San Frutos is a systemic therapist, sexologist and author of the story Un secreto pelirrojo (A Redhaired Secret, 2022), published by Bellaterra. Baró San Frutos is a member of both the GrApSIA family support organization and Kaleidos, and has regularly appeared both in the media and at institutional events that highlight intersex rights. Baró San Frutos came to Kaleidos in mid-2019 through Iolanda Melero Puche, an intersex activist and president of GrApSIA. As part of her work as a secretary at Kaleidos, she mediates between the association and other groups to collaborate on events, organise activities and address the needs of intersex people who require counselling. This chapter presents the account that emerged from a conversation between Camino Baró San Frutos and Lucas Platero, a trans activist and researcher, that took place on 9 January 2023.[6] The conversation explores the current situation around rights for intersex individuals in Spain.

The needs of intersex people

Although it may sound utopian, there is a very real need for intersex people to be included in the collective imaginary. One possible way to achieve that goal is through culture. We need to exist, to leave behind the mythological spaces where they called us hermaphrodites, like whimsical, make-believe creations. We need to exist so that the little ones who are incarnating this reality can experience it as a positive thing, and envision themselves in the future. If we do not exist, it is impossible to craft this forward-looking perspective in a healthy way. My call for recognition is highly symbolic, but it is not difficult. We only need to be made visible, to be mentioned, to be included, to be incorporated into the cultural register, to create an intersex cultural register! To create benchmarks.

On a more specific and urgent level, there is a need to unify health protocols to handle cases of diverse sex development (to use the clinical nomenclature), ensuring that the smallest number of operations are performed on the bodies of intersex children. Putting it another way: to ban cosmetic surgeries that do not correspond to a medical need. Many different intersex realities exist, and a percentage of them may require clinical monitoring, with specific operations, but they in no way make up the majority. I mention this as being most urgent because, nowadays, the medical supervision that an intersex person receives depends a lot on where in Spain they are born or where the case is monitored. Even within the same autonomous community with explicit legislation on the matter, it is possible to find medical professionals who do not respect minimal intervention

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[6] This interview was conducted three weeks before 28 February 2023, when the Spanish Parliament passed Law 4/2023 guaranteeing LGBTI+ rights (commonly referred to as the ‘New Trans Law’), which is discussed as a pending matter in the text.

protocols. The most pressing need is to enter the healthcare sector, challenge how intersex bodies are viewed in clinical practice and provide psychosocial resources to families so that they have the most information possible when they must take decisions. In any case, steering them towards intersex associations, for intersex individuals or their families, is imperative.

Secondly, the procedures related to entering the baby's sex in the civil registry need to be loosened. We need to relax the time limits for officially registering the baby's sex, or set provisional time periods in place. One month, one year, two years? That does not seem like enough time. Each case has its own particular features; each person their own experience. I understand that these measures may be problematic in terms of applying them, but proposing general time limits for the entire population also makes things quite difficult when members of the intersex community may have different needs. Rigidly limiting deadlines is complicated and tricky. We are talking about this subject, but it is hard to come up with a specific proposal that meets the needs of all intersex individuals. Generally speaking, we support relaxing all the procedures that may be related to the administration and the civil registration of intersex people, because we have found that you have to provide masses of reports and evidence to certify your sex, and this completely exhausts the families. However, relaxing administrative procedures only during childhood can also be problematic. For example, what happens if we establish the limit for sex assignment at six years old? Some people would be left out. Many conditions show up during puberty, and intersex adolescences, not only during childhood. How should we handle these cases? From my personal point of view, I insist on using the verbs 'loosen' or 'relax' and on helping families and intersex minors with these procedures, on the basis that this is a delicate situation, and sometimes it is not easy to fit into a male or female category.

Thirdly, we need changes in education from the earliest stages. Along with culture, education is the second pillar supporting the intersex imaginary. This would foster a type of sex education that includes body and sexual diversity beginning in pre-school. We engage in sex education from the moment we first hold a baby. A rigid upbringing that only takes in account binary models for bodies (male or female) does not benefit anybody, not even people who view themselves as 'endosex'. Once again, I want to stress that this has enormous potential in terms of helping the child to envision themselves in the future. We need education and visibility, to provide role models. I hope that, little by little, more public people who do not exclusively belong to the field of activism become visible. I am talking about seeing intersex people in sports, culture, politics and so forth. If you do not know anybody who is like you, it is easy to fall into the trap of viewing yourself as something monstrous. This comes up a lot in conversations between intersex people. In the end, 'we are monsters who have to go through the workshop'. People like us who make ourselves visible, do so in order to overturn this idea. Intersexualities are not an aberration, an alteration or a disorder. Intersexualities must be celebrated as a marvellous phenomenon of nature that appears amongst almost 2 per cent of the population, which is not a negligible number, and confirms that our anatomy is not strictly black and white.

Intersex activism

In the last 10 years, the activism of intersex persons has changed. As far back as 1996, when the Intersex Society of North America (ISNA) was founded, this new movement began to leave its mark. And in the last 10 years, interest has increased in research into intersex realities with a social emphasis. Until that time, biomedical research predominated, while in the last decade, interest has grown in breaking away from binarisms, as embodied in intersexualities, and in the impact of this opening-up on psychosocial research.

When you are a person living in this community, you become aware that the last 10 years have been very important for certain people, writing in the first person and showing their faces. What visibility did intersex people have on social networks or in the media 10 years ago? Some very important work was being done to aggregate the intersex experience, which led to the creation of associations like GrApSIA, but this was all done less publicly and within closed circles. I would say that all that earlier work served to support us and give us enormous strength. At GrApSIA, we found many of the people who campaign with us in national intersex activism, and their website contains resources, stories and guides that have quenched the thirst for information for many intersex people and their families. This website is loaded with content, but only people who are interested in the subject are familiar with it. I think this is where we need to make a leap. To transform something that brings us together on a personal level and make it visible to the public. First, we appeared in the media using pseudonyms, with the pictures of our face and our voices distorted, but speaking in the first person. Then, little by little, the pseudonyms (which implicated our families) went away, and not only did they show our faces, but the whole body. These last 10 years have been very powerful. However, looking abroad, the videos that we get here are an inspiration for all of us.

We come from an activism that focused on patient care, allowing the medical staff to learn about intersexuality, not do things that they should not do, and respect patient rights. Now, we are empowering intersex individuals, which has involved a turn, a change from patient organization to a social movement that demands the right to body diversity. This movement is similar to other social movements, such as those mobilised by the deaf, or the family organizations of trans children and adults. The Spanish branch of GrApSIA, which was founded approximately 23 years ago, serves as a welcome resource for all families of patients who have received a diagnosis, and is funded thanks to the family members of people with androgen insensitivity who wish to meet up with other families in the same situation. This is a mutual support group that hosts several annual get-togethers, in the form of conferences (closed and aimed at adult intersex individuals and their families) and more entertaining meetings (closed and designed for the intersex children in the association to get to know each other). As an association, it has grown and changed some of its formats to be more political. For example, last year, some rainbow flag bracelets were designed with the words ‘intersex visibility’, something that would have been unthinkable in the early years of GrApSIA. There have been many advances, but the purpose has never ceased to be to provide a very supportive family space for all these people, a meeting point for family members who continue to get together every year because they have formed ties, even if their intersex children are not members of the association. We are very grateful to GrApSIA, for serving as a starting point for all intersex people; they do commendable work. The peace of mind that you get from knowing that there are more people like you out there, who want to meet you, to give you information, let you talk with other people your age, from your province. The value is incalculable.

At the same time, as the years pass by, many intersex adults and their family members are looking to meet other needs, including the need to take action and be visible on a more political level. This was the basis of the foundation of associations like Kaleidos, i de intersex, Caminar Intersex, KRISOL in Andalusia and so forth. They represent the movement’s latest efforts during the last decade.

The legal context

During the last two years in Spain, there has been an intense debate around a national LGBTI+ law that has included intersex rights. In this context, different individual autonomous community laws have tried to protect the intersex reality, leading to the inclusion of the letter ‘I’ in the acronym LGBTIQA+. This is a particular position, where the debates do not only involve gender identity, but also sexuality. Indeed, the ‘I’ is often excluded from the acronym. For us, it is important to be included, not only for reasons of visibility, but also to participate in other battles that we view as sister battles, because we share many challenges. Being part of the LGBTIQA+ acronym comes with more advantages than disadvantages. For some intersex people, it is the feeling of belonging to a group. These abbreviations and letters have historically been the target of specific types of violence that are closely related to what we have experienced. This is helping us to leave the label of ‘patient’ in the past, of belonging to the hospital and clinical monitoring, and to replace this with feeling like a political actor, belonging to an extremely broad diversity that advocates manifestos and makes demands similar to ours. To defend bodily autonomy, the freedom of desire, so many things that have been denied to intersex people. At the collective level, as plural experiences, each person will have their own opinion, but personally speaking, this gives me an enormous sense of belonging.

At this time, the law has been passed by the Congress of Deputies and is now headed to the Senate.[7] If we are lucky and it is passed there, the next question will concern how it is going to be applied; there is always a leap from the written text to application and, as we know, the hospitals continue to do what they want, despite the autonomous community laws that are already on the books. Passing a law does mean one step forward, but it is more important to guarantee the application of that law and the mechanisms that are going to implement it, in order to confirm that it is being enforced.Moreover, drafting laws cannot be the only way. At Kaleidos, we are trying to collaborate with hospitals and serve on the ethics committees that study each case, contributing our first-person experiences. Additionally, from a psychosocial perspective, we are trying meet with particular people in healthcare periodically, such as professionals in the Vall d'Hebron Hospital in Barcelona, the Hospital de la Paz in Madrid and the Hospital La Fe in Valencia. We hold meetings from time to time to see how we can continue to make advances together, because we understand that both parties are interested in seeing this change, and it is not only intersex people who benefit from the exchange, but the medical professionals as well. For medical institutions, this provides an opportunity to consult other sources, humbly recognizing that the education they received about intersexualities and body diversity was lacking.

At the same time, we in the intersex community have a unanimous opinion about the national law, which is the impression that they tried to fix something without fully understanding it and, moreover, quite hastily and urgently. We did not detect any careful consideration, any effort to focus on the complexity of the intersex reality. This produced some degree of discomfort around the final text and how it may be interpreted by the medical community, whose practice is increasingly defensive. We are concerned that this will somehow have an effect, not violent to the extent of mutilation, but taking a position at the opposite extreme. Doctors who say that they are not going to perform any kind of operation when, as I mentioned earlier, some intersex cases actually require these from a health standpoint. In this respect, we are dissatisfied. On the other hand, it is true that the intersex coalition with LGBTI groups has been in many pride celebrations, and nothing like this has never occurred in the history of the intersex community. I was very excited when all of us went out in our yellow T-shirts, walking down the Paseo del Prado and Castellana, shouting our intersex demands. It is great, that they are including us in this debate and that we are more and more visible, but even though we appear in the acronym, I think there is a lot more talk about the other letters, and the 'I' is still the great unknown. Sometimes, they do not even mention us. There are so many times that I have missed hearing people from the LGBTIQ+ community talk about intersexualities! Sometimes I come across people who talk about intersexuality when they want to illustrate some idea about gender performativity or refer to queer. And I have the feeling that it is used as an example, without really getting into what intersex is. My co-activists always give me the same answer: if they do not say anything, it is because they do not know anything and they do not want to make a mistake. But why do they not want to know? Why not mention it, why not try? Personally, I think that our potential is untapped in queer activism. Our non-binary bodies are dynamite for sexual dimorphism, the evidence that we can no longer continue to segregate people into two non-existent categories.

Other people in the community believe that including ourselves in this amalgamation of letters takes attention away from the particular features of each intersex experience. Before we joined this acronym, people had to fully understand what intersex meant in order to avoid making generalities. Some intersex people have even proposed going it alone, for this very reason, so that we are not merged into a single political category that does not correspond very much – or at all – to the individual characteristics of each person in it. This is a tragedy in political terms. It is important not to mix different realities like trans and intersex, but to talk about the individuality of each intersex experience in order to avoid a unified political position that strikes me as a trap.

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[7] Law 4/2023 of 28 February 2023 entered into force on 2 March 2023.

The representation of intersex reality

One of Kaleidos's aims is to transform how intersex people are represented. In recent years, different cultural productions have played a crucial role in conveying our realities. For example, at the presentation of Mer Gómez's book *La rebelión de las hienas (The Rebellion of the Hyenas),* which we recently shared at the Mary Read bookshop in Madrid, I mentioned that I discovered the term 'intersex' thanks to my therapist, who told me, 'You are an intersex person'. And I said, 'Wow, what does intersex mean?' I remember how she – who was aware of my interiorised interphobia – did the research for me. She investigated intersex cultural material, to make the task easier for me. And I remember that one of the first resources that she quite aptly offered me was *Orquídea, mi aventura intersexual (Orchids, My Intersex Adventure, 2010).* For me, this was a documentary with a capital 'D'; I remember it made my head explode. Before that, I had always moved in the land of intersex as illness, as in 'I suffer from a syndrome, a strange illness'. I had never expressed any questions about my heterosexuality, or thought that this would be shaken by discovering a diagnosis. But suddenly, this documentary told me that an intersex girl can be happy, and even end up adopting a baby. I ended up watching it through tears, telling myself that despite having this strange disease, I am going to achieve the heteronormative goal of adopting a baby and being happy like the lead character. Fortunately, this changed over the years, as my needs transformed and I eventually left the patient label behind and assumed a political label that requires other resources.

Returning to intersex cultural material, I need to highlight Floriane Devigne's film *Ni d'Ève, ni d'Adam. Une histoire intersexe (No Box for Me: An Intersex Story,* 2018), a landmark work. Moreover, there is a consensus in the intersex world that this is one of the most sincere, honest films about our reality. The film is about an intersex person who interviews other intersex people of different genders and with different conditions. The correspondence between the main character and an intersex woman who is not represented as such, because she is in a very early stage of the process, is particularly beautiful. The two act as sources of encouragement and mutual support. I would also like to draw renewed attention to the play Hermafroditas a caballo o la rebelión del deseo (Hermaphrodites Halfway, or the Rebellion of Desire, Colectivo Que no Salga de Aquí, 2021), which was a revolution for me. When they called that 'horde of hermaphrodites' to go to Barcelona and tape – for an entire day – the different images that appear in the play, it was pure ecstasy for me. The theatre has always had something very special that films and television shows do not. You are breathing, sitting there, watching a person who you admire, who is talking about their story, and it is yours, too. The moment is thrilling. I cried so much. When I went to the premiere, it was incredible, and it is still hitting the Catalonian circuit. I just wish it would get to the other autonomous communities soon.

I also recently discovered an Italian film on Netflix, Arianna (Carlo Lavagna, 2015), which quite accurately represents the experience of an intersex person. I recognised myself in it, and I would recommend it because of the research that went into it, all very sensitive and detailed, even the choice of the film's actor and her particular physical characteristics. Even the music and location, an Italian region of Tuscany that is quite wild. Intersex appeals to a nature that cannot be contained; even though you try to contain it, it spills out.

Theatre is a very useful medium for initiating a conversation with the public about our condition. The play *Tilindula; Memorias de una mujer invisible (Tilindula: Memories of an Invisible Woman,* Miguel Ángel Quirós, 2022), premiered in Alcalá de Henares before moving on to the town of Loeches, near Madrid, and other places. The work was written by César González, an associate from the *Orbita Diversa* feminist LGBTIAQ+ association that I belong to here in Madrid, who also plays the leading role. The play tells the story of an intersex person who lived in a town in the province of Extremadura in the early twentieth century, and pays tribute to all the intersex people living in rural areas who managed to avoid the medical magnifying glass, but lived with the finger-pointing and under the stigma of being the person who could not go to the dance with the other women, who could not have a partner, or get married, or have children. It is a very lovely and respectful tribute, done with great care. I know that the author also interviewed different intersex people before writing the script. I highly recommend the play, and I am particularly fond of it.

When I participated in the theatre encounters with the *Orbita Diversa* organization in 2019, I was able to present my story, *A Redhaired Secret* (which at that time was titled Andrea) for the first time, and it was a transformative experience. These were micro-theatre street pieces. I would surprise unknown people in the square outside the Reina Sofia Museum in Madrid, people with their suitcases going to the Atocha train station, and I would say, 'If you have five minutes, I'll tell you a story that you're never going to forget'. I was dressed for the part as Andrea, the young lead character, acting out the story with another person, and I asked them some questions: 'Have you ever felt that you don't fit into the gender binary norm? What have you had to do to fit that norm? Do you know any intersex people? Well, now you know one; nice to meet you'. And I gave them a pamphlet about intersexuality. The conversation was so sincere, so nice… You opened a channel telling your story, through a little tale. The micro-theatre that I did with *Orbita Diversa*, the micro-theatre that Mer Gómez did in Salamanca, La bicha rara del cruce (*The Weirdo at the Crossroads*, 2020), addressed the question 'So you're not a woman and you're not a man?' with the answer 'I am whatever you want me to be'. This was do-it-yourself theatre, creating content using accessible communicative modes that were within our reach.

The self-production of intersex cultural content is extremely important as a matter of social justice. It is up to us to talk to intersex people in the first person, and up to us to do it using a first-person cultural register. Other people should not speak for us; we can claim that agency. This means breaking a pact with the medical institution, a pact of silence. We activists aspire to make a transformative cultural change; we aim high. It makes me laugh, but a few years ago, I myself began to film a documentary with a colleague; we even did a teaser trailer. We imagined ourselves receiving a Goya Award, but the truth is that we did not even get any funding.

Another example of the flights of our imagination and desire: the other day, I was thinking it over, that I work next to the Museum of Anthropology, across from the Atocha station, and every day I see posters for temporary exhibitions. I thought, 'What about an exhibition about the Intersex Spring, that would collect testimonies about how the activist movement grew in Spain? We could include drawings from when we were little kids and some of our videos. I have big aspirations, the biggest'. I said to myself, 'And if I drop by there and I ask, as just another citizen, what do I need to do to be able to exhibit here, in the National Museum of Anthropology?' Then, in your inner dialogue, you run up against reality. 'Is anybody going to be interested in this subject? Do they know about us, do they know what we are going to talk to them about? It may be too soon. Down, Camino, down…'

However, I do not believe that these fanciful rushes are negative and they do not catch me by surprise. It is we intersex people who have had to sit in a hospital chair passively, as patients, silently obeying. Why a patient? This word comes from the Latin patientem, meaning suffering. 'Patient' is also a polysemic word, the person who has patience, who patiently receives what is given to them. You sit in a chair and you receive guidelines about hormones, operations, treatments. They take you out of the chair to strip you, to look at your whole body on the inside, on the outside, with different students. They tell you that you cannot tell anyone what is happening to you; they take you out of the office to talk to your father, your mother, to whoever, to talk about you without you there. And you are not there. You cannot speak directly, although they invite you to ask questions. They say, 'Do you have any questions?' You know that if you ask a question, you are breaking the overprotection pact you have with your father, with your mother and you do not want to create an uncomfortable situation. You stay silent, and you cannot even think of any questions to ask, because you have no agency in all this. You are an object moved from one place to another. They would tell me I had an appointment at the hospital, which in my head translated into 'tomorrow I'll be wearing new underwear'. Completely passively, you receive some treatment, the review of a test, a densitometry or whatever is planned for you that day. That is why being able to produce your own cultural register means completely escaping from the role of patient. And doing it using your own voice strikes me as fundamental. It means empowerment, an act of justice for your own life, for your own history. Who has told your reality? Suddenly, you are telling it, as much as you want and however you want, when you want and to whomever you want. That is everything. How many friendships, family members, etc. have passed through our lives without knowing about this part of us!

Generally speaking, being represented in the social imaginary means that some films, books or events become essential in terms of being able to mould your subjectivity. Consuming cultural products that appeal to other experiences like trans nurtures us, because of the parallels we find in inhabiting uncomfortable bodies from a social perspective. But with intersex cultural productions, we go en masse! Intersex is so exceptional and unique, that when something like Tilindula premieres in Alcalá de Henares, 30 kilometres from Madrid, people come all the way from Valencia and other places. People come just to see the play, because it is something that you cannot miss. It gives me goosebumps, the mobilizing potential of the cultural register and the events where we intersex people are now.

At the same time, one of our fears every time a film comes out is: will they know how to explain our condition? Can it be confused with trans? For example, the film *The Danish Girl* is about an intersex person, but in the end, it was shot like a trans story. *The Danish Girl* is a horrible film. Ignorance can lead to mixed realities. We may aim for the very top, but sometimes, we end up more micro, because we play with what we have on hand.

The Intersex Spring

You could do an interesting study of the chronology of the Intersex Spring. I would not dare to, because I am very bad with dates and I am unsure about when the different events that propelled our activist system took place. You would have to go back quite far, 20 years with María José Martínez Patiño, and that high-profile case of intersexuality. She is always named as the benchmark, but at no point did she want to be one. She was forced to come out of a closet that she was not even aware of. The seeds of this Intersex Spring can also be found in GrApSIA, where some of the people have contacts in other countries where they do not speak of syndromes, but of differences in sex development or diversity of sex development, and have other points of view. And this is being brought to Spain. It appears often in the book by Mer Gómez, how little by little the Intersex Spring is growing, even reflecting on it with you, including forerunners. Perhaps it would need to talk about how the mass media acted, how the media treated María José Martínez Patiño; that definitely got the wheels rolling for everything that came later. It cannot simply be limited to yellow journalism, which said ‘Patiño is a guy’. Surely this moved something, some person, a family member, a father or mother, who said, ‘This cannot go on like this. Let’s get together and create something.’ This, then, produced critical reasoning; the reason that things are the way they are is because we’re all hiding here together. There is some degree of secrecy in these GrApSIA meetings: ‘Don’t let any journalists sneak in; don’t let anyone sneak in who’s going to take a picture of an intersex person’. How can we put an end to this secrecy? By having some people who are now adults normalise it, of course, but also by validating the fear felt by many family members, that their children are suffering.

One historical landmark for our Intersex Spring was the discussion that we held in 2020 (Kaleidos, 2020). It was incredible, because we formulated the questions ourselves, we did all the organisation beforehand, about how we wanted the questions to be asked, how we wanted to divide our group, who wanted to answer. It was a more fluid and free space to express what each person wanted to say. Just designing the poster for the discussion was one of the most exciting things I have ever experienced. There were two people on the poster who had never appeared in any public act under their own names; they had used pseudonyms. And when they saw that the other three of us at the event were using our names and surnames, they said ‘I don’t care what happens at home; get rid of the pseudonym and put my name and my surnames on it!’ It was a pioneering discussion in Spain at national level. It was incredible to be aware of the power of conveying that something historical and groundbreaking, pioneering was happening. You could also sense very strong emotions from the audience.

An activist on public display

Activism, a presence in the media and self-representation through theatre or performance art means being visible in the public space. This visibility has a clear impact on the private lives of activists. For example, we have to prepare ourselves for an interview in advance, asking for the interview script beforehand, so we know what questions they are going to ask. When the interview is drawn up using disinformation, it may include something that makes you feel bad or put you in a difficult position. I would summarise the impact of my public exposure as an activist as positive and I have had few negative experiences that have upset me or made me feel uncomfortable. In general, the media people who have worked with me have treated me with enormous respect and great sensitivity. I would even say that we have established close ties with some of the people we have worked with, and very quickly. I suppose this is because you are talking about a subject related to sexuality, which is in turn related to the greatest pantomime that exists in this world. But why must we accept that all sexuality is equal? When you open a connection and you say: 'To start with, I was born with a vulva, but later I had two testicles in my groin. They discovered them when I was four years old, and I also have XY chromosomes. And I have never menstruated. If I have a vagina? I had to have a vaginoplasty'. To say this to a media outlet like Freeda was a bombshell. I remember, when they turned off the spotlights, the person who was interviewing me leaned over and said, 'Wow, well I have to tell you that I…' Suddenly, they tore up the script and turned off the recorder to tell me something personal, because they had connected with the vulnerability of my story. They tell you something very private about themselves and this creates a very lovely bond. I am happy about this part of the process, but also with the result. There are some videos I watch where I say, 'Oh dear! I said that really badly!' Or, 'I wasn't very careful!' You have to be careful because you are representing many very different people, and you cannot speak as if your reality is the only one. This is an enormous fear about activism that I've always had.

At the same time, because there are so few of us who are visible within this activism, it starts to get tiring. If only we had some new hands, and we could take care of all the proposals we receive. Public exposure and visibility also take their toll. Visibility is very important, but not, of course, at any price, or on the shoulders of the same person. I am beginning to understand what the older activists told me: 'Camino, you've started out too strong; pace yourself'. It depends on where you are in life, because in the beginning, it caught me when my personal life was very full. That came to an end in 2022, and I am kind of down personally speaking, so everything really affects me deeply. You cannot dissociate to talk about how they operated on you. You are totally connected with your body, with your emotions. And you are wiped out after the public exposure and by how people may judge you. You are not saying these words on behalf of activism and with a flag. These are words that are difficult for you to say and are loaded. It is critical to understand that behind each person who shows their face or body in activism is the part that you do not see, how you get home and you pull yourself together.

There is wear and tear. Public exposure is very important, but it does not come free. It comes at a cost. Especially now with the appearance of RadFem, anti-trans feminism/TERF discourses, where intersex has suddenly appeared. For example, during the online workshops held by the Autonomous University of Mexico, Amelia Valcárcel said that intersex persons do not exist and that one sex always dominates over the other. As far as I know, this type of discourse has not had much impact so far. And that makes me think. Why hasn't it had an impact? Maybe because we continue to be very much in the shadows. Did the people who listened to this talk by Amelia Valcárcel just listen and then automatically delete it, just set it aside? Did they decide to attack trans, which is currently the bullseye? On the social networks, on my private Instagram account, where I have some content about sexuality and I describe myself as an intersex activist, only one or two people have written me in this vein, saying things like 'You are a bunch of scammers with your numbers, there is no intersex population', 'the natural order of biology speaks for itself' and so forth. With some exceptions that are so trivial that it makes me wonder if it is an advantage or a disadvantage. If we were more visible, maybe we would be getting attacked more by these people. But that is not the case. I have talked to other people and they share this perception. Even if you look at my videos, 99.9 per cent of the comments are positive; only a couple are a little muddled.

But, in addition to Amelia Valcárcel and her discourse, other people are questioning the intersex reality, like some Asturian authors at the University of Oviedo, with their book *Nadie nace en un cuerpo equivocado* (*Nobody is Born in the Wrong Body*, Errasti and Pérez, 2022). They mention the term intersex using denial and anecdote, using the concept of alteration. But this does not appear to have had an impact on our activism for now. Unfortunately, it has had, on trans reality.

In any case, despite its current impact, disseminating unfounded information on purpose, like denying the existence of intersexuality, is very serious. I would love to meet with these intersex deniers and talk to them, even recommend some books like *Evolution's Rainbow* (Roughgarden, 2021). Denying someone's existence is hate speech.The changes needed in Spanish society

To end, I would like to stress that the fundamental change needed in Spanish society to improve the lives of intersex persons, to restore dignity, respect and the recognition of intersex individuals involves – as I said repeatedly at the beginning of the conversation – education. I counsel a 12-year-old intersex girl who is suffering enormously in school. The other day, her teacher asked the boys in the class to leave the room and only the girls to stay. Then she said, 'I want to tell you that some of you will have already begun or are about to begin to menstruate. You are all going to menstruate because you are all going to be able to be mothers. You should know that I have feminine hygiene products here in this drawer that you can use'. And of course, the little girl I am treating is not going to menstruate and she is in that group of girls, listening to a whole talk that does not include her.

I would like to see society change. Not only in terms of intersex people, but with regard to the claims made by other people, who have so little information about intersex. I operate in a bubble, an oasis, where people – regardless of their gender expression – ask about the pronouns people want to use, and they speak very respectfully about your privacy, in a non-invasive way. For example, they ask, 'Hey, how do you feel about physical contact?' I love that and it is what I want! Not only for them, or for intersex reality, but for every type of reality found in Spanish society overall. It would be something that would help everybody so much, not only those of us in the LGBTIQ+ community.

It should be the case that the changes and proposals that we envision for intersex people produce changes across society, so that we take better care of ourselves and pay more respect to our bodies, our needs and our diverse ways of being in the world.

References

Bakhtin, Mikhail (1979). *The Dialogic Imagination: Four Essays*. University of Texas Press.

Baró San Frutos, Camino (2022). *Un secreto pelirrojo*. Bellaterra.

Devigne, Floriane (2018). *No Box for Me: An Intersex Story* (Ni d'Adán ni d´Ève). France.

Fernández-Garrido, Sam, & Medina-Domeneq, Rosa (2020). Bridging the Sexes: Feelings, Professional Communities and Emotional Practices in the Spanish Intersex Clinic. *Science as Culture, 29*(4), 546-567.

Errasti, José y Mariano Pérez (2022). *Nadie nace en un cuerpo equivocado.* Deusto.

Gómez, Mer (2022). *La rebelión de las hienas. Relatos corporales de personas intersex*. Bellaterra.

Gómez, Mer (2023). *Las hermafroditas del siglo XXI: de objetos del discurso a sujetos políticos. Soliloquios corporales y nuevos enunciados sobre la intersexualidad* [Doctoral Dissertation]. Universidad del País Vasco / Euskal Herriko Unibertsitatea. https://addi.ehu.es/bitstream/handle/10810/63231/TESIS_GOMEZ_SANCHEZ_MARIA.pdf?sequence=1&isAllowed=y

Gómez, Mer (2021). *Hermafroditas, a caballo, la rebelión del deseo*. Salamanca.

Gómez, Mer (2020). *La bicha rara del cruce*. Salamanca.

Government of Spain (2023). 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. BOE 51, March 1st, 2023.

Gregori, Nuria F. (2016). *Diagnóstico de las diferentes realidades, posicionamientos y demandas de la población intersexual o con DSD (diferencias del desarrollo sexual) en Barcelona.* Ajuntament de Barcelona. https://bcnroc.ajuntament.barcelona.cat/jspui/handle/11703/106232

Gregori Flor, Nuria, García Dauder, Dau, & Hurtado García, Inmaculada (2018). Bioethics and Intersex: 'Time out'. A paradigm shift on Intersex Management in the Spanish context. *Athenea Digital*, 18(2), e1899. https://doi.org/10.5565/rev/athenea.1899

Griffiths, M. (1995). *Feminisms and the Self: The Web of Identity*. Routledge.

Haraway, Donna (1991). *Simians, Cyborgs, and Women: The Reinvention of Nature.* Routledge.

Haraway, Donna (1992). The Promises of Monsters: A Regenerative Politics for Inappropriate Others. *Cultural Studies, 6*(1), 127-151.

Heart, Phoebe (2010). Orchids, *My Intersex Adventure*. Australia.

Lavagna, Carlo (2015). *Arianna*. Italia.

Kaleidos (2020). Conversatorio Intersex, with Camino Baró, Laura Vila K., Yolanda Melero, Ana Belén Francia and Mer Gómez. 14/10/2020. https://youtu.be/uem56orHJOo

Montenegro-Martínez, Marisela, Balasch, Marcel, & Pujol-Tarrés, Joan (2023). A methodological proposal from situated knowledge epistemology: Narrative Productions. *Qualitative Research in Psychology, 20*(4), 543–551. https://doi.org/10.1080/14780887.2022.2135278

Quirós, Miguel Ángel (2022). Tilindula. *Memorias de una mujer invisible.* Alcalá de Henares, Madrid.

Platero, Lucas (2020). Recognition and Distribution of Trans Rights in Spain. *Politics and Governance, 8*(3), 253-265. https://doi.org/10.17645/pag.v8i3.2856

Platero, Lucas (2014). *Trans*exualidades. Acompañamientos, factores de salud y recursos educativos.* Bellaterra.

Pujol-Tarrés, Joan (2023). The methodological and epistemic narrative of narrative productions. *Qualitative Research in Psychology,* 1–14. https://doi.org/10.1080/14780887.2023.2183914

Roughgarden, Joan (2021). *El arcoíris de la evolución. Diversidad, género y sexualidad en la naturaleza y en las personas.* Capitán Swing.

Scharenberg, Antje (2023). Contested knowledges: Negotiating the epistemic politics of engaged activist ethnography. *Ethnography*, 14661381231169167. https://doi.org/10.1177/14661381231169167

Suess Schwend, Amets (2018). Derechos de las personas trans e intersex. Revisión del marco legislativo en el contexto español desde una perspectiva de despatologización y derechos humanos. *Revista Derecho y Salud, 28*(Extraordinario XXVII Congreso), 97-115.

5. The trouble with DSD-Life studies

Martin Gramc

Introduction

Medical treatment of intersex bodies has been, for a long time, the matter of a heated debate between medical professionals, intersex people, and the scientific community. Medical professionals and part of the scientific community claim that medical treatment serves intersex people and helps them navigate everyday life. The basis for such claims has been case based on a single case study and the power of medical authority (Karkazis, 2008). In the 1980s, when a minority of scientists and intersex people began raising awareness of detrimental treatment, the medical establishment responded with a refute of medical treatment and claims of improved medical care. However, the given data did not support that (Carpenter, 2018). Studies based on large samples could not be found, and not even the introduction of new guidelines in the Chicago Consensus Statement aimed at overall care for intersex people (Hughes et al., 2006; Lee et al., 2016) brought a substantial change in research on the quality of life. The first large-sample studies on the quality of life of intersex people were first conducted at the end of the previous decade under the name of DSD-Life, a project financed by the EU Horizon 2020 funding scheme (Röhle et al., 2017). The previous studies provided conflicting evidence and poor methodology (Lux et al., 2009), which led the researchers in the DSD-Life consortium to conduct extensive sample studies considering the critique to deliver comprehensive results on the quality of life of intersex people. However, the DSD-Life studies left some answers and critiques unresolved.

This chapter provides a critical account of the methodology used in the DSD-Life studies. It is a systemic review focusing on the methodology and account of the historical background of the papers published as part of the DSD-Life study. The methodology has been the most contested part of the medical treatment of intersex bodies as it was rarely based on large samples and control groups (Lux et al., 2009; Karkazis, 2008). Despite the aim of the DSD-Life studies to address the methodological drawback in the previous studies, there seems to be no mention of a paradigm shift in the medical treatment of intersex bodies and the new disciplinary approaches, such as multidisciplinary and patient-centred care, introduced in the Chicago Consensus Statement.

Hence, I take a closer look at the historical background and mention of the paradigm shift in the consensus statement that has been considered in the DSD-Life studies and the studies' limitations.

The first part of the chapter introduces the historical background of the medical treatment of intersex bodies to provide the most crucial aspects of the care that led to critique and official policy change. This is followed by an outline of the Chicago Consensus Statement and the literature about the change in medical treatment to show the relevance of the improvement of care for intersex people. After this, I critically examine the DSD life studies on quality of life. The DSD-Life studies are examined against the backdrop of historical background, i.e., the lack of it, primarily by focusing on the methodological aspect and, when mentioned, on the ethical aspects. By closely examining the methodology in the DSD-Life studies while bearing in mind the historical background of medical treatment, the chapter reveals the need for serious revaluation of DSD life studies and implementation of historical context in the research life quality in different generations of intersex people.

Non-optimal history of medical treatment

The middle of the 20th century was the turning point in the medical and biochemical treatment and research of intersex people. The change came, first and foremost, in a paradigm shift later known as the Optimal Gender Policy (OGP). Psychological treatment was introduced as an important part of the new medical protocols in Baltimore, the hub of cutting-edge research in the emerging biomedical and surgical treatment of intersex people.

Pediatric endocrinologist Lawson Wilkins recognised the advantages of a multidisciplinary approach in the care of intersex people (Redick in Karkazis, 2008). His team included gynaecologist surgeon Howard Jones, urologist William Scott, experts in psychiatry Joan and John Hampson and psychologist John Money, who joined the team as the last member. The novelty was not in the multidisciplinary team but in the approach. John Money and Joan and John Hampson introduced the theory of gender (role/identity) based on people with Variation of Sex Characteristics (VSC) who are sexually, anatomically, and psycho-socially ambiguous . The support for their theory was based on a few repeatedly cited cases. However, it was widely accepted because of the prestige of its proponents and its resonance with conceptions of gender at the time (Kessler, 1998).

Money and the Hampsons refused chromosomal, gonadal, hormonal sex, and sex characteristics as decisive markers of gender and gender roles (Diamond and Sigmundson, 1997; Money, Hampson, and Hampson, 1957; Karkazis, 2008). An infant's gender role—one's outer expressions and subjective experiences—would later be developed into the term gender identity/role, as first devised by Money and Hampsons (John Money, 1994). Medical interventions during the first two years of an infant's life would not bear psychologically or sexually negative consequences for people with VSC if they were raised as men and women because, in that period, the nature/nurture interaction is the most plastic (Kessler, 1998; Karkazis, 2008; John Money, 1985). Money and the Hampsons relied on biological traits but would not reduce gender identity/role to them (Karkazis, 2008; Money, Hampson, and Hampson, 1957). The detachment of gender roles and sex allowed Money and the Hampsons to integrate the psychosocial orientation of an intersex person in the social imaginaries of masculinity and femininity (Rubin, 2012). For Money and the Hampsons, people with VSC represented the prima facie object of human gender development and sexuality (Karkazis, 2008; Money, Hampson, and Hampson, 1960). Their theories drew upon the theories of developmental psychology and animal behaviour of Konrad Lorenz and their test samples were comprised mainly of white people (Klöppel, 2006; Money, Hampson, and Hampson, 1960; Magubane, 2014).

Even though OGP was the golden standard for more than half a century, the first critique of OGP appeared in the 1960s when biologist Milton Diamond argued that gender identity is primarily rooted in biological traits of humans, later followed by the critique of urologist William Reiner (Karkazis, 2008). The critique of OGP in social sciences and humanities started in the early 1990s when Suzanne Kessler (Kessler, 1998; Dreger and Herndon, 2009) published her groundbreaking paper, The Medical Construction of Gender: Case Management of Intersexed Infants. Her work posed a serious critique of OGP and Money's concepts from the perspective of social sciences and humanities. Kessler pointed out that OGP was premised on the assumptions that genitals are naturally binary, ambiguous genitalia should be surgically "corrected", gender (or gender identity/role in Money's terms) is per se binary, genitals are markers of sex, and that psychologists and medical professionals have the authority to define gender by treating genitals and thus shape the relationship between the two (Kessler, 1998). In her study, Kessler showed that medical professionals rely on social imaginaries to define and surgically treat the genitals and the relationship between the two.

The list of problems introduced in OGP could be summarised in the following ways: poor surgical outcomes; multiple repair surgeries; lack of data based on extensive samples; sexist, homophobic and transphobic assumptions in medical treatments and guidelines; breach of informed consent policies; and the push for social conformism at the expense of bodily integrity and the difference and the absence of psychosocial support (Dreger and Herndon, 2009; Creighton et al., 2012; Michala et al., 2014).

As OGP was based on the plasticity of an infant's psychosocial inner life, it enabled medical professionals and psychologists to operationalise their prejudice, which should function as pointers in the life trajectory of an intersex person. It is essential to highlight that the assessment criteria in the psychosocial studies in the Optimal Gender Policy era were predominantly quantitative and focused on gender-related outcomes, anatomy, and sexuality, relying on the theoretical assumption that prenatal androgens cause pathology in intersex people (Stout et al., 2010). The critique of OGP did not explicitly address the nature of these assumptions, which functioned as a projection onto the malleable psychosocial entity of an intersex person. The critique in social sciences and humanities was concomitantly followed by a critique of intersex people who, at the end of the second millennium, expressed the deracinating effects of OGP on their lives (Dreger and Herndon, 2009; Davis, 2016).

New care approaches at the turn of the millennia?

Only a few intersex individuals made it to the consensus conference organised by Lawson Wilkins Pediatric Endocrine Society and the European Society for Pediatric Endocrinology, where new guidelines and treatment for intersex people were introduced under the name Consensus Statement on Management of Intersex Disorders (Carpenter, 2018; Dreger and Herndon, 2009; Hughes et al., 2006). The consensus statement introduced general guidelines in the treatment of intersex people with new nomenclature rooted primarily in medical terms and secondly in socio-psychological terms (Hughes et al., 2006). The statement was written to improve the quality of care for intersex persons. It introduced the notion of health care professional teams which ought to include pediatric endocrinologists, urologists, surgeons, psychologists or psychiatrists, gynaecologists, geneticists, neonatologists and, if available, social workers, nurses, and medical ethicists (Hughes et al., 2006; Lee et al., 2016). Moreover, medical professionals are expected to communicate with family and educate other health care staff (Hughes et al., 2006) because intersex conditions per se demand multi/interdisciplinary treatment (Wiesemann et al., 2010) because human sex is multidimensional—it is determined by many different factors (Cresti, Nave, and Lala, 2018).

The consensus update of 2016 enforced the idea of shared decision-making to enable patients and their families to make fully informed decisions (Lee et al., 2016) by drawing on the respect for patients' self-determination and participatory rights of children (Wiesemann et al., 2010). The consensus and its update have suggested postponing early surgical (cosmetic) interventions (Hughes et al., 2006; Lee et al., 2016) motivated by a family-centred approach (Cools et al., 2018), according to which parents have the right to decide for their children.

The statement acknowledged a lack of evidence in support of early surgeries, but it did not prohibit or strictly advise against them (Hughes et al., 2006). Even though there have been calls for a moratorium on non-consensual surgeries by activists (Carpenter, 2016; Davis, 2016; Holmes, 2008), medical professionals (Cools et al., 2018; Wiesemann et al., 2010) and international human rights bodies (UN Human Rights Council, 2015; European Union Agency for Fundamental Rights, 2015) the evidence suggests that the surgeries continued to be performed at the same rate (Creighton et al., 2012; Michala et al., 2014). What is more, the call for more collaboration among health care professionals and more psychosocial support for intersex people and their parents has also not been met in practice as the psychosocial support is sidelined against more medicalised care, and there is a lack of collaboration and exchange of practice and knowledge among the health care professionals in the teams . These trends in the care of intersex people suggest that clinical practices have not been impacted by the Chicago consensus (Carpenter, 2016). However, it is hard to tell to what extent the change has been implemented because there is a lack of research on the implementation of the consensus guidelines.

However, in 2009, one study (Lux et al., 2009) assessed the physical and psychosocial life across all DSD diagnostic groups in German-speaking countries in Europe. However, it lacked the representativeness of participants, consistent medical data, and the differences in the quality of medical care (Röhle et al., 2017). The lack of significant sample quantitative surveys on the quality of life in intersex people remained immense even a decade after the Chicago Consensus introduced new guidelines.

Quality of DSD-Life studies

The DSD-Life consortium was established among 16 European partners from Germany, France, the Netherlands, Poland, Sweden, and the United Kingdom to address the dearth of data on quality of life on long-term outcomes of surgical and hormonal therapy and psychosocial support (Röhle et al., 2017). The DSD-Life study aimed to examine and compare the long-term surgical, hormonal treatment, and psychosocial outcomes in adolescents and adults with VSC to deliver recommendations for improvement of care (Röhle et al., 2017). This chapter aims to critically assess the methodology of the DSD-Life studies to highlight the lack of historical context and paradigm change and how that impacted the study results.

I performed a PubMed database search to collect the material for the analysis. Two search terms were performed on 3 March 2023: “DSD-Life” or “DSD-Life study”. Inclusion criteria were papers published in peer-reviewed journals written in English. The research gave 35 results, next imported into Zotero and then screened based on title and abstract. The first screening gave 27 results. In the next step, the full-text versions of these articles were examined, and two more papers excluded, one because it did not refer to quality of life and the other because it was a study protocol (Röhle et al., 2017). The data from the final 25 papers was extracted by making a Microsoft Excel spreadsheet. The spreadsheet included sections for author name, year of publication, country of origin, name of the journal, study objective, methodology, sampling, measure instruments, key findings, participation rate, patient cohort, historical background, paradigm shift, medical management, ethical reflection, and study limitations.

The study protocol provided general information about the aims, methodology, and context of DSD-Life. The study was a non-interventional, clinical, cross-sectional study; the physical health data was gathered from past medical files and clinical examinations done as part of the study. The data for psychosocial health was collected through a self-reported questionnaire examining factors for special health care needs, demographics, and mental health issues (Röhle et al., 2017). The eligibility criteria for inclusion were that participants had to be intersex and older than 16 years. The participants were recruited via medical centres, the project website, and support group contact. The response rate in the study was 36.1%. Some 1,161 out of 3,217 potential participants participated in the study, and the mean age was 32.4 years. The youngest participant was 16, and the oldest was 75 (Röhle et al., 2017). The limitations of the overall study included missing data because some respondents did not complete the questionnaire or because the previous charts of older participants had been destroyed after 30 years in accordance with hospital regulations, lack of a control group, and missing consent forms (Röhle et al. 2017).The vast majority of papers were published in medical or healthcare journals (de Vries et al., 2019; Duranteau et al., 2021; Falhammar et al., 2018; Franik et al., 2022; Gehrmann et al., 2019; Gong et al., 2021; Krege et al., 2022; Kreukels et al., 2019; 2018; Liedmeier et al., 2021; Noordman et al., 2021; 2019; Nordenström et al., 2018; Nygren et al., 2019; Rapp et al., 2021; 2018; Słowikowska-Hilczer et al., 2017; Thyen et al., 2018; Tschaidse et al., 2022; van de Grift et al., 2018; van de Grift, Kreukels, and DSD-Life, 2019; van de Grift, 2021; van de Grift et al., 2022).Two papers were published in social science journals (Bennecke, Köhler, et al., 2021; Bennecke, Bernstein, et al., 2021). Only one paper was based on mixed method methodology (Duranteau et al., 2021) and the rest were quantitative methods (Bennecke, Bernstein, et al., 2021; Bennecke, Köhler, et al., 2021; Falhammar et al., 2018; Franik et al., 2022; Gehrmann et al., 2019; Gong et al., 2021; Krege et al., 2022; Kreukels et al., 2019; 2018; Liedmeier et al., 2021; Noordman et al., 2019; 2021; Nordenström et al., 2018; Nygren et al., 2019; Rapp et al., 2021; 2018; Słowikowska-Hilczer et al., 2017; Thyen et al., 2018; Tschaidse et al., 2022; van de Grift et al., 2018; van de Grift, Kreukels, and DSD-Life, 2019; van de Grift, 2021; van de Grift et al., 2022).

Half of the studies used descriptive statistics as their instruments (Bennecke, Bernstein, et al., 2021; Duranteau et al., 2021; Gehrmann et al., 2019; Gong et al., 2021; Krege et al., 2022; Kreukels et al., 2018; Noordman et al., 2019; Nordenström et al., 2018; Rapp et al., 2021; Słowikowska-Hilczer et al., 2017; Thyen et al., 2018; van de Grift, Kreukels, and DSD-Life, 2019; van de Grift et al., 2022). Less than half of the studies used linear or multiple regression analysis as their instruments

(Bennecke, Köhler et al., 2021; de Vries et al., 2019; Falhammar et al., 2018; Franik et al., 2022; Kreukels et al., 2019; Nygren et al., 2019; Rapp et al., 2018; Tschaidse et al., 2022; van de Grift et al., 2018; van de Grift, 2021).

Table 1: General qualities of the DSD-Life studies

Author	Year	Journal	Methodology	Instruments	Participation rate	Patient cohort
Bennecke et. al.	2021	Archives of Sexual Behavior	quantitative study	descriptive statistics	36,10%	adolescents, adults
Bennecke et. al.	2021	The Journal of Sex Research	quantitative study	logistic regression	36,10%	adolescents, adults
de Vries et. al.	2019	Psychosomatic Medicine	quantitative study	linear regression	32,62%	adolescents, adults
Duranteau et. al.	2021	Journal of Pediatric and Adolescent Gynecology	mixed method	descriptive analysis	2,47%	adolescents, adults
Falhammar et. al.	2022	Endocrine Connections	quantitative study	logistic regression model	36,10%	adolescents, adults
Franik et. al.	2022	Endocrine Connections	quantitative study	linear regression analysis	7,11%	adolescents, adults
Gehrmann et. al.	2019	Journal of the Endocrine Society	quantitative study	descriptive analysis	3,16%	adolescents, adults
Gong et. al.	2021	Journal of the Endocrine Society	quantitative study	descriptive statistics	7,70%	adolescents, adults
Krege et. al.	2022	Journal of Clinical Medicine	quantitative study	descriptive analysis	7,84%	adolescents, adults
Kreukels et. al.	2019	Journal of Sex & Marital Therapy	quantitative study	logistic regression analysis	36,10%	adolescents, adults
Kreukels et. al.	2018	The Journal of Sexual Medicine	quantitative study	descriptive analysis	36,10%	adolescents, adults
Liedmeier et. al.	2021	Comprehensive Psychoneuroendocrinology	quantitative study	descriptive, inferential analysis and multivariate analysis	36,10%	adolescents, adults
Noordman et. al.	2019	Pediatric endocrinology reviews: PER	quantitative study	descriptive analysis	11,39 %	adolescents, adults
Noordman et. al.	2021	Comprehensive Psychoneuroendocrinology	quantitative study	binary logistic regression, linear regression, and descriptive statistics	11,39%	adolescents, adults
Nordenström et. al.	2018	Clinical Endocrinology	quantitative study	descriptive analysis	36,10%	adolescents, adults
Nygren et. al.	2019	Clinical Endocrinology	quantitative study	linear regression analysis	36,10%	adolescents, adults
Rapp et. al.	2021	Journal of Pediatric Urology	quantitative study	descriptive analysis	48% of 36,10 %	adolescents, adults

Author	**Year**	**Journal**	**Methodology**	**Instruments**	**Participation rate**	**Patient cohort**
Rapp et. al.	2018	Health and Quality of Life Outcomes	quantitative study	multiple linear regression	36,10%	adolescents, adults
Słowikowska-Hilczer et. al.	2017	Fertility and Sterility	quantitative study	descriptive analysis	36,10%	adolescents, adults
Thyen et. al.	2018	BMC health services research	quantitative study	descriptive analysis	29,4%	adolescents, adults
Tschaidse et. al.	2022	Journal of Clinical Medicine	quantitative study	multiple linear regression	6,31%	adolescents, adults
van de Grift	2021	Psychological Medicine	quantitative study	linear regression analysis	28,0%	adolescents, adults
van de Grift et. al.	2019	Human Reproduction	quantitative study	descriptive analysis	21,6%	adolescents, adults
van de Grift et. al.	2022	BJU International	quantitative study	descriptive analysis	34,0%	adolescents, adults
van de Grift et. al.	2018	Health Psychology	quantitative study	linear regression analysis	36,10%	adolescents, adults

The vast majority of papers studied the entire population of people with VSC (Bennecke, Bernstein, et al., 2021; Bennecke, Köhler, et al., 2021; de Vries et al., 2019; Falhammar et al., 2018; Kreukels et al., 2019; 2018; Liedmeier et al., 2021; Nordenström et al., 2018; Nygren et al., 2019; Rapp et al., 2021; 2018; Thyen et al., 2018; van de Grift et al., 2018; Słowikowska-Hilczer et al., 2017). Two studies focused on Turner Syndrome (Noordman et al., 2019; 2021) and two more centred on the XY-DSD category (Gong et al., 2021; van de Grift, 2021). One study examined only CAH females (Tschaidse et al., 2022), one studied only males (Gehrmann et al., 2019), and one focused on the entire CAH category (Krege et al., 2022). In one paper, authors studied people with CAIS (Duranteau et al., 2021), another focused on Klinefelter syndrome (Franik et al., 2022), one examined females with any DSD classified variation (van de Grift, Kreukels, and DSD-Life, 2019), and in another, the authors focused on the participants who underwent masculinising surgery (van de Grift et al., 2022).

Historical background about the optimal gender policy and its related issues were referenced in only two papers (van de Grift et al., 2018; van de Grift, 2021). One paper focused on the acceptance of diagnosis (van de Grift, 2021) in participants on the XY-DSD spectrum, among whom some underwent genital surgery. The study limitations of the paper were inclusion criteria that allowed only people who fit within a gender binary to be included, low participation rate, selection bias, and no definitive conclusions. The Optimal Gender Policy is described, and a critique is provided. The other paper (van de Grift et al., 2018) examined body image and related mental health in the entire population, where some participants underwent genital surgery, hormonal treatment, or both. In the paper, the authors briefly mentioned the Optimal Gender Policy that advised doctors and parents to be secretive to prevent psychological harm. The secretiveness of the doctors is in contrast with the latest findings, which suggest that more medical professionals openly share information with young intersex people about their variation (Roen et al., 2023; L-M Liao et al., 2010).

Table 2: Historical background, paradigm shift and ethical reflection

Author	Historical background	Mention of paradigm shift	Medical management	Ethical reflection
Bennecke et. al.	No	No	vaginoplasty, clitoris reduction, hypospadias repair	Yes
Bennecke et. al.	No	Yes	No	No
de Vries et. al.	No	No	No	No
Duranteau et. al.	Yes	Yes	gonadectomy, vaginoplasty, vaginal dilation, genital examination	No
Falhammar et. al.	No	No	No	No
Franik et. al.	No	No	No	No
Gehrmann et. al.	No	No	Yes, hormone therapy	No
Gong et. al.	No	No	hormone replacement therapy, gonadectomy	No
Krege et. al.	No	Yes	masculinisation, feminisation, genital surgery, clitoris surgery and vaginoplasty, vaginal dilatation	No
Kreukels et. al.	No	No	Genital surgery, but not in all participants.	No
Kreukels et. al.	No	No	No	Yes
Liedmeier et. al.	No	No	No	No
Noordman et. al.	No	No	No	No
Noordman et. al.	No	No	No	No
Nordenström et. al.	No	No	No	No
Nygren et. al.	No	No	No	No
Rapp et. al.	No	Yes	Yes, genital surgery	Yes
Rapp et. al.	No	Yes	No	No
Słowikowska-Hilczer et. al.	No	No	gonadectomy, ART,	No
Thyen et. al.	No	No	No	No
Tschaidse et. al.	No	No	hormone therapy and genital surgery	No
van de Grift	Yes	Yes.	genital surgery, but not in all participants.	No
van de Grift et. al.	No	No	estrogen replacement treatments, gonadectomy and breast augmentation	No
van de Grift et. al.	No	No	masculinising surgery (hypospadias surgery and orchidopexy, gonadectomy, uterus removal, breast reduction).	No
van de Grift et. al.	Yes	Yes	hormone therapy and genital surgery	No

The study limitations in this paper were, to some extent, similar, as they also included selection, confirmation and recall bias, inconclusive data, and lack of representative sample.

In two papers, the past medical management is only briefly related to methodological issues such as small samples and missing data (Bennecke, Bernstein, et al., 2021; Duranteau et al., 2021). Only in the paper by Bennecke and colleagues (Bennecke, Bernstein, et al., 2021) is there a short ethical reflection on the timing of surgery. The authors state that a decision about surgery involves a clash of values, which should not be resolved based on the attitudes of a majority because patient autonomy is essential. It is also because young children cannot exercise autonomous decision-making. Therefore, the parents should be presented with different options when discussing surgery at the legislative level. The drawback of the study was the selection of respondents who were familiar with the ethical debate on genital surgery alongside the absence of participants who were not familiar with information on genital surgery, whose inclusion would have provided different insights and a more nuanced perspective on genital surgery. In the study by Duranteau and colleagues (Duranteau et al., 2021), the list of limitations is longer because it involved the previously mentioned selection bias, plus missing data, small sample sizes, a lack of representativeness, and the fact that the assessment was based on data from the Optimal Gender Policy.

Two more papers briefly mentioned the change of surgical techniques from the Optimal Gender Policy era to post-Chicago Consensus statement time (Słowikowska-Hilczer et al., 2017; Tschaidse et al., 2022). None of the studies included ethical reflection, even though in one study (Tschaidse et al., 2022), CAH female participants underwent either genital surgery or hormone therapy. In the other study (Słowikowska-Hilczer et al., 2017), some of the participants from the entire DSD spectrum underwent gonadectomy or were provided with some form of assisted reproductive technology. The study limitations by Słowikowska-Hilczer and colleagues (Słowikowska-Hilczer et al., 2017) included selection bias, missing data, and the assessment based on historical data. In contrast, the limitation of the study that focused on body image and received psychosocial support in CAH females by Tschaidse and colleagues (Tschaidse et al., 2022) was the low rate of participants who received psychosocial support.

Paradigm shift in the consensus statement is mentioned in one-fifth of the papers, but it is not examined in depth (Bennecke, Köhler et al., 2021; Rapp et al., 2018; van de Grift et al., 2018; Duranteau et al., 2021; Krege et al., 2022; Rapp et al., 2021). In three papers, the paradigm shifts only referred to vocabulary (Bennecke, Köhler et al., 2021; Rapp et al., 2018; van de Grift et al., 2018). One mentioned the change in gonadectomy practice (Duranteau et al., 2021); in the second, the change in providing information on surgery to young children is shortly sketched out (Krege et al., 2022); and in the third, the change was examined in terms of diagnostics (Rapp et al., 2021). Two further studies did not mention any paradigm shift but only quoted consensus statements (Bennecke, Bernstein et al., 2021; Kreukels et al., 2018).

Half of the studies mention no historical background or paradigm shift (Falhammar et al., 2018; Franik et al., 2022; Gehrmann et al., 2019; Gong et al., 2021; Kreukels et al., 2019; Liedmeier et al., 2021; Noordman et al., 2021; Nordenström et al., 2018; Nygren et al., 2019; Thyen et al., 2018; van de Grift, Kreukels and DSD-Life, 2019; van de Grift et al., 2022). The study limitations in these studies included selection bias, missing data, time-consuming questionnaires, lack of control groups, retrospective data collection, assessment based on historical data, low participation rate, and lack of standardised and documented clinical findings.

Conclusion

DSD-Life project addressed the long-standing gap in research on quality of life. However, as the present literature review revealed, its conceptual framework and methodology left some critical factors in the quality of life unaddressed. First, the unaddressed factors are primarily related to past practices and age differences as participants' ages vary from 16 to 67 years, suggesting that different techniques had treated people of different ages and had different responses and the mention of paradigm shift. It is not insignificant to highlight the historical background because the guidelines and past practices were aimed at different goals than current guidelines and practices. Past and present practice, despite the change in discourse, impact the quality of life of intersex people, but to differing levels which are not acknowledged in the DSD-Life studies. The time differences must be considered when assessing the quality of life in the intersex population, as children born before the implementation of the Chicago Guidelines in 2006 received different care than children born after the consensus statement (Eder, 2022; Karkazis, 2008; Kessler, 1998).

Second, the care under optimal gender policy focused on gender identity and surgical adaptation to the assigned gender of rearing, which substantially impacted the quality of life in intersex children. The consensus statement guidelines shifted the focus on physical and mental health in intersex and children. However, the DSD-Life study failed to acknowledge different management approaches in the conceptual framework of the study protocol.

Third, the lack of analysis and acknowledgement of conceptual differences in medical management before and after the consensus statement only begs the question of how the results of the DSD study can be adequately assessed. It leads one to legitimately think that the omission of conceptual differences under two different paradigms in the DSD-Life studies served to support the medical establishment in continuing with the old practices under a new name. This idea is clearly supported by the data after the consensus statement's introduction, which shows that the surgery rate has not substantially changed (Creighton et al., 2012; Michala et al., 2014; Klöppel, 2016).

The limitations in the studies that provided the account of the paradigm shift and historical background do not in any way support the questioning of the utility of assessing the outcomes in the DSD-Life study. The limitations include the use of historical data, selection bias, missing data, low participation rate, and lack of control groups, which supports the thesis that it is important to consider the historical background and paradigm shift in assessing the DSD-Life studies. The selection bias and low participation, as relatively common limitations, helped researchers find the answers they were expecting, which is not particular to the DSD-Life study. However, it is important to point out because these two limitations contributed to the more specific issues in assessing the data related to the use of historical and missing data. The importance of historical data is decontextualised and diluted by selecting the participants before the paradigm shift whose experience is similar to those who were treated afterwards. Moreover, the missing data, due to its destruction following hospital regulations, excludes the issues of deplorable outcomes of medical management in many individuals with VSC. Deplorable outcomes, data destruction, and missing data prevent the longitudinal assessment and comparison of their quality of life and cross-sectional assessment and comparison with the other VSC cohorts.

The assessment of outcome in DSD-Life studies based on historical background would provide more nuanced results. The results would indicate differences in quality of life in intersex people and among generations. It would supply a more refined picture of how different medical treatments impact sexuality, friendships, family relationships, and overall life satisfaction in intersex people. Despite methodological shortcomings, the DSD-Life studies should not be discarded as they provide a large-scale insight into the physical and mental health of intersex populations that is rare, if not nonexistent. Furthermore, this calls for future research that will engage with the historical background when assessing the quality of life in intersex people.

Addendum

The following recommendations for future research guidelines on the care for people with VSC came from discussions about this paper between myself and my supervisor, dr. Jürg Streuli.

- Inclusive Research Design: People with VSC and their parents should be included in the research from the initial stages of research design. Their insights can shape research questions and methodologies to address their needs better.
- Ethical Considerations: Future research should abide by ethical standards ensuring participant privacy, informed consent, and sensitivity to personal narratives.
- Co-Creation of Knowledge: Individuals with healthcare experiences should actively contribute to interpreting findings, and their perspectives should co-write the research narrative.

- Community Engagement: Healthcare professionals, peer groups, and advocacy organisations should collaborate to keep research aligned with the community's evolving needs.
- Dissemination and Accessibility: The research findings should be presented in an accessible way to people with VSC and the scientific community, using clear language, visual aids, and community-focused platforms.
- Impact and Implementation: Research with people with VSC should lead to specific positive changes, specifically to the implementation of adequate psychosocial support that would contribute to improved shared decision-making and non-medicalised and de-stigmatising psychosocial support.

References

Bennecke, Elena, Stephanie Bernstein, Peter Lee, Tim C. van de Grift, Agneta Nordenskjöld, Marion Rapp, Margaret Simmonds, et al. (2021). 'Early Genital Surgery in Disorders/Differences of Sex Development: Patients' Perspectives'. *Archives of Sexual Behavior* 50 (3): 913–23. https://doi.org/10.1007/s10508-021-01953-6.

Bennecke, Elena, Birgit Köhler, Robert Röhle, Ute Thyen, Katharina Gehrmann, Peter Lee, Anna Nordenström, Peggy Cohen-Kettenis, Clair Bouvattier, and Claudia Wiesemann (2021). Disorders or Differences of Sex Development? Views of Affected Individuals on DSD Terminology. *Journal of Sex Research* 58 (4): 522–31. https://doi.org/10.1080/00224499.2019.1703130.

Carpenter, Morgan (2016). 'The Human Rights of Intersex People: Addressing Harmful Practices and Rhetoric of Change'. *Reproductive Health Matters* 24 (47): 74–84. https://doi.org/10.1016/j.rhm.2016.06.003.

Carpenter, Morgan (2018). 'The "Normalization" of Intersex Bodies and "Othering" of Intersex Identities in Australia'. *Journal of Bioethical Inquiry* 15 (4): 487–95. https://doi.org/10.1007/s11673-018-9855-8.

Cools, Martine, Anna Nordenström, Ralitsa Robeva, Joanne Hall, Puck Westerveld, Christa Flück, Birgit Köhler, et al. (2018). Caring for Individuals with a Difference of Sex Development (DSD): A Consensus Statement. *Nature Reviews Endocrinology* 14 (7): 415–29. https://doi.org/10.1038/s41574-018-0010-8.

Creighton, Sarah, Steven D. Chernausek, Rodrigo Romao, Philip Ransley, and Joao Pippi Salle (2012). Timing and Nature of Reconstructive Surgery for Disorders of Sex Development – Introduction. *Journal of Pediatric Urology*, Working Party on DSD Evaluation. Fondation Mérieux, Annecy, France, March 14–17, 2012, 8 (6): 602–10. https://doi.org/10.1016/j.jpurol.2012.10.001.

Cresti, M., E. Nave, and R. Lala (2018). Intersexual Births: The Epistemology of Sex and Ethics of Sex Assignment. *Journal of Bioethical Inquiry* 15 (4): 557–68. https://doi.org/10.1007/s11673-018-9880-7.

Davis, Georgiann (2016). *Contesting Intersex: The Dubious Diagnosis*. New York University Press.

Diamond, Milton, and H. Keith Sigmundson (1997). Sex Reassignment at Birth: Long-Term Review and Clinical Implications. *Archives of Pediatrics & Adolescent Medicine* 151 (3): 298–304. https://doi.org/10.1001/archpedi.1997.02170400084015.

Dreger, Alice D., and April M. Herndon (2009). Progress and Politics in the Intersex Rights Movement: Feminist Theory in Action. *GLQ: A Journal of Lesbian and Gay Studies* 15 (2): 199–224.

Duranteau, Lise, Marion Rapp, Tim C. van de Grift, Angelica L. Hirschberg, Agneta Nordenskjöld, and DSD-Life group (2021). Participant- and Clinician-Reported Long-Term Outcomes After Surgery in Individuals with Complete Androgen Insensitivity Syndrome. *Journal of Pediatric and Adolescent Gynecology* 34 (2): 168–75. https://doi.org/10.1016/j.jpag.2020.11.012.

Eder, Sandra (2022). *How the Clinic Made Gender: The Medical History of a Transformative Idea*. University of Chicago Press. https://press.uchicago.edu/ucp/books/book/chicago/H/bo156724705.html.

European Union Agency for Fundamental Rights (2015). The Fundamental Rights Situation of Intersex People. https://fra.europa.eu/en/publication/2015/fundamental-rights-situation-intersex-people.

Falhammar, Henrik, Hedi Claahsen-van der Grinten, Nicole Reisch, Jolanta Slowikowska-Hilczer, Anna Nordenström, Robert Roehle, Claire Bouvattier, Baudewijntje P. C. Kreukels, Birgit Köhler, and DSD-Life group (2018). Health Status in 1040 Adults with Disorders of Sex Development (DSD): A European Multicenter Study. *Endocrine Connections* 7 (3): 466–78. https://doi.org/10.1530/EC-18-0031.

Franik, Sebastian, Kathrin Fleischer, Barbara Kortmann, Nike M. Stikkelbroeck, Kathleen D'Hauwers, Claire Bouvattier, Jolanta Slowikowska-Hilczer, et al. (2022). The Impact of Klinefelter Syndrome on Socioeconomic Status: A Multicenter Study. *Endocrine Connections* 11 (7): e220010. https://doi.org/10.1530/EC-22-0010.

Gehrmann, Katharina, Manon Engels, Elena Bennecke, Claire Bouvattier, Henrik Falhammar, Baudewijntje P. C. Kreukels, Anna Nordenstrom, et al. (2019). Sexuality in Males With Congenital Adrenal Hyperplasia Resulting From 21-Hydroxylase Deficiency. *Journal of the Endocrine Society* 3 (8): 1445–56. https://doi.org/10.1210/js.2019-00082.

Gong, Xin Li, Klemens Raile, Jolanta Slowikowska-Hilczer, Catherine Pienkowski, Marcus Quinkler, Robert Roehle, Anna Nordenström, and Uta Neumann (2021). Physical and Reported Subjective Health Status in 222 Individuals with XY Disorder of Sex Development. *Journal of the Endocrine Society* 5 (8): bvab103. https://doi.org/10.1210/jendso/bvab103.

Gramc, Martin, Jürg Streuli, and Eva de Clercq (2021). Multidisciplinary Teams Caring for People with Variations of Sex Characteristics: A Scoping Review. *BMJ Paediatrics Open* 5 (1): e001257. https://doi.org/10.1136/bmjpo-2021-001257.

Grift, Tim C. van de, Peggy T. Cohen-Kettenis, Annelou L. C. de Vries, Baudewijntje P. C. Kreukels, and null (on behalf of DSD-Life) (2018). Body Image and Self-Esteem in Disorders of Sex Development: A European Multicenter Study. *Health Psychology: Official Journal of the Division of Health Psychology, American Psychological Association* 37 (4): 334–43. https://doi.org/10.1037/hea0000600.

Grift, Tim C. van de, Baudewijntje P. C. Kreukels, and DSD-Life (2019). Breast Development and Satisfaction in Women with Disorders/Differences of Sex Development. *Human Reproduction (Oxford, England)* 34 (12): 2410–17. https://doi.org/10.1093/humrep/dez230.

Grift, Tim C. van de, Marion Rapp, Gundela Holmdahl, Lise Duranteau, Agneta Nordenskjold, and the DSD-Life Group (2022). Masculinizing Surgery in Disorders/Differences of Sex Development: Clinician- and Participant-Evaluated Appearance and Function. *BJU International* 129 (3): 394–405. https://doi.org/10.1111/bju.15369.

Grift, Tim C. van de (2021). Condition Openness Is Associated with Better Mental Health in Individuals with an Intersex/Differences of Sex Development Condition: Structural Equation Modeling of European Multicenter Data. *Psychological Medicine*, October, 1–12. https://doi.org/10.1017/S0033291721004001.

Holmes, M. Morgan (2008). Mind the Gaps: Intersex and (Re-Productive) Spaces in Disability Studies and Bioethics. *Journal of Bioethical Inquiry* 5 (2): 169–81. https://doi.org/10.1007/s11673-007-9073-2.

Hughes, I A, C Houk, S F Ahmed, P A Lee, and LWPES1/ESPE2 Consensus Group (2006). Consensus Statement on Management of Intersex Disorders. *Archives of Disease in Childhood* 91 (7): 554–63. https://doi.org/10.1136/adc.2006.098319.

Karkazis, Katrina (2008). *Fixing Sex: Intersex, Medical Authority and Lived Experience*. Duke University Press.

Kessler, Suzanne (1998). *Lessons from the Intersexed*. Rutgers University Press. https://www.amazon.com/Lessons-Intersexed-Suzanne-J-Kessler/dp/0813525306.

Klöppel, Ulrike (2006). 'Die Formierung von gender am "Naturexperiment" Intersexualität in der zweiten Hälfte des 20. Jahrhunderts'. *NTM International Journal of History & Ethics of Natural Sciences, Technology & Medicine* 14 (4): 231–40. https://doi.org/10.1007/s00048-006-0256-4.

Klöppel, Ulrike (2016). Zur Aktualität kosmetischer Operationen „uneindeutiger. *Bulletin Texte / Zentrum für Transdisziplinäre Geschlechterstudien / Humboldt-Universität zu Berlin*, no. 42: 3–85. https://doi.org/10.25595/12.

Krege, Susanne, Henrik Falhammar, Hildegard Lax, Robert Roehle, Hedi Claahsen-van der Grinten, Barbara Kortmann, Lise Duranteau, and Agneta Nordenskjöld (2022). Long-Term Results of Surgical Treatment and Patient-Reported Outcomes in Congenital Adrenal Hyperplasia—A Multicenter European Registry Study. *Journal of Clinical Medicine* 11 (15): 4629. https://doi.org/10.3390/jcm11154629.

Kreukels, Baudewijntje P. C., Peggy T. Cohen-Kettenis, Robert Roehle, Tim C. van de Grift, Jolanta Slowikowska-Hilczer, Hedi Claahsen-van der Grinten, Angelica Lindén Hirschberg, et al. (2019). Sexuality in Adults with Differences/Disorders of Sex Development (DSD): Findings from the DSD-Life Study. *Journal of Sex & Marital Therapy* 45 (8): 688–705. https://doi.org/10.1080/0092623X.2019.1610123.

Kreukels, Baudewijntje P. C., Birgit Köhler, Anna Nordenström, Robert Roehle, Ute Thyen, Claire Bouvattier, Annelou L. C. de Vries, Peggy T. Cohen-Kettenis, and DSD-Life group (2018). Gender Dysphoria and Gender Change in Disorders of Sex Development/Intersex Conditions: Results From the DSD-Life Study. *The Journal of Sexual Medicine* 15 (5): 777–85. https://doi.org/10.1016/j.jsxm.2018.02.021.

Lee, Peter A., Anna Nordenström, Christopher P. Houk, S. Faisal Ahmed, Richard Auchus, Arlene Baratz, Katharine Baratz Dalke, et al. (2016). Global Disorders of Sex Development Update since 2006: Perceptions, Approach and Care. *Hormone Research in Paediatrics* 85 (3): 158–80. https://doi.org/10.1159/000442975.

Liao, Lih-Mei, and Katrina Roen (2021). The Role of Psychologists in Multi-Disciplinary Teams for Intersex/Diverse Sex Development: Interviews with British and Swedish Clinical Specialists. *Psychology & Sexuality* 12 (3): 202–16. https://doi.org/10.1080/19419899.2019.1689158.

Liao, L-M, H Green, Sm Creighton, Ns Crouch, and Gs Conway (2010). Service Users' Experiences of Obtaining and Giving Information about Disorders of Sex Development. *BJOG: An International Journal of Obstetrics & Gynaecology* 117 (2): 193–99. https://doi.org/10.1111/j.1471-0528.2009.02385.x.

Liedmeier, Ariane, David Jendryczko, Marion Rapp, Robert Roehle, Ute Thyen, Baudewijntje P. C. Kreukels, and DSD-Life group (2021). The Influence of Psychosocial and Sexual Wellbeing on Quality of Life in Women with Differences of Sexual Development. *Comprehensive Psychoneuroendocrinology* 8 (November): 100087. https://doi.org/10.1016/j.cpnec.2021.100087.

Lux, Anke, Siegfried Kropf, Eva Kleinemeier, Martina Jürgensen, Ute Thyen, and The DSD Network Working Group (2009). Clinical Evaluation Study of the German Network of Disorders of Sex Development (DSD)/Intersexuality: Study Design, Description of the Study Population, and Data Quality. *BMC Public Health* 9 (1): 110. https://doi.org/10.1186/1471-2458-9-110.

Magubane, Zine (2014). Spectacles and Scholarship: Caster Semenya, Intersex Studies, and the Problem of Race in Feminist Theory. *Signs: Journal of Women in Culture and Society* 39 (3): 761–85. https://doi.org/10.1086/674301.

Michala, Lina, Lih-Mei Liao, Dan Wood, Gerard S. Conway, and Sarah M. Creighton (2014). Practice Changes in Childhood Surgery for Ambiguous Genitalia? *Journal of Pediatric Urology* 10 (5): 934–39. https://doi.org/10.1016/j.jpurol.2014.01.030.

Money, J., J. G. Hampson, and J. L. Hampson (1957). Imprinting and the Establishment of Gender Role. *A.M.A. Archives of Neurology and Psychiatry* 77 (3): 333–36. https://doi.org/10.1001/archneurpsyc.1957.02330330119019.

Money, John (1985). Gender: History, Theory and Usage of the Term in Sexology and Its Relationship to Nature/Nurture. *Journal of Sex & Marital Therapy* 11 (2): 71–79. https://doi.org/10.1080/00926238508406072.

Money, John (1994). The Concept of Gender Identity Disorder in Childhood and Adolescence after 39 Years. *Journal of Sex & Marital Therapy* 20 (3): 163–77. https://doi.org/10.1080/00926239408403428.

Money, John, John L. Hampson, and Joan G. Hampson (1960). Hermaphroditism: Psychology & Case Management. *Canadian Psychiatric Association Journal* 5 (2): 131–33. https://doi.org/10.1177/070674376000500214.

Noordman, Iris D., Janiëlle Aem van der Velden, Henri Jlm Timmers, Catherine Pienkowski, Birgit Köhler, Marlies Kempers, Nicole Reisch, et al. (2019). Karyotype - Phenotype Associations in Patients with Turner Syndrome. *Pediatric Endocrinology Reviews: PER* 16 (4): 431–40. https://doi.org/10.17458/per.vol16.2019.nvt.karyotypeturnersyndrome.

Noordman, Iris D., Janiëlle Aem van der Velden, Henri Jlm Timmers, Nicole Reisch, Annette Richter-Unruh, Catherine Pienkowksi, Nel Roeleveld, Hedi L. Claahsen-van der Grinten, and DSD-Life group (2021). Socioeconomic Status in Patients with Turner Syndrome. *Comprehensive Psychoneuroendocrinology* 5 (February): 100030. https://doi.org/10.1016/j.cpnec.2021.100030.

Nordenström, Anna, Robert Röhle, Ute Thyen, Claire Bouvattier, Jolanta Slowikowska-Hilczer, Nicole Reisch, Hedi Claahsen van der Grinten, et al. (2018). Hormone Therapy and Patient Satisfaction with Treatment, in a Large Cohort of Diverse Disorders of Sex Development. *Clinical Endocrinology* 88 (3): 397–408. https://doi.org/10.1111/cen.13518.

Nygren, Ulrika, Maria Södersten, Ute Thyen, Birgit Köhler, Agneta Nordenskjöld, and the DSD-Life Group (2019). Voice Dissatisfaction in Individuals with a Disorder of Sex Development. *Clinical Endocrinology* 91 (1): 219–27. https://doi.org/10.1111/cen.14000.

Rapp, Marion, Lise Duranteau, Tim C. van de Grift, Justine Schober, Angelica L. Hirschberg, Susanne Krege, Anna Nordenstrom, et al. (2021). Self- and Proxy-Reported Outcomes after Surgery in People with Disorders/Differences of Sex Development (DSD) in Europe (DSD-Life). *Journal of Pediatric Urology* 17 (3): 353–65. https://doi.org/10.1016/j.jpurol.2020.12.007.

Rapp, Marion, Esther Mueller-Godeffroy, Peter Lee, Robert Roehle, Baudewijntje P. C. Kreukels, Birgit Köhler, Anna Nordenström, et al. (2018). Multicentre Cross-Sectional Clinical Evaluation Study about Quality of Life in Adults with Disorders/Differences of Sex Development (DSD) Compared to Country Specific Reference Populations (DSD-Life). *Health and Quality of Life Outcomes* 16 (1): 54. https://doi.org/10.1186/s12955-018-0881-3.

Roen, Katrina, Tove Lundberg, Peter Hegarty, and Lih-Mei Liao (2023). Whose Responsibility Is It to Talk with Children and Young People about Intersex/Differences in Sex Development? Young People's, Caregivers' and Health Professionals' Perspectives. *Frontiers in Urology* 3. https://www.frontiersin.org/articles/10.3389/fruro.2023.1089198.

Röhle, Robert, Katharina Gehrmann, Maria Szarras-Czapnik, Hedi Claahsen-van der Grinten, Catherine Pienkowski, Claire Bouvattier, Peggy Cohen-Kettenis, et al. (2017). Participation of Adults with Disorders/Differences of Sex Development (DSD) in the Clinical Study DSD-Life: Design, Methodology, Recruitment, Data Quality and Study Population. *BMC Endocrine Disorders* 17 (1): 52. https://doi.org/10.1186/s12902-017-0198-y.

Rubin, David A. (2012). "An Unnamed Blank That Craved a Name": A Genealogy of Intersex as Gender. *Signs: Journal of Women in Culture and Society* 37 (4): 883–908. https://doi.org/10.1086/664471.

Słowikowska-Hilczer, Jolanta, Angelica Lindén Hirschberg, Hedi Claahsen-van der Grinten, Nicole Reisch, Claire Bouvattier, Ute Thyen, Peggy Cohen Kettenis, et al. (2017). Fertility Outcome and Information on Fertility Issues in Individuals with Different Forms of Disorders of Sex Development: Findings from the DSD-Life Study. *Fertility and Sterility* 108 (5): 822–31. https://doi.org/10.1016/j.fertnstert.2017.08.013.

Stout, Stephanie A., Margarita Litvak, Natashia M. Robbins, and David E. Sandberg (2010). Congenital Adrenal Hyperplasia: Classification of Studies Employing Psychological Endpoints. *International Journal of Pediatric Endocrinology* 2010: 191520. https://doi.org/10.1155/2010/191520.

Thyen, Ute, Till Ittermann, Steffen Flessa, Holger Muehlan, Wiebke Birnbaum, Marion Rapp, Louise Marshall, et al. (2018). Quality of Health Care in Adolescents and Adults with Disorders/Differences of Sex Development (DSD) in Six European Countries (DSD-Life). *BMC Health Services Research* 18 (1): 527. https://doi.org/10.1186/s12913-018-3342-0.

Tschaidse, Lea, Marcus Quinkler, Hedi Claahsen-van der Grinten, Anna Nordenström, Aude De Brac de la Perriere, Matthias K. Auer, and Nicole Reisch (2022). Body Image and Quality of Life in Women with Congenital Adrenal Hyperplasia. *Journal of Clinical Medicine* 11 (15): 4506. https://doi.org/10.3390/jcm11154506.

UN Human Rights Council (2015). Report of the Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment. United Nations. A/HRC/28/68. https://www.refworld.org/docid/550824454.html [accessed 21 July 2021].

Vries, Annelou L. C. de, Robert Roehle, Louise Marshall, Louise Frisén, Tim C. van de Grift, Baudewijntje P. C. Kreukels, Claire Bouvattier, et al. (2019). Mental Health of a Large Group of Adults With Disorders of Sex Development in Six European Countries. *Psychosomatic Medicine* 81 (7): 629–40. https://doi.org/10.1097/PSY.0000000000000718.

Wiesemann, Claudia, Susanne Ude-Koeller, Gernot H. G. Sinnecker, and Ute Thyen (2010). Ethical Principles and Recommendations for the Medical Management of Differences of Sex Development (DSD)/Intersex in Children and Adolescents. *European Journal of Pediatrics* 169 (6): 671–79. https://doi.org/10.1007/s00431-009-1086-x.

6.Infants, Children and Young People with Variations of Sex Characteristics: A Pan-European Survey of the Perceptions of Multidisciplinary Teams and Peer Support Organisation members

Daria Abrosimova, Martin Gramc, Surya Monro, John Stephenson, and Jürg StreuliIntroduction and background

The Chicago Consensus Statement of 2006 offered recommendations concerning transparent communication with the families of intersex children, psychosocial support, and multidisciplinary care (Hughes et al 2006). It stressed the importance of collaborative efforts between healthcare teams and individuals with Variations of Sex Characteristics (VSCs) and their families (Hughes et al 2006, Pasterski et al 2010). The Consensus Statement introduced psychosocial care for individuals with VSC as an integral part of care provided by mental health providers, assisting children with VSC and their parents/guardians in addressing matters related to sexuality, relationships, and general mental well-being (Hughes et al 2006). The statement highlighted the crucial role of psychosocial support in providing care for individuals with VSC and their families, particularly at the point of diagnosis, to aid in making appropriate care decisions (see Monro et al 2017). An update emphasised the role of psychosocial support in enabling individuals with VSC to connect with the VSC community, highlighting the importance of peer support groups in this process (Lee et al 2016). Prior studies have underlined the paramount importance of psychosocial support in caring for minors with VSC and their families (Cools et al 2018).

There is acknowledgement of the scarcity of psychosocial providers (Lee et al 2020) and some studies have found inadequate resources and quality of psychosocial support (Benneke et al 2015, Ernst et al 2018). There have been observations that psychosocial care still tends to adopt a medicalised approach, with medical professionals primarily organizing, guiding, and managing consultations on VSC (Danon and Schweizer 2020, Liao and Roen 2019). Reports have also emerged of harmful practices, for example when psychologists may be complicit in enforcing neovaginal dilation in children (Monro et al 2017).

More broadly, criticism has been directed at the Consensus Statement and its update for not adequately addressing medical practices that could have adverse consequences. Claims for changes in practice have been challenged, citing a lack of evidence (Creighton et al 2014). The perpetuation of such practices is recognised as a violation of human rights, as highlighted by various human rights bodies, including the United Nations (Karkazis 2008, Council of Europe Commissioner on Human Rights 2015, see also Carpenter 2018). These bodies advocate for restrictions on, and legal prohibition of, medically unnecessary surgeries, implementation of anti-discrimination laws, protection of the rights to private life and physical integrity, and respect for bodily autonomy (OHCHR 2019) European Agency for Fundamental Rights 2015). Some countries, such as Malta, Portugal, Iceland, Germany, Greece, and Spain, have legally prohibited medically unnecessary surgical interventions, though not all have clearly defined legal consequences for breaches of these prohibitions (Mestre 2022, Zelayandía-González 2023). These legal restrictions aim to foster improved medical care, which includes the provision of psychosocial support (von Wahl 2021).

Following a review of the literature (for example Ernst et al 2018, Danon et al 2021) , we identified gaps in knowledge in relation to several key areas, including the use of terminology, psychosocial care, and the provision of peer support. We also recognised the lack of knowledge about key issues such as attitudes to the provision of psychosocial care and medical interventions, which prompted us to conduct this pioneering survey which gathered findings from a number of European countries. The survey is innovative in including the views of both healthcare practitioners and peer support group members, including activists who provide support to families and individuals in relation to healthcare.

This chapter aims to describe the findings from the survey, including the issue of psychosocial care and other key aspects of health care practice in the field of variations of sex characteristics (often known as Disorders or differences of sex development (DSD/dsd) in medical settings).These aspects include terminology, perceived barriers to care and to medical interventions, factors influencing decision-making processes of healthcare practitioners, and attitudes about possible reasons to perform surgery.

Methods

The research was conducted during the period from October 2022 to January 2023. Informants in the field of medical care for individuals with VSC at a European level were selected using a snowball purposive selection procedure. The inclusion criteria for participants were as follows:

1. Health care professionals working in a European multidisciplinary team providing care for children with VSC and their parents/guardians, or members of peer support groups collaborating with multidisciplinary teams.
2. Medical specialists (primarily endocrinologists and urologists) or psychosocial support providers (psychologists and psychiatrists) with several years of experience in caring for children with VSC.

Ethical approval for the study was obtained from the CEBES Review Board, the ethics committee of the Institute of Bioethics and the History of Medicine, University of Zurich, in February 2022.

The participants were asked various questions, including:

- Use of terminology.
- The timing and extent/type of psychosocial support offered to parents/guardians in their current practice.
- Attitudes about the legitimacy of performing surgery on minors with VSC/DSD.
- The methods of collaboration with peer support and health care providers.
- Influences on decision making processes by healthcare practitioners.
- Barriers for minors and their parents/guardians/legal guardians.
- Perceptions of challenges faced by medical professionals.

A total of 301 participants completed surveys were received. The demographic and clinical variables collected included gender, age group, region of origin, best description of position, best description of role, health facility, and the existence of a specialised/multidisciplinary VSC/DSD care team in the participant's institution. The sample data were summarised descriptively using tabulated data and cross-tabulations for categorical items. Key variables, such as challenges faced by medical professionals (measured using 5-point Likert-style items), and methods of collaboration with healthcare providers and peer-support providers (binary Yes/No items), were represented graphically. The relationship between the type of psychosocial support and the level of practice, as well as the association between the point of implementation of psychosocial support and the level of practice, were also represented graphically. The association between the point of implementation of psychosocial support and the level of practice was tested using chi-squared testing without any prior hypotheses. No corrections for multiple comparisons were made, but may be applied informally. All analyses were based on valid responses only.

Descriptive summary of sample

Demographic and clinical variables are summarised in Table 1 below. Many questionnaire items were omitted by several respondents.

Table 1: Descriptive summary of sample

Variable	Frequency (valid %)
Gender: not specified as intersex (n=67)	
Female	40 (59.7%)
Female / non-binary	5 (7.5%)
Male	14 (20.9%)
Male/ non-binary	1 (1.5%)
Non-binary	7 (10.4%)
Gender: specified as intersex (n=16)	5 (31.3%)
Female	3 (18.8%)
Male Non-binary	3 (18.8%)
No gender designation	5 (31.3%)
Age group (n=108)	
26-40	37 (34.3%)
41-60	52 (48.1%)
61-70	17 (15.7%)
>70	2 (1.9%)
Region of origin (n=107)	
Asia	4 (3.7%)
Australia/New Zealand	4 (3.7%)
Europe	96 (89.7%)
Europe/Africa	1 (0.9%)
United States	2 (1.9%)
Best description of position (n=222)	
Provider of medical care	65 (29.3%)
Provider of psychological/social services	31 (14.0%)
Provider of peer support	84 (37.8%)
Other	42 (18.9%)
Best description of role (n=96)	
Geneticist	3 (3.1%)
Gynaecologist	3 (3.1%)
Endocrinologist	23 (24.0%)
Ethicist	1 (1.0%)
Surgeon	6 (6.3%)
Paediatrician	10 (10.4%)
Psychologist	14 (14.6%)
Psychiatrist	4 (4.2%)
Social worker	3 (3.1%)
Urologist	7 (7.3%)
Other	22 (22.9%)
Health facility (n=95)	
Public university hospital	61 (64.2%)
Public non-university hospital	17 (17.9%)
Private institution/hospital	6 (6.3%)
Other	11 (11.6%)
Specialised/multidisciplinary VSC/DSD care team in institution (n=94)	
Yes	72 (76.6%)
No	18 (19.1%)
Not sure	4 (4.3%)

Findings

Descriptive analysis was conducted on the data and this is presented below in the following order: Use of terminology, the use and types of psychosocial support, reasons perceived as legitimate for performing surgery, methods of collaboration between healthcare practitioners and peer support organisations (including activist organisations), the factors influencing decision making about care for minors with variations of sex characteristics, perceived barriers to healthcare, challenges, and some general statements.

Use of terminology

Several items elicited responses measuring respondents' use of intersex-related terminology. Respondents were asked to assess the frequency of their use of the following terms: 'intersex'; 'VSC'; DSD[8]; dsd[9]; the specific name of the condition; the specific ICD[10] code.Respondents were asked to rate their use of each term when talking with their colleagues about minors with VSC/DSD; when talking with the parents/guardians or guardians of minors with VSC/DSD; and when talking directly with minors with VSC/DSD. Each item was answered on a 5-point Likert scale, scored as follows: Never = 1 point; Almost never = 2 points; Occasionally/Sometimes = 3 points; Almost every time = 4 points; Every time = 5 points.

A measure of the frequency of use of each term of interest was derived as a simple summation of scores associated with use of the term to the three groups of interest. Hence a score from 3 to 15 could be obtained for each term used; with a score of 3 points representing a term that was never used to any of the groups of interest by the respondent concerned; and a score of 15 points representing a term that was used on every occasion to all of the groups of interest by the respondent concerned. A score of 9 points indicated medium levels of use.

The mean usage scores obtained in this way for the terminology considered for respondents who provided valid responses to all items (n=114)is shown in Figures 1a, b and c. All terminology was used with children less than with colleagues or parents/guardians. All terminology except 'variations of sex characteristics' was used less with parents/guardians than with colleagues. The specific name of the condition was the terminology used most often to all groups, with average scores of 3.51 to 3.77 representing communication levels between 'occasionally/sometimes' and 'almost every time'. The specific ICD code was used less than any other form of terminology to all groups; scores for this term represented usage of between 'never' and 'almost never'.

It may be seen that the specific name of the condition is used to all groups more than other terms. The ICD code is most rarely used.

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[8] Disorders of Sex Development.

[9] Differences of sex development.

[10] International Classification of Diseases.

Figure 1(a): Distribution of responses related to use of terminology when talking to colleagues

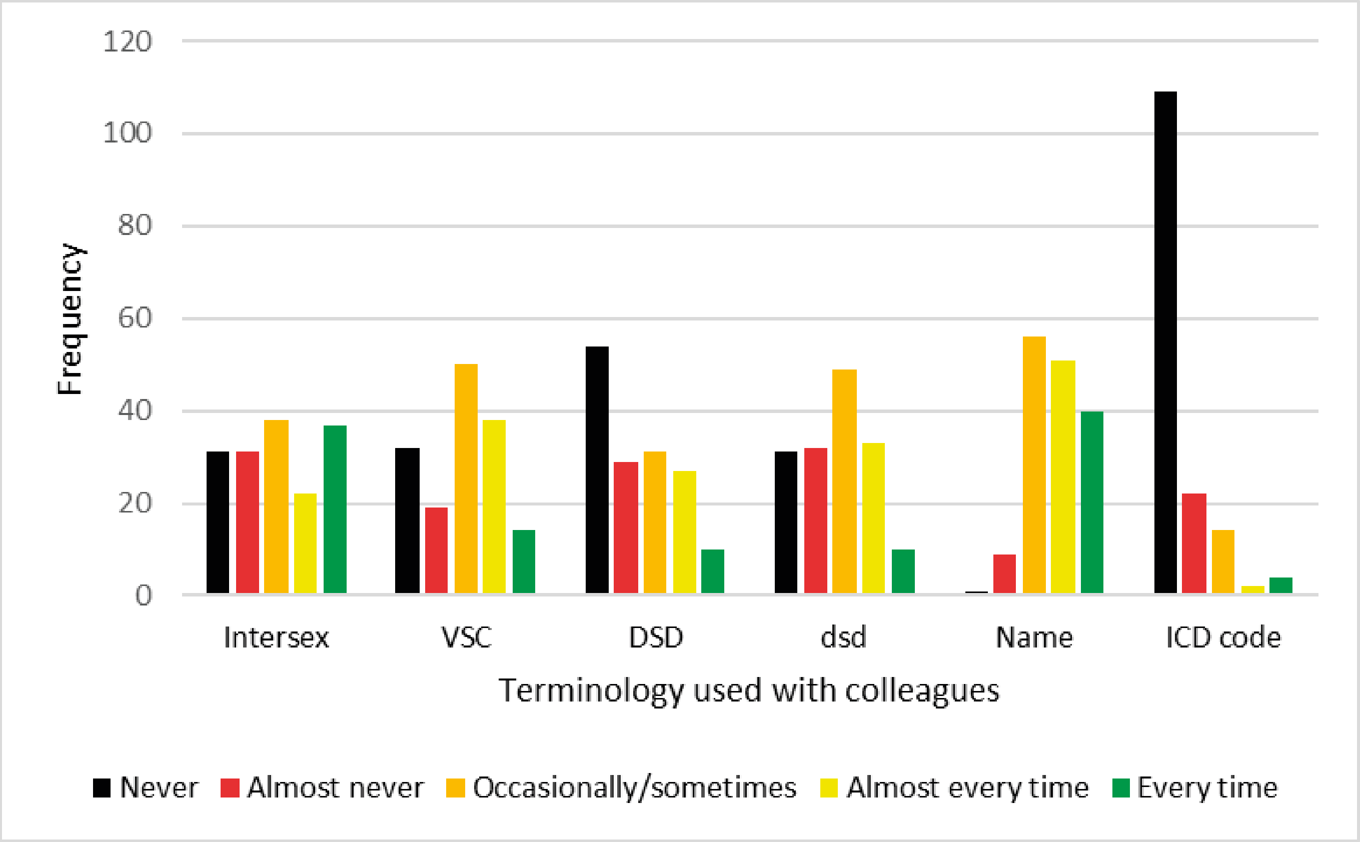


Figure 1(b): Distribution of responses related to use of terminology when talking to parents/ guardians

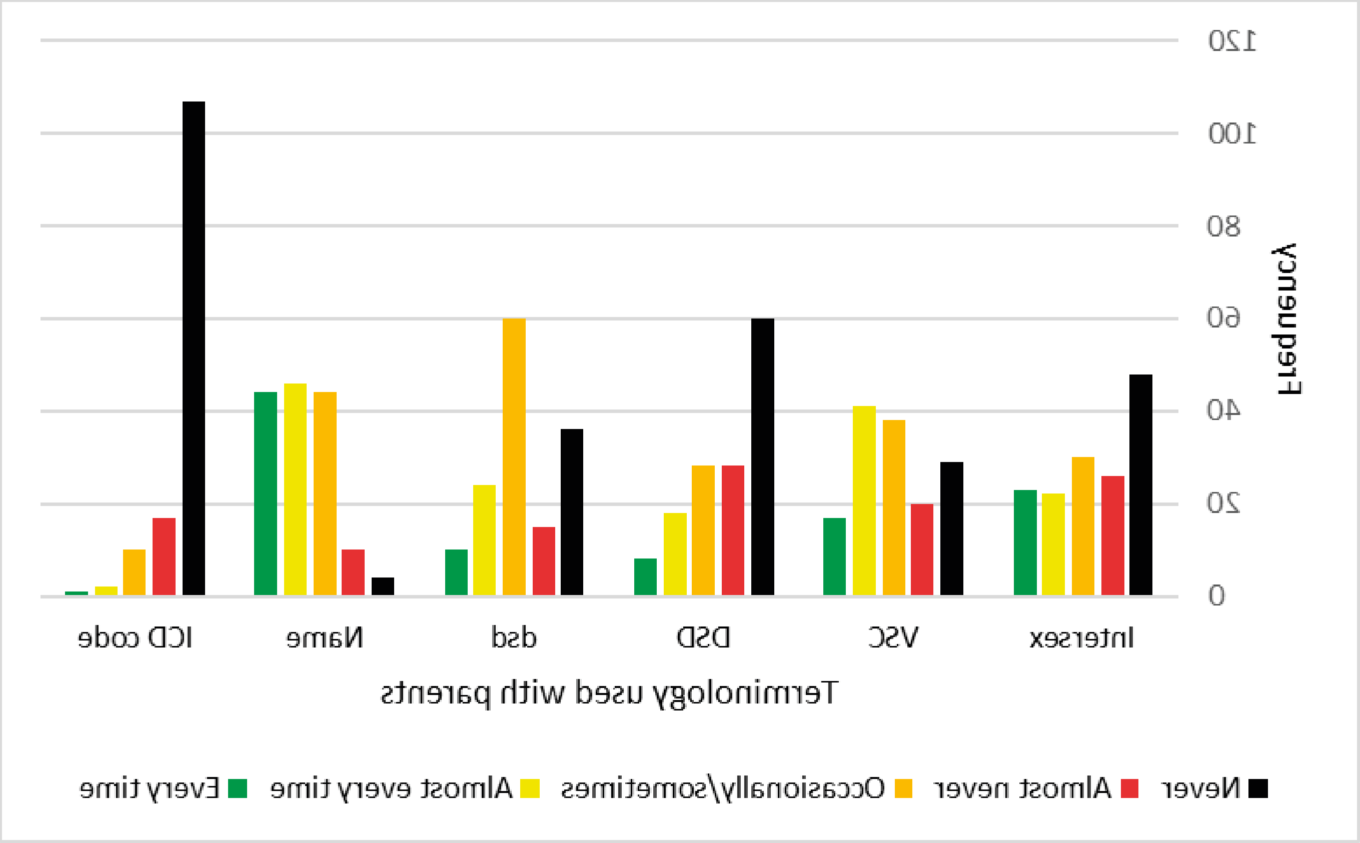
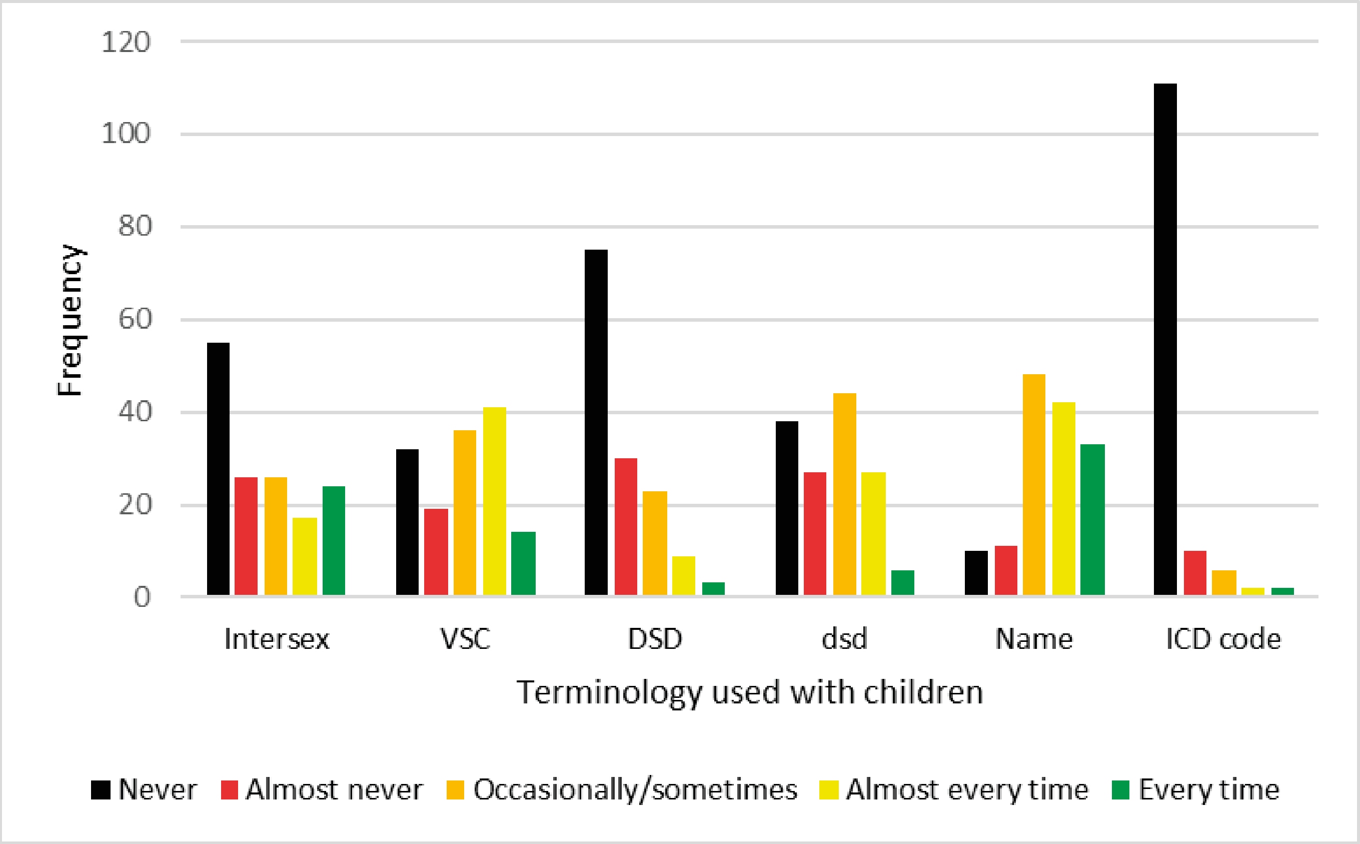


Figure 1(c): Distribution of responses related to use of terminology when talking to children



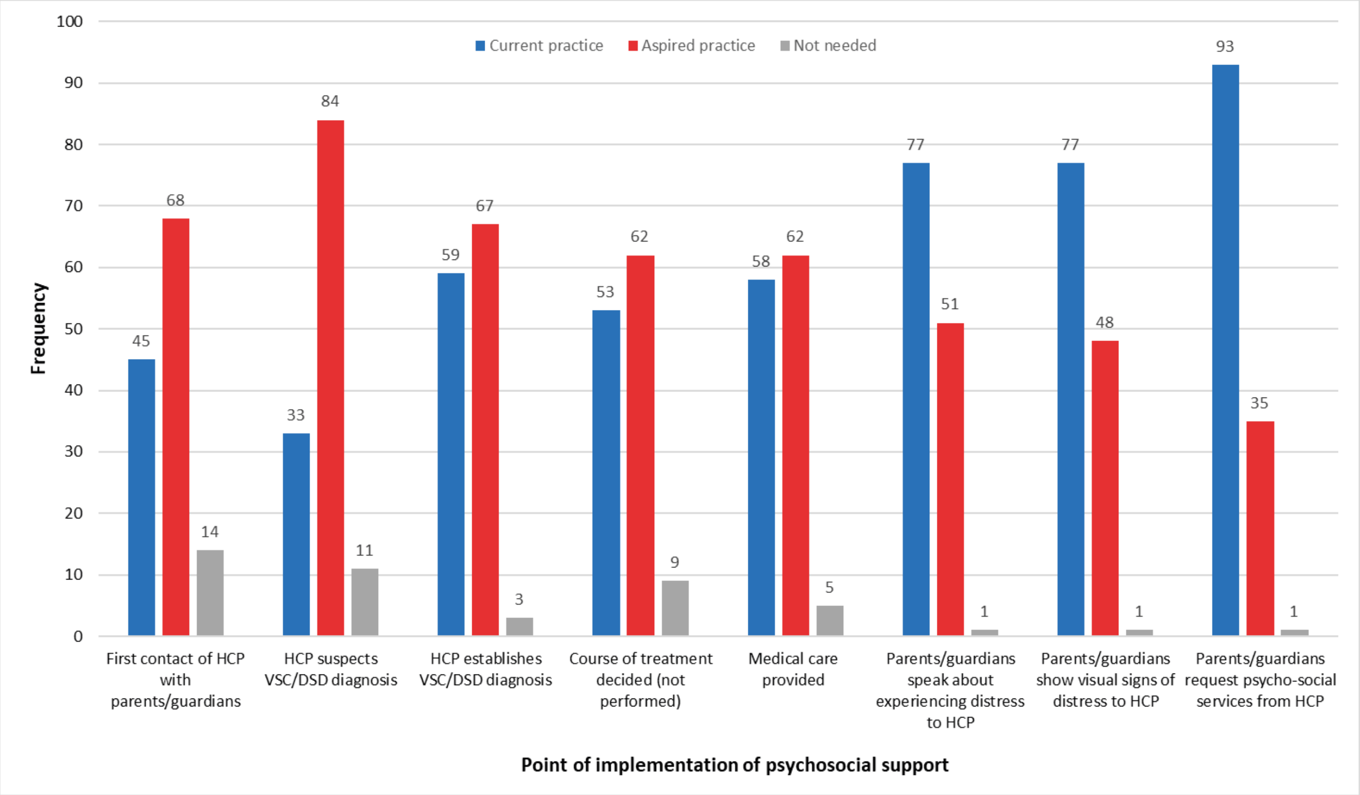
Point at which psychosocial support was implemented

Respondents were asked to state their view of when psychosocial support was implemented; considering eight possible events. Options in all cases were 'current practice" 'aspired practice' or 'not needed'. Respondents were offered to complete one of two versions of the item, with similar, but not identical, wording in both versions. These items were considered to be equivalent for the purposes of this analysis. The events offered were as follows:

- During the first contact of the healthcare provider with the parents/guardians/legal guardians of the patient
- When the healthcare provider suspects VSC/DSD diagnosis
- When the healthcare provider establishes VSC/DSD diagnosis
- When a course of treatment is decided but not performed
- When medical care was provided (surgery, hormonal treatment, etc.)
- When the parents/guardians/legal guardians speak about experiencing distress to the healthcare provider
- When the parents/guardians/legal guardians show visual signs of distress to the healthcare provider
- When the parents/guardians/legal guardians request psychosocial services from the healthcare provider

Between 121 and 125 respondents gave valid responses to each of the above items. Responses are summarised in Figure 2 below. The option 'not needed' was selected by only a very small number of respondents in each case. Current practice appears to be skewed towards implementing psychosocial support primarily on request by parents/guardians/guardians (93 respondents; 75.0%); or when parents/guardians/guardians speak about experiencing distress (77 respondents; 61.6%) or show visible signs of distress to healthcare practitioners (77 respondents; 62.6%). The most example of practice which was aspired, but not currently achieved, was the implementation of psychosocial support when a healthcare practitioner suspects a VSC/DSD diagnosis; aspired to by 84 respondents (67.2%); but current practice for only 33 (26.4%).

Figure 2: Anticipated point of implementation of psychosocial support



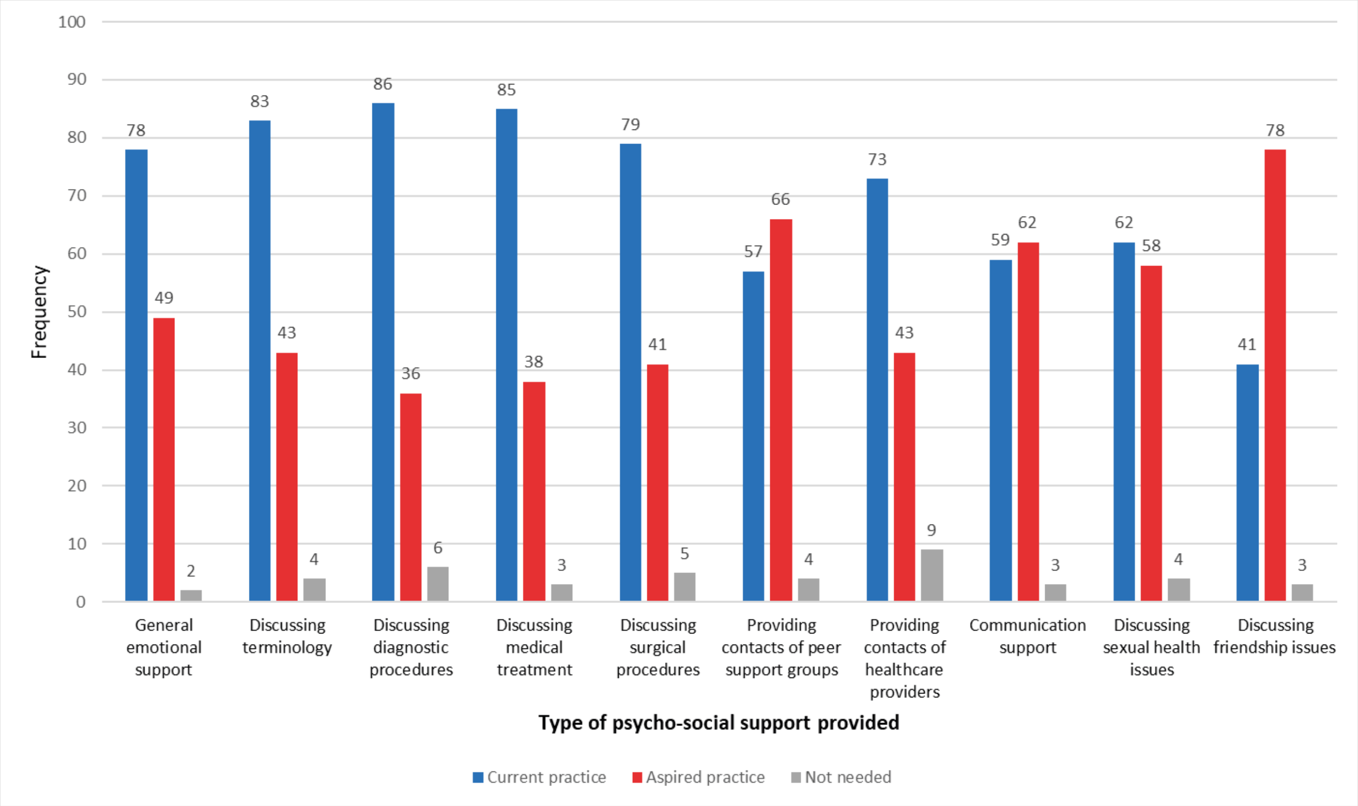
Extent of psychosocial support offered

Respondents were asked to state their view of when psychosocial support was offered in their organisation, considering 10 support activities. Options in all cases were ‘current practice” ‘aspired practice’ or ‘not needed’. Respondents were offered to complete one of two versions of the item, with similar, but not identical, wording in both versions. These items were considered to be equivalent for the purposes of this analysis. The events offered were as follows:

- General emotional support
- Discussing/explaining the terminology
- Discussing/explaining diagnostic procedures
- Discussing/explaining medical treatment
- Discussing/explaining surgical procedures
- Providing contacts of peer support groups
- Providing contacts of healthcare providers
- Communication support for parents/guardians to talk with their child, sibling, other family members
- Discussing sexual health issues (e.g. fertility, romantic relationships)
- Discussing/guiding through friendship issues

Between 119 and 126 respondents gave valid responses to each of the above items. Responses are summarised in Figure 3 below. Most common features of current practice included discussing diagnostic procedures (86 respondents; 69.4%); with similar frequencies and proportions of general emotional support, discussing terminology and discussing medical treatment. Discussing friendship issues (78 respondents; 66.1%) was an aspect of support that was aspired to substantially more than it was actually provided (41 respondents; 34.8%).

Figure 3: Extent of psychosocial support offered by respondent's organisation



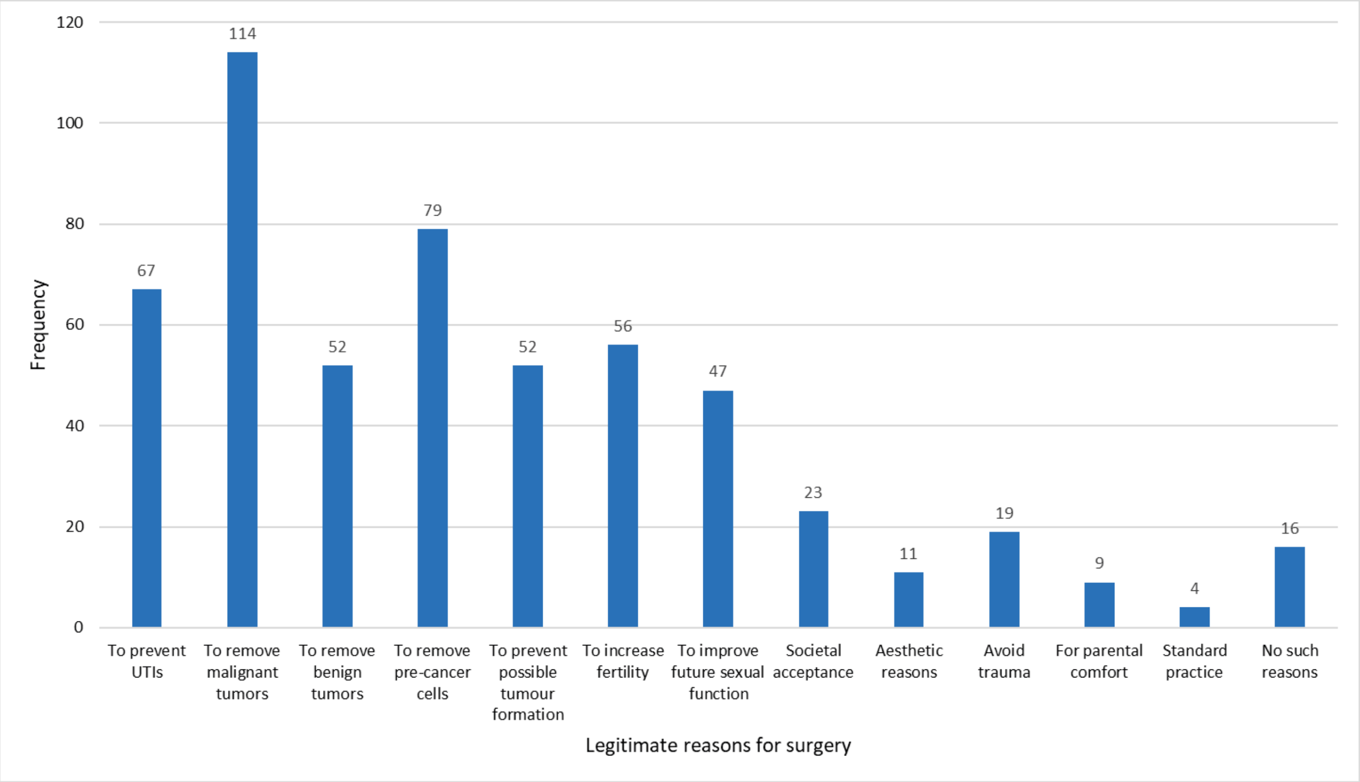
Perceptions of reasons to perform surgery

Respondents were asked whether it would be legitimate to perform surgery on minors with VSC/DSD for various reasons. Options in all case were Yes or No; more than one option could be selected by respondents. Possible reasons were provided, with the knowledge that these some 'reasons' are very problematic; the aim was only to ascertain the views of survey respondents. The 'reasons' offered were as follows:

- To prevent UTIs (Urinary Tract Infections)
- To remove malignant tumours
- To remove benign tumours
- To remove pre-cancer cells
- To prevent the possible formation of tumours
- To increase fertility
- To improve future sexual function
- To make the child accepted in society
- For aesthetic reasons
- To perform it under the age of long memory formation
- For parental comfort
- Standard practice in my profession
- There are no such reasons

134 valid responses were received; summarised in Figure 4. It may be seen that the only reasons identified by more than 50% of respondents were To remove malignant tumours and To remove pre-cancerous cells. 16 respondents (11.9% of those providing a valid response) stated that no reasons existed to perform surgery on minors with VSC/DSD.

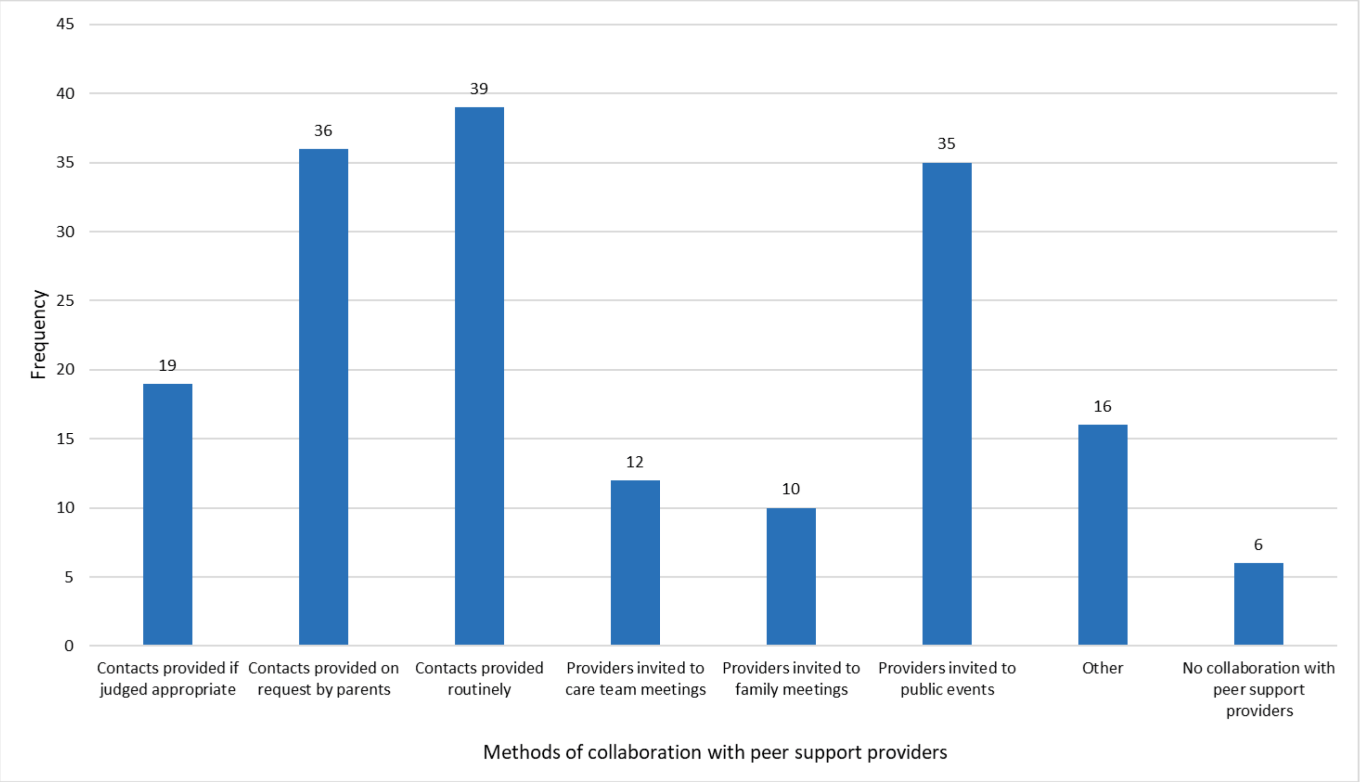
Figure 4: Perceptions of legitimate reasons perform surgery on minors with VSC/DSD



Methods of collaboration with peer support providers

Respondents were asked about the methods of collaboration with peer support providers used by their organisation. Options in all case were Yes or No; more than one option could be selected by respondents. 72 respondents provided 1 or more valid responses; summarised in Figure 5. More than half of respondents reported providing contact routinely, or on request by parents/guardians or legal guardians of the child. More than half of respondents also reported inviting peer support providers to public events. Six respondents stated that their organisation did not collaborate with peer support providers. Routine contact, contact provided on request and invitations to providers to attend public events were the most commonly reported methods of collaboration; all reported by about 50% of respondents.

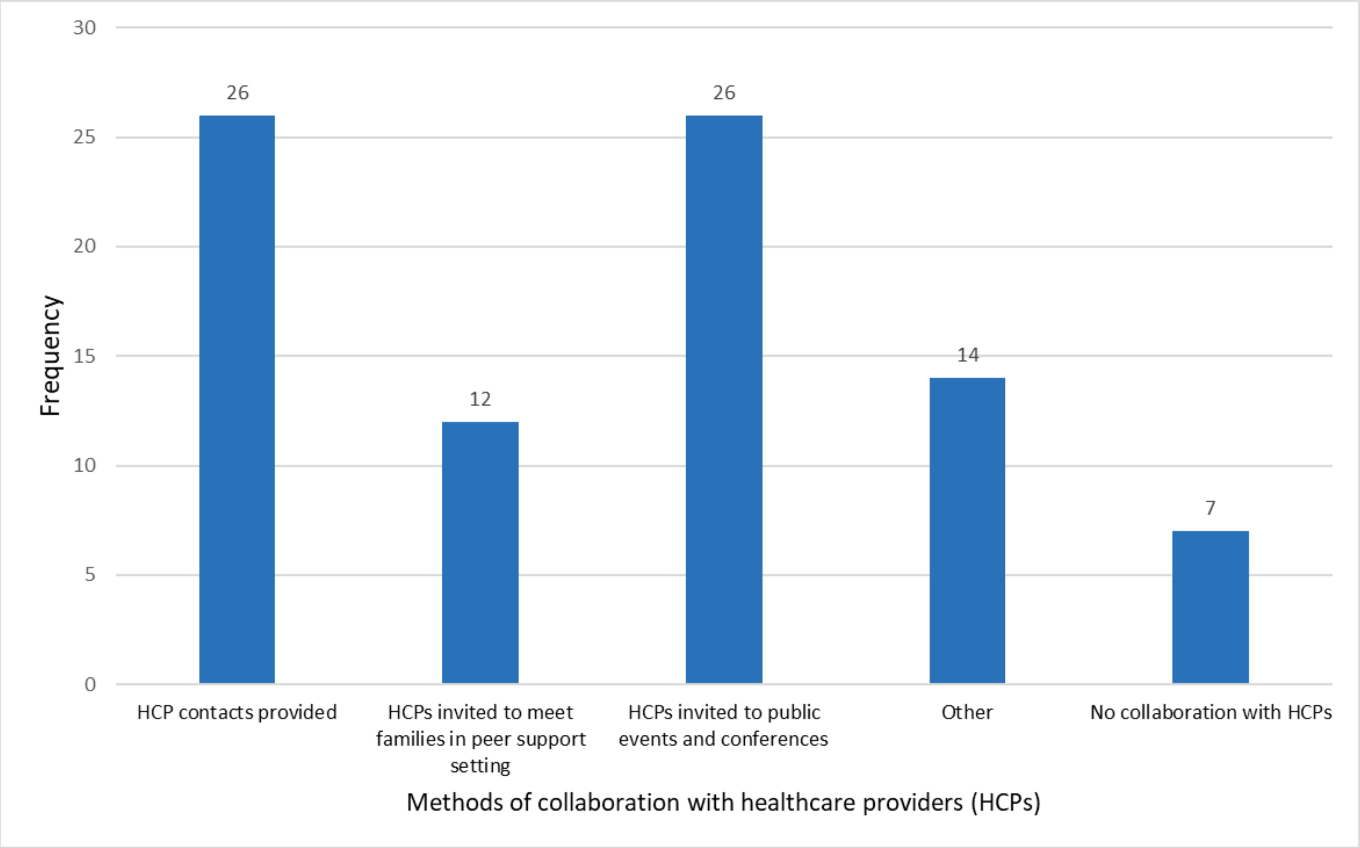
Figure 5: Methods of collaboration with peer support providers



Methods of collaboration with health care providers

Peer support respondents were asked about the methods of collaboration with healthcare providers (HCPs) used by their organisation. Options in all case were Yes or No; more than one option could be selected by respondents. 48 respondents provided 1 or more valid responses; summarised in Figure 6. More than half of respondents reported providing contact details of HCPs to the parents/guardians or legal guardians of the child. More than half of respondents also reported inviting HCPs to public events and conferences. Seven respondents (14.3% of those providing a valid response) stated that their organisation did not collaborate with HCPs.

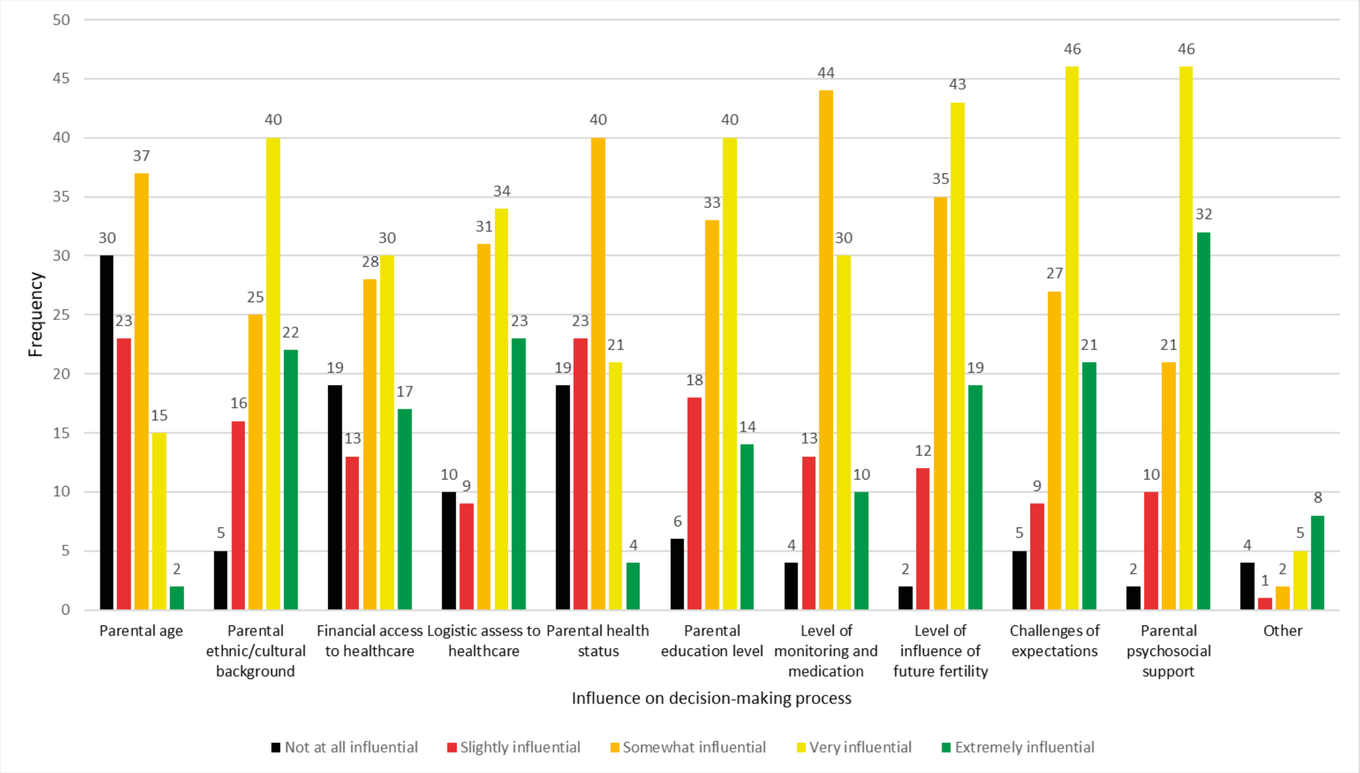
Figure 6: Methods of collaboration with health care providers



Influence on decision-making process

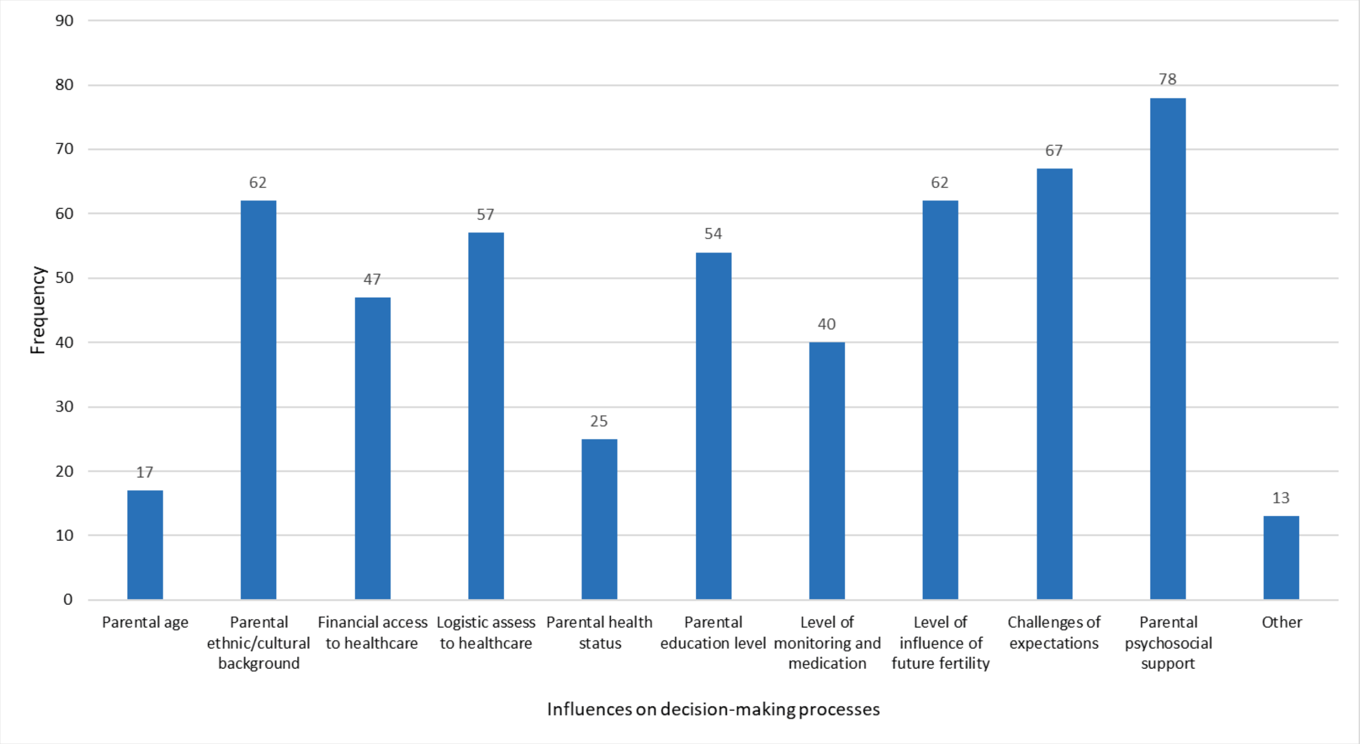
Respondents were asked about the influences which they or their organisations were subject to the decision-making process. Options in all case were Not at all influential, Slightly influential, Somewhat influential, Very influential or Extremely influential. 111 valid responses were received; summarised in Figure 7. More than half of respondents reported providing contact details of HCPs to the parents/guardians or legal guardians of the child. More than half of respondents also reported inviting HCPs to public events and conferences. Seven respondents (14.0% of those providing a valid response) stated that their organisation did not collaborate with HCPs.

Figure 7: Influences on decision-making processes



The number of respondents who rated each factor as Very influential or Extremely influential is summarised in Figure 8 below. Most were rated in this way by over 50% of respondents, with amount of parental psychosocial support available received having the highest ratings of “very influential” or “extremely influential” (78 respondents; 70.3% of valid responses). Challenges of parental expectations, parents/guardians’ ethnic or cultural backgrounds, and the level of influence of future fertility were also options selected by a clear majority of respondents.

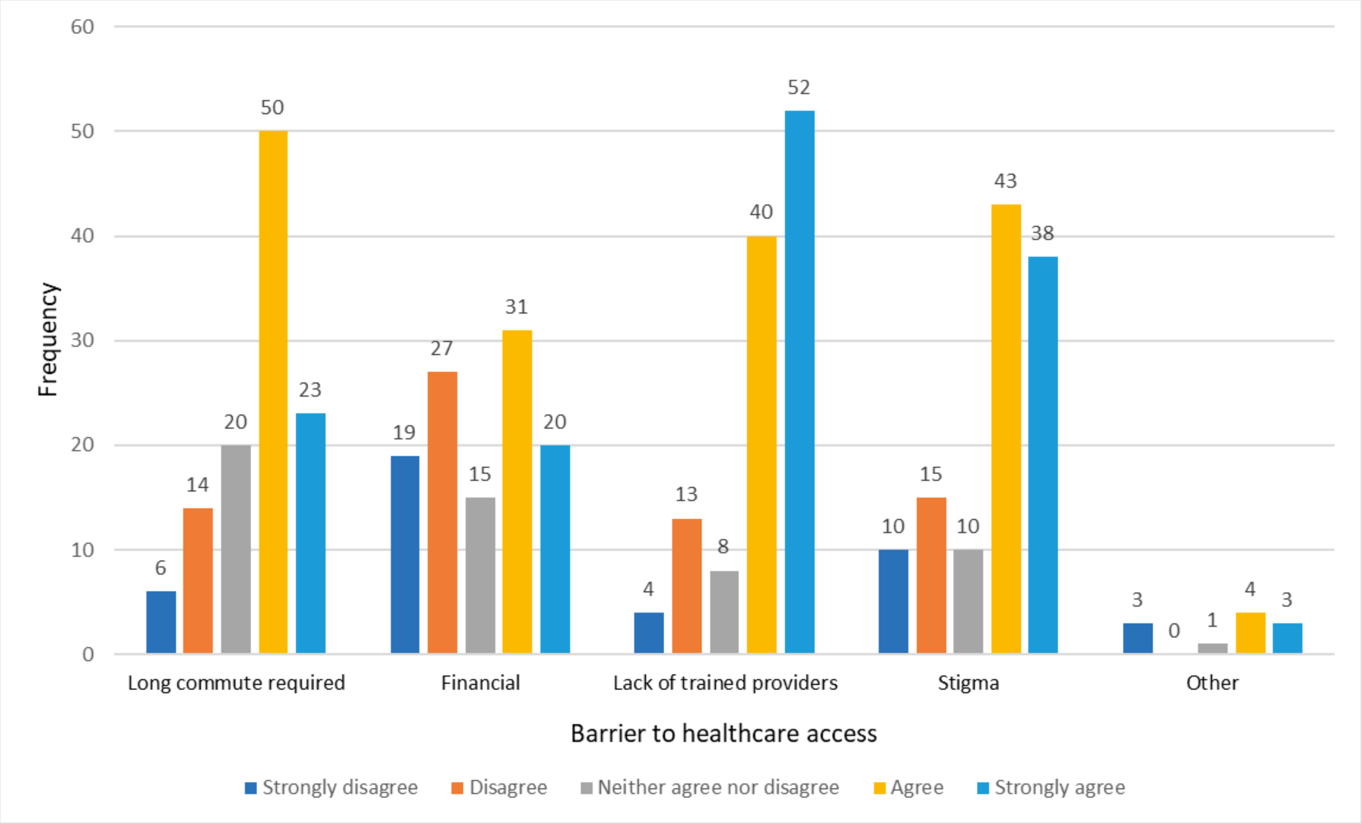
Figure 8: Proportion of respondents rating factors relating to decision-making processes as ‘very influential’ or ‘extremely influential’



Identification of barriers

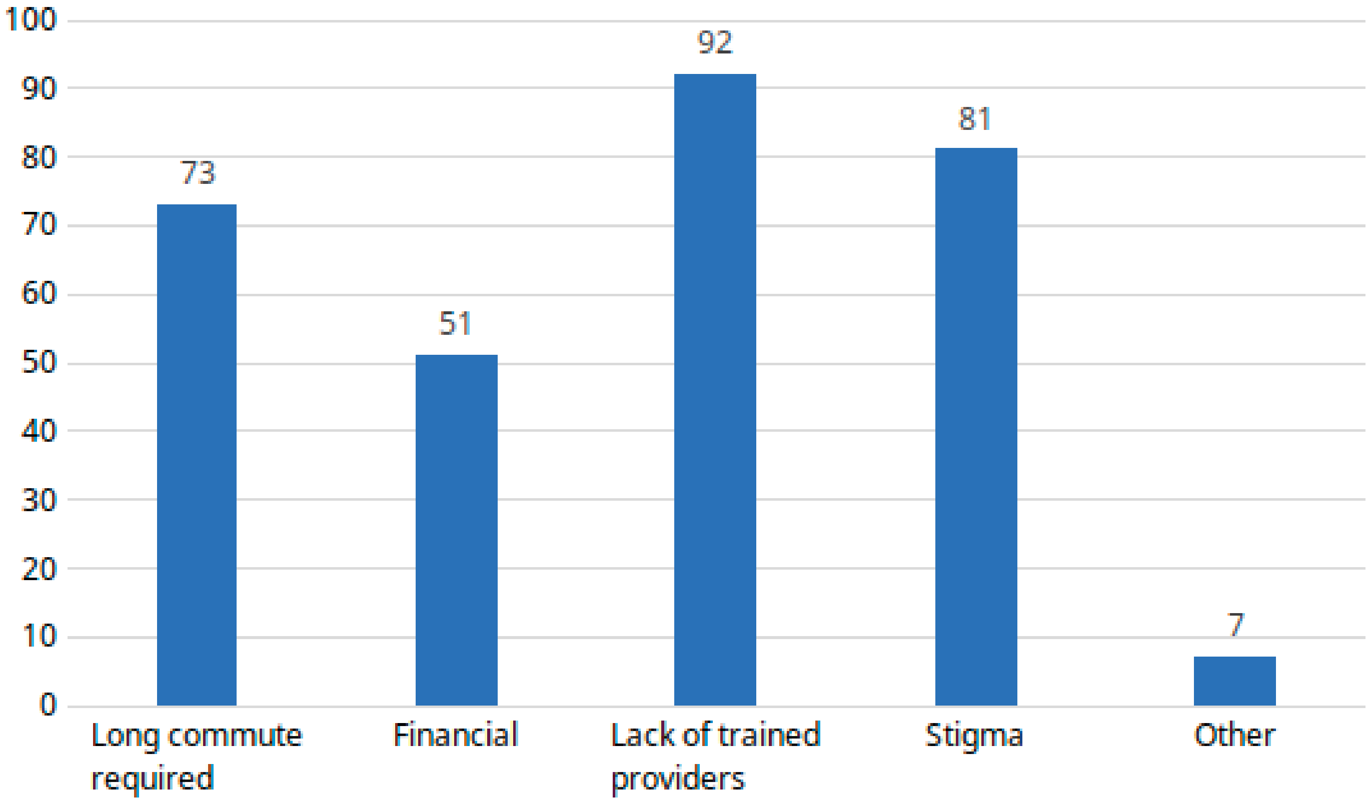
Respondents were asked to provide their perceptions about barriers to access of healthcare. Options in all case were Strongly disagree, Disagree, Neither agree nor disagree, Agree and Strongly agree. 117 valid responses were received; summarised in Figure 9. Lack of trained providers and stigma appeared to be the factors responsible for reduced access to quality healthcare.

Figure 9: Barriers to quality healthcare



The number of respondents who responded with Strongly agree or Agree to the statement that a particular factor was a barrier to health care access is summarised in Figure 10 below. Most were rated in this way by over 50% of respondents, with lack of trained providers and stigma, as noted above, as factors identified as being responsible for reduced access to quality healthcare.

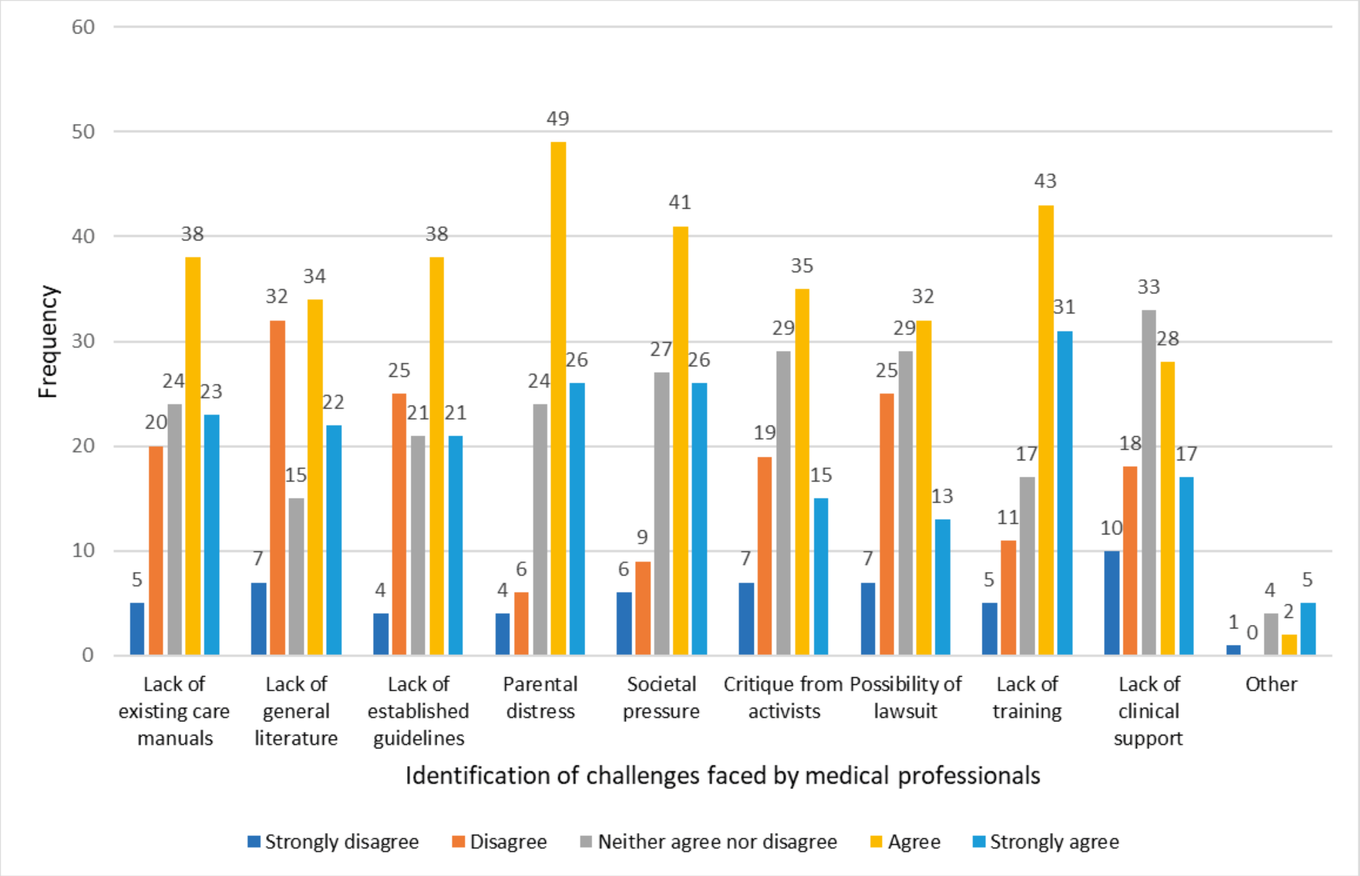
Figure 10: proportion of respondents who agreed or strongly agreed that a factor was a barrier to accessing quality healthcare



Identification of challenges faced by medical professionals

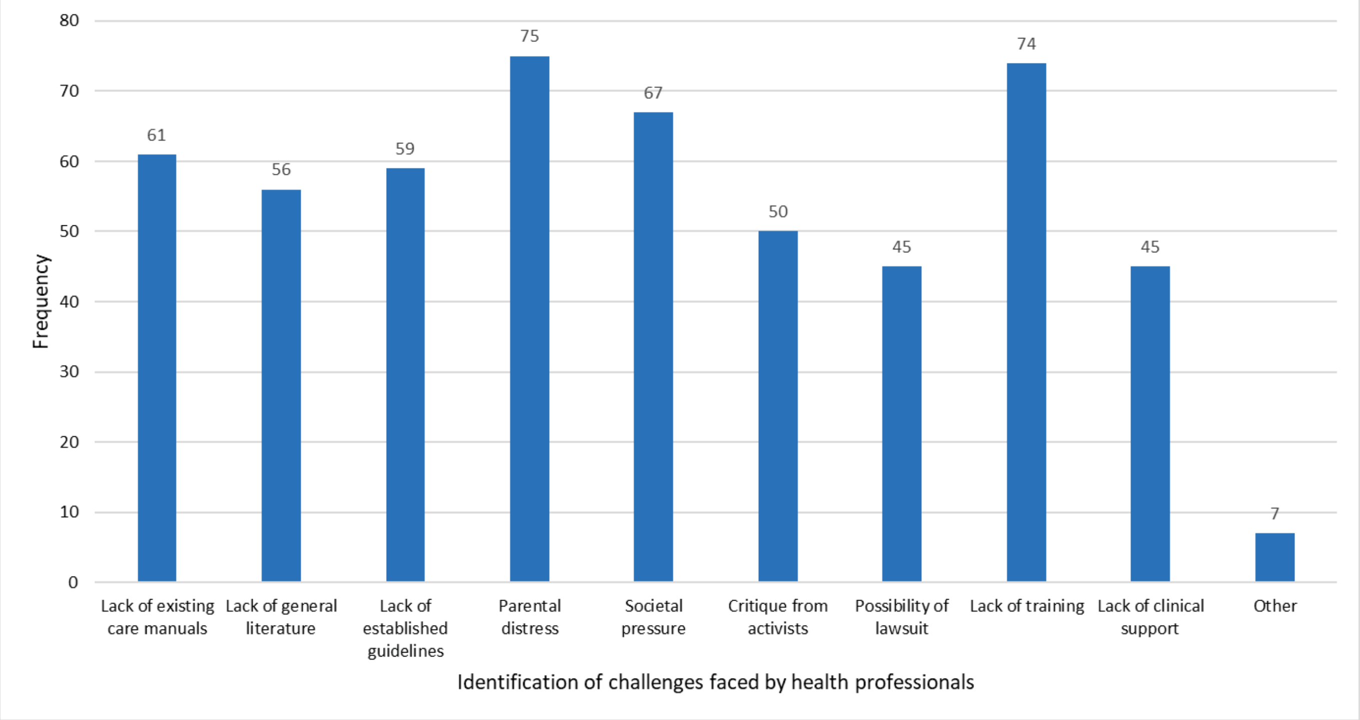
Respondents were asked to rate the extent of challenges faced by medical professionals. Options in all case were Strongly disagree, Disagree, Neither agree nor disagree, Agree and Strongly agree. 110 valid responses were received; summarised in Figure 11. Parental distress and lack of training appeared to be the most difficult challenges faced by medical professionals.

Figure 11: identification of challenges faced by medical professionals



The number of respondents who responded with Strongly agree or Agree to the statement that a particular factor represented a challenge to health care professionals is summarised in Figure 12 below. Most were rated in this way by over 50% of respondents, with amount of parental distress (75 respondents; 68.2% of valid responses) and lack of training (74 respondents; 67.3% of valid responses) having the highest proportions of respondents who Strongly agreed or Agreed that the factor represented a challenge to health care professionals.

Figure 12: Proportion of respondents who agreed or strongly agreed that a factor represented a challenge to health care professionals



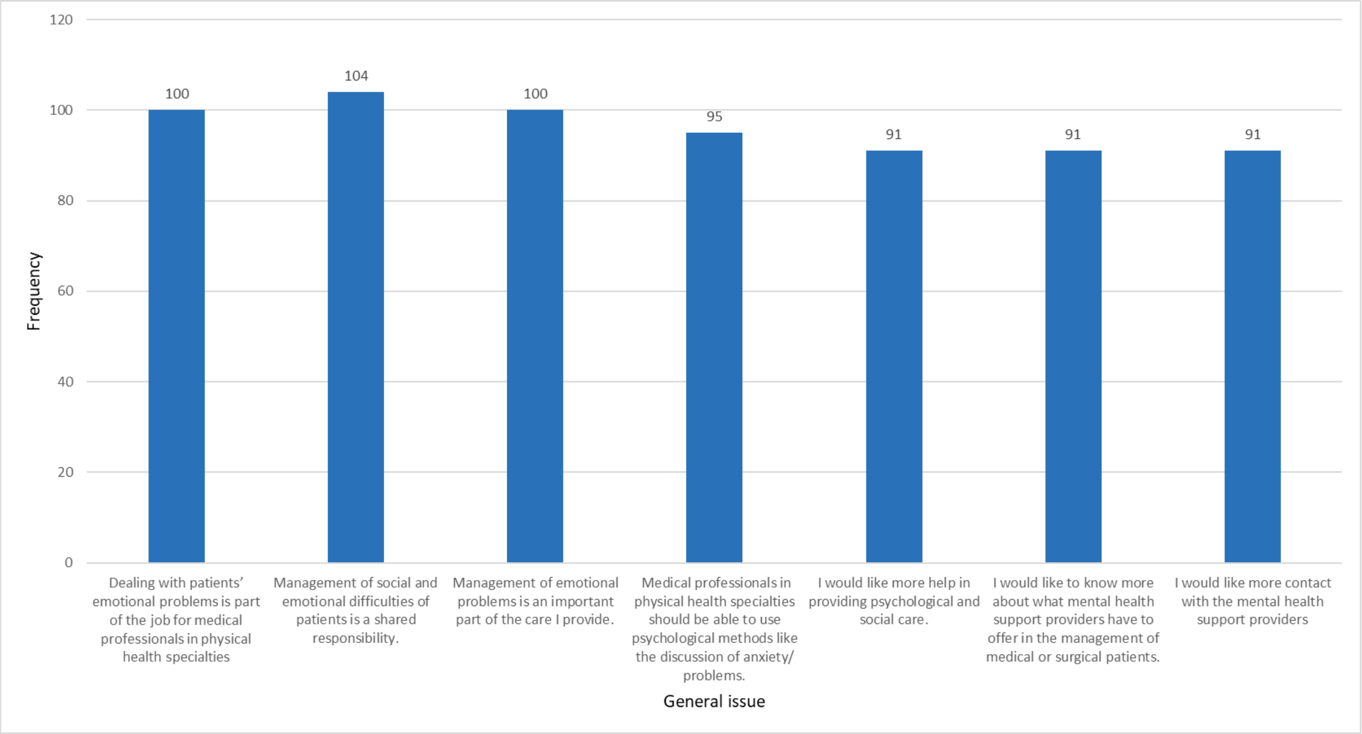
General statements

Respondents were asked whether or not they agreed with a set of general statements relating to the treatment of intersex patients. The statements were as follows:

- Dealing with patients’ emotional problems is part of the job for medical professionals in physical health specialties
- Management of social and emotional difficulties of patients is a shared responsibility.
- Management of emotional problems is an important part of the care I provide.
- Medical professionals in physical health specialties should be able to use psychological methods like the discussion of anxiety/ problems.
- I would like more help in providing psychological and social care.
- I would like to know more about what mental health support providers have to offer in the management of medical or surgical patients.
- I would like more contact with the mental health support providers

Options were Agree or Disagree in all cases. The proportion of respondents agreeing with each statement is summarised in Figure 13. It may be seen that almost all respondents agreed with all statements, with no particular statement attracting substantially higher levels of agreement than any other.

Figure 13: level of agreement with general statements about the treatment of intersex patients



Discussion and conclusion

The survey started with questions about terminology. Terminology is important in this field because the terms used have implications for the way that people with variations of sex characteristics are thought about and treated. As indicated above, the term 'Disorders of Sex Development' (DSD) was introduced in the Chicago Consensus Statement 2006 (Hughes et al 2006) and subsequently this term, and the term 'differences of sex development' are used in medical settings for people who are intersex and/or have variations of sex characteristics. Some people with variations of sex characteristics – and parents/guardians with children with these – support the use of these terms because they provide access to treatment (see Griffiths 2018). However the term 'Disorders of Sex Development' has been heavily criticised by intersex people and allies because pathologisation is used to legitimate non-consensual, harmful, irreversible medical interventions on minors (see for example Rubin 2017) and the use of 'differences of sex development (dsd)' is also problematic because of the easy slide, via the acronym, into the pathologising 'Disorders of Sex Development' (Monro et al 2017).

The survey results showed that healthcare practitioners and peer support group members used terms in varied ways, depending on who they were speaking to. Typically, the name of the medical condition was used when talking to parents/guardians and children, whilst when talking with colleagues, the term DSD or dsd was used. What is noticeable is that there appears to have been a partial shift towards the wider adoption of the non-pathologising terms 'variations in sex characteristics' and 'intersex'. Holmes (2009) discusses the rejuvenation of the notion of intersex after the introduction of DSD terminology (in the Consensus statement 2006). This rejuvenation has now been complemented by the introduction of the term 'Variations of Sex Characteristics.' This term, which was given traction when Malta gave legal protection on the grounds of 'sex characteristics' (Monro et al 2021), is now being used quite widely. Importantly, it provides a means of including all people who have some kind of sex variation, regardless of whether or not they identify as intersex.

The survey provides information about the type of psychosocial care offered, and at what point it is offered. The majority of survey respondents reported that psychosocial support currently addressed terminology, diagnostic procedures, and medical interventions. Provision of peer support contacts was less common, as was discussion of sexual health issues. What is noticeable is the gap between aspired provision and current provision; whilst 84% of respondents said the provision of psychosocial support at the point of diagnosis of a variation of sex characteristic is aspired to, only 33% reported that this was current practice. The provision of psychosocial support was more common when parents/guardians expressed distress (which could be, for example, after irreversible interventions have been performed) but even at that stage, it was not always provided. Likewise the survey findings showed there was some collaboration between healthcare practitioners and peer support groups, but where collaborations were in place, these were mostly limited to the provision of contacts or invitation to public events, rather than more substantive involvement such as inclusion in care team meetings. These findings were mirrored by reports from over half of the peer support respondents that they were involved in providing healthcare contacts to families, and were invited to healthcare-related events. These findings therefore show that overall there is a substantial way to go in ensuring that psychosocial support, including peer support, is provided to parents/guardians and carers before any irreversible medical interventions are performed. They also show that the updated Consensus guidelines concerning the inclusion of psychosocial care and peer support contacts as part of multi-disciplinary team support for families with a child with a variation of sex characteristic are not being met, especially in relation to peer support. Existing research discusses the need for the development of non-surgical care pathways and the capacity building and resourcing of peer support and intersex NGOs who can help improve healthcare (Monro et al 2017, Monro et al 2019).

The survey findings provide important information about the perceived barriers to care provision to children with variations of sex characteristics and their families. A large proportion of respondents agreed that a lack of trained providers, issues of stigma, and the long commute that families sometimes face in reaching care providers were substantial barriers to quality healthcare. The survey also indicated that factors such as perceptions of parental cultural background and educational level played an important role in decision making for healthcare professionals; this implies that healthcare professionals may be mediating a challenging world where factors such as socioeconomic inequalities are at play, but also that the subjective perceptions of these professionals may lead to inequitable care provision (for example, surgery could be used where parents are perceived as in need of a ‘quick fix’ due to traditionalist views and/or a lack of education, therefore disadvantaging a child who may have to endure a lifetime of problems resulting from surgery). Reform to ensure that appropriate care, including medical protocols and resourcing to support their implementation, can be seen as essential in the field of variations of sex characteristics (Crocetti et al 2020).

There were quite divergent views on challenges to care providers, but some interesting themes emerged. Whilst as noted above, parental distress and a lack of training were seen as the biggest challenges, other challenges were very specific to the contested nature of current medical approaches to intersex. 50% of respondents agreed or strongly agreed that critique from activists was a challenge, and 45% agreed or strongly agreed that the possibility of a lawsuit was a challenge. This could indicate that these respondents may be aware that continuation of practices of non-vital and irreversible medical interventions on minors is problematic and that these practices are becoming increasingly untenable. 67% of respondents also agreed or strongly agreed that social pressures are a challenge; whilst the type of social pressure is unstated this could refer to the pressures that healthcare professionals are placed under when families demand a quick surgical ‘fix’ for variations of sex characteristics, even though outcomes can be very poor (see Monro et al 2017). In relation to attitudes about reasons to carry out surgical interventions on minors, the survey results showed almost unanimous support for surgery to remove malignancies, which tallies with guidance from activists and others for the use of surgery on minors for critical conditions; but there is also a substantial amount of support for surgery for other reasons, including to improve sexual function and to prevent possible tumour formation. Some respondents perceived that surgeries were legitimate for social acceptance (23 out of 134), for aesthetic reasons (11 out of 134) and/or parental comfort (9 out of 134). These reasons can be criticised, for example the use of surgery to improve sexual function is due to notions that a child will have heterosexual sex in the future (Crocetti et al 2020), which may well not be the case, as intersex adults have varied sexual orientations (Monro et al 2017). In relation to the avoidance of tumours, some studies also support delaying interventions until a child is old enough to make an informed decision (Bougeneres et al 2017). The survey findings regarding surgery may indicate that attitudes and practices are changing; only 4 out of the 134 participants thought that it is legitimate as it is standard practice, but at the same time the results indicate that healthcare professionals' support for surgeries for socially-driven and non-vital reasons is still quite strong.

This study is limited in that the sample was self-selecting and modest. It does not attempt to provide generalisable results; rather, to provide an indication of key issues in some European countries, as viewed by medical professionals and peer support providers. Overall, the survey provided information about the perceptions of healthcare providers with direct involvement in medical provision to minors with variations of sex characteristics and their families, and the perceptions of peer supporters. It highlights key concerns shared across the two groups, such as the need for the early provision of psychosocial care to families who have a suspected diagnosis of a variation of sex characteristic. The chapter also indicates that there is much work to be done to ensure that appropriate healthcare is provided to infants, children and young people and their families across Europe.

References

Bennecke, E., Werner-Rosen, K., Thyen, U., Kleinemeier E., Lux, A., Jürgensen, M., Grüters, A., and Köhler. B. (2015). Subjective need for psychological support (PsySupp) in parents/guardians of children and adolescents with disorders of sex development (dsd). *European Journal of Pediatrics*, 174(10):1287–97.

Bougnères, P., Bouvattier, C., Cartigy, M., and Michala, L. (2017). Deferring surgical treatment of ambiguous genitalia into adolescence in girls with 21-Hydroxylase Deficiency: A feasibility study. *International Journal of Pediatric Endocrinology*, 2017:3.

Carpenter, M. (2018). The 'Normalisation' of Intersex Bodies and 'Othering' of Intersex Identities. In: A. Dutta, J.M. Scherpe, & T. Helms (Eds.), *The Legal Status of Intersex Persons. Intersentia* (pp. 445–514). [https://www.cambridge.org/core/books/legal-status-of-intersex-persons/normalisation-of-intersex-bodies-and-othering-of-intersex-identities/05CE047B705691070D430A0177CDD6D9 accessed 10.04.2023].

Cools, M., Nordenström, A., Robeva, R., Hall, J., Westerveld, P., Flück, C., Köhler, B., Berra, M., Springer, A., Schweizer, K., & Pasterski, V. (2018). Caring for individuals with a difference of sex development (DSD): A Consensus Statement. *Nature Reviews Endocrinology*, 14(7):415–29.

Council of Europe Commissioner of Human Rights (2015). Human rights and intersex people. Council of Europe. [https://book.coe.int/en/commissioner-for-human-rights/6683-pdf-human-rights-and-intersex-people.html accessed 05.04.2023].

Creighton, S. M., Michala, L., Mushtaq, I., Yaron, M. (2014). Childhood surgery for ambiguous genitalia: Glimpses of practice changes or more of the same? *Psychology & Sexuality*, 5(1): 34–43.

Crocetti, D., Monro, S., Vecchietti, V., Yeadon-Lee, T. (2020) 'Towards an Agency-based Model of Intersex, Variations of Sex Characteristics (VSC), and DSD/dsd Health', *Culture, Health and Sexuality*, 23(4), 500-515.

Danon, L. M., Schweizer, K. (2021). Psychosocial approaches and discursive gaps in intersex healthcare: Findings from an Israeli–German action research study. *Culture, Health and Sexuality*, 23(4): 441-456.

Ernst, M. M., Liao, L. M., Baratz, A. B., & Sandberg, D. E. (2018). Disorders of Sex Development/ Intersex: Gaps in psychosocial care for children. *Pediatrics*, 1;142(2): e20174045.

European Union Agency for Fundamental Rights. (2015). The fundamental rights situation of intersex people. [https://fra.europa.eu/en/publication/2015/fundamental-rights-situation-intersex-people accessed 20.04.2021]

Holmes, M. (2009). ‘Introduction: Straddling past, present and future’. In: M. Holmes (Ed.) *Critical Intersex* (pp. 1-15) Ashgate Publishing Limited.

Hughes, I. A., Houk, C., Ahmed, S. F, & Lee P. A. (2006). Consensus statement on management of intersex disorders. *Journal of Pediatric Urology*, 2(3):148–62.

Karkazis, K. (2008). Fixing Sex: *Intersex, Medical Authority and Lived Experience*. Duke University Press.

Lee, P. A., Fuqua, J. S., Houk, C., P., Kogan, B. A., Mazur, T., Caldamone, A. (2020). Individualized care for patients with intersex (disorders/differences of sex development): part I. *Journal of Pediatric Urology*, 16(2):230–7.

Lee, P. A., Nordenström, A., Houk, C. P., Ahmed, S. F., Auchus, R., Baratz, A., Baratz Balke, K., Liao, L. M., Looijenga 3rd, L. H. J., Mazor, T., Meyer-Bahlburg, H. F. L., Mouriquand, P., Quigley, C.A., Sandberg, D. E., Vilain, E., Witchel, S., and Global DSD Update Consortium. (2016). Global Disorders of Sex Development update since 2006: Perceptions, approach and care. *Hormonal Research in Paediatrics*, 85(3):158–80.

Liao, L. M., Roen, K. (2019). The role of psychologists in multi-disciplinary teams for intersex/diverse sex development: interviews with British and Swedish clinical specialists. *Psychology & Sexuality*, 13: 202-216: 10.1080/19419899.2019.1689158

Mestre, Y. (2022). The human rights situation of intersex people: An analysis of Europe and Latin America. *Social Sciences*, 11(7): 317.

Monro, S., Carpenter, M., Crocetti, D., Davis, G., Garland, F., Griffiths, D., Hegarty, P., Travis, M., Cabral, M. and Aggleton, P. (2021). Intersex: Cultural and Social Perspectives, *Culture, Health and Sexuality*, https://www.tandfonline.com/doi/full/10.1080/13691058.2021.1899529?src=

Monro, S., Crocetti, D., and Yeadon-Lee, T. (2019). Intersex/variations of sex characteristics and DSD citizenship in the UK, Italy and Switzerland’ *Journal of Citizenship Studies*, https://www.tandfonline.com/doi/full/10.1080/13621025.2019.1645813

Monro S, Crocetti D, Yeadon-Lee T, Garland F, Travis M. (2017). Intersex, Variations of Sex Characteristics, and DSD: The Need for Change. University of Huddersfield. [https://www.hud.ac.uk/news/ accessed 21.04.2023]

OHCRH (2019). Background Note on Human Rights Violations against Intersex People. Geneva: United Nations Human Rights Office. [https://www.ohchr.org/en/documents/tools-and-resources/background-note-human-rights-violations-against-intersex-people accessed 17.04.2023].

Pasterski, V., Prentice, P., Hughes, I. A. (2010) Impact of the consensus statement and the new DSD classification system. *Best Practice & Research Clinical Endocrinolology & Metabolism*. 24(2):187–95.

Rubin, D.A. (2017). Intersex Matters: *Biomedical Embodiment, Gender Recognition, and Transnational Activism*. SUNY Press.

von Wahl, A. (2021). From object to subject: Intersex activism and the rise and fall of the gender binary in Germany. *Social Politics: International Studies in Gender, State & Society*, 28(3): 755–777.

Zelayandía-González, E. (2023) The growing visibility of intersex demands at the United Nations: A review of the treaty bodies' concluding observations. *Social Sciences*. 12(2): 73.

7. The Human Rights Situation of Intersex People: An Analysis of Europe and Latin America[11]

Yessica Mestre

Introduction

Intersexuality is a term that designates various conditions in which a person is born with diverse sex characteristics that differ from traditional definitions of male and female. According to Khanna (2021), "to be intersex means that a person has genitals, reproductive organs, secondary sex characteristics, hormones and chromosomes that fall outside the commonly known binary definitions of either male or female sex" (p. 186). Since intersex individuals have characteristics that do not fit into masculine and feminine roles, beliefs and practices, they suffer discrimination and stigmatisation from birth. According to Human Rights Watch, intersex people are subjected to medical treatments that can permanently harm them from infancy (Tamar-Mattis & Knight, 2017). In general terms, violence against intersex individuals results from misinformation, stereotypes and myths circulating about intersex. Subsequently, the trauma arising from these acts connects intersex people's conditions with human rights research and practice (Lev, 2006).

When addressing the violence committed against intersex people, it is essential to differentiate the concepts of sexual orientation, gender identity, and sex characteristics to distinguish their fight for the respect of their rights from other population groups that may have also suffered discrimination within these terms. The Yogyakarta Principles (YP, 2007) refer to sexual orientation as "each person's capacity for profound emotional, affectional and sexual attraction to, and intimate and sexual relations with, individuals of a different gender or the same gender or more than one gender" (p. 6). In addition, the same document conceives the concept of gender identity as "each person's deeply felt internal and individual experience of gender, which may or may not correspond with the sex assigned at birth, including the personal sense of the body (which may involve, if freely chosen, modification of bodily appearance or function by medical, surgical or other means) and other expressions of gender, including dress, speech and mannerisms" (YP, 2007, p. 6). In contrast to these concepts, sexual characteristics can be regarded 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" (YP+10, 2017, p. 6). Intersex activists emphasise that, by subsuming the notion of sex characteristics within the LGBT human rights framework, there is a risk of creating misconceptions around bodily diverse populations and neglecting important issues that intersex people face, such as epistemic injustice (Carpenter, 2015).

In this sense, according to the United Nations "between 0.05% and 1.7% of the population is born with intersex traits" (UN, 2017, p.1), which means that they have variations in their sex characteristics that do not fit the medical and social definitions of male and female. Hence, they are subject to discrimination and other human rights violations based on the variation of their sexual characteristics (Ghattas, 2019). According to a previous study on the situation of intersex people in Europe, perfectly healthy intersex individuals have also experienced prenatal interventions and medical interventions on their bodies (Monro et al., 2019, as cited in Ghattas, 2019). The documentation analysed indicates that the major struggles intersex people face are related to society's perception of the variation of their sex characteristics. Therefore, from an early age, intersex people are subjected to so-called sex-normalising surgeries, which can be understood as irreversible procedures performed on intersex children to assign a sex that fits the gender role according to social expectations (Tamar-Mattis & Knight, 2017). These "[i]nvasive, irreversible and

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non-emergency medical interventions" have resulted in traumatic experiences that intersex people undergo from an early age (Ghattas, 2019, p.15).

Existing research on human rights law and the human rights of intersex people in Europe and Latin America has addressed the role of the law in protecting the life of bodily diverse people. Garland and Slokenberga (2018) have explored medical practices on intersex children to explain how, in Europe, these practices entail human rights violations, according to the guidelines of the United Nations, the Council of Europe and the European Union values. However, few European countries, including Malta, Portugal, Germany and Iceland, have strictly prohibited medical procedures and treatments of intersex children. In Latin America, legal research frameworks have addressed the human rights of intersex people. For instance, Flores-Manzano and Vázquez-Martínez (2021) demonstrated how the human rights of intersex communities have been violated, stigmatised and made invisible in Ecuador without present regulations having achieved greater inclusion. In Chile, the legal problems associated with intersex status have also been investigated.

Grez (2020) argued that the intersex human rights struggle extends to medical practice and law borders. There remain social norms and beliefs that encourage discrimination and violence toward intersex people, which is why protecting them against violations of their human right to bodily integrity is urgent.

Injustice against intersex people in Latin America and Europe calls for research as to whether human rights are enshrined in the legal provisions. A comparative investigation of these matters would also deepen the analysis of intersex people's human rights on both continents and would help us to better understand why such a framework is needed to improve the lives of intersex people. This research explores the current human rights situation of intersex people in Europe and Latin America through a scoping review and a legal research framework that includes the analysis of activist documents. Accordingly, it seeks to understand the general human rights provisions related to intersex people in these continents by also reviewing intersex activist perspectives on these legal developments. Thus, it aims to understand how European and Latin American states have established measures to protect intersex people's human rights at different levels. In addition, this research interrogates the existing gaps between the parameters provided by international law and their application in the national legislation. Both Europe and Latin America have distinct trajectories of legal development, sociocultural contexts and activism for intersex human rights, and may, therefore, provide different approaches. While in Europe the results of activism have encouraged legislation that promotes the protection of the rights of intersex people (OII Europe, 2022), in Latin America, the recognition of their problems has been first acknowledged in the decisions of the courts, and these sentences have been used accordingly as tools to protect the rights of intersex people and advocate for a legislation that guarantees their rights (Pikramenou, 2019). The different legal dynamics of these continents are the reason why they were chosen as cases of study for this research.

This article is divided into four main sections. First, the methodological strategy to analyse the current human rights situation of intersex communities in Latin America and Europe will be described. Second, an analysis will be provided of the human rights violations based on gender expression/identity and sex characteristics. Subsequently, a discussion will take place on the current status of intersex human rights in both regions. The final section will present the concluding remarks of the study.

Materials and Methods

This research is the result of a scoping review and legal research that includes publications and reports of major intersex NGOs and institutions. In this section, the approaches to data collection and analysis are addressed.

Scoping Review

A scoping review was carried out to analyse the human rights situation of intersex people in Europe and Latin America. Scoping reviews have become a well-known technique for synthesising research evidence in epidemiology and synthesis studies, but also in the context of social sciences (Pham et al., 2014). According to Pham et al. (2014) the primary purpose of this review modality is to identify available research evidence on a given topic.

In this research, the scoping review was conducted to analyse the contemporary development of intersex human rights and their most common violations. Consequently, recent literature on the protection of the human rights of intersex individuals was identified, examining their political demands and the legal and public policy gaps concerning their protection.

The literature review was conducted between 2015 and 2021. To identify the correct content, “intersex” OR “DSD” OR “differences in sex development” OR “disorders of sex development” AND “human rights” were used as keywords. SCOPUS, Web of Science and PubMed databases with texts in English were the sources. In addition, Scielo, a database with a predominance of texts in Spanish and Portuguese, was chosen to provide more coverage of the cultural environment, particularly for Latin America. Across the databases mentioned, 165 articles were found. Subsequently, 21 duplicates were removed, leaving 144 articles. Their titles and abstracts were analysed for relevance to the study topic. After this process, 45 articles were selected for inclusion in the final analysis.

Legal Research Approach and Review of Activist Documents

Although this paper is based on the references found in the scoping review, it focuses more thoroughly on the legal instruments for protecting the human rights of intersex people, since the purpose of the study was not only to explore the current situation of intersex human rights in Europe and Latin America but also to examine their effective application. This research is based on the comparative analysis of the legal context of intersex people’s human rights in Europe and Latin America.

To better understand this approach, it is essential to explain the legal doctrine used. Van Hoecke (2011) described the legal doctrine as a set of specific actions such as interpreting texts, creating arguments, providing empirical evidence for these arguments, creating axioms and logical suppositions, and assuming positionings. In a strict sense, the legal doctrine is a normative and argumentative discipline because it deals with interpreting texts and arguments (Van Hoecke, 2011). Subsequently, the legal doctrine has been defined as an empirical discipline because it presents research questions that lead to creating statements that are then tested through empirical data collection (Van Hoecke, 2011). Furthermore, since legal doctrine is a discipline that explains why norms are valid in each society, it provides explanations, axioms and logical statements (Van Hoecke, 2011). Finally, the legal doctrine is a normative discipline because it describes the norms and systematises them, assumes positions, and adopts values and interests (Van Hoecke, 2011).

According to Van Hoecke (2011), the different definitions of legal doctrine led to the adoption of plural methodologies to address the place of norms in a given society. As a result, numerous sources can be considered in methodologies to explore legal doctrines. For instance, a researcher can incorporate law cases, scholarly writings and primary sources to create and sustain arguments and normative positions (Van Hoecke, 2011). Hence, legal research is an approach that focuses on laws and regulations and the functioning of organisations and institutions in legal research society (Van Hoecke, 2011). Leeuw and Hands (2016) also explained that legal research considers the consequences of laws for individuals, organisations and social actors. Thus, the legal research approach assumed in this research included examining publications and reports of major intersex NGOs and institutions. Through the review of these documents, the way intersex activism evaluates the implementation of these laws and regulations in everyday life was analysed.

Data Collection, Systematising and Review

The process of collecting, systematising and reviewing information comprehends different levels. First, the legal issue addressed in this research was described, which is the protection of the human rights of intersex people. In that sense, numerous sources were considered, such as jurisprudence of national and international courts, recommendations of international organisations, statements and publications from intersex NGOs, with 43 legal documents and 27 publications of intersex NGOs reviewed. Additionally, attention was paid to the institutions, and a distinction was made according to their international, regional or national scope. The institutions analysed in this research were the United Nations, the European Parliament, the Council of Europe, the European Court of Human Rights, and the Inter-American Commission on Human Rights. Regarding the national legislations, the countries of Spain, Belgium, Germany, Iceland, Portugal, Malta, Colombia, Mexico, Argentina, Chile and Costa Rica were studied to establish legal comparisons. Finally, this research collected experiences and data from declarations and reports made by the NGOs OII Europe, ILGA-Europe, Intersex Human Rights Australia–IHRA, Brújula Intersexual, StopIGM, and other individual intersex activists.

Results and Discussion

Human Rights Violations Based on Gender Expression/Identity and Sex Characteristics

Traditionally, the presence of differences within a diverse society, such as the contrasting ways of expressing one's sex, gender identity or the diversity of bodies, has promoted discriminatory scenarios where a person becomes a subject of violence or marginalisation because of their bodily difference (UN, 2001). Discussing these scenarios exposes the legal systems' difficulties in eradicating unequal treatment and discriminatory practices. The scoping review and legal research, including the review of activist documents, explained a number of essential advances in intersex human rights, elucidating experiences and mechanisms for their protection. It is essential to highlight how intersex organisations assert that gender recognition is not enough to protect the right to the physical and mental integrity of intersex people (IHRA, 2019). In addition, social movements have highlighted how significant it is not to confuse sex and gender when considering intersex human rights, which are mainly determined by sex characteristics and embodied experiences (IHRA, 2019).

These legal developments, debates and disputes can be interpreted in the context of the Convention on the Rights of the Child (CRC) (UN, 1989) and the United Nations Convention against Torture and Other Cruel and Inhuman or Degrading Treatment or Punishment (UNCAT) (UN, 1987) to elucidate the struggles against cruel medical procedures, self- recognition and identity, and the right to truth. There are differences in how these legal documents mention intersex human rights. On the one hand, the Yogyakarta Principles plus 10 (YP+10, 2017) explicitly address the human rights of intersex people. On the other hand, the CRC (UN,1989) and the UNCAT (UN, 1987) affirm the universal application of human rights that can be used for intersex individuals.

The Yogyakarta Principles (YP, 2007) were launched in 2007 by experts and activists from different fields to apply the Universal Declaration of Human Rights (UDHR) (UN, 1948) in response to massive human rights abuses related to sexual orientation, gender expression/identity and sex characteristics. The initial idea of this civil society manifestation was to articulate universal values applicable to sexual orientation and gender identity and to clarify concepts to avoid discriminatory treatment (O´Flaherty, 2015). Since its creation, this statement has achieved an international influence and positive impact; however, there were issues that the first version did not explicitly cover, and, in 2017, additional principles were developed to extend some topics. The guarantee of the protection of human rights of intersex people was one of the main aims of the new approach. Thus, the YP+10 (2017) considers sex characteristics and relevant situations for intersex people.

There are serious human rights violations associated with bodily perception. In consequence, YP+10 (2017) includes crucial matters, such as the right to bodily and mental integrity, the right to legal gender recognition, and the right to truth. In addition, the YP+10 (2017) proposes states' obligations that are essential for the legal defence of intersex human rights. The YP+10 Principle 32, which mandates the right to bodily and mental integrity, and its obligation "D" prescribe how intersex child protection must be developed:

> STATES SHALL: (...)
>
> (D) Bearing in mind the child's right to life, non-discrimination, the best interests of the child, and respect for the child's views, ensure that children are fully consulted and informed regarding any modifications to their sex characteristics necessary to avoid or remedy proven, serious physical harm, and ensure that any such modifications are consented to by the child concerned in a manner consistent with the child's evolving capacity; (YP+10, 2017, p.10)

This obligation focuses on one of the main aspects of the defence of intersex human rights, the agency of children and their best interest when performing medical procedures at an early age (YP+10, 2017). Carrying out medical interventions which are strongly influenced by social stereotypes and not biological needs is a violation of the UDHR (UN, 1948). Article 3, which concerns the right to life, liberty, and security of the person, and Article 5, linked to the prohibition of torture, punishments, or degrading treatments, can be interpreted in relation to the protection of intersex children against abuse presented by medical treatment (UN, 1948). The same tenet is also established by Article 7 of the International Covenant on Civil and Political Rights (CCPR) (UN, 1966), which prohibits torture or degrading conduct against people, specifying that a human being cannot be subjected to experimentation without her/his/their free consent. In addition, the CRC (UN, 1989), in its Article 24, determined that States Parties must implement all effective measures to abolish traditional health practices, which also applies to the protection of intersex children. Consequently, Article 37 prescribes that no child shall suffer any type of degrading treatment or punishment.

Concerning the right to legal recognition, the YP+10 (2017), in its Principle 31 and obligation "B", points out the state's obligation to ensure modification of names, based on the self-determination of the person:

> (B) Ensure access to a quick, transparent and accessible mechanism to change names, including to gender-neutral names, based on the self-determination of the person; (YP+10, 2017, p. 9)

Administrative procedures linked to gender assignment at the moment of birth and the desire to change this in the future should not be discriminatory and, whether or not they actually are discriminatory, they should be considered a violation of the UDHR (UN, 1948). Article 6, which mentions that "everyone has the right to recognition everywhere as a person before the law", represents this mandate. Moreover, Article 7 affirms that all people are entitled to equal protection before the law without discrimination. In the same vein, the CCPR (UN, 1966) in Article 16 states that "everyone shall have the right to recognition everywhere as a person before the law". Furthermore, the CRC (UN, 1989) in Article 7 recognises "the right to every child to acquire a nationality". Moreover, Article 8 clearly states that when a "child is illegally deprived of some or all of the elements of his or her identity, States Parties shall provide appropriate assistance and protection, with a view to re-establishing speedily his or her identity". Finally, the CRC completed the ruling with Article 8, n. 2, which calls on the states to provide appropriate assistance and protection to re-establish the rights of children when they are "illegally deprived of some or all the elements of their identity". In this sense, these legal tools provide human rights-based arguments for parents of intersex people who want to classify them at birth in a binary category or would like to wait until the intersex person decides to modify the category initially assigned when they are older.

The third important statement for intersex people in the YP+10 (2017) is Principle 37, the right to truth, which contains an important state duty to intersex people in its obligation "C". The YP+10 (2017) directly mandates the protection of intersex people's rights to know the truth about their medical histories. The circumstances surrounding invasive medical interventions related to the bodies of intersex people in the early stages of life are accompanied by secrecy in the procedures, the prohibition of the parents from telling their children about the interventions performed, and the denial of access to medical records (Horowicz, 2017). Intersex people are denied the truth about the medical procedures performed on their bodies, and how these procedures can impact their body and identity, and this constitutes a violation of the right to autonomy, identity and personality.

It is possible to appreciate that the legal framework for claiming the right to truth and protecting intersex people against these violations is not as well developed as the right to bodily and mental integrity and its link with torture, or the legal recognition and its link with equal treatment before the law. However, the right to truth has been established under the umbrella of transitional justice, understanding transitional justice as the process of a society from conflict to peace after systematic human rights violations. In this context, the achievement of justice during the restructuring of society gives legitimacy to the new state institutions (Sweeney, 2018).

There are intersex human rights violations related to medical procedures, self-recognition and identity, and truth. The scoping review and the legal research framework with the review of activist documents illustrated how the knowledge produced on the human rights of intersex people represents a predominant interest in the first two legal matters. The right of intersex communities to the truth has been tenuously addressed in legal research because this issue has not been fully developed in international human rights law, either. Consequently, it is important to inquire about the collective struggle of intersex persons for their right to the truth, which includes complete knowledge about the medical procedures performed on their bodies.

Current Human Rights Situation of Intersex People in Europe and Latin America

The protection of intersex people's human rights has been a matter of recognition and awareness in Europe and Latin America, acquiring more visibility in the last decade thanks to intersex advocacy and activism efforts. Although there have been significant steps toward constructing intersex human rights frameworks, there is still a gap between the parameters provided by international law, which is not strictly enforceable, and the application of these in the national legislation.

Europe

The research included a review of resolutions, recommendations and reports of the European Union institutions, as well as intersex-related legislation in some countries of the European continent were analysed. The European Union (EU) has an institutionalised structure distinguished by its strong representation in fields such as human rights protection. Its legal framework is characterised by fundamental values that are not subject to exceptions, with a horizontal system for the protection of fundamental rights, which mean the prevalence of these rights must be considered by all internal bodies, regardless of the topics they cover (European Parliament, 2021). Moreover, there are specialised bodies that deal with the topics directly related to human rights protection: the Council of Europe (CoE), the European Parliament, the European Union Agency for Fundamental Rights (FRA) and the European Court of Human Rights (ECHR).

Over the past few years, EU bodies have issued resolutions and recommendations for its member states to stop the practice of sex-normalising surgeries on intersex children. In 2013, the Parliamentary Assembly of the Council of Europe (PACE) was the first to show its concern for the physical integrity of intersex children regarding the performance of cosmetic surgeries within the

EU (PACE, 2013). Years later, the FRA (2015) and the Commissioner of Human Rights of the Council of Europe (CoE, 2015) issued reports on the situation of intersex people and the need to protect their human rights in Europe. Furthermore, in a 2017 resolution, the PACE (2017) confirmed that these surgeries have shown "(...) no evidence to support the long-term success of such treatments, no immediate danger to health and no genuine therapeutic purpose for the treatment" (p. 1). Following this idea, the European Parliament (2019) pointed out in resolution in 2019 the "urgent need to address violations of the human rights of intersex people, and calls on the Commission and the Member States to propose legislation to address these issues" (p. 4).

European laws and courts' rulings are not only tools to interpret legal principles but also a means to struggle for intersex rights. Some of these legal documents directly mention intersex people, while others assume that the rights of bodily diverse communities are of direct application in the human rights field. Regarding torture, the European Court of Human Rights (EctHR) has extended the scope to consider the applicability of the European Convention of Human Rights, Article 3, when (i) the treatment performed is inhuman and degrading, which includes not only physical but also mental suffering (CoE, 2021), and (ii) such treatment reaches a deep level of psychological anguish.[12] In addition to these requirements, the intensifying criterion to classify the actions under Article 3 is "the suspicion that it is committed under the inevitable context of discrimination based on sex, age, race, ethnic origin and religion"[13] or that it is committed "particularly to children and other vulnerable members of society", which requires reinforced protection as a positive obligation of Article 3.[14] Furthermore, concerning the case of medical interventions, the ECHR has emphasised that the procedures that violate physical integrity must have a solid justification for creating such an amount of suffering.[15] Moreover, the 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.[16]

As reported in the Council of Europe's issue paper, for intersex children, the medical procedures performed, which begin at birth and in childhood, and later hormonal treatments in adolescence and adulthood may lead to lifelong physical and mental con- sequences (CoE, 2015). In addition, the intensity of an unnecessary clinical intervention can cause bodily humiliation, great pain and traumatisation; thus, the report describes how medical diagnoses given to an intersex child become a reason to transform their body without their consent and provoke unnecessary suffering. Thus, the Council of Europe (CoE, 2015) expressed disapproval of these corrective surgeries and stated the need for the legal prohibition of these practices.

Establishment of positive obligations regarding these practices has been achieved by some European countries that have become leaders in the protection of the human rights of intersex people. Malta, Portugal, Iceland and Germany have achieved greater protection of the fundamental rights of intersex people, particularly children, who are the most vulnerable to unnecessary medical interventions during the first stages of their lives. Meanwhile, Belgium and Spain are currently in the legal process of creating their national regulations regarding intersex human rights.

Malta was the first country to recognise and protect the rights of a person based on their sex characteristics. Its government enacted in 2015 a law called the Gender Identity, Gender Expression

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[12] The European Court of Human Rights. 1999. Case V. vs. the United Kingdom, p. 71.

[13] The European Court of Human Rights. 1978. Case Irland v. the U.K, pp. 161–62.

[14] The European Court of Human Rights. 2006. Case Mubilanzila Mayeka and Kaniki Mitunga v. Belgium, p. 17.

[15] The European Court of Human Rights. 2006b. Case Jalloh v. Germany.

[16] The European Court of Human Rights. 2001. Case Z vs. the United Kingdom, p. 109.

and Sex Characteristics Act,[17] which, besides ensuring the self-determination and expression of gender identity for Maltese citizens, condemns any medical treatment or intervention performed to adjust children's sex characteristics without their informed consent. Furthermore, the law contemplates the parents' consent as a replacement only under exceptional circumstances and the support of an interdisciplinary team elected by the government to ensure the child's best interests.[18] According to intersex activism, this law is vital because it protects the territory of sex characteristics and mandates caring for the children's physical integrity (Ghattas, 2015). Additionally, the law forbids genital mutilation, which is one of the most disturbing concerns for intersex people.[19]Along the same lines, Portugal adopted a law in 2018 to regulate the same two concerns: the self-determination and expression of gender identity and the protection of the physical integrity of an intersex person against modifying their sex characteristics. This Portuguese law prohibits medical interventions on intersex people "until the moment that is a manifestation of their gender identity" (Article 5) and as long as there is no "proven risk" to the health of the intersex person.[20]Another notable legislative act is the one issued by the government of Iceland in 2019[21] which focuses on gender recognition. The law regulates important aspects regarding intersex people's rights in its Article 11a, according to which: (i) permanent changes "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"; (ii) the duty of hospitals is to provide "counselling and support" for the guardians and child; (iii) the possibility for the guardians and child to "seek expert opinion outside the team on the necessity of such treatment, free of charge" is required; and (iv) an important step for data collection is the mandate that medical institutions "enter information on the treatment into the health record and provide the Director of Health with information on the number and nature of surgical operations and medication and the age of those who undergo these changes." This law considers many crucial aspects for the protection of the rights of intersex people. Sadly, regarding the right to bodily integrity, there are some exceptions. The law excludes hypospadias and micropenis from these regulations, indicating that in these cases the permanent changes "shall not be performed unless a detailed assessment of possible advantages and consequences in the short and long term has been undertaken, including the consequences of not performing a surgical operation or providing medication or postponing it until the child can express its will." This decision has been made even when there were reports documenting the serious human rights violations that these procedures constitute for intersex people (StopIGM, 2020a).

Because the laws from Malta, Portugal and Iceland address similar aims, their effectiveness can be compared. Intersex activists in Europe have pointed out that even though these countries recognise the need to protect intersex people from these medical abuses, there are still extensive gaps in the current legislation (StopIGM, 2019a). Regardless of the norm, paediatric units of public and private hospitals still consider intersex traits as "abnormalities", and therefore, they openly acknowledge the need for a surgical "correction", "reconstruction", or "repair" of the minor's body (StopIGM, 2019a, p. 56; 2019b, p. 21).

Thus, these three countries have established regulations prohibiting unnecessary medical interventions but they have not defined a clear legal consequence if those prohibitions are carried out. If the treating doctor performs surgery without informed consent and there is no imminent risk to the health of the child, the three countries' laws fail to define the specific type of sanction (administrative, civil, or criminal). If the norm prohibits specific conduct, their legal duty would be to

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[17] Malta Gender Identity, Gender Expression and Sex Characteristics Act No. XI.

[18] Malta Gender Identity, Gender Expression and Sex Characteristics Act No. XI 2015. Article 17.

[19] Lei n.º 38/2018. Direito à autodeterminação da identidade de género e expressão de género e à proteção das características sexuais de cada pessoa.

[20] Lei n.º 38/2018. Direito à autodeterminação da identidade de género e expressão de género e à proteção das características sexuais de cada pessoa. Article 15.

[21] Iceland Act on Gender Autonomy No 80 /2019 as amended by Act No. 159/2019, No. 152/2020 and No. 154/2020.

establish the consequences for its non-compliance, but since there are no clear judicial measures, it is impossible to advance to a stage of compensation/reparation for the victims. This results in another serious legal gap in the legislations.

In the cases of Germany and Belgium, both countries recognised the right of intersex people to choose a non-binary or diverse option in the civil register. Regarding the German civil register, there are two regulations, one created in 2013 which prescribes that a child who cannot be assigned to the male or female sex should be registered without any legal gender, and a later gender register could be added with a medical certificate that proves the binary sex.[22] The second regulation in 2018 gave the option for intersex babies to be registered in a category named "divers".[23] Both regulations were criticised by intersex activists since they potentially increase the pressure for gender assignation and the stigmatisation of a child with a medical diagnosis related to intersex traits (ILGA Europe, 2018; OII Europe, 2013, 2018). Additionally, the German Congress lately approved a law to ban unnecessary medical procedures for intersex children until they can express their full and informed consent or until it is approved by the Court.[24] However, according to activists, some loopholes would allow these surgeries to be performed; if the intersex condition is not reported, doctors can implement any treatment of the person, and again, there is no concrete legal consequence for violating the law (Haug, 2021; Intergeschlechtliche Menschen e.V. Bundesverband, 2021; OII Europe, 2021a).I

n Belgium, the situation is also recent. In 2021, the House of Representatives called on the government through a resolution to legislate in the protection of the physical integrity of intersex children and ensure the prohibition of medical treatments without the informed and full consent of the intersex person.[25] Currently, this bill is in progress, and intersex activists have maintained the importance of this step in protecting the rights of intersex people, emphasising that further legislation is needed to comprehensively cover points that the resolution did not mention regarding harmful practices (OII Europe, 2021b).

Lastly, Spain constitutionally recognises the autonomy of its regions, which enjoy a certain level of independence in the administration of some of the national mandates,[26] thereby introducing a diverse range of rights protections. Hence, the legal status of medical interventions depends on the region where the intersex baby is born. For instance, if the birth takes place in Madrid, Aragón, Murcia or the Canary Islands,[27] the regional legislations protect the children and prohibit unnecessary medical procedures to the intersex person. If, on the contrary, the person is born in another region, the legal protection to safeguard the rights to bodily integrity will depend on the legal advances that community has made in strengthening the protection of the human rights of

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[22] Gesetz zur Änderung personenstandsrechtlicher Vorschriften, May 2013.

[23] Gesetz zur Änderung der in das Geburtenregister einzutragenden Angaben, December 2018.

[24] Gesetz zum Schutz von Kindern mit Varianten der Geschlechtsentwicklung, 21 May 2021

[25] Chambre des représentants de Belgique, Résolution 0043/008, 11 February 2021.

[26] Constitución Española de 1978, Título VIII. De la Organización Territorial del Estado, Capítulo tercero. De las Comunidades Autónomas.

[27] Ley 2/2016, de 29 de marzo, de Identidad y Expresión de Género e Igualdad Social y no Discriminación de la Comunidad de Madrid, Ley 8/2016, de 27 de mayo, de igualdad social de lesbianas, gais, bisexuales, transexuales, transgénero e intersexuales, y de políticas públicas contra la discriminación por orientación sexual e identidad de género en la Comunidad Autónoma de la Región de Murcia, Ley 4/2018, de 19 de abril, de Identidad y Expresión de Género e Igualdad Social y no Discriminación de la Comunidad Autónoma de Aragón, Ley 2/2021, de 7 de junio, de igualdad social y no discriminación por razón de identidad de género, expresión de género y características sexuales en la Comunidad Autónoma de Canarias.

intersex people. Thus, some intersex people in Spain have greater guarantees of legal protection of their rights, whereas others may encounter obstacles to obtaining legal recognition.

Regarding national legislation, Spain does not have a law that directly protects intersex people's human rights. However, a draft bill is in progress for the effective equality of trans people and the guarantee of LGTBI rights.[28] This draft bill has a depathologising approach, where the intersex person will have comprehensive healthcare, and forbids any genital modification practices in the newborn, except "in cases where medical indications require otherwise to protect the health of the person".[29] Another aspect to highlight is the one-year period that the government will give the parents of the intersex baby to register the sex in the civil registry, in the light of this draft bill.[30]

Aside from these three states, most European states lack harmonisation between the decisions issued by European entities and their materialisation in national legislation regarding intersex people's rights. Regardless of the strong recommendations made by the European institutions, according to the FRA report published in 2015, "sex (re)assignment or sex-related surgery seems to be performed on intersex children, and young people, in at least 21 EU Member States" (FRA, 2015, p. 6). This means that, despite of the deficiency of evidence proving these so-called corrective procedures to be necessary, most countries continue to neglect the creation of legislation that prohibits non-consensual surgeries on sex characteristics.

In France, according to the Periodic Report on the CCPR elaborated by the NGOs StopIGM and GISS/Alter Corpus, numerous forms of intersex genital mutilation continue to be practised, such as unnecessary medical procedures and cosmetic genital surgeries (StopIGM, 2020b) through public institutions such as the Reference Centre for Rare Diseases (DevGen, 2022). The national guidelines contemplate numerous treatments for intersex newborns without medical necessity, interventions like "'masculinising' genital surgeries, 'feminising' procedures, and sterilising procedures are carried out in public university clinics to intersex children where approximately 86% are under four years" (StopIGM, 2020b, p. 20). These procedures are justified as a means, for example, to "restore functional genital anatomy to allow future penetrative intercourse (as a male or a female)", "avoid stigmatization related to atypical anatomy" and "respond to the parents' desire to bring up a child in the best possible conditions" (StopIGM, 2016, p. 10).

This same line of action has been taken in other European countries, for example, in the UK no specific rule bans intersex surgeries (Nelson, 2018). Therefore, these surgeries can generally be performed with valid legal consent. However, children and infants cannot give informed consent, which means British law assumes the parents' responsibility is to provide informed consent under the Children Act (Nelson, 2018). In another 'shadow report' prepared by the Intersex NGOs in the UK, it was argued that intersex genital surgery practices are still widely practised in the UK (StopIGM, 2019d). As in France, intersex child surgeries are permitted through the public health system and facilitated by third parties (StopIGM, 2019d). Although this country is committed to preventing surgeries and any cruel or degrading treatment against intersex people, medical procedures for bodily diverse children are still being normalised to remove their "atypical" sex traits (Monro et al., 2017, p. 11). Hence, intersex people continue to be victims of serious human rights violations with procedures such as "masculinising genital surgical procedures that are unnecessary for basic functioning are routinely advocated and performed in NHS hospitals for hypospadias, for social rather than medical reasons" or "clitorectomies which are entirely unnecessary for medical reasons" (Monro et al., 2017, p. 11).

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[28] Anteproyecto de Ley para la igualdad real y efectiva de las personas trans y para la garantía de los derechos de las personas LGTBI, June 2021.

[29] Anteproyecto de Ley para la igualdad real y efectiva de las personas trans y para la garantía de los derechos de las personas LGTBI, June 2021, Articulo 18.

[30] Anteproyecto de Ley para la igualdad real y efectiva de las personas trans y para la garantía de los derechos de las personas LGTBI, June 2021, Articulo 71.

Another important human rights violation observed in the research is the lack of compensation and recognition of the intersex victims for the mentioned practices. For instance, in Austria the absence of data collection and monitoring and the difficulties intersex people have accessing their clinical records has created a hostile environment for them to claim their rights in the court (StopIGM, 2019e). The consequence of this is a culture of impunity and difficulty of access to justice.

The previous national situations made it possible to appreciate the diversity of legislation and current human rights protection in Europe. The scoping review and the legal research framework with the review of activist documents showed to what extent major violations of human rights prevail in European laws, especially in terms of medical procedures and gender recognition. In this regard, European countries' realities are heterogeneous and, therefore, the degrees of recognition of the rights of intersex people are diverse. There are countries with conservative cultures and restrictive gender recognition legislations that are reluctant to guarantee a dignified life for LGBTI communities and particularly for trans and intersex people, such as Hungary, Lithuania, Slovenia, Sweden and the United Kingdom. On the contrary, there are countries that demonstrate greater inclusion in legislation, which is evident in how intersex people have used the law to defend equality. This situation has particularly prevailed in Malta, Portugal, Germany, and Iceland, and it is in progress for Belgium and Spain. According to the results of this research, none of these countries has completed its development or public discussion of the right to truth as a guarantee of the achievement of social justice for the intersex community.

Latin America

Latin America has a history of social movements claiming participatory actions reflecting diversity and experiences that are mirrored in the exercise of rights (Dagnino, 2006). Hence, the countries of Latin America share a common past of violence in addition to cultural beliefs which promote sexual hierarchies and endonormativity practices that legitimise violence and punishment of people with sexual orientations, gender expressions/identities and sex characteristics that differ from the norm. Usually, this violence is nurtured by traditional conceptions of men's and women's roles in society. In this way, the protection of human rights and the creation of anti-discrimination laws for the LGBTI population in Latin America are invisible to state authorities, leaving the region with one of the highest rates of violence against this population (SinViolencia LGBTI, 2019).

The Inter-American Commission of Human Rights (IACHR, 2015) has defined the violence in the Latin American region against the LGBTI population as a social phenomenon called bias violence. According to Motta and Sáez (2008), this violence emerges from the preconception that all members of a particular group must have or develop specific characteristics of their community. In this sense, a person's appearance with different bodily expressions or gender identities creates negative attitudes and value judgements.

Regarding the specific concerns of intersex people, regional recognition and awareness have increased considerably in the last decade. For example, in 2013 the IACHR (2013) held the first public hearing to understand intersex issues in the region. Intersex activists and advocates expressed their experiences: the types of violence, not only medical, that intersex people suffer during the process of "normalisation"; the clinical methods of standardising intersex bodies and their irreversible consequences; and the national legislations which directly violate international children rights. As a result, the Commission recognised the severe violations of human rights that intersex people undergo for having a diverse body and gave suggestions to the countries to promote good practices (IACHR, 2012).

The IACHR (2015) stressed the severe human rights violations that the states commit, such as forced sterilisation, genital "normalisation", denial of medical records and health insurance services, secrecy in the procedures, and the absence of informed consent. Conclusively, it encouraged the member states to create public policies and legislation to stop unnecessary medical interventions without free and informed consent; to provide support to families and intersex children; to generate awareness campaigns on the effects of "normalisation" interventions of intersex children;

and to develop educational campaigns to end the stereotypes and invisibility that surround intersex people (IACHR, 2015).

Unlike Europe, Latin America does not have a clear regionalisation process, which means that, although there are regional entities, normative unification processes are difficult to achieve; this leads to a significant differentiation in the legislation and gathering of data for the region, which is also heterogeneous in the legal advances regarding the protection of intersex human rights (Rueda, 2009). Nevertheless, forums and collaborations have been conducted to pursue regional activism. For instance, the San José de Costa Rica Statement was signed in the First Latin American Regional Conference of Intersex People in 2018. This conference was sought by intersex activists to generate collective demands in Latin America and the Caribbean for stopping human rights violations by the states, regional institutions, medical constituencies and the media (Conferencia Regional Latinoamericana y del Caribe de Personas Intersex, 2018). The second version of this regional activism meeting was held in 2020 in Argentina; around 30 activists gathered to discuss the human rights situation of intersex people in Latin America (Balderrama, 2020).

There have been jurisprudential advances in Latin America and the Caribbean; it is possible to find examples of protection of intersex people from abuses of their human rights. Since there is a considerable difference in terms of the development of intersex human rights among the countries, it is challenging to make a general review of the topic in the region; instead, it is more accurate to highlight the major advances of some nations and name specific state regulations whose modification should be considered.Among the positive precedents in intersex human rights protection, Colombia should be mentioned. In the 1990s,[31] this country was one of the earliest in the world to establish the right to the autonomy and bodily integrity of a person when their sex characteristics differ from the traditional binary models (Zelada & Nicoli, 2019). Their Constitutional Court (CCC) developed parameters to consider whether it is possible or not to perform a medical intervention: (i) the urgency of the treatment; (ii) the risk and impact on the current and future autonomy of the minor; and (iii) the age of the minor. These parameters force the examination of the consequences of such interventions in the minor's life, and if the treatment is invasive and irreversible, the minor must wait until they are old enough to decide for themselves.[32]

For the protection of the rights of intersex people, in 1999 the Court made a judgement on whether the parents could authorise a medical and surgical intervention for readjusting the genitals of an intersex infant.[33] The Court ruled that the intersex minor must decide the gender with which they identify, and hence, the ruling indicated that the age of five years is the minimum threshold for a person to consent in an informed way to the possible invasive treatments. Also, it established that parental consent is legitimate for children under this age only if informed consent is sufficiently capable of efficiently supporting the decision.[34]

However, in Colombia, no law prohibits the authorities from executing unnecessary medical interventions on intersex children. According to the document issued by the Capital City Hall, "Diagnosis of the situation of intersex people in Bogotá" (Alcaldía Mayor de Bogotá, 2014, own translation), the problem with intersex invisibility in Colombia and the consequent lack of normative advances is the weak consolidation of intersex as a political identity. Unlike the lesbian, gay, bisexual and trans sectors, in the intersex community there is an absence of leadership that reacts to the confusion and ignorance around being an intersex person (Alcaldía Mayor de Bogotá, 2014).

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[31] See the rulings of the Colombian Constitutional Court N. T-594 of 1993, T-539 of 1994, T-097 of 1994, SU-623 of 2001, C-577 of 2011, SU-617 of 2014.

[32] Colombian Constitutional Court, Ruling N. T-477/95, 31–32

[33] Colombian Constitutional Court, Ruling N. SU-337/99, 36.

[34] Colombian Constitutional Cort, Ruling N. SU-337/99, 99–100.

There are other relevant Latin American examples that have improved the legal protection of intersex human rights. For instance, Argentina's evolution in the recognition of gender identities has continuously improved, as was the case with the Gender Identity Law enacted in 2012, which opened the door to (i) creating a gender identity where people can modify their body without third party considerations, ordering the state to cover the necessary surgeries and hormonal treatments as part of the Mandatory Medical Plan, (ii) offering guidelines for human rights-based procedures in the rectification of sex registration, and (iii) recognising the citizen's right to decent treatment, allowing themselves the gender identity they want, including the use of a different name from the one that appears in their legal documents.[35]

This law is a worldwide example because it is not framed in binary categories; on the contrary, it encourages respect for diversity and self-perception of gender and body, which has become a crucial argument for international trans and intersex advocacy (OUT-Right, 2012). Regarding exclusively intersex matters, in 2020 Argentina proposed a bill elaborated by intersex and LGBTI activists to guarantee the protection of human rights of people based on their sex characteristics.[36] The bill includes aspects such as the right to bodily and sexual diversity, the prohibition of any procedure without the full and informed consent of the person whose body is involved, the right to receive truthful information about the people's sex characteristics, the right to determine their sex on the medical certificate, the right to be registered or modify the civil register, the right to have proper social security assistance, the protection against acts of discrimination, and the creation of a truth commission to clarify the events that previously occurred in the country related to body modification procedures for people with variations of sex characteristics.[37]

It is expected that the approval of this law will change the current situation in Argentina for intersex people, since genital mutilations and other medical procedures are still being carried out in health institutions that continue to recommend early interventions in babies born with intersex traits (StopIGM, 2017). In this sense, there remain many Latin American countries that sponsor, through their public health institutions, unnecessary medical procedures and pathologising treatment for intersex people (StopIGM, 2017). For instance, protocols to quickly frame the newborn intersex child in a specific gender are implemented in Brazilian hospitals. Consequently, medical personnel can proceed with medical intervention, enforcing under a pathologising language the idea of sex assignation on behalf of the parents (Machado, 2009).

In Mexico, according to the Periodic Report of the CCPR elaborated by the NGOs StopIGM and Brújula Intersexual (StopIGM, 2019c), there is (i) an absence of national regulations to stop cosmetic surgeries in intersex children, (ii) a lack of administrative measures to enforce the application of the little existing guidance for these people in hospitals, (iii) indiscriminate medicalisation of bodily diversity accompanied by degrading treatment such as repeated genital examinations and photographs for scientific research, which constitute harmful practices, and (iv) pathologising recommendations of early interventions for children in order to "deal" with intersex traits. Thus, the report mentions that these practices remain typical, encouraging public health institutions and paediatric associations to follow treatment guidelines that go against the human rights of intersex people (StopIGM, 2019c). These are intended under the umbrella of early intervention to prevent future stigmatisation, create "normal" appearances, avoid cancer risk and reduce possible "negative feelings" for the children and their parents. (StopIGM, 2019c).

Since the region represents a significant gap in creating legal protocols, Costa Rica is another example where hospitals implement their procedures to effect medical interventions (Rueda, 2017). In their medical institutions, it is more suitable to hide the intersex condition, so the parents will not question the interventions or "create confusion where there is none" (Rueda, 2017, s.p.).

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[35] Ley Argentina de Identidad de Género No. 26.743, 24 May.

[36] Proyecto de Ley sobre la Protección Integral de las Características Sexuales, S-2090/19, November 2020.

[37] See 25 above.

Thus, intersex traits are still considered a pathology for healthcare providers, and intersex activism urgently demands change (Rivera & Jiménez, 2017).

As in Europe, Latin American states lack governmental regulations that strictly forbid genital mutilation and unnecessary procedures for intersex children (Rivera & Jiménez, 2017). For instance, Chile issued in December 2015 a legal notification ordering a stop to unnecessary treatments of intersex children (Ministerio de Salud, Gobierno de Chile, 2015). Nevertheless, one year later, the government issued a new notification contradicting the initial one and falling back in protecting the rights of intersex (Ministerio de Salud, Gobierno de Chile, 2016). It defined the condition of hypospadia as a medical emergency, implemented the term Disorders of Sex Development, and changed the wording of the text from the "need" to defer to the "possibility" of deferring surgery until the patient can show trends of sexual identity, among other changes (Ministerio de Salud, Gobierno de Chile, 2016). For activists, this new regulation was considered a pathologisation of intersex traits and their further medicalisation. Thus, this notification justified procedures that extend from "the intervention through unnecessary and non-consensual hormonal therapies that have repeatedly resulted in serious consequences to the health of the intersex individual, to surgeries that can be compared to forced sterilisation and genital mutilation procedures" [38] (Inter & Aoi, 2016, s.p.).

This scoping review and legal research, including the review of activist documents, demonstrated that Latin America has a long history of human rights law developments and struggles. In this context, intersex people have used international human rights law to defend their freedoms and lives against degrading medical treatment, violence and discrimination. Since Latin America is part of a heterogeneous continent and does not display a solid regionalisation process as in Europe, it is essential to analyse what happens in each country regarding the human rights of intersex people, who in some cases have joined LGBT movements to make more visible the failures of the state toward them. Although Latin America continues to experience setbacks in the defence of the rights to sexual and bodily diversity, there are countries that have stood out worldwide, either because their courts have developed the framework to guarantee human rights, as in Colombia, or because they are making extraordinary progress, as in Argentina, or have exhaustively researched intersex issues through strong activism, as in the case of Mexico (Alcántara, 2019). However, as in Europe, in Latin America, the right of intersex people to the truth continues to fall into a gap in human rights research.

Conclusions

This research explored the current status of intersex human rights in Latin America and Europe. To undertake this aim, a scoping review and legal research, including the review of activist documents, were conducted to allow a better understanding of the experiences of intersex individuals in these regions. Because of this methodology, questions about how European and Latin American states have addressed the human rights of intersex people and the gaps in legislative measures to protect them were approached. Although Europe represents a regionalisation process that translates into parliaments, commissions and courts, Latin America has shown progress in terms of the inclusion of intersex people through the IACHR and national courts. Thus, this research identified existing legal sources on human rights concerning intersex people that mention the exercise of their rights to self-determination and identity, to be protected from cruel and degrading treatment, and to be effectively included. In addition, there are provisions in Europe and Latin America that prohibit surgeries on intersex children and violence against them.

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[38] Own translation from Spanish ["la intervención a través de terapias hormonales innecesarias y no consentidas que en repetidas ocasiones han derivado en graves secuelas a la salud del individuo intersexual, pasando por cirugías que se pueden comparar con procedimientos de esterilización forzada y mutilación genital"].

The analysis of treaties, conventions, regulations, laws, jurisprudence, recommendations, institutional declarations, activist statements and reports evidenced that intersex people in Europe and Latin America experience many forms of discrimination and violence based on stereotypes and myths about what is male and female. Two topics predominate in international human rights law: first, their right to bodily integrity and protection from cruel and degrading treatment in the medical field, and second, their right to self-determination and identity, which is reflected in the possibility of choosing a gender, and these are evidenced in legal documents. These rights have also emerged in United Nations international regulations as a critical element in guaranteeing intersex people's human rights. The YP+10 are essential in this matter and their content appears implicitly or explicitly in the legal developments of European and Latin American countries.

In addition, this research provided insights into how intersex organisations perceive current developments of the human rights framework to protect their rights. For instance, in Europe, intersex organisations have clearly identified violations of the right to integrity and claim for intersex people the right not to be subjected to medical treatments or surgeries during infancy. In this case, within Europe, some states' progress is needed to establish additional mechanisms that will effectively implement the existing human rights frameworks. In contrast, in Latin America, intersex organisations also identify challenges in the general development and recognition of a human rights framework for intersex people. Legal initiatives are present in some Latin American countries to guarantee the rights of intersex people, mainly their rights to bodily integrity, self-determination and identity. However, legal advancements are required concerning the prohibition of sex-normalising surgeries. Another important finding in both regions is the lack of reparation and judicial mechanisms for intersex people who have been the victims of massive human rights violations during their lives. Legal tools that not only acknowledge but also aim to repair their suffering are essential to promote real change. The insights provided by this research reveal how important it is to continue evaluating the legal framework from a comparative perspective to better understand what happens to intersex people in each country within the same region and between regions.

Whether social beliefs regarding gender, and, thus, the political approaches that prevail in both Europe and Latin America, are obstacles to implementing public policies for intersex people remains a pending research question. If European and Latin American societies do not develop a cultural openness toward gender and bodily diversities, intersex individuals will continue to experience violence against their bodies. Consequently, in Europe, it is important to continue working on the effective implementation of regulations to protect the intersex community and the typification of tangible sanctions for non-compliance. In addition, in Latin America, it is essential that states commit to developing policies based on a human rights approach to enable intersex people to have a dignified life and independent recognition. Finally, it is necessary to remember that human rights are not only a tool to better interpret the law and create more efficient public policies, but primarily a means to achieve social justice.

References

Alcaldía Mayor de Bogotá. (2014). *Diagnóstico de situación de personas intersexuales en Bogotá*. http://www.sdp. gov.co/sites/default/files/diagnostico_personas_intersexuales.pdf

Alcántara, E. (2019). *Brújula Intersexual, conocer otras realidades*. https://luchadoras.mx/brujulaintersexual- conocer-otras-realidades/

Balderrama, C. (2020). *Así se vivió la II Conferencia Interamericana y del Caribe de Personas Intersex*. https://agenciapresentes.org/2020/02/14/asi-se-vivio-la-ii-conferencia-interamericana-y-del-caribe-de-personasintersex/

Carpenter, M. (2015). *Intersex and ageing*. https://morgancarpenter.com/intersex-and-ageing/

CoE, Council of Europe, Commissioner for Human Rights. (2015). *Human rights and intersex people. Issue paper*. https://rm.coe.int/16806da5d4

CoE, Council of Europe. (2021*). Yearbook of the European Convention on Human Rights / Annuaire de la Convention Européenne des Droits de l'Homme*. https://brill.com/view/title/57217

Conferencia Regional Latinoamericana y del Caribe de Personas Intersex (2018*). Declaración de San José de Costa Rica*. https://brujulaintersexual.org/2018/04/02/declaracion-de-san-jose-de-costa-rica/

Dagnino, E. (2006). Meanings of citizenship in Latin America. *Canadian Journal of Latin American and Caribbean Studies, 31*, 15–51. https://doi.org/10.1080/08263663.2006.10816901

DevGen, Centre de Référénce du Développement Génital du Fœtus à l'Adulte. (2022). *Webpage.* https://www.developpement-genital.org/

European Parliament. (2019). *The rights of intersex people. Resolution 2878*. http://www.europarl.europa.eu/doceo/ document/B-8-2019-0101_EN.pdf

European Parliament. (2021). *The protection of fundamental rights in the EU: Fact sheets on the European Union.* https://www.europarl.europa.eu/factsheets/en/sheet/146/the-protection-offundamental-rights-in-the-eu

Flores-Manzano, M., & Vázquez-Martínez, M. (2021). Eficacia en la tutela y protección de los derechos humanos de las personas intersex en la actual legislación ecuatoriana. *Dominio de Las Ciencias. Revista Científica, 7*, 590–617. https://doi.org/10.23857/dc.v7i2.1819

FRA, European Union Agency for Fundamental Rights. (2015). *The fundamental rights situation of intersex people*. https://fra.europa.eu/en/publication/2015/fundamental-rights-situation-intersex-people

Garland, J., & Slokenberga, S. (2018). Protecting the rights of children with intersex conditions from nonconsensual gender-conforming medical interventions: The view from Europe. *Medical Law Review, 27*, 482–508 https://doi.org/10.1093/medlaw/fwy039

Ghattas, D. C. (2015). *Standing up for the human rights of intersex people - how can you help?* ILGA Europe, OII Europe. https://www.ilgaeurope.org/sites/default/files/how_to_be_a_great_intersex_ally_a_toolkit_for_ngos_and_decision_makers_december_2015_updated.pdf

Ghattas, D. C. (2019). *Protecting intersex people in Europe: A toolkit for law and policymakers*. https: https://diprece.minsal.cl/wrdprss_minsal/wp-content/uploads/2018/03/Circular-08-22-12-15-Instruye-Sobre-Ciertos-Aspectos-de-la-atenci%C3%B3n-de....pdf

Grez, M. (2020). *Las personas intersexuales frente al Derecho: Estudio exploratorio de tres problemas jurídicos*. [Bachelor's Thesis]. Universidad de Chile. https://repositorio.uchile.cl/handle/2250/173871

Haug, O. (2021). *Germany just banned on surgeries on intersex infants. Advocates say it doesn't go far enough*. https://www.them.us/story/germany-banned-intersex-surgeries-on-infants

Horowicz, E. (2017). Intersex children: Whom are we treating. *Medical Law International, 17*, 183–218.

IACHR, Inter-American Commission on Human Rights. (2013). *Public hearing about the human rights situation of intersex people in America, 147th period*. https://www.youtube.com/watch?v=245zpmTobCM&ab_channel=OASOEAVideos

IACHR, Inter-American Commission on Human Rights. (2015). *Violence against LGBTI persons*. IACHR. http://www.oas.org/en/iachr/reports/pdfs/violencelgbtipersons.pdf

IHRA, Intersex Human Rights Australia. (2019). *Intersex is not a gender identity, and the implications for legislation*. https://ihra.org.au/17680/intersex-characteristics-not-gender-identity/

ILGA Europe. (2018). *Non-binary gender registration models in Europe*. https://www.ilga-europe.org/sites/ default/files/non-binary_gender_registration_models_in_europe_0.pdf

Inter, L., & Aoi, A. (2016). *Circular 7 de 2016: Un paso atrás en la lucha por los derechos humanos de las personas intersexuales en Chile*. https://brujulaintersexual.files.wordpress.com/2017/06/circular-7-laura-yhana11.pdf

Intergeschlechtliche Menschen e.V. Bundesverband (2021). *Bundestag beschließt Gesetz zum Schutz von Kindern mit Varianten der Geschlechtsentwicklung*. https://im-ev.de/wp-content/uploads/2021/03/2021-03-26-PM-Verbot-von-Operationen.pdf

Khanna, N. (2021). Invisibility and trauma in the intersex Community. In E. Lund, C. Burgess & J. Johnson (Eds.), *Violence against LGBTQ+ persons: Research, practice, and advocacy* (pp. 185-94). Springer.

Leeuw, L., & Schmeet, H. (2016). *Empirical legal research: A guidance book for lawyers, legislatures and regulators.* Eward Elgar Publishing Limited.

Lev, A. (2006). Intersexuality in the family: An unacknowledged trauma. *Journal of Gay & Lesbian Psychotherapy, 10*, 27–75. https://doi.org/10.1300/J236v10n02_03

Machado, P. (2009). Intersexuality and sexual rights in Southern Brazil. *Culture, Health & Sexuality, 11*, 237–50. https://doi.org/10.1080/13691050802233454

Ministerio de Salud, Gobierno de Chile. (2015). *Circular 18 de Diciembre 2015*. https://diprece.minsal.cl/wrdprss_minsal/wp-content/uploads/2018/03/Circular-08-22-12-15-Instruye-Sobre-Ciertos-Aspectos-de-la-atenci%C3%B3n-de....pdf

Ministerio de Salud, Gobierno de Chile. (2016). *Circular N. 7 August 2016*. https://diprece.minsal.cl/wrdprss_minsal/ wp-content/uploads/2018/03/Circular-aclaratoria-002.pdf

Monro, S., Crocetti D., Yeadon-Lee, T., Garland, F., & Travis, M. (2017). *Intersex, variations of sex characteristics, and DSD: The need for change. Research Report.* University of Huddersfield. http://eprints.hud.ac.uk/id/eprint/ 33535/

Motta, C., & Sáez, M. (2008). *La mirada de los jueces: Sexualidades diversas en la jurisprudencia latinoamericana*. Siglo del Hombre.

Nelson, A. (2018). *Genital normalising surgeries on intersex infants: A scandal in waiting*? University of Manchester, Policy Manchester Blog. https://blog.policy.manchester.ac.uk/posts/2018/05/genital-normalising-surgeries-on-intersex-infants-a-scandal-in- waiting/

O'Flaherty, M. (2015). The Yogyakarta Principles at ten. *Nordic Journal of Human Rights, 33,* 280–98. https://doi.org/10.1080/18918131.2015.1127009

OII Europe. (2013). *Sham package for intersex: Leaving sex entry open is not an option*. https://oiieurope.org/bluff- package-for-inter-leaving-sex-entry-open-is-not-an-option/

OII Europe. (2018). *Germany misses the chance for basing its third gender marker law on human rights*. https://oiieurope.org/really-germany/

OII Europe. (2021a). *A good first step: Germany adopts law banning IGM. However, there is still room for improvement.* https://oiieurope.org/a-good-first-step-germany-adopts-law-banning-igm/

OII Europe. (2021b). *Belgian House of Representatives adopts resolution on protecting intersex rights*. https://oiieurope.org/belgian-resolution-on-protecting-intersex-rights/

OII Europe. (2022). *Good practice map 2021.* https://www.oiieurope.org/good-practice-map-2021/

OUT-Right. (2012). *Argentina adopts landmark legislation in recognition of gender identity*.

https://outrightinternational.org/content/argentina-adopts-landmark-legislation-recognition-gender-identityit%E2%80%99s-%E2%80%98talk-town%E2%80%99-south

PACE, Parliamentary Assembly of the Council of Europe. (2013). *Children's right to physical Iintegrity. Resolution 1952*. https://pace.coe.int/en/files/20174#trace-4

PACE, Parliamentary Assembly of the Council of Europe. (2017). *Promoting the human rights of and eliminating discrimination against intersex people. Resolution 2191*. http://assembly.coe.int/nw/xml/XRef/Xref-XML2HTML-en.asp? fileid=24232

Pham, M., Rajic´, A., Greig, J., Sargeant, J., Papadopoulos, A., & McEwen, S. (2014). A scoping review of scoping reviews: Advancing the approach and enhancing *the* consistency. *Research Synthesis Method, 5,* 371–85. https://doi.org/10.1002/jrsm.1123

Pikramenou, N. (2019). *Intersex rights, Living between sexes*. Springer.

Rivera, A., & Jiménez, N. (2017). *Informe sobre la Situación de las personas intersex en las Américas, Costa Rica y Chile, en el marco del periodo 161 de Sesiones de la Comisión Interamericana de Derechos Humanos de la Organización de Estados Americanos*. http://www.mulabilatino.org/publicaciones/informe%20sobre%20la%20situacion%20de%20las%20personas%20intersex%20periodo%20161%20CIDH.pdf

Rueda, A. (2017). *I de invisibles, intersexualidad en Costa Rica, cuerpos alterados*. https://especiales.ameliarueda.com//intersexualidad/

Rueda, F. (2009). *La integración económica de Europa y América Latina en perspectiva comparada*. https://nuso.org/articulo/la-integracion-economica-de-europa-y-america-latina-en-perspectiva-comparada/

SinViolencia LGBTI. (2019). *El Prejuicio no conoce fronteras. Homicidios de lesbianas, gay, bisexuales, trans e intersex en países de América Latina y el Caribe 2014–2019*. https://sinviolencia.lgbt/wp-content/uploads/20 19/08/Informe_Prejuicios_compressed.pdf

StopIGM. (2016). *Report to the 7th and 8th Report of France on the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW) + Supplement "Intersex, IGM and Human Rights"*. https://intersex.shadowreport. org/public/2016-CEDAW-France-NGO-Zwischengeschlecht-Intersex-IGM.pdf

StopIGM. (2017). *Report to the 5th and 6th Periodic Report of Argentina to the 6th and 7th Periodic Report of Argentina on the Convention Against Torture (C.A.T.).* https://intersex.shadowreport.org/public/2017-CAT-Justicia- IntersexZwischengeschlecht-IGM.pdf

StopIGM. (2019a). *Report to Malta's 3rd to 6th Report on the Convention on the Child's Rights (C.R.C.).* https://tbinternet.ohchr.org/Treaties/CRC/Shared%20Documents/MLT/INT_CRC_NGO_MLT_34709_E.pdf

StopIGM. (2019b). *Report to the 5th to 6th Report of Portugal on the Convention on the Child's Rights (C.R.C.).* https://tbinternet.ohchr.org/Treaties/CRC/Shared%20Documents/PRT/INT_CRC_NGO_PRT_35876_E.pdf

StopIGM. (2019c). *Report to the 6th Periodic Report of Mexico on the International Covenant on Civil and Political Rights (CCPR).* https://intersex.shadowreport.org/public/2019-CCPR-Mexico-NGO-Intersex-Brujula-StopIGM.pdf

StopIGM. (2019d). *Report to the 6th Report of the United Kingdom on the Convention Against Torture (CAT).* https://intersex.shadowreport.org/public/2019-CAT-UK-NGO-Coalition-Intersex-IGM.pdf

StopIGM. (2019e). *Report to the 5th to 6th of Austria on the Convention on the Child's Rights (C.R.C.).* https://intersex.shadowreport.org/public/2019-CRC-PSWG-Austria-NGO-Zwischengeschlecht-Intersex-IGM.pdf

StopIGM. (2020a*). Report to the 5th to 6th of Iceland on the Convention on the Child's Rights (C.R.C.).* https://tbinternet.ohchr.org/Treaties/CRC/Shared%20Documents/ISL/INT_CRC_NGO_ISL_43247_E.pdf

StopIGM. (2020b). *Report to the 6th to 7th of France on the Convention on the Child's Rights (C.R.C.).* https://intersex.shadowreport.org/public/2020-CRC-France-LOIPR-NGO-Intersex-IGM.pdf

Sweeney, J. (2018). The elusive right to truth in transitional human rights jurisprudence. *International and Comparative Law Quarterly, 6,* 353–87. doi:10.1017/S0020589317000586

Tamar-Mattis, S., & Knight, K. (2017). *"I want to be like nature made me": Medically unnecessary surgeries on intersex children in the US.* Human Rights Watch. https://www.hrw.org/report/2017/07/25/iwant-be-nature-made- me/medically-unnecessary-surgeries-intersex-children-us

UN, United Nations. (1948) *General Assembly Resolution 217A. The Universal Declaration of Human Rights*. https://www.un.org/en/about-us/universal-declaration-of-human-rights

UN, United Nations. (1966). *General Assembly Resolution 2200A. International Covenant on Civil and Political Rights*. https://www.ohchr.org/en/instruments-mechanisms/instruments/international-covenant-civil-and-political-rights

UN, United Nations. (1987). *General Assembly Resolution 39/46. Convention against Torture and Other Cruel, Inhuman or Degrad- ing Treatment or Punishment*. https://treaties.un.org/pages/ViewDetails.aspx?src=IND&mtdsg_no=IV-9& chapter=4&clang=_en

UN, United Nations. (1989). *General Assembly Resolution 44/25. Convention on the Rights of the Child*. https://treaties.un.org/pages/ViewDetails.aspx?src=IND&mtdsg_no=IV-11&chapter=4&clang=_en

UN, United Nations. (2001). *Report of the Special Rapporteur on the Question of Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment. A/56/156*. https://digitallibrary.un.org/record/446206

UN, United Nations. (2017). *Fact sheet intersex*. www.unfe.org/wp-content/uploads/2017/05/UNFE-Intersex.pdf

Van Hoecke, M. (2011). *Methodologies of Legal Research Which Kind of Method for What Kind of Discipline?* Bloomsbury Publishing.

YP, The Yogyakarta Principles. Principles on the application of international human rights law in relation to sexual orientation and gender identity. (2007). https://yogyakartaprinciples.org/

YP+10, The Yogyakarta Principles Plus 10. Additional principles and state obligations 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). https://yogyakartaprinciples.org/principles-en/yp10/

Zelada, C., & Quesada, D. (2019). Lxs otrxs invisibles: Hacia una narrativa jurídica para la prohibición de las cirugías de “normalización genital”. *IUS ET VERITAS, 59,* 124–44. https://doi.org/10.18800/iusetveritas.201902.009

8. Intersex People's Human Rights and Their Lived Experiences in Malta

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Introduction

In the last decade, European States such as Germany, Greece, Iceland, Malta, Portugal and Spain have developed human rights frameworks for the protection of intersex people as the consequence of continuous intersex advocacy and activism efforts (Martinez Mestre, 2022; Zelayandía-González, 2023). In 2015, Malta became the first country across the globe to adopt legislation which prioritised the children's rights-based approach to intersex issues, guaranteeing them the protection of their right to bodily integrity, physical autonomy, and self-determination through the Gender Identity, Gender Expression and Sex Characteristics Act (hereinafter referred to as the GIGESC Act) (Garland & Travis, 2022; GIGESC Act, 2015). The legislation has been welcomed and praised by various activist organisations and has been referred to as a "landmark case for intersex rights within European reform" (Editorial, 2014). The enactment of the GIGESC Act in 2015 was followed by amendments in various Maltese secondary legislations and the development of new policies for safeguarding the rights of intersex people.[39]

This chapter aims to understand and analyse the human rights protection provided by the Maltese legal framework which caters to the interests of the intersex community and to what extent some of the legal protections have impacted the lived experiences of intersex people in Malta. To understand the Maltese legal framework, we have analysed the primary and secondary legislation and policies which deal with intersex rights and examined how it impacts the status and rights of intersex people. Further, to understand the implementation of the legal reforms and their consequences on the lived experiences of intersex in Malta, we have laid down the preliminary findings of the interviews conducted with various stakeholders in Malta. The stakeholders included academics, biomedical scientists, non-profit professionals, policymakers and government officers. The interviews were conducted and are being analysed using Martin Heidegger's hermeneutic phenomenological approach, which focuses on uncovering what it really means "to be a person *in* the world" (Heidegger, 1962, in Draucker, 1999, p. 361). Heidegger's work on hermeneutics is based on the belief that when we ask theoretical questions about human existence or in Heidegger's term '*Being*' as '*Dasein'* (being in the world), we can understand their experience of being human (Dibley et al., 2020), which in our research refers to uncovering and understanding what it is to be intersex in Malta and the meaning of their experiences.

Background

The concerns regarding intersex human rights were first raised in Malta in the year 2013. Malta hosted the Third International Intersex Forum in Valletta between 29 November and 1 December 2013, which was supported by the International Lesbian, Gay, Bisexual, Trans, and Intersex Association[40] (hereinafter referred to as ILGA) and ILGA-Europe.[41] The event brought

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[39] These legislations and policies include the Trans, Gender Variant, and Intersex Students in Schools Policy [Schools Policy] (2015), the Equality for Men and Women Act, 2002, the Marriage Act and Other Laws (Amendment) [Marriage Act], 2017 and the Gender-Based Violence and Domestic Violence Act, 2018.

[40] ILGA World is a worldwide federation with more than 1,900 organisations from over 160 countries. It advocates for the human rights of lesbian, gay, bisexual, trans, and intersex (LGBTI) communities. It has ECOSOC consultative status at the UN. The ILGA World is based in six different regions: Pan Africa ILGA, ILGA Asia, ILGA-Europe, ILGALAC, ILGA North America and ILGA Oceania (ILGA World, 2023).

[41] ILGA-Europe (2023) is a member of the ILGA World, working for the human rights of LGBTI people in Europe and Central Asia. It is an international non-government umbrella organisation which networks over 700 organisations across Europe and Central Asia.

together 34 intersex activists from across the globe, representing 30 intersex organisations (Third International Intersex Forum, 2013). The event's focus was to affirm the reality of the intersex community and its existence in all regions and countries of the world (Third International Intersex Forum, 2013). The Forum supported the principles which were already established in the First and Second International Intersex Forums and extended the demands to "aiming to end discrimination against intersex people and to ensure the right to bodily integrity, physical autonomy, and self-determination" (Third International Intersex Forum, 2013, s.p.).

This event was followed by the government of Malta launching an online consultation on 29 October 2014, intending to collect opinions and inputs from the public, civil society organisations, business organisations, political parties, government organisations, trade unions, and others towards the process of forming the GIGESC Act (Ministry of Social Dialogue, Consumer Affairs and Civil Liberties [MSD], 2015a). The parliament's goal was to introduce a reform that would eliminate discrimination against intersex people and allow trans people to have the right to determine their identity. As part of their efforts to achieve these changes, the LGBTI Consultative Council took charge and drafted the GIGESC Bill (MSD, 2015a).

Methodology of Legal Research

In the traditional legal research discipline, positive law is understood through the sources of authoritative texts like doctrinal literature, judgments, legislations, and treaties (Langbroek et al., 2017). To evaluate the legal framework and human rights mechanisms for the protection of the rights of intersex people, one of the methodologies employed by the researchers is doctrinal legal research. This methodology is distinguished by its focus on studying legal texts and is often described as "black-letter law" (Chynoweth, 2008, p. 29). Legal doctrinal research aims to provide a comprehensive and organised explanation of the principles, rules, and concepts that govern a particular legal system or institution. It also involves analysing the relationship between these principles, rules, and concepts to address any uncertainties and gaps in existing laws (Smits, 2017). S.N. Jain (2010) explains doctrinal research as that which:

> of course, involves analysis of case law, arranging, ordering, and systematising legal propositions, and study of legal institutions, but it does more—it creates law and its major tool (but not the only tool) to do so is through legal reasoning or rational deduction (p. 68).

Under doctrinal research, the question is "What is the law?" in a particular context (Chynoweth, 2008). Paul Chynoweth has observed that in asking "What is the law?" doctrinal research does not concern itself with research *about* the law, but it takes what Hart describes as an "internal, participant-orientated epistemological approach to its object of study" (Chynoweth, 2008, p. 30). Therefore, this type of research, according to Chynoweth, can be characterised as an exploration within the domain of law itself, aligning with the perspective that it is research *in* law (Arthurs, 1983).

One of the limitations discussed repeatedly concerning doctrinal research is its aloofness from social realities (Bhat, 2020). William Twining (1976, as cited in Hutchinson, 2013) observed that by just focusing on the rules of law and not indulging in a more systematic study of the social background of its origin and its impact on society, doctrinal legal research has escaped the social realities. Further, it also faces the danger of being influenced by the researcher's views, leading to a narrower analysis of the text under investigation (Hutchinson, 2013).

Doctrinal legal research is helpful for this research on intersex human rights in Malta to understand and analyse the present laws and policies and identify gaps in the legal system, if any, which will further help in understanding how the laws can be reformed. However, to avoid confining the research to a narrow analysis and encompassing social realities, the researchers have integrated the methodology of socio-legal research. As doctrinal legal research is entirely based on the existing doctrines and authoritative texts of law, it is unaffected by the empirical world (Chynoweth, 2008). Its function is solely normative, where it is only concerned with the prescriptive content and not the effect and impact of the legal norm (O’Donovan, 2016). However, socio-legal methodology tackles the silences in doctrinal legal research and adopts a more realistic analysis of law, consisting of the law’s actual function in society (O’Donovan, 2016).

Scholars have observed that law is a component of the wider social and political structure and is interconnected to it in a variety of ways (Thomas, 1986). The law cannot be viewed as a force to which society is subjected; instead, law shapes and is shaped by social, political, and economic factors (Socio-Legal Studies Association [SLSA], 2021, para 1.2.1). Hence, law can only be adequately understood if studied in a social context. On the one hand, doctrinal research is complemented as the ”law in the book” (Argyrou, 2017, p. 95), while on the other hand, the socio-legal method is seen as ”law in context” (Chynoweth, 2008, p. 31).

Nicola Lacey (1996) observed two concerns that are dealt with by socio-legal scholarship. Firstly, socio-legal research identifies legal practices within the realm of social practices constituting their immediate environment, where the social practices influence or interact with the law. These social practices are inclusive of administrative, commercial, economic, and other disciplinary practices. Secondly, socio-legal research studies the legal practices within the context of empirical inquiry, which examines the legal articulation and expression of the particular law and the meaning and effect of the laws as they are interpreted and enforced in a state and experienced by the people.

One of the challenges of socio-legal research, which is relevant to this research, is the fear of ”am I still a lawyer?” as discussed by Darren O’Donovan (2016, p. 22). This refers to the fear of deviating too far from the professional legal context. O’Donovan (2016) has observed that:

> As lawyers, we are imbued with ‘internal conventional perspective’, where quality is judged predominantly by demonstrating adherence to the accepted norms of an internal discourse. I would argue that students tend to overestimate the pre-eminence of doctrinal approaches in academia and practice, with the result that ‘academic’ approaches to law attract negative preconceptions. (p. 22)

O’Donovan (2016) has explained how this anxiety in the minds of young researchers and PhD students can be tackled. He has observed that it is necessary to be aware of that socio-legal methods exist on a continuum. He has referred to the typology of multidisciplinary research identified by Mattias Siems (2009)[42] to underline how socio-legal study contains a phase of “return to law,” where the researcher comes back to analyse the impact research has upon the legal system (O’Donovan, 2016, p. 25). Henceforth, it is unlikely for a law student or researcher to engage in research in a mono-disciplinary approach involving only sociology or philosophy (O’Donovan, 2016). The research would mostly always come back to the legal analysis of the social research conducted by the researcher.

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[42] There are four types of interdisciplinary work identified by Siems, which include:

- Basic interdisciplinary research: it covers using similar research questions as is used in traditional legal research, such as those relating to whether the law or legal norm matters.
- Advanced interdisciplinary research type 1: in this research, the research questions do not revolve around the law. This research attempts to provide a comprehensive view of a topic rather than just analysing the law.
- Advanced interdisciplinary research type 2: deals with integrating scientific methods into legal analysis and thinking.
- Advanced interdisciplinary research type 3: this research type combines advanced interdisciplinary research type 1 and type 2, asks an interdisciplinary question, and attempts to integrate the scientific method into legal analysis and thinking (Siems, 2009).

Overview of laws

On 1st April 2015, the Maltese government unanimously enacted the GIGESC Act, which has been described as "the most expansive, ground-breaking, and comprehensive bill of its kind" (Wipfler, 2016, p. 511). It made Malta the first nation to outlaw unnecessary medical interventions on intersex minors. It does not only guarantee the protection of intersex people's rights of bodily integrity, physical autonomy, and self-determination but also emphasises the promotion of anti-discrimination and equality policies to ensure their welfare (GIGESC Act, 2015, s 13). The legislation is based on the substantive equality model, a holistic approach to bringing legal reform (Garland & Travis, 2018).

Similarly, various policies have been developed, and domestic legislation has been amended over the years to engage with the protection of the rights of intersex people. These include the Trans, Gender Variant, and Intersex Students in Schools Policy (2015) (hereinafter referred to as the Schools Policy). The Maltese Ministry for Education and Employment developed the Schools Policy in June 2015, based on the context of the Framework for the Education Strategy for Malta 2014-2024 and adhered to the values provided in the Respect for All Framework (Schools Policy, 2015). The Framework for the Education Strategy for Malta 2014-2024 is very much in check with the Sustainable Development Goal 4 of UNESCO, which deals with providing inclusive and equitable quality education to everyone and promoting opportunities for lifelong learning for all (UNESCO, n.d.). The framework has four main targets to achieve: making the secondary schooling structure driven by the values of inclusion, social justice, equity, and diversity (Schools Policy, 2015).

Another law which has been amended to account for the GIGESC Act is *The Equality for Men and Women Act,* 2002 which now includes "sex characteristics" as a protected ground under the definition of "discrimination" (Equality for Men and Women Act, 2003, s 2(1)), making any kind of negative discrimination based on sex characteristics in professional setups and educational institutions unlawful (Equality for Men and Women Act, 2003, s 4 & 8). In a similar vein, *The Marriage Act and Other Laws (Amendment)*, 2017, has brought amendments to multiple provisions of the Criminal Code to make them gender-neutral (Marriage Act and Other Laws (Amendment) [Marriage Act], 2017). For instance, the words "husband or wife" under Article 62 of the Code have been substituted for "spouse." The terms "father-in-law or mother-in-law, son-in-law or daughter-in-law" have been substituted for the words "parents of either spouse, spouses of either child" (Marriage Act, 2017, s 3). Such minor changes in the legislation significantly impact the status of same-sex relationships as they provide equal rights to them as those enjoyed by opposite-sex couples (Wootton et al., 2019). Furthermore, the *Gender-Based Violence and Domestic Violence Act* of 2018 protects victims of domestic violence in a family or domestic unit (Gender Based Violence and Domestic Violence Act, 2018, s 2).[43] Section 4 of the 2018 Act specifies that its provisions shall be implemented without discrimination, especially concerning protecting the victims' rights. The provision has laid down various grounds for non-discrimination, one of which is the "sex or sex characteristics" of the person concerned, making it a point that persons with variations of sex characteristics are also protected under the Act without any discrimination.

These laws and policies framed to protect the identity and human rights of intersex people in Malta have made it one of the leading nations in intersex protection and rights. It has provided a model of good practice that other states can follow to create holistic reform in intersex rights

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[43] "Family or domestic unit" is inclusive of persons who reside together, who have separated and those who do not reside together in the same household. It includes current or former spouses (dissolved or declared nullified), civil union partners, cohabitants, or any person living in the same household as the offender or having lived with the offender within a period of three years preceding the offence. It also includes persons who are or were in an informal relationship, who have been formally or informally engaged with the plans to marry or enter a civil union and the persons having or having had a child in common. The definition also deals with persons who are related to each other through consanguinity or affinity up to the third degree and any ascendant or descendant (Gender Based Violence and Domestic Violence Act, 2018).

(Garland & Travis, 2018). In the next section of the chapter, we will look in detail at all these rights enshrined in the legal framework of Malta and understand the role they play in ensuring the well-being of the intersex community.

Human Rights of intersex people

Right to Self-Determination of Gender

This chapter follows the structure of the GIGESC Act in addressing the rights to bodily integrity, physical autonomy, and self-determination of intersex people. It initiates by examining the right to self-determination as outlined in the GIGESC Act, 2015, section 3, along with other interconnected rights provisioned in the legislation. Subsequently, it discussed the right to bodily integrity and physical autonomy, as detailed in section 14 of the GIGESC Act, 2015, alongside its corresponding rights.

The right to self-determination is enshrined under Principle Three of the Yogyakarta Principles,[44] which deals with the right to recognition before the law. The Principle reads in part that "each person's self-defined sexual orientation and gender identity is integral to their personality and is one of the most basic aspects of self-determination, dignity, and freedom" (International Commission of Jurists, 2006, p. 11). The UN Human Rights Council has also observed the right to self-determination of gender and stated that a lack of legal recognition, as well as the right to self-determine diverse gender identities, also compromises a person's right to health, freedom of movement, and other human rights (Independent Expert on sexual orientation and gender identity [IESOGI], 2018).

The demand to provide intersex people the right to self-determination was raised in the First and Second International Intersex Forum and was reaffirmed in the Malta Declaration (Third International Intersex Forum, 2013). When the GIGESC Act was enacted, the framers enshrined this right to establish that all citizens and residents of Malta have the right to their gender identity and the right to change their gender identity without the need to prove any psychiatric or pathological intervention (GIGESC Act, 2015, s 3(1), 3(4) & 4). Section 3 of the Act includes the right to be recognised according to the gender identity of the person concerned, associated with and the right to free development of their person according to their gender identity (GIGESC Act, 2015, s 3(1)a & 3(1)(b)). It further states that the gender identity of every person shall be respected at all times (GIGESC Act, 2015, s 3(3)). A de-pathologised approach is adopted to ensure that people can exercise their right to gender identity. The provision states that it shall not be required for them to provide proof of "surgical procedure for total or partial genital reassignment, hormonal therapies or any other psychiatric, psychological or medical treatment" to exercise their right under the Act (GIGESC Act, 2015, s 3(4)).

The right to request a change in one's gender and first name to reflect the self-determined gender identity is also provisioned under the Act (GIGESC Act, 2015, s 4(1)). The person concerned shall only be required to produce a declaratory public deed to the notary published in accordance with Section 5 of the Act, and no other evidence shall be needed for making a change in their gender identity (GIGESC Act, 2015, s 4(3)). The depathologised approach applied to enjoy the right to gender identity is also extended to situations where the person is changing their gender identity,

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[44] The Yogyakarta Principles (YP) were adopted in 2006 and have eventually developed into "an authoritative statement of the human rights of persons of 'diverse sexual orientations and gender identities'" (Editorial, n.d.). The YP sets forth the principles on how international human rights law should apply to sexual orientation and gender identity. The principles themselves do not constitute a legally binding part of international human rights law. However, they affirm the existing rights and binding international legal standards, such as the rights set under ICCPR. The Yogyakarta Principles include access to justice, non-discrimination, the right to education, employment, healthcare, privacy, the right to freedom of expression and assembly and many other rights (International Commission of Jurists, 2006).

as the documents listed for drawing up the declaratory public deed do not include any documents that concern pathologising procedures (GIGESC Act, 2015, s 5(1)). This right extends to refugees under the Refugees Act and minors through persons exercising parental authority over the minor (GIGESC Act, 2015, s 4(8) & 7).

However, it is important to acknowledge that not all intersex people either require or wish for a change in their gender identity (IHRA, 2012). Many intersex people are comfortable with their gender according to the sex they have been assigned at birth. However, in some situations, they might feel the need to change it to identify with a gender different from the sex assigned at birth (Viloria & Zzyym, 2015). Nikoletta Pikramenou (2019) has observed the ways the sex/gender system adversely impacts the human rights of intersex people, as society and law try to "normalise" and "fit them in" the binary gender system and stated that "due to the binary understanding of 'sex', intersex people, tend to cause the sex/gender system 'explode' and society and the law in an effort to 'normalise' them and 'fit them in', violate their fundamental human rights" (p. 25). Hence, providing the right to gender identity and the right to change it without pathological proof is just the first and frontal step towards holistic well-being. It is a status-based reform as it initiates a symbolic shift, a more formal shift in the journey of providing people with the right and equality of gender identity (Garland & Travis, 2018). However, to ensure that people can effectively enjoy the right to self-determination on a more substantive account, it is necessary to tackle the issues of stigma and exclusion (Davis, 2015; IESOGI, n.d.) and the disadvantage and marginalisation faced by people whose sex and gender do not comply with the expectations of society and the legal system (Pikramenou, 2019). According to Fae Garland and Mitchell Travis (2018), implementing more substantive and holistic policies could support this process.

The incorporation of the right to self-determination is also beneficial for parents who face pressure to make decisions about their newborn's registration of sex and potential medical intervention. Prior to 2015, the parents had three days from the birth of a child to register their birth, which also included the declaration of sex at the registry office (Civil Code, 1868, a 278C). However, since the amendment of the Civil Code, the parents of the newborn child can opt for non-declaration of sex on the child's birth certificate till the child reaches the age of 18 years (GIGESC Act, 2015, s 18(c); Civil Code (amendment of 2015), 1868, a 278C). This shifts the autonomy from the parents and doctors to the child to determine their registration of gender. Further, it reduces the pressure on parents to consent to irreversible medical interventions for their intersex child as they get the alternative to delay the registration of sex until the children develop their gender identity (Ní Mhuirthile, 2018). In 2015, Malta also introduced 'X' markers on passports and identity cards (MSD, 2015b), which was established by the International Civil Aviation Organisation (hereinafter referred to as ICAO) in 1996 in its guidelines for machine-readable travel documents and passports (Quinan & Hunt, 2023; International Civil Aviation Organisation [ICAO], 2021). ICAO's measure paved the way for its 193 member states, Malta being one of them, to undertake similar measures for improving mobility and migration opportunities for the gender variant and non-binary populations, which is seldom used (Quinan & Hunt, 2023). Malta adopted the LGBTIQ Action Plan 2015-2017, which introduced 'X' markers as an alternative to 'M' and 'F' markers on identity cards and passports for people who prefer not to specify their gender on these documents (MSD, 2015b). This also provides an option for individuals who do not identify as male or female or identify as both.

However, the stigma and prejudice attached to intersex and non-binary gender identities can lead to the failure of the implementation of either leaving the gender marker blank or opting for the 'X' marker. For instance, in 2013, Australia introduced the third marker for ensuring that non-binary people, including intersex people who identify outside the male and female gender categories, can have an option for gender identification on birth certificates and other documents (Australian Government, Attorney General's Department, n.d.). The purpose of this change was to give autonomy to people to choose their gender and to reduce medical interventions on intersex children, as parents would have the option at the time of birth to choose the 'X' marker when the sex of the child is ambiguous or undetermined. Nevertheless, Morgan Carpenter (2018) suggests that even after introducing the third-sex model, cases of medical intervention continued to occur in Australia due to the stigma attached to it and the failure to establish a relationship between the new classification and medical intervention. The fear and shame attached to the public disclosure of an individual falling under the category ‘X’ are also one of the primary reasons medical practitioners and parents still prefer to intervene medically rather than waiting for the concerned individual to make their conscious decision (Carpenter, 2018). Hence, even though such a de-pathologised approach aims to reduce the social pressure on the parents, it can lead to the contrary due to the shame attached to being identified, eventually making it largely unhelpful to the intersex community. John George Peristiany (1966) observed that the basis for honour and shame is mainly related to a person’s sex and sexual elements; for instance, a man’s power is measured by his sexual prowess, and he should always be ready to prove that he has testicles, whereas, for a woman, her chastity and virginity before marriage are of utmost importance, and if they are not able to reflect these qualities, it brings shame. Peristiany (1969) has also extensively talked about a person’s honour and how it is of the highest social value, determining their status in society (Peristiany, 1966, as cited in Herr, 1969). These concepts of honour and shame discussed by Peristiany are very relevant when it comes to understanding the shame and stigma attached to intersex variations and intersex people and their parents’ fear of losing honour and being shamed (Sytsma, 2006).

To ensure that individuals can exercise their right to self-determination and to reduce the pressure on parents to make a decision regarding their intersex child’s gender identity process, whether it be to decide on the gender marker or medical interventions, it is necessary to address the concern of shame and also the issues which revolve around the medical management of intersex children along with implementing de-pathologising approaches. The issues of medical management often include selective abortion of intersex foetuses (Holmes, 2008; Lum, 2023), intersex infanticide (Behrens, 2020; Collison, 2018; Benini, 2018), intersex genital mutilation (IGM) (Warne & Raza, 2008), normalising surgeries (Greenberg, 2003; Dolgin, 2017), and deception or withholding information from the patient, and their families about the intersex traits/variations (Dickens, 2018), to name a few. Bernard M. Dickens (2018) states that:

> It was observed 20 years ago in medical practice that parents of intersex children and the children as they mature ‘are lied to; risky procedures are performed without follow-up; consent is not fully informed; autonomy and health are risked because of unproven (and even disproven) fears that atypical anatomy will lead to psychological disaster. (p. 258)

These issues were also addressed in the Malta Declaration (Third International Intersex Forum, 2013), some of which progressed in the provisions of the GIGESC Act, especially concerning IGM and normalising surgeries and treatments (GIGESC Act, 2015, s 14).

Right to Bodily Integrity and Physical Autonomy

ILGA Europe defines *bodily integrity* as a principle wherein, when we are in a situation concerning our bodies, we, including children, have the right to autonomy and self-determination over our bodies (ILGA-Europe, 2022). Within this definition, ILGA-Europe (2022) has noted that bodily integrity includes having protection from intersex genital mutilation and forced medical interventions. UNFPA (2022, s.p.) refers to a person’s power and agency to choose their own body and observed that bodily autonomy means “my body is for me; my body is my own”. The GIGESC Act reiterated the same principle in Section 14, which is considered the most innovative aspect of the Act (Ní Mhuirthile, 2018).

Section 14 of the Act makes it unlawful for medical practitioners and other professionals to carry out any sex assignment treatments and/or surgical interventions on the sex characteristics of minors when such an intervention and/or treatment can be delayed until the person concerned can provide their informed consent regarding the surgery and/or treatment. In a situation where the minor consents to such treatment and/or intervention, it can be conveyed by the minor’s parents or tutor for the treatment and/or intervention to be conducted (GIGESC Act, 2015, s 14(1)). The legislation obligates the medical professional to ensure that the best interest of the minor is given paramount consideration under Article 3 of the Convention on the Rights of the Child and that their views are given regard, taking into account their age and maturity in situations where the decision of treatment is being expressed by the parents or tutor of the minor (GIGESC Act, 2015, s 14(5)). It also sets forth “exceptional circumstances” under which surgery can be conducted even though the minor does not have the capacity to consent to it (GIGESC Act, 2015, s 14(2)). However, the provision has failed to define these “exceptional circumstances.” No clear definition of ‘exceptional circumstances’ exists within the Maltese law or the pronouncements of the ECHR. A better definition of “exceptional circumstances” would have given further assistance in ensuring the protection of the right to bodily integrity of intersex minors (Zelayandía-González, 2023). Nonetheless, keeping in mind the spirit of the law, it is pointed out in the provision that “medical intervention which is driven by social factors without the consent of the individual concerned will be in violation of this Act” (GIGESC Act, 2015, s 14(2)). That said, the legislation has not defined what the “social factors” include, making it a “legally ambiguous term” (Zelayandía-González, 2023, p. 137).

Even though various organisations have admired this provision and has led to the Act becoming an example for “other states to review and reform their legislation with the same aim and in this spirit” (TGEU Press Release, 2015, para. 1), it must be noted that it is not free from criticism. Various concerns have been raised that the GIGESC Act “lacks ‘bite’” (Garland & Travis, 2018, p. 604). According to Garland and Travis (2018), there exists no adequate legal protection under the Act to prevent unnecessary non-consensual medical intervention on the bodies of intersex minors. In cases where doctors conduct such surgeries against the provisions of the GIGESC Act, they face a minimal fine of €500- €1,000 (GIGESC Act, 2015, s 11(3); Garland & Travis, 2018). This fine is equivalent to punishments for off-duty taxis not being parked off-street, which attracts a penalty of €500 in Malta (Light Passenger Transport Services and Vehicle Hire Services Regulations, 2020). By contrast, in cases of non-medical female genital mutilation (hereinafter referred to as FGM), the Maltese Criminal Code has much more severe punishment for performing FGM than that of IGM. In the case of the performance of non-medical FGM, the offender is liable to the punishment of imprisonment for a minimum of five years, which may extend to ten years (Criminal Code, 1854, a 251E(1)). This punishment elevates to a period of six to twenty years in case the performance of FGM leads to the death of the victim within forty days of the operation (Criminal Code, 1854, a 251E(2)(a)(i)) and imprisonment for six to twelve years if the death occurs after forty days of the operation but within one year (Criminal Code, 1854, a 251E(2)(a)(ii)). The provision also states that in cases where death ensues because of a supervening accidental cause and not due to the nature or natural consequence of the intervention, the offender shall be liable for a punishment of imprisonment for six to twelve years (Criminal Code, 1854, a 251E(2)(b)). The provision under clause (2)(b) of Article 251E does not specify any time limit on the death of the victim. Furthermore, in a situation where a person wilfully fails to prevent or report non-medical FGM is liable for a more significant penalty (not less than €1,000 and up to €5,000) than that of a person performing IGM on intersex children (Criminal Code, 1854, a 251E(4)).

Markus Bauer and Daniela Truffer (2019) have argued that Maltese paediatric surgeons consciously refuse to stop advocating IGM practices and participate in them regularly, even after the law has been enforced in the country to stop such practices. They further observed that all forms of intersex genital mutilation practices are still widespread and ongoing in Malta, both inside the state and overseas. Domestically, the University Children’s Hospitals are funded to advocate, prescribe, and perpetrate the practice of intersex genital mutilation (Bauer & Truffer, 2019). Further, according to several reports, intersex infants are traditionally referred to contractual hospitals reportedly in the UK (Bauer & Truffer, 2017; Bauer & Truffer, 2019), Belgium (Bosman, 2019), and Italy (Bauer & Truffer, 2019). Keeping in mind the issue of IGM cases being referred to other countries, the Act has no provision to provide extra-territorial protection to intersex children to eliminate unnecessary medical intervention on their bodies overseas. In a situation where a medical practitioner refers to or recommends conducting surgeries or treatments outside the state of Malta, the Act does not hold the medical practitioner accountable for violation of the provisions of the Act. However, in cases of FGM, the Maltese courts bestow the power of extra-territorial jurisdiction provided that some part of the action took place in Malta or either the offender or the victim is a citizen or permanent/habitual resident of Malta (Criminal Code, 1854, a 251I). A similar provision for the protection of intersex children from medical intervention overseas can help safeguard their right to bodily integrity to a higher standard.

If we look deeper into Section 14, sub-section 1 provides that sex assignment treatments or surgical interventions can be carried out if the minor gives their informed consent through their parents or tutors. However, the provision does not elaborate on how it shall be ensured that the child's consent is informed, and it is their decision to go ahead with the treatment or surgery, as their consent can be derived through parental and societal pressure or expectations to fall under the binary notions of sex.

Section 14(2) sets out the exceptions to Section 14(1), stating that medical treatment can be carried out on minors in exceptional circumstances, and only mentions the term "treatment" and not "surgical intervention," making the intention of the lawmakers unclear. It is ambiguous as to whether surgical intervention can be carried out on minors who cannot give informed consent or not. For instance, in a situation where the minor concerned consents to a treatment like psychological support but does not intend to consent to surgical intervention, no provision indicates what measures should be taken and how to draw the difference between the "treatment" and "surgical intervention."

Further, according to the legislation, in cases where a minor requires treatment but is unable to give consent, under the exceptional circumstances defined under Section 14(2), the interdisciplinary team and the parental authority or the tutor of the minor must come to an agreement regarding such medical intervention. Section 14(4) deals with the composition of the interdisciplinary team, and it states that the team shall be composed of professionals who are considered appropriate by the Ministry for Home Affairs, Security, Reforms, and Equality (GIGESC Act, 2015, s 14(4)). However, the provision is unclear about who these professionals shall be, whether they shall be paediatric consultants, endocrine specialists, paediatric nurses, social workers, child psychologists, or child rights officers or advocates, to name a few. Further, the legislation does not specify the number of professionals the minister should appoint to form the interdisciplinary team. The Act overlooks the potential challenges that may arise in implementing this provision if the interdisciplinary team consists of numerous members, taking into consideration that matters concerning intersex individuals still carry stigma and are often handled discreetly (Cilia, 2016). This secrecy can create discomfort for parents and tutors when disclosing the minor's situation to a large team of professionals.

In one of the interviews conducted by *Vice*, Hida Viloria, one of the first openly intersex people and a prominent intersex advocate, noted that the wording of the GIGESC Act does not entirely disapprove of the prejudice society has against intersex people and traits and considers intersex as something that can be "fixed" (Hay, 2015). The words denote that the medical interventions shall be "deferred" until the child "can provide informed consent" (GIGESC Act, 2015, s 14(1)). She stated in the interview that:

> Imagine if we wrote about reparative therapies for homosexuals in that way. The similar phrase would be: Reparative electroshock therapies for homosexual youth must be postponed until those individuals are old enough to give consent. It's easier to notice when you think about it with a different population group that's less stigmatized today, that the statement implies that these procedures 'will' happen. (Viloria in Hay, 2015, para. 9)

The argument presented by Viloria raises an essential question of whether postponing medical intervention on intersex children is the same as accepting intersex people or is just assuming that eventually, the child would choose to fit into the binary system of gender and till then the surgeries should be put off (Hay, 2015). As the argument presents, the provision can be indicative of just postponing medical interventions on minors, that sooner or later, the intersex person must undergo medical intervention to make themselves a part of the gender/sex binary system. However, this argument can be refuted by bringing into light the spirit of the legislation, which focuses on a person's right to self-determination of gender. By eliminating the scope of medical intervention, the state would not only take the risk of not giving medical assistance in exceptional circumstances where the individual requires medical assistance but also take away their right to self-determination.

Right to equality and Anti-discrimination

Along with the right to self-determination, bodily integrity, and physical autonomy, it is also necessary for a state to support the reforms with holistic measures, which can give real resilience to intersex people (Garland & Travis, 2018). One such measure is to ensure that intersex people are treated equally and not victims of discrimination. The right to equality and anti-discrimination has been enshrined in the GIGESC Act under Section 13. It states that "every norm, regulation, and procedure shall respect the right to gender identity. No norm or regulation or procedure may limit, restrict, or annul the exercise of the right to gender identity, and all norms must be interpreted and enforced in a manner that favours access to this right" (GIGESC Act, 2015, s 13(1)). It is the duty of private and public sectors and agencies to promote equality of opportunity and ensure that unlawful discrimination and harassment based on someone's sexual orientation, gender identity, gender expression, and sex characteristics is eliminated (GIGESC Act, 2015, s 13(2),(3)).

Various pieces of secondary legislation have also been amended in Malta to make them more inclusive of the intersex community. "Sex characteristics" have been incorporated into the legal framework to make them gender-neutral and protect intersex people from discrimination and violence. For instance, the term "sex characteristics" has also been added to the ground under the definition of "discrimination" in the *Equality for Men and Women Act 2003*, which states that treating any person less favourably than another person due to reasons such as sex characteristics is construed as discrimination (Equality for Men and Women Act, 2003, s 2). The scope of protection under the law also extends to discrimination people face during employment (Equality for Men and Women Act, 2003, s 4). A very innovative aspect of this legislation is that it also extends to make it unlawful to discriminate against the parents or guardians of intersex people (Equality for Men and Women Act, 2003, s 2(3)(c)).

Similarly, the *Gender-Based Violence and Domestic Violence Act 2018* has also incorporated provisions which clearly protect intersex people from gender-based violence and domestic violence without any discrimination based on their sex characteristics. Domestic violence is defined to include all such acts and omissions that cause physical and, or moral harm or suffering through "verbal, physical, sexual, psychological, or economic" violence. It also includes threats of such acts and omissions, coercion, or arbitrary deprivation of liberty (Gender Based Violence and Domestic Violence Act, 2018, s 4). This provision has paved the way to interpret domestic violence in various ways. It does not constrain it to limited acts and omissions, which can be beneficial for an intersex person to seek justice, not only in situations where they might be facing mental and physical abuse but also for the trauma and sufferings they face due to non-consensual medical interventions on their bodies.

It is important to note that no case has been filed in the Maltese courts for unnecessary medical intervention on intersex people, discrimination, or violence on the grounds of sex characteristics or any offence under any of the primary or secondary legislation. A possible reason for not filing cases and seeking justice is that intersex people want to hide their identity and are afraid that somebody will know that they are intersex, even within their families (Garland & Travis, 2018, p. 598). Intersex people are forced to remain "in the closet" most of their lives, and it is not easy for them to come out and express themselves without the fear of being discriminated against, stigmatised, and judged (Jones, 2018).

Furthermore, no effective legal measure under the Act ensures access to redress and justice for individuals who have already undergone medical intervention. Additionally, the prescription that determines the statutory limitation period of any criminal matter in Malta is based on the severity of the punishment of the offence (Criminal Code, 1854, a 688). Article 688(e) of the Criminal Code states that when the term of imprisonment is less than one year or a fine (as is the case for offences under Section 14 of the GIGESC Act), the criminal action is barred by the lapse of two years. This prescriptive period prohibits intersex adults from calling a court for the medical intervention they underwent in their childhood. Many intersex individuals find out about their childhood medical history much later in their lives (Ghattas, 2015), and severe trauma caused by the medical intervention or the disclosure of such intervention prohibits them from acting in time (Bauer & Truffer, 2019). This delay leads to non-admission of cases as the incidence has already occurred beyond the prescribed time of limitation. Hitherto, no victim of unnecessary medical intervention has sought legal remedy in the courts of Malta.

The laws adopted and amendments brought to the Maltese legal system are progressive and considered to set an example for other states to review and amend their policies (TGEU Press Release, 2015). Nonetheless, these progressive reforms cannot be taken for granted as there is no data available regarding how intersex people are treated in Malta and if they can freely and equally exercise their rights without facing any discrimination or violence based on their sex characteristics. Even if we take into consideration the Schools Policy of 2015, which was framed with the aims of achieving anti-discrimination, equality and safety of all students (Schools Policy, 2015), there is no record of whether and how this policy is being implemented in Malta. The policy has stated that the issues of discrimination, bullying, and unfair treatment shall be tackled by advocating the well-being and rights of the students (Weiler, 2003). However, the policymakers have taken no further official measures to ensure that the schools follow these recommendations. Therefore, while the state has made efforts to formulate the legal framework, it is crucial to examine further the barriers hindering its effective implementation (Carpenter, 2016).

Other Rights

One of the developments made in Malta to ensure intersex people can exercise their rights is to strengthen the protection under the right to privacy. International committees and courts of law have interpreted the right to privacy in various ways. The European Court of Human Rights has defined privacy or private life as the multiple aspects of the physical and social identity of a person (*S. and Marper v. The United Kingdom [GC]*, 2008). While interpreting the ambit of the right to respect for private and family life, home and correspondence enshrined under Article 8 of the European Convention of Human Rights, the ECtHR observed that it is inclusive of the right to personal autonomy and self-determination (*Glass v. The United Kingdom*, 2004; *Trocellier v. France*, 2006; *Juhnke v. Turkey*, 2008; *Codarcea v. Romania*, 2009). As per the OII Europe submission to the UN Special Rapporteur on the Right to Privacy, the right to privacy is inclusive of various aspects of an intersex person's life, such as medical interventions, healthcare, violence and discrimination they face, and education (OII Europe, 2020).

Malta has incorporated many of these aspects, discussed at the international level, into its legal framework and has also exclusively dealt with the right to privacy of intersex people. The Schools Policy of 2015 states that students must have the right to privacy and confidentiality and further observed that it should not be the duty of intersex students nor should they be expected to disclose any information about their intersex traits or their experience of being intersex (Schools Policy, 2015; Weiler, 2003). Even under the GIGESC Act, Section 8 clearly states that the act of birth is solely and exclusively accessible to the person to whom it relates and when they have attained the age of eighteen or by a court order. The legislation also protects the privacy of the people who have availed the provisions of the Act. It states that if any person commits the offence of exposing, insulting, or reviling any such person who has availed the provisions of the Act, they should "upon conviction, be liable to a fine of not less than one thousand euro and not exceeding five thousand euros" (GIGESC Act, 2015, s 11(1)), which is even higher a fine compared to when a medical practitioner conducts an unnecessary medical or surgical intervention on a minor (GIGESC Act, 2015, s 11(3)).

The GIGESC Act has also dealt with the right to seek counselling under Section 15, according to which any person who is seeking psychosocial counselling, support and medical interventions relating to their sex and gender should be given support by psychologists and medical practitioners or peer counselling. Further, the support provided needs to be expert-sensitive and individually tailored. The provision extends to ensure that these services are provided to the people from the time of their diagnosis or self-referral to such time they find it necessary (GIGESC Act, 2015, s 15). The inclusion of providing support for as long as necessary can be considered one of the breakthrough measures, as it may be interpreted to support the mental health of not only those who have been diagnosed or self-referred in recent years of life but also older intersex people who require the support. The current legal systems for intersex people around Europe do not have any provision for the protection of the mental health of older intersex people, making Malta the only state that has incorporated a legal provision to ensure that older intersex peoples' well-being is also supported.

However, the right exists on paper; the bigger question is whether it is actionable. It is necessary to have professionals trained to deal with issues faced by people with variations of sex characteristics to implement this provision, raising an essential question of whether there are trained practitioners to provide tailored support to intersex people because the issues faced by intersex people are not very well known in Malta (Cilia, 2016). The Schools Policy also mentioned the need to have school counsellors advocating for and supporting intersex students and providing information and resources to students to build an inclusive environment for all students. That said, the question again surfaces whether school councillors have the expertise to support intersex students. Gabi Calleja, Head of the SOGIGESC Unit at the Human Rights Directorate of Malta, in one of her interviews in 2017, mentioned that the Ministry of Education, in collaboration with the experts from the LGBTIQ movement in Malta, was delivering training to psychologists, counsellors, and other staff of the school (Expert, 2017). However, no data is available on whether the training is still delivered to the school staff and how these pieces of training have impacted the students and the functioning of the school administration.

The issue of language and terminology was also introduced in the Schools Policy, where it is indicated that pathologising and stigmatising terms like “disorders of sex development” or “hermaphrodite” should be avoided while referring to intersex people (Schools Policy, 2015). The measure to promote inclusive language in schools intends to establish affirmation, recognition, and respect for all in spite of differences. However, it can also lead to reinforcing exclusion or segregation of intersex and other gender nonconforming and non-binary students through labelling (Cassar, 2018). Gabriella Owen (2017), while observing how the notions of transgender identity in the curriculum of sexuality education shall be perceived, noted that we need to start thinking “how to radically reconceptualise the work of sexuality education in such a way that it does not rely on gendered or sexual identity categories for its efficacy” (p. 568). This question can also be raised when we are trying to define intersex and try to come up with a way that does not exclude intersex people solely based on sex characteristics categories but appreciates and celebrates the uniqueness of all the students.

Following the discussion of the aforementioned rights and the protection under the Maltese legal framework, it is crucial to direct our attention to the point that there are also no measures in place to ensure data collection and monitoring on intersex births, surgeries, and costs (Bauer & Truffer, 2019). Claudia Bartolo Tabone (2020) observed that a law which is meant to protect intersex people must have the voices of intersex people. She pressed on the importance of collecting data and information by understanding the lived experiences, histories, and expectations of intersex people. Despite progressive laws in Malta, intersex identity and the issues faced by intersex people are considered “quite novel”, and their experiences are hardly ever heard, specifically in the Maltese context (Cilia, 2016). It is challenging to effectively highlight and monitor the implementation of laws and policies related to intersex people due to the lack of data collection and representation of intersex voices. Additionally, the novel element of intersex identity and the issues faced by the intersex community further complicate the analysis of whether these legislations are being violated and what other possible discrimination intersex people are facing.

LIVED EXPERIENCES OF INTERSEX PEOPLE IN MALTA

Methodology for Empirical Study

Hermeneutic phenomenology underpinned the research methodology, with hermeneutic interviews conducted to understand the lived experiences of intersex people in Malta. Hermeneutic phenomenology is a complex 'way-of-thinking' methodology which can be traced back to the 19th-century scholar Friedrich Schleiermacher, who observed phenomenology as the "basis for the art of understanding" (Dibley et al., 2020, p. 8). Schleiermacher is known to have transformed Biblical hermeneutics into a general hermeneutic, which allowed the incorporation of all kinds of texts (Capetz, 2009). One of his key ideas emphasised that interpreters shall strive to understand the spirit of the text, which encompasses the author's thoughts and feelings at the time of writing (Ricoeur, 1977). It involves two aspects or dimensions, the interpretation of language and the interpretation of thought, to re-experience the author's psychology and what they thought at the particular time of writing to come to a new understanding (Ricoeur, 1977). Schleiermacher's work on hermeneutics laid the foundation for a range of subsequent movements in understanding hermeneutics. There exists a long history of thoughts which contributes to Schleiermacher's notion of understanding that includes revealing what is already known or which was possibly hidden before (Dibley et al., 2020). Other philosophers took up Schleiermacher's work with their own variations, including Wilhelm Dilthey, Franz Brentano, Martin Heidegger and Hans-Georg Gadamer (Dibley et al., 2020).

This research focuses on Heidegger's hermeneutic phenomenology, which emphasises the ontological status of phenomenology (Heidegger, 1962; Laverty, 2003). Heidegger was a student and later an academic assistant of Edmund Husserl, known as the founder of phenomenology (Moran, 2005). Husserl's philosophy gave superiority to the lived experiences of human beings, rejecting the notion that empirical science is the only way to find 'truth' (Dibley et al., 2020). Husserl suggested that to understand the lived experiences of people, the researcher should set aside their own experiences and pre-conceived notions of the phenomena they are researching, also known as bracketing or phenomenological reduction (Moran, 2005). However, considering Heidegger's hermeneutic phenomenology, much weight has been given to the lived experiences and pre-understanding of the researcher as well as that of the participants (Dibley et al., 2020; Miles et al., 2013).

Heidegger's hermeneutic phenomenology focuses on '*Dasein*', which he views as the human being *in* the world, unlike Husserl's being *of* the world. Heidegger has observed that the most basic structure of the being of Dasein is the state of *'being-in-the-world,'* that Dasein exists within the world and not outside of it (Heidegger, 1962; Gorner, 2007). Heidegger emphasises that humans sometimes interact or make decisions which are unconscious and not thought through, but these decisions are based on their lived experience of the world they are part of (Dibley et al., 2020; Heidegger, 1962). Hence, the focus of hermeneutic phenomenological research is to bring forth the understanding participants have of the phenomenon through the stories that the participants tell of their lived experiences (Oerther, 2020). From the Heideggerian point of view, it is the researcher's job to uncover the participants' experiences as they show themselves in the particular phenomena. When one hears and uncovers the meaning and understanding the participants give to the particular phenomena, it leads to understanding what it is to be a human being in their world at that given time and place.

Applying hermeneutic phenomenology to research helps us understand experiences as they are presented to us, which helps uncover or see what may be overlooked or inauthentically represented. To understand the deeper meaning of lived experiences, one must appreciate the importance of diving into the hermeneutic circle, which requires the researcher to go back and forth in questioning of their prior knowledge (Dibley et al., 2020) and to think about and understand the parts and the whole simultaneously (Palmer, 1969). The circular process of revisiting and revising our interpretation as we engage with the parts and whole gradually leads to a better understanding of the phenomena. When we understand the lived experiences of the phenomena, it leads to the discovery of the meaning of the phenomena. Hence, in this research, understanding the lived experiences of intersex people leads to a better understanding of what it means to be intersex in Malta at present. The lived experiences of being intersex in Malta can be uncovered through hermeneutic phenomenology. It also sheds light on how the legal reform in intersex rights has affected their experiences.

The interviews with the stakeholders who are closely working with or are associated with the intersex community and the experiences and stories they shared enable an understanding to emerge of what it means to be intersex in Malta. Most importantly, conducting interviews by applying hermeneutic phenomenology gives participants the control to narrate their stories and experiences the way they understand and feel them. As an interviewer, the researcher takes a back seat and seeks to understand the meaning of the experiences the participants gave.

Five people were interviewed in Malta, including stakeholders working closely with the intersex community. The stakeholders in Malta are all from different professional backgrounds. These participants were interviewed in their professional capacities to give insight into their lived experiences regarding their interactions with intersex people and their families. The question posed was:

‘Would you like to share your experiences working with intersex people or for the rights of intersex people? How would you describe the current situation of intersex people in Malta?’

Pseudonyms	**Pronoun**	**Profession**
Aldreda	She/her	Biomedical Scientist
Berta	She/her	Academic
Manann	They/them	Policymaker
Orsel	She/her	Government officer
Ruzar	He/him	Non-profit professional

The researchers faced a few limitations during the data collection and analysis stages. Firstly, given the nature of the project focusing on the protection of the rights of intersex people and aiming to understand the meaning intersex people give to their lived experiences, it was challenging to secure interviews with any intersex person from Malta due to the stigma associated with intersex status and the general lack of awareness about the intersex community (Davis, 2015; Cilia, 2016). Secondly, attempts to contact doctors, particularly surgeons, who play a crucial role in the diagnosis and treatment of intersex traits, were unsuccessful. The absence of their input in the research means that the lived experiences of these professionals of the phenomena are not incorporated into the study.

Intersex Invisibility and its Interplay with Law in Malta

Among the many themes explored in the interviews conducted with the intersex community in Malta, invisibility surfaced as one of the prominent ones. This book’s focus centred on the theme of invisibility concerning intersex people in Malta. It was reiterated on multiple occasions as a critical factor the intersex community face and how invisibility affects their experience of living in Maltese society. Aldreda, the biomedical scientist, in her interview, observed that:

> *“Intersex tends to be you know, I mean, partly forgotten, they are invisible, you know, I mean, it doesn’t happen. So, I think that’s one of the issues.”*

Orsel explained in her interview that the knowledge of intersex lives is very minimal in Malta, and it is difficult to suggest how well-integrated the intersex community is in Maltese society:

> *"We know so very little about the life trajectories of intersex people in Malta that it's very hard to say how well-integrated or not they are in Maltese society. I don't know whether they have been able to build relationships, have children, you know, have normal life trajectories. They are really quite invisible…"*

Orsel also mentioned that her office offers educators and public servants training on intersex topics. However, due to the lack of awareness about intersex variations and the fact that the intersex community is often hidden, people find it challenging to understand and conceptualise what it means to be intersex.

> *"We tend to include, to provide an explanation of intersex whenever we do training, to someone who are going to educate, then there's police, you know, public servants, whatever. So, we explain what intersex is… but the reality is that many people have never encountered anyone, you know, who is openly intersex, we don't really have an intersex community. So, it is very difficult to conceptualise what… being intersex is for most people."*

It also became apparent from the comments made by many of the participants that the invisibility of the community was also a big gap and issue during the formation of the GIGESC Act. According to some of the participants, the legislative changes that were incorporated to protect the rights of intersex people in Malta did not have representation from Maltese intersex people as the demand for the legal reform did not come from the intersex community, which is still very invisible in the Maltese context. Manann, who is a policymaker, discussed this issue in their interview and expressed their concerns that the people of the community did not lead the change:

> *"In Malta, there was absolutely nothing around intersex, we barely knew anything about like, I didn't know any intersex person or anyone who says 'Hey, I am intersex'… that for me, that was, is, and it's gonna continue to be for a while, one of the biggest gaps in terms of the process… Yeah, when the Minister came and she was like, 'we need to do something about this,' we are like, 'no' that was my reaction. No, because they have no intersex people, like who's telling you, like who's demanding this change. I know that you've heard it from a bunch of people from all over the world, which is great. But what about Maltese? You know, like, I mean, the reason I have arguments about this is because I very much believe in changes being led by the people."*

Aldreda showed concern that no one from the intersex community in Malta speaks up or demands a change. She explained that every country has their own society and mentality, which also reflects the demands and needs of people. She further observed that, as no intersex person in Malta has come forward to express their demands, it is difficult to understand what changes they want in Malta:

> *"Intersex community is not forthcoming with their needs. No one speaks, no one speaks out. It's very difficult to find out what exactly they want. Because if anything, I mean we can't speak to people, intersex people living outside of Malta. You know Malta is Malta, the community in Malta is, the society is different from elsewhere, you know. In my case I would like to know what they want in Malta you know; I mean, I can speak to people living in the US and in Australia and anywhere else in the world, but you know, even the mentality is different. So, people, for example, I don't know in Indonesia, for example, they would ask for something, people in the US they ask for something else, people in Malta, they may ask for something different but if they don't speak out, we won't get to know what they want."*

Most of the interviewed stakeholders observed during the interview that even after instituting the legal changes for the protection of intersex rights, the visibility of intersex people remained nominal. Aldreda stated that:

> *"If anything, even now we don't know who's intersex, and who's not… Now that the laws are even more friendly, rainbow friendly, you would have expected that people would, you know, sort of come out and perhaps ask questions about the provisions in the law, but that didn't happen."*

Ruzar showed his concern on the matter of the intersex community still not being recognised even after the policy development in Malta. He explained that proper recognition of intersex people is not achieved by just putting them on a piece of legal paper but by knowing their journey and experiences of being intersex. He posed various questions that need to be answered to really recognise intersex people, but Malta has not managed to find the answers to them.

> *"Now, if we're talking about intersex, and the keyword that I'd like to focus on here is recognition of intersex people, and that is within itself, also within the law… the real recognition of intersex people, rather than the recognition of intersex people just on a piece of paper… the real recognition of intersex people meaning where are they in the community? What are they doing? What is their journey from birth to adulthood? And what are the challenges that individuals are facing through their experience? That is something… that there's no answer for. I mean, there's a lot of questions but there's no answer for."*

In the interview with Berta, the issue of intersex invisibility and its interplay with the Maltese legal system was discussed, and she observed that the provisions of the GIGESC Act have created awareness about intersex people. However, it was not promoted enough to increase that awareness.

> *"I mean I would say that the law in itself… I was gonna say increased awareness, but I'm not sure if it increased the awareness or it created awareness because I don't think that there was any awareness prior to that generally, in the general public. Not only in the general public but also in professionals. So, I think that, that in itself is something good that came out. Having said that, intersex never got the coverage… I mean, as you know the law was a GIGESC law, it was gender identity, gender expression and sexual characteristics. It never got the coverage that the gender identity and gender expression parts of it if you like. But, so although it, the law, just by being present in the law created some sort of awareness. That awareness wasn't, so if you like, you know created the spark. That spark was never fanned, you know, to create a fully formed fire, right of awareness.*
>
> *"I think that spark needs to be fanned to create a proper fire of awareness rather than it remaining just a spark that some people see and some people don't."*

Orsel presented a similar perspective about the Schools Policy. She acknowledged that schools in Malta do come across concerns relating to gender identity, but it is not the same case with intersex. She explained that the main aim of the policy is to raise awareness about intersex issues in schools: about intersex issues in schools:

> *"It's not like we have had cases in schools. We have had many relating to gender identity, but I'm not aware of any cases where schools were faced with issues because they have an intersex child, for example. So again, you know, the policy is more about raising awareness than anything when it comes to intersex."*

Discussion

In summary, according to the interview participants, one of the issues faced by intersex people in Malta is the intersex community's invisibility. They indicate that prior to 2015 when the GIGESC Act was enacted and other legislative and policy reforms were introduced, the intersex population was hidden in Malta. Even today, not enough is known about their life trajectories and how well (or not) the intersex community is integrated with Maltese society. As was suggested by Orsel in her interview, the term intersex is often unknown and unheard of, which results in a lack of disclosure to raise visibility. This invisibility of the intersex community in Malta creates uncertainty about the lives of intersex people. The fact that the invisibility of the intersex community leads to unawareness about intersex people's lives and life trajectories also raises the point of whether society knows how to ask the questions that would bring knowledge about intersex issues to light. Another intriguing question that emerges in this context is what factors contribute to the silence and invisibility of intersex individuals in Malta. While all participants noted the lack of visibility of intersex issues, no discussion delved into the underlying reasons for this phenomenon.

The issue of invisibility also makes it difficult for the general public to understand the sensitivity of the issues and problems that intersex people face. The interviews revealed that not many people in Malta have come across intersex people, as the intersex community is invisible and not widely known in Malta. Invisibility is the vehicle through which being intersex is being experienced. Intersex people experience this invisibility by not being spoken about or seen, raising an important question: Must society personally encounter something to accept its existence and acknowledge its reality? Does an issue have to be visible to us to accept its existence? Michael S. Kimmel discussed the relationship between privilege and invisibility (Kimmel, 1993). He noted that when we are privileged enough not to be affected by an issue, that issue often becomes invisible to us, referring to the issues of race, class, and gender. However, his observations are also relevant to the issue of intersex invisibility. He has stated that "the very processes that confer privilege to one group and not to another group are often invisible to those upon whom that privilege is conferred" (Kimmel, 1993, p. 30). Hence, when society is not affected by the issues faced by the intersex community, those issues become invisible to it as a whole. This raises the question of whether society can acknowledge and accept intersex even if they cannot fully understand it or if it is invisible to them. Those who have not encountered intersex individuals may struggle to conceptualise what intersex is and the issues faced by people with intersex traits, as observed by Orsel in her interview. However, this difficulty can be resolved by raising awareness and making the realities of the experiences of intersex people more visible (Davis, 2015). Surveys conducted over the past decade have highlighted the various issues faced by the intersex community, including their invisibility and lack of awareness in society (World Bank Group, 2018; FRA, 2020; OII Europe & ILGA-Europe, 2023). Therefore, it is essential to take steps towards visibility and to understand and acknowledge the realities of intersex people and the human rights issues they face.

Even when the GIGESC Bill was being formed, the demand for the change did not come from the local people of the community. Moreover, there was no representation of intersex people who were residing in Malta at that time. The traditional notion of "nothing about us, without us" is fundamental to sound policymaking (Isom & Balasuriya, 2021, p. 121). It is crucial to involve those most impacted by a policy in its planning, implementation, and evaluation processes (Jürgens, 2005; Lynch, Windle & Ahmed, 2021). James I. Charlton, in his book *Nothing About Us Without Us: Disability Oppression and Empowerment,* highlights the importance of the involvement of people with disabilities most affected by a policy in the decision-making process. He argues that "experiential knowledge of these people is pivotal in making decisions that affect their lives" (Charlton, 2000, p. 17). Orla and James, in their book *Giving Voice to Diversity in Criminological Research: 'Nothing about Us without Us'*, observed that the policies which do not include the participation of the specific population are hollow (Lynch, Windle & Ahmed, 2021). The invisibility of intersex people in the process of policy development in Malta is concerning, as it lacks the experiential knowledge of intersex people residing in Malta. It also makes it challenging to identify and understand the needs and demands of intersex people in Malta. In most of the interviews, it was conveyed that even after the law was enforced, the invisibility of intersex people pertained. It was observed that the GIGESC Act created awareness about intersex people in Malta, but it was not given much coverage to raise or increase that awareness. The relation between law and the invisibility of intersex people is intertwined. On the one side, the laws were framed to create awareness about intersex people and make them more visible. However, it was suggested in the interviews that it did not get the proper coverage and is not being implemented optimally because of the invisibility of intersex and the lack of awareness about the issues faced by them.

It is important to note that the intersex community is a hidden population because of the personal and social factors which influence their decision to hide their identities or be open about them. The stigma and secrecy attached to intersex prevent individuals and their families from speaking out (Davis, 2015), pushing them further to remain hidden. In one of World Bank Group's surveys to understand the lives of the LGBTI people in Southeastern Europe,[45] it was found that only two per cent of the intersex participants were open about being intersex, and ninety-three per cent of the participants were not open or mostly not open about their sex characteristics (World Bank, 2018). Previous studies showed that the fear of being subjected to discrimination and abuse if an individual's intersex status is discovered is real. According to the secondary data analysis conducted by OII Europe and ILGA-Europe using the FRA 2019 LGBTI Survey II (FRA, 2020), almost half (49.40 per cent) of the intersex respondents revealed that they had faced physical and/or sexual assaults in the five years preceding the survey simply because they were intersex (Russell et al., 2023). According to Russell et al. (2023), a similarly high percentage of intersex respondents reported being harassed in the last five years, with a total of 72.81% of intersex people facing harassment. Considering the fear of harassment, discrimination and physical and/or sexual attacks, it is not very surprising to acknowledge the invisibility of the intersex community.

In such situations, according to Ghattas (2019), it becomes a necessity to protect the rights of the intersex community and for the law to be implemented to its greatest extent. However, for a better enactment, it is necessary to ensure that people are educated and aware of intersex people, creating a safe and friendly space for the intersex community to become visible. Many social issues, such as stigma, prejudice, hate crimes, and negative portrayal in media, need to be tackled (IESOGI, n.d.) to raise visibility.

Conclusion

The reforms brought into the legal framework of Malta have been applauded across the globe. It is considered a historic breakthrough, especially with respect to the GIGESC Act (TGEU Press Release, 2015) and has also set an example for other states to work towards intersex equality and human rights. The rights protected by the GIGESC Act, and other policies and secondary legislations of Malta are very progressive and innovative. From the conversations with the stakeholders, it became apparent that the legislative changes did create awareness about intersex people and their human rights which was lacking in Malta prior to 2015.

Within the legal framework, a lot of ambiguity exists especially regarding the provisions of the GIGESC Act. For instance, the legislation is not clear whether hypospadias is considered intersex or not, and the legislation is silent about cases being referred to other countries. These loopholes and ambiguities require better clarification; however, no cases have been filled in the courts of law in Malta, and neither have these issues been raised in public spaces, due to various reasons I have discussed throughout the chapter. To raise these issues and for a better implementation of the law, the visibility of the intersex community is one of the essentials. As there is a lack of data regarding how the existing reforms are being implemented and their impact on intersex people, it becomes difficult to make a conclusive judgment. Hence, forming laws on paper is not sufficient; a lot more is required to be done to ensure that these reforms are implemented successfully and to achieve a broader and more significant social change.

References

Argyrou, A. (2017). Making the Case for Case Studies in Empirical Legal Research. *Utrecht Law Review*, *13*(3), 95. https://doi.org/10.18352/ulr.409

Arthurs, H. Wi. (1983). *Law and learning: Report to the Social Sciences and Humanities Research Council of Canada= Le droit et le savoir*. Information Division, The Council.

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[45] The survey included people from seven countries in Southeastern Europe: five in the Western Balkans - Albania, Bosnia and Herzegovina, Kosovo, FYR Macedonia, and Montenegro; as well as two European Union (EU) member states, Croatia and Slovenia. The survey was conducted to understand the lives of the LGBTI community better and was based on the FRA survey conducted in 2012 (FRA, 2014).

Australian Government, Attorney General's Department. (n.d.). *Australian Government Guidelines on the Recognition of Sex and Gender*. Attorney-General's Department. https://www.ag.gov.au/rights-and-protections/human-rights-and-anti-discrimination/australian-government-guidelines-recognition-sex-and-gender

Bartolo Tabone, C. (2020, October 1). Intersex: The Invisible 'I'. *Bioethics and the Five Senses: Between Clinical Practices and Metaphors*. *International Bioethics Conference*. University of Malta.

Bauer, M., & Truffer, D. (2017). *2017 CRPD UK Intersex NGO Coalition Report (for Session)*. StopIGM.org. https://intersex.shadowreport.org/post/2017/09/01/2017-CRPD-UK-Intersex-NGO-Coalition-Report-%28for-Session%29

Bauer, M., & Truffer, D. (2019). *NGO Report to the 3rd to 6th Report of Malta on the Convention on the Rights of the Child (CRC)*. StopIGM.org. https://intersex.shadowreport.org/post/2019/05/15/2019-CRC-Malta-Intersex-NGO-Report

Behrens, K. G. (2020). A principled ethical approach to intersex paediatric surgeries. *BMC Medical Ethics*, *21*(108). https://doi.org/10.1186/s12910-020-00550-x

Benini, M. (2018, March 22). *Killed at Birth: The Slaughtering of Intersex Babies.* Il Grande Colibrì. https://www.ilgrandecolibri.com/en/killed-intersex-babies/

Bhat, P. I. (2020). Doctrinal Legal Research as a Means of Synthesizing Facts, Thoughts, and Legal Principles. In P. I. Bhat (Ed.), *Idea and Methods of Legal Research* (p. 0). Oxford University Press. https://doi.org/10.1093/oso/9780199493098.003.0005

Bosman, T. (2019). *2018 CRC Belgium Intersex NGO Report*. StopIGM.org, & Intersex Belgium. https://intersex.shadowreport.org/post/2019/01/15/2018-CRC-Belgium-Intersex-NGO-Report

Capetz, P. E. (2009). Friedrich Schleiermacher on the Old Testament. *The Harvard Theological Review*, *102*(3), 297-325.

Carpenter, M. (2016). The human rights of intersex people: Addressing harmful practices and rhetoric of change. *Reproductive Health Matters*, *24*(47). https://doi.org/10.1016/j.rhm.2016.06.003

Carpenter, M. (2018). The "Normalization" of Intersex Bodies and "Othering" of Intersex Identities in Australia. *Journal of Bioethical Inquiry, 15,* 487-495.

Cassar, J. (2018). A 'Diffractive' Exploration of Inclusive School Policy about Trans, Gender Variant and Intersex Students. In R. V. Nata (Ed.), *Progress in education* (pp. 163-181). Nova Publishers.

Charlton, J. I. (2000). *Nothing About Us Without Us: Disability Oppression and Empowerment*. University of California Press.

Chynoweth, P. (2008). Legal research. In A. Knight & L. Ruddock (Eds.), *Advanced research methods in the built environment* (Vol. 1). Wiley-Blackwell.

Cilia, M. (2016*). The current situation of intersex persons in Malta: Shifting away from the medical paradigm towards social justice*. University of Malta. https://www.um.edu.mt/library/oar/handle/123456789/99460

Civil Code, Pub. L. No. as amended by XI.2015.18 (1868) (2015) (Malta).

Civil Code, Pub. L. No. Ordinance VII (1868) (Malta).

Codarcea v. Romania, 31675/04 (ECHR 2009/15 2 June 2009).

Collison, C. (2018). Intersex babies killed at birth because 'they're bad omens.' *Mail & Guardian.* https://mg.co.za/article/2018-01-24-00-intersex-babies-killed-at-birth-because-theyre-bad-omens/

Criminal Code, Cap. 9 (1854) (Malta).

Davis, G. (2015). *Contesting Intersex: The Dubious Diagnosis*. NYU Press.

Dibley, L., Dickerson, S., Duffy, M., & Vandermause, R. (2020). *Doing Hermeneutic Phenomenological Research*. SAGE Publications Ltd.

Dickens, B. (2018). Management of Intersex Newborns: Legal and Ethical Developments. *Int J Gynaecol Obstet*, *143*(2), 255-259. https://doi.org/10.1002/ijgo.12573

Dolgin, J. L. (2017). Discriminating Gender: Legal, Medical, and Social Presumptions About Transgender and Intersex People. *Southwestern Law Review*, *47*, 61-114.

Draucker, C. B. (1999). The critique of Heideggerian hermeneutical nursing research. *Journal of Advanced Nursing*, *30*(2), 360-373. https://doi.org/10.1046/j.1365-2648.1999.01091.x

Editorial. (2014, December 4). OII-Europe applauds Malta's Gender Identity, Gender Expression and Sex Characteristics Act. *OII Europe*. https://www.oiieurope.org/oii-europe-applauds-maltas-gender-identity-gender-expression-and-sex-characteristics-act/

Editorial. (n.d.). The Yogyakarta Principles—An Overview. *The Yogyakarta Principles*. http://yogyakartaprinciples.org/principles-en/about-the-yogyakarta-principles-2/

Equality for Men and Women Act, Pub. L. No. ACT I of 2003, 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 (2003) (Malta).

Expert. (2017). *Respect for All: What does this mean for Malta's trans, gender variant and intersex students?* School Education Gateway. https://www.schooleducationgateway.eu/en/pub/viewpoints/experts/respect-for-all-what-does-thi.htm

FRA, European Union Agency for Fundamental Rights. (2014). *EU LGBT survey. European Union lesbian, gay, bisexual and transgender survey.* Publications Office of the European Union. https://fra.europa.eu/en/publication/2014/eu-lgbt-survey-european-union-lesbian-gay-bisexual-and-transgender-survey-main

FRA, European Union Agency for Fundamental Rights. (2020). *A long way to go for LGBTI equality*. https://fra.europa.eu/en/publication/2020/eu-lgbti-survey-results

Garland, F., & Travis, M. (2018). Legislating intersex equality: Building the resilience of intersex people through law. *Legal Studies*, *38*(4), 587-606. https://doi.org/10.1017/lst.2018.17

Garland, F., & Travis, M. (2022). *Intersex Embodiment: Legal Frameworks beyond Identity and Disorder*. Bristol University Press. https://doi.org/10.46692/9781529217391.006

Gender Based Violence and Domestic Violence Act, Pub. L. No. Act XIII of 2018, as amended by Act XXIV of 2019, (2018).

GIGESC Act, Gender Identity, Gender Expression and Sex Characteristics Act, Pub. L. No. ACT XI of 2015, CAP. 540 (2015) (Malta).

Ghattas, D. C. (2015). *Standing up for human rights of intersex people- how can you help?* ILGA-Europe, & OII Europe. https://ilga-europe.org/report/standing-up-for-human-rights-of-intersex-people/

Ghattas, D. C. (2019). *Protecting Intersex People in Europe: A Toolkit for Law and Policymakers*. OII Europe, & ILGA- Europe. https://oiieurope.org/wp-content/uploads/2019/05/Protecting_intersex_in_Europe_toolkit.pdf

Glass v. The United Kingdom, 61827/00 (ECHR 9 March 2004).

Gorner, P. (2007). *Heidegger's Being and Time: An Introduction*. Cambridge University Press. https://doi.org/10.1017/CBO9780511808036

Greenberg, J. A. (2003). Legal Aspects of Gender Assignment. *The Endocrinologist, 13*(3), 277-286.

Hay, M. (2015). What Will Malta's New Intersex Law Mean for the Rest of the World? *Vice*. https://www.vice.com/en/article/exqn77/maltas-new-intersex-legislation-is-the-most-progressive-in-the-world-192

Heidegger, M. (1962). *Being and time*. Harper.

Herr, R. (1969). Honour and Shame: The Values of Mediterranean Society. Edited by Jean G. Persistiany (Chicago: University of Chicago Press, 1966. Pp. 265). *Journal of Social History*, *3*(1), 89-92. https://doi.org/10.1353/jsh/3.1.89

Holmes, M. M. (2008). Mind the Gaps: Intersex and (Re-productive) Spaces in Disability Studies and Bioethics. *Journal of Bioethical Inquiry*, *5*(2), 169–181. https://doi.org/10.1007/s11673-007-9073-2

Hutchinson, T. (2013). Doctrinal Research: Researching the Jury. In D. Watkins & M. Burton (Eds.), *Research Methods in Law* (1st ed.). Routledge.

IESOGI, Independent Expert on Sexual Orientation and Gender Identity. (n.d.). *The struggle of trans and gender-diverse persons*. OHCHR. https://www.ohchr.org/en/special-procedures/ie-sexual-orientation-and-gender-identity/struggle-trans-and-gender-diverse-persons

IHRA, Intersex Human Rights Australia. (2012, March 21). *Intersex is not a gender identity and the implications for legislation*. IHRA. https://ihra.org.au/17680/intersex-characteristics-not-gender-identity/

ILGA-Europe. (2022). *Bodily Integrity*. https://www.ilga-europe.org/topics/bodily-integrity/

ILGA-Europe. (2023). *About us.* https://www.ilga-europe.org/about-us/

ILGA World, International Lesbian, Gay, Bisexual, Trans and Intersex Association. (2023). *About us.* https://ilga.org/about-us

Independent Expert on sexual orientation and gender identity. (2018). *Report on Legal Recognition of Gender Identity and Depathologization*. OHCHR. https://www.ohchr.org/en/calls-for-input/report-legal-recognition-gender-identity-and-depathologization

ICAO, International Civil Aviation Organisation. (2021). *Machine Readable Travel Documents, Eighth Edition* (Doc 9303). International Civil Aviation Organisation.

International Commission of Jurists. (2006). The Yogyakarta Principles. Principles on the *Application of International Human Rights Law in relation to Sexual Orientation and Gender Identity*. https://yogyakartaprinciples.org/wp-content/uploads/2016/08/principles_en.pdf

Isom, J., & Balasuriya, L. (2021). Nothing About Us Without Us in Policy Creation and Implementation. *Psychiatric Services*, *72*(2), 121.

Jain, S. N. (2010). Doctrinal and Non-doctrinal Legal Research. In S. K. Verma & A. Wani (Eds.), *Legal Research and Methodology* (2nd ed., Pp. 68). Indian Law Institute.

Jones, T. (2018). Intersex Studies: A Systematic Review of International Health Literature. *SAGE Open*, *8*(2). https://doi.org/10.1177/2158244017745577

Juhnke v. Turkey, 52515/99 (ECHR 13 May 2008).

Jürgens, R. (2005). *Nothing about us without us: Greater, meaningful involvement of people who use illegal drugs: a public health, ethical, and human rights imperative*. Canadian HIV/AIDS Legal Network. https://www.drugsandalcohol.ie/6302/

Kimmel, M. S. (1993). Invisible masculinity. *Society*, *30*(6), 30, 28-35. https://doi.org/10.1007/BF02700272

Lacey, N. (1996). Normative Reconstruction in Socio-Legal Theory. *Social & Legal Studies*, *5*(2), 131–157. https://doi.org/10.1177/096466399600500201

Langbroek, P. M., van den Bos, K., Simon Thomas, M., Milo, J. M., & van Rossum, W. M. (2017). Methodology of Legal Research: Challenges and Opportunities. *Utrecht Law Review*, *13*(3). https://papers.ssrn.com/abstract=3118156

Laverty, S. M. (2003). Hermeneutic Phenomenology and Phenomenology: A Comparison of Historical and Methodological Considerations. *International Journal of Qualitative Methods*, *2*(3). https://doi.org/10.1177/160940690300200303

Light Passenger Transport Services and Vehicle Hire Services Regulations, Pub. L. No. Subsidiary Legislation 499.68, Legal Notice 366 of 2020 as amended by Legal Notices 344 of 2021, 336 of 2022 And 111 And 186 of 2023 (2020) (Malta).

Lum, S. (2023). D5.2.1 Intersex Framings Within International Human Rights Law. In T. Ní Mhuirthile & A. Suess Schwend (Eds.), *eReport on Law, Ethics and Human Right*s (pp. 6- 38). INIA: Intersex New Interdisciplinary Approaches, Dublin City University.

Lynch, O., Windle, J., & Ahmed, Y. (2021). *Giving Voice to Diversity in Criminological Research: 'Nothing about Us without Us'*. Policy Press.

Marriage Act, Marriage Act and other Laws (Amendment), Pub. L. No. ACT No. XXIII of 2017 (2017) (Malta).

Martinez Mestre, Y. (2022). The Human Rights Situation of Intersex People: An Analysis of Europe and Latin America. *Social Sciences*, *11*(7), 317. https://doi.org/10.3390/socsci11070317

Miles, M., Chapman, Y., Francis, K., & Taylor, B. (2013). Exploring Heideggerian hermeneutic phenomenology: A perfect fit for midwifery research. *Women and Birth*, *26*(4), 273-276. https://doi.org/10.1016/j.wombi.2013.06.003

MSD, Ministry for Social Dialogues, Consumer Affairs and Civil Liberties. (2015a). *Gender Identity, Gender Expression and Sex Characteristics Act*. *Submissions Report.* Government of Malta. https://meae.gov.mt/en/public_consultations/msdc/documents/2014%20-%20gigesc/gigesc%20-%20outcome%20report.pdf

MSD, Ministry for Social Dialogues, Consumer Affairs and Civil Liberties. (2015b). *LGBTIQ Action Plan 2015 – 2017*. Government of Malta. https://humanrights.gov.mt/en/Documents/Publications/LGBTI%20Action%20Plan%202015-2017.pdf

Moran, D. (2005). *Edmund Husserl: Founder of Phenomenology* (1st edition). Polity.

Ní Mhuirthile, T. (2018). Malta. In A. Dutta, J. M. Scherpe, & T. Helms (Eds.), *The Legal Status of Intersex Persons* (pp. 357-368). Intersentia. https://doi.org/10.1017/9781780687704.022

O'Donovan, D. (2016). Socio-Legal Methodology: Conceptual Underpinnings, Justifications and Practical Pitfalls. In *Legal Research Methods: Principles and Practicalities* (p. 31).

Oerther, S. (2020). Analysis methods in hermeneutic phenomenological research: Interpretive profiles. *Frontiers of Nursing*, *7*(4), 293-298. https://doi.org/10.2478/fon-2020-0038

OHCHR, United Nations Human Rights Office of the High Commissioner. (2019). *Background Note on Human Rights Violations against Intersex People*. OHCHR. https://www.ohchr.org/en/documents/tools-and-resources/background-note-human-rights-violations-against-intersex-people

OII Europe. (2020a). *Intersex children and the violation of their right to privacy: OII Europe submission to the UN Special Rapporteur on the Right to Privacy*. https://www.oiieurope.org/intersex-children-and-the-violation-of-their-right-to-privacy/

OII Europe. (2020b). Intersex people in Europe face physical violence and harassment. *OII Europe*. https://www.oiieurope.org/physical-violence-and-harassment/

Owen, G. (2017). Adolescence, Trans Phenomena, and the Politics of Sexuality Education. In L. Allen & M. Rasmussen (Eds.), *The Palgrave Handbook of Sexuality Education* (pp. 555-570). Palgrave Macmillan.

Palmer, R. E. (1969). *Hermeneutics: Interpretation Theory in Schleiermacher, Dilthey, Heidegger, and Gadamer*. Northwestern University Press.

Peristiany, J. G. (1966). *Honour and Shame: The Values of Mediterranean Society*. University of Chicago Press.

Pikramenou, N. (2019). *Intersex Rights Living Between Sexes* (1st edition). Springer International Publishing.

Quinan, C. L., & Hunt, M. (2023). Non-binary gender markers: Mobility, migration, and media reception in Europe and beyond. *European Journal of Women's Studies*, *30*(3), 380-390. https://doi.org/10.1177/13505068211024891

Ricoeur, P. (1977). Schleiermacher's Hermeneutics. *The Monist*, *60*(2), 181-197.

Russell, C. B., Amoroso, I., Hugo, J., & Kromminga, I. A. (2023). *Intersections: Diving into the FRA LGBTI II Survey Data – Intersex Briefing | ILGA-Europe*. OII Europe, & ILGA-Europe. https://www.ilga-europe.org/report/intersections-intersex-diving-into-the-fra-lgbti-ii-survey-data/

S. and Marper v. The United Kingdom [GC], 30562/04 and 30566/04 (ECHR 4 December 2008). https://hudoc.echr.coe.int/fre#{%22itemid%22:[%22002-1784%22]}

Schools Policy, Trans, Gender Variant and Intersex Students in Schools Policy, 24 (2015) (Malta).

Siems, M. (2009). The Taxonomy of Interdisciplinary Legal Research: Finding the Way Out of the Desert. *Journal of Commonwealth Law and Legal Education*, *7*, 5–17.

SLSA, Socio-Legal Studies Association. (2021). *Statement of Principles of Ethical Research Practice*. Socio-Legal Studies Association. https://www.slsa.ac.uk/index.php/ethics-statement

Smits, J. M. (2015). What is Legal Doctrine? On the Aims and Methods of Legal-Dogmatic Research. In R. van Gestel, H.-W. Micklitz, & E. L. Rubin (Eds.), *Rethinking Legal Scholarship: A Transatlantic Dialogue* (pp. 207–228). Cambridge University Press.

Sytsma, S. E. (2006). Intersexuality, Cultural Influences, and Cultural Relativism. In S. E. Sytsma (Ed.), *Ethics and Intersex* (pp. 259–270). Springer Netherlands. https://doi.org/10.1007/1-4220-4314-7_16

TGEU Press Release. (2015). *Malta Adopts Ground-breaking Trans and Intersex Law.* TGEU. https://tgeu.org/malta-adopts-ground-breaking-trans-intersex-law/

Third International Intersex Forum (2013). *Malta Declaration.* OII Europe. https://www.oiieurope.org/malta-declaration/

Thomas, P. (1986). Curriculum Development in Legal Studies. *Law Teacher*, *20*.

Trocellier v. France, 75725/01 (ECHR 5 October 2006).

Twining, W. L. (1976). Taylor Lectures 1975. In *Academic Law and Legal Development*. University of Lagos Law Faculty. As cited in Hutchinson, T. (2013). Doctrinal Research: Researching the Jury. In D. Watkins & M. Burton (Eds.), *Research Methods in Law* (1st ed.). Routledge.

UNESCO. (n.d.). *Transforming our world: the 2030 Agenda for Sustainable Development*. UNESCO. https://sdgs.un.org/2030agenda

UNFPA, United Nations Population Fund. (2022). *Bodily autonomy: A fundamental right*. UNFPA. https://www.unfpa.org/press/bodily-autonomy-fundamental-right

Viloria, H., & Zzyym, D. (2015). *How Intersex People Identify*. Intersex Campaign for Equality. https://www.intersexequality.com/how-intersex-people-identify/

Warne, G. L., & Raza, J. (2008). Disorders of sex development (DSDs), their presentation and management in different cultures. *Reviews in Endocrine & Metabolic Disorders*, *9*(3), 227-236. https://doi.org/10.1007/s11154-008-9084-2

Weiler, E. M. (2003). Making school safe for sexual minority students. *Principal Leadership Magazine*, *4*(4).

Wipfler, A. J.. (2016). Identity Crisis: The Limitations of Expanding Government Recognition of Gender Identity and the Possibility of Genderless Identity Documents. Harvard Journal of Law and Gender, 39, 491-554.

Wootton, A. R., Drabble, L. A., Riggle, E. D. B., Veldhuis, C. B., Bitcon, C., Trocki, K. F., & Hughes, T. L. (2019). Impacts of Marriage Legalization on the Experiences of Sexual Minority Women in Work and Community Contexts. *Journal of GLBT Family Studies*, *15*(3), 211–234. https://doi.org/10.1080/1550428X.2018.1474829

World Bank Group. (2018). *Life on the Margins: Survey Results of the Experiences of LGBTI People in Southeastern Europe*. World Bank Group. https://documents1.worldbank.org/curated/en/123651538514203449/pdf/130420-REPLACEMENT-PUBLIC-FINAL-WEB-Life-on-the-Margins-Survey-Results-of-the-Experiences-of-LGBTI-People-in-Southeastern-Europe.pdf

Zelayandía González, E. (2023). D5.2.5 Report on systematic explorative review of European national legislations related to the human rights protection of intersex people and their implementation. In T. Ní Mhuirthile & A. Suess Schwend (Eds.), *eReport on Law, Ethics and Human Right*s (pp. 125 - 168). INIA: Intersex New Interdisciplinary Approaches, Dublin City University.

9. The Growing Visibility of Intersex Demands at the United Nations: A Review of the Treaty Bodies' Concluding Observations[46]

Ernesto Zelayandía-González

Introduction

'Intersex' is an umbrella term used in activist and human rights circles to describe "a wide range of innate bodily variations in sex characteristics. 'Intersex' people are born with sex characteristics that do not fit typical definitions of male or female bodies, including sexual anatomy, reproductive organs, hormonal patterns, and/or chromosomal patterns" (Office of the United Nations High Commissioner for Human Rights [OHCHR, 2019, p. 2).

Throughout Europe and around the world, intersex people face a wide range of human rights violations based on different variations of their sex characteristics, and are subject to stigma, misrecognition, pathologisation, violence (including medical violence), and degrading, humiliating, and inhuman treatments (Council of Europe [CoE], 2015; Inter-American Commission on Human Rights [IACHR], 2015; OHCHR, 2019). Likewise, intersex persons are exposed to different forms of discrimination that they experience through their life cycles, for example, in healthcare, education, or employment settings, among others (Bauer et al., 2020; Carpenter, 2016; Travis, 2015). One of the main concerns of intersex activists and civil society organisations (CSOs) continues to be surgical interventions performed during childhood (including to newborns) with the aim of 'normalising' intersex bodies to fit the socially and medically accepted male/female binaries (Bauer et al., 2020). These surgeries are often framed by activists as forms of mutilation and/or torture or 'intersex genital mutilation' (IGM) (OII Europe 2021; Stop IGM n.d.-a). In this paper, the term 'Intersex genital surgery' (IGS) is used, as the term IGM does not seem to be widely adopted by UN treaty bodies that continue to call, however, member states to put a stop to 'surgeries and treatments' that go against human rights standards. Regarding the European region, according to the European Union Agency for Fundamental Rights (FRA), 'normalisation' surgeries are carried out on intersex children in at least 21 member states of the European Union (EU) (European Union Agency for Fundamental Rights [FRA], 2015). Among the member states of the EU and the Council of Europe (CoE), only five countries (Malta, Portugal, Iceland, Germany, Greece) have legislation that provide some form of protection against these types of interventions during early childhood.[47]

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[47] See: The law of Malta (2015) "on gender identity, gender expression, and sex characteristics" [The Gender Identity, Gender Expression and Sex Characteristics Act]; Portugal (2018) Lei n.º 38/2018. "Right to self-determination of gender identity and gender expression and the protection of each person's sexual characteristics" [Direito à autodeterminação da identidade de género e expressão de género e à proteção das características sexuais de cada pessoa]; Icelandic (2019) "Gender Autonomy Act" [Kynrænt sjálfræði] Germany (2021) law "for the protection of children with variants of sex development." [Gesetz zum Schutz von Kindern mit Varianten der Geschlechtsentwicklung]; Greece (2022) Law No. 4958/2022 "Reforms in medically assisted reproduction and other urgent regulations" [Νόμος 4958/2022: Μεταρρυθμίσεις στην ιατρικώς υποβοηθούμενη αναπαραγωγή και άλλες επείγουσες ρυθμίσεις.] Government Gazette 142/A/21-7-2022.

In recent years, intersex activist movements have turned to the international fora and institutions to expose their needs and human rights demands, and arguably, these institutions have started to listen and increase visibility of the human rights demands of intersex people (Ammaturo, 2016; Bauer et al., 2020; Rubin, 2015). However, little attention has been given in the field of intersex studies and social movements to activist groups' interactions with international human rights bodies and their efforts to raise awareness and visibility of their cause. A notable exception is the work of Saskia Ravesloot (2021), who has followed the inclusion of intersex issues in the recommendations of the Human Rights Council's Universal Periodic Review, looking specifically at the nature, content, and framing of such recommendations. More recently, Garland et al. (2022) also analysed the barriers and challenges in transposing international recommendations into domestic change. My research aims to expand the current literature on intersex activist groups' engagements with international institutions and supplement existing gaps concerning UN treaty bodies.

My goal is providing empirical evidence of the growing visibility and acceptability intersex activists' concerns are getting amongst international human rights mechanisms such as the UN treaty bodies, with the aim of showing that activists' claims are supported by experts in the field of human rights with specific mandates to overview states' compliance with international obligations. My findings indicate that there has been an increasing visibility or intersex concerns since 2009 and that main human rights' visible demands focus on intersex genital surgery; autonomy and bodily integrity; and redress and reparations concerns, claims that align with those demands coming from activist groups.

For this research piece I followed the inclusion and visibility of intersex issues in the text of the United Nations distinct treaty bodies' (UN TBs) concluding observations and recommendations. Three main questions guide this research: 1) To what extent are intersex issues made visible through UN TBs recommendations and concluding observations? 2) How are treaty bodies' recommendations shaped by activist groups demands? 3) How is intersex genital surgery understood and framed as a human rights problem by treaty bodies? To analyse these questions, I conducted a content analysis of the UN treaty bodies' concluding observations reports that include mentions of the word intersex. I reviewed the UN Human Rights Index for mentions of 'intersex' and 'intersexuality' because research suggests these terms are widely used by activists and human rights bodies (Dreger & Herndon, 2009; Jones, 2018; Lundberg et al., 2018; Monro et al., 2019; Reis, 2007) up to June 2021 and disaggregated the data pertaining to the nine core treaty bodies' concluding observations reports. This query resulted in 495 global mentions of the word intersex in the body of 230 concluding observation reports. Later, I did a second search and applied other terms used by activists, academics, and medical practitioners such as 'disorders of sex development', 'differences of sex development', and 'sex characteristics'. The second search did not alter the results from the first search.

This paper is structured as follows I start with a general overview and introduction to intersex activism and present evidence for its increasing internationalisation, which supports my argument about increasing visibility in transnational settings. Second, I provide a background information on treaty bodies, their functioning, and the different ways in which social movements and activist groups carry out advocacy and lobbying efforts with these and other human rights monitoring bodies. Third, I describe the methodology I used for tracking explicit references or mentions of intersex issues in treaty bodies' reports and present my findings via a content analysis. Fourth, I explore in depth the way intersex genital surgery is framed by the different UN treaty bodies as a human rights violation, considering legal and activist arguments in my analysis. Because of the large data set of information found globally, in this paper I limit most of my findings to the European region, as this is also the continent that has received the largest number of concluding observations and recommendations by treaty bodies.

The Internationalisation of Intersex Activism

Intersex activism has been around since the early 1990s (Bauer et al., 2020; Dreger & Herndon, 2009) and compared to other social movements, such as feminist or LGBT collectives, intersex collectives and activist groups are relatively small. Over the last decade, however, there has been an internationalisation of intersex activism, with the creation of regional and international networks and organisations. These networks provide a forum for interaction, strategising and advocacy for the rights and political goals of this movement at the regional and global levels (Carpenter, 2016; Rubin, 2015). Over the last 15 years, international networks of intersex activists have increasingly advocated the use of human rights discourses and legal frameworks to shape their demands and voice their concerns, most notably their opposition to intersex 'normalising' surgeries (Ammaturo, 2016; Bauer et al., 2020; Winter Pereira, 2022).

After I conducted a rapid review of activist websites, press releases, public statements, reports, and lawsuit documents, the prevalence of human rights discourses and framings was evident. This was also noted by scholarship that has observed the increased number of direct advocacy opportunities with different human rights monitoring bodies (HRMB), such as the special procedures of the United Nations, the Human Rights Council, and the UN treaty bodies, the Council of Europe (CoE) and certain agencies and bodies of the European Union (Bauer et al., 2020). The literature also shows that these HRMBs are beginning to pay attention and listen to the demands of intersex activists (Ammaturo, 2016; Bauer et al., 2020; Crocetti et al., 2020; Suess Schwend, 2018). Some HRMBs have responded to these demands with a series of observations and recommendations aimed at ensuring the rights of intersex people at the State level, reminding the States of their obligations under international human rights standards they have adopted (Bauer et al., 2020; CoE, 2015; European Parliament, 2019; FRA, 2015; Ghattas, 2019; Parliamentary Assembly of the Council of Europe [PACE], 2017; OHCHR, 2019).

There is plenty of scholarship on how social movements and activist groups engage with international human rights institutions, notably the United Nations, with the aim of influencing international and domestic policy and moving their political goals forward. Gaer (2003), for instance, has noted the historical increase of civil society participation within the UN institutions, and particularly the importance of civil society group engagements for the functioning of the UN treaty bodies. Johnstone (2006) has written about feminist groups' engagements with international law and UN institutions with the aim of advancing gender mainstreaming goals. Joachim's (2003) work on feminist movements' investments with the United Nations' agenda reflects on framing processes to recognise violence against women and sexual and reproductive health as human rights issues, whether these were previously not only obscured from the UN political agenda but also not associated with human rights framings.

In the field of LGBT and queer politics and activism, Vance and colleagues' work (Vance et al., 2018) explore the 'rise' of LGBT issues amongst United Nations institutions as well as the framing of LGBT rights as human rights. Similarly, D'Amico (2015) observed the interactions between political opportunities structures, collective action framing processes, and resource mobilisation with the successful inclusion of LGBT issues within the UN agenda. Another valuable contribution is that of Mulé's work (Mulé, 2018), which extensively describes the personal experiences of LGBT identifying activists when engaging with the United Nations, as well as strategies for navigating the rise of counternarratives. These are just some examples of how different groups and social movements have taken a strategic turn to engage with institutions such as the United Nations to amplify their demands.

The different forms in which activists and NGOs engage with international bodies in hopes of creating or igniting change at the local level is the matter of study of what is known as the ´boomerang effect´ in social movements, international relations and international politics studies (Allendoerfer et al., 2020; Keck & Sikkink, 2018; Waites, 2019). As Dondoli (2015) notes, civil society engagements with human rights bodies take different shapes and forms. NGOs and activists lobby governments and politicians to ratify human rights treaties that make states subjects of international monitoring and accountability, activists then gather information regarding human rights violations and inform monitoring bodies. Some activists also support and talk to victims, submit reports to monitoring bodies and national human rights institutions, propose appropriate language and terminologies for law and policy making, participate as observers in public sessions, provide expert knowledge in private meetings, and propose new and innovative ways to understand and frame human rights. Furthermore, activist groups follow up on resolutions and recommendations of monitoring institutions and hold the state accountable for its actions and international commitments made, and then they do it again once a reporting cycle restarts (Dondoli, 2015).

Like feminists, LGBT groups, and many others, international intersex activist organisations and networks of organisations also engage in these practices (Garland et al., 2022; Winter Pereira, 2022). Groups such as OII Europe (2015, 2020), Intersex Human Rights Australia (IHRA) (n.d., 2019a, 2019b), Zwischengeschlecht (Stop IGM, n.d.-b), and the NNID Foundation (Netherlands organisation for sex diversity) (Intersexrights.org, n.d.) often participate in meetings, compile information on human rights violations, and submit information and reports to different human rights monitoring bodies, notably the UN treaty bodies, whenever there is a reporting period Zwischengeschlecht, for example, collaborates with local organisations that may have less experience working in transnational global settings or may not be familiar with the UN or specific mechanisms to submit NGO (shadow) reports to treaty bodies and committee members (Winter Pereira, 2022).

These different forms of engagement have often turned fruitful. At the United Nations, intersex issues have been mentioned at Human Rights Council's universal periodic review (UPR) since 2011 and have since added up more than 600 UPR recommendations that broadly mention intersex people and call upon member states to protect the rights of this group of people (Ravesloot, 2021). Likewise, to date, there are more than 500 treaty bodies' concluding observations calling member states to fulfil their human rights obligations as they specifically pertain to intersex people. To date, OII Europe (2020) has monitored that no less than 74 shadow reports have been submitted to UN TBs by civil society organisations specifically talking about the situation of intersex people's rights. These reports not only provide committee members with the most up to date information but also follow up on the best (or worst) practices of States and give proposals for recommendations, which, if accepted by committee members, will translate into official policy recommendations given by the treaty monitoring body to the state, not just the government in turn or the executive branch, but the state as a subject of international law.

Looking for Signs of Intersex Visibility Within the United Nations: Research Methodology, Analysis, and Findings

The main motivation behind my research is to bring attention to the fact that UN TBs are increasingly paying attention to intersex human rights issues and, in doing so, show that activists' claims are supported by experts in the field of human rights with specific mandates to overview states' compliance with international obligations.

Within the universal system of human rights, treaty bodies are committees with the legal mandate to monitor state governments' implementation of their obligations under specific human rights treaties. International practice recognises the existence of nine human rights 'core' treaties (or conventions)[48] and ten monitoring bodies.[49] The treaty bodies are “committees of independent experts whose mandate emanates from the nine core international human rights treaties” (OHCHR, 2017, p. 2). These experts have the task to monitor the state parties’ human rights obligations under their respective treaty (Collister et al., 2015; Mechlem, 2009; O’Flaherty, 2006).

All treaty bodies, except for the Subcommittee on Prevention of Torture (SPT), receive and consider reports submitted by state parties on the implementation of their specific mandate treaty and issue concluding observations, which include a series of recommendations to guide states in the better fulfilment of their international obligations. These general comments and recommendations are interpretations of specific substantive or procedural provisions of their respective treaties and/or address relevant issues pertaining to their mandate treaty (Collister et al., 2015; OHCHR, 2017). Some treaty bodies may have the mandate to consider individual communications and inter-state complaints, to initiate inquiries, or carry out investigations through country visits (Collister et al., 2015; OHCHR, 2017). The way these tasks are carried out is based and described in their mandate treaty. As stated by the International Service for Human Rights (ISHR), an NGO specialised in training human rights defenders for working with UN institutions, “The main purpose of the reporting process is for the treaty bodies to examine the level of the state’s implementation of its obligations under the treaties” (Collister et al., 2015, p. 14).

With the purpose of exploring how treaty bodies recalled intersex issues in the text of their reporting documents, I conducted a content analysis of the UN treaty bodies concluding observation reports that include mentions of the word intersex. I reviewed the UN Human Rights Index for mentions of ‘intersex’, ‘intersexuality’, ‘disorders of sex development’, ‘differences of sex development’, and ‘sex characteristics’ until the end of June 2021 and disaggregated the data pertaining to the nine core treaty bodies concluding observations reports. I excluded the SPT because of significant differences on how this particular body carries out its reporting and deleted duplicated results. This query resulted in 495 global mentions of the word intersex in the body of 230 concluding observation reports (see: Table 1).

Table 1.

Global mentions of intersex issues segregated into reports, concluding observations (cobs), and recommendations (recs).

SCOPE	DATA	TOTAL REFERENCES	TOTAL REPORTS	COBS	RECS
GLOBAL	INTERSEX MENTIONS	495	230	252	244

Interestingly, the query showed zero mentions of the medical term ‘Disorders of sex development’ (DSD) coming from the UN treaty bodies, except for a recommendation made to Denmark, in which the CESCR committee asks the state to “Replace in its legislation the concept of ‘disorders (differences) of sex development’ with a definition of intersex person in which

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[48] These are: the Convention on the Elimination of All Forms of Racial Discrimination (ICERD, 21 December 1965), the International Covenant on Civil and Political Rights (ICCPR, 16 December 1966), the International Covenant on Economic, Social, and Cultural Rights (ICESCR, 16 December 1966), the Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW, 18 December 1979), the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (CAT, 10 December 1984), the Convention on the Rights of the Child (CRC, 20 November 1989) the International Convention on the Protection of the Rights of All Migrant Workers and Members of Their Families (ICMW, 18 December 1990), the International Convention for the Protection of All Persons from Enforced Disappearance (CPED, 20 December 2006), the Convention on the Rights of Persons with Disabilities (CRPD, 13 December 2006).

[49] There are also optional protocols that are adjacent to the nine core treaty bodies already mentioned. But for the purposes of this research, I only consider the main treaty bodies.

differences in sex characteristics include genitals, gonads and chromosome patterns" (United Nations, 2019, parr 65). The DSD term was originally adopted in 2006 by a group of specialised medical practitioners and has since become popular in the medical community to refer to people with uncommon sex traits and characteristics (Lee et al., 2016; Hughes et al., 2006). However, it has been rejected by human rights advocates and intersex activists as they consider it pathologising, with one of the reasons being that it locates power/knowledge primarily in the medical community rather than in people with lived experience (Davis, 2014; Garland et al., 2022). This is an interesting finding that could indicate the medicalised DSD terminology is a language that is rejected also in the ambit of the United Nations. The term 'differences of sex development' is also mostly absent from the treaty bodies' reports, with the only mention being the case of the recommendation made to Denmark mentioned above. 'sex characteristics' is also a term that has not been yet widely adopted by the UN treaty bodies, having only found 9 mentions from 8 report documents.

To look at intersex visibility from a comparative perspective, the tables below show how 'intersex' mentions in the TBs' report documents compared to other groups of people or issues. These numbers would suggest that while intersex is not as widely mentioned or visible as references to *gay* people or issues such as *HIV*, for example, it does have the same kind of visibility as groups such as *transgender women*[50] or issues such as *female genital mutilation* (see: Table 2 and Table 3).

Table 2.

Mentions of 'intersex' compared to other selected groups in TBs' reports.

Groups	**UNTB References**
Intersex	495
Lesbian	652
Lesbian Women	9
Bisexual	642
Trans women	186
Transgender women	169
Gay	80422

Table 3.

Mentions of 'intersex' compared to other selected issues in TBs' reports.

Issues	**UNTB References**
Intersex	495
Female genital mutilation	542
Obstetric violence	5
Rare disease	3
HIV	80422

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[50] The table looks at trans and transgender women combined results.

Disorders of sex development	1

Because mentions in UN TBs' documents do not necessarily translate into substantive recognition of rights, I examined the way in which these references were made. I analysed if these references were recommendations given to states for law and/or policy change or merely noted observations. I also examined which TBs are giving visibility to intersex groups' concerns, which regions have received most recommendations, and which issues or concerns coming from activist groups are getting the attention of UN TBs. To limit the scope of my analysis, I focused it on the European region.

Content Analysis

Concluding Observations and Recommendations Concerning Intersex People

To start my analysis, I segregated mentions of the word 'intersex' into observations (n = 252) and recommendations (n = 244). This distinction is made on the basis that treaty bodies' observations can note progress or specific situations the UN TB wants to highlight, and observations can also note concerns or pressing situations of worry. Recommendations, on the other hand, explicitly call for state governments' action. After analysing the data concerning observations/recommendations and taking time as a factor, an interesting finding was that there seemed to be an increase in references to intersex issues and intersexuality by TBs until 2017, when there was a record number of 57 references that year alone supporting the claim that intersex visibility is increasing. Since 2018, however, there seems to be a decrease of intersex references in TBs' reports. From 2019 onwards the impact of COVID may have had a role to play, however further research outside of the scope of this paper needs to be done as to investigate why the decrease has occurred (see: Figure 1).

Figure 1.

Global mentions of intersex issues segregated into recommendations and concerns/observations.

Which Treaty Bodies Are Giving Visibility to Intersex Issues? I also segregated the data by the different treaty bodies to explore which venue seemed more 'open' to hearing intersex activists' demands or shedding a light on intersex issues. In this case, the Committee on the Elimination of

Discrimination against Women (CEDAW committee) appeared to be the one body with the highest number of references to 'intersex persons' on a global scale, and it was also the TB that made the first ever intersex recommendation back in 2009 (see: Table 4 and Figure 2).

Figure 2.

Global mentions of intersex issues by treaty bodies considering time as a factor.

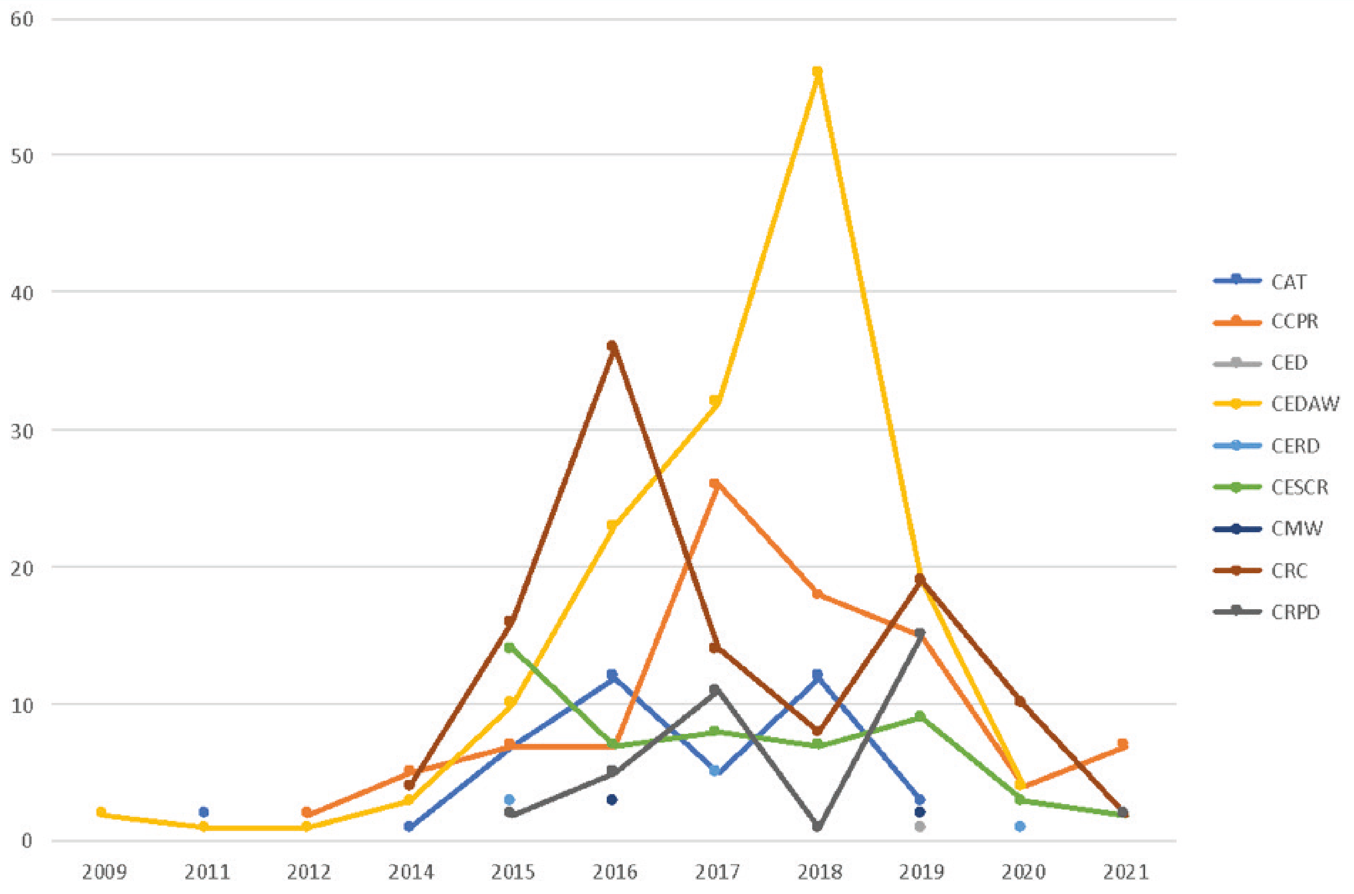


Table 4.

Mentions of intersex issues segregated by issuing treaty body.

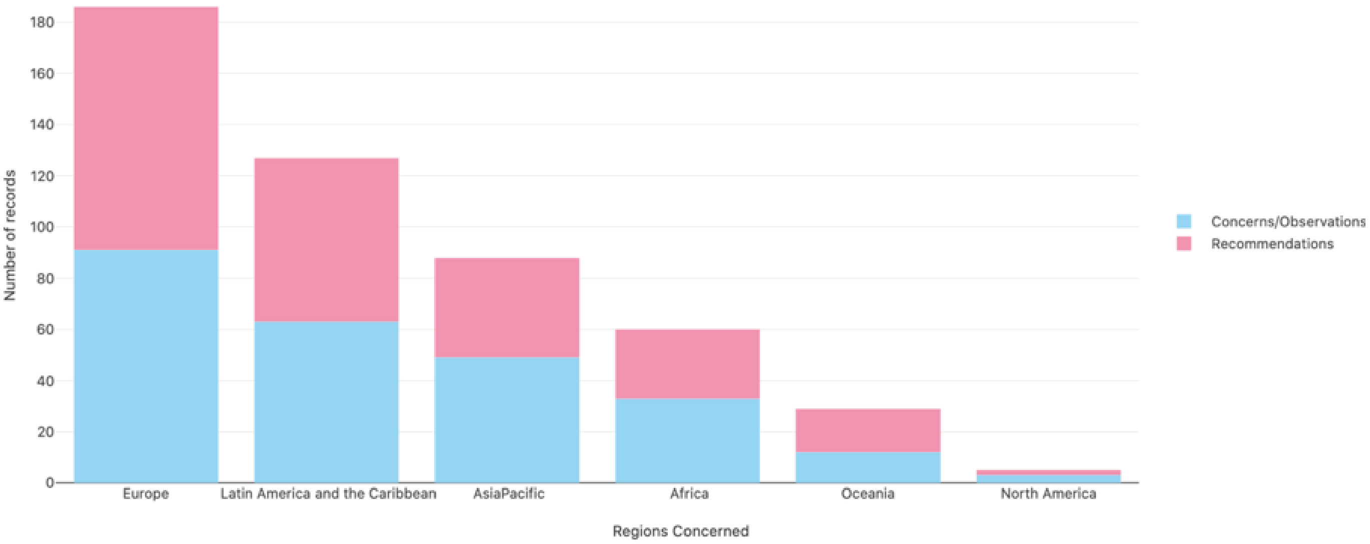
SCOPE	ISSUING TREATY BODY	TOTAL REFERENCES	REPORT REFERENCES	COBS	RECS
GLOBAL	Committee against Torture (CAT Committee)	42	21	21	21
GLOBAL	Human Rights Committee (HRCtee)	91	43	53	38
GLOBAL	Committee on Enforced Disappearances (CED Committee)	1	1	1	0
GLOBAL	Committee on the Elimination of Discrimination against Women (CEDAW Committee)	149	55	76	73
GLOBAL	Committee on the Elimination of Racial Discrimination (CERD Committee)	9	6	5	4

GLOBAL	Committee on Economic, Social and Cultural Rights (CESCR Committee)	50	27	27	23
GLOBAL	Committee on the Protection of Migrant Workers (CMW Committee)	5	2	3	2
GLOBAL	Committee on the Rights of the Child (CRC Committee)	112	61	49	63
GLOBAL	Committee on the Rights of Persons with Disabilities (CRPD Committee)	36	14	16	20

Visibility by Regions. Because of the large number of global references to intersex issues (n 495), I decided to reduce the data analysed by segregating it by region and limit the second part of my analysis to one specific region. Europe was selected as is the region with the largest number of recommendations and concluding observations, a total of 186 references to intersex issues within 87 unique treaty bodies' reports.[51] I also decided to focus on recommendations as they invite for state action, which, in the case of Europe, amounts to 95 recommendations present in 73 TBs' reports. In this sense, subsequent data in this paper analyses European recommendations unless stated otherwise (see Figure 3 and Figure 4).

Figure 3.

Number of treaty bodies' observations and recommendations segregated by regions.



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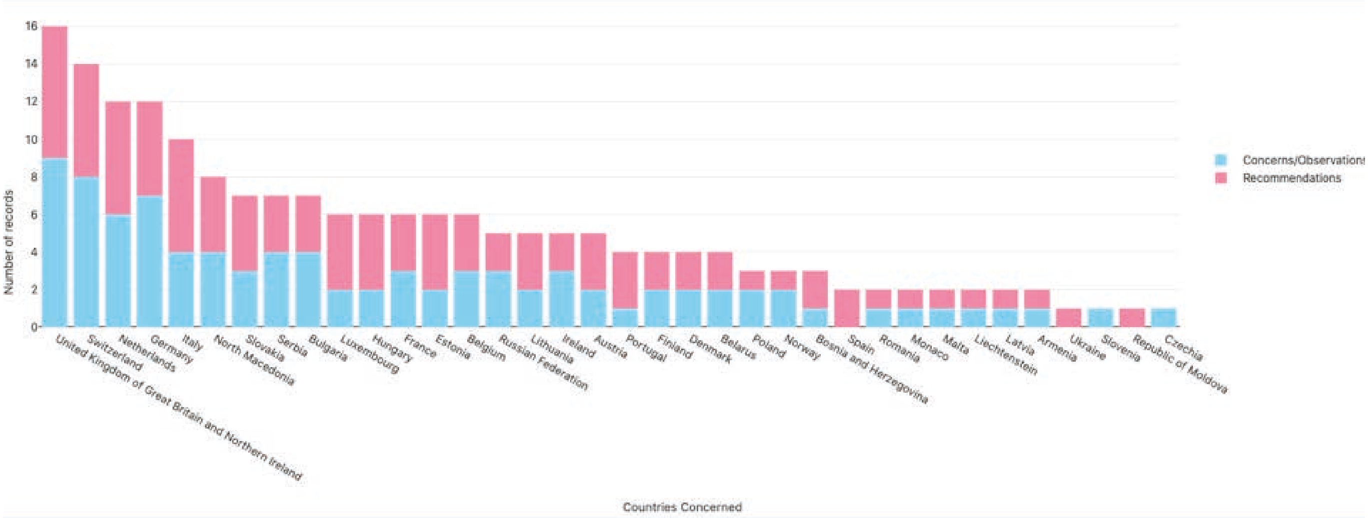
[51] These data consider Western Europe and Eastern Europe data together, while the UN official UHRI data seem to divide it.

Figure 4.

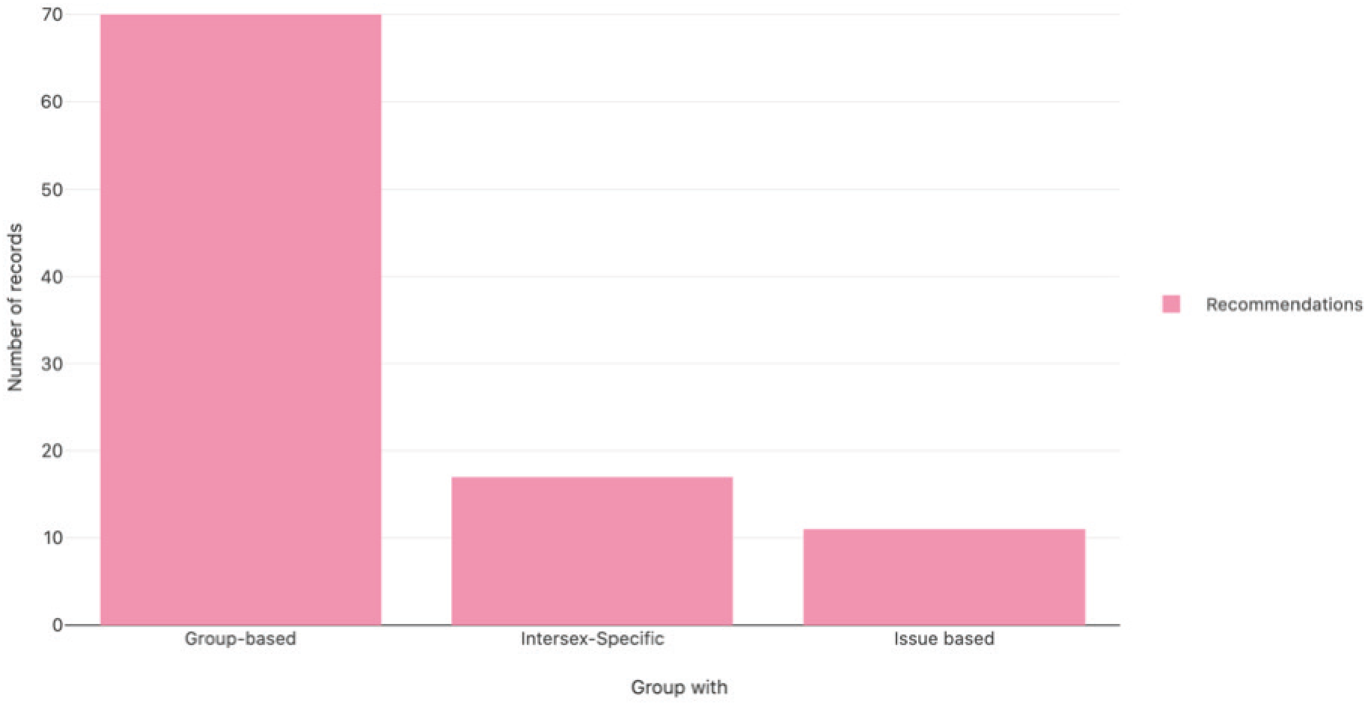
Number of treaty bodies' observations and recommendations for European countries.



Visible as an Intersex Specific Issue or Grouped Together with Others? Intersex activist groups and intersex related scholarship have expressed concerns over the risk of intersex-specific issues and demands being diluted, that is, made less visible or left behind when grouped together within the umbrella acronym 'LGBTI' (Bauer et al., 2020; Jones, 2018), particularly those claims related to intersex genital surgery, sex characteristics, and bodily integrity. For instance, when analysing the results of the UK's LGBT 2017 survey, Garland and Travis (2020b) note the limitation in responses specific to intersex people or intersex issues, as the survey was primarily targeted towards the LGBT community (and framed as such). Because of these concerns of conflation, another aspect that I examined was if intersex issues were considered by TBs as specific or standalone issues (e.g., 'intersexuality') or as issues pertaining to intersex people as a specific group (e.g., 'intersex persons', 'intersex children') or, on the contrary, if issues were considered in conjunction with other groups (e.g., 'LGBTI', 'vulnerable groups') (see Figure 5).

Figure 5.

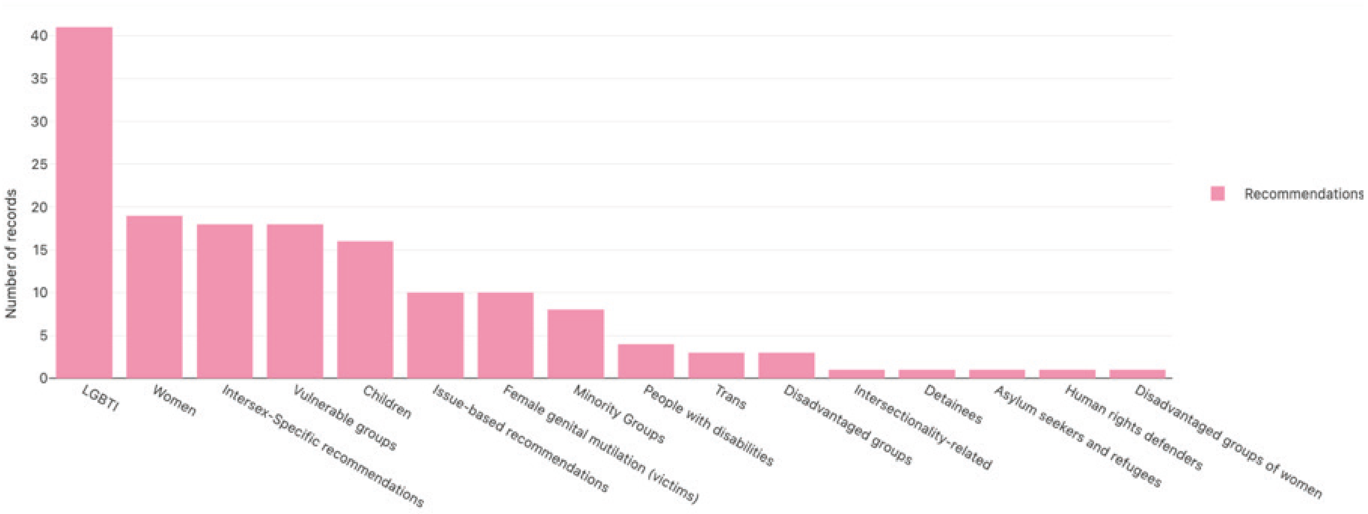
Number of TBs' recommendations only for European countries segregated in group-based, issue-specific, or intersex-specific recommendations.



When recommendations were found under the section 'intersexuality', 'intersex persons', or similar, these were coded as *intersex-specific* recommendations; on the contrary, if intersex people were considered or mentioned as part of a larger group of persons, the recommendations were coded *group-based*. This information was coded and verified by looking at both the text of the report document and the section in which the recommendations were situated in the report. A third type of recommendations emerged and were coded as '*issue-based*' recommendations, which are documents that do not focus on groups but rather particular issues (e.g., non-discrimination as opposed to 'LGBTI discrimination' or the 'right to health', 'harmful practices', amongst others) (see Figure 6).

Figure 6.

Number of TBs' recommendations only for European countries segregated into groups or themes that intersex people were frequently associated with.



The analysis showed that most of the recommendations coming from treaty bodies are group-based and, in this same line, most mentions of intersex issues are associated with LGBTI people. Other groups that intersex people are often associated with are women (this is related to the large number of CEDAW references), vulnerable or minority groups, and children. Intersex issues are also raised as part of *issue-based* recommendations, particularly in the 'health' or 'harmful practices' thematic sections of TBs' reports. Some treaty bodies, however, are starting to include a specific section in their reports dedicated to examining the situation of the rights of intersex people. This can be seen as a positive development, as once a section is included in the body of a report it is likely that it will be reproduced in subsequent reports. This is potentially true not only for the reviewed country but also for the reviews of other countries as well.

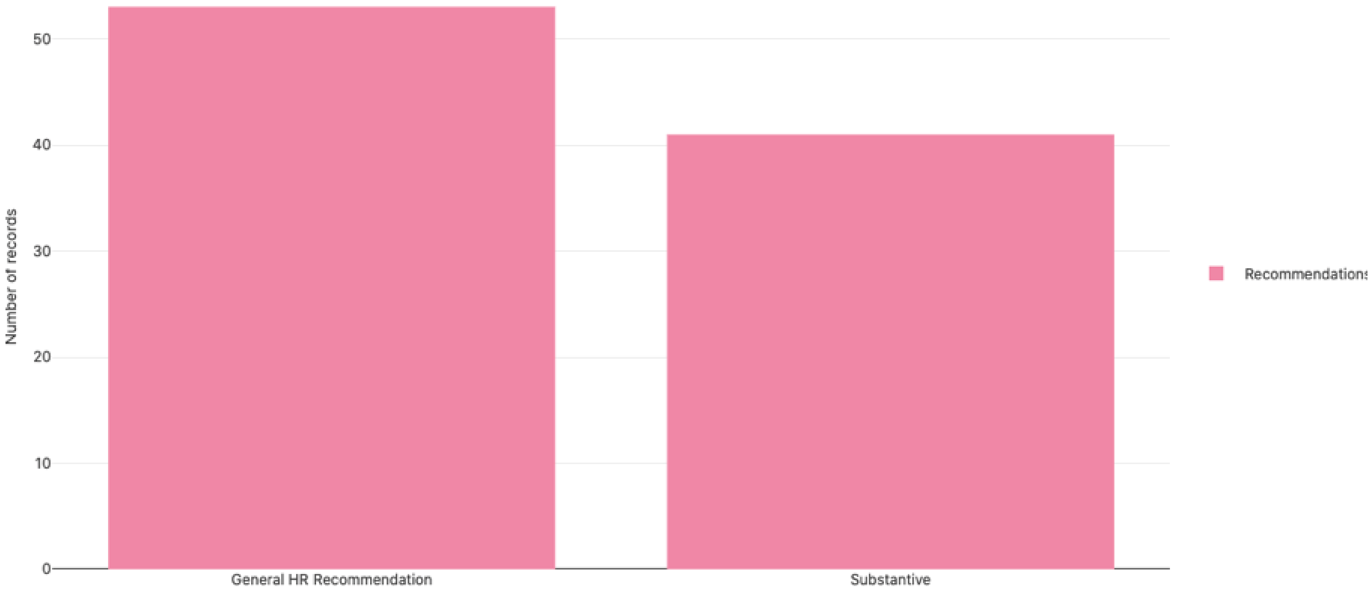
Substantive or General Recommendations? Are the Treaty Bodies Listening to Activists?

Another aspect that was considered in the analysis is whether TBs' recommendations echoed intersex activist groups' human rights demands present in activists' public documents. For this analysis, the Malta declaration, a document emerging from the Third International Intersex Forum that took place in Valletta, Malta in 2013 (Suess Schwend, 2018; Third International Intersex Forum, 2013), was selected as the primary source of reference to activists' claims, as it provides a comprehensive list of issues (problems) and demands (solutions). The Malta declaration also gathers the views of 34 activists representing 30 intersex organisations from different continents, making it more 'universal'.

For this part of the analysis, if recommendations echoed with issues listed in the Malta declaration (or other activist documents) they were coded as *substantive* recommendations, as they are deemed to address issues specially related to the lived experiences of intersex persons, according to activist groups' demands. If TBs' recommendations were issued on broader terms, for instance, regarding issues such as the general prevention of discrimination, stigma or violence, the recommendations were coded as *general* human rights recommendations (even if they explicitly included intersex persons), as resonance with the specific demands of intersex activist groups was minimal. Results show a total of 41 substantive recommendations in an equal number of reports directed towards 18 European countries (see: Figure 7). Out of these numbers, 38 recommendations speak about IGS (same number of countries).

Figure 7.

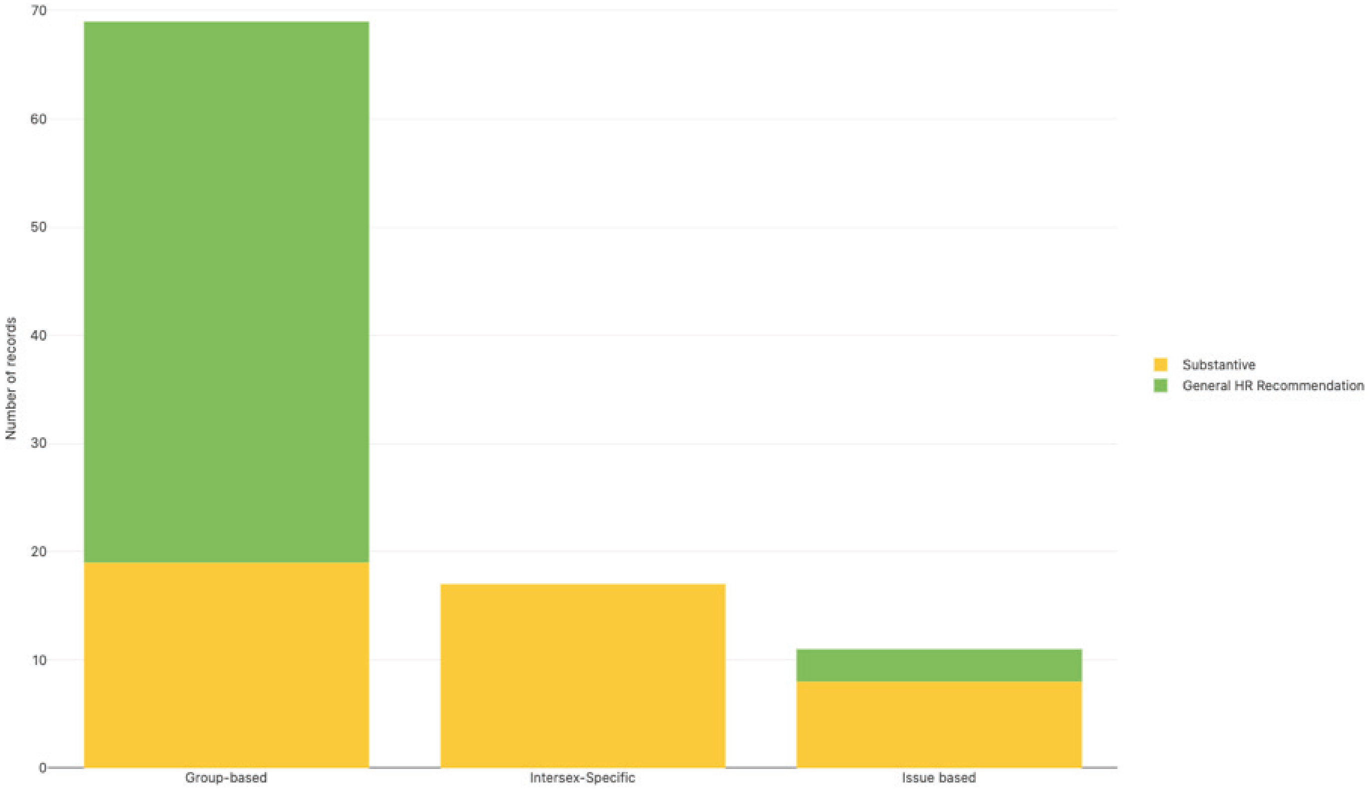
Number of treaty bodies' recommendations only for European countries segregated in substantive and general human rights recommendations.



When analysing the European data for substantive and general recommendations together with the *group-based, issue-based*, or *intersex-specific* data, I noted that while most recommendations continue to be group-based, they still contain a large number of substantive recommendations that align with intersex activist demands (see: Figure 8). Likewise, and perhaps unsurprisingly, all intersex-specific recommendations were also coded as substantive recommendations, which can be seen as a positive development, as group-specific recommendations are most likely to resonate with intersex activist groups' demands and result in substantive recommendations calling for specific state actions. Finally, most issue-based recommendations were found to also be substantive, which can be explained by the large number of intersex substantive recommendations that can be found when TBs analyse FGM (female genital mutilation) and IGS under the lens of 'harmful practices'. On this point, an interesting fact to highlight is that while there is a number of reports that consider intersex surgeries under the analysis of harmful practices or (female) genital mutilation, there was only one report from the CEDAW committee that framed normalising surgeries as 'intersex genital mutilation' (IGM). On this point, literature suggests that the 'mutilation' frame can be quite polarising, with most medical practitioners interviewed against it (Crocetti et al., 2020). In this sense, maybe it is a valid to question to ask if the rejection of the IGM terminology by the UN TBs, despite its use by activists and presence in activist documents and shadow reports, might be an indication of a 'compromise' position that recognises this harmful practice as a human rights violation but is not ready yet to grant 'mutilation status' such as the one given to FGM, considering the cultural politics and medical jurisdiction around it (Ammaturo, 2016; Fraser, 2016; Rubin, 2015). Additionally, as Garland et al. (2022) have noticed, the United Nations does not have jurisdiction or the power to change medical practice, international human rights law operates at a different scale, and new protocols and standards of care for intersex people's treatments and protections against IGS would need to be negotiated between the State and medical institutions and practitioners, a less 'polarising' frame might facilitate such 'negotiations'.

Figure 8.

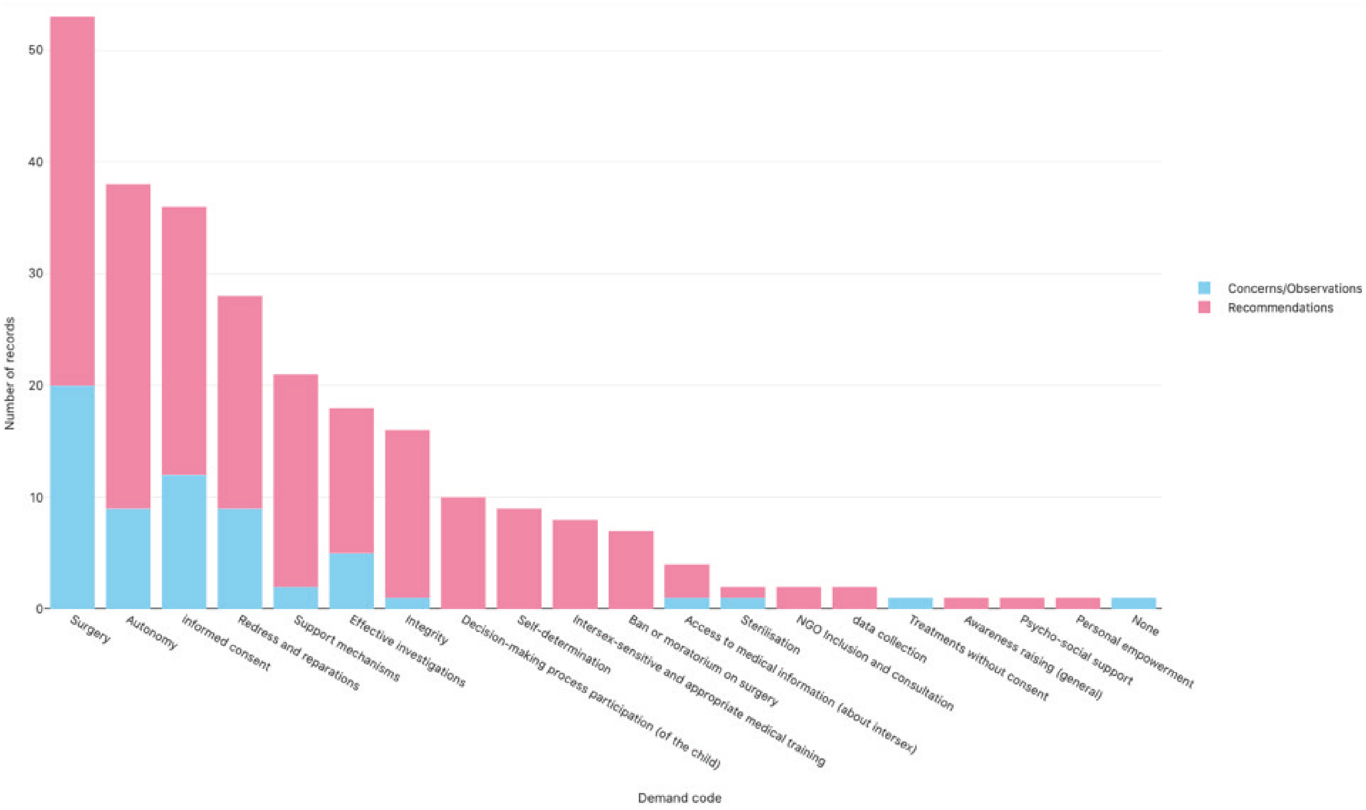
Number of TBs' recommendations only for European countries segregated in group-based, issue-specific, or intersex-specific recommendations, together with substantive or general recommendations data.



What Demands Are Most Visible? I also examined the main aspects or activists' demands the TBs have considered as priorities and decided to make visible within their reports. I found that the main issues explicitly stated in the treaty bodies' reports referred to issues related to intersex genital surgery as well as autonomy, integrity, and informed consent claims. Other issues with high visibility were demands related to effective investigations and redress mechanisms, as well as support mechanisms for intersex people and their families. There were also other issues present in the Malta declaration in 2013 (Third International Intersex Forum, 2013) that were less visible amongst the recommendations, for example, financial support for NGOs as well as their inclusion in consultation processes, claims regarding general societal awareness of intersex issues, and claims regarding sterilisation as a consequence of IGS (see Figure 9).

Figure 9.

Number of TBs' recommendations only for European countries segregated by activists' demands (Malta declaration).



Resonance Analysis

Finding Resonance? Intersex Activists' Claims and UN Institutional Frames

Following the content analysis, I applied a framing resonance and legal analysis to the main claim highlighted by treaty bodies; this is IGS as a human rights violation. In the field of social movement studies, 'resonance' or 'cultural resonance' is used to describe how certain frames used by social movements to disseminate their demands can adapt to the already existing cultural values or ideas in order to achieve acceptability (Benford & Snow, 2000; Ferree, 2003; Snow et al., 1986). Here I use the term in a slightly different way and suggest that institutions, like cultures and societies, also possess values and ideas that are produced and reproduced through their daily functioning. Moreover, institutions like the United Nations and affiliated bodies have a strong link to legally binding frameworks; therefore, I suggest that the acceptability of certain aspects of activist claims as rights violations and subsequent visibility, expressed in the form of concluding observations and recommendations by treaty bodies, is linked to the acceptability (resonance) activists' claims find in ideas (frameworks) that already exist and have been accepted by the UN treaty bodies.

In particular, the framing of IGS as a human rights violation is linked to aspects already recognised by TBs as human rights violations, for example, the prohibition of ill-treatment or torture, the right to the highest attainable standard of health, or the rights of the child to develop and to live a life free of violence. In this sense, intersex activists are not claiming anything new or the creation of 'new rights', but rather they demand the explicit recognition of a series of harmful practices and abuses that culminate in the form of intersex genital surgery as human rights violations and protections against them.

Intersex Genital Surgery as a Human Rights Violation

Intersex genital surgery is the main concern by human rights activists and has been framed as a practice that contradicts many human rights standards (Bauer et al., 2020; Ghattas, 2019; Third International Intersex Forum, 2013). This issue was raised in 42 treaty body reports out of the 87 pertaining to the European continent. Some elements found in the way TBs frame intersex genital surgery can serve to better analyse what these institutions perceive as problematic with this medical practice, and also if these understandings align with activists' claims. The main aspects of surgery highlighted by TBs in the reports concerning European countries are that:

- They are medically unnecessary
- They are non-urgent
- They are carried out too early or the main victims are infants or children
- They are intended to decide or assign sex
- They are irreversible or have long-lasting consequences
- They entail pain or suffering

I grouped these 'problematic' aspects into three themes: the need or necessity of IGS, the timing or temporality of IGS, and the consequences of IGS. Below is a summary analysis of what literature and activist claims have stated on these specific aspects.

The Necessity of IGS. In the European countries examined, the TBs noted the issue of medical necessity in 31 out of 42 concluding observation reports that touched upon the topic of IGS. In medicine, if a procedure is not necessary for the preservation of life or bodily functions, it is said that it is elective (Gardner & Sandberg, 2018). Regarding medical necessity, literature suggests that a large number of the surgeries performed on intersex children are medically unnecessary, meaning they are not strictly oriented towards preserving the life or bodily functions of the child, but rather that they are performed to 'assign' a sex or 'orient' their gender identity (Ammaturo, 2016; Chase, 2013; CoE, 2015; FRA, 2015; Rubin, 2012). Likewise, activist documents have noted concerns that when law or policy makes references to surgical 'medical necessity' too much power is left in the hands of doctors, who are the ones that ultimately decide what medical necessity means (Ghattas, 2019). Literature also questions that doctors' opinions on the necessity of the surgeries are not free of biases, despite being often presented as such. Doctors' opinions may be influenced by cultural biases regarding gender performativity and sex appearance within the binary and normative male/female paradigm, just as everyone else's (Gardner & Sandberg, 2018; Hegarty et al., 2021; Meoded Danon, 2019; Rubin, 2012). Intersex studies scholarship also shows that it is not 'easy' for doctors to define what is and what is not medically 'necessary' and different views and biases weigh in on the doctors' decision-making process (Gardner & Sandberg, 2018; Hegarty et al., 2021).

A 2019 guide created by activists and directed towards law and policy makers recommends stakeholders to avoid referring to medical necessity in intersex-related legislation:

There are few and relatively rare cases in which the intersex infant's life is at risk and immediate treatment is actually indicated/necessary. All other interventions, despite being deferrable, are presented as equally "medically necessary" based on a misconception of what constitutes a societal problem and what is medically indicated. Evidence shows that instead of increasing an intersex individual's health, interventions "too often lead to the opposite result". Despite this contrary evidence, as well as a lack of positive evidence, many medical guidelines still recommend invasive surgeries and other invasive medical treatments on intersex individuals as a medical necessity, thus reinforcing the medical indication as determined by doctors (Ghattas, 2019, p. 19).

Legally, the issue of medical necessity comes into play for considering 'justifications' for cases when there is an infringement on human rights in order to determine if such intrusion is permissible or not. The Council of Europe's (1997) Oviedo convention, for example, considers exceptions regarding medical liability for harms and damages caused when consent cannot be obtained but the life of the patient is in danger. A framing by TBs that considers IGS as a right violation only in cases where it is medically unnecessary is already weighting in the value of a life vis a vis the value of bodily integrity. Such framing is also consistent with intersex activist groups' demands, who do not oppose life-saving surgeries but rather question the ambiguity of what is considered medically necessary (Ghattas, 2019).

The Temporality of IGM. The topic of temporality is visible in two distinct ways in the recommendations and concluding observations of treaty bodies. On the one hand, there are mentions that IGS is a 'non-urgent' procedure and therefore doctors can wait to perform it. The issue of urgency was present in 6 out of 42 records that mention IGS in the European region. Temporality is also present when references are made to the age of the persons undergoing these procedures and their inability to effectively consent. Treaty bodies referred to the early age, infancy, or childhood of the person undergoing IGS in 42 out of 42 records.

The first point on the urgency of treatments, including surgical but also hormonal and other medical treatments, is closely related to the medical necessity of interventions. Research suggests that when surgeries cannot be described as 'medically necessary' for the purposes of preserving the life of the child, they are often framed as 'social emergencies' and this way the need for 'urgent' treatment is justified (Ammaturo, 2016; Meoded Danon, 2018). Scholars such as Battaglino (2019) suggest that this feeling of urgency comes not from the fear of irreversible loss of the child's life or bodily functions but out of fear for the social consequences that waiting to 'define a sex' can have in the child's gender socialisation process. The importance that doctors and society at large give to the gender socialisation process has been noted by the United Nations treaty bodies, as in several recommendations and concluding observations examined, where the TBs recognise that IGSs are carried out for other than medical purposes, e.g., for the purpose of 'assigning sex'.[52] On the issue of temporality, Garland and Travis (2020a) consider that "it seems, is not only being used to justify non-therapeutic medical interventions on intersex infants, but it is also used to abrogate the responsibility of the medical profession in the face of mounting external scrutiny" (p. 123). They argue that the medical profession and institutional power/knowledge has successfully framed intersex bodies as temporal and in need of a fix. This notion has facilitated the claim that an intersex birth is a situation of emergency in childhood, but only a temporary one that can be 'solved'. Likewise, the authors consider that while this narrative helps maintain intersex bodies and 'diagnosis' under medical authority, it also deters it from legal responsibility and criticisms from

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52 See for example: Committee against Torture Concluding observations on the sixth periodic report of Austria. 27 January 2016. CAT/C/AUT/CO/6, Human Rights Committee. Concluding observations on the sixth periodic report of Belgium. 6 December 2019. CCPR/C/BEL/CO/6, Human Rights Committee. Concluding observations on the seventh periodic report of Finland. 3 May 2021. CCPR/C/FIN/CO/7, Committee against Torture. Concluding observations on the seventh periodic report of France. 10 June 2016. CAT/C/FRA/CO/7, Committee on Economic, Social and Cultural Rights. Concluding observations on the sixth periodic report of Germany. 27 November 2018. E/C.12/DEU/CO/6, Committee on the Elimination of Discrimination against Women. Concluding observations on the combined sixth and seventh periodic reports of Ireland. 9 March 2017. CEDAW/C/IRL/CO/6-7.

activists, families, and others over human rights abuses as ‘emergency situations’, especially those in medicine, are often a subject of less scrutiny.

Another issue highlighted by the TBs, related to temporality, is that IGS is carried out ‘too early’, ‘during infancy’, or carried out in ‘babies or children’. [53] All of these references signal a child rights-centric view of looking at the issue (Schneider, 2013; Zillén et al., 2017). This view by TBs is helpful in terms of centring specific circumstances faced by children as rights-bearers. In the particular case of intersex children, issues regarding their right to be free from violence, the right to the highest attainable standard of health, protection from harmful practices affecting their health, the right to their own development, the right to receive age-appropriate (medical) information, the right to participate in decision making processes over their medical treatment, and the right to be heard and that their views are taken into consideration in matters that affect them, all recognised by the UN (1989) Convention on the Rights of the Child, are highlighted in treaty body reports.

While a child-centric view is certainly a welcome approach made by TBs, careful consideration needs to be made not to frame IGS as an issue that exclusively pertains to children and limited to the violation of the child’s agency or an event that has no repercussions into adulthood. For example, Garland and Travis (2020a) have noted the lack of importance aspects related to sexual health and pleasure are given during infancy and childhood when doing an assessment of the necessity of IGS. Berry and Monro (2022) have noted the lack of a perspective that considers the repercussions that unnecessary medical procedures and treatments have on older intersex persons and their healthcare needs. A single emphasis on children might risk making intersex adults’ struggles with the consequences of IGS invisible and leaving them out of the conversation. Indeed, in this research it was found that even when TBs’ recommendations are substantive and specific, these tend to focus on intersex children, perhaps leaving intersex activists’ claims for sustained, appropriate and informed healthcare for intersex adults who have undergone IGS and care for older intersex persons less visible (Berry & Monro, 2022; Latham & Barrett, 2015). A positive approach in the way TBs frame IGS should include both mentions to intersex children and adults’ rights.[54]

Consequences of IGS. The last two issues highlighted by treaty bodies have to do with the effects of IGS[55] these being that they are ’irreversible’, have ’long standing consequences’, and

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[53] See for instance: Human Rights Committee. Concluding observations on the sixth periodic report of Belgium. 6 December 2019. CCPR/C/BEL/CO/6 Parr.22; Committee on the Rights of the Child, Concluding observations on the combined third to sixth periodic reports of Malta. 26 June 2019. CRC/C/MLT/CO/3-6 Parr.29; Committee on the Elimination of Discrimination against Women Concluding observations on the combined fourth and fifth periodic reports of Switzerland. 25 November 2016 CEDAW/C/CHE/CO/4-5 Parr.24.

[54] See also Carpenter (2015) describing intersectional approaches, including an aging perspective, for the protection of the rights of intersex persons.

[55] Committee against Torture Concluding observations on the sixth periodic report of Austria. 27 January 2016. CAT/C/AUT/CO/6, Committee on Economic, Social and Cultural Rights. Concluding observations on the fifth periodic report of Belgium. 26 March 2020. E/C.12/BEL/CO/5, Committee against Torture. Concluding observations on the combined sixth and seventh periodic reports of Denmark. 4 February 2016. CAT/C/DNK/CO/6-7, Committee on the Elimination of Discrimination against Women. Concluding observations on the combined seventh and eighth periodic reports of Germany. 9 March 2017 CEDAW/C/DEU/CO/7-8, Committee on Economic, Social and Cultural Rights. Concluding observations on the sixth periodic report of Germany. 27 November 2018. E/C.12/DEU/CO/6, Committee on the Rights of the Child. Concluding observations on the combined third and fourth periodic reports of Ireland. 1 March 2016. CRC/C/IRL/CO/3-4, Committee on the Rights of the Child, Concluding observations on the combined third to sixth periodic reports of Malta. 26 June 2019. CRC/C/MLT/CO/3-6, Committee on the Rights of the Child. Concluding observations on the combined second to fourth periodic reports of Switzerland. 26 February 2015. CRC/C/CHE/CO/2-4, Committee on the Elimination of Discrimination against Women Concluding observations on the combined fourth and fifth periodic reports of Switzerland. 25 November 2016. CEDAW/C/CHE/CO/4-5, Committee on the Rights of the Child Concluding observations on the fifth periodic

that these interventions often entail some degree of pain or 'suffering'. References to long-lasting consequences of IGS were present in 11 out 42 TBs' reports that mention IGS, and references to the negative effects of IGS were found in 13 out of 42 records.[56]

A recognition by TBs that considers the consequences of IGS is a welcomed development, as IGS is often not a single occurrence event but rather the start of a series of episodes, surgeries and other forms of medical treatments (such as hormonal treatment) oriented towards the 'normalisation' of genital appearance at childhood, puberty, and adulthood (Creighton et al., 2001; Grabham, 2007; Hegarty et al., 2021). Unlike most commonly-known and socially-accepted types of elective and cosmetic surgeries (e.g., plastic surgery), most types of IGS will entail significant levels of pain and discomfort that go beyond a single surgical episode for the growing child and adolescent (Creighton et al., 2001; Garland & Travis, 2020; Grabham, 2007; Hegarty et al., 2021). For example, vaginal construction interventions often include dilation regimes carried out as the person grows older; these regimes can be painful, prolonged, and invasive (Creighton et al., 2001; Hegarty et al., 2021). Relevant literature also explains the results of these treatments and surgeries are not always guaranteed, as information on the level of satisfaction coming from adults who have experience these surgeries is varied and inconclusive (Köhler et al., 2012; Kreukels et al., 2019; Lee et al., 2012; Schweizer et al., 2014). Both activist documents and scholarship addressing the consequences of intersex genital surgery often recount the negative experiences of people who have undergone such procedures (Fraser, 2016; Ghattas, 2019; Ghattas et al., 2019; Grabham, 2007; Monro et al., 2019). Often these interventions are performed on the basis that surgery is necessary in order to facilitate heterosexual sexual intercourse in adulthood, assuming the person's sexual orientation even before puberty (Chase, 2013; Fausto-Sterling, 2000; Griffiths, 2018; Svoboda, 2013).

Legally, the importance TBs give to the consequences of IGS could be related to the way international law understands 'permissible' infringements of human rights as opposed to those that are not tolerated or are unjustifiable, as well as the distinction that comes from drawing the line between abuse and a violation to the prohibition of cruel, inhumane, degrading treatment or torture (Bauer et al., 2020; De Vos, 2007; *M v France*, 2022; Nowak, 2012). Understanding the prolonged and harmful effects of IGS helps sustain the claim that this medical practice should not be permitted under international law standards without the full informed consent of the person undergoing these procedures.

Conclusions

In this work, I have tried to demonstrate that there has been an increasing visibility of intersex issues and awareness of the human rights violations that intersex people face within international human rights monitoring bodies. Using the case of the United Nations treaty bodies I have shown that increasingly UN TBs are echoing activists' demands and bringing visibility to these demands as human rights violations in the international fora.

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report of the United Kingdom of Great Britain and Northern Ireland. 12 July 2016, CRC/C/GBR/CO/5, Committee against Torture Concluding observations on the sixth periodic report of the United Kingdom of Great Britain and Northern Ireland. 7 June 2019. CAT/C/GBR/CO/6.

[56] See for example: Committee against Torture. Concluding observations on the combined sixth and seventh periodic reports of Denmark. 4 February 2016. CAT/C/DNK/CO/6-7, Committee on Economic, Social and Cultural Rights. Concluding observations on the fifth periodic report of Belgium. 26 March 2020. E/C.12/BEL/CO/5, Committee against Torture. Concluding observations on the seventh periodic report of France. 10 June 2016. CAT/C/FRA/CO/7, Committee on the Elimination of Discrimination against Women. Concluding observations on the combined seventh and eighth periodic reports of Germany. 9 March 2017. CEDAW/C/DEU/CO/7-8, Committee on the Rights of the Child. Concluding observations on the combined third and fourth periodic reports of Ireland. 1 March 2016. CRC/C/IRL/CO/3-4, Committee on the Elimination of Discrimination against Women. Concluding observations on the combined sixth and seventh periodic reports of Luxembourg.

To sum up my findings, results show a total of 41 intersex substantive recommendations and an equal number of reports directed towards 18 European countries; out of these, 38 recommendations speak about IGS, with the earliest record made in 2015. Notwithstanding these numbers, as stated above, only five European countries have legal regulations in place protecting intersex people from medically unnecessary genital surgeries, showing a worrying tendency to non-implementation of the UN TBs' recommendations.

My findings also indicate that from 2009 until 2017 there was an increase in the number of observations, concerns, and recommendations regarding intersex human rights made public by treaty bodies. Some treaty bodies like the Committee on the Elimination of Discrimination Against Women have notably raised the visibility of intersex issues amongst TBs, raising concerns about IGS under the 'harmful practices' section of their reports.

While most recommendations that mention 'intersex' concerned general human rights and topics such as the prevention of violence or discrimination concerns, other substantive issues raised by intersex activists such as IGS, autonomy and agency claims, demands for redress and reparations, and claims for support mechanisms are also gaining visibility. Indeed, some treaty bodies are starting to gather segregated data about the situation of intersex rights and have included an 'intersex-specific' section in the body of their reports. This can be seen as a positive development, as TBs would likely follow up on the progress or challenges of the reviewed country. Likewise, my findings indicate that while most recommendations that consider intersex issues are still grouped together with other groups of people, notably LGBT persons or considered as part issue-based recommendations, for example, those concerning the 'right to health' or 'harmful practices', this grouping does not mean that intersex specific concerns such as IGS are not given visibility.

While my findings show there is a limited explicit use of the 'mutilation' frame by UN TBs, the analysis of IGS, particularly by the CEDAW committee, under the lens of 'harmful practices' and often grouping IGS with female genital cutting or female genital mutilation concerns indicates to me that there is an understanding of activists' concerns while perhaps only a partial recognition of them. As stated above, this might also be a strategy by the UN TBs not to 'polarise' the issue.

When looking specifically at how treaty bodies understand intersex genital surgery as a human rights violation, I discovered that issues regarding the necessity, temporality, and consequences of IGS are highlighted by TBs noticeably echoing activists' claims of how different aspects of IGS as a practice are harmful for intersex people. To protect intersex persons from violations to their bodily integrity, activist groups such as OII Europe and ILGA Europe have recommended "the creation of a law that protects a person from any non-emergency interventions on the person's sex characteristics until the person is mature enough to express, if they want, their wish for surgical or other medical intervention and provide informed consent. Such legislation is the only way to stop the violation of the bodily integrity of intersex people and ensure their right to self-determination" (Ghattas, 2019, p. 15). This recommendation is also echoed by many treaty bodies when dealing with the topic of IGS.

Regarding the future, my research shows that while some of intersex activists' demands seem to have found an echo with treaty bodies at the institutional level, such as IGS as a rights violation, there are still some demands that remain less visible if not invisible altogether. Issues concerning general societal awareness of intersex issues and access to comprehensive information about being intersex—perhaps better achieved via educational approaches and policies—remain to be appropriately considered by the UN TBs. Other harmful practices such as forced sterilisations, prenatal screenings, and selective abortions have so far been ignored in official human rights documents, as well as the recognition of damages caused by pathologising approaches towards intersex people's bodies.

Likewise, there seems to be a failure between treaty bodies' recommendations to guarantee intersex people's rights, particularly those pertaining to the prohibition of medically unnecessary genital surgery, and implementation at the state level. In my analysis of the European data, for instance, I discovered that 18 European countries have received recommendations concerning IGS, with the earliest record made in 2015. According to the FRA (2015), however, only four (now five) European countries have legal regulations in place protecting intersex people from unnecessary surgical 'normalising' treatments.[57] While complying with UN TBs recommendations is voluntary for treaty member states, this shows a worrying tendency to non-implementation of the UN TBs recommendations. Like Garland and Travis (2020a), I also must note that the lack of successful follow-up and implementation of the UN TBs' recommendations does not mean this strategy should be abandoned. Activists from all causes, including intersex rights activists, use these bodies recommendations to strengthen their arguments at the domestic level, in what is known as the boomerang effect and in order to push for change. However, activists also need to be aware at the limitations of the UN system and its non-binding nature, as well as the general limitations of international human rights (soft) law (Mechlem, 2009; O'Flaherty, 2006). Actions that focus on multiple arenas or "interscalar" (Garland et al., 2022, p. 22) strategies (that are indeed happening) are needed in other to go from visibility to substantive change and rights recognition at the domestic level.

Overall, I believe a comprehensive understanding of how activists' claims resonate and are echoed by human rights institutions is helpful for social movements when designing tactics and creating strategies aimed at increasing visibility, especially if resources are scarce and some issues need to be prioritised. For institutions and relevant stakeholders, having this kind of information might lead to internal reflections on the work that still needs to be done, especially regarding claims that remain unheard or unaddressed. This research piece has tried to do just that and provide a view of the trajectory of the visibility of intersex issues within the documents of the UN treaty bodies with the aim of supporting intersex people's rights realisation through empirical evidence.

References

Allendoerfer, M. G., Murdie, A., & Welch, R. M. (2020). The path of the boomerang: Human Rights campaigns, third-party pressure, and human rights. *International Studies Quarterly*, *64*(1), 111–119. doi:10.1093/ISQ/SQZ082.

Ammaturo, F. R. (2016). Intersexuality and the 'right to bodily integrity'. *Social & Legal Studies*, *25*(5), 591–610. doi:10.1177/0964663916636441.

Battaglino, V. L. (2019). Intersexualidad: un análisis crítico de las representaciones socioculturales hegemónicas de los cuerpos y las identidades. *Methaodos. Revista de Ciencias Sociales, 7(1)*, 41–54. doi:10.17502/m.rcs.v7i1.275.

Bauer, M., Truffer, D., & Crocetti, D. (2020). Intersex human rights. *International Journal of Human Rights*, *24*(6), 724–749. doi:10.1080/13642987.2019.1671354.

Benford, R. D., & Snow, D. A. (2000). Framing processes and social movements: An overview and assessment. *Annual Review of Sociology*, *26*, 611–639. doi:10.1146/ANNUREV.SOC.26.1.611.

Berry, A. W., & Monro, S. (2022). Ageing in obscurity: a critical literature review regarding older intersex people. *Sexual and Reproductive Health Matters*, *30*(1). doi:10.1080/26410397.2022.2136027.

Carpenter, M. (2015). *Intersex and ageing*. https://morgancarpenter.com/intersex-and-ageing/

Carpenter, M. (2016). The human rights of intersex people: addressing harmful practices and rhetoric of change. *Reproductive Health Matters*, *24*(47), 74–84. doi:10.1016/j.rhm.2016.06.003.

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[57] Now 5 countries considering the most recent developments in Greece.

Chase, C. (2013). Hermaphrodites with attitude: Mapping the emergence of intersex political activism. In S. Stryker & S. Whittle (Eds.), *The Transgender Studies Reader* (pp. 300–314). Routledge. doi: 10.4324/9780203955055.

Council of Europe [Coe]. (1997). *Convention for the protection of Human Rights and dignity of the human being with regard to the application of biology and medicine: Convention on human rights and biomedicine. (Oviedo Convention), opened for signature on 4 April 1997.* https://www.coe.int/en/web/bioethics/oviedo-convention

Council of Europe's Commissioner for Human Rights. (2015). *Human rights and intersex people. Issue paper*. https://rm.coe.int/16806da5d4

Collister, H., Helm, T., Patel, P., & Starrenburg, O. (Eds.). (2015). *A simple guide to the UN treaty bodies.* International Service for Human Rights.

Creighton, S. M., Minto, C. L., & Steele, S. J. (2001). Objective cosmetic and anatomical outcomes at adolescence of feminising surgery for ambiguous genitalia done in childhood. *The Lancet*, *358*(9276), 124–125. doi:10.1016/S0140-6736(01)05343-0.

Crocetti, D., Arfini, E. A. G., Monro, S., & Yeadon-Lee, T. (2020). 'You're basically calling doctors torturers': stakeholder framing issues around naming intersex rights claims as human rights abuses. *Sociology of Health & Illness*, *42*(4), 943–958. doi:10.1111/1467-9566.13072.

D'Amico, F. (2015). LGBT and (Dis)United Nations: Sexual and gender minorities, international law, and UN politics. In M. Lavinas Picq & M. Thiel (Eds.), *Sexualities in World Politics* (pp. 54–74). Routledge. doi:10.4324/9781315743721-4.

Davis, G. (2014). The power in a name: diagnostic terminology and diverse experiences. *Psychology and Sexuality*, *5*(1), 15–27. doi:10.1080/19419899.2013.831212.

De Vos, C. M. (2007). Mind the Gap: Purpose, pain, and the difference between torture and inhuman treatment. *Human Rights Brief*, *14*(2), 4-10.

Dondoli, G. (2015). LGBTI activism influencing foreign legislation. *Melb. J. Int'l L.*, *16*, 124-144.

Dreger, A. D., & Herndon, A. M. (2009). Progress and politics in the intersex rights movement feminist theory in action. *GLQ*, *15*(2), 199–200. doi:10.1215/10642684-2008-134.

European Union Agency for Fundamental Rights [FRA]. (2015). *The fundamental rights situation of intersex people.* https://fra.europa.eu/en/publication/2015/fundamental-rights-situation-intersex-people

European Parliament. Resolution of 14 February 2019 on the Rights of Intersex People. 2018/2878(RSP). OJ C 449/142. https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=CELEX%3ª52019IP0128

Fausto-Sterling, A. (2000). *Sexing the body: Gender politics and the construction of sexuality*. Basic Books.

Ferree, M. M. (2003). Resonance and Radicalism: Feminist Framing in the Abortion Debates of the United States and Germany. *American Journal of Sociology*, *109*(2), 304–344. Doi:10.1086/378343.

Fraser, S. (2016). Constructing the female body: using female genital mutilation law to address genital-normalizing surgery on intersex children in the United States. *International Journal of Human Rights in Healthcare*, *9*(1), 62–72. Doi:10.1108/IJHRH-05-2015-0014/FULL/XML.

Gaer, F. D. (2003). Implementing international human rights norms: UN human rights treaty bodies and NGOs. *Journal of Human Rights*, *2*(3), 339–357. Doi:10.1080/1475483032000133024.

Gardner, M., & Sandberg, D. E. (2018). Navigating surgical decision making in disorders of sex development (DSD). *Frontiers in Pediatrics*, *6*, 339. Doi:10.3389/fped.2018.00339.

Garland, F., & Travis, M. (2020a). Temporal bodies: Emergencies, emergence, and intersex embodiment. In C. Dietz, M. Travis and M. Thomson. (Eds.), *A jurisprudence of the body* (pp. 119–47). Palgrave Macmillan.

Garland, F., & Travis, M. (2020b). Making the state responsible: Intersex embodiment, medical jurisdiction, and state responsibility. *Journal of Law and Society*, *47*(2), 298–324. Doi:10.1111/JOLS.12223.

Garland, F., Lalor, K., & Travis, M. (2022). Intersex activism, medical power/knowledge and the scalar limitations of the United Nations. *Human Rights Law Review*, *22*(3). Doi:10.1093/HRLR/NGAC020.

Ghattas, D. C. (2019). *Protecting intersex people in Europe: a toolkit for law and policymakers*. ILGA Europe, & OII Europe. https://www.oiieurope.org/protecting-intersex-people-in-europe-a-toolkit-for-law-and-policy-makers/

Ghattas, D. C., Kromminga, I. A., Kuzemko, I., Anderson, K., & Aegerter, A. (Eds.) (2019). *#MyIntersexStory. Personal accounts by intersex people living in Europe.* OII Europe. https://www.oiieurope.org/wp-content/uploads/2019/11/testimonial_broch_21-21cm_for_web.pdf

Grabham, E. (2007). Citizen bodies, intersex citizenship. *Sexualities*, *10*(1), 29–48. Doi:10.1177/1363460707072951.

Griffiths, D. A. (2018). Diagnosing sex: Intersex surgery and 'sex change' in Britain 1930-1955. *Sexualities*, *21*(3), 476–495. Doi:10.1177/1363460717740339.

Hegarty, P., Prandelli, M., Lundberg, T., Liao, L.-M., Creighton, S., & Roen, K. (2021). Drawing the line between essential and nonessential interventions on intersex characteristics with European health care professionals. *Review of General Psychology*, *25*(1), 101–114. Doi:10.1177/1089268020963622.

Hughes, I. A., Houk, C., Ahmed, S. F., Lee, P. A., & Lawson, W. (2006). Consensus statement on management of intersex disorders. *Journal of Pediatric Urology*, *2*(3), 148–162. Doi:10.1016/j.jpurol.2006.03.004.

Inter-American Commission on Human Rights [IACHR]. (2015). *Violence against lesbian, gay, bisexual, trans and intersex persons in the Americas*. http://www.oas.org/en/iachr/reports/pdfs/violencelgbtipersons.pdf

Intersex Human Rights Australia [IHRA], (n.d.) *Public submissions*. https://ihra.org.au/category/articles/submissions/

Intersex Human Rights Australia [IHRA] (2019a). *Press release (24 July 2019) "Shadow report submission to the UN CRPD".* https://ihra.org.au/35529/shadow-report-crpd-2019

Intersex Human Rights Australia [IHRA] (2019b). *Press release (11 June 2019) "Shadow report submission to the Committee on the Elimination of Discrimination against Women" (2018).* https://ihra.org.au/32166/shadow-report-submission-cedaw/

Intersexrights.org (n.d.) Webpage. *NNID Foundation, Netherlands organisation for sex diversity*. https://intersexrights.org/

Joachim, J. (2003). Framing issues and seizing opportunities: The UN, NGOs, and women's rights. *International Studies Quarterly*, *47*(2), 247–274. doi:10.1111/1468-2478.4702005.

Johnstone, R. L. (2006). Feminist influences on the United Nations human rights treaty bodies. *Human Rights Quarterly*, *28*(1), 148–185.

Jones, T. (2018). Intersex studies: A systematic review of international health literature. *SAGE Open*, *8*(2), 215824401774557. doi:10.1177/2158244017745577.

Keck, M. E., & Sikkink, K. (2018). Transnational advocacy networks in international and regional politics. *International Social Science Journal*, *68*(227–228), 65–76. doi:10.1111/issj.1218.

Köhler, B., Kleinemeier, E., Lux, A., Hiort, O., Grüters, A., Thyen, U., & DSD Network Working Group. (2012). Satisfaction with genital surgery and sexual life of adults with xy disorders of sex development: results from the German clinical evaluation study. *The Journal of Clinical Endocrinology & Metabolism*, *97*(2), 577–588. doi:10.1210/JC.2011-1441.

Kreukels, B.P., Cohen-Kettenis, P.T., Roehle, R., van de Grift, T.C., Slowikowska-Hilczer, J., Claahsen-van der Grinten, H., Lindén Hirschberg, A., de Vries, A.L., Reisch, N., Bouvattier, C., Nordenström, A., Thyen, U., and Köhler, B., on behalf of The Dsd-Life Group (2019). Sexuality in Adults with Differences/Disorders of Sex Development (DSD): Findings from the dsd-LIFE Study. *Journal of Sex & Marital Therapy*, *45*(8), 688–705. doi:10.1080/0092623X.2019.1610123.

Latham, J. R., & Barrett, C. (2015). Appropriate bodies and other damn lies: Intersex ageing and aged care. *Australasian Journal on Ageing*, *34 Suppl 2*, 19–20. doi:10.1111/AJAG.12275.

Lee, P. A, Nordenström, A., Houk, C. P., Ahmed, S. F., Auchus, R., Baratz, A., Baratz Dalke, K., Liao, L.M., Lin-Su, K., Mazur, T. and Meyer-Bahlburg, H. F., Mouriquand, P., Quigley C. A., Sandberg, D. E., & Witchel, S. (2016). Global disorders of sex development update since 2006: Perceptions, approach and care. *Hormone Research in Paediatrics*, *85*(3), 158–180. doi:10.1159/000442975.

Lee, P. A., Schober, J., Nordenström, A., Hoebeke, P., Houk, C., Looijenga, L., Manzoni, G., Reiner, W. & Woodhouse, C., (2012). Review of recent outcome data of disorders of sex development (DSD): Emphasis on surgical and sexual outcomes. *Journal of Pediatric Urology*, *8*(6), 611–615. doi:10.1016/J.JPUROL.2012.10.017.

Lundberg, T., Hegarty, P., & Roen, K. (2018). Making sense of 'Intersex' and 'DSD': how laypeople understand and use terminology. *Psychology and Sexuality*, *9*(2), 161–173. doi:10.1080/19419899.2018.1453862.

M v. France. Eur. Ct. H.R 42821/18. (2022).

Mechlem, K. (2009). Treaty bodies and the interpretation of human rights. *Vanderbilt Journal of Transnational Law* 42: 905.

Meoded Danon, L. (2018). Time matters for intersex bodies: Between socio-medical time and somatic time. *Social Science and Medicine*, *208*, 89–97. doi:10.1016/j.socscimed.2018.05.019.

Meoded Danon, L. (2019). Comparing contemporary medical treatment practices aimed at intersex/DSD bodies in Israel and Germany. *Sociology of Health & Illness*, *41*(1), 143–164. doi:10.1111/1467-9566.12812.

Monro, S., Crocetti, D., & Yeadon-Lee, T. (2019). Intersex/variations of sex characteristics and DSD citizenship in the UK, Italy and Switzerland. *Citizenship Studies*, *23*(8), 780–797. doi:10.1080/13621025.2019.1645813.

Mulé, N. J. (2018). LGBTQI-identified human rights defenders: courage in the face of adversity at the United Nations. *Gender and Development*, *26*(1), 89–101. doi:10.1080/13552074.2018.1429099.

Nowak, M. (2012). What's in a name? The prohibitions on torture and ill treatment today. In C. Gearty & C. Douzinas (Eds.), *The Cambridge Companion to Human Rights Law* (pp. 307–328). Cambridge University Press. doi:10.1017/CCO9781139060875.022.

O'Flaherty, M. (2006) The Concluding observations of United Nations human rights treaty bodies. *Human Rights Law Review,* 6: 27–52.

Office of the United Nations High Commissioner for Human Rights [OHCHR]. (2017). *Reporting to the United Nations human rights treaty bodies training guide. Part I.* https://www.ohchr.org/en/publications/ohchr-training-package-reporting-united-nations-human-rights-treaty-bodies

Office of the United Nations High Commissioner for Human Rights [OHCHR]. (2019). *Background note on human rights violations against intersex people*. https://www.ohchr.org/en/documents/tools-and-resources/background-note-human-rights-violations-against-intersex-people

OII Europe (2015). *Press release: "30th session of the UN Human Rights Council intersex side event".* https://www.oiieurope.org/30th-session-of-the-un-human-rights-council-intersex-side-event/

OII Europe (2020). *List of intersex specific shadow reports to UN committees from CoE Region and from countries monitoring the CoE Region*. https://www.oiieurope.org/wp-content/uploads/2018/09/List-of-intersex-specific-shadow-reports-to-UN-committees-OII-Europe-June_2020.pdf

OII Europe (2021). *Intersex Genital Mutilation.* https://www.oiieurope.org/igm/

Parliamentary Assembly of the Council of Europe [PACE] (2017). Resolution 2191 (2017). Promoting the Human Rights of and eliminating Discrimination against Intersex People. Text adopted by the Assembly on 12 October 2017. https://assembly.coe.int/nw/xml/XRef/Xref-XML2HTML-en.asp?fileid=24232

Ravesloot, S. (2021). The universal periodic review beyond the binary advancing the rights of persons with variations in sex characteristics. *Papers of 8th International Conference on Gender & Women Studies.*

Reis, E. (2007). Divergence or disorder?: The politics of naming intersex. *Perspectives in Biology and Medicine*, *50*(4), 535–543. doi:10.1353/pbm.2007.0054

Rubin, D. A. (2012). "An unnamed blank that craved a name": A genealogy of intersex as gender. *Signs: Journal of Women in Culture and Society*, *37*(4), 883–908. doi:10.1086/664471.

Rubin, D. A. (2015). Provincializing intersex: US intersex activism, human rights, and transnational body. *Frontiers: A Journal of Women Studies*, *36*(3), 51–83. doi:10.5250/fronjwomestud.36.3.0051.

Schneider, E. (2013). *An insight into respect for the rights of trans and intersex children in Europe.* Intersex & Transgender Luxembourg a.s.b.l.

Schweizer, K., Brunner, F., Handford, C., & Richter-Appelt, H. (2014). Gender experience and satisfaction with gender allocation in adults with diverse intersex conditions (divergences of sex development, DSD). *Psychology and Sexuality*, *5*(1), 56–82. doi:10.1080/19419899.2013.831216

Snow, D. A., Rochford, E. B., Worden, S. K., & Benford, R. D. (1986). Frame alignment processes, micromobilization, and movement participation. *American Sociological Review*, *51*(4), 464. doi:10.2307/2095581.

Stop IGM (n.d.-a). *What is IGM?* https://stopigm.org/what-is-igm/

Stop IGM (n.d.-b). *About the NGO*. https://stopigm.org/about-us/about-the-ngo/

Suess Schwend, A. (2018). Derechos de las personas trans e intersex: Revisión del marco legislativo en el contexto español desde una perspectiva de despatologización y derechos humanos. *Revista Derecho y Salud*, *28* (Extraordinario 1), 97–115.

Svoboda, S. J. (2013). Promoting genital autonomy by exploring commonalities between male, female, intersex, and cosmetic female genital cutting. *Global Discourse*, *3*(2), 237–255. doi:10.1080/23269995.2013.804757.

The Third International Intersex Forum. (2013). *Malta Declaration. Public Statement by the Third International Intersex Forum*. https://www.oiieurope.org/public-statement-by-the-third-international-intersex-forum/

Travis, M. (2015). Accommodating intersexuality in European Union anti-discrimination law. *European Law Journal*, *21*(2), 180–199. doi:10.1111/eulj.12111

United Nations, General Assembly. (1989). Convention on the Rights of the Child, 20 November 1989*.* https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-rights-child

United Nations. Committee on Economic, Social and Cultural Rights (2019). Concluding observations on sixth periodic report of Denmark. E/C.12/DNK/CO/6 (Nov. 12, 2019). https://www.ohchr.org/en/documents/concluding-observations/ec12dnkco6-committee-economic-social-and-cultural-rights

Vance, K., Mulé, N. J., Khan, M., & McKenzie, C. (2018). The rise of SOGI: human rights for LGBT people at the United Nations. In N. Nicol, R. Lusimbo, N. J. Mulé, A. Jjuuko, S. Ursel, A. Wahab, & P. Waugh (Eds.), *Envisioning Global LGBT Human Rights: (Neo)colonialism, Neoliberalism, Resistance and Hope.* (pp. 223–245). University of London. doi:10.14296/818.9780993110283

Waites, M. (2019). Decolonizing the boomerang effect in global queer politics: A new critical framework for sociological analysis of human rights contestation. *International Sociology*, *34*(4), 382–401. doi:10.1177/0268580919851425

Winter Pereira, L. (2022). Intersex legal activism. United Nations on the human rights of intersex people. *The Age of Human Rights Journal*, *18*(18), 181–197. doi:10.17561/TAHRJ.V18.7047

Zillén, K., Garland, J., & Slokenberga, S. (2017). *The rights of children in biomedicine: Challenges posed by scientific advances and uncertainties.* Committee on Bioethics of the Council of Europe.

Author's Biographies

Daria Abrosimova earned a degree in sociology from Moscow State Lomonosov University. Afterwards, she pursued a career in marketing research, working as a research expert in the pharmaceutical and financial industries. Simultaneously, she acted as a human rights activist and later co-founded her initiative. She educated medical professionals on working with intersex people and continues to pursue projects to improve medical care for intersex people in Russia. Since September 2020, she has been pursuing a 36-month Marie Skłodowska Curie fellowship and PhD at the Institute of Biomedical Ethics and History of Medicine at the University of Zurich, focusing on parental decision-making in clinical settings.

Audrey Aegerter is a PhD student who, after completing her master's degree in children's rights studies at the Université de Genève, joined the INIA project and the Université Libre de Bruxelles team in March 2021. Her doctoral research focuses on sociology, specifically the sociology of social movements. She is investigating the emergence of intersex activism in Europe, with a particular emphasis on individual trajectories to intersex activism in Belgium and Germany. Additionally, she serves as a board member of the French-speaking Intersex Research Network (RéFri).

Camino Baró is a clinical psychologist and sexologist specialising in systemic therapy, providing support to the LGBTQIAQ+ community. She is the secretary of the Intersex Association KALEIDOS, an organisation advocating for bodily diversity in Spain. Additionally, she is a member of GRAPSIA (Androgen Insensitivity Support Group and Related Conditions), actively involved in advocating for the rights of intersex individuals. She has authored a children's book, "A Redheaded Secret", published by Editorial Bellaterra. She is engaged as a first-person activist for intersex rights, participating in informative workshops across various national Spanish universities, international institutions, and media.

Adeline Berry is a transgender and intersex research fellow at the University of Huddersfield. Their PhD research explored the experiences and needs of older European intersex people. They are chair of Intersex Ireland and a board member of the Sex Work Research Hub and the Irish Sex Work Research Network. They have authored peer-reviewed papers and book chapters on older intersex people as well as on sex work and have spoken on both subjects internationally. In 2021, their artwork was included in Berlin's Schwulesmuseum's first intersex-themed art show, Mercury Rising: Inter Herm*story[ies] Now and Then, which can be seen in the 2023 film Every Body, from Focus Features. They live in Manchester with their wife, Leea.

Somya Dixit is a human rights activist and researcher in Ireland. She received her LLM in international human rights from the University of Leeds, UK. Over the past decade, she has actively engaged in various human rights advocacy work in both Asian and European contexts, dedicating the last four years to advocating for intersex rights. Currently pursuing her PhD in law at Dublin City University, Somya's research is titled "Realising Rights: Framing Legislative and Policy Reform to Improve the Lived Experience of Intersex in Ireland and Malta." She commenced her 24-month Marie Skłodowska Curie fellowship at DCU in February 2022.

Mel Duffy is associate professor in sociology and sexuality studies based at Dublin City University. She is a national and international expert in hermeneutic phenomenology and the co-author of *Doing Hermeneutic Phenomenological Research: A Practical Guide* (SAGE 2020). Her work focuses on LGBTQI+ experiences of living the lives they find themselves in, writing and presenting on lesbian health and healthcare, coming out, relationship and sexuality education, disability, identity, residential care, homecare, and experiences of health outcomes.

Martin Gramc is a researcher in gender and sexual minority studies from Slovenia. Gramc received his PhD in bioethics from the University of Zürich and their MA in gender studies from the University of Ljubljana. During the past five years, theey have actively participated in LGBTI+ organisations and campaigns at home, in Croatia, and in Germany (Berlin), where they also collaborated with feminist and migrant initiatives. As a researcher, Martin has been collaborating with the Peace Institute in Ljubljana, working on projects centred around migrant issues, LGBTIQ+ minorities, and topics in political philosophy. Martin commenced a 34-month Marie Skłodowska Curie fellowship at the University of Zurich in Switzerland in January 2021 and finished it in December 2023.

Yessica Mestre Martínez finished her bachelor's degree in law at the Universidad de Santo Tomás, Colombia and began to work in an NGO, building projects for the re-socialisation of victims of the Colombian armed conflict and the recognition of the LGBTI population as independent victims of this conflict. Following this, she worked at the Colombian Ministry of Public Affairs, creating public policy for the LGBTI community, which included the particular needs of the intersex population. Yessica also worked at the Ministry of Agriculture of Colombia protecting the human rights of the indigenous population. She then moved to Budapest to study for a master's in international relations to understand intersex causes in Europe better. Yessica commenced her 36-month Marie Skłodowska Curie fellowship at *Escuela Andaluza de Salud Pública* in Spain in January 2021.

Surya Monro is a sociology and social policy professor based at Loughborough University, UK. Surya has published substantially in the fields of gender and sexuality, notably on LGBT and intersex issues. She is the author of *Gender Politics: Citizenship, Activism, and Sexual Diversity* (Pluto Press 2005) co-author of *Sexuality, Equality and Diversity* (Palgrave MacMillan, 2012), author of *Bisexuality* (Palgrave MacMillan, 2015), co-author of *Intersex, Variations if Sex Characteristics and DSD: The Need for Change* (University of Huddersfield 2017) and co-editor of *Queer in Africa* (Routledge 2018). She leads the Intersex: New Interdisciplinary Approaches project (INIA) in collaboration with intersex activists and academics.

Marisela Montenegro is a psychologist from the Universidad Central de Venezuela. She is a lecturer in the Department of Social Psychology at the Universitat Autònoma de Barcelona. Her research focuses on the critical and decolonial analysis of research, teaching, and social work in social services for migrant women, social movements, disability, collective memory, and the social construction of gender and sexuality. She has recently coordinated the European project "Building Inclusive Societies: Diversifying Knowledge and Tackling Discrimination through Civil Society Participation in Universities". She currently leads the UAB Team within the European Commission's Marie Skłodowska-Curie Actions program: "Intersex - New Interdisciplinary Approaches" (INIA).

Tanya Ni Mhuirthile is an associate professor of law at Dublin City University. Her research interrogates the interaction between the body and law and draws on human rights law, medical law, law & gender theory, and feminist jurisprudence. She has advised government ministers, public representatives, civil and public servants, and many NGOs, nationally and internationally, on drafting legislation and developing public policy in relation to her areas of interest. Tanya was the PI on the Irish Research Council-funded project *Mapping the Lived Experiences of Intersex/Variations of Sex Characteristics in Ireland: Contextualising Lay and Professional Knowledge to Enable Development of Appropriate Law and Policy* (IRC Coalesce 2019/156) and is the DCU lead on the European Commission funded project INIA: Intersex - New Innovative Approaches (MSCA ITN 859869).

Lucas Platero is a trans activist who is an associate professor in social psychology at the Rey Juan Carlos University (URJC) and the Director of University Publications at Bellaterra Publishing House. In 2020, Platero was awarded the Emma Goldman Prize for supporting new feminist knowledge in Europe. His activism and research activity focuses on the intersections of sexuality, gender, disability, memory, and pedagogy, areas in which Platero has published extensively. His latest participation in EU-funded projects includes his leadership in the URJC with the Colourful Childhoods (CERV-2021-DAPHNE, 2022-24) and as a researcher at INIA, Intersex – New Interdisciplinary Approaches (2020-24), Horizon 2020 Marie Sklodowska-Curie Actions.

Joan Pujol-Tarrés is a senior lecturer at the Department of Social Psychology at the Universitat Autònoma de Barcelona. He worked as a lecturer at the University of Huddersfield (UK, 1996-97), did research at the University of Reading as a post-doctoral honorary visiting fellow with a Batista i Roca Scholarship (UK, 1994-95), and received the National Prize in Social Sciences from the 'La Caixa' Foundation for the work *Non-delinquents: how citizens understand criminality* (1993-94). Joan participates in LGBTI activism, has been a member of the *Catalan Gay Liberation Front* (FAGC) since 1998, and was heavily involved in Barcelona's queer movement of the '00s. Current areas of research include parenthood and disability (*Social Inclusion*, with Sanmiquel-Molinero and Montenegro-Martínez, 2023); Narrative Productions (*Qualitative Research in Psychology*, 2023); postcolonial social intervention (*Critical and Radical Social Work*, with Montenegro-Martínez, 2022); and trans-activism (*Critical Social Policy*, with Espejo and Aljama, 2020).

Sean Saifa Wall is a Black, queer, intersex activist and rising scholar. Born and raised in the Bronx, New York, Wall attended Williams College, where he received a Mellon Mays Undergraduate Fellowship to research topics such as *The Social Origins of Hip Hop* and *Black middle-class gentrification in Harlem*. Since graduating from Williams, Wall has worked on a number of research projects that amplify the voices of queer, transgender, and people of colour populations. Currently, Wall is a Marie Skłowdoska-Curie fellow and PhD candidate at the University of Huddersfield in England, examining the erasure of intersex people from social policy in Ireland and England.

John Stephenson is a reader (associate professor) of biomedical statistics at the University of Huddersfield, United Kingdom (2010—present date). He has also worked as a visiting research fellow at several universities in Australia, where he currently holds honorary appointments. Stephenson has ten years' experience as a mathematical/statistical modeller in the UK nuclear industry. Stephenson works collaboratively with clinicians in academia, industry, and health services across various biomedical, clinical, and social science contexts, contributing to study design, data analysis, and interpretation using advanced statistical methodologies. Stephenson has co-authored over 160 Scopus-index publications and is an editorial board member of several academic journals.

Jürg Streuli is the designated head of the Foundation Dialogue Ethics (Stiftung Dialog Ethik), Zurich and co-head of the Pediatric Advanced Care Team at the Children's Hospital of Eastern Switzerland. Since 2010, he has been actively publishing and teaching bioethics, notably specialising in issues related to intersex and variations of sex conditions (VSC). As an expert for the Swiss National Advisory Commission on Biomedical Ethics NEK-CNE, Streuli contributed to developing ethical principles and recommendations. In 2023, Streuli co-founded VARIA, an initiative dedicated to advancing understanding and advocacy for intersex rights and medical ethics, focusing on implementing a holistic, non-medicalised approach to support individuals with VSC and their families.

Amets Suess Schwend holds a PhD in social anthropology, an MA in art therapy and an MA/BA in sociology. They work in research and teaching at the Andalusian School of Public Health *(Escuela Andaluza de Salud Pública, EASP),* Granada, Spain. Their recent publications focus on intersex and trans studies, human rights, de-pathologisation, and research epistemologies, methodologies, and ethics. They participate in international and European projects, working groups and networks related to intersex and trans studies, human rights and de-pathologisation. They currently lead the EASP team within the Innovative Training Network INIA: Intersex – New Interdisciplinary Approaches, funded by the European Commission's Marie Skłodowska-Curie Actions programme, supervising the PhD theses of two INIA researchers at the University of Granada.

Ernesto Zelayandía-González is a citizen of El Salvador; he started his 36-month Marie Skłodowska Curie fellowship in Spain in January 2021 as an early career researcher at *Escuela Andaluza de Salud Pública* and PhD candidate at the University of Granada. Ernesto holds an LLB from the Central American University in San Salvador and an LLM in human rights from the Central European University in Budapest. He also has an MSc in human rights and politics from the London School of Economics and Political Sciences in London. Ernesto has also worked as a fellow for the Human Rights Campaign and as a legal fellow for the Rapporteurship on the rights of LGBTI persons at the Inter-American Commission on Human Rights.