social sciences

Special Issue Reprint

Centring Intersex

Global and Local Dimensions

Edited by
Surya Monro, Tanya Ni Mhuirthile, Amets Suess-Schwend, Fae Garland,
Daniela Crocetti, David Andrew Griffiths and Katrina Roen

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This is a reprint of articles from the Special Issue published online in the open access journal *Social Sciences* (ISSN 2076-0760) (available at: https://www.mdpi.com/journal/socsci/special_issues/431WJN8HZ5).

For citation purposes, cite each article independently as indicated on the article page online and as indicated below:

Lastname, Firstname, Firstname Lastname, and Firstname Lastname. Article Title. *Journal Name* **Year**, *Volume Number*, Page Range.

ISBN 978-3-7258-2619-3 (Hbk)
ISBN 978-3-7258-2620-9 (PDF)
doi.org/10.3390/books978-3-7258-2620-9

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Editorial

Editorial Introduction to Centring Intersex Issues: Global and Local Dimensions

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This Special Issue showcases the expanding body of international scholarly work within intersex studies. Intersex studies is an interdisciplinary field of scholarship that critically examines and challenges societal norms, medical practices, legal premises, and cultural assumptions surrounding innate variations of sex characteristics (VSCs). This field goes beyond medical definitions of intersex bodily variations, exploring the social, cultural, and political dimensions of intersex experiences (Monro et al. 2021). Instead of concentrating on defining intersex, this expanding body of research addresses the issues that intersex people encounter; these encompass systematic oppression, discrimination, and violations of human rights (Ghattas 2013; FRA 2015; Carpenter 2016). With this Special Issue, we also explore the strategies employed for addressing these challenges (Preves 2005; Crocetti et al. 2020). Providing a non-medical social framing, in 2016, Miriam van der Have stated that "intersex variations are not an abnormality or disease. Intersex refers to the lived experience of the socio-cultural consequences of being born with a body that does not fit within the normative definitions of 'man' and 'woman'. In short, it is about our experiences and not a medical diagnosis" (van Heesch 2016, n.p.; own translation). As not all people with variations of sex characteristics identify with the term intersex, throughout the editorial we will use both 'intersex people' and 'people with VSCs'.

Intersex studies builds on the intersections between academic research, activism, and community advocacy, seeking a co-production of knowledge to deconstruct stigmatising narratives and contribute to broader discourses on bodily autonomy. Drawing on the early work of Kessler (1998), Dreger (1998), Chase (1998), and Fausto-Sterling (2000), the field has expanded to address a range of issues such as the impact of medical interventions (Carpenter 2018; Berry and Monro 2022), the construction of pathology (Cabral Grinspan and Benzur 2005; Griffiths 2018), avenues for legal and social change (Garland and Travis 2018; Pikramenou 2019), the human rights violations faced by intersex individuals (Carpenter 2016, 2018, 2021b; Bauer et al. 2020), rights mobilisation (Chase 1998; Preves 2005; Crocetti et al. 2020), psychosocial healthcare (Roen 2019; Crocetti et al. 2021b, 2023; Gramc et al. 2024), and societal perspectives on intersex issues (Lundberg et al. 2018; Hegarty

Citation: Crocetti, Daniela, Fae Garland, David Andrew Griffiths, Surya Monro, Tanya Ní Mhuirthile, Katrina Roen, Prashant Singh, and Amets Suess-Schwend. 2024. Editorial Introduction to Centring Intersex Issues: Global and Local Dimensions. *Social Sciences* 13: 602. https://doi.org/10.3390/socsci13110602

Received: 9 October 2024
Accepted: 9 October 2024
Published: 5 November 2024

and Smith 2023). Intersex studies continues to evolve, with some scholars linking experience with theory making (Holmes 2009; Davis 2015; Malatino 2019) and addressing epistemic injustice in intersex-related knowledge production (Aegerter 2022; Bastien-Charlebois 2017; Suess-Schwend 2023a, 2023b; Carpenter 2024).

In this Special Issue, some authors situate their analyses within broader global dynamics, seeking to understanding how specific issues transcend national or regional boundaries. Ongoing global dynamics include the canonisation of international medical protocols and discriminatory frameworks (Carpenter 2016), but also international human rights proclamations (Bauer et al. 2020; Carpenter 2021a; OHCHR 2023) and the solidification of international activist networks and collaborations (Astraea Lesbian Foundation for Justice 2023) such as the Latin American network (as addressed in Brújula Intersexual's article in this Special Issue).

Addressing intersex issues from a global perspective requires acknowledging the neocolonial spread of Anglocentric, 'western' medical protocols (Eckert 2016) that disrupt the right to bodily autonomy as well as non-pathological experiences of intersex bodies. Authors such as Magubane (2014) and Swarr (2023) examined the historical racialisation embedded in the pathologisation of VSCs, as well as the imposition of racialised hierarchies in the medicalisation of intersex bodies. Scholars have highlighted the racialised, racist, and sexist discourses embedded in the spectacularisation of 'sex verification' in sports (Macharia 2009, referenced in Swarr 2023; Hoad 2010; Karkazis and Jordan-Young 2018). We can also note how the 'global' pathological model has displaced historical non-pathological categories (see 'belle donne' in Crocetti 2013). Similarly, scholars have identified the limited utility of legal responses that shy away from confronting the often harsh reality of pathologisation (Pikramenou 2019; Ní Mhuirthile et al. 2022; Garland and Travis 2023; Kennedy 2024).

Globally, individuals with intersex variations and diverse sex characteristics continue to face persistent human and civil rights violations (UN 2019). Empirical research on decision-making in healthcare has indicated how the type of counselling parents receive might subtly shape their choices (Streuli et al. 2013). Others point to a lack of consensus across clinicians' perspectives regarding interventions on minors (Liao et al. 2019; Hegarty et al. 2021), delaying a paradigm change that promotes bodily autonomy. Research in Australia (Carpenter 2018), Hong Kong (King 2023), India (Rajam and Banerjee 2021), Europe (Monro et al. 2019; Aegerter 2022; Ní Mhuirthile et al. 2022), Latin America (Laura-Inter and Alcántara 2023), and South Africa (Swarr 2023), as well as activist statements[1], indicate the persistent application of an interventionist medical model across the globe; a model that is increasingly met with global and local critique. The criminalisation of LGBT+ people may concurrently lead to the increased abuse and stigmatisation of intersex individuals (Carpenter 2016); such problems can even occur in places that are considered 'LGBT+-friendly' (Butler 2024).

A growing number of nations have introduced regulations attempting to stem rights abuses for people with VSCs. These countries have adopted varying strategies; recent examples include the legal prohibition of proxy consent for sex characteristic modifications in Malta (GIGESC 2015) (Malta 2015), the partial legal restriction of surgical interventions on minors in Kenya (Children Act 2022) (Kenya 2022), the classification of surgical intervention as 'Restricted Medical Treatments' in the Australian Capital Territories (Variation in Sex Characteristics (Restricted Medical Treatment) Act 2023) (Australian Capital Territories 2023), the introduction of guidelines prohibiting non-essential and irreversible intersex medical interventions for those under the age of 12 in Taiwan (Taiwan 2018), the criminalisation of IGM (Intersex Genital Mutilation) in Greece in 2022 (Greece 2022), and the prohibiting of intersex-related genital modification practices in Spain in 2023 (Spain 2023). Concurrently, there is a rising tide of international and local activism dedicated to demonstrating that intersex experiences can also be beautiful in an effort to transcend the challenges of rights abuses (IGLYO et al. 2016; OII Europe 2023). By examining global trends and systemic issues, scholars in this field aim to contribute to a more holistic and informed approach to addressing the complex and multifaceted aspects of intersex lives on a global scale.

In juxtaposition to the investigation of global dynamics, local analyses explore the lived experiences of intersex individuals within a specific community or locality, considering factors such as cultural beliefs and social attitudes (Cabral Grinspan 2009; Davis 2015; Rajam and Banerjee 2021; Crocetti et al. 2021a; Ní Mhuirthile et al. 2022; Laura-Inter and Alcántara 2023; Swarr 2023), legal frameworks (Ghattas 2013; Garland and Travis 2023; Ní Mhuirthile 2024), and healthcare practices (Monro et al. 2017; Crocetti et al. 2021b, 2023; Berry and Monro 2022; Monro et al. 2024). The goal is to uncover how the specificities of local contexts contribute to the social, medical, and legal construction of intersex bodies, the challenges faced by individuals, and the possibilities for activism and advocacy within specific settings. Local analyses within critical intersex studies contribute to a more nuanced understanding of intersex issues, emphasising the importance of context-specific understanding, awareness campaigns, and policy changes that address the unique needs and concerns of intersex individuals within a given locality. This approach recognises that the impact of societal norms, medical practices, and cultural attitudes toward intersex people can vary significantly across different locales.

Although earlier scholarship and activism in this area were Anglophone-dominated and more visible in the global north, there has been an expansion of the field. Scholarship in French (e.g., Bastien-Charlebois 2014, 2017; Aegerter 2022), Portuguese (e.g., Machado 2014; Freitas and Machado 2015), Spanish (e.g., Cabral Grinspan 2009; Laura-Inter and Alcántara 2023; Suess-Schwend 2023a), and other languages is growing. In 2020, the Réseau francophone de recherche sur l'intersexuation (RéFRI) was founded, a network of Francophone scholars providing recommendations for ethical research on intersex issues (RéFRI 2020). Brújula Intersexual's article in this Special Issue attests to the growth and significance of Spanish-language activism and scholarship. Creating a multi-language dialogue is a challenge for this field, like many others, and we acknowledge the limitations of producing this Special Issue as an entirely Anglophone publication.

The articles presented in this Special Issue were developed from presentations at the international online conference, Centring Intersex Issues: Global and Local Dimensions, held on 20–23 February 2023[2]. The conference's ethos was to provide a space to decentre Anglophone and Eurocentric narratives. To support this, the event was held online and in rotating time zones to ensure global participation from the Americas, Europe/Africa, and Asia/Oceania. However, trying to ensure full global participation through multi-lingual participation proved to be a challenging task that was only partially achieved. English was the primary language of the conference, while participants provided translations in the verbal discussion and the chat. The one panel presented in Spanish included a professional SPA-ENG translator. Other efforts to increase global participation and engagement included pre-recorded conference presentations for asynchronous viewing, subtitles, and online social spaces held in different time zones. Facilitating a multi-lingual global discussion is a priority in this field, especially given the way global activism has outpaced scholarship in its linguistic and geographical diversity. The difficulties produced in maintaining an English-language dominated space are evident and much more work is needed to facilitate multi-lingual dialogue within intersex studies.

The conference aimed to facilitate the ongoing development of an international network of scholars, students, and stakeholders with an interest in supporting intersex people's equality, wellbeing, and social and economic success. It developed original knowledge across a range of fields and academic disciplines. The conference also generated improved policy advice for key stakeholders, especially those in policy and practice positions across sectors such as healthcare, education, and social work. Despite the linguistic limitations, the conference achieved a broad range of global representation, facilitated by the parallel programming of colleagues in Europe/Africa and Asia/Oceania.

Whilst it is beyond the scope of this Editorial to summarise the breadth of knowledge presented in the conference, some highlights are presented from the three keynotes, as these informed the articles in this Special Issue. The conference panels addressed a wide range of issues from legal progress and medical practice to representations and self-determination across diverse geographical and cultural contexts.

Mauro Cabral Grinspan's keynote speech addressed the impact of global movements, such as the anti-gender movement, which pose risks to public understandings of intersex issues and rights struggles (recorded in English and Spanish). Regardless of internal divisions, anti-gender movements share a common belief in the natural, binary, and self-evident nature of sex, perpetuating the erasure or pathologisation of VSCs. Additionally, progressive responses from endosex communities (i.e., communities of people whose sex characteristics are perceived to meet medical/social norms for binary-sexed bodies), despite good intentions, may inadvertently instrumentalise intersex experiences and bodies, reinforcing the invisibility of the institutional mechanisms shaping the concept of sex. Cabral Grinspan argued that intersex engagement with both anti-gender movements and progressive endosex responses should be rooted in an intersectional, human rights-based approach focusing on bodily integrity, decisional autonomy, reparations, and truth.

Sharon Preves' keynote speech investigated 30 years of intersex activism in the US and Canada. Preves presented a historical comparative study of first, second, and third generation intersex activists, aiming to address research gaps regarding intersex adults, intersex experiences and aging, and generational differences among intersex activists. Preves explored the impact of medicalisation on intersex adults as they age and how past medical trauma affects their ongoing relationship with healthcare and their overall physical and mental health. Moreover, Preves raised the question of how the experiences of older intersex adults compare with those of young adults who have come of age in a social context that is far more accepting of sex, gender, and sexual diversity.

Hiker Chiu's keynote described the influence of Buddhism in Taiwan and other countries across Asia. Whilst Chiu expressed a great deal of respect for Buddhism as a faith, they described problematic interpretations of the concept of 'karma' in relation to intersex people. Unfortunately, within Buddhism, being intersex has been framed as a negative result of karma from previous lives. According to Chiu's analysis, this leads to stigmatisation and discrimination against intersex people. Parents may feel guilty about having an intersex child, may mistreat them, and/or force them to have unwanted medical interventions. Chiu pointed out that discriminatory and negative behaviours towards intersex children and adults go against the Buddhist principles of kindness for all. Buddhism recognises human diversity and the body as an illusion; there is, therefore, a good basis for positive reworkings of Buddhist scripture. From an activist perspective, strategies and solutions for reframing traditional discriminatory stances were discussed, as well as the development of the Intersex Asia network.

The conference brought together a diverse group of activists and experts to share their perspectives on intersex rights and experiences. The Anglophone American, European, and African activist panel highlighted the varied experiences and challenges faced by intersex individuals in the US, the UK, Europe, and Africa, offering a rich spectrum of insights from leading activists into the movement's progress and ongoing struggles. Similarly, the Brújula Intersexual Panel shed light on the experiences of the Spanish-speaking intersex activist network in Latin America and Spain, discussing both region-specific issues and global activism goals.

The conference also featured an interesting medical ally panel with Marina Elichiry and Frances Grimstad. Elichiry discussed how, due to increased awareness of the harm they can bring, major hospitals in Argentina have decided to defer surgeries such as clitorectomies and vaginoplasties on minors too young to give informed consent. She emphasised the importance of collaboration between medical practitioners and intersex activists in driving positive change. Grimstad discussed the structure of the healthcare system in the US, noting while there have been some developments in relation to the Consensus statement (see Lee et al. 2016), significant work remains to be done.

The conference contributed to the development of international activist and academic networks in this field, presenting the results of a growing number of larger research projects in intersex studies. Fae Garland and Mitch Travis presented their new book, *Intersex Embodiment: Legal Frameworks Beyond Identity and Disorder*, which examines the divergent medical, political, and legal constructions of intersex bodies (Garland and Travis 2023). They used empirical data to explore how intersex people are embodied through these frameworks, which, in turn, influence their lived experiences. Through their analysis, Garland and Travis (2023) revealed the factors that motivate and influence the way in which policy makers and legislators approach the area of intersex rights. They reflected on the limitations of law as the primary vehicle in challenging healthcare's framing of intersex variations as a 'disorder' to be fixed. They also offered a more holistic account of intersex justice, which is underpinned by psychosocial support and respect for bodily integrity.

A number of presentations at the conference also drew on the recent EUICIT project[3], which was conducted from 2016 to 2019 and produced comparative research across three European countries (funded by a European Commission Marie Skłodowska Curie grant (number 703352)). Interviews were conducted in Italy, Switzerland, and the UK in order to gain an in-depth understanding of intersex activists; variation-specific health advocates; and medical, policy, and other stakeholder perspectives in the three countries. Policy documents, human rights proclamations, and relevant studies in the literature were also examined. The data gathered in this project identifies a range of views regarding the regulation of cosmetic medical interventions on infants and children (Crocetti et al. 2020). Intersex stakeholders indicate that medical self-regulation is currently inadequate in addressing the sensitive rights issues regarding medical treatment in childhood (Crocetti et al. 2020, 2021b). The national health statistics and medical publications reviewed during the project clearly indicate that early childhood 'normalising' surgeries and other interventions continue to be practiced in most countries (for UK, see Monro et al. 2017; for Italy, see Crocetti et al. 2021a). This is even the case in countries where legal protections have been instated, such as in Malta, Columbia, and Portugal (see Garland and Travis 2023). Examples of good practice were found amongst some individual healthcare practitioners in different national settings. However, without specific human rights guidelines, the medical abuse of infants and children with VSCs continues to be an international problem (Bauer et al. 2020; UN 2024). The EUICIT project also found that most intersex and VSCs stakeholders would like to see medical attention shifted away from the bodily modification of minors without their consent and towards a focus on life-long health (Crocetti et al. 2020). According to the conclusions of the project, as in other areas where patients' rights have been neglected, governmental bodies must step in and address these failings in citizenship rights via legal and other means (Monro et al. 2019).

Building on the findings from the EUICIT project, in 2020 the INIA: Intersex—New Interdisciplinary Approaches international consortium[4] began work on a large research programme to address intersex people's wellbeing and human rights from a variety of perspectives. The programme trained a cohort of 10 early-stage researchers working collaboratively to develop knowledge aimed at informing policy making and practice across a range of key sectors. Contributing to intersex studies, the INIA research projects aim to be relevant to a range of stakeholders across sectors, such as social policy, and academic disciplines, including sociology, political science, cultural studies, organisational studies, education, socio-legal studies, and social work. The research findings are wide-ranging (see Montenegro et al. 2024). For example, they show that VSCs could be a critical area of public health work, as well as an emerging area of work concerning equality, diversity, and inclusion (Monro et al. 2023). The results indicate a dearth of intersex visibility in key areas including social policy, education, and elder care (see, for example, Berry and Monro 2022). Intersex people and those with VSCs face major health challenges and discrimination, and there is a pressing need for appropriate healthcare (Gramc et al. 2021). At the same time, international awareness is growing concerning the human rights abuses that intersex people face (Mestre Martínez 2022; Ní Mhuirthile and Suess-Schwend 2023; Zelayandía-González 2023).

The articles in this Special Issue cover several themes relevant to intersex studies. Together, they provide perspectives for analysing the opposing framings of intersex characteristics as bodily variations—as opposed to a difference to be fixed or eliminated—from quite different disciplinary standpoints. The importance of the co-production of knowledge between intersex and endosex people is addressed in several of the included articles. Together, they address global issues concerning medical interventions on minors, legal and ethical strategies, and local contexts in countries including Aotearoa (New Zealand), Australia, Canada, France, Greece, Ireland, Malta, Mexico, and Latin America.

Some contributions to this Special Issue focus on the important role of community and activism. The article by Eva Alcántara, Frida Flores and Carlos Narváez-Pichardo of Brújula Intersexual investigates how the emergence of the Spanish-speaking intersex community and their strategies are intertwined, both internationally and in Mexico. In outlining the Australian capital territory's legal reform of clinical practice, Morgan Carpenter highlights the importance of the role of intersex activism in recentring legal and civic focus upon harmful medical practices. The article *From Intersex Activism to Lawmaking: The Legal Ban of Intersex Genital Mutilations (IGM)*, authored by Nikoletta Pikramenou from Greece, addresses the collaborative strategic efforts of activists that led to the historic Greek law protecting intersex minors' bodily integrity.

Several of the articles in this Special Issue address not only the very practical strategic ways in which intersex activism has impacted national protections, but also global considerations of intersex rights. Pikramenou's article outlines the process that brought the Greek law to fruition while discussing the layered strategies that intersex activism involves, including the creation of local and international networks. Carpenter critiques the efforts of some to reduce intersex people's rights claims to antidiscrimination regulation or third gender markers. Offering a nuanced critique of the historical construction of intersex variations as disordered sex development in need of 'fixing', Carpenter identifies legal strategies for better protecting intersex minors, and therefore potentially better supporting the well-being of intersex adults. As previously addressed in Carpenter's (2021a) discussion of the addition of 'sex characteristics' as a protected attribute in the Yogyakarta Principles +10 (YP+10 2017), the construction of 'universal' laws and rights capable of protecting intersex individuals from medical and social harm in all social, cultural, and geographical contexts is far from simple.

The strategic use of 'sex characteristics' as protected attributes hailed from the landmark Maltese 2015 GIGESC law (Malta 2015). Bartolo Tabone, Garland, and Travis's article investigates the extent to which this reform has impacted the cultural visibility and recognition of intersex people in Malta. The article highlights the issues in implementing this legal statute. These authors also focus on the role of medical language and localised understandings of intersex terminology in bypassing the protections promised by the Maltese law. Further research gaps in existing 'universal' protections are addressed in Ravesloot's analysis of UPR (Universal Periodical Review) recommendations for banning IGM. Ravesloot discusses the potential epistemic violence that might be perpetuated by these recommendations if they do not fully consider the conditions under which consent is mobilised. In a complementary approach, Roen and Sterling look at issues of parental consent for hypospadias surgery on minors, bringing both the psychosocial and legal literature into dialogue and seeking to expand understandings of free and informed consent in healthcare contexts.

Terminology, umbrella terms, and nomenclature continue to be a contested issue in this field. The term VSCs is strategically used both to appeal to 'sex characteristics' as protected attributes, but also to unify individuals who might not otherwise recognise themselves in the intersex umbrella, as highlighted by Bartolo Tabone, Garland, and Travis. According to their analysis, the term DSD (Disorders of Sex Development) is primarily used in the medical literature in contexts that see intersex variations as disorders. Meanwhile, some patient groups and medical allies use dsd (differences of sex development, in lowercase), trying to avoid some stigmatising aspects while still folding physical variations into medical contexts. Bartolo Tabone, Garland, and Travis highlight how others may only be familiar with variation-specific medical terms, perhaps participating in variation-specific associations that address experiences and health issues. According to their analysis, the term intersex is employed by activists and allies who seek human and social rights and is also sometimes used as a personal identity term. Pikramenou discusses the rationale behind the decision to advocate for the use of the English term “intersex” written in Greek letters (ίντερσεξ) as opposed to “middlesex” (μεσοφυλικός/mesofylikos or μεσόφυλος/mesofylos) or the Greek language term for intersex which is “diafylikoi” (διαφυλικοί). The latter is often confused with the Greek word for trans people, “diemfylikoi” (διεμφυλικοί) (Intersex Greece 2023, n.p.).

Research continues to indicate that intersex adults and adults with VSCs may have difficulty accessing adequate healthcare; this is partly due to the concentration of DSD clinical practice and research on diagnosis and bodily modification practices in pediatrics (Berry and Monro 2022; Ní Mhuirthile et al. 2022; Crocetti et al. 2023). In this Special Issue, Bastien-Charlebois explores historical documents in order to address the interests and motives of the medical practitioners who helped establish—first in the US and then globally—the pediatric interventionist medical model (Karkazis 2008). In particular, Bastien-Charlebois establishes how surgical motivations are often centred on professional interests rather than children’s wellbeing. Roen, Breen, and Yee’s article adds to Bastien-Charlebois’s historical premise a contemporary analysis of recent surgery data in Aotearoa (New Zealand). They propose interdisciplinary dialogue as one of the paths towards rights-based intersex healthcare. Like other authors in this Special Issue, they also suggest that the medical use of multiple terminologies can mask the frequency of surgical interventions, as well as the urgency of rights issues. By investigating the use of prenatal dexamethasone (DEX) treatment for CAH (Congenital Adrenal Hyperplasia) in France, Raz further addresses the “mechanisms of ignorance production” that function as an obstacle to rights implementation. They analyse how intersex experiences are rendered socially invisible (unthinkable) through both social and medical mechanisms, as well as how information surrounding the problematic aspects of DEX treatment are treated as “uncomfortable knowledge” and ignored within the medical frames that continue to prescribe it.

Knowledge production is a running theme in many of the articles in this issue, which is not surprising for a field where those directly implicated are advocating for a significant paradigm change in research and clinical practice (Bastien-Charlebois 2017; Jenkins and Short 2017; Suess-Schwend 2023a, 2023b). In this Special Issue, Suess-Schwend addresses the epistemological development of the interdisciplinary field of intersex studies itself. Reflecting the analyses of other authors in this issue, the article situates the field as being co-produced as a dialogue between intersex academics and allies, activists, and human rights bodies, where actors may occupy multiple roles. Suess-Schwend further raises the question about how epistemological perspectives in intersex studies can be of use for developing strategies for the human rights protection of intersex people. Duffy and Ní Mhuirthile’s article reflects on how hermeneutic phenomenology might be employed as a methodology to further address intersex experiences in a manner that is ethically informed and benefits both participants and the wider struggle for rights. Ethics in qualitative research with vulnerable populations is another issue that spans many research fields. Mestre-Martínez’s article provides an analysis of the perspectives contributed by experts in research ethics, researchers, and research participants on ethical aspects in intersex-related research, exploring experiences that qualify the ‘nothing about us without us’ adage developed in numerous rights arenas.

This Special Issue builds upon the increasingly interdisciplinary field of knowledge constructed in intersex studies over the last decades (Monro et al. 2021). Its aim is to further expand the questions being posed in the field and inspire additional research beyond the articles presented here. Acknowledging the unequal structuring of academia, we recognise the appropriation and colonisation of intersex lives by endosex health professionals and researchers (Bastien-Charlebois 2017; Monro et al. 2021; Swarr 2023), which may take place for personal gain without sufficient commitment to positive change. Those who have experienced medical abuse or social discrimination may face obstacles in accessing academia and contributing to knowledge production (Suess-Schwend 2023a, 2023b). We also acknowledge the limitations of addressing global discussions in a monolingual format, as well as the use of English in perpetuating the institution of false knowledge hierarchies. Global collaboration between intersex and endosex individuals in this field is one of the keys to addressing these disparities. We hope that this Special Issue will stimulate impactful scholarship in this field and beyond.

Author Contributions: First draft: D.C.; contributions and review: F.G., D.A.G., S.M., T.N.M., K.R., P.S. and A.S.-S. All authors have read and agreed to the published version of the manuscript.

Funding: The production of this Special Issue was generously supported by the University of Huddersfield (International Collaboration Fund); a grant from the EU COST: European Cooperation in Science and Technology—COST Action LGBTI+ Social and Economic (in)equalities (CA19103) project; and sponsorship from *Social Sciences*. This work was also carried out with the help of the INIA: Intersex—New Interdisciplinary Approaches' Innovative Training Network, which was supported by a grant from the European Commission's Marie Skłodowska-Curie Actions program under grant number 859869. This editorial only reflects the views of the authors and the European Commission is not responsible for any use that may be made of the information it contains.

Acknowledgments: We would like to acknowledge and thank all the contributors to the Special Issue and the Centring Intersex Issues conference. We also wish to acknowledge and thank all the research participants and those working tirelessly to support intersex people's wellbeing and human rights. Lastly, we wish to thank Clare Desplats her hard work in making the conference and this Special Issue possible, as well as colleagues from *Social Sciences* for their support.

Conflicts of Interest: The authors declare no conflicts of interest.

Notes

[1] For international and regional intersex activist statements please see, among others: International Intersex Forum 2011, 2012, 2013, 2014; European Intersex Meeting 2014; Australian and Aotearoa/New Zealand Intersex Community Organisations 2017; African Intersex Movement 2017, 2019, 2023; First European Intersex Community Event 2017; Asian Intersex Movement 2018; Conferencia Regional Latinoamericana y del Caribe de Personas Intersex 2018; Intersex Asia 2023.

[2] See: Centring Intersex Issues: Global and Local Dimensions Conference. https://research.hud.ac.uk/institutes-centres/cacs/research-areas/intersex-studies/intersex-studies-conference/ (accessed on 30 August 2024).

[3] See: EUICIT: EU Intersex Citizenship. https://cordis.europa.eu/project/id/703352 (accessed on 30 August 2024).

[4] See: INIA: Intersex—New Interdisciplinary Approaches. https://intersexnew.co.uk/ (accessed on 30 August 2024).

References

Aegerter, Audrey. 2022. Enjeux et Controverses Quant à la Participation d'Activistes Intersexes au Consensus de Chicago. *Santé Publique* 34: 59–67. [CrossRef]

African Intersex Movement. 2017. Public Statement by the African Intersex Movement. Available online: https://www.astraeafoundation.org/stories/public-statement-african-intersex-movement/ (accessed on 17 May 2024).

African Intersex Movement. 2019. African Intersex Movement—Africa's Regional Intersex Network—Established. Available online: https://www.astraeafoundation.org/stories/african-intersex-movement-network-founded-in-kenya/ (accessed on 17 May 2024).

African Intersex Movement. 2023. *The 3rd African Intersex Movement Statement. Theme: Reconnecting and Shaping Our Narrative*. Nairobi: African Intersex Movement.

Asian Intersex Movement. 2018. Public Statement. Available online: https://intersexrights.org/ic/public-statement-by-the-asian-intersex-movement/ (accessed on 8 October 2024).

Astraea Lesbian Foundation for Justice. 2023. Celebrating Our 2023 Intersex Human Rights Fund Grantees. Available online: https://astraeafoundation.org/stories/iad-2023/ (accessed on 29 August 2024).

Australian and Aotearoa/New Zealand Intersex Community Organisations. 2017. Darlington Statement. Available online: https://darlington.org.au/statement (accessed on 9 August 2024).

Australian Capital Territories, Australia. 2023. Variation in Sex Characteristics (Restricted Medical Treatment) Act. Available online: https://www.legislation.act.gov.au/View/GetHTMLFile/a/2023-23/current/html/2023-23.html#nowhere (accessed on 8 October 2024).

Bastien-Charlebois, Janik. 2014. Femmes intersexes: Sujet politique extrême du féminisme (Intersex Women, Feminism's Extreme Political Subject). *Recherches Féministes* 27: 237. [CrossRef]

Bastien-Charlebois, Janik. 2017. Les sujets intersexes peuvent-ils (se) penser? Les empiétements de l'injustice épistémique sur le processus de subjectivation politique des personnes intersex(ué)es (Can Intersex subjects reflect (upon themselves)? The encroachment of epistemic injustice on the political subjectification of intersex people). *Socio* 9: 143–62. [CrossRef]

Bauer, Markus, Daniela Crocetti, and Daniela Truffer. 2020. Intersex and Human Rights. *The International Journal of Human Rights* 24: 724–49. [CrossRef]

Berry, Adeline W., and Surya Monro. 2022. Ageing in obscurity: A critical literature review regarding older intersex people. *Sexual and Reproductive Health Matters* 30: 2136027. [CrossRef]

Butler, Judith. 2024. *Who's Afraid of Gender?* Toronto: Alfred A. Knopf Canada.

Cabral Grinspan, Mauro, ed. 2009. *Interdicciones. Escrituras de la Intersexualidad en Castellano*. Córdoba: Anarrés Editorial.

Cabral Grinspan, Mauro, and Gabriel Benzur. 2005. Cuando digo intersex. Un diálogo introductorio a la intersexualidad. *Cadernos Pagu* 24: 283–304. [CrossRef]

Carpenter, Morgan. 2016. The human rights of intersex people: Addressing harmful practices and rhetoric of change. *Reproductive Health Matters* 24: 74–84. [CrossRef]

Carpenter, Morgan. 2018. The "normalization" of intersex bodies and "othering" of intersex identities in Australia. *Journal of Bioethical Inquiry* 15: 487–95. [CrossRef]

Carpenter, Morgan. 2021a. Intersex human rights, sexual orientation, gender identity, sex characteristics and the Yogyakarta Principles plus 10. *Culture, Health & Sexuality* 23: 516–32. [CrossRef]

Carpenter, Morgan. 2021b. Intersex variations, human rights, and the international classification of diseases. *Health and Human Rights* 20: 205–14.

Carpenter, Morgan. 2024. Fixing bodies and shaping narratives: Epistemic injustice and the responses of medicine and bioethics to intersex human rights demands. *Clinical Ethics* 19: 3–17. [CrossRef]

Chase, Cheryl. 1998. Hermaphrodites with Attitude: Mapping the Emergence of Intersex Political Activism. *GLQ: A Journal of Lesbian and Gay Studies* 4: 189–211. [CrossRef]

Conferencia Regional Latinoamericana y del Caribe de Personas Intersex. 2018. Declaración de San José de Costa Rica (San José de Costa Rica Statement). Available online: https://brujulaintersexual.org/2018/04/02/declaracion-de-san-jose-de-costa-rica/ (accessed on 17 May 2024).

Crocetti, Daniela. 2013. *L'invisibile Intersex. Storie di Corpi Medicalizzati*. Pisa: Edizioni ETS.

Crocetti, Daniela, Adeline Berry, and Surya Monro. 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* 26: 332–45.

Crocetti, Daniela, Elia A. G. Arfini, Surya Monro, and Tray Yeadon-Lee. 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: 943–58. [CrossRef] [PubMed]

Crocetti, Daniela, Surya Monro, and Tray Yeadon-Lee. 2021a. Rhetoric of Change: Intersex rights claims, rhetoric and medical practice in Italy. *Rivista Illuminazioni* 55: 146–94.

Crocetti, Daniela, Surya Monro, Valentino Vecchietti, and Tray Yeadon-Lee. 2021b. Towards an agency-based model of intersex, variations of sex characteristics (VSC) and DSD/dsd health. *Culture, Health and Sexuality* 23: 500–15. [CrossRef]

Davis, Georgiann. 2015. Normalizing intersex: The transformative power of stories. *Narrative Inquiry in Bioethics* 5: 87–89. [CrossRef]

Dreger, Alice. 1998. *Hermaphrodites and the Medical Invention of Sex*. Cambridge: Harvard University Press.

Eckert, Lena. 2016. *Intersexualization: The Clinic and the Colony*. New York and Abingdon: Routledge.

European Intersex Meeting. 2014. Statement of Riga. Available online: https://www.oiieurope.org/statement-of-riga/ (accessed on 17 May 2024).

Fausto-Sterling, Anne. 2000. *Sexing the Body: Gender Politics and the Construction of Sexuality*. New York: Basic Books.

First European Intersex Community Event. 2017. Vienna Statement of the First European Intersex Community Event. Available online: https://www.oiieurope.org/statement-1st-european-intersex-community-event-vienna-30st-31st-march-2017/ (accessed on 17 May 2024).

FRA—European Union Agency for Fundamental Rights. 2015. *The Fundamental Rights Situation of Intersex People*. Vienna: FRA.

Freitas, Janaina, and Paula Sandrine Machado. 2015. Rastreando corpos, produzindo sexos: A inserção da hiperplasia adrenal congênita no teste do pezinho (Tracking bodies, producing sexes: The insertion of congenital adrenal hyperplasia on newborn screening). *Mediações-Revista de Ciências Sociais* 20: 130–50. [CrossRef]

Garland, Fae, and Mitchell Travis. 2018. Legislating Intersex Equality: Building the Resilience of Intersex People through Law. *Legal Studies* 38: 587–606. [CrossRef]

Garland, Fae, and Mitchell Travis. 2023. *Intersex Embodiment. Legal Frameworks Beyond Identity and Disorder*. Bristol: Policy Press.

Ghattas, Dan Christian. 2013. *Human Rights Between the Sexes: A Preliminary Study on the Life Situations of Inter* Individuals*. Berlin: Heinrich Böll Stiftung.

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: e001257. [CrossRef]

Gramc, Martin, Surya Monro, John Stephenson, and Jürg Streuli. 2024. Psychosocial Support for Parents, Infants, Children, and Adolescents with Variations of Sex Characteristics: Results from a Pan-European Survey. *Behavioural Sciences* 14: 832. [CrossRef] [PubMed]

Greece. 2022. Law Nr. 4958/2022. Νόμος 4958/2022: Μεταρρυθμι’σεις στην ιατρικως’ υποβοηθου’μενη αναπαραγωγη’ και α’λλες επει’γουσες ρυθμι’σεις. Government Gazette 142/A/21-7-2022. Available online: https://intersexgreece.org.gr/en/2022/07/25/3449/ (accessed on 17 May 2024).

Griffiths, David A. 2018. Shifting Syndromes: Sex Chromosome Variations and Intersex Classifications. *Social Studies of Science* 48: 125–48. [CrossRef] [PubMed]

Hegarty, Peter, and Annette Smith. 2023. Public understanding of intersex: An update on recent findings. *International Journal of Impotence Research* 35: 72–77. [CrossRef] [PubMed]

Hegarty, Peter, Marta Prandelli, Tove Lundberg, Lih-Mei Liao, Sarah Creighton, and Katrina Roen. 2021. Drawing the line between essential and nonessential interventions on intersex characteristics with European health care professionals. *Review of General Psychology* 25: 101–14. [CrossRef]

Hoad, Neville. 2010. “Run, Caster Semenya, Run!” Nativism and the Translations of Gender Variance. *Safundi* 11: 397–405. [CrossRef]

Holmes, Morgan. 2009. *Critical Intersex*. Farnham: Ashgate.

IGLYO, OII Europe, and interACT. 2016. We Are Here: Intersex Youth. Available online: https://www.youtube.com/watch?v=16gQDXxsnjM&t=53s (accessed on 29 August 2024).

International Intersex Forum. 2011. Media Release. First Ever International Intersex Forum. Available online: https://ihra.org.au/14340/first-international-intersex-forum/ (accessed on 19 May 2024).

International Intersex Forum. 2012. Second International Intersex Forum. Stockholm, 9–11 December 2012. Available online: https://ilga.org/news/second-international-intersex-forum-stockholm-9-11-december-2012/ (accessed on 17 May 2024).

International Intersex Forum. 2013. Malta Declaration. Available online: https://www.oiieurope.org/malta-declaration/ (accessed on 17 May 2024).

International Intersex Forum. 2014. Fourth International Intersex Forum—Media Statement. Available online: https://www.oiieurope.org/wp-content/uploads/2017/04/EDITED-FINAL-FINAL-FINAL-PressRelease4thForum.pdf (accessed on 17 May 2024).

Intersex Asia. 2023. Asian Intersex Statement 2023. Available online: https://intersexasia.org/wp-content/uploads/2024/09/Asian_statement_2023_Official_27Dec.pdf (accessed on 8 October 2024).

Intersex Greece. 2023. Hate Speech against Intersex People in Greece. Available online: https://intersexgreece.org.gr/wp-content/uploads/2023/06/Hate-speech-against-intersex-people-in-Greece-report-EN_May23-2.pdf (accessed on 17 May 2024).

Jenkins, Tania M., and Susan E. Short. 2017. Negotiating intersex: A case for revising the theory of social diagnosis. *Social Science & Medicine* 175: 91–98. [CrossRef]

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

Karkazis, Katrina, and Rebecca M. Jordan-Young. 2018. The Powers of Testosterone: Obscuring Race and Regional Bias in the Regulation of Women Athletes. *Feminist Formations* 30: 1–39. [CrossRef]

Kennedy, Aileen. 2024. *Law, Gender Identity and the Brain: Exploring Brain-Sex Theories in Judicial Decisions on Trans and Intersex Minors*. Abingdon: Routledge.

Kenya. 2022. The Children Act, 2022. Kenya Gazette Supplement, Acts 2022. 12 July 2022. pp. 419–608. Available online: https://kenyalaw.org/kl/fileadmin/pdfdownloads/Acts/2022/TheChildrenAct_2022.pdf (accessed on 8 October 2024).

Kessler, Suzanne J. 1998. *Lessons from the Intersexed*. New Brunswick: Rutgers University Press.

King, Brian W. 2023. Communicating health knowledges across clinic and community: The case of sex characteristics in plurilingual Hong Kong. In *Language, Health and Culture: Problematising the Centres and Peripheries of Healthcare Communication Research*. Edited by Olga Zayts-Spence and Susan M. Bridges. Abingdon and New York: Routledge, pp. 101–18.

Laura-Inter [pseud], and Eva Alcántara, eds. 2023. Brújula. Voces de la Intersexualidad en México. Serie Habitaciones Nueve; Ciudad de México: Editorial 17, Instituto de Estudios Críticos.

Lee, Peter, Anna Nordenström, Christopher P. Houk, S. Faisal Ahmed, Richard Auchus, Arlene Baratz, Katharine Baratz Dalke, Lih-Mei Liao, Karen Lin-Su, Leendert H.J. Looijenga, 3rd, and et al. 2016. Global Disorders of Sex Development Update since 2006: Perceptions, Approach and Care. *Hormone Research in Paediatrics* 85: 158–80. [CrossRef]

Liao, Lih-Mei, Peter Hegarty, Sarah Creighton, Tove Lundberg, and Katrina Roen. 2019. Clitoral surgery on minors: An interview study with clinical experts of differences of sex development. *BMJ Open* 9: e025821. [CrossRef]

Lundberg, Tove, Peter Hegarty, and Katrina Roen. 2018. Making Sense of “Intersex” and “DSD”: How Laypeople with Varying Experience of Intersex/DSD Understand and Use Terminology. *Psychology & Sexuality* 9: 161–73. [CrossRef]

Machado, Paula Sandrine. 2014. (Des)fazer corpo, (re)fazer teoria: Um balanço da produção acadêmica nas ciências humanas e sociais sobre intersexualidade e sua articulação com a produção latino-americana ((Un)do body, (re)do theory: Taking a stock on the academic production in humanities and social sciences regarding intersexuality and its articulation with the latin-american production). *Cadernos Pagu* 42: 141–58. [CrossRef]

Macharia, Keguro. 2009. On Caster Semenya. *Gukira*, September 20. Available online: https://gukira.wordpress.com/2009/09/20/on-caster-semenya/ (accessed on 17 May 2024).

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: 761–85. [CrossRef]

Malatino, Hil. 2019. *Queer Embodiment: Monstrosity, Medical Violence, and Intersex Experience*. Lincoln: University of Nebraska Press.

Malta. 2015. Gender Identity, Gender Expression and Sex Characteristics Act, 14 April 2015. ACT XI of 2015, as Amended by Acts XX of 2015 and LVI or 2016 and XIII of 2018. Available online: https://legislation.mt/eli/cap/540/eng/pdf (accessed 8 October 2024).

Mestre Martínez, Yessica. 2022. The Human Rights Situation of Intersex People: An Analysis of Europe and Latin America. *Social Sciences* 11: 317. [CrossRef]

Monro, Surya, Addy Berry, Morgan Carpenter, Daniela Crocetti, and Sean Saifa Wall. 2024. *Intersex, Variations of Sex Characteristics and DSD: Critical Approaches*. Routledge Advances in Critical Diversities Series; London and New York: Routledge.

Monro, Surya, Daniela Crocetti, and Tracey Yeadon-Lee. 2019. Intersex/variations of sex characteristics and DSD citizenship in the UK, Italy and Switzerland. *Journal of Citizenship Studies* 23: 780–97. [CrossRef]

Monro, Surya, Daniela Crocetti, Tray Yeadon-Lee, Fae Garland, and Mitchell Travis. 2017. *Intersex, Variations of Sex Characteristics, and DSD: The Need for Change*. Huddersfield: University of Huddersfield Press.

Monro, Surya, Morgan Carpenter, Daniela Crocetti, Georgiann Davis, Fae Garland, David Griffith, Mauro Cabral Grinspan, and Peter Aggleton. 2021. Intersex: Cultural and social perspectives. *Culture, Health & Sexuality* 23: 431–40. [CrossRef]

Monro, Surya, Sean Saifa Wall, and Wood Kate. 2023. Intersex Equality and Diversity and Social Policy: Silences, absences, and erasures in Ireland and the UK. *Critical Social Policy* 44: 3–22. [CrossRef]

Montenegro, Marisela, Joan Pujol, Lucas Platero, Amets Suess-Schwend, and Surya Monro, eds. 2024. *Intersex Studies: A Multidisciplinary Exploration*. Barcelona: Universitat Autònoma de Barcelona.

Ní Mhuirthile, Tanya. 2024. Intersex in Ireland: A Legal History from Ancient Times to the Present Day. In *The Politics of Gender and Sexuality in Modern Ireland: A Reader*. Edited by Jennifer Redmond and Mary McAuliffe. Dublin: Four Courts Press, pp. 102–18.

Ní Mhuirthile, Tanya, and Amets Suess-Schwend, eds. 2023. *e-Report on Law, Ethics and Human Rights. INIA: Intersex—Interdisciplinary Approaches*. Dublin: DCU, Dublin City University. Available online: https://doras.dcu.ie/26873/ (accessed on 17 May 2024).

Ní Mhuirthile, Tanya, Maria Feeney, Mel Duffy, and Anthony Staines. 2022. *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*. Dublin: Dublin City University.

OHCHR. 2023. OHCHR Technical Note on the Human Rights of Intersex People: Human Rights Standards and Good Practices. Available online: https://www.ohchr.org/sites/default/files/2023-11/ohchr-technical-note-rights-intersex-people.pdf (accessed on 9 August 2024).

OII Europe. 2023. OII Europe Campaign Depath Intersex. Available online: https://campaigns.oiieurope.org/depath/ (accessed on 17 May 2024).

Pikramenou, Nikoletta. 2019. *Intersex Rights: Living between Sexes*. Cham: Springer Nature.

Preves, Sharon E. 2005. Out of the O.R. and into the Streets: Exploring the Impact of the Intersex Media Activism. *Cardozo Journal of Equal Rights and Social Justice* 12: 247. Available online: https://www.cardozoersj.com/volume-12 (accessed on 8 October 2024).

Rajam, Sharda, and Atreyo Banerjee. 2021. Right to Genital Integrity: Law, Limbo, and the Status of Intersex Children in India. *Columbia Journal of Gender & Law* 42: 130–82. [CrossRef]

RéFRI—Réseau francophone de recherche sur l'intersexuation. 2020. Recommandations pour une recherche respectueuse sur l'intersexuation. Available online: https://refri.hypotheses.org/recommandations-aux-chercheur%C2%B7e%C2%B7s (accessed on 17 May 2024).

Roen, Katrina. 2019. Intersex or Diverse Sex Development: Critical Review of Psychosocial Health Care Research and Indications for Practice. *Journal of Sex Research* 56: 511–28. [CrossRef]

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. Boletín del Estado Nr. 51. 1 March 2023. Available online: https://www.boe.es/buscar/act.php?id=BOE-A-2023-5366 (accessed on 8 October 2024).

Streuli, Jürg C., Effy Vayena, Yvonne Cavicchia-Balmer, and Johannes Huber. 2013. Shaping Parents: Impact of Contrasting Professional Counselling on Parents Decision Making for Children with Disorders of Sex Development. *The Journal of Sexual Medicine* 10: 1953–60. [CrossRef]

Suess-Schwend, Amets. 2023a. Ética de la despatologización: Un concepto en proceso. In *Etnografía y Feminismos. Restituyendo saberes y prácticas de investigación*. Edited by Carmen Gregorio Gil and Belén García Peral. Bern: Peter Lang, pp. 369–98.

Suess-Schwend, Amets. 2023b. The clinical gaze on gender and bodily diversity in childhood and adolescence: Critical perspectives. In *Child-Friendly Perspectives on Gender and Sexual Diversity. Beyond Adultcentrism*. Edited by José Antonio Langarita, Ana Cristina Santos, Marisela Montenegro and Mojca Urek. London and New York: Routledge, pp. 26–46.

Swarr, Amanda L. 2023. *Envisioning African Intersex: Challenging Colonial and Racist Legacies in South African Medicine*. Durham: Duke University Press.

Taiwan. 2018. Ministry of Health and Welfare, R.O.C. (Taiwan) (2018-11-02). 附件) 衛生福利部未成年雙性人之醫療矯正手術共同性建議原則 [(Appendice) Recommended Common Principles Regarding Corrective Surgery on Non-Adult Intersex Persons, Ministry of Health and Welfare]. Available online: https://www.mohw.gov.tw/dl-49519-a05c5250-5bbb-4cfc-929a-9b886be2d46e.html (accessed on 17 May 2024).

UN—United Nations, Human Rights Council. 2024. *Combating Discrimination, Violence and Harmful Practices Against Intersex Persons: Resolution Adopted by the Human Rights Council on 4 April 2024*. Geneva: Human Rights Council. Available online: https://digitallibrary.un.org/record/4045699?v=pdf (accessed on 20 September 2024).

UN—United Nations, Office of the United Nations High Commissioner for Human Rights. 2019. *Background Note on Human Rights Violations Against Intersex People*. Geneva: Office of the United Nations High Commissioner for Human Rights. Available online: https://www.ohchr.org/sites/default/files/Documents/Issues/Discrimination/LGBT/BackgroundNoteHumanRightsViolationsagainstIntersexPeople.pdf (accessed on 17 May 2024).

van Heesch, Margriet. 2016. 85,000 Nederlanders hebben een intersekseconditie. Tijd om hen te leren kennen. De Correspondent. Available online: https://decorrespondent.nl/4960/85-000-nederlanders-hebben-een-intersekseconditie-tijd-om-hen-te-leren-kennen/1145407160480-97dbf2e4 (accessed on 9 August 2024).

YP+10—The Yogyakarta Principles Plus 10. 2017. 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. Available online: https://yogyakartaprinciples.org/wp-content/uploads/2022/02/021522-Principios-de-Yogyakarta-mas-10.pdf (accessed on 17 May 2024).

Zelayandía-González, Ernesto. 2023. The Growing Visibility of Intersex Demands at the United Nations: A Review of the Treaty Bodies Conclusion Observations. *Social Sciences* 12: 73. [CrossRef]

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Article

Brújula Intersexual: Working Strategies, the Emergence of the Mexican Intersex Community, and Its Relationship with the Intersex Movement

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Abstract: After a decade of work, Brújula Intersexual has become a reference in Mexico and Latin America. However, the presence of the Latin American intersex movement in the specialised literature in English is restricted. We consider that conducting a self-reflexive review of Brújula Intersexual could contribute to understanding (1) the work strategies implemented by Brújula Intersexual; (2) the formation of the Spanish-speaking intersex community and movement in Mexico; and (3) the heterogeneous dynamics of the global intersex movement. We designed a qualitative–quantitative study involving discussion meetings with the Brújula Intersexual team, revision of the Brújula Intersexual archive, a scoping review, and a timeline. The results and discussion are focused on two axes: (1) Brújula Intersexual: structure and working strategies, in which two concepts are developed, namely, the intimate sphere and the atmosphere of trust; (2) The articulation of Brújula Intersexual within the intersex movement and its resonances in public policy. Researching Brújula Intersexual contributes to the collective memory and reveals important events that link the Spanish-speaking and global anglophone intersex movements. In particular, Brújula Intersexual was configured as a critical counter-device that manages intense flows of affection, allowing for the production of new subjectivation modes for people with intersex bodies.

Keywords: Brújula Intersexual; intersex; Spanish-speaking intersex movement; human rights; evidence-based activism

Citation: Alcántara, Eva, Laura Inter, Frida Flores, and Carlos Narváez-Pichardo. 2024. Brújula Intersexual: Working Strategies, the Emergence of the Mexican Intersex Community, and Its Relationship with the Intersex Movement. *Social Sciences* 13: 414. https://doi.org/10.3390/socsci13080414

Academic Editors: Surya Monro, Tanya Ni Mhuirthile, Amets Suess-Schwend, Fae Garland, Daniela Crocetti, David Andrew Griffiths and Katrina Roen

Received: 26 March 2024
Revised: 26 July 2024
Accepted: 26 July 2024
Published: 8 August 2024

1. Introduction

Over the last thirty years, thanks to the actions of the international intersex movement, the visibility of intersex people has increased worldwide. Intersex activism began in the 1990s; however, situations of medical violence and social discrimination have not yet been effectively resolved (Carpenter 2022). Interest in intersex issues is often limited to theoretical discussions anchored to the regime of sexual difference and sex/gender dichotomies. We understand the deconstructive potential that intersex experiences bring and know that it is essential to develop a new sexual epistemology. However, we concur with Monro et al. (2021) that it is urgent to anchor this interest to singular and localised experiences, with the everyday issues and human rights violations faced by intersex people in the foreground.

Over the past three decades, the intersex movement has diversified. Its configuration is heterogeneous, and its dynamics are transnational (Rubin 2017). Unique forms of intersex activism occur across the globe, given the diverse historical and local conditions and variable economic, social, political, cultural, and technological dynamics. Even so, global discussions—both those related to medical protocols and those that flow within the human rights system—are conducted primarily in English, with a predominance of actors and issues located in Global North countries (Cabral in Vieira et al. 2021; Carpenter 2022). This has meant that the field of knowledge on intersex issues is unevenly structured according to a hierarchy of values on which knowledge (1) circulates in English, (2) is generated in the USA and Europe, (3) is supported by or emerges in academic contexts, and (4) is available in digital format. Processes of racism and precarious economies limit the presence of the Latin American intersex movement in global discussions, both in activism and in critical intersex studies written in Spanish and Portuguese (Cabral in Vieira et al. 2021). We concur with Mauro Cabral, the first intersex activist in Latin America, that "o que a dominação sobre o ativismo intersex e a academia intersex tende a produzir é um disciplinamento colonial na forma como a intersexualidade é pensada e escrita. [. . .] Por que o inglês é sempre a língua correta para falar sobre intersexualidade?" ("What the domination over intersex activism and intersex academia tends to produce is a colonial discipline in the way intersex is thought of and written [. . .]. Why would English be the right language to speak about intersex?") (Vieira et al. 2021, p. 225; own translation).

Given this situation, it is important to offer a first analysis of Brújula Intersexual and the work conducted over the last decade in English using an academic format. On the 27th of October 2013, Laura Inter[1] created a Facebook page in Spanish named Brújula Intersexual. At present, Brújula Intersexual operates using virtual meeting spaces, including *Facebook* (11,300 followers), Instagram (5300 followers), *X/Twitter* (3090 followers), and a website. According to the statistics of the website *brujulaintersexual.org*, from February 2015 to October 2023, it accumulated 1,514,881 visits, of which 73.95% corresponded to America, 25.25% to Europe, 0.56% to Asia, 0.13% to Oceania, and 0.12% to Africa. In particular, Latin America and the Caribbean accounted for 63.8% of the total number of visitors. The highest number of visits were from Mexico (25.81%), Spain (22.86%), Argentina (11.74%), the United States of America (9.91%), Colombia (6.92%), Chile (4.71%), and Peru (3.36%), which together accounted for 85.31% of the total visits. In line with the impact reflected in these numbers, Alejandra Sánchez Monroy (2021) has situated Brújula Intersexual as a central reference for the problematisation of the violence and discrimination experienced by intersex people, not only in Mexico but also beyond national borders.

Given the need to better understand the emergence of the Spanish-speaking intersex community and the dynamics of Latin American movements, as well as the role that Brújula Intersexual plays in it, we consider four questions: (1) What is Brújula Intersexual? (2) What actions and strategies have been implemented, and what results have been achieved? (3) What role has Brújula Intersexual played in the creation of the Spanish-speaking intersex community? (4) How is it related to the global anglophone intersex movement? In order to answer these questions, we propose three objectives. The first is to analyse Brújula Intersexual, the work strategies implemented for over a decade, and the results that have been achieved. The second objective is to identify key coordinates of the Spanish-speaking intersex community and movement, as well as the roles that Brújula Intersexual play in this context. Finally, the third objective is to analyse the Mexican intersex movement, both within the Spanish-speaking intersex movements—located in Latin America and Spain—and within the global anglophone intersex movement.

Intersex Movement in Latin America

Regardless of language or geographical region, the intersex movement in Latin America shares with the global anglophone movement an interest in making visible the situations of medical violence, discrimination, and violations of the right to bodily autonomy and integrity faced by people born with variations in sex characteristics. In particular, there is a shared desire to protect intersex bodies from pathologisation and medical procedures that are not consented to in a free, full, and informed manner by the person themselves, which represent violations of the right to health, privacy, confidentiality, and bodily integrity (Cabral and Carpenter 2018).

In an interview published in Portuguese, Mauro Cabral stated that his initial approach to activism was through consulting what was happening in the Intersex Society of North

America (ISNA) in the mid-1990s (Vieira et al. 2021). He recounts that he conducted these consultations on a computer in the university library and began translating the texts from English into Spanish. In 1999, he travelled to the United States for the first time to attend a regional LGBT conference, and in 2002, he began to work on a Latin American programme for an organisation working with the International Gay and Lesbian Human Rights Commission. In 2004, Mauro Cabral presented intersex issues at the United Nations for the first time, and in 2005, he became the coordinator of the trans and intersex area for the Latin American programme. It was also in those years—namely, 2004/2005—that Paula Machado (in Brazil) and Eva Alcántara (in Mexico) began researching and writing on intersex issues in their countries, remaining active to date. The intersex activist work of Natasha Jiménez in Costa Rica also began during this period. It was at the IV Conference of the International Association for the Study of Sexuality, Culture, and Society, held in Lima, Peru, in June 2007, that a roundtable on intersex issues was held, which brought together Mauro Cabral, Paula Machado, and Eva Alcántara. The event was also attended by Natasha Jiménez. After that meeting and at the proposal of Mauro Cabral, this small group began a partnership called the *Consorcio Latinoamericano de Trabajo sobre Intersexualidades,* which, according to Mauro Cabral, allowed for an exchange that generated the first discussions on how intersex experiences occurred in the Latin American region (Vieira et al. 2021). At present, based on available information in the Brújula Intersexual archive and Aguirre Arauz (2023), the Latin American intersex movement is active in Argentina, Brazil, Costa Rica, Colombia, Chile, Ecuador, Mexico, the Dominican Republic, Peru, Uruguay, and Venezuela.

Understanding the trajectory of the intersex movement in Latin America would require a detailed study that has not yet been written. Latin America is a region that shares historical events as well as cultural and political characteristics; however, like any large region of the world, there are important differences from one country to another, as well as within each country. The commonalities in the demands of the Latin American intersex movement have been gathered in the San José de Costa Rica Statement (First Latin American Regional Conference of Intersex Persons 2018), a document that systematises the demands of the Latin American intersex movement as well as the call that intersex people have made to the States and different social and private sectors. This document adopted the premises of the Public Statement by the Third International Intersex Forum held in Malta in 2013. The second Latin American and Caribbean Conference brought together thirty intersex activists in Buenos Aires, Argentina, in 2020.

Academic production on intersex issues is grounded in North American intersex studies. Some of these classic authors are well-known by Latin American intersex activists and specialised academics, including Cheryl Chase (1998), Morgan Holmes (2009), Iain Morland (2009), Suzanne Kessler (2002), Anne Fausto-Sterlling (2006), Alice Dreger (2003), Ellen Feder (2014), Katrina Karkazis (2008), and Georgiann Davis (2015), among others. We agree with Cabral (as quoted in Vieira et al. 2021) that it is relevant to open the conceptual, theoretical, and political framework to other languages, which is why it is important to mention that the Latin American intersex activism movement also has a solid written production with ethnographic research—both in Spanish and Portuguese—which allows us to contextualise and historicise some of the social and cultural dynamics in which intersex experiences take place.

In Mexico, anthropological research is part of the broader field of anthropology of sexuality, which was consolidated in Latin America in the 1980s. This field emerged linked to feminist and sexual dissidence thought, as well as to social knowledge committed to several social and cultural dynamics that assume "su producción representa un recurso político y simbólico que distintos sujetos y grupos pueden utilizar para potenciar sus demandas y sus acciones" ("its production represents a political and symbolic resource that different subjects and groups can use to empower their demands and actions") (Parrini and Tinat 2022, p. 18). We refer to the pioneering work of Mauro Cabral, whose theoretical production is disseminated and deserves to be compiled. Cabral edited *Interdicciones:*

Escrituras de la intersexualidad en castellano (Cabral 2009), which remains an indispensable reference in Spanish. The political involvement of this Argentinian activist has been essential; his work as the director of Global Action for Trans Equality has had an impact on a global scale. He was one of the signatories of the Yogyakarta Principles—a key document for legislative changes in several countries—and his work with the World Health Organisation has sought to influence the way in which the medical system understands and manages intersex individuals. Paula Machado is also an established academic reference in Latin America. Her ethnographic doctoral research, *O sexo dos anjos. Representações e práticas em torno do gerenciamento sociomédico e cotidiano da intersexualidade* (Machado 2008) gave way to a solid written production that continues to date. In Spain, we have several commonalities with the work of Nuria Gregori (2015) and her doctoral research entitled *Encuentros y des-encuentros en torno a las intersexualidades/DSD: narrativas, procesos y emergencias*. In Mexico, we refer to the pioneering ethnographic work of Eva Alcántara (2012), as well as the research of Mara Toledo (2018, 2021), Alejandra Sánchez Monroy (2021), and the audiovisual production of the Mexican intersex activist Adiós al Futuro (2018). Finally, the book *Brújula. Voces de la intersexualidad en México*, coordinated by Laura-Inter and Alcántara (2024), brings together texts of analysts, activists, intersex people, and the testimonials of family members.

2. Study Design and Methods

Those of us who write this article are part of the mechanism that directed Brújula Intersexual in its first decade of work. We know how challenging it is to approach our analysis while simultaneously occupying the positions of both the researcher and the researched. More than an autoethnography, we conceive of this work within the framework of an experimental anthropology of the contemporary (Rabinow 2006; Restrepo and Parrini 2021; Fernández de Rota 2023). In this sense, we agree with Paul Rabinow (2006) that "the challenge is to invent new forms of inquiry, writing, and ethics for an anthropology of the contemporary," as the problem to be solved is "how to rethink and remake the conditions of contemporary knowledge production, dissemination, and critique in the interpretative sciences?" (p. 1). With this in mind, we set out to retrace our steps to understand the working strategies of Brújula Intersexual.

At Brújula Intersexual, we assume that we must invent new routes to solve old problems. The traditional positivist research paradigm assumes a logic that opposes dichotomous pairs: subject/object, researcher/researched, theory/practice, and subjective/objective. By looking through an intersex lens, we have sought to dismantle binary logic. Intersex experiences enabled what Iain Morland (2009) called an "'afterwardsness' of intersex and its many lessons" (p. 192), which led us to dismantle the "sexdualidad [. . .] la lógica dual que sostiene la noción tradicional de la diferencia sexual y de la sexualidad en general como oposición" (sexduality [. . .] the dual logic that sustains the traditional notion of sexual difference and sexuality in general as oppositional) (Derrida in Berger 2015, p. 17). We extend this deconstructive approach to dismantle the binary logic that operates in research practices. We form ourselves as a collaborative research team that recognises the unique knowledge and different capacities of each member.

We conducted a qualitative–quantitative study that involved:

1. Periodic work meetings and discussions—we held meetings to discuss in pairs and as a team, and together, we chose the concepts to develop and proceeded to construct the structure of the article and write it. In addition, we carried out the revision of a specialised bibliography.
2. Revision and analysis of the Brújula Intersexual archive—published and unpublished materials produced within a ten-year period were analysed. The timeframe covered the emergence of Brújula Intersexual from the 27th of October 2013 to the 8th of August 2023. We located materials produced that contain testimonies in the Brújula Intersexual archive—describing both everyday situations and intimate experiences—in order to reflect on how we came to them (Brújula Intersexual 2023a; Laura-Inter and

Alcántara 2024). This unveiled the basis of the functional mechanism of Brújula. With this in mind, we went back to reading, searching for resonances in the literature that would allow us to understand and explain that mechanism. In this research, ethical considerations regarding the use of cited testimonies were followed. The four intersex individuals who provided their testimonies for the Brújula Intersexual YouTube channel were informed that their testimonies would be used for this manuscript. They provided us with informed consent letters.

3. A scoping review— we conducted a scoping review (Table S1) covering October 2013 to August 2023, using the keywords *Brújula_Intersexual, Laura_Inter,* and *Encuesta_Intersex* as search queries. We reviewed the sources and the form in which the keyword *Brújula_Intersexual* was referred to in digital spaces. The information obtained was organised by the research term in reverse chronological order in spreadsheets along with the following aspects: publication date, title, author, country, and type of document. The academic research was extended to two databases: *Ebsco* and *Jstor*. The name *Laura_Inter* was also sought on Academia.edu, yielding 3547 mentions in papers; however, as access was not paid, it was not possible to review the sources. The data collected were organised in tables and graphs.
4. A timeline—to understand the chronology and events relevant to Brújula Intersexual located at three levels (national, regional, and global), we developed a timeline (Timeline S1). For this purpose, the timeline created by Hana Aoi/Sánchez Monroy (2018) was taken as an initial reference. Events referred to in research carried out by former and current core members of Brújula Intersexual were added to this timeline: Alcántara (2012), Toledo (2018, 2021), and Sánchez Monroy (2021). The Timeline of Intersex History found on (WikiPedia n.d.) was consulted. The timeline was completed through an intentional internet data search that included other relevant events on intersex activism in Mexico and Latin America linked to the work of Brújula Intersexual.

3. Results and Discussion

The analysis that we decided to present is not exhaustive but rather problem-oriented (Rabinow 2006). Considering the questions that we formulated, the objectives that we set, and the way in which we organised the information collected, we decided to develop two axes of analysis. In different proportions, each author contributed fragments of written text. A first draft in Spanish was assembled by the first author, which was subsequently revised by the team. Finally, it was translated into English by the third author and revised by the team.

The first axis presents the structure and working strategies of Brújula Intersexual and introduces two concepts: the *intimate sphere* and the *atmosphere of trust*. The second axis explores the activation of the intersex movement in Mexico, the articulation of Brújula Intersexual within the intersex movement, and presents some strategies that impacted public policy.

3.1. Brújula Intersexual: Structure and Working Strategies

When Laura Inter founded Brújula Intersexual, she desired to meet other intersex people and, therefore, imagined a place that could serve as a guide for other people. Ten years later, Laura Inter and those of us who write this article are surprised by the scope of that initial desire, and we wonder: What is Brújula Intersexual, and how does it work? To answer these questions, we developed the following two sections: In the first section, we address the structure of what we call Brújula. In the second section, we explain the axis of the working strategies of Brújula Intersexual, for which we propose two concepts: the intimate sphere and the atmosphere of trust.

3.1.1. An Organic, Spherical and Layered Device

The structure of Brújula is more animate than inert; it is an organic device. Its shape is spherical, and its interior resembles the layers of an onion. The nucleus of Brújula consists of five people, three of whom have been constant over the first decade. Those who have been part of the nucleus have different professional backgrounds and have contributed a wide range of knowledge that is fundamental to understanding and influencing issues related to intersex, including intersex experiences, computer skills, human rights, Lacanian psychoanalysis, feminisms, gender studies, anthropology, computer systems, engineering, internal medicine, bioethics, social networking, languages, graphic design, and writing. We highlight that the three people who have remained stable in the project have subjective strengthening practices, which have allowed them to maintain certain emotional stability: Buddhism and/or Lacanian psychoanalysis. Having financial resources was also an important factor that was gradually achieved. More robust financial stability for the only person who receives a full-time salary from the project's funding has not yet been achieved, and most of the contributions of endosex people have been voluntary. In addition to the authors of this article, the core group has involved the participation of Mara Toledo (2015 to 2020), Hana Aoi (2016 to 2020), and Mar Is (2015 to present). A total of four intersex people and three endosex people have participated or are participating in the core group. All of them have at least a bachelor's degree, and two of them obtained professional degrees with research linked to their involvement at Brújula Intersexual.

The next layer is made up of around ten people, not only from the Mexican intersex community but also from Spain, Venezuela, and Argentina. This work was carried out through specific projects, and the participants were paid per project: drawing, embroidery, illustrations, writing texts, co-production of informative materials and different contents, providing accompaniment, and participating in interviews, talks, workshops, and classes. The third layer of collaborators consists of around eighty people from the Mexican intersex community, as well as twenty more people located in Colombia, Argentina, Chile, Peru, Guatemala, Venezuela, Bolivia, the Dominican Republic, Costa Rica, and Spain. Their contributions consisted of written testimonies. The methodology based on testimonies was the basis for the materials produced and the workshops, conferences, and media in which Brújula Intersexual participated.

The fourth layer that has projected Brújula Intersexual is its allies. These are professionals who have great recognition and prestige in their field, some of whom work in state institutions and are decision-makers. The connection with people in the National Council for the Prevention of Discrimination (CONAPRED) and the Human Rights Commission of Mexico City (CDHCM) has been important. A sister project with whom we have a lot in common, who also supported us from the beginning and sometimes advised us, is *17, Instituto de Estudios Críticos* (https://17instituto.org/), a space for critical theory that was conceived as a post-university at the crossroads of academia, culture, and psychoanalysis. Its publishing house, *Editorial 17,* published *El libro intersexual* (Adiós al Futuro 2018) and *Brújula. Voces de la intersexualidad en México* (Laura-Inter and Alcántara 2024).

Initially, Brújula Intersexual was self-funded by its founder, Laura Inter. Fundraising enabled her to sustain her work, and in 2015, it became possible to obtain the first funding from the Intersex Human Rights Fund of the Astraea Lesbian Foundation for Justice, which has been maintained to date. In 2020, *Fondo Semillas* provided Brújula Intersexual with additional funding, which continues to date. Over these years, the project has also received occasional financial support from other sources. Between 2019 and 2023, funding averaged USD 19,980 per year. There is no certainty regarding how long we will continue receiving this funding. The intersex people participating in the core group do not have health insurance or any other social benefits.

3.1.2. Mechanism: Intimate Sphere and Atmosphere of Trust

Intersex disrupts the sexual binary that assumes a man/woman as a dichotomous relationship. The existence of intersexed bodies demonstrates that sex is not just a matter of two opposing and mutually exclusive categories whose ultimate truth would be found in biological characteristics. As stated by Monique Wittig, the category of sex is a product of heterosexual society: "straight society is based on the necessity of the different/other at every level. It cannot work economically, symbolically, linguistically, or politically without this concept. This necessity of the different/other is an ontological one for the whole conglomerate of sciences and disciplines that I call the straight mind. But what is the different/other if not the dominated?" (Wittig 1980, p. 163).

We think of Brújula Intersexual as a laboratory where we test how to reconnect people with other people living similar situations, with their bodies, and with the joy of living. We understand that trust is an essential factor for adults to seek help, and that is where it is indispensable to imagine a place where other people, as Laura Inter stated, "did not feel as lost and alone as I once did" (Laura-Inter 2015, p. 97). In this sense, the intersex community turns out to be fundamental, as it is easier to communicate with a person who has gone through similar situations. We believe that this form of authentic meeting is capable of fracturing the dominant meaning from the medical gaze, which is subsumed within what Monique Wittig (1980) called *The straight mind*: the framework of thought that—through social institutions—structures and imposes a hierarchy of value that takes heterosexuality as the dominant norm, the same one that conceives sex as universal, natural, dichotomous, and binary.

If the medical dispositive of intersex works on the unique case, in Brújula Intersexual, we work on the unique—the singularity—to generate not a case but a house, a territory built of common fabric, making a displacement of place where someone can be one more person and feel that lives in the company of other equals possible. Below, we develop two notions and present some of the testimonies collected from Brújula Intersexual on the occasion of its tenth anniversary. These and other testimonies can be found in the documentary film *Abriendo la Brújula* (Brújula Intersexual 2023a).

> Hi. My name is Mer. I have Complete Androgen Insensitivity Syndrome, 46 XY.
>
> I came across Brújula Intersexual looking for answers, looking to understand a bit more and to understand myself. Also, I found a lot of stories that represented me that I did not know about or could not find. And the most important thing I found were people—people who not only had the same thing that happened to me but who understood me when I talked to them. And in our case, finding someone who understands you, someone you can talk to, and, on the other side, realising that they understand what you are saying, that they understand what you feel or your feelings. . . that is immense.
>
> So, the most important thing I found was people who understood me and wanted me not to be the only one but just another person, and I am grateful for that. (Brújula Intersexual 2023b, translated by Frida Flores)

The listening carried out in Brújula Intersexual spaces is characterised by being patient, respectful, and deeply aware of the uniqueness of each person and each lived experience. This listening configures a space that we have denominated the *intimate sphere*, which is not only about hearing words but also about understanding the silences, the emotional resonances, and the flows of affection presented. Listening goes beyond the verbal; it tries to embrace the person as a whole and to make space for their fears, hopes, and traumas. This type of listening allows people to feel safe and validated. Subjectivity is anchored in cis-heteronormativity as a compass that guides the sense of the world and verifies its coordinates in the lives we are living. Thus, cis-heteronormativity permeates all of Western culture, placing sexual practices, modes of relationship, and the social representations that shape it at the top of the hierarchy of value. At Brújula Intersexual, we have understood that this regime is sustained simultaneously in several dimensions: economic, social, political, psychic, and affective. The disruptive potential of intersex requires an exercise of cognitive and affective deconstruction that works to resituate what cruelty, violence, exclusion, and mockery have left in intersex people. It is clear that those of us who do not enter the cis-heteronormative system are repelled, rejected, or, at the very least, ignored. Through recognising the prevalence of the cis-heteronormative regime in the interpretation of our bodies, the listening carried out at Brújula Intersexual provides a possibility to resituate the coordinates that guide one's life and the meaning of living.

We foster an *atmosphere of trust* where individuals can express themselves freely and without fear of judgement. Listening is active, not only seeking to understand but also to support and accompany. We recognise the complexity of the individual experience and how complicated it is to share experiences; as such, we do not pressure anybody. Listening becomes an act of caring and respect, often being the first step in a process of healing and self-acceptance.

People often come into contact with Brújula Intersexual via Facebook, email, or the website. Sometimes, our support groups for specific intersex variations are the first point of contact. Over the years, the number of people who approach us has increased.

> Particularly for me, as Camino Baró, an activist, you have helped me a lot. . . but also in my more *private sphere*, in my *personal sphere*, to gradually graduate the information that I could assimilate to reduce that feeling of loneliness that you have when you discover that you are a person with an intersex condition, and then you realise that there are many other variants, many other realities. After all, many people may be in the same situation as you. (Brújula Intersexual 2023c, translated by Frida Flores)

How does one participate in someone's most private and personal sphere? Especially when healthcare experiences have created an "ontological insecurity [. . .] a profound insecurity about the body and being, and one's right to ownership of both" (Karkazis 2008, p. 219). The concepts of *intimate sphere* and *atmosphere of trust* have their roots in the work of Rodrigo Parrini (2018), Suely Rolnik (2021), and Benjamin Mayer Foulkes (2022). The *intimate sphere* is a space that, once formed, allows the structure of the social bond to be intervened in (Mayer Foulkes 2022). The *intimate sphere* emerges, where a shared inner world is generated in the encounter between two people. When people with intersex bodies begin to connect with each other, a common fabric is built. This world in common opens the door to another mode of subjectivation. We take from Felix Guattari (1992) the notion of *friendly complicity* to understand that, in such a relationship, there is always a third term, namely, the world that is being woven, that is being worked. The *intimate sphere* is this space of shelter that allows for subjective explorations derived from the *atmosphere of trust*, which enables the presence of sympathy, thus tuning a channel of affinity that prepares the possibility of dialogue to a frequency characterised by shelter and conviviality (Parrini 2018, p. 200). The encounter has the quality of an event characterised by flows of affection that activate the impulse by introducing a rupture where, before, there was a fixation of a material and unconscious order (Rolnik 2021, pp. 32–33). This activation has the force:

> "To disarm the configurations of power [. . .] it neither begins nor ends in the individual [. . .] such a practice feeds on resonances of other efforts going on the same direction and the collective force they promote, not only because of their power of pollination but also and fundamentally because of the synergies they produce. [. . .] Such resonances and synergies produced create the conditions for the formation of a common collective body whose power of invention, acting under singular and variable conditions, can become strong enough to contain the power of forces prevailing in other constellations [. . .] With these synergies, ways are opened to divert such power from its destructive destiny." (Rolnik 2021, pp. 33–34, translated by Frida Flores)

Guattari and Rolnik (2006) stated that "lo que caracteriza a los nuevos movimientos sociales no es solo una resistencia contra ese proceso general de serialización de la subjetividad, sino la tentativa de producir modos de subjetivación originales y singulares, procesos de singularización subjetiva" (what characterises new social movements is not only a resistance against its general process of serialisation, but the attempt to produce original and singular modes of subjectivation) (p. 61).

> My name is Pauli. I am a member of Potencia Intersex [. . .] I came to Brújula in 2018 with quite an existential crisis, without knowing who I was, without knowing what place or group I belonged to, and I was able to find in this space not only a lot of containment and understanding, but also the possibility of being part of a movement that goes beyond Brújula, that goes beyond me. This movement is the global intersex movement, the intersex movement in the world, of which Brújula Intersexual is part, and it is a fundamental part, because it has been one of the first organisations that started to promote and generate information in Spanish, and also, in some way, to promote spaces for meeting, conversation, talk, dialogue about our corporealities.
>
> Through Brújula, I could understand that I wasn't a person with a disease, but a body different from other bodies and that I belonged to a group of people who respond to an international political movement that seeks to end genital mutilation in childhood, which is part of the experiences that intersex people go throughout our lives and that increasingly needs to be heard, to be listened to, to be seen. . . because, even today in all parts of the world or in many parts of the world, there are still children who undergo surgery to be mutilated and their bodies corrected and, so they can fit into the binary logics that move the world. (Brújula Intersexual 2023d, translated by Frida Flores)

Intimate spheres have the potential to destabilise the dominant forms of subjectivation. What happens in the *intimate sphere* disrupts the psychic and political dimensions simultaneously, blurring the boundaries between one and the other. The work of the intersex movement intervenes in the political dimension while disrupting the ontological dimension of sexduality. Understanding how the axes of power that underpin gender norms work has been vital for intersex people. In consonance with the Mexican psychoanalyst Benjamín Mayer Foulkes, we conceive our work as a critical counter-device that operates through the deconstruction of the social bond in a twofold way. Mayer Foulkes (2023) proposed the deployment of the formulas of the four discourses proposed by the psychoanalyst Jacques Lacan, denominating two of them as *subjectivising deconstruction* and *instituting deconstruction*. The first is related to providing an environment in which desire can make its way—in this case, facilitated by the *intimate sphere* and the *atmosphere of trust*—which encourages the life potency of a singular subject. Meanwhile, instituting deconstruction implies not only dismantling the existing sex-gender structures but also constructing new signifiers that make it possible to situate oneself differently in the social world.

We think that, in this moment of history, the term *intersexual* in Spanish (intersex in English) guides another existence, this time inscribed in the coordinates of possibility and encounter. The collective agency of this term and its reinscription in the human rights framework open up a possible path of subjective reconfiguration and community emancipation. In our experience, it is not a matter of assuming an identity label but of locating intersex issues as the central point that guides where a personal search begins, a journey that will always be singular.

> I had the feeling that it was a congenital malformation, as I was told to call it, and that I was a genetic accident, as if I were. . . I don't know. . . an alien. However, through research I found other doctors who had a different sense of how to treat my medical condition or my diagnosis, which is Total Androgen Insensitivity. So that's how I found Brújula.
>
> [. . .] Thanks to them, I have recognised that I am part of a tribe, that I am not alone, that there are many of us but we have to start speaking out to make visible a condition that has been seen as a stigma, as something shameful that should not be talked about.
>
> I think that genitalisation of our lives has been what has caused us the most harm, because we have been made to feel that there is a kind of handicap in our human condition compared to the rest of the people. However, thanks to Brújula I have

> found that this is not so, that I do not have to degrade the situation I live with and that I should feel proud. And the actions that I take will benefit me, the people in my tribe, and those who will come into existence in the future. (Brújula Intersexual 2023e, translated by Frida Flores)

The first contact at Brújula Intersexual is Laura Inter. Given her workload, she has not been able to keep an exhaustive record of the intersex people who contact her, including family members of people with intersex variations. We estimate that only 10% of the people we have had contact with in this decade have either shared their life story, decided to get involved in activism or participated in activities promoted by Brújula Intersexual, participated in another intersex organisation, or have decided to attend community meetings. This implies that public access to what takes place in the *intimate sphere* is limited to those who participate in the meetings. We can share that the main issue that occurs during the initial meeting usually corresponds to doubts related to intersex bodily variations and the effects associated with them. The vast majority of people who contact us have not wanted to get in touch with other people with similar life experiences. They are people reaching out to us with particular inquiries: they have doubts about their bodies or about the surgical procedures performed on them during childhood or adolescence without their consent and want to know what exactly was done to them, or they need to resolve health situations that have not been addressed (some associated with non-consensual genital surgeries). Others did not undergo surgeries in childhood and are going through a process of deliberating whether or not to have the surgeries; others require information on how to make their gender change in their official documents; others want to know their chances of becoming pregnant; others seek informed and qualified medical or psychological support; and others simply want to be listened to by someone who understands them.

Regarding family members, commonly the person who contacts us is the mother. When their children are young, they usually seek information that helps them to better understand their child’s situation; they also have doubts about the surgical procedures proposed by doctors and seek wider and more understandable information about what happens to their child, and, in cases of CAH, they ask about pharmacological treatment. When their daughters or sons are adolescents or young adults and underwent genital surgery in childhood, the mother commonly has questions about the associated physical or mental health problems and seeks support and information. At Brújula Intersexual, we embrace the call that—from the San José de Costa Rica Statement—is made to families to open their ears beyond the cis-heteronormative medical system, to study the issue from the information produced by intersex activism, and to join us in our work to unmask human rights violations.

It is important to note that the *intimate sphere* is generated between peers, not only intersex people but also between endosex and intersex people, between endosex people, between intersex activists and mothers of intersex children, and between former patients and health professionals who participate in the core group of Brújula Intersexual. To understand that intersex bodies are not homogeneous, that there is no uniformity of circumstances, and, above all, to listen directly to the voices of people, we invite you to read the book *Brújula. Voces de la intersexualidad en México* (Laura-Inter and Alcántara 2024), which brings together texts of analysis; testimonies of activists, intersex people, and family members; and the findings of Dr. Narváez, a doctor specialising in internal medicine and to whom we refer people seeking medical attention.

3.2. The Articulation of Brújula Intersexual within the Intersex Movement and Its Resonances in Public Policy

The term intersex is a century old. It was not initially linked to the human rights activist movement but instead emerged within the medical system (Carpenter 2022). In Spanish, we find that the term *estados intersexuales* was used to group what were considered to be “patologías de los caracteres sexuales” (pathologies of sex characteristics) (Marañón 1951, p. 67). This was the first denomination used in the Mexican medical system (Matus

1972). Therefore, how did intersex become the cardinal point that oriented encounters and activated the movement in Spanish? In the following paragraphs, we will analyse what happened from the experience of Laura Inter, who selected that term as the guiding direction of Brújula.

Laura Inter was born in 1983. Her body presented genital variations that included a larger-than-usual clitoris and a urogenital orifice. While she was not subject to genital surgeries, she endured constant genital examinations during childhood. At the age of 15, in 1998, Laura Inter wondered why her body was considered different and began an internet search based on terms she had found in her medical records: Pseudohermaphroditism, Congenital Adrenal Hyperplasia (CAH), and genital malformation. These words led her primarily to medical references, and two years later, she found the English term intersex. 'Intersex' guided her to two websites: Bodies Like Ours and the Intersex Society of North America. Using a dictionary as a translation tool, she participated in an online forum, where she received a response from Betsy Driver—co-founder of Bodies Like Ours—who was also born with CAH and is an intersex activist in the United States. This is how she found other people with intersex bodies who spoke English, and the exchange with them provided her with new affirmative coordinates that allowed her to redefine her body and understand that sexuality comes in many forms:

> I realized I was not "deformed", that there was nothing wrong with my body, that intersex is not a disease in itself, and that my genitals were quite healthy as they were and were not a problem. I understood that intersex is more common and more normal than we think. This helped me to find peace with my body. I also found people who had not had surgery and to my surprise they were healthy, and had satisfying sex lives, which reassured me. I have come to understand, through my own experience, that being intersex opens a whole new world of possibilities around sexuality. Our anatomies may oblige us to rethink sexuality, to challenge sexist or preconceived ideas about it, and this is a good thing. Now I am sure that nonconsenting surgeries, genital exams in infancy and early childhood, as well as the language doctors use, only serve to make things worse. (Laura-Inter 2015, p. 97)

Laura Inter thought that there should be other intersex people who spoke Spanish, and she restarted the search for the Spanish word *intersexualidad*. She did not find a community but was able to contact other people in Mexico and also found texts written by Mauro Cabral, where the term *intersexualidad* appeared as a main axis in the reflection. Thus, the terms intersex and *intersexualidad* became the epicentre for exploring new paths and catalysing the encounter that led to the emergence of Spanish activist movements.

How did the extensive search for the terms intersex, intersexual, and intersexualidad begin on the American continent? To address this question, we used Google Trends to inspect the frequency of searches for these terms in Mexico, Colombia, Chile, and Argentina, as well as in the United States and Spain. As can be seen in Figure S1, the results indicate that, in the last decade, searches for these terms have been consistent with a slight increase. Frida Flores drew our attention to another term that appears frequently in medical records, which she used when she started her search on the internet: hermaphrodite. To our surprise, this word persists as a predominant search term in several Latin American countries, while the term intersex is the second most common and has gained ground in the last decade (Figure S2). Michel Foucault (2001) showed the centrality of this term in structuring the field of teratology and constructing the representation of the monster in the 18th century, thus delimiting the field of abnormality and establishing the coordinates of biological legal regulations. Alice Dreger (2003) analysed the centrality of the term hermaphrodite to the medical invention of sex. This term was taken up by the scientific medical discourse and has been rejected by the intersex movement, as it is pejorative and evokes stigmatising images that are also inaccurate. Bo Laurent attempted to reappropriate the term with an emancipatory impetus in the 1990s (Chase 1998). Figure S2 shows that, in the United States, there is a clear downward trend in search frequency for the term hermaphrodite, while searches for the term intersex have increased. Intersex and hermaphroditism came to be used in medical environments as synonyms. Hermaphrodite and pseudohermaphrodite are words that once indicated individual diagnoses and, therefore, can be found in medical records (Carpenter 2022). It would be interesting to think about what condenses the term hermaphrodite and its representation, as it persists not only on Google Trends but also in current cultural narratives and cinematic representations (Amato 2016). We believe that, in the fight for representation, it is relevant to continue using the term intersex as a bridge to open up a reflection on the human rights of people who present congenital bodily variability concerning sex characteristics. In this sense, we concur with Morgan Holmes that: "'Intersex' is not a final term, nor the most appropriate term, but a powerful term whose historical, social and political importance remains *critical* as a tool for interrogating heteronormative and bionormative presuppositions about proper embodiment. Intersex also remains a *critical* site for our interrogation of the limits of its ability to speak of and to the experiences of self of those so labelled, and a *critical* site for the examination of scholarship on intersexuality" (Holmes 2009, p. 7).

Resonances and synergies of intersex movements are amplified in the form of expansive circular waves—rings that spread energy from the epicentre outwards (Rolnik 2021). The public presence of Brújula Intersexual shows an increasing trend that follows this dynamic. In the Timeline of Relevant Intersex Events (Timeline S1), we can see that this increase is related to a broader strengthening of intersex activism in Spanish, as well as the presence of Latin American intersex activists—including Laura Inter and other Mexican intersex activists—in meetings held in countries of the Global North. Regional and global intersex meetings allowed for networking, the exchange of information, and the fine-tuning of intervention strategies. Among the most important collaborations that we have carried out with the international intersex movement, it is possible to mention four: (1) the presentation—together with the Swiss NGO StopIGM.org and intersex activists—of reports on genital mutilation in Mexico, Chile, and Spain before the CRC 2017, CEDAW 2018, and CCPR 2019. These reports succeeded in getting the UN to make a declaration regarding the insufficient support and lack of effective resources to address the claims of intersex people in Mexico who underwent unnecessary medical interventions; (2) in April 2017, Laura Inter attended the 4th International Intersex Forum in Amsterdam with activists for different regions; (3) in 2017, Laura Inter participated in the Public Hearing on the human rights situations of intersex people in the Americas, before the IACHR in Washington D.C.; and (4) members of the core group of Brújula Intersexual took part in the committee that organised the First Latin American and Caribbean Conference of Intersex People in Costa Rica in 2018 and the Second Intersex Conference of Latin America and the Caribbean in 2020.

Table S1 presents the information gathered extensively through the scoping review, which is presented in a synthesised form in the Figures 1–4. As can be seen from Figure 1, there was a gradual and increasing number of mentions per year of the keywords *Brújula_Intersexual, Laura_Inter,* and *Encuesta_Intersex* as search queries, starting in 2016. If we add the coordinates provided by Timeline S1, it reveals that other Spanish-speaking intersex organisations gradually began to emerge. In Mexico, *Proyecto Intersexual* (2015), *Vivir y Ser Intersex* (2016), and *Intersex y Andrógino* (2016) have been founded. Laura Inter received messages from people located in other Latin American countries who were interested in being part of the project, which is why some projects emerged at the beginning as "branches" of Brújula Intersexual. Over time, Laura Inter encouraged those people to become independent, which produced (among other things) a change in the name of some projects, such as *Brújula Intersexual Chile* to *Intersexuales Chile*, and *Brújula Intersexual Colombia* to *Colombia Intersex* (currently inactive), both founded in 2016. In 2018, *Brújula Intersexual Argentina* was founded, which became *Orquidea Intersexual*. In Spain, we closely suppoted *Caminar Intersex* since their foundation in 2019 and in 2020 the same happened with the *Asociación Peruana de Personas Intersexuales* (also known as *Perú Intersex*), and with *Argentina Intersex*. From 2020 on, more intersex websites in Spanish began to emerge, and we believe this is the reason for the decrease in the number of visits to the Brújula Intersexual website: 2015/50,054 visits; 2016/100,707 visits; 2017/130,547 visits; 2018/192,324; 2019/281,174 visits; 2020/278,896 visits; 2021/192,400 visits; 2022/173,461 visits; 2023/144,459 visits (according to the statistics of the website *brujulaintersexual.org*).

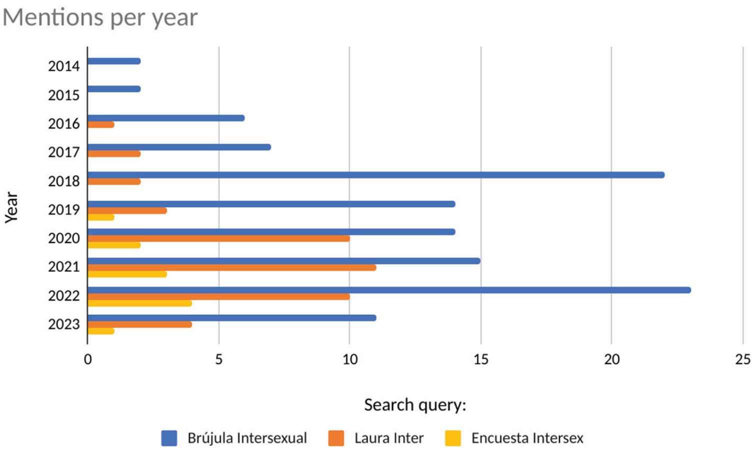

Figure 1. Mentions per year.

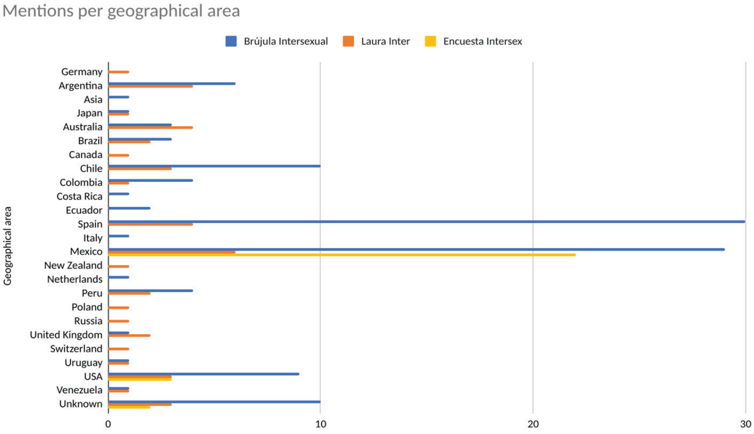

Figure 2. Mentions per geographical area.

Figure 2 shows the countries with the highest number of mentions of the terms used, which, in decreasing order, are Mexico, Spain, the United States, Chile, Argentina, Australia, Peru, Colombia, and Brazil. This does not imply that the intersex movement is not active in other countries in the region but, rather, that Brújula Intersexual and the work conducted have circulated more in the aforementioned countries.

According to the consultations that we received during the first decade, we believe that the impact of Brújula Intersexual in those countries is related to (1) the presence of legal demands and/or legal and/or human rights debates linked to intersex medical care; (2) the presence of Spanish speakers interested in the issue, such as intersex people, mothers, and also journalists and academics; (3) the country where Brújula Intersexual was founded and where it operates; (4) access to the internet and social networks; (5) the economic capacity of the country; and (6) the presence of networks of work and sociability among intersex activists located in different countries.

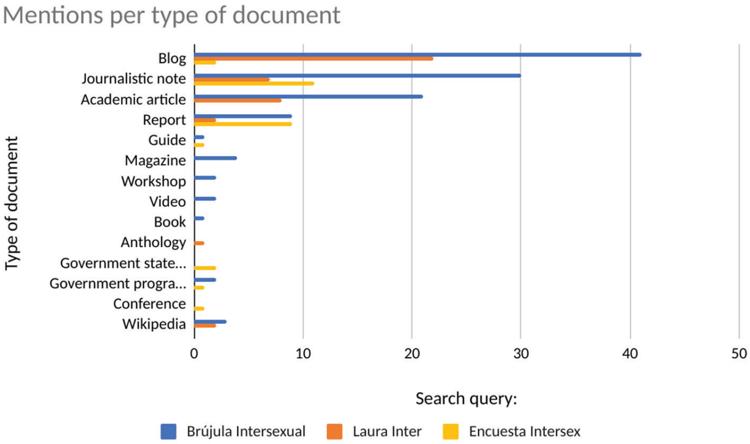

Figure 3. Mentions per type of document.

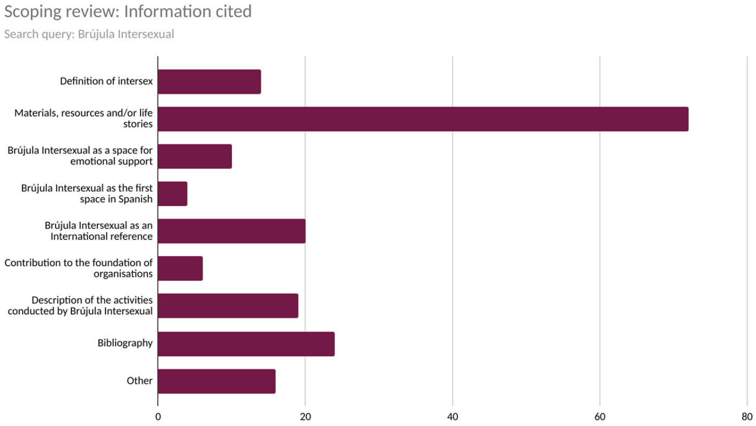

Figure 4. Information cited.

Spheres of Insurrection and Public Space

Over this first decade, the second aspect of *Brújula Intersexual's* work in Mexico refers to the public space, which is the most visible part of the project. In line with what Suely Rolnik (2021) denotes, *Spheres of insurrection*, we consider our work to be part of a set of micropolitical interventions aimed at destabilising the dominant forms of subjectivation rooted in the regime of sexual difference and dichotomous sex. This regime has an institutional dimension that regulates the state, which is why we have been interested in intervening in this biopolitical organisation. Below are some of the strategies that we have implemented to transform the public policies that regulate intersexuality.

Brújula Intersexual's work in the public space includes collaboration with state institutions and universities, the creation of materials and informative brochures, and participation in training courses and workshops. All of these activities are aimed at raising awareness of the human rights violations and discrimination experienced by intersex people. With this, we seek to influence the generation of public policies and the transformation of institutional practices that respond to the knowledge of the daily situations and violence experienced by people with variations in sex characteristics.

To understand the resonances of Brujula Intersexual's work in the public space, we analysed in Figure 3 the variety of documents in which the terms *Brújula_Intersexual*, *Laura_Inter*, and *Encuesta_Intersex* are referred; while Figure 4 summarises a more detailed approach to the types of mentions that we were able to identify with respect to the keyword *Brújula_Intersexual*. We have the impression that this technique allowed us to identify a kind of magnetic field that responds and mobilises with a peculiar dynamic. We set ourselves the task of reviewing each URL that mentioned the keyword to answer two questions: How is *Brújula_Intersexual* quoted? And what content produced by *Brújula_Intersexual* is retrieved or mentioned?

A first approximation allowed us to identify the following: (1) There are four fields in which the search term moves—media, emancipation movements, government, and academia. (2) The boundaries between the identified fields are porous and sometimes are not easy to discern, as a mention can oscillate between two or more fields. (3) There is a networked circulation that interweaves *Brújula_Intersexual* not only with intersex activism but also with other social emancipation movements, including LGBT+, feminism, and the disability movement, among others. (4) Table S1, as a whole, shows that the energy generated by the intersex movement tends to expand and circulate, establishing connections of varying intensity that multiply over time.

A more detailed review of the data allowed us to classify the type of format in which the search terms were mentioned (Figure 3). The most accessible was through blogs—the same format in which Brújula Intersexual operates—being one of the most accessible and popular ways to build communities and networks. The second is journalistic notes. We believe that this is due to the growing interest in intersex issues in recent years as a result of various debates around intersex birth registration and positions on a third legal gender (Cabral 2014). In Mexico, the association of the word intersex with a third gender led to the presentation of three misguided bills, which sought to register babies with intersex bodies outside of binary girl/boy assignment. In Figure 3, the third place is for academic articles, both in Spanish and English, which seems to indicate an increasing interest in non-pathologising approaches to intersex experiences.

More detailed information on how Brújula Intersexual has been mentioned can be found in Figure 4. The mentions highlight the most visible part of our work, including collaborations with state institutions and universities, the creation of informative materials, and participation in trainings and workshops. Through these actions, we seek to influence the formulation of public policies and the transformation of institutional practices to address everyday situations and combat the violence faced by people with intersex variations. Our objective with this public participation was to raise awareness about human rights violations and discrimination against intersex people.

From 2021 onwards, mentions of the term *Brújula_Intersexual* increased considerably in different media formats. Timeline S1 shows the years in which relevant public policies materials (to which we contributed) were published; for instance, the *Guía para la atención a la intersexualidad y variación de la diferenciación sexual* by the Ministry of Health (Secretaría de Salud 2017) and the results of the *Intersex Survey* (2020). Other published materials that have been adopted in institutional spaces related with public policies are *Guía sobre Intersexualidad para madres y padres* (2022); *Guía para madres y padres Hiperplasia Suprarrenal Congénita* (2022); *Folleto sobre Intersexualidad en las escuelas* (2023); *Microrrelatos sobre intersexualidad* (2023); *¿Qué del hospital enferma? Relatos intersex sobre atención médica* (2023); and the short film *Abriendo la Brújula* (2023).

4. Conclusions

Over the past three decades, the intersex movement has diversified its configuration and expanded its scope transnationally, facing significant challenges due to diverse economic, social, and cultural dynamics around the world. However, despite the increased visibility and multiplicity of intersex activism, unresolved situations of medical violence and social discrimination persist. Most global discussions—both medical and human rights-based—are primarily conducted in English, leading to the effect of remaining dominated by actors from the Global North, thus creating an unequal knowledge structure around intersex.

Brújula Intersexual was founded in 2013. From then on, it has played a crucial role in the visibility and problematisation of intersex people in Mexico and beyond. Brújula Intersexual's structure is organic and dynamic, and collaboration and knowledge exchange have been key elements in its operation. Digital platforms are the vehicle through which it has been possible to reach a wide and diverse audience. The testimony-based work methodology has allowed this organisation to capture and give voice to the unique experiences of intersex people, contributing to the construction of a resilient and supportive network. Community-building and trust-building were the key focus of its work in the first decade. Brújula Intersexual is referred to as a safe space where it is possible to share experiences and find support. In terms of impact, Brújula Intersexual has managed to influence public policies in Mexico by collaborating with state and educational institutions and generating informative materials. It has sought the transformation of institutional practices through the training of public servants. Brújula Intersexual's work is characterised by a profound connection with its members, seeking to balance the demands of restorative justice for past injustices with the creation of new narratives and tools for a better future for intersex people.

The analysis of cis-heteronormativity has allowed us to deconstruct the binary logic that underlies intersex medical care. Understanding that the categorisation of sex is a product of the heterosexual regime has helped us to understand its functioning at the economic, symbolic, linguistic, and political levels. At Brújula Intersexual, we have worked to dismantle this dual logic, creating a space where intersex people can reconnect with their bodies and live their lives with joy and authenticity.

Intersex activism faces ongoing challenges, especially in contexts of economic precariousness and structural violence in the Global South. The visibility and circulation of the demands of the intersex movement add to the dynamics of contemporary sexual politics occurring on a global scale, as well as in Latin America and Mexico in particular. It is not possible to develop an analysis of these dynamics at length, but it is relevant to mention that the human rights framework has made it possible to construct a robust basis for collective emancipation. This is a transformation that Paul Preciado (2022) has called "un proceso de mutación planetaria en curso [. . .] una serie de micromutaciones que llevarán, tarde o temprano, esta es la apuesta, a la transformación del régimen sexual, racial y productivo de la modernidad en una nueva configuración de las relaciones históricas entre poder, saber y vida" ("an ongoing process of planetary mutation [. . .] a series of micro mutations that will lead, sooner or later, this is the bet, to the transformation of the sexual, racial, and productive regime of modernity to a new configuration of historical relations between power, knowledge and life") (p. 31; own translation). This process is not exempt from confrontations and hostilities. In particular, that which mobilises the anti-gender movement needs to be addressed, hence the importance of "exploring TERFnesses" to understand "the links between anti-trans feminist activism, institutional politics, and anti-gender movements" (Cabral Grinspan et al. 2023, p. 10).

Intersex activism is not massive, and it is not the same everywhere. In Latin America, the visibility and circulation of the demands of the intersex movement take place in countries with all types of violence, great social inequalities, and economic difficulties (Borón 2020). In the countries of the global south, facing these difficulties, particularly economic precariousness, is a daily challenge. This reality has led some people to perceive activism as a way to improve their life situations. In this context, claiming to be intersex can be perceived as the first step in accessing sources of funding. There have been cases of people claiming to have variations in sex characteristics when this does not correspond to their reality. They create intersex organisations with the objective of accessing funding sources, which is sometimes successful. Activists impact on three dimensions simultaneously: on a social level, they inform intersex issues; on a political level, they reinscribe them within the human rights framework; and, on a theoretical level, they push for a different reading of the world, which is essential to transform intersex healthcare practices. Therefore, activist work requires a careful and responsible approach.

At Brújula Intersexual, we perform committed activism that is characterised by listening and the formation of close and meaningful networks between its members, collaborators, and other intersex people and their families. Not everything has been harmonious, and there have been many disagreements, some of which have ended in breakups. We have worked with heavy emotional burdens, which is exhausting, frequently struggling to maintain our sanity in a tidal wave of affective intensity. Rather than a calm river, this work has flowed in the middle of the storm. These bonds are often intense, and therefore, overflowing is inevitable as people approach us with traumatic situations and strong emotional burdens (Melero 2023). Over the years, we have faced complex situations associated with feelings of anguish, depression, anxiety, or anger. We have consciously tried to ensure that the activism carried out by Brújula Intersexual is based on creativity, intelligence, and a deep connection with other people. We try to find a balance between the past, the present, and the future; as such, we work not only to demand restorative justice for past injustices but also with current issues, such as the physical repercussions from surgeries and mental health repercussions that generate an emotional overflow that is very difficult to deal with on a daily basis. In addition, we deal with what continues to happen every day in paediatric hospitals around the world. We are in contact with mothers and intersex children, and we desire a better future for them. We work towards generating new narratives and creating new tools that allow intersex individuals to have a different life, one in which their human rights are respected, where they can grow up free from discrimination and violence, and where they can access information that allows them to have a better life.

Supplementary Materials: The following supporting information can be downloaded at: https://www.mdpi.com/article/10.3390/socsci13080414/s1, Figure S1: Graphs obtained from Google Trends 1; Figure S2: Graphs obtained from Google Trends 2; Table S1: Scoping Review; Timeline S1: Timeline of relevant events in intersex activism.

Author Contributions: Conceptualisation, E.A. and L.I.; methodology, E.A., L.I. and F.F.; formal analysis, E.A., L.I. and F.F.; investigation, E.A., L.I., F.F. and C.N.-P.; resources, E.A., L.I. and F.F.; writing—original draft preparation, E.A.; writing—review and editing, E.A., L.I., F.F. and C.N.-P.; project administration, E.A. and L.I.; English translation: F.F. All authors have read and agreed to the published version of the manuscript.

Funding: Author 1 was granted by the Consejo Nacional de Humanidades Ciencias y Tecnologías (00000). Author 2 was funded by Fondo Semillas. Authors 3 and 4 received no external funding.

Institutional Review Board Statement: Ethical review and approval were waived for this study because the testimonies used in this paper were produced for another purpose, specifically for the tenth anniversary of BI. The individuals whose testimonies are referred to gave their authorization for them to be reproduced in this work. No therapeutic interventions were carried out in this study, and there is no associated risk.

Informed Consent Statement: Informed consent was obtained from all subjects involved in the study. Written informed consent has been obtained from the participants to publish this paper.

Data Availability Statement: The original contributions presented in the study are included in the article/Supplementary Materials, further inquiries can be directed to the corresponding authors.

Acknowledgments: The authors would like to thank all the people who have contributed to and trusted Brújula Intersexual. They extend their gratitude to Lina Martínez Hernández and Helena López González de Orduña for their support with the revision of the translation of this paper and for their valuable feedback. They also appreciate the contributions from the discussions held at the Centring Intersex Conference and the Intersex: New Interdisciplinary Approaches project. Finally, they would like to thank the anonymous reviewers for their generous feedback on this paper. This paper reflects only the views of the authors, and does not necessarily reflect the opinions of the individuals and the agencies we acknowledge.

Conflicts of Interest: The authors declare no conflicts of interest. The funders had no role in the design of the study, in the collection, analysis, or interpretation of data, in the writing of the manuscript, or in the decision to publish the results.

Note

[1] In this article, we refer to Laura Inter in three different ways: (1) Laura Inter as an intersex person and activist, (2) Laura-Inter as an author, and (3) *Laura_Inter* as a search term. We found in different publications that Laura-Inter is cited as Inter, L.; however, this does not seem to be the most appropriate to us, as Laura-Inter is a pseudonym, and Inter is not her last name.

References

Adiós al Futuro. 2018. *El Libro Intersexual*. Habitaciones 3. México: Editorial 17.

Aguirre Arauz, Patricio. 2023. La Intersexualidad y Los Derechos Humanos En América Latina: Estado de Situación 2007–2021. *Debate Feminista* 65: 179–211. [CrossRef]

Alcántara, Eva. 2012. Llamado Intersexual: Discurso, Prácticas y Sujetos en México. Ph.D. thesis, Universidad Autónoma Metropolitana, Mexico City, Mexico.

Amato, Viola. 2016. *Intersex Narratives*. Bielefeld: Transcript Verlag.

Berger, Anne Emmanuelle. 2015. Los Fines de Un Idioma o La "Diferencia Sexual". *Revista Interdisciplinaria de Estudios de Género de El Colegio de México* 1: 6–31. [CrossRef]

Borón, Atilio. 2020. *América Latina en la Geopolítica del Imperialismo*. Buenos Aires: Editorial XYZ.

Brújula Intersexual. 2023a. *Abriendo la Brújula. Video*. Available online: https://www.youtube.com/watch?v=3XlkVJJVgbI (accessed on 14 November 2023).

Brújula Intersexual. 2023b. Camino Baró | Mensaje Por El X Aniversario de Brújula Intersexual. Video, min 00:17–00:57. Available online: https://www.youtube.com/watch?v=sjdLv3_fKLg (accessed on 14 November 2023).

Brújula Intersexual. 2023c. Mer Chalu | Mensaje Por El X Aniversario de Brújula Intersexual. Video, min 00:04–01:23. Available online: https://www.youtube.com/watch?v=_N6yb1Iekls (accessed on 14 November 2023).

Brújula Intersexual. 2023d. Orquídea | Mensaje Por El X Aniversario de Brújula Intersexual. Video, min 00:50–1:28 and 01:54–03:02. Available online: https://www.youtube.com/watch?v=eAmK05EnuVQ (accessed on 14 November 2023).

Brújula Intersexual. 2023e. Pauli | Mensaje Por El X Aniversario de Brújula Intersexual. Video, min 00:03–00:07 and 00:19–02:02. Available online: https://youtu.be/kEIJ-vU58Ww?feature=shared (accessed on 14 November 2023).

Cabral, Mauro. 2014. Derecho a la igualdad. Tercera posición en materia de género. Corte Suprema, Australia, NSW Registrar of Births, Deaths and Marriages v. Norrie, 2 de abril de 2014. *Revista Derechos Humanos* 3: 199–212.

Cabral, Mauro, and Morgan Carpenter. 2018. Gendering the Lens: Critical Reflections on Gender, Hospitality and Torture. In *Gender Perspectives on Torture: Law and Practice*. Washington, DC: Center for Human Rights & Humanitarian Law, Washington College of Law, American University, pp. 183–96.

Cabral, Mauro, ed. 2009. *Interdicciones: Escrituras de la Intersexualidad en Castellano*. Córdoba: Anarrés Editorial.

Cabral Grinspan, Mauro, Ilana Eloit, David Paternotte, and Mierke Verloo. 2023. Exploring TERFness. *DiGeSt Journal of Diversity and Gender Studies* 10: 1–13. [CrossRef]

Carpenter, Morgan. 2022. Global Intersex, an Afterword: Global Medicine, Connected Communities, and Universal Human Rights. In *Interdisciplinary and Global Perspectives on Intersex*. Edited by Megan Walker. London: Palgrave Macmillan, pp. 263–80.

Chase, Cheryl. 1998. Hermaphrodites with Attitude: Mapping the Emergence of Intersex Political Activism. *A Journal of Lesbian and Gay Studies* 4: 189–211. [CrossRef]

Davis, Georgiann. 2015. *Contesting Intersex. The Dubious Diagnosis*. New York: New York University Press.

Dreger, Alice Domurat. 2003. *Hermaphrodites and the Medical Invention of Sex*, 4th ed. Cambridge, MA: Harvard University Press.

Fausto-Sterlling, Anne. 2006. *Cuerpos Sexuados*. Barcelona: Melusina.

Feder, Ellen. 2014. *Making Sense of Intersex. Changing Ethical Perspectives in Biomedicine*. Bloomington: Indiana University Press.

Fernández de Rota, Antón. 2023. Paul Rabinow y La Antropología de Lo Contemporáneo. *Disparidades. Revista de Antropología* 78: e004. [CrossRef]

First Latin American Regional Conference of Intersex Persons. 2018. San José de Costa Rica Statement. Available online: https://brujulaintersexual.org/2018/04/13/san-jose-de-costa-rica-statement/ (accessed on 26 January 2024).

Foucault, Michel. 2001. Clase del 22 de enero de 1975. In *Los anormales*, 2nd ed. Buenos Aires: Fondo de Cultura Económica, pp. 61–82.

Gregori, Nuria. 2015. Encuentros y Desencuentros en torno a las Intersexualidades/DSD: Narrativas, Procesos y Emergencias. Ph.D. thesis, Universitat de Valencia, Valencia, Spain.

Guattari, Felix. 1992. Entrevista Félix Guattari Televisión Griega. Available online: https://youtu.be/7M928Npi6tg?feature=shared (accessed on 26 January 2024).

Guattari, Félix, and Suely Rolnik. 2006. *Micropolítica. Cartografías Del Deseo*. Madrid: Traficantes de sueños.

Holmes, Morgan. 2009. *Critical Intersex. Queer Interventions*. Ireland: Routlege.

Karkazis, Katrina. 2008. *Fixing Sex. Intersex, Medical Authority, and Lived Experience*. Durham: Duke University Press. [CrossRef]

Kessler, Suzanne J. 2002. *Lessons from Intersexed*, 3rd ed. Chicago: University of Chicago.

Laura-Inter [pseud]. 2015. Finding My Compass. *Narrative Inquiry in Bioethics* 5: 95–98. [CrossRef]

Laura-Inter [pseud], and Eva Alcántara, eds. 2024. *Brújula. Voces de La Intersexualidad En México*. Habitaciones 9. Mexico: Editorial 17. Available online: https://diecisiete.org/portadas/brujula-voces-de-la-intersexualidad-en-mexico (accessed on 26 January 2024).

Machado, Paula. 2008. O Sexo Dos Anjos. Representações e Práticas Em Torno Do Gerenciamento Sociomédico e Cotidiano Da Intersexualidade. Ph.D. thesis, Universidade Federal do Rio Grande do Sul, Porto Alegre, Brazil.

Marañón, Gregorio. 1951. *Los Estados Intersexuales Del Hombre y La Mujer*. México: Ediciones Arcos.

Matus, Alfonso. 1972. Conductas terapéuticas en problemas de intersexo. Especialidad en. Pediatria thesis, Universidad Nacional Autónoma de México, Ciudad de México, Mexico.

Mayer Foulkes, Benjamin. 2022. On Deconstruction as a Social Bond: Field Notes on 17, Institute of Critical Studies, 2001–2022. Webinar at Institute of Latin American Studies Columbia. Available online: https://www.youtube.com/watch?v=UDdB1w905Rs (accessed on 26 January 2024).

Mayer Foulkes, Benjamin. 2023. Ensamblaje crítico. Una Alianza social y Económica Productiva. Available online: https://diecisiete.org/actualidad/ensamble-critico-una-alianza-social-y-economica-pro-ductiva (accessed on 12 September 2023).

Melero, Iolanda. 2023. Ponencia Iolanda Melero Puche. In *I Jornada sobre intersexualidad del Ministerio de Igualdad*; Madrid: Ministerio de Igualdad, pp. 39–43. Available online: https://www.igualdad.gob.es/wp-content/uploads/JORNADAS_INTERSEX_accesible.pdf (accessed on 26 January 2024).

Monro, Surya, Morgan Carpenter, Daniela Crocetti, Georgiann Davis, Fae Garland, David Griffiths, Peter Hegarty, Mitchell Travis, Mauro Cabral, and Peter Aggleton. 2021. Intersex: Cultural and social perspectives. *Culture, Health & Sexuality* 23: 431–40. [CrossRef]

Morland, Iain. 2009. Introduction: Lessons From the Octopus. *A Journal of Lesbian and Gay Studies. Intersex and After* 15: 191–97. [CrossRef]

Parrini, Rodrigo. 2018. *Deseografías. Una antropología del deseo*. México: Universidad Autónoma Metropolitana.

Parrini, Rodrigo, and Karine Tinat, eds. 2022. *El Sexo y El Texto. Etnografías y Sexualidad En América Latina*. México: El Colegio de México.

Preciado, Paul B. 2022. *Dysphoria Mundi*. Barcelona: Anagrama.

Rabinow, Paul. 2006. Steps Toward an Anthropological Laboratory. Laboratory for the Anthropology of the Contemporary. Available online: https://www.ram-wan.net/restrepo/teorias-antrop-contem/Rabinow_Laboratory.pdf (accessed on 26 January 2024).

Restrepo, Eduardo, and Rodrigo Parrini. 2021. Etnografía y Producción Conceptual: De La Descripción Densa a La Teorización Singular. Conversación Con Rodrigo Parrini. *Tabula Rasa* 38: 329–62. [CrossRef]

Rolnik, Suely. 2021. *Esferas de la insurrección. Apuntes para descolonizar el inconsciente*, 2nd ed. Buenos Aires: Tinta Limon.

Rubin, David A. 2017. *Intersex Matters*. Albany: State University New York Press.

Sánchez Monroy, María Alejandra. 2018. Infografía Personas Intersex y Derechos Humanos. *Dfensor, Revista de derechos Humanos* 3: 26–27.

Sánchez Monroy, María Alejandra. 2021. Romper el Silencio, Ocupar el Espacio: Cuerpo, Experiencia y Enunciación de Tres Activistas Intersex de México. Master's thesis, Universidad Autónoma Metropolitana, Mexico City, Mexico.

Secretaría de Salud. 2017. *Guía para la atención a la intersexualidad y variación de la diferenciación sexual*, Protocolo Para el Acceso sin Discriminación a la Prestación de Servicios de Atención Médica de las Personas Lésbico, Gay, Bisexual, Transexual, Travesti, Transgénero e Intersexual y Guías de Atención Específicas, Mexico City, Mexico. Available online: https://www.gob.mx/cms/uploads/attachment/file/558167/Versi_n_15_DE_JUNIO_2020_Protocolo_Comunidad_LGBTTI_DT_Versi_n_V_20.pdf (accessed on 26 January 2024).

Toledo, Mara. 2018. Aproximación Antropológica a la Experiencia Intersexual en Tres Contextos Culturales Diferentes en México. Bachelor's thesis, Escuela Nacional de Antropología e Historia, Mexico City, Mexico.

Toledo, Mara. 2021. Erótica Del Vínculo de La Experiencias Intersexuales En México: Indicios de Violencia y Derivas Del Deseo. Master's thesis, Centro de Investigaciones y Estudios Superiores en Antropología Social, Mexico City, Mexico.

Vieira, Amiel, Anacely Guimarães Costa, Bárbara Gomes Pires, and Marina Cortez. 2021. A Excepcionalidade Da América Latina. *Revista Periódicus* 1: 220–39. [CrossRef]

WikiPedia Foundation. n.d. 'Timeline of Intersex History'. Wikipedia. Available online: https://en.wikipedia.org/wiki/Timeline_of_intersex_history (accessed on 26 January 2024).

Wittig, Monique. 1980. The Straight Mind. *Feminist Issues* 1: 103–11. [CrossRef]

social sciences

MDPI

Perspective

From Harmful Practices and Instrumentalisation, towards Legislative Protections and Community-Owned Healthcare Services: The Context and Goals of the Intersex Movement in Australia

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Abstract: People with innate variations of sex characteristics (also known as intersex traits or disorders or differences of sex development) have any of a wide range of innate physical traits that differ from medical and social norms for female and male bodies. Responses to these physical differences create experiences and risks of stigmatisation, discrimination, violence, and harmful medical practices intended to promote social and familial integration and conformity with gender stereotypes. As is evident globally, the Australian policy response to the existence and needs of people with innate variations of sex characteristics has been largely incoherent, variously framing the population as having disordered sex development in need of "fixing", and a third sex/gender identity group in need of recognition, with only recent engagement by intersex community-controlled civil society organisations. This paper presents an overview of the context and goals of the intersex human rights movement in Australia. Australian intersex community organisations have sought to apply human rights norms and develop new infrastructure to address key health and human rights issues, and necessitating new ways of resolving policy incoherence. Together with human rights, mental health, and public health institutions, they have called for significant changes to medical models of care and reform to research and classification systems. Intersex community organising and resourcing have made a tangible difference. The Australian Capital Territory is the first jurisdiction in the country to move ahead with reforms to clinical practice, including a legislative prohibition of certain practices without personal informed consent, oversight of clinical decision-making, and investment in psychosocial support. A national community-controlled psychosocial support service has also commenced.

Keywords: intersex; disorders of sex development; LGBT; human rights; social policy; health policy

Citation: Carpenter, Morgan. 2024. From Harmful Practices and Instrumentalisation, towards Legislative Protections and Community-Owned Healthcare Services: The Context and Goals of the Intersex Movement in Australia. *Social Sciences* 13: 191. https://doi.org/10.3390/socsci13040191

Academic Editor: Nigel Parton

Received: 26 January 2024
Revised: 22 March 2024
Accepted: 22 March 2024
Published: 27 March 2024

1. Introduction

People with innate variations of sex characteristics, or intersex traits, have any of a wide range of innate physical traits that differ from medical and social norms for female and male bodies. Responses to these perceptions of difference create experiences and risks of stigmatisation, discrimination, violence, and harmful medical practices intended to promote social and familial integration and conformity with gender stereotypes.

Like all stigmatised populations, a range of different language is used to describe intersex traits, but many individuals with these traits lack access to words that can help them understand themselves. Dominant ideological frameworks treat people with intersex traits as disordered and in need of "fixing", or elimination from the gene pool, and as an "other" third category of sex, in need of recognition. Each framework is reflected in different data, including disease and procedure classifications, and sex/gender classifications. Neither approach respects the diversity of the population and differing personal values and preferences. Both approaches contribute to widespread experiences of stigma and shame, including in social, intimate, and clinical settings.

This context provides a challenging landscape where different institutions have developed distinct and incommensurate policies and practices that treat the population in different ways. Policy and public incomprehension and incoherence also mean that the goals and work of the intersex movement are often poorly recognised or understood.

While multiple analyses of the early intersex movement in the United States and Canada exist (an early insider perspective can be read in (Chase 1998)), and recent legal attention has focused on advocacy within the international human rights system (Bauer et al. 2019; Lum 2021; Zelayandia-Gonzalez 2023), fewer studies have considered the goals and work of the contemporary intersex movement outside of North America, and no comparable peer-reviewed analysis has yet been published on intersex advocacy in Australia. The intention of this paper is to present a coherent overview and analysis of community responses to policy and public incoherence. The paper presents a comprehensive overview of the history and context for community development, advocacy and service delivery, and the work of community organisations to construct and seek reform. The paper begins by summarising contested definitions of the population, and outlining health issues and medical treatment practices. The paper then considers the historical context, recent developments in advocacy and service delivery, and community goals for the future.

2. Defining the Population

The population is known using a range of different terms, each associated with distinct values and contested borders. The term intersex has a medical origin and was appropriated or adopted by the first self-organised groups of intersex people in the 1990s. Up until 2006, the term intersex coexisted with pejorative traditional terms such as “hermaphrodite”, and the clinical term “pseudo-hermaphrodite”.

In 2005, an invite-only clinical meeting and subsequent “consensus statement on management of intersex disorders” introduced a new clinical umbrella term of “disorders of sex development” (DSD) (Hughes et al. 2006; Houk et al. 2006), sometimes referred to by similar terms such as “disorders of sexual differentiation” (Medicare Benefits Schedule Review Taskforce 2020) and “differences of sex development” (Kalfa et al. 2024). While these terms have been implemented within medicine, globally, they have never been accepted or adopted by community and patient organisations in Australia.

Individuals also use specific diagnostic terminology, with more than 40 distinct entities such as:

- Chromosomal variations: such as 47,XXY (Klinefelter syndrome), 45,X0 (Turner syndrome), mosaicism, mixed gonadal dysgenesis.
- Androgen production or action in people with XY chromosomes: androgen insensitivity (AIS), 5 alpha reductase deficiency, 17 beta hydroxysteroid dehydrogenase 3 deficiency.
- Androgen production in people with XX chromosomes: congenital adrenal hyperplasia, maternal androgen excess, aromatase deficiency.
- Structural variations affecting gonad or genital development: micropenis, anorchia (no testes), ovotestes, hypospadias, cloacal and bladder exstrophies, vaginal agenesis (MURCS/MRKH), gonadal dysgenesis, familial hypogonadism.

Diagnostic terminology is undergoing rapid change, from terminology using eponyms and language based on terms using the word hermaphroditism, towards descriptive terms and terms arising from genetics research.

Many Australian institutions persist in framing intersex variously as a sexual orientation (“LGBTI or heterosexual”) or a gender identity; a sex, indeterminate sex, third sex category, and “sex diverse”; or a population constructed as both adults with a marginalised identity and babies subjected to surgery. For example, some national sporting, scientific, and mental health organisations have framed intersex as a form of gender diversity (Australian Sports Commission and CSIRO 2022; Headspace 2020).

Adults with innate variations of sex characteristics have higher rates of sexuality and gender diversity or discomfort with gender roles than the general population (T. Jones 2016; Furtado et al. 2012; Nimkarn and New 2010). These factors and the possibility of so-called "natural experiments" mean that clinical work aimed at establishing the genetic or environmental origins of sexuality and gender identity has taken place on people with intersex variations (see, for example, Meyer-Bahlburg 1990). However, people with intersex variations can grow up to be heterosexual or not and cisgender women or men or not, while infants and children lack the age and agency to express any identity.

The high prevalence of misconceptions means that it is common for the word intersex to be included in descriptions of LGBTI or related population groupings without comprehending or attending to the specific needs and circumstances of the population. A national mental health organisation, for example, presents mental health considerations as relating to respect for pronouns and avoidance of heteronormative language (Headspace 2020). The diverse lifelong or chosen legal or social statuses of individuals with innate variations of sex characteristics are frequently disregarded or not comprehended (Carpenter 2020). This should be understood to directly impact service utilisation, disclosure, engagement, and nomenclature preferences by people with lived experience, irrespective of their actual identities.

A neutral language of innate "variations of sex characteristics" (VSCs or IVSCs) was introduced by community organisations in Australia and Aotearoa New Zealand from 2017 (AIS Support Group Australia et al. 2017). This terminology aims to avoid many misconceptions that impact the population, and it has utility in both legal protections from harmful practices and discrimination (Australian Capital Territory 2023), and in data collection (Australian Bureau of Statistics 2021).

The boundaries of all definitions are to some extent subjective, reflecting shifts in social and clinical constructions of boundaries between "normal" and "abnormal" bodies, as well as the role of subjective judgements by clinical individuals and groups in problematising bodies that are different. Nevertheless, Australian intersex community-controlled organisations exist for all people who risk or experience stigma and discrimination because of their innate sex characteristics or sex development, and their families.

Many people do not have a language to describe themselves. Up until 2006, with variable change since that date, many people have not been told their diagnosis, nor the facts about their medical treatment (Lee et al. 2016; Office of the Privacy Commissioner 2018; Carpenter 2024). This was thought to protect individuals from stigma but also to promote conformity with social expectations. For example, women with complete androgen insensitivity (and XY chromosomes and testes) have been told they had hysterectomies when they never had a uterus (Carpenter 2024). Disclosure of long-term consequences of surgeries has also been limited, and individuals informed of their diagnosis have been encouraged not to disclose their traits to others (Intersex Peer Support Australia 2023).

3. Health Issues

Individuals with some traits experience specific risks, including for mental health issues arising from experiences of trauma, stigmatisation, and shame, including experiences arising in medical settings. Some traits are sometimes associated with specific health issues, frequently including innate or iatrogenic infertility. Some traits need urgent treatment or may be fatal if not treated (such as salt wasting congenital adrenal hyperplasia or bladder exstrophy). Newborn bloodspot screening has been introduced to identify risks associated with salt wasting. Some traits are associated with cancer risks in gonads such as testes, ovotestes, or streak gonads. Gonadal cancer risks have an unhelpful history of exaggeration and intertwining with "psychosocial" rationales for treatment (Senate 2013; Carpenter and Intersex Human Rights Australia 2022). Psychosocial rationales are aimed at eliminating risks of stigmatisation through surgery and hormonal treatment, facilitating "social or familial integration", and mitigating parental distress. Some traits are associated with cardiovascular, skeletal, renal, neurodevelopmental, and other issues.

Diagnosis can occur prenatally, at birth, during childhood or adolescence, and later in life—for example, due to diagnosis of an intersex trait in a relative of a prospective parent, genital appearance at birth, a failure to menstruate in an adolescent girl, atypical pubertal development, or infertility. Medical responses aim to make bodies appear or function more typically in line with sex observed or assigned at birth. Depending on age of diagnosis, this can lead to medical treatments that an individual would not choose for themselves. Genetics research is contributing to the prenatal elimination of human tissues with intersex traits (Eggers et al. 2016; Amor 2020)—for example, as part of "risk estimation" in "reproductive planning for the family" (O'Connell et al. 2021; Amor 2020), despite concerns about the ethical basis for their elimination (Kirk et al. 2020; Carpenter and Intersex Human Rights Australia 2020).

Many people with innate variations of sex characteristics have significant health issues arising from medical treatment. This particularly includes experiences of trauma, loss of sensation and sexual function from unnecessary early medical interventions; limited or absent disclosure of health information, and a lack of ability to make informed decisions about treatment, including lack of access to resourced peer support; and distress from infertility or limited fertility (Office of the High Commissioner for Human Rights 2019; Australian Human Rights Commission 2021; Carpenter 2024).

It remains the norm for children with intersex variations who have a diagnosis to be subjected to surgical and/or hormonal interventions early in life (see, for example, Adikari et al. 2019). These interventions are intended to make children's bodies appear or function in ways that are more typical for observed/assigned sex and gender. For example, Australia's paediatric endocrine group has described "surgical management" as indicated "for the purpose of appearance including reduction of an enlarged clitoris or repair or construction of a urinary outlet to the end of the penis", despite "particular concern" regarding post-surgical "sexual function and sensation" (Australasian Paediatric Endocrine Group et al. 2013). "Normalising" surgeries and hormonal interventions are frequently grounded in gender stereotypes or psychosocial rationales for treatment.

Clear demonstrations of underlying gender stereotypes can be found in clinical propositions that girls with intersex variations need surgery to "enhance" genital appearance, while boys need surgery to ensure a "functional" norm of standing to urinate (Carpenter 2024; Family Court of Australia 2016; Australasian Paediatric Endocrine Group et al. 2013). Instead of mitigating risks of discrimination and stigmatisation, the Senate Community Affairs References Committee and community, public health, and human rights institutions regard these interventions as examples of discriminatory treatment, associated with the stigmatisation of bodies that are different (Senate 2013; Australian Human Rights Commission 2021; Public Health Association of Australia 2021).

These interventions can deliberately pre-empt choices made by individuals and assume future values and preferences. In addition, there is no evidence that surgeries are capable of addressing risks of stigmatisation (Lee et al. 2016; Australian Human Rights Commission 2021; Liao 2022). Medical examinations and experiences, ignorance, and shame exacerbate experiences of stigmatisation, with an impact on mental health (Liao 2022; Hegarty 2023; Hart and Shakespeare-Finch 2021; Schützmann et al. 2009) as well as sexual function and sensation.

Contested by intersex community organisations since the 1990s, the pre-emptive treatment model has been perpetuated by lack of disclosure and awareness of medical practices and by the marginalisation and exclusion of both people with lived experience and psychosocial professionals (Carpenter 2024). Medical practices are set out in invite-only expert "consensus statements" due to a lack of supporting evidence and even a lack of clinical consensus regarding surgical timing, indications, and evaluation of outcome (Lee et al. 2016). The lack of evidence and clinical consensus, as well as evidence of lack of clinical adherence to clinical guidelines, mean that guidelines are unlikely to change medical practice without the external imposition of new parameters for clinical decision-making via legislative reform (Intersex Human Rights Australia 2020).

Multidisciplinary teams evaluating treatment may consider only a subset of patients posing ethical or diagnostic “dilemmas” (Vora et al. 2016) and are led by surgeons or endocrinologists. Psychosocial care for families and individuals is often poorly understood and regarded as relevant only after surgical or hormonal treatment (Carpenter 2024). Community organisations are absent (Gramc et al. 2021; Liao 2022). The mere existence of multidisciplinary teams has been proposed as a way of improving care and sidestepping legal oversight (Vora et al. 2016), but “medically unnecessary surgical procedures that carry significant risk of harm continue to be presented as legitimate options” (Human Rights Watch 2017). At the same time, Australian clinical reports have persistently misrepresented community and institutional calls for oversight and an end to unnecessary or deferable procedures as if they are a call to end all medical treatment for children, including uncontentious and non-deferable treatment (Carpenter 2024; O’Connor 2016, p. 531; Vora et al. 2021, p. 5; Australian Human Rights Commission 2021, p. 131).

4. The Historical Context in Australia

As biological variations, intersex traits have always existed in humans, other mammals, and other species. Traditional Christian and Islamic law and common law had places for “hermaphrodites” or “al-khunthā”, to be treated as female or male, with different legal rights depending on predominant characteristics or method of urination. The term hermaphrodite has since taken on specific meanings in biology; these traditional terms are now often understood to be pejorative, and their long legal history has largely been erased. Historical First Nations approaches in these lands are not well understood; for example, the views of Tiwi subjects of scarce early Australian medical journal reports are difficult to distinguish from the medical gaze (Ford 1941; Walker et al. 1970).

Medicalisation of people with innate variations of sex characteristics occurred alongside medicalisation of sexuality and gender diverse populations, arising from moral panics about people who break social, legal, and religious expectations for women and men, girls and boys (Reis 2009). As recently as a national inquiry into religious freedoms in 2018, no evidence was found of religious motivations to discriminate against intersex people (Ruddock et al. 2018). However, moral panics about transgender people, biological-only definitions of sex that cannot account for actual observed or assigned sex, and continued associations between intersex and LGBT populations mean that conservative religious bodies are beginning to reinterpret traditional understandings to, for example, discuss “disorders of sexual development” in the same manner as transgender populations (Intersex Human Rights Australia and GATE 2019; Synod of the Diocese of Tasmania 2023).

Early surgical, hormonal, and associated interventions on infants and children arose in the 1930s and became widespread in the 1950s (Hampson et al. 1956; Reis 2009), reaching Australia by at least the 1960s (Fraser et al. 1966) and still remaining routine today (Adikari et al. 2019; Hutson et al. 2020).

The Family Court has adjudicated “special medical procedures” involving medical interventions with sterilising effects, at least since passage of the Family Law Act 1975 (Commonwealth). The Court appears to have approved every relevant case involving children with innate variations of sex characteristics, approving surgical and/or hormonal treatment in line with clinical affidavits. For example, the sterilisation of a child was authorised in the judgement of a 2016 Family Court case where the judge referred to a history of feminising surgeries on an infant as surgeries that “enhanced the appearance of her female genitalia”; that surgical history had not been the subject of court oversight (Family Court of Australia 2016; Kelly and Smith 2017; M. Jones 2018; Overington 2016). Brennan J. in the High Court of Australia, has asserted that surgeries aimed at ameliorating “cosmetic deformities” and “pathological conditions” are “therapeutic” while questioning the ability to distinguish between therapeutic and non-therapeutic treatment (High Court of Australia 1992). Australian clinicians have asserted that the review of “challenging DSD cases” or ethical or diagnostic “dilemmas” by multidisciplinary teams provides a viable alternative to court oversight (Vora et al. 2016).

The United Nations Office of the High Commissioner for Human Rights has expressed concern that "Loose conceptions of medical necessity or therapeutic treatment may facilitate social and cultural rationales, and other rationales that lack evidence of urgent need" (Office of the High Commissioner for Human Rights 2019). Nevertheless, the Australian government asserted in 2021 that "Court authorisation is required for any surgical or sterilisation procedure that is not medically necessary for children with intersex characteristics" (Working Group on the Universal Periodic Review 2021). This statement is not borne out in evidence from the 2016 Family Court case regarding surgical interventions that "enhanced the appearance" of female genitalia prior to the court case, nor subsequent clinical reports (for example, note the matter of fact disclosure of feminising surgery on infants disclosed in Adikari et al. 2019; Carpenter 2024).

Constructions of intersex people as a third sex, neither female nor male, have been evident in court decisions dating back to 1979; these adversely impact men and women with intersex variations and make their lived experiences incomprehensible. In 1979, a man, assigned male at birth with XX sex chromosomes, was described as a "true hermaphrodite" in a Family Court decision to annul his marriage (Family Court of Australia 1979). Legal discussion of his case described him as a "true trans-sexual" "assigned" by "sex change surgery" (Bailey 1979), despite his being registered male at birth, with no evidence of any attempt to change that sex registration. While criticised as creating a precedent out of step with historical norms (Finlay 1980), the decision has since remained cited as a case of a man's "mistaken identity"—that he was not really a man (Family Court of Australia 2018). Contrarily, a first passport with an "X" sex marker was issued in 2002, to a West Australian with 47,XXY chromosomes who sought this option (Butler 2003; Meyer-Bahlburg et al. 2004). Reporting of this passport decision plausibly contributed to a change in clinical nomenclature in 2006 (Hughes et al. 2006).

A public, policy, and academic focus on matters of identity has remained pervasive since (see, for example, Fenton-Glynn 2018), despite community calls to better respect the plurality of identities, lived experiences, and preferences within the population of people with innate variations of sex characteristics. For example, the "X" sex marker on passports remains associated with intersex bodies today, despite longstanding attempts to address the underlying national guidelines (National LGBTI Health Alliance et al. 2015).

The first waves of legislation referring to the population occurred in the 1990s and early 2000s, largely predating or unresponsive to intersex community development work:

- In a wave of legislation introducing anti-discrimination protections for transgender people, where definitions of transgender or gender identity included reference to "people of indeterminate sex" (Carpenter 2022). This is still evident in New South Wales anti-discrimination legislation introduced in 1996 (New South Wales 1996) and has been replaced in most jurisdictions by protections on grounds of "sex characteristics".
- In a wave of legislation (all but Western Australia between 1994 and 2000) to prohibit female genital mutilation, containing exceptions permitting surgery on children with "ambivalent sex". This is still evident in the criminal codes of most States and Territories (Attorney General's Department 2013).
- An overlapping wave of legislation regulated the recognition of transgender people, where "reassignment surgery" has been defined to include surgery to resolve or eliminate "ambiguities" in children's sex characteristics (Carpenter 2023). This remains evident in the Western Australian criminal code and gender recognition legislation (Western Australia 2000, 2004).

It seems likely that some of these developments occurred due to advocacy by transgender people, possibly informed by the 1979 Family Court decision. While these can be expected to be well intentioned, they arise out of a different set of interests and have contributed to incomprehension and harm. Some of the beliefs underlying this advocacy include a belief that association of "transsexualism" with unambiguously biological causes would ameliorate stigma and facilitate access to surgical interventions experienced by intersex people (Wallbank 2015; critiqued in Carpenter 2018).

The first Australian community organisation (Intersex Peer Support Australia or IPSA, then known as the Androgen Insensitivity Syndrome Support Group Australia), became peer-led in 1996 and registered in 2001. Originally only for people with androgen insensitivity, it was established alongside a small number of other diagnosis-specific groups. IPSA now supports all people who experience or risk stigmatisation and harm because of their innate sex characteristics and their families, and it is still run by volunteers. Intersex Human Rights Australia (IHRA) was established in 2009 and registered in 2010 to focus on health and human rights policy; funded by foreign philanthropy, its first staff were appointed at the end of 2016. IHRA began offering psychosocial support services for individuals and family members through the InterLink program in 2023, with pilot funding from the federal Department of Social Services. While still limited, resourcing has made a critical difference to the ability of IHRA to promote reform and deliver community services.

The first government reports referring to a “GLBTI” population were published over two decades ago in Victoria and addressed intersex health issues (Ministerial Advisory Committee on Gay and Lesbian Health 2002). In contrast to contemporaneous legal developments where opposition to association of intersex traits with the attribute of gender identity in anti-discrimination law was unsuccessful, this positive development was influenced by early intersex advocates and provides an indication of a longstanding community focus on health policy. Misconceptions remain pervasive in policy and LGBTQ+ community settings. With recent and important exceptions, there has been limited attention to the specific needs and circumstances of people with innate variations of sex characteristics, evidenced by a lack of widespread understanding of those needs and circumstances, and a preoccupation with identity-based protections and recognition (Carpenter 2021).

5. Recent Developments

With a growth in Australian intersex organising and resourcing over the last decade, new anti-discrimination protections have been implemented: opportunistically on grounds of intersex status in the Commonwealth in 2013, then in Tasmania and South Australia, and then on grounds of sex characteristics (Australian Capital Territory, Northern Territory, Queensland, Victoria, and Tasmania, with commitments made in the Commonwealth Parliament (Burke 2022), in Western Australia, and with a proposal before the New South Wales Parliament).

Advocacy by IHRA and disability organisations led to the explicit inclusion of intersex people in a Senate Community Affairs References Committee inquiry into involuntary or coerced sterilisation (Senate 2013). This was likely the first parliamentary inquiry into intersex health issues anywhere in the world. Reporting in October 2013, it called for significant reform to clinical practice, including establishment of human rights affirming guidelines for treatment that favour deferral of non-urgent treatment until people are old enough to make their own decisions. It also called for independent oversight of clinical decisions and resourcing for psychosocial support for individuals and families. No recommendations were implemented.

In 2017, community organisations and advocates gathered at an event in Darlington, Sydney, and developed a common platform known as the Darlington Statement (AIS Support Group Australia et al. 2017). It calls for protections from discrimination and harm, including through the criminalisation of deferrable medical interventions, independent oversight of clinical practices, resourcing for psychosocial support for individuals and families, and more.

In 2017, the Australian Human Rights Commission established an inquiry into medical practices. This followed advocacy by IHRA and also reporting of a 2016 Family Court case. Following a process supported by a reference group including community, legal, human rights, and clinical experts, it reported in 2021 (Australian Human Rights Commission 2021). In considering rationales for contested medical interventions, the Commission found that:

> *Psychosocial rationales do not rise to the standard of medical necessity to avoid serious harm, given that less intrusive options exist that should be preferred, and that psycho-*

> *logical and psychiatric experts do not believe that there is any robust scientific evidence to support the assertion that interventions in the circumstances are in the individual's best interests.* (Australian Human Rights Commission 2021)

In considering the case for binding legislation and regulation in place of non-binding clinical guidance, it found that:

> *There is a real risk that medical interventions, other than on grounds of medical necessity, may be undertaken in the future. This position is informed by the views of a range of clinicians that psychosocial factors are justifiable considerations for medical interventions, with such justifications given weight in leading international guidance documents. Therefore, overall cultural change would be unlikely in the absence of binding directions.* (Australian Human Rights Commission 2021)

The Commission called for the criminalisation of unnecessary medical interventions, with legislation and regulation to be "guided by a human rights framework based on the following principles":

- "Bodily integrity principle", recognising that all "people have the right to autonomy and bodily integrity".
- "Children's agency principle", recognising the evolving capacity of children to express their views and have their views taken into account as they get older.
- "Precautionary principle", where medical interventions should be deferred until a child can express their own views regarding treatment, "where safe to do so".
- "Medical necessity principle", recognising that some interventions on children are necessary if "required urgently to avoid serious harm to the child".
- "Independent oversight principle", where decisions about medical necessity are subject to "effective independent oversight" due to the impact and "risk of making a wrong decision" (Australian Human Rights Commission 2021).

Following a formal commitment in 2019, the Australian Capital Territory (ACT) government undertook a process of reform to clinical practices. This led, in 2023, to the introduction and passing of legislation to protect the rights of people with innate variations of sex characteristics in medical settings, alongside significant investment in psychosocial support. The legislation provides for a criminal prohibition of certain interventions, and oversight for interventions on individuals with certain variations if they are unable to personally consent (Australian Capital Territory 2023; Carpenter 2023). Provisions ensuring transparency and reporting of medical interventions, and the establishment of a Restricted Medical Treatment Assessment Board and Variations in Sex Characteristics Psychosocial Support Service, are internationally significant (Carpenter 2023). Biomedical organisations have opposed legislation. However, mental health and public health organisations have supported the reforms by the ACT government (Public Health Association of Australia 2022, 2023; Chief Minister, Treasury and Economic Development Directorate 2021). The State of Victoria has made similar commitments to reform (Department of Health 2021), with legislation anticipated to be introduced during 2024 (Department of Health 2023).

Community organisations have also begun to develop models of care and offer psychosocial support services to individuals and caregivers (Queensland Council for LGBTI Health, Intersex Human Rights Australia, and Intersex Peer Support Australia 2020a, 2020b, 2020c, 2020d), as well as critiquing existing Australian bioethical frameworks (Carpenter 2024). In 2023, the InterLink service was rolled out nationally to provide one-on-one support and group support for individuals and caregivers.

Positive developments in some jurisdictions of the Australian federation—those aligned with community demands—may be explained by the existence in those jurisdictions of governmental structures supporting community engagement, population size, community organising, and resourcing. Underpinning this, community development and networking has contributed to the development of better tools, platforms, and concepts to promote coherent understandings of the population.

6. Research and Data

Clinical practices in Australia are poorly documented in clinical reports (an exception being a brief summary of practices at a Queensland clinic in Adikari et al. 2019), but significant evidence has been constructed in clinical literature, legal cases, and engagement with national and State/Territory inquiries. As is the case elsewhere, Australian clinical studies predominantly comprise paediatric surgeons and endocrinologists studying surgical outcomes in their own paediatric patients, subject to confirmation bias, ascertainment bias, lack of standardised protocols, and other methodological concerns (Carpenter et al. 2024), often with the intention of justifying unnecessary surgical practices.

Clinical research has, for example, compared people with intersex variations against the experiences of children with a serious bowel disorder to assert that early feminising and masculinising surgeries are justified on children on the basis of satisfactory outcomes, despite lower likelihoods of experiences of orgasm and greater frequencies of pain during intercourse, and despite significant levels of distress in the population (Warne et al. 2005; Schützmann et al. 2009). Clinicians in a Victorian hospital have reported more recently on findings from studies of their own patients subjected to feminising surgeries in infancy for congenital adrenal hyperplasia; despite low response rates, reports detail outcomes of post-surgical clitoral sensitivity testing ("vibration" tests) in participating adolescents and adults, respondents' views, and (reported separately) increased probabilities of incontinence and other urinary issues (Bogdanska et al. 2015; Villegas et al. 2015; Bogdanska et al. 2018; Preston et al. 2024). Early masculinising surgeries at the same institution lack long-term follow up, with limited clinical research examining outcomes in adolescent boys, who are too young to establish long-term outcomes (Carpenter 2022; Hutson 2020). Surgeon expertise and techniques are framed as a contributing factor to improved outcomes (Hutson et al. 2020), evading arguments about the necessity or timing of surgery (Carpenter 2024). Outcomes elsewhere in Australia are not documented.

Recent international studies have explicitly sought to justify early medical interventions; these reports clearly show a lack of consensus amongst people with lived experience about the necessity and timing of surgery, identifying both significant adverse anatomical and psychosocial outcomes, as well as significant differences between patient-reported and clinician-reported evaluations of outcomes (Kalfa et al. 2024; van de Grift et al. 2022). Community organisations argue that research aimed at justifying practices that violate individuals' human rights is unethical (Carpenter 2022).

Significant Australian public research funds have been invested for more than twenty years in establishing genetic aetiologies for intersex traits. This research has been justified in part by experiences of trauma and distress in parents and people with innate variations, and conducted using human genetic samples and genetically-engineered animal models (Koyama 2003; University of Queensland n.d.; Hudson Institute of Medical Research 2020). A 2020 summary states that DSDs "are surprisingly common, and can result in genital abnormalities, gender mis-assignment, infertility and psychological trauma" (Hudson Institute of Medical Research 2020). The use of psychosocial rationales in genetics research is particularly striking given the role of harmful practices in producing poor mental health outcomes and the absence of resourcing for community-based and clinical psychosocial support services prior to the establishment of the InterLink program and ACT's hospital psychosocial support service in 2023. Further, the research is used not merely to improve diagnosis, but also to facilitate "family planning", i.e., the elimination of intersex traits from the gene pool on the basis of their undesirability (Carpenter and Intersex Human Rights Australia 2020; Kirk et al. 2020; O'Connell et al. 2021).

Data on clinical practices are available in disease classifications and Medicare Benefits Schedule (MBS) procedure classifications. Procedure codes include the paediatric-only "Congenital disorder of sexual differentiation with urogenital sinus, external genitoplasty with endoscopy and vaginoplasty" (37,848) and also "Hypospadias, examination under anaesthesia with erection test, on a person under 10 years of age" (37,816). In a process that lacked community engagement, language in the MBS associated with some paediatric surgeries was updated to "congenital disorders of sexual differentiation" as part of a review concluded in 2020 (Medicare Benefits Schedule Review Taskforce 2020). A 2019 Taskforce report stated that "Patients with DSD remain free to choose their social identity", while the availability and utilisation of these paediatric-only codes indicates that patients are not free to choose their own treatment or its timing (Medicare Benefits Schedule Review Taskforce 2019).

MBS procedure reimbursement numbers are not a good fit with known data on practices in individual hospitals; for example, the number of feminising surgeries at a single Victorian hospital reported in 2013 exceeds the national number of relevant reimbursements in contemporaneous MBS data cubes (Carpenter 2018, 2022). Given a lack of clarity about the number of procedures on children with innate variations of sex characteristics, the Victorian state government has sought to ascertain procedure volumes in that jurisdiction, but without clear conclusions. The ACT government has also sought to establish accurate numbers on procedures in its jurisdiction and has made reporting on procedures a key component of 2023 legislative reforms (Australian Capital Territory 2023). It is currently expected that this will require the development of new standards during an initial legislative implementation period.

Despite work by some leading researchers to ensure meaningful inclusion of people with intersex variations (Amos et al. 2022), "LGBTI" studies are predominantly focused on the experiences of adults with marginalised identities, and/or have had goals or preconceptions that make it difficult for people with innate variations of sex characteristics to see our needs reflected. Misconceptions remain pervasive, such as framings of intersex as a third sex, a gender, a sexual orientation, or an identity in need of recognition. These reflect a profound lack of comprehension of the population and lack of engagement with the literature, adversely impacting engagement and participation rates. Due to safeguarding and reputational risks, IHRA is unable to share most surveys but seeks to influence better practices.

An Australian pilot sociological study in 2015 on people "born with atypical sex characteristics" with 272 respondents found significant concerns, including adverse outcomes arising from medical interventions without personal consent and the impact of stigma and social, familial, and clinical attitudes; high rates of disability and poverty; and variable completion of schooling and other educational stages (T. Jones et al. 2016). While the study's descriptive title facilitated questions about nomenclature preferences, the study is a convenience sample with its own methodological limitations. It is possible to argue that no research on people with innate variations of sex characteristics has yet been truly representative, and such a study may be implausible due to the legacy of non-disclosure and partial disclosure (Carpenter 2022, 2024).

In what some researchers have termed a transition from "paediatric emergencies to a sense of abandonment" (Crocetti et al. 2023), a lack of clinical attention to the outcomes and experiences of adults with innate variations of sex characteristics contributes to a lack of structured research available on adult health and well-being. Recent US research has found a relationship between early surgeries without personal consent and later avoidance of healthcare, including both preventative and emergency healthcare (Wang et al. 2023), while Australian qualitative research has identified benefits from social and community connection (Hart and Shakespeare-Finch 2021).

The Australian Bureau of Statistics Standard on Sex, Gender, Variations of Sex Characteristics, and Sexual Orientation seeks to facilitate consistent, coherent data collection practices that respect the diversity of the population, particularly diversity in preferences for sex and gender classifications (Australian Bureau of Statistics 2021; Carpenter and Intersex Human Rights Australia 2019). It achieves this by defining sex initially in relation to legal registration at birth, where registration is typically based on sex characteristics observed at birth. The Standard is as yet unevenly implemented (Australian Bureau of Statistics 2022), but it forms the basis for new general practice guidelines (Royal Australian College of General Practitioners 2021) and a draft national statement on sex, gender, variations in sex characteristics, and sexual orientation in health and medical research (National Health and Medical Research Council and Department of Health and Aged Care 2023).

7. Community Perspectives Looking towards the Future

People with innate variations of sex characteristics are faced with a challenging set of radically different ideas about who we are and how we should live, and these limit individuals' agency to freely express values, preferences, and choices.

These different ideas include a medical model that seeks to "fix" intersex bodies, engaging multiple human rights issues, including the rights to security, bodily and mental integrity, health, sexual and reproductive rights, privacy, legal capacity, and non-discrimination (Office of the High Commissioner for Human Rights 2019). Current and historic practices also violate rights to freedom from harmful practices, ill-treatment, and violence (Office of the High Commissioner for Human Rights 2019). Additionally, people with innate variations of sex characteristics can have health needs that need attention, including some risks that can result in harm if not addressed.

At the same time, legal and social constructions of intersex reflect novel and simplistic ways of classifying and recognising people with innate variations of sex characteristics that fail to respect the diversity of individuals' lived experiences, values, and preferences.

These issues mean that intersex health and human rights advocacy is driven by simple propositions grounded in respect for the diversity of the population and its plurality in values and preferences, such that:

- To the maximum extent possible, everyone should be able to make their own decisions about their own bodies.
- Individuals should be able to access safe, appropriate, and timely medical treatment in line with actual needs and sex characteristics, including treatments that are necessary for health and well-being and treatments that affirm their values and preferences (AIS Support Group Australia et al. 2017).
- Social and community connection to other people with lived experience is essential for good health outcomes, informed decision-making, and the constructive amelioration of stigma, shame, and trauma (Hart and Shakespeare-Finch 2021).
- To the maximum extent possible, everyone should be able to make their own decisions about their identities and expression.
- A novel biologically-defined legal sex category termed "intersex" fails to respect the diversity of the population and the rights of individuals to self-determination (AIS Support Group Australia et al. 2017) and so is not supported.
- Even where considered inconvenient, birth-registered sex should always be respected unless an individual indicates otherwise (Carpenter 2020).
- It is necessary to address misinformation, disinformation, and a lack of interdisciplinary engagement across silos in order to implement effective, coherent reforms to legislation, regulation, policy, and practice.

Intersex community responses to challenging clinical, legal, and social environments have taken the form of community and capacity building, research and documentation, engagement with clinicians, legal and human rights institutions and policymakers, and the provision of trauma-informed psychosocial and peer support services. Key components of this work include attempts to create engagement across institutional silos, promoting coherent policy development that respects the plurality of individual preferences and values.

Working with other stakeholders, intersex community organisations seek to transform models of care from narrow biomedical approaches that "manage" atypical bodies through surgical and endocrinological interventions, to approaches that centre the role of psychological support in co-ordinating care, supporting caregivers, addressing stigma, and helping individuals to understand and express their own values and preferences for treatment (Carpenter 2023). As has occurred in the ACT, legislative reform appears to be a prerequisite to other forms of reform to clinical practice, such as investment in clinical and community-based psychosocial support. Intersex community organisations seek nationally consistent reforms in line with these developments.

Intersex community organisations also seek to implement and evaluate best practice healthcare pathways and develop new bioethical frameworks that centre psychosocial support and respond to community, mental health, public health, and human rights perspectives (Carpenter 2024). These include a toolkit of healthcare pathways resources developed by Bonnie Hart that present a set of best practice indicators matched to industry accreditations standards, detailing the role of peer support and advocacy services in helping individuals and families navigate healthcare services across the lifespan (Queensland Council for LGBTI Health, Intersex Human Rights Australia, and Intersex Peer Support Australia 2020a, 2020b, 2020c, 2020d). Over the next decade, community goals include the provision of intersex community-controlled healthcare services, including psychosocial support, GP services, genetic counselling, and allied health services.

In relation to MBS procedure codes, community organisations seek to eliminate paediatric-only reimbursement codes for unnecessary early surgeries and improve safe access to healthcare by adolescents and adults. Community organisations also seek to improve safe access to appropriate healthcare through the Pharmaceutical Benefits Scheme, screening programs, and adult sexual and reproductive health services, including access to fertility-related services, and call on governments to also consider how to meaningfully respond to calls for redress for people subjected to interventions without personal informed consent—for example, through access to subsidised care plans (Intersex Human Rights Australia 2022).

Reform to promote coherent data collection needs to encompass classifications of demographic data and procedure data. Reform of sex, gender, and variations of sex characteristics classifications in hospitals and other settings should align with the Australian Bureau of Statistics Standard. Data on procedures do not currently adequately capture information on numbers and rationales for medical interventions on children with innate variations of sex characteristics. It appears that reform will also be necessary to ensure adequate reporting to new legislative oversight bodies, and jurisdictions enacting legislative reforms must consider how to ensure national consistency in reporting arrangements. Consideration should be given to ways of extending the preservation of medical records. In relation to research, community organisations aim to secure resources for community-based participatory research, addressing community priorities and pervasive data gaps, while also working to ensure that medical and health research funds are not used to justify human rights violations.

In relation to education, Australian researchers report a "lack of a systematic" and affirmative approach to messaging in school curricula and support services, including in puberty and consent education (Brömdal et al. 2020; Zavros-Orr 2021). Similarly, recent international research shows best-selling psychology textbooks provide an uneven representation of the population that can lack engagement with lived experience and even "obscure genuine healthcare concerns" (Hegarty and Vaughan 2024). Improvements to better engage with lived experience and healthcare needs can promote a better understanding of the population and mitigate risks of stigmatisation and shame.

8. Conclusions

Unique features of developments in Australia include a history of incommensurate and disjointed legal and clinical policy, as well as a poorly recognised history of regulation of certain surgeries on children; nationwide policy attempts to address "LGBTI" human rights concerns; and the growth of intersex community organising to promote human rights and health, engage in community development, research, and advocacy, and develop a common community platform.

Intersex community organising and resourcing has made a difference, evidenced through significant developments in policy attention and direction, legislative reform, and service delivery. Australian intersex community organisations have sought to apply human rights norms, construct new ways of resolving policy incoherence, and develop new infrastructure to address community-identified health and human rights issues.

Consistent with calls made in the community consensus platform and by the Australian Human Rights Commission, the Australian Capital Territory is the first jurisdiction to move ahead with reforms to clinical practice, including a legislative prohibition of certain practices without personal informed consent, oversight of clinical decision-making, and investment in psychosocial support. A community psychosocial support service has also commenced. Additionally, recent developments have opened up a significant fracture within medicine, where positions on the regulation of medical practices expressed by mental health practitioners and some other national health and medical organisations are now aligned with the community platform. Together with human rights institutions and institutions of mental health and public health practitioners, community organisations have called for significant changes to medical models of care and reform to research and classification systems.

Activities to respect, protect, and fulfil the human rights of people with innate variations of sex characteristics remain a work in progress, but they can now build on significant progress, including the community platform, national inquiries, law reform, new models for resourced psychosocial support, and the development of new statistical standards.

Funding: This research received no external funding.

Institutional Review Board Statement: Not applicable.

Informed Consent Statement: Not applicable.

Data Availability Statement: Data sharing is not applicable to this article.

Acknowledgments: The author would like to thank the staff and board of Intersex Human Rights Australia and the anonymous reviewers for their generous and thoughtful feedback on this paper. He would also like to thank participants in the Centring Intersex conference, in February 2023, for their kind feedback on a presentation of the issues discussed in this paper.

Conflicts of Interest: Morgan Carpenter is Executive Director of Intersex Human Rights Australia and a Research Affiliate in the University of Sydney School of Public Health. He has been contracted to the UN Office of the High Commissioner for Human Rights and the Australian Capital Territory Government. He does or has participated in reference groups for the Australian Bureau of Statistics, Australian Department of Health and Aged Care, Australian Human Rights Commission, and New South Wales Health. He has also been appointed to the Australian Capital Territory's new Restricted Medical Treatment Assessment Board.

References

Adikari, T., B. O'Brien, T. Bagchi, and R. M. N. Kimble. 2019. Presentations and Outcomes of Patients with Disorders of Sexual Development (DSD) in a Tertiary Paediatric and Adolescent Gynaecology (PAG) Service. Paper presented at the RANZCOG Annual Scientific Meeting, Melbourne, Australia, October 13–16. Available online: https://ranzcogasm.com.au/wp-content/uploads/2019/10/243.pdf (accessed on 26 January 2024).

AIS Support Group Australia, Intersex Trust Aotearoa New Zealand, Organisation Intersex International Australia, Eve Black, Kylie Bond, Tony Briffa, Morgan Carpenter, Candice Cody, Alex David, Betsy Driver, and et al. 2017. Darlington Statement. Available online: https://darlington.org.au/statement (accessed on 26 January 2024).

Amor, David. 2020. Genetic Counselling. In *Disorders | Differences of Sex Development: An Integrated Approach to Management*. Edited by John Hutson, Sonia R. Grover, Michele A. O'Connell, Aurore Bouty and Chloe A. Hanna. Singapore: Springer, pp. 281–93. [CrossRef]

Amos, Natalie, Bonnie Hart, Adam O. Hill, G. J. Melendez-Torres, Ruth McNair, Marina Carman, Anthony Lyons, and Adam Bourne. 2022. Health Intervention Experiences and Associated Mental Health Outcomes in a Sample of LGBTQ People with Intersex Variations in Australia. *Culture, Health & Sexuality* 25: 833–46. [CrossRef]

Attorney General's Department. 2013. *Review of Australia's Female Genital Mutilation Legal Framework—Final Report*. Canberra: Attorney General's Department.

Australasian Paediatric Endocrine Group, Jacqueline Hewitt, Garry Warne, Paul Hofman, and Andrew Cotterill. 2013. Submission of the Australasian Paediatric Endocrine Group to the Senate Inquiry into the Involuntary or Coerced Sterilization of People with Disabilities in Australia: Regarding the Management of Children with Disorders of Sex Development. Submission. Available online: http://www.aph.gov.au/DocumentStore.ashx?id=aafe43f3-c6a2-4525-ad16-15e4210ee0ac&subId=16191 (accessed on 27 June 2013).

Australian Bureau of Statistics. 2021. Standard for Sex, Gender, Variations of Sex Characteristics and Sexual Orientation Variables. January 14. Available online: https://www.abs.gov.au/statistics/standards/standard-sex-gender-variations-sex-characteristics-and-sexual-orientation-variables/latest-release (accessed on 26 January 2024).

Australian Bureau of Statistics. 2022. Analysis of Non-Binary Sex Responses. September 27. Available online: https://www.abs.gov.au/articles/analysis-non-binary-sex-responses (accessed on 26 January 2024).

Australian Capital Territory. 2023. Variation in Sex Characteristics (Restricted Medical Treatment) Bill 2023 Explanatory Memorandum. Available online: https://legislation.act.gov.au/b/db_67369/ (accessed on 26 January 2024).

Australian Human Rights Commission. 2021. *Ensuring Health and Bodily Integrity: Towards a Human Rights Approach for People Born with Variations in Sex Characteristics*; Sydney: Australian Human Rights Commission. Available online: https://humanrights.gov.au/intersex-report-2021 (accessed on 26 January 2024).

Australian Sports Commission and CSIRO. 2022. The Future of Australian Sport Megatrends Shaping the Sport Sector over Coming Decades. Available online: https://www.clearinghouseforsport.gov.au/__data/assets/pdf_file/0020/1082333/The-Future-of-Australian-Sport-Second-Megatrends-Full-Report.pdf (accessed on 26 January 2024).

Bailey, Rebecca J. 1979. Family Law–Decree of Nullity of Marriage of True Hermaphrodite Who Has Undergone Sex-Change Surgery. *Australian Law Journal* 53: 659–65.

Bauer, Markus, Daniela Truffer, and Daniela Crocetti. 2019. Intersex Human Rights. *The International Journal of Human Rights* 24: 724–49. [CrossRef]

Bogdanska, M., A. Morris, J. M. Hutson, Y. Heloury, and S. R. Grover. 2015. Long-Term Urinary Symptoms in Adolescent and Adult Women with Congenital Adrenal Hyperplasia. Paper presented at the 5th I-DSD Symposium, Ghent, Belgium, June 11.

Bogdanska, M., A. Morris, J. M. Hutson, Y. Heloury, and S. R. Grover. 2018. Long-Term Urinary Symptoms in Adolescent and Adult Women with Congenital Adrenal Hyperplasia. *Journal of Pediatric Urology* 14: 240.e1–240.e5. [CrossRef] [PubMed]

Brömdal, Annette, Agli Zavros-Orr, Lisahunter, Kirstine Hand, and Bonnie Hart. 2020. Towards a Whole-School Approach for Sexuality Education in Supporting and Upholding the Rights and Health of Students with Intersex Variations. *Sex Education* 21: 568–83. [CrossRef]

Burke, Tony. 2022. Re: Fair Work Act. December 22. Personal communication.

Butler, Julie. 2003. X Marks the Spot for Intersex Alex. *The West Australian*, January 11. Available online: http://www.bodieslikeours.org/intersexalex.html(accessed on 25 October 2004).

Carpenter, Morgan. 2018. The "Normalisation" of Intersex Bodies and "Othering" of Intersex Identities. In *The Legal Status of Intersex Persons*. Edited by Jens Scherpe, Anatol Dutta and Tobias Helms. Cambridge: Intersentia, pp. 445–514. [CrossRef]

Carpenter, Morgan. 2020. Caster Semenya's Life and Achievements Are Cause for Celebration, Respect and Inclusion; Her Exclusion Is Consequential. *Journal of Medical Ethics* 46: 593–94. [CrossRef] [PubMed]

Carpenter, Morgan. 2021. Intersex Human Rights, Sexual Orientation, Gender Identity, Sex Characteristics and the Yogyakarta Principles plus 10. *Culture, Health & Sexuality* 23: 516–32. [CrossRef]

Carpenter, Morgan. 2022. Ambivalent Attention and Indeterminate Outcomes: Constructing Intersex and DSD in Australian Data. University of Huddersfield. Available online: http://www.intersexnew.co.uk/wp-content/uploads/2023/04/Morgan-Carpenter-MNC-publication-version-aihw-paper.pdf (accessed on 26 January 2024).

Carpenter, Morgan. 2023. Protecting Intersex People from Harmful Practices in Medical Settings: A New Benchmark in the Australian Capital Territory. *Australian Journal of Human Rights* 29: 409–17. [CrossRef]

Carpenter, Morgan. 2024. Fixing Bodies and Shaping Narratives: Epistemic Injustice and the Responses of Medicine and Bioethics to Intersex Human Rights Demands. *Clinical Ethics* 19: 3–17. [CrossRef]

Carpenter, Morgan, and Intersex Human Rights Australia. 2019. Researching Intersex Populations. Intersex Human Rights Australia. July 23. Available online: https://ihra.org.au/research/ (accessed on 26 January 2024).

Carpenter, Morgan, and Intersex Human Rights Australia. 2020. Genomics and Genetic Selection. Available online: https://ihra.org.au/eugenics/ (accessed on 26 January 2024).

Carpenter, Morgan, and Intersex Human Rights Australia. 2022. Submission to the Inquiry on Universal Access to Reproductive Healthcare. Intersex Human Rights Australia. Available online: https://www.aph.gov.au/DocumentStore.ashx?id=50a5b1b6-1216-47b1-a4c6-042198096a35&subId=727846 (accessed on 26 January 2024).

Carpenter, Morgan, Cynthia Kraus, and Brian D. Earp. 2024. "Should We Correct Hypospadias during Childhood?" A Question of Facts and Values. *Journal of Pediatric Urology*, *in press*. [CrossRef] [PubMed]

Chase, Cheryl. 1998. Hermaphrodites With Attitude: Mapping the Emergence of Intersex Political Activism. *GLQ: A Journal of Lesbian and Gay Studies* 4: 189–211. [CrossRef]

Chief Minister, Treasury and Economic Development Directorate. 2021. Protecting the Rights of Intersex People in Medical Settings Listening Report on Submissions Received about Regulatory Options. Available online: https://www.cmtedd.act.gov.au/__data/assets/pdf_file/0008/2004110/Options-Paper-Listening-Report.pdf (accessed on 26 January 2024).

Crocetti, Daniela, Adeline Berry, and Surya Monro. 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* 26: 332–45. [CrossRef]

Department of Health. 2021. (I) Am Equal: Future Directions for Victoria's Intersex Community. Available online: https://www2.health.vic.gov.au/about/publications/factsheets/i-am-equal (accessed on 26 January 2024).

Department of Health. 2023. Victoria's Intersex Protection System. Engage Victoria. June 18. Available online: https://engage.vic.gov.au/intersex-protection-system (accessed on 26 January 2024).

Eggers, Stefanie, Simon Sadedin, Jocelyn A. van den Bergen, Gorjana Robevska, Thomas Ohnesorg, Jacqueline Hewitt, Luke Lambeth, Aurore Bouty, Ingrid M. Knarston, Tiong Yang Tan, and et al. 2016. Disorders of Sex Development: Insights from Targeted Gene Sequencing of a Large International Patient Cohort. *Genome Biology* 17: 243. [CrossRef] [PubMed]

Family Court of Australia. 1979. *In the Marriage of C and D (Falsely Called C). FLC 90-636*. Brisbane: Family Court of Australia at Brisbane.

Family Court of Australia. 2016. Re: Carla (Medical Procedure) FamCA 7. Available online: http://www.austlii.edu.au/cgi-bin/sinodisp/au/cases/cth/FamCA/2016/7.html (accessed on 7 December 2016).

Family Court of Australia. 2018. Tien-Lao & Tien-Lao. FamCA 953. Available online: http://www.austlii.edu.au/cgi-bin/viewdoc/au/cases/cth/FamCA/2018/953.html?context=1;query=Transgender%20marriage%20austin;mask_path=au/cases/cth/FamCA+au/cases/cth/FamCAFC (accessed on 10 December 2018).

Fenton-Glynn, Claire. 2018. The Legal Status of Intersex Persons in Australia. In *The Legal Status of Intersex Persons*. Edited by Jens Scherpe, Anatol Dutta and Tobias Helms. Cambridge: Intersentia, pp. 243–53. Available online: http://intersentia.com/en/the-legal-status-of-intersex-persons.html (accessed on 12 September 2018).

Finlay, Henry A. 1980. Sexual Identity and the Law of Nullity. *Australian Law Journal* 54: 115–26.

Ford, Edward. 1941. Congenital Abnormalities of the Genitalia in Related Bathurst Island Natives. *Medical Journal of Australia* 1: 450–51. [CrossRef]

Fraser, Kenneth, M. J. J. O'Reilly, and J. R. Rintoul. 1966. Hermaphroditus Verus, with Report of a Case. *Medical Journal of Australia* 1: 1003–8. [CrossRef] [PubMed]

Furtado, Paulo Sampaio, Felipe Moraes, Renata Lago, Luciana Oliveira Barros, Maria Betânia Toralles, and Ubirajara Barroso. 2012. Gender Dysphoria Associated with Disorders of Sex Development. *Nature Reviews Urology* 9: 620–27. [CrossRef]

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: e001257. [CrossRef]

Hampson, Joan G., John Money, and John L. Hampson. 1956. Hermaphrodism: Recommendations Concerning Case Management. *The Journal of Clinical Endocrinology & Metabolism* 16: 547–56. [CrossRef]

Hart, Bonnie, and Jane Shakespeare-Finch. 2021. Intersex Lived Experience: Trauma and Posttraumatic Growth in Narratives. *Psychology & Sexuality* 13: 912–30. [CrossRef]

Headspace. 2020. Clinical Toolkit Clinical Tips: Gender Diversity. Available online: https://headspace.org.au/assets/download-cards/CT-Gender-Diversity.pdf (accessed on 26 January 2024).

Hegarty, Peter. 2023. The Psychology of People with Variable Sex Characteristics/Intersex. *Current Opinion in Psychology* 49: 101539. [CrossRef] [PubMed]

Hegarty, Peter, and Sam Vaughan. 2024. Intersex in the USA's Best-Selling Undergraduate Psychology Textbooks: Uneven Critique in an Ongoing Scientific and Ethical Crisis. *Sex Roles*. [CrossRef]

High Court of Australia. 1992. *Department of Health and Community Services v JWB and SMB (Marion's Case)*. Parkes: High Court of Australia.

Houk, Christopher P., Ieuan A. Hughes, S. Faisal Ahmed, Peter A. Lee, and Writing Committee for the International Intersex Consensus Conference Participants. 2006. Summary of Consensus Statement on Intersex Disorders and Their Management. *Pediatrics* 118: 753–57. [CrossRef] [PubMed]

Hudson Institute of Medical Research. 2020. NHMRC Ideas Grants Success. Hudson Institute of Medical Research. December 15. Available online: https://www.hudson.org.au/news/nhmrc-ideas-grants-success/ (accessed on 26 January 2024).

Hughes, Ieuan A., Chris Houk, S. Faisal Ahmed, Peter A. Lee, and Lawson Wilkins Pediatric Endocrine Society. 2006. Consensus Statement on Management of Intersex Disorders. *Archives of Disease in Childhood* 91: 554–63. [CrossRef] [PubMed]

Human Rights Watch. 2017. "I Want to Be Like Nature Made Me". Available online: https://www.hrw.org/report/2017/07/25/i-want-be-nature-made-me/medically-unnecessary-surgeries-intersex-children-us (accessed on 26 January 2024).

Hutson, John. 2020. Short, Medium and Long-Term Outcomes for DSD at The Royal Children's Hospital. In *Disorders|Differences of Sex Development: An Integrated Approach to Management*. Edited by John Hutson, Sonia R. Grover, Michele A. O'Connell, Aurore Bouty and Chloe A. Hanna. Singapore: Springer, pp. 305–18. [CrossRef]

Hutson, John, Sonia Grover, Clare Delany, and Morgan Carpenter. 2020. Intersexion: The Birth of Ambiguity. Paper presented at the Melbourne Medical Student Conference 2020, Melbourne, Australia, June 23; Available online: https://ihra.org.au/36471/intersexion-mdscx-2020/ (accessed on 26 January 2024).

Intersex Human Rights Australia. 2020. Clinical Guidelines. August 14. Available online: https://ihra.org.au/guidelines/ (accessed on 26 January 2024).

Intersex Human Rights Australia. 2022. Call for Action by the New Government. Available online: https://ihra.org.au/39860/call-for-action-2022/ (accessed on 26 January 2024).

Intersex Human Rights Australia and GATE. 2019. Joint Statement to the Congregation for Catholic Education. Intersex Human Rights Australia. June 17. Available online: https://ihra.org.au/35418/joint-statement-congregation-catholic-education/ (accessed on 26 January 2024).

Intersex Peer Support Australia. 2023. *Unspoken A Collection of Untold Intersex Stories*. Canberra: Intersex Peer Support Australia.

Jones, Melinda. 2018. Children's Health Rights and Gender Issues. *Children's Rights in Health Care*, 382–424. [CrossRef]

Jones, Tiffany. 2016. The Needs of Students with Intersex Variations. *Sex Education* 16: 602–18. [CrossRef]

Jones, Tiffany, Bonnie Hart, Morgan Carpenter, Gavi Ansara, William Leonard, and Jayne Lucke. 2016. *Intersex: Stories and Statistics from Australia*. Cambridge: Open Book Publishers. Available online: https://researchers.mq.edu.au/en/publications/intersex-stories-and-statistics-from-australia (accessed on 26 January 2024).

Kalfa, Nicolas, Josefin Nordenström, Gunter De Win, and Piet Hoebeke. 2024. Adult Outcomes of Urinary, Sexual Functions and Fertility after Pediatric Management of Differences in Sex Development: Who Should Be Followed and How? *Journal of Pediatric Urology*, *in press*. [CrossRef]

Kelly, Fiona, and Malcolm K. Smith. 2017. Should Court Authorisation Be Required for Surgery on Intersex Children? A Critique of the Family Court Decision in Re Carla. *Australian Journal of Family Law* 31: 118–33.

Kirk, Edwin P., Royston Ong, Kirsten Boggs, Tristan Hardy, Sarah Righetti, Ben Kamien, Tony Roscioli, David J. Amor, Madhura Bakshi, Clara W. T. Chung, and et al. 2020. Gene Selection for the Australian Reproductive Genetic Carrier Screening Project ("Mackenzie's Mission"). *European Journal of Human Genetics* 29: 79–87. [CrossRef] [PubMed]

Koyama, Emi. 2003. Intersexcritiques: Notes on Intersex, Disability, and Biomedical Ethics. Intersex Initiative Portland. Available online: http://www.intersexinitiative.org/publications/pdf/intersexcritiques.pdf (accessed on 26 January 2024).

Lee, Peter A., Anna Nordenström, Christopher P. Houk, S. Faisal Ahmed, Richard Auchus, Arlene Baratz, Katharine Baratz Dalke, Lih-Mei Liao, Karen Lin-Su, Leendert H. J. Looijenga, 3rd, and et al. 2016. Global Disorders of Sex Development Update since 2006: Perceptions, Approach and Care. *Hormone Research in Paediatrics* 85: 158–80. [CrossRef]

Liao, Lih-Mei. 2022. *Variations in Sex Development: Medicine, Culture and Psychological Practice*, 1st ed. Cambridge: Cambridge University Press. [CrossRef]

Lum, Stephanie. 2021. Intersex Framings within International Human Rights Law. *King's Inns Law Review* 10: 77–99.

Medicare Benefits Schedule Review Taskforce. 2019. Report from the Paediatric Surgery Advisory Group. Available online: https://www.health.gov.au/resources/publications/final-clinical-committee-report-for-paediatric-surgery (accessed on 26 January 2024).

Medicare Benefits Schedule Review Taskforce. 2020. Taskforce Report on Paediatric Surgery MBS Items. Available online: https://www.health.gov.au/resources/publications/taskforce-final-report-paediatric-surgery-mbs-items (accessed on 26 January 2024).

Meyer-Bahlburg, Heino F. L. 1990. Will Prenatal Hormone Treatment Prevent Homosexuality? *Journal of Child and Adolescent Psychopharmacology* 1: 279–83. [CrossRef]

Meyer-Bahlburg, Heino F. L., Claude J. Migeon, Gary D. Berkovitz, J. P. Gearhart, C. Dolezal, and Amy B. Wisniewski. 2004. Attitudes of Adult 46,XY Intersex Persons to Clinical Management Policies. *The Journal of Urology* 171: 1615–19. [CrossRef] [PubMed]

Ministerial Advisory Committee on Gay and Lesbian Health. 2002. *What's the Difference? Health Issues of Major Concern to Gay, Lesbian, Bisexual, Transgender and Intersex (GLBTI) Victorians*. Research Paper. Melbourne: Department of Human Services.

National Health and Medical Research Council and Department of Health and Aged Care. 2023. Statement on Sex, Gender, Variations of Sex Characteristics and Sexual Orientation in Health and Medical Research. Available online: https://consultations.health.gov.au/health-economics-and-research-division/nhmrc-mrff-draft-statement/ (accessed on 26 January 2024).

National LGBTI Health Alliance, A Gender Agenda, Organisation Intersex International Australia, Trans Formative, and Transgender Victoria. 2015. RE: Commonwealth Attorney-General's Department Review of the Australian Government Guidelines on the Recognition of Sex and Gender', September 24. Available online: https://ihra.org.au/30043/joint-submission-federal-sexgender-guidelines/ (accessed on 26 January 2024).

New South Wales. 1996. Transgender (Anti-Discrimination and Other Acts Amendment) Act 1996 No 22. Available online: http://www.austlii.edu.au/au/legis/nsw/num_act/taoaaa1996n22541.pdf (accessed on 26 January 2024).

Nimkarn, Saroj, and Maria I. New. 2010. Congenital Adrenal Hyperplasia Due to 21-Hydroxylase Deficiency. *Annals of the New York Academy of Sciences* 1192: 5–11. [CrossRef] [PubMed]

O'Connell, Michele A., Gabby Atlas, Katie Ayers, and Andrew Sinclair. 2021. Establishing a Molecular Genetic Diagnosis in Children with Differences of Sex Development: A Clinical Approach. *Hormone Research in Paediatrics* 96: 128–43. [CrossRef] [PubMed]

O'Connor, Mike. 2016. The Treatment of Intersex and the Problem of Delay: The Australian Senate Inquiry into Intersex Surgery and Conflicting Human Rights for Children. *Journal of Law and Medicine* 23: 531–43.

Office of the High Commissioner for Human Rights. 2019. Background Note on Human Rights Violations against Intersex People. Available online: https://www.ohchr.org/en/documents/tools-and-resources/background-note-human-rights-violations-against-intersex-people (accessed on 26 January 2024).

Office of the Privacy Commissioner. 2018. Handling Health Information of Intersex Individuals. *Office of the Privacy Commissioner (Blog)*. March 2. Available online: https://www.privacy.org.nz/blog/handling-health-information-of-intersex-individuals/ (accessed on 26 January 2024).

Overington, Caroline. 2016. Family Court Backs Parents on Removal of Gonads from Intersex Child. *The Australian*. December 7. Available online: http://www.theaustralian.com.au/news/health-science/family-court-backs-parents-on-removal-of-gonads-from-intersex-child/news-story/60df936c557e2e21707eb198f1300276 (accessed on 26 January 2024).

Preston, M., A. Morris, R. Villegas, J. Huston, Y. Heloury, and S. R. Grover. 2024. Surgical Timing and Complications, with Body Image, Quality of Life, Sexual Function and Genital Sensation in Patients with Congenital Adrenal Hyperplasia. *Journal of Pediatric Urology*, *in press*. [CrossRef]

Public Health Association of Australia. 2021. The Health of People with Diverse Genders, Sexualities, and Sex Characteristics Policy Position Statement. Available online: https://www.phaa.net.au/documents/item/5352 (accessed on 26 January 2024).

Public Health Association of Australia. 2022. Variations in Sex Characteristics (Restricted Medical Treatment) Bill 2022. July 7. Available online: https://www.phaa.net.au/documents/item/5646 (accessed on 26 January 2024).

Public Health Association of Australia. 2023. "An Important Step Forward": If Passed, a New ACT Bill Will Help Protect the Human Rights of Intersex Children. Intouch Public Health. April 28. Available online: https://intouchpublichealth.net.au/an-important-step-forward-if-passed-a-new-act-bill-will-help-protect-the-human-rights-of-intersex-children/ (accessed on 26 January 2024).

Queensland Council for LGBTI Health, Intersex Human Rights Australia, and Intersex Peer Support Australia. 2020a. Intersex Health and Wellbeing Best Practice Indicators. Available online: https://ihra.org.au/pathways/ (accessed on 26 January 2024).

Queensland Council for LGBTI Health, Intersex Human Rights Australia, and Intersex Peer Support Australia. 2020b. Intersex Health and Wellbeing Healthcare and Service Map. Available online: https://ihra.org.au/pathways/ (accessed on 26 January 2024).

Queensland Council for LGBTI Health, Intersex Human Rights Australia, and Intersex Peer Support Australia. 2020c. Intersex Health and Wellbeing Psychosocial Impact Map. Available online: https://ihra.org.au/pathways/ (accessed on 26 January 2024).

Queensland Council for LGBTI Health, Intersex Human Rights Australia, and Intersex Peer Support Australia. 2020d. Intersex Health and Wellbeing Service Referral Flowchart. Available online: https://ihra.org.au/pathways/ (accessed on 26 January 2024).

Reis, Elizabeth. 2009. *Bodies in Doubt: An American History of Intersex*. Baltimore: Johns Hopkins University Press.

Royal Australian College of General Practitioners. 2021. RACGP Standards for General Practices (5th Edition) Fact Sheet: Collecting and Recording Information about Patient Sex, Gender, Variations of Sex Characteristics and Sexual Orientation. Available online: https://www.racgp.org.au/FSDEDEV/media/documents/Running%20a%20practice/Practice%20standards/5th%20edition/Collecting-and-recording-information-about-patient-sex-gender.pdf (accessed on 26 January 2024).

Ruddock, Philip, Rosalind Croucher, Annabelle Bennett, Frank Brennan, and Nicholas Aroney. 2018. Religious Freedom Review: Report of the Expert Panel. Australian Government. Available online: https://www.ag.gov.au/rights-and-protections/publications/expert-panel-report-religious-freedom-review (accessed on 26 January 2024).

Schützmann, Karsten, Lisa Brinkmann, Melanie Schacht, and Hertha Richter-Appelt. 2009. Psychological Distress, Self-Harming Behavior, and Suicidal Tendencies in Adults with Disorders of Sex Development. *Archives of Sexual Behavior* 38: 16–33. [CrossRef]

Senate. 2013. Involuntary or Coerced Sterilisation of Intersex People in Australia. Available online: http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Involuntary_Sterilisation/Sec_Report/index (accessed on 26 January 2024).

Synod of the Diocese of Tasmania. 2023. Minutes of the Second Ordinary Session of the 55th Synod of the Diocese of Tasmania. Available online: https://anglicantas.org.au/synod-2023/ (accessed on 26 January 2024).

University of Queensland. n.d. NHMRC PROGRAM GRANT: Molecular Genetics of Sex Determination and Gonad Development—UQ Researchers. Undated. Available online: http://researchers.uq.edu.au/research-project/7617 (accessed on 26 January 2024).

van de Grift, Tim C., 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: 394–405. [CrossRef] [PubMed]

Villegas, R., A. Morris, M. Bogdanska, and S. R. Grover. 2015. Congenital Adrenal Hyperplasia (CAH) in Melbourne: Surgical Timing and Complications, with Outcomes Including Body Image and Genital Sensation in a Cohort Study. Paper presented at the 5th I-DSD Symposium, Ghent, Belgium, June 11.

Vora, Komal A., Chloe A. Hanna, Kristen A. Neville, Philip B. Bergman, Sonia R. Grover, Michele A. O'Connell, and Shubha Srinivasan. 2021. Role of Cross-campus Multidisciplinary Team Meetings in Decision-making for Children and Adolescents with Differences of Sex Development/Intersex. *Journal of Paediatrics and Child Health* 57: 1402–7. [CrossRef] [PubMed]

Vora, Komal A., Chloe Hanna, Philip Bergman, Justin Brown, Rebecca Deans, Sonia Grover, and Yves Heloury. 2016. Multidisciplinary Team (MDT) Review of Management Decisions in Disorders/Differences of Sex Development (DSD): Experience of Two Paediatric Tertiary Hospital Networks. Paper presented at the Australasian Paediatric Endocrine Group Annual Scientific Meeting—APEG 2016, Alice Springs, NT, Australia, August 14–17; Alice Springs: Alice Springs Convention Centre.

Walker, A. C., E. M. Stack, and W. A. Horsfall. 1970. Familial Male Pseudohermaphroditism. *Medical Journal of Australia* 1: 156–60. [CrossRef]

Wallbank, Rachael. 2015. The Legal Status of People Who Experience Difference in Sexual Formation and Gender Expression in Australia. In *The Legal Status of Transsexual and Transgender Persons*. Edited by Jens M. Scherpe. Cambridge: Intersentia, pp. 457–526.

Wang, Jeremy C., Katharine B. Dalke, Rahul Nachnani, Arlene B. Baratz, and Jason D. Flatt. 2023. Medical Mistrust Mediates the Relationship Between Nonconsensual Intersex Surgery and Healthcare Avoidance Among Intersex Adults. *Annals of Behavioral Medicine* 57: 1024–31. [CrossRef] [PubMed]

Warne, Garry, Sonia Grover, John Hutson, Andrew Sinclair, Sylvia Metcalfe, Elisabeth Northam, Justin Freeman, and Murdoch Children's Research Institute Sex Study Group. 2005. A Long-Term Outcome Study of Intersex Conditions. *Journal of Pediatric Endocrinology & Metabolism: JPEM* 18: 555–67.

Western Australia. 2000. *Gender Reassignment Act 2000*. Perth: Government of Western Australia.

Western Australia. 2004. *Criminal Code Amendment Act 2004*. Perth: Government of Western Australia.

Working Group on the Universal Periodic Review. 2021. *Report of the Working Group on the Universal Periodic Review Australia Addendum Views on Conclusions and/or Recommendations, Voluntary Commitments and Replies Presented by the State under Review. A/HRC/47/8/Add.1*. New York: United Nations General Assembly. Geneva: Human Rights Council.

Zavros-Orr, Agli. 2021. Raising Awareness and Visibility of the "I": An Appraisal of Curricula and Its Impact on Children with Intersex Variations. *Psychology of Sexualities Review* 12: 34–48. [CrossRef]

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

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From Intersex Activism to Law-Making—The Legal Ban of Intersex Genital Mutilation (IGM) in Greece

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Abstract: In 2022, Greece became the fifth country in the world to legally ban Intersex Genital Mutilation (IGM). The bill was prepared by the Ministry of Health and the intersex-led organisation “Intersex Greece”. Even though the organisation was only established in 2021, it was actively engaged in the whole law-making process, which resulted in a legal text that became a best practice worldwide. This article tracks the history of the intersex movement in Greece and shows that the movement emerged around 2009. Then, based on online interviews, blogs, videos and articles, all strategies and alliances used by the movement over the years to advocate for intersex rights are explored, especially in the year 2017 when the law on Legal Gender Recognition (LGR) was passed and in 2022 when IGM was banned. Furthermore, online public documents from the Greek Parliament are consulted to provide a comprehensive analysis of how the social, cultural, economic, and political environment in the country affected these legal developments. Based on the above evidence, this article shows that the law-making process on IGM in Greece started 13 years before the law and was the outcome of a long process of multiple and unique intersecting factors.

Keywords: intersex movement; legal change; IGM ban; Intersex Greece

Citation: Pikramenou, Nikoletta. 2024. From Intersex Activism to Law-Making—The Legal Ban of Intersex Genital Mutilation (IGM) in Greece. *Social Sciences* 13: 221. https://doi.org/10.3390/socsci13040221

Academic Editors: Surya Monro, Tanya Ni Mhuirthile, Amets Suess Schwend, Fae Garland, Daniela Crocetti, David Andrew Griffiths and Katrina Roen

Received: 7 March 2024
Revised: 9 April 2024
Accepted: 15 April 2024
Published: 18 April 2024

1. Introduction

Intersex people are born with sex characteristics that do not fit typical binary notions of male or female bodies.[1] As of 2019, 131 million people have been born with intersex traits (Ibid. See also (Ghattas 2019, p. 9)), meaning that almost 1 person in 60 has a variation of sex characteristics.[2] Even though the term “intersex” is an umbrella term used to describe a wide range of natural bodily variations, the term “middlesex” in Greece (μεσοφυλικός/mesofylikos or μεσόφυλος/mesofylos) is often wrongly used, failing to express the intersex reality. Thus, the intersex community has been advocating to completely remove it from public documents and replace it with the term “intersex” written in Greek letters (΄ιντεϱσεξ). This term might not be Greek, but it is preferred because, in the Greek language, the term for trans people is “diemfylikoi” (διεμφυλικοί) and is confused with the term for intersex, which is “diafylikoi” (διαφυλικοί) (Intersex Greece 2023, p. 8).

According to Intersex Greece, the sole intersex-led organisation in the country, the initiation of the intersex movement’s organisational efforts dates back to 2006, when a group of intersex women and parents of intersex girls created a collective. In 2013, a secret Facebook group of mothers of XXY children started its activity online. The group initially used medical names such as “Klinefelter syndrome” and “Turner syndrome”, as its members were not aware that all these variations were grouped under the umbrella term “intersex” (Ibid.). In 2021, this group evolved into an organisation, and on 19 July 2022, Greece became the fifth country in the world to ban Intersex Genital Mutilation (IGM)[3] and criminalise doctors who perform it with Law 4958/2022 (Intersex Greece 2022). Preceding Greece, Malta, Portugal, Germany, and Iceland had already prohibited Intersex Genital Mutilation (IGM), with only Malta going a step further by criminalising it (see Section 3).

The primary objective of this article is to demonstrate the intrinsic connection between the legal changes that transpired in 2022 and the organisational efforts within the intersex community—a connection influenced by a variety of cultural, social, political, and economic factors. In pursuit of this objective, the article traces the evolution of the intersex movement in Greece by examining available online evidence. The investigation reveals that the Greek intersex movement began gaining visibility around 2009, marked by the publication of an online blog wherein an intersex individual shared their personal story. Then, based on online interviews, blogs, videos, and articles by intersex activists, all strategies and alliances used by the movement over the years to advocate for intersex rights are explored, especially in 2017, when the law on Legal Gender Recognition (LGR) was passed, and 2022, when IGM was banned. Furthermore, online journal articles and public documents from the Greek Parliament are consulted to conduct a comprehensive analysis of how the social, cultural, economic, and political environment in the country affected these legal developments. This study also incorporates sources from countries other than Greece to underscore the linkages between national developments and broader European and global contexts.

In this article, an online methodology was preferred as intersex organisations have flagged the risks that traditional methods of collecting and analysing data through interviews held by non-intersex researchers may entail. For instance, Morgan Carpenter mentioned in 2012 that "research on intersex populations frequently suffers from framing effects" and highlighted the importance of community-based participatory research that recognises and responds to those distinct concerns (Carpenter 2012). Nonetheless, in 2021, Intersex Greece publicly denounced a university research project where its members participated and were interviewed by non-intersex researchers. The organisation claimed that the analysis and interpretation of data were problematic, leading to an "incomplete and non-inclusive portrayal of the intersex reality and intersex experience" (Intersex Greece 2023, p. 28). This paper seeks to deploy the plethora of already published online testimonies and interviews by intersex individuals and offer an alternative method, in an effort not to re-traumatise a community already burdened with physical and psychological distress. The author used sources that are online and public and produced by key figures of the debate following purposive sampling, led by a historical analysis of the sources available. The search engine that was used was Google, and 15 online pages are included in this article based on the selection criteria.

Lastly, this article aims to expand the field of intersex studies as, until now, it has mostly focused on Catholic, Protestant, Western, Northern European, and Anglo-Saxon countries,[4] failing to depict the situation of intersex rights in countries such as Greece, which is an orthodox country, situated in Southeastern Europe on the southern part of the Balkan Peninsula. This occurrence is attributed to various factors, such as the nascent nature of the field of intersex studies, economic disparities among countries, and language barriers. To address the language barrier, two annexes have been appended to the conclusion of this article, featuring translations of pivotal documents from Greek to English. This inclusion aims to facilitate global dissemination and be useful to individuals actively involved in advocating for intersex rights. It is important to acknowledge that dialogues documented in parliamentary proceedings may potentially be triggering for certain audiences.

2. The Emergence of the Greek Intersex Movement

2.1. The Very Beginning: Intersex Stories "Blossoming" Online (2009–2017)

The global intersex movement gained momentum in the 1990s (Greenberg 2012, p. 85) and has experienced substantial expansion in the subsequent years, persisting to the present day. According to the Astraea Lesbian Foundation for Justice, the first organisations emerged in Australia, North America, Germany, New Zealand, Argentina, and South Africa (Astraea Lesbian Foundation for Justice 2016, p. 10). During the 2000s, the number of groups working for the human rights of intersex people kept on growing steadily. Between 2012 and 2014 in particular, intersex activists founded more than 10 new groups, including the creation of OII Europe,[5] an umbrella organisation campaigning at the European level (Ibid.). Amidst this explosive development of the intersex movement,[6] the blog "Intersex

Flower Greece" was created in 2009 by a person who identified as an intersex woman born with XY chromosomes and used the online name "Intersex Flower."[7] The year of its creation is not a simple coincidence: in their first post, "Caster Semenya," they explain that they were inspired by the global attention that the athlete received the same year.

Semenya won the women's 800 m gold medal at the World Athletics Championships in Berlin in 2009, and her performance triggered a number of questions (Swarr et al. 2009, p. 657) related to her sex characteristics.[8] Scholars have drawn from Semenya's case to criticise outdated policies that rigidly define the female–male binary as an absolute norm (See, for instance, (De Marcilla Musté 2022)) and suggest education on intersex issues as a tool towards equality (See Swarr et al. 2009; Jensen et al. 2022). Nonetheless, an element that is overlooked in academic discourse is the timing: Semenya's case became viral in 2009, meaning that it coincided with the explosive expansion of the intersex movement (Howe et al. 2017, p. 12). It could be assumed that Semenya's case played a pivotal role in elevating intersex visibility and empowering individuals within the intersex community to claim their rights. This, in turn, may have contributed to the hastening of community organising efforts.

The first post of Intersex Flower received nine responses, sparking prompt discussions on the appropriate terminology to be employed in Greek discourse concerning intersex issues. "Hermaphrodite" was already considered as a term that fails to depict the variations of sex characteristics of intersex people, while the earlier mentioned term "diaphylikos" (διαφυλικός, intersex) was often confused with the term "diemphylikos" (διεμφυλικός, trans). Intersex Flower stated that they had been in touch with intersex women in Greece online. However, organising and publicly disclosing their identity posed challenges due to media perpetuating negative stereotypes about intersex individuals. This was compounded by journalists' lack of awareness regarding intersex issues.[9]

The next post of Intersex Flower followed the same day, and they narrate how they discovered they were intersex during puberty and the lack of scientific knowledge from the medical community regarding their "condition". In the post that followed, on 31 August 2009, they explained that doctors presented to their parents only one option, which was the performance of IGM, and the doctors did not inform Intersex Flower even though they were 15 years old and could make decisions for themselves. On the same day, Intersex Flower uploaded a new text, which presented in more detail how they were mistreated by several doctors and in different hospitals due to a lack of knowledge and prejudice. At the end of the text, they mention that there will be a new text, but the blog has not been updated since 2009. Still, the first online denouncement of medical violence against intersex people remains on the internet, signalling the public birth of the intersex movement in Greece.

2.2. Out and Proud! Standing Up for Intersex Rights (2017–2021)

On 26 October 2017, the day of intersex visibility, Lakis Kandilis gave the first interview as an intersex person to *Antivirus Magazine* (Thanopoulos 2017b). He explained that he chose to openly identify as an intersex person with the intention of increasing the visibility of such individuals (Ibid.). He shared his story saying that in 2010, at the age of 28, he experienced severe pains followed by blood loss. After visiting several doctors who could not issue a diagnosis, he was sent to Thessaloniki Hospital. There, a team of 12 doctors determined that he was born with XXY. However, due to the absence of current scientific knowledge, they terrified him by suggesting that by the age of 35, he might develop breast cancer (Ibid.). Later in 2018, it appears that Kandilis talked publicly during the Radical Pride of Thessaloniki.[10]

Before Kandillis, on 6 October 2017, Irene (Rinio) Simeonidou gave her first interview to the same magazine, a journal primarily addressed to Lesbian, Gay, Bisexual, Trans, and Queer (LGBTQ) people (Thanopoulos 2017a). She mentioned that she became aware of intersex in 2009 when she was pregnant with her second child. The doctor at the local hospital recommended terminating her pregnancy solely because they had identified a karyotype that was "uncommon." Despite the doctor's advice, she decided not to terminate her pregnancy and to give birth to her child. Afterwards, she established a webpage, and numerous families reached out to her facing similar situations: doctors advising them to terminate pregnancies due to the likelihood of their children being born intersex. She also noted that families who chose not to terminate faced pressure from doctors to undergo surgeries on their children in order to conform to the female–male binary.

Simeonidou's interview was the first to shed light on selective abortions that take place because the foetuses have karyotypes that fall outside of the XX and XY binary. These karyotypes, apart from their divergence from what is considered "normal," do not display any diagnosable illness. This was probably the first interview to spark a dialogue on selective and forced abortions not only at the national but also at the international level. At present, the issue is included in the demands[11] and submissions (See, for example, (Written Individual Submission 2018, p. 2)) of the intersex community and in public speeches[12] of intersex activists, but no other parent[13] has raised it publicly. It is worth noting that even though in 2022 the United Nations Committee on Economic, Social and Cultural Rights in its General Comment No. 22 characterised selective abortions as a form of violence against intersex persons, intersex advocacy still focuses primarily on the performance of IGM as a form of violence and torture.[14] This may be due to two factors. First, there is not as much data available on selective abortions as on the performance of IGM.[15] Second, the topic of abortions may be considered as more "controversial" and including it as a top priority in the intersex advocacy agendas could lead to a backlash. Especially during recent years, there have been rapid developments concerning the right to abortion[16] in many countries worldwide, exacerbating the controversies that have surrounded the issue for decades (See Kelley et al. 1993; Tamney et al. 1992).

Following this interview, Simeonidou garnered increased attention. From 2017 onwards, despite not being an intersex individual herself, her story became the primary result on the internet when someone searched for information on intersex. After her appearance in the Greek Parliament in 2017 (See Section 3), she gave an interview to *LiFO* (Antonopoulos 2017), a mainstream and influential publication, where she shared her personal story and parenting experience. She also focused on the alliances she had made, as in the absence of intersex-led organisations, she partnered with national LGBT organisations such as Rainbow School and Rainbow Families (Verde 2017). In 2019, she published an article together with a picture of her child from the European Intersex Community Event (Simeonidou 2019), meaning that she had been receiving support from OII Europe. She focused again on her story and provided some data, stating that "today we know that more than 80% of intersex pregnancies are terminated unnecessarily, with medical prompting or pressure and the frightened consent of uninformed or fearful parents, purely because of prejudice" (Ibid.). The data to which she referred are probably based on information personally gathered by her over the years, as she did not attach any source. The same year, she shared her story during TEDxLesvos (TedxTalks 2018), and at present, this video has had 7.300 views.

Simeonidou's narrative continues to be the most widely covered in Greece. However, it is noteworthy that she is not intersex herself. Her story primarily revolves around selective abortions, setting it apart from other parents' accounts that often centre on decisions related to the performance of Intersex Genital Mutilation (IGM) on their children.[17] The publicity and acceptance that her story received could originate from Greek culture and values, and it could be linked with the role of the mother in Greek society (See Romero and Cid López 2018; Myers n.d.). Davaki states that in Greece, the heteronormative family is considered a sacred institution and motherhood is highly valued (See Davaki 2013). Tsouroufli notes that Greek literature is replete with heroic, selfless mothers who have suffered silently to protect their honour and children (Tsouroufli 2020). Christensen also underlines that, in Ancient Greece, women, and especially mothers, were of decisive importance in the world of poetry and mythology, and there was an entire genre of poetry dedicated to telling the stories of heroic families based on daughters-in-law and mothers, who helped humanise the heroes (Christensen 2023). It could be assumed that Greeks appeared to be receptive to Irene's story because she impersonates a "selfless", "modern hero" mother who did everything to protect her child's life despite the doctors' advice.

According to the official website of Intersex Greece, the organisation began its activity as a "collective" and online. It started as a small group on Facebook, which, by 2021, had more than 240 members, including 120 families of intersex children and adults.[18] This small group evolved into a nationwide organisation of intersex people, their families, and allies located in all parts of Greece.[19] After the establishment of the organisation, Simeonidou stated that through the provision of peer-to-peer support, "more than 10 children who would have been victims of ignorance or misinformation have been saved in the last decade from involuntary terminations of pregnancies or cosmetic surgeries" (Elmatzoglou 2021). This statement underscores that putting an end to such practices is one of the organisation's foremost priorities. The first public event of the organisation took place in 2021, making it a landmark year for the visibility of the intersex movement in Greece.[20] Drawing from information available on the organisation's Facebook page, in the years that followed, they started raising awareness on intersex issues through events that were addressed to the medical community, teachers, families and the public in general.[21] In 2021, Kandilis called intersex people in the country to join the movement (Antivirus Magazine 2021), but he remains the only intersex person to have come out publicly, and even though Intersex Greece is intersex-led, there are no other members to date that have shared their experiences publicly.[22]

Intersex Greece managed to achieve legal change the year after its official establishment, and this is extremely rapid compared to the time that other organisations required in Greece to achieve similar results. For instance, the Transgender Association was officially established in 2010,[23] and it achieved legal change seven years later, with the law on LGR (See Section 3). This very rapid growth of the organisation could be explained by the size of the global intersex movement compared to other LGBT movements.[24] The global count of intersex activists is relatively modest, but with the backing of ally organisations, intersex groups are actively collaborating, supporting one another, and achieving their advocacy objectives (Howe et al. 2017, p. 23).

3. Law 4491/2017: A "Missed Chance" for Intersex Rights?

The first attempt to legally ban IGM in Greece was in 2017. Before 2017, the only country that had legally banned IGM was Malta, with the Gender Identity, Gender Expression and Sex Characteristics (GIGESC) Act.[25] At the time, Malta had elected a Labour-led government, which created an LGBT-friendly Ministry for Civil Liberties. Still, there were no intersex-led organisations in the country, and this gap was filled by international intersex activists. After the IGM ban in Malta, it was reported that governmental delegations, including those from Greece, visited the country to inform changes to their own laws (Howe et al. 2017, p. 9). Indeed, the Maltese law with a focus on the protection of gender identity is referenced several times in reports by the Greek National Commission on Human Rights in 2015[26] and the documents published by the Hellenic Parliament together with Law 4491/2017.[27]

In 2017, the coalition of the Radical Left (SYRIZA) and the Independent Hellenes (ANEL) governed Greece (Mylonas 2018, p. 121). The economy remained fragile, meaning that the Bill was passed in a period of political instability (UNHCR 2017). The Bill was drafted by a committee consisting mainly of academics (Kaiafa-Kmpanti et al. 2017, pp. 1, 7), and it appears that the only member of the civil society involved was the Transgender Association. However, according to its president, Marina Galanou, they did not have the chance to be actively engaged throughout the process (Ibid, p. 7). On 3 April 2017, an event was organised in Thessaloniki where academics, politicians, and activists who took part in the law-making talked about the Bill that was already submitted to the Ministry of Justice on 18 November 2016. In their presentations, they mention intersex several times, and a member of the committee, Professor Katerina Fountedaki, analysed Article 2, which provides the definition of “sex characteristics,” and Article 7 (See Appendix A), which bans IGM (Ibid.). The term “sex characteristics” used in the text is a legal term that was introduced in 2015 by the Maltese Act to offer protection to intersex people for the first time. Since then, the term has been widely used in international and European documents to refer to intersex people (For example, see Free & Equal UN 2017; The European Parliament 2019). Even though Article 2 remained in the text that reached the Parliament, Article 7 disappeared when the text was delivered from the Drafting Committee to the Ministry of Justice, Transparency and Human Rights and never reached the Parliament.[28]

In June 2017, and before the Bill reached the Parliament, SYRIZA organised an event during Pride Festival and the General Secretary of Transparency and Human Rights and said that there would be a new Bill specifically on intersex children in collaboration with the Ministry of Health (Left 2017). Later, in September 2017, Simeonidou went to the Parliament, representing the organisation “Rainbow School” and presented the issues that intersex children face and shared her story on sex-selective abortions. While at the parliament, Kontonis, who was the Minister of Justice, Transparency and Human Rights, told her that “this bill does not refer to intersex persons” (See Appendix A) and repeated what the General Secretary had earlier said about a new Bill on intersex. It is clear that the intentions of the Drafting Committee were to include the ban of IGM in the Bill, while the intentions of the Ministry were to only limit this Bill to trans individuals; hence, Art. 7 was deleted before reaching the parliament. Unfortunately, Art. 2 on “sex characteristics” was not deleted, and this sparked endless confusion and controversial discussions during the voting process. In the Explanatory Memorandum of the Bill, “sex characteristics” is used to refer to trans individuals and elaborate on the fact that the law protects the gender identity of trans persons through their LGR and “sex characteristics” since they will not have to go through a surgical operation to access LGR (Ibid.). In the same document, the term “biological characteristics” is used in an effort to explain that the Bill applies to both trans and intersex people, as both—whether they are trans or “middlesex”—experience “gender dysphoria.”[29] On the contrary, the Report for the Bill, which was prepared by the Scientific Service of the Parliament, does not link the Bill to intersex people (Ibid.).

The confusion escalated during the discussions at the Parliament on 9–10 October 2017. Delis, Giokas and Pafilis from the Communist Party of Greece stated that transgender persons experience a conflict between their “sex characteristics” and the gender with which they identify (Ibid.). This is not in line with the definitions issued by human rights institutions. For example, according to the definition of the Commissioner for Human Rights, “transgender persons include persons who have a gender identity which is different from the gender assigned to them at birth” (Commissioner for Human Rights 2011, p. 132). Karakostas, Michaloliakos, Koukoutsis from Golden Dawn referred to sex characteristics to show that they are strictly biological and therefore gender cannot change as it is predetermined during the foetal phase (See Appendix A). In that case, the term “sex characteristics” was used by the far right to rationalise their opposition to the Bill, claiming that they combat the destruction of the human race—a theory used widely by the anti-LGBTI movements (See Strand et al. 2021). Kiriazidis of Nea Dimokratia said that more experts are needed to verify whether an individual is eligible for LGR because the Bill, as it stands, is confusing as it includes “sex characteristics” in Art. 2, which are biological. However, the rest of the provisions stipulate that they can change according to the person’s will (See Appendix A). Amidst this confusion, Kontonis clarified that the Bill was not about intersex, and he referred to the developments regarding the protection of their rights at the Council of Europe (CoE): “intersex people should also be given the opportunity to identify themselves and not necessarily in the male-female binary, but that there should be a blank or third entry, something that we must also take seriously into account in this bill and that we will submit the relevant amendment”. (Ibid.). Kontonis was referring to Resolution 2191 (2017) (Parliamentary Assembly 2017), but Art. 7 was about the ban on surgeries performed on intersex infants and not about the LGR of intersex. Later, Ourousidis from SYRIZA referred to Simeonidou’s presentation and linked surgeries and abortions to LGR as doctors aim to either fit intersex people in the binary or terminate their lives before they are born due to the absence of their LGR (Ibid.).

It is with no doubt that IGM could have been banned in Greece in 2017, but the Ministry decided that it should be postponed in a political move that is not surprising. The same occurred with civil unions, which used to be exclusionary against same-sex couples, and Law 4356/2015 granted them access when the country was called to implement the ECtHR's decision in Vallianatos and Others v. Greece. Regarding trans rights, before Law 4491/2017, the developments at the ECtHR with Goodwin v. UK and at the CoE with Resolution 2048 (2015) (Parliamentary Assembly 2015) were referenced many times in key events and documents.[30] Nevertheless, the exclusion of intersex people from the Bill was profoundly problematic, revealing a glaring lack of education on intersex issues among the vast majority of those involved in the entire legislative process. The term "sex characteristics", intended to safeguard the rights of intersex individuals, unfortunately, had adverse effects on trans rights and led to the complete invisibility of intersex people. In his first interview, Kandilis stated that Law 4491/2017 was a "missed chance" for intersex rights.[31] Indeed, the legal protection of the rights to bodily integrity and self-determination for intersex infants and children has been established since 2017. However, the effective implementation of Article 7 would likely have faced considerable challenges, given the widespread misinformation about intersex issues and their frequent confusion with transgender concerns.

4. Law 4958/2022, Articles 17 to 20: "A Law about Us with Us"[32]

From 2017 to 2022, three additional European countries legally prohibited IGM: Portugal, Germany[33] and Iceland.[34] In Greece, in 2022, Nea Dimokratia was in power, having secured a single-party majority in the 2019 elections (Freedom House 2022). The economy was slowly recovering compared to the conditions in 2017 (Bank of Greece Monetary Policy 2023). On 17 March 2021, the prime minister decided to form a committee to draft the National Strategy for Equality of LGBTQI+ (National Strategy for the Equality of LGBTQI+ 2021). This development followed the European Union's LGBTIQ Equality Strategy 2020–2025 (European Commission 2023). For the first time, the National Strategy incorporated an analysis of intersex issues (National Strategy for the Equality of LGBTQI+ 2021, pp. 51–53), following a comprehensive submission received by the Committee from Intersex Greece (Intersex Greece 2021). This submission proved immensely valuable, marking the first instance where intersex issues were distinctly separated from transgender ones. Finally, the term "sex characteristics" was appropriately employed, and the approved term "intersex"—as recognised by the Greek community—was consistently utilised throughout the text. Moreover, the submission established the primary priorities for the protection of intersex rights, with the foremost priority being the prohibition of "normalising" surgeries on intersex infants and children. Additional priorities encompassed advocating for the inclusion of the protective term "sex characteristics" in all relevant legal documents for intersex people,[35] ensuring access to their medical records and promoting inclusive and non-pathologising healthcare services, especially for intersex infants and children. It also involved creating mechanisms for psychosocial support for intersex individuals and their families, integrating intersex issues into education and awareness-raising programs, establishing a secure school environment for intersex individuals, and introducing integration programs for intersex people in employment.

Shortly after the publication of the Strategy, Intersex Greece began working closely with the Ministry of Health on the draft text of Law 4958/2022 (Intersex Greece 2022), and this is the first main difference compared to the drafting of Law 4491/2017: an intersex-led organisation was involved in the process, whereas previously only academics and a trans-led organisation were engaged. The second substantial difference lies in the legislative context. In 2017, Articles 2 and 7 were part of a Bill related to transgender rights crafted by the Ministry of Justice. In contrast, in 2022, Articles 17 to 20 were incorporated into a Bill focused on reforms in medically assisted reproduction,[36] prepared by the Ministry of Health. This indicated that the Bill was not directly linked to LGBT rights but rather centred on sexual, reproductive, and women's rights.

Initially, Articles 17–20 were consolidated under Article 16 of the Bill, and they were separated when the Explanatory Memorandum was released. This provision specifically prohibits medical procedures and treatments, including surgical or hormonal interventions, for the total or partial alteration of sex characteristics in intersex minors below the age of 15.[37] The intersex minor could go through such procedures only after permission, which is granted with the decision of the County Court, following the opinion of an interdisciplinary committee. In situations where medical operations are conducted, leading to a misalignment between the gender of the intersex person and the initially registered gender, it is feasible to rectify the latter through a court decision.[38] Physicians who fail to adhere to the stipulations outlined in the provisions are subject to disciplinary and administrative sanctions, a minimum imprisonment term of six months, fines, and, in any case, are barred from practising medicine. The Ministry of Health published an Analysis of the effects of the regulations of the Bill and stated that Art. 16 "protects the bodily integrity of intersex persons and ensures the normal development of their gender and their right to bodily self-determination." (See Appendix B). The Memorandum contained exactly the same information as the report on the analysis of the effects. The Report of the General Accounting Office of the State, which was published on 8 July 2022, added another effect of the Bill that was not highlighted in previous documents—it mentioned that Art. 20 on the sanctions of doctors who perform IGM will possibly increase the public revenue (Ibid.).

The Bill was published for online public consultation from 20 June 2022 to 4 July 2022, and a total of 132 comments were received, of which only 5 concerned the provisions on intersex.[39] All five comments focused mainly on the word "intersex" (ίντεϱσεξ) and proposed that the Greek word "diafylikos" (διαφυλικός) should be used because this is a national text (Ibid.). The number of comments that this Bill received was significantly lower than the Bill on LGR, which received 863 in total.[40] During the time of the consultation, Intersex Greece's members gave interviews to mainstream media to educate the public using scientific data and stories of families of intersex children (See Pikramenou and Rinio 2022; Maxouri 2022). The Minister of Health had announced as early as May that, following the introduction of the provision banning conversion therapies, the Ministry would also incorporate a provision specifically addressing intersex issues (Iefimerida 2022). It seems that the Ministry deliberately did not include the IGM ban in the Bill on conversion therapies since this could create similar tensions to those in 2017.

On 13 July 2022, Intersex Greece's members attended the hearing of Civil Society Organisations (CSOs) at the Parliament. Simeonidou shared her story on sex-selective abortions and stories from intersex survivors of IGM practices (Papaioannou 2022). On 19 July 2022, the Bill was voted on, and discussions were predominantly centred on matters related to women's rights. Notably, the new provisions allowed women aged 54 to access Assisted Reproductive Technologies (ART) and cryopreservation for social reasons, generating considerable debate (See Appendix B). Agathopoulou from SYRIZA and Arsenis from DiEM25 had several objections when it came to the safeguarding of women's rights and the commercialisation of ART. Nonetheless, regarding the provisions of IGM, both officials stated that they would vote in favour. Agathopoulou also referred to previous fruitless efforts saying that this was a "longstanding demand of the LGBTQI community, as also articulated in a conclusion by a committee of the Ministry of Health during the SYRIZA government." (Ibid. See also Section 3). A pathologising approach to intersex was adopted by Athanasiou from Greek Solution and Markou from SYRIZA, who were both parliamentarians and physicians. Athanasiou said that, in the case of intersex children, the doctor has to guide the parents during prenatal screening, confirming implicitly the practice of sex-selective abortions. Markou considered the word "intersex" inappropriate and blamed it on the fact that no endocrinologists were involved in the process, and he suggested the use of the pathologising term "congenital malformations". (Ibid.). Apatzidi from DiEM25 raised questions regarding the age limit, the conduct of operations under medical necessity, and the requirement for court involvement. Lioupis from Nea Dimokratia argued that the age limit was a positive element but did not justify it. Euthumiou from Nea Dimokratia said that these provisions followed the prohibition of conversion therapies, confirming the information mentioned above, namely that the IGM ban was strategically included in this Bill. The Prime Minister and the Minister of Health emphasised a "reliance on emotions" and centred their attention on Simeonidou's speech, expressing how deeply moved they were by the challenges faced by intersex children and their families over the years (Ibid.). This was also a strategy followed by Intersex Greece, as they always shared multiple personal stories along with scientific data to inform the public and inspire empathy.

The provisions on the IGM ban passed almost unanimously, and they were among the only ones that did not receive "NO". Despite the success, it is doubted whether those who voted had a sound understanding of intersex. After all, in the course of the vote, the words "sex change" and "transgender" were sometimes used in an ambiguous manner,[41] and no in-depth information was given regarding the law.[42] Art. 17 of Greek law 4958/2022[43] stipulates that an intersex minor who is older than 15 years old may undergo medical operations and treatments only with their free and informed consent. On the consent of a minor, the provision refers to Law 3418/2005, which, according to sub-paragraph aa), states, "If the patient is a minor, consent shall be given by those who exercise parental care or guardianship. However, their opinion shall also be taken into account if, in the opinion of the doctor, the minor has the age, mental and emotional maturity to understand their state of health, the content of the medical act and the consequences or effects or risks of that act". If the intersex minor is under 15 years of age, medical procedures and treatments are prohibited. However, if permission has been granted by the County Court, medical acts are allowed. The permission is granted only for medical procedures and treatments that cannot be postponed, provided that they will not cause future and irreversible complications to the minor's health. The County Court follows a non-contentious proceeding according to which the court may, without the existence of a pre-existing dispute, grant judicial protection for the purpose of safeguarding or protecting the interest of the intersex minor and therefore, the permission granted by the court is not subject to appeal. The hearing is held behind closed doors to protect the privacy of the intersex child. For permission to be granted, the following are required: (a) an opinion of a multidisciplinary committee; (b) a hearing of the representative of the interdisciplinary committee; and (c) a hearing of the intersex minor by the judge. The permission is not required when the medical procedure or treatment is necessary to prevent a risk to the life or health of the minor within the meaning of Law 3418/2005: "3. In exceptional cases, consent is not required: (a) in urgent cases, in which appropriate consent cannot be obtained and there is an immediate, absolute and urgent need for medical care and (c) where the parents of a minor patient or the relatives of a patient who cannot for any reason consent or other third parties who have the power of consent for the patient refuse to give the necessary consent and there is a need for immediate intervention in order to prevent a risk to the life or health of the patient".

Based on Art. 18, the interdisciplinary committee consists of one doctor with experience in operations on intersex individuals or any interventions of "normalisation" of sex characteristics, or as they are called in the medical community, "Disorders of Sex Development (DSD)" or "Congenital Anomalies". These medical terms are stigmatising and often unjustifiably pathologise intersex bodies, but they were used in the text to clarify the interventions to which the law refers and to avoid confusion with procedures carried out on trans people following their informed consent. Furthermore, the committee consists of one legal expert with expertise in bioethics, one psychologist with expertise in issues that intersex people are experiencing, one social worker with expertise in issues that intersex people are experiencing, and one representative of the intersex civil society with relevant expertise in issues that intersex people are encountering. Art. 19 stipulates that in the case that medical operations are performed and result in a discrepancy between the gender of the intersex person and the already registered gender, there is the possibility of amending the registered gender by court decision. It is worth noting that, in Greece, there are two genders on birth certificates and identity documents: "female" and "male". Therefore, intersex persons are not yet legally able to identify as they wish if their gender does not comply with the female–male binary. In other countries in Europe, such as Germany and Austria, and in the world, such as Australia, intersex people have the option to self-identify outside the binary using "diverse", "X", or "other". So far, in Greece, there are no similar legal developments.

Lastly, Art. 20 states that "doctors who perform medical procedures or treatments to minor intersex persons in violation of Article 17, in addition to the foreseen disciplinary and administrative sanctions, are punished with a prison sentence of at least six (6) months and a fine. The repeated performance of the act of the first paragraph constitutes an aggravating circumstance. In any case and regardless of the amount of the imposed penalty, the guilty is mandatorily punished with the additional penalty of Article 65 of the Criminal Code (Law 4619/2019, A' 95), on the prohibition to practice the profession".

To grasp the Greek legal text, it is essential to realise that it is a combination of the previous Art. 7, which never reached the Parliament in 2017 (See Appendix A), and elements from the Maltese,[44] German,[45] and Icelandic law.[46] In detail, Art. 7 discusses Maltese law, German law, and Icelandic law, which include multidisciplinary committees that, under different circumstances, assess the situation of the intersex minor. Maltese law punishes physicians who perform IGM; German law requires approval by the family court regarding some interventions; Art. 7 and Icelandic law set age limits; and Art. 7 outlined a procedure for the correction of the registered gender of an intersex child who had undergone surgery.

In general, Greek law exhibits two primary strengths. First, it clarifies the terminology by explicitly using the terms "intersex" and "sex characteristics," thereby addressing previous confusion. Second, the legislation strengthens protection by criminalising all practices of Intersex Genital Mutilation (IGM) through sanctions imposed on physicians. The main negative points of the law include the age limit, the presence of a committee, and the court procedure. First, the age limit was never justified in the parliament, even though the question was posed during the vote. The previous Art. 7, which was removed from the LGR Bill in 2017, did not specify an age limit. Moreover, the current law mentions Law 3418/2005 and sub-paragraph aa, which does not indicate a specific age limit either but mentions the doctor as the person responsible for judging whether the minor has the required "age, mental and emotional maturity". Such provision could be proved problematic and therefore it should be crucial to ensure that the minor intersex person over 15 years of age can give informed consent only if (a) the information provided to the minor is based on up-to-date medical information on the risks, medium- and long-term consequences, the availability of alternative medical options, and non-medical information on the living conditions of persons with natural variations of sex characteristics; (b) the minor should be provided with individualised psychological or psychosocial counselling and peer counselling, as it is important that an independent professional with experience in intersex issues (e.g., a psychologist) is involved in the process, in addition to the doctor in charge of the planned intervention or treatment, to assess the minor's ability to consent. As of now, it appears that there is no consensus on those age limits since, for instance, Icelandic law establishes a different limit of 16 years of age. This implies that, in the absence of a consensus, the effectiveness of such age limits will become apparent during the implementation process. Secondly, the presence of a committee might prove complex since, in many cases, a significant portion of its members belong to the medical community. This composition raises concerns about the potential pathologising character of decisions made by the committee. Nonetheless, this is the first law where the committee also includes a representative of intersex civil society. Third, the court procedure, even though it is non-contentious, might also prove problematic due to the lack of training of judges on LGBTI issues in the country; the first—and so far the only—seminar for judges on intersex was held in 2022 (Pikramenou 2022a). OII Europe has highlighted some additional omissions in the law, which encompass ensuring that mature individuals have access to all necessary comprehensive information for fully informed consent; involving an independent third party to assess a minor's capacity to provide informed consent; recognising the right to psychological and psychosocial support; acknowledging past harm (albeit partially during the voting process[47]); providing for low-threshold means of reparation; and establishing a monitoring mechanism to assess the implementation of the law (OII Europe 2022).[48]

5. Conclusions

In 2010, Greenberg said that feminists can benefit from the intersex movement and the broader LGBT movement through the examination of their strategies and alliances (Greenberg et al. 2010, p. 14). In the context of Greece, the intersex movement is inherently feminist. Its origins trace back to the organisation of intersex women, families of intersex girls, and a group of mothers of intersex children. This collective effort laid the groundwork for the formal establishment of the organisation Intersex Greece. Additionally, at the very core of the organisation's demands, there is not only the ban on IGM but also the ban on sex-selective abortions of intersex foetuses, which prevail in Greece, as the parliamentarians implicitly confirmed during the voting process. Even though the organisation has raised the issue multiple times, the global intersex movement and jurisdictions still seem hesitant to set it as a priority.

The case of Greece highlights that the legal prohibition of Intersex Genital Mutilation (IGM) materialised only when an intersex-led organisation actively participated in the process. The primary obstacle to earlier efforts to ban IGM stemmed from a lack of education on intersex issues. At the time, those involved in the process, including LGBT CSOs, lacked a comprehensive understanding of intersex issues. In the absence of an intersex-led organisation, awareness-raising initiatives on intersex were non-existent. Furthermore, terms like "sex characteristics" were misused to advance anti-LGBT ideologies and pathologise both trans and intersex individuals. Later, in 2022, the results of the involvement of Intersex Greece in the process became evident as human-rights-based terminology was used, and the law itself included unique elements, such as the participation of a member of the intersex CSO in the interdisciplinary committee. Moreover, the inclusion of provisions on intersex in the law was facilitated by a less tumultuous political and economic environment compared to 2017. Distancing intersex issues from LGBT concerns, as demonstrated by the challenges faced during the Law on Legal Gender Recognition (LGR), proved to be a strategic move. Moreover, the intersex movement employed the media strategically, not only to inform the public but also to foster empathy, ultimately seeking to overturn the negative image associated with intersex in previous years.

While Greek law is not without its flaws, it does boast some robust elements, making it one of the notable examples among the limited number of laws in existence. The continuous efforts of the intersex movement since the 1990s to ban Intersex Genital Mutilation (IGM) have encountered challenges. Many jurisdictions remain hesitant to challenge the female–male binary, and when they do, it is often approached experimentally, given the lack of consensus on how to effectively ban IGM while safeguarding the rights of intersex individuals. Presently, there is a lack of official governmental data on the implementation of IGM laws due to the absence of monitoring mechanisms. The only available—albeit unofficial—data pertain to Malta and indicate that the law is not fully implemented (See StopIGM 2019; Garland and Travis 2022). Intersex Greece has already expressed its concerns regarding the implementation of the law, citing the very low levels of awareness on intersex issues and the absence of a monitoring mechanism as significant concerns (Intersex Greece 2023). Indeed, the effectiveness of Greek law may hinge on the actions taken in the coming years. Still, the Greek case has already left a valuable legacy, exemplified by intersex activists who have transitioned into law-makers, actively participating in legislative processes aimed at safeguarding their own rights.

Funding: This research was funded by the European Union (ERC Consolidator, Abortion Figurations, 101044421).

Institutional Review Board Statement: Not applicable.

Informed Consent Statement: Not applicable.

Data Availability Statement: The original contributions presented in the study are included in the article/supplementary material, further inquiries can be directed to the corresponding author/s.

Acknowledgments: In this inaugural publication, I assume the dual role of academic and activist. My heartfelt gratitude extends first to Irene Simeonidou as her invitation to join the intersex movement in 2019 as a legal expert and ally has been transformative. I am deeply indebted to Lakis Kandilis, Vasso Vouvaki, and Eleni Pateraki for their unwavering support and immense trust over the years, alongside all the members of Intersex Greece. This work would have been inconceivable without you. In navigating the law-making process, my sincere thanks go to Dan Christian Ghattas and all members of OII Europe for their invaluable guidance. I express appreciation to Kimberly Zieselman and InterAct for their steadfast support, and I extend gratitude to Alexis Patelis and Prodromos Pyrros for their seamless collaboration. Lastly, I would like to acknowledge Professor Marta Bucholc for her insightful feedback and ethical approach to intersex research.

Conflicts of Interest: The views and opinions expressed are those of the author(s) only and do not necessarily reflect those of the European Union or the European Research Council. Neither the European Union nor the granting authority can be held responsible for them. The author declares no conflict of interest.

Appendix A

1. LGR Bill as of 18.11.2016

Article 2. Definitions.

2. Sex characteristics are the chromosomal, genetic and anatomical characteristics of the individual, which include primary characteristics, such as reproductive organs, and secondary characteristics, such as muscle mass, breast development or hair growth.

Article 7. Minors.

1. Any medical treatment, such as surgical or hormonal treatment, for the total or partial change of the sex characteristics of a minor is prohibited, unless it is in the best interests of the minor's health, in which case it is carried out with the consent of their parents or commissioner or without consent if the conditions set out in Article 12 para. 3a and c of Law 3481/2005 apply. In this case, prior approval of a Special Interdisciplinary Committee consisting of a paediatric endocrinologist, a geneticist, a paediatric surgeon, a paediatric urologist or paediatric gynaecologist, a paediatric psychiatrist or paediatric psychologist, a social worker and a paediatrician is required for the performance of the medical operations concerned. The manner in which this Committee is to be set up and its operation shall be determined by a decision of the Minister of Health, which shall be published in the Government Gazette. The same medical operations on a minor who has reached the age of 12 shall require the minor's personal consent.
2. In the case of the performance of the medical operations referred to in par. 1, which results in a discrepancy with the registered gender of the minor, the correction of their registered gender shall be decided by the court, if requested by their parents or their commissioner or the public prosecutor or even ex officio. The court shall adjudicate in accordance with the procedure of voluntary jurisdiction in accordance with Article 782 of the Code of Civil Procedure. The court, depending on the maturity of the minor, must also hear the minor's own opinion as well as the opinion of their parents and decide in the best interests of the minor. The application shall state the new gender, the name chosen and the adjusted surname in relation to it. The application shall be accompanied with copies of the birth and naming certificates of the minor, as well as a copy of the approval of the Special Interdisciplinary Committee referred to in paragraph 1.

2. LGR Bill as it reached the Parliament and then passed into Law 4491/2017

Article 2. Definitions.
Same.
Article 7. Other provisions.

1. In the first subparagraph of par. 1: "In particular in the case of gender correction, a court decision is sufficient if it is final."
2. In paragraph. 1 of Article 1 and in paragraphs 1 and 1. 1 of Article 2 of Law 927/1929 (A'139), after the words 'gender identity card', the words 'gender characteristics' shall be added.

3. Explanatory Memorandum of the Bill "Legal recognition of gender identity—National Mechanism for the Development, Monitoring and Evaluation of Action Plans for the Rights of the Child"

Article 1 of the bill contains two general declarations. The first relates to the possibility of trans persons to correct their registered gender and the second to their actual status, as determined by their sex characteristics. It is thus established in the first paragraph that a person has the right to recognition of their gender identity as an element of his or her personality, and in the second paragraph that a person has the right to respect for their personality on the basis of their sex characteristics. (. . .) In particular, the regard for sex characteristics is underscored by the combined effect of Articles 2 and 3 of the Bill, i.e., the assumption that medical interventions for the total or partial change of sex characteristics must be freely chosen by the person concerned and do not constitute a compulsory condition for the person to proceed to legal gender correction.

Article 2 provides definitions of gender identity and sex characteristics. Gender identity is defined in the first paragraph as the internal and personal way in which a person experiences their own gender, irrespective of the gender assigned at birth on the basis of biological characteristics. This way may be in complete contradiction with the person's biological characteristics and the associated assigned sex, but it may also be in partial contradiction if there are mixed biological characteristics, i.e., characteristics that do not fall within the standard definitions of male and female, in which case it would be an 'intersex' person (in the obsolete and inappropriate terminology of 'hermaphrodite'). In other words, the reference in the bill to 'biological characteristics' in general means that the bill applies to—and recognition of gender identity can be requested by—all persons who feel 'gender dysphoria', whether they are transgender or middlesex.

3. Parliament—Minutes of proceedings

Wednesday 27 September 2017
Stavros Kontonis (Minister of Justice, Transparency and Human Rights): But this bill is not about intersex people.
Irene Simeonidou (Member of the "Rainbow School" group): Yes, but it is about the recognition of gender identity. Intersex people usually have different gender identities, so they are the first in line to use it.
Stavros Kontonis: This will be dealt in a bill that will be submitted jointly by the Ministry of Justice and the Ministry of Health.
(. . .)

Monday 9 October 2017
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Evagelos Karakostas (Golden dawn): (. . .) The Emeritus Professor of Neurology of the Aristotle University of Thessaloniki stressed that the characteristics of the sex of a person are predetermined, apart from the genome, in the brain, that there are indeed many differences between the two sexes, but the most important difference, which begins from intrauterine life, from the moment of organogenesis of the brain in the fourth foetal month, is in the so-called "amygdaloid nucleus." In conclusion it was said that from birth to death these differences remain unchanged and unaltered. (. . .)

pp. 328–29

Ioannis Delis (Communist Party of Greece): (. . .) If the government wanted to address existing issues that transgender people and middlesex children are facing, then it would adopt the scientifically documented and deeply humane position of the Communist Party of Greece for their full protection and for the effective safeguarding of their rights.
What is this position? The Communist Party of Greece recognises the right of a transgender person to change their gender on legal documents. That is, it recognises it for those cases in which, for biological, social or other reasons, a person experiences an intense internal conflict between the characteristics of their sex and the gender to which they feel they belong to. (. . .) These are theories that distract in an absolute and unscientific way from the biological characteristics of sex, which are, of course, objectively determined by the individual's perception of their gender.

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Stavros Kontonis (Minister of Justice, Transparency and Human Rights): By the way, this week is the Parliamentary Assembly of the Council of Europe. Normally I should be there now, as should the rapporteur of SYRIZA too, but I stayed in Athens for this particular bill. In fact, on Thursday, the Council of Europe is discussing—and it looks like it will be voted through, since it was passed unanimously by the Committee—the resolution on the elimination of discrimination against intersex people, (in Greek—diafylika) or middlesex people, that is, people born with sexual characteristics that are not exclusively male or female.
It is proposed, on the basis of the resolution, that intersex people should also be given the opportunity to identify themselves and not necessarily in the male-female binary, but that there should be a blank or third entry, something that we must also take seriously into account in this bill and that we will submit the relevant amendment.

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Dimitrios Kiriazidis (Nea Dimokratia): While you are telling us that a person has the right to respect for their personality on the basis of their sex characteristics, which, of course, according to common experience and logic, are purely biological and relate to the person's physical condition, as you mention in paragraph 2 of Article 2, you then come along and tell us that these characteristics change according to the person's will. But is this a question of will or of reality? (. . .)

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Nikolaos Michaloliakos (Golden Dawn): (. . .) It is characteristic of what the bill says that gender identity means the internal and personal way in which a person experiences their own gender regardless of the gender from which they were registered after birth based on their biological characteristics. Then, biological characteristics do not matter at all.

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Georgios Oursouzidis (SYRIZA): The representative of the group "Rainbow School," a parent, said (. . .) In particular, middlesex infants, when their sex image does not fall within the typical image of male-female, the typical external anatomy, their gender is arbitrarily registered. Often this is accompanied by cosmetic and irreversible surgical procedures (. . .) In many cases, in fact, if prenatal testing has been done, parents are advised to terminate the healthy middlesex embryo because there is no provision for the existence of a human being outside the male-female dipole, and as a result healthy middlesex embryos are not even given the right to life.

Page 385
Ioannis Giokas (Communist Party of Greece):For a number of reasons, biological, social or otherwise, (the person is) experiencing an intense conflict between sex characteristics and the gender to which they feel they belong, it is required to be based on certain objective criteria (. . .) and not on a simple application without any social support and protection.

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Dimitrios Koukoutsis (Golden Dawn): (. . .) But—no matter how much you may wish it—biological characteristics cannot be changed. Is it ever possible to give variation and fluidity to the human sex?

Page 414
Athanasios Pafilis (Communist Party of Greece): (. . .) The Communist Party of Greece recognises the right to change gender in legal documents in cases where the individual experiences a strong conflict between the characteristics of their sex and the gender to which they feel they belong for biological, social, and other reasons.

Appendix B

1. Analysis of the Effects of the Regulation, Title of the Regulation under Assessment: Bill of the Ministry of Health entitled "Reforms in medically assisted reproduction"

Article 16: Intersex persons are persons born with sex characteristics that do not fit the medical or social norms of female or male bodies. These variations may occur in primary sex characteristics (such as internal and external genitalia and chromosomal and hormonal structure) and/or secondary sex characteristics (such as muscle mass, hair distribution and stature). The regulation protects the bodily integrity of intersex persons and ensures the normal development of their gender and their right to bodily self-determination. (. . .)

2. Report of the General Accounting Office of the State (Art. 75 par. 1 of the Constitution)

V. On the state budget
Possible increase in revenue from the collection of fines and the conversion of prison sentences into financial penalties in cases of violation of relevant regulations, for the protection of the individual rights of intersex persons. (Article 20).

3. Parliament—Minutes of proceedings

Eirini—Eleni Agathopoulou (SYRIZA): So, women from fifty-two to fifty-four years old have to something lose. Which women and how many are they? It would be good if you could tell us.
Foteini Arampatzi (Nea Dimokratia): Even if there is just one, why do you mind?
President (Nikitas Kaklamanis): What are we doing now?
Eirini—Eleni Agathopoulou (Nea Dimokratia): Mr President, I see a disturbance that is not justified.
(. . .)
Finally, with regard to Articles 17–20 on the change of sex characteristics of intersex minors, (. . .) The regulation is a longstanding demand of the LGBTQI community, as also articulated in a conclusion by a committee of the Ministry of Health during the SYRIZA government and the Transgender Association on the access of LGBTQI people to the health system. The regulation is also welcomed by the non-governmental organisation "Intersex Greece."
Our sole objection in this regard is the potential bypassing of the procedure outlined in the Bill if the situation is deemed urgent, without specifying any procedure or safeguard to assess whether a case genuinely qualifies as urgent. Thus, while the Bill correctly provides for a decision by a magistrates' court, following a recommendation by a special multidisciplinary committee, to operate on a minor under the age of fifteen, the procedure is bypassed if the medical operation or treatment is necessary to prevent danger to the life or health of the minor, without providing otherwise.

Georgios Lamproulis (Communist Party of Greece): The provisions of the proposed bill do not ensure free, all-round, all-systemic, social support for intersex people (. . .) Specifically, interdisciplinary support should be based on the cooperation of paediatricians, endocrinologists, urologists, surgeons, general pathologists, paedopsychiatrists, psychologists and social workers with appropriate specialisation.
(. . .) Corresponding scientific, social support, of course, is needed throughout the life course of an intersex person, even after adulthood. The opinion of the scientific committee is

therefore necessary even after the age of fifteen, in order to ensure the safeguard of the protection of the rights of children. Of course, here too, the Ministry, the Minister, did not present the corresponding scientific data.

Maria Athanasiou (Greek Solution): With regard to intersex children in the third part of the Bill, articles 17–20, we refer to the fact that intersex children with down syndrome, turner syndrome, etc., are born this way because of a mistake in the reduction process. None of the parents are to blame, it happened. However, the doctor has to guide in the framework of prenatal screening. After all, this is the purpose of the check-up. In any case, intersex children are born sterile and do not become sterile after the operation, because we also heard this in the committee. (. . .)

Maria Apatzidi (DiEM25): (. . .) The articles for us are moving to a positive direction, of course according to the collective Intersex Greece that participated in the consultation of the bill. (. . .) How can the requirement of a court order for medical procedures for intersex children under fifteen but not from fifteen to seventeen be justified? (. . .) Furthermore, how can a distinction be justified between, on the one hand, medical operations relating to the sex of intersex children and, on the other hand, other operations which are considered necessary for the survival of the individual or to ensure their mental and physical health? For example, routine surgeries, transplants, and so on. (. . .) Why is court intervention required in order to correct the registered gender of the intersex child?

Athanasios Lioupis (Nea Dimokratia): An age distinction is made. It is recognised that those persons who wish to do so and are older than fifteen years of age, provided that parental consent is given, are allowed to undergo medical procedures and treatments (. . .) An attempt is therefore made to respect the wishes of intersex minors and, concurrently, to improve their social and economic situation. The representative of the Association Intersex Greece said that she was delighted with the new regulations. (. . .)

Konstantinos Markou (SYRIZA): (. . .) And I think it is inappropriate for a bill, in a Government Gazette, to say “intersex.” It is wrong. So you can—I inform you and as an endocrinologist (. . .) And as a specialist, well, I say that you can adopt the term “congenital malformations,” which describes exactly the group you want to support. Of course, you do not have endocrinologists in the committee, which goes without saying (. . .). I will end by saying that you had the opportunity with this bill to improve a little bit the tragic situations of transgender people who have sex change operations, mastectomies, hysterectomies. They are not covered. (. . .)

Kriton-Ilias Arsenis (DiEM25): DiEM25 will stand against this unprecedented abuse of society. We vote against this bill. We will vote in favour of any positive amendments for intersex people and HIV-positive people, but we will never participate in this mill of favours that you have set.

Anna Euthimiou (Nea Dimokratia): I believe that today is a historic moment for all intersex children in Greece with these provisions (. . .) They follow the provisions of the prohibition of conversion therapies, which you, Minister, and I was the rapporteur on the Personal Doctor Bill, introduced.

Kiriakos Mitsotakis (Prime Minister): (. . .) Mr. Minister, I listened carefully, and I am not hiding my emotion, to what the representatives of intersex people testified in the committee of the Parliament, and I learned a lot that I did not know about what happens on the fringes of Greek families, without most of the time being widely known. I was sincerely sorry for the mistakes of the past that led to dramas because we lacked knowledge and courage, and I realised how important the initiatives we are taking today are for these fellow citizens (. . .)

Yianis Varoufakis (DiEM25): Yes, we have to agree and congratulate you, Minister, on the sex change regulations for the LGBTI community, for intersex people.

Athanasios Plevris (Minister of Health): (. . .) I honestly felt embarrassed when I heard the stories of these people and I think everyone on the committee was moved when we

> heard the representative of their organisation. (. . .) A concern was raised by the special rapporteur for DiEM25 because there is always this, there is always this in all the processes of medical operations on a minor, that there may be a moment when the doctor has to do something quickly. It is an emergency situation that exists and is foreseen everywhere. For these scenarios, we have established a more stringent framework compared to the framework governing other medical procedures you mentioned. That is, if the child requires participation in a clinical drug trial, a transplant, or a life-saving surgery. This framework is precisely more stringent because we consider that these are interventions that are not linked at that moment to the person's life and the risk but are linked to a decision that will accompany them for the rest of their lives. So we consider it to be a weighted provision which was of course also supported by the Intersex Greece community.
>
> Konstantina (Nantia) Giannakopoulou (PASOK): I will conclude with the very important article, which has to do with the provisions concerning intersex minors, where for the first time they are given the opportunity to undergo medical operations and sex change when they reach the age of fifteen only with their free consent, after informing themselves or persons exercising parental guardianship.

Notes

[1] (Free & Equal UN 2017), What does "intersex" mean?

[2] Ibid. It is essential to note that this information serves to provide the reader with a general understanding of intersex statistics; however, from a non-discrimination and human rights perspective, numbers do not really matter when explaining who intersex people are. See also (Pikramenou 2019).

[3] In this article, the term Intersex Genital Mutilation (IGM) is preferred as it is also used by the organisation Intersex Greece on their official website—see https://intersexgreece.org.gr/intersex-101/. accessed 22 March 2023. It should be noted that there is research criticising this term; for instance, Rubin, in the article (Rubin 2015), shows how the language of IGM is based on an analogy with Female Genital Mutilation (FGM) that could potentially have imperialistic implications.

[4] See, for example, Monro et al. (2021), where a variety of novel insights on intersex is offered. However, data originate mostly from regions in Europe, such as Western and Northern Europe.

[5] See OII Europe, About OII Europe, https://www.oiieurope.org/about/, accessed on 22 March 2023.

[6] A comprehensive list of intersex groups can be found here: (InterAct 2022), last updated on 7 November 2022.

[7] Intersex Flower Greece (2009). The pronoun "they" will be used when referring to Intersex Flower in the text as their preferred pronoun is not mentioned in the blog.

[8] In July 2023, the ECtHR found a violation of Art. 14 together with Art. 8 for discrimination on grounds of sex and sex characteristics: (Judgment 2023).

[9] The internet has consistently played a pivotal role in intersex activism, inspiring numerous activists to openly express their identity and advocate for their rights. For example, Irene Kuzemko has stated that thanks to the online public intersex figures, she realised that her story was not unique (Kuzemko 2023).

[10] Intersex Greece (2021). See also Section 32, The Establishment of Intersex Greece (2021–2022).

[11] In the (Malta Declaration 2013), intersex activists stated explicitly "to put an end to preimplantation genetic diagnosis, prenatal screening and treatment, and selective abortion of intersex foetuses".

[12] See the keynote lecture by (Cabral Grinspan 2020, p. 2).

[13] In 2023, Simeonidou shared her story at the Council of Europe at the Conference Advancing the Human Rights of Intersex People (2023).

[14] For an extensive list, see (Ghattas 2019), Appendix https://www.ilga-europe.org/files/uploads/2022/04/Protecting_intersex_in_Europe_Appendix.pdf., accessed on 23 March 2023.

[15] The most comprehensive quantitative study to date seems to be the "World Atlas of Birth Defects" by the World Health Organization (WHO), which was referenced in 2014 by StopIGM.org. in the online article "Selective Intersex Abortions: XXY 74%, Indeterminate Sex 47%, Hypospadias 2%". Such terminations appear to be higher when the foetus is XXY and of indeterminate sex, compared to hypospadias (StopIGM.org 2014).

[16] For the developments in Europe, see (Bucholc 2022), and for the developments in the United States, see (Coen-Sanchez et al. 2022). Also see (Bucholc forthcoming).

[17] For example, a parent from Iceland shared for the publication *#MyIntersexStory*: "I as a parent made choices that should not have been mine to make and most definitely not the doctors to make, I firmly believe that the intersex individual should be the only one allowed to make choices regarding their own body, there must be an end to unnecessary medical treatment and

surgery of intersex individuals without their consent. We as parents should not have the right to give this consent" OII Europe, #MyIntersexStory, p. 59, 2019 https://oiieurope.org/wp-content/uploads/2019/11/testimonial_broch_21-21cm_for_web.pdf, accessed on 5 April 2023. See also (Audr XY 2019).

[18] Intersex Greece, About us, https://intersexgreece.org.gr/en/about-us/#ld-1618924549019-e7e5159b-e5d8, accessed on 6 April 2023.

[19] "With the decision no. 477/2021 of the Athens County Court, the statute of the association with the name" Intersex Greece-Greek community of Intersex" was approved" from Intersex Greece's Facebook page, https://www.facebook.com/IntersexGr/photos/a.108099634748969/255653043326960/, accessed on 20 April 2023.

[20] Intersex Greece, 1st Public Event for Intersex Human Rights in Greece—"Intersex Rights and Claims in Greece", https://intersexgreece.org.gr/en/2021/06/09/1st-public-event-for-intersex-human-rights-in-greece-intersex-rights-and-claims-in-greece/, accessed on 10 April 2023.

[21] See, for example, on the Facebook page of the organisation "Ελληνική Κοινότητα ίντεϱσεξ—Intersex Greece": Event discussion on the topic "You are born intersex, you do not become one" in the city of Xanthi on 4 February 2022 at 19:00 at Filoistron Café, https://www.facebook.com/IntersexGr/photos/a.108099634748969/281958234029774/, accessed on 20 April 2023. Presentation of the outcomes of the research "Hate Speech against intersex people in Greece", Public Market of Kipseli, Athens on 15 September 2022 at 17:00, https://www.facebook.com/events/625178702648699/?ref=newsfeed, accessed on 20 April 2023.

[22] The same issue has been highlighted by other organisations in neighbouring countries; see (XY Spectrum 2018, 0′50″).

[23] The Transgender Association's homepage (in Greek), https://tgender.gr/ accessed on 24 April 2023.

[24] For LGBT movements and legal change, see (Barclay et al. 2009).

[25] For more information on the GIGESC Act, see Ministry for Social Dialogue, Consumer Affairs and Civil Liberties, GIGESC Act, https://meae.gov.mt/en/public_consultations/msdc/pages/consultations/gigesc.aspx., accessed on 25 April 2023.

[26] See (National Commission on Human Rights 2015). It has to be noted that the terminology used in this report is not accurate as it uses "middlesex" (μεσοφυλικό) to describe intersex and "diaphyliko" (διαφυλικό) to describe trans persons, even though it is the Greek term for intersex.

[27] See Explanatory Memorandum of the Bill "Legal recognition of gender identity—National Mechanism for the Development, Monitoring and Evaluation of Action Plans for the Rights of the Child, https://www.hellenicparliament.gr/, accessed on 24 April 2023.

[28] See (Pikramenou 2019, sct. 4.3.3.). "Greece", 2019.

[29] Ibid. Note that both the terms "gender dysphoria" and "middlesex" are non-human-rights-based terms that stigmatise and pathologise the trans and intersex communities.

[30] See, for example, (Kaiafa-Kmpanti et al. 2017) and the Report for the Bill prepared by the Scientific Service of the Parliament, 2017 (both in Greek).

[31] See Section 2 above on the establishment of Intersex Greece.

[32] The title is inspired by Intersex Greece's slogan "Nothing about us, Without us".

[33] For a comprehensive overview of intersex laws in Europe until 2019, see (Pikramenou 2019), Chapter 4: Intersex in Europe. For a more recent overview, see (Mestre 2022).

[34] For an analysis of the Icelandic law, see (Alaattinoglu 2022).

[35] Until now, "sex characteristics" have been included in some legal documents, such as Law No. 4443/2016, since one of the grounds for τηε protection against discrimination in the field of employment. Law 927/1979 was amended with Par. 2 of Article 7 of Law 4491/2017 and added "sex characteristics" to public incitement to violence or hatred. Law No. 4619/2019 amended the Penal Code and Article 82A on crimes with racist characteristics and added "sex characteristics" to the list of aggravating circumstances. Law 5029/2023 "We live together in harmony—Breaking the silence": regulations for the prevention and treatment of violence and bullying in schools and other provisions included sex characteristics in the actions of the Ministry of Education on bullying and discrimination in schools (Intersex Greece 2023, pp. 15–16).

[36] Bill of the Ministry of Health "Reforms in medically assisted reproduction" (in Greek) https://www.hellenicparliament.gr/en/, accessed on 24 April 2023.

[37] The provisions of the Bill, which were afterwards passed into Law, are available here in English: (Pikramenou 2022b).

[38] Ibid. Note that, in Greece, there are two genders on birth certificates and identity documents: "female" and "male". Therefore, intersex persons are not yet legally able to identify as they wish if their gender does not comply with the female–male binary.

[39] The comments are available (in Greek) in WordPress, www.opengov.gr. Accessed on 24 April 2023.

[40] The comments are available (in Greek) at http://www.opengov.gr/ministryofjustice/?p=8074. Accessed on 24 April 2023

[41] See Ibid, Varoufakis and Markou.

[42] See Ibid., Plevris.

[43] See the official website of Intersex Greece: (Pikramenou 2022b).

[44] Ministry for Social Dialogue, Consumer Affairs and Civil Liberties, Gender Identity, Gender Expression and Sex Characteristics Act and OII Europe, Press Release: OII Europe applauds Malta's Gender Identity, Gender Expression and Sex Characteristics

Act, 2015, https://www.oiieurope.org/press-release-oii-europe-applauds-maltas-gender-identity-gender-expression-and-sex-characteristics-act/, accessed on 10 May 2023.

[45] Deutscher Bundestag, Drucksache 19/27929 (in German) and OII Europe, A good first step: Germany adopts law banning IGM. But there is still room for improvement, 2021, https://www.oiieurope.org/a-good-first-step-germany-adopts-law-banning-igm/, accessed on 10 May 2023.

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

[47] See Appendix B, Plevris and Mitsotakis.

[48] OII Europe, Good practice map 2022 and the 14 IGM ban indicators published by OII Europe in 2023.

References

Alaattinoglu, Daniela. 2022. Intersex Rights in the Icelandic Gender Autonomy Act. *SSRN*. Available online: https://ssrn.com/abstract=4252270 (accessed on 30 April 2023).

Antivirus Magazine. 2021. The Difficulties and Discriminations That Intersex People Face. 30′25″. Available online: https://www.youtube.com/watch?v=PpKhco8NiR4&t=1881s&ab_channel=antivirusmagazine (accessed on 20 April 2023). (In Greek).

Antonopoulos, Thodoris. 2017. Rinio, What Does It Mean to Be the Parent of an Intersex Child? *Lifo*. Available online: https://www.lifo.gr/lgbtqi/rinio-ti-simainei-na-eisai-goneas-intersex-paidioy (accessed on 5 April 2023).

Astraea Lesbian Foundation for Justice. 2016. *We Are Real: The Growing Movement Advancing the Human Rights of Intersex People*. New York: Astraea Lesbian Foundation for Justice.

Audr XY. 2019. Intersex Motherhood: Grief, Loneliness and Education. Available online: https://www.youtube.com/watch?v=XKVUb6g-Uns (accessed on 5 April 2023).

Bank of Greece Monetary Policy Report 2022–23. 2023. Available online: https://www.bankofgreece.gr/en/news-and-media/press-office/news-list/news?announcement=c08891c8-6f4f-4bf7-99fb-c599b96bd328 (accessed on 1 May 2023).

Barclay, Scott, Mary Bernstein, and Anna-Maria Marshall, eds. 2009. *Queer Mobilizations: LGBT Activists Confront the Law*. New York: NYU Press. Available online: http://www.jstor.org/stable/j.ctt9qfm4c (accessed on 10 May 2023).

Bucholc, Marta. 2022. Abortion Law and Human Rights in Poland: The Closing of the Jurisprudential Horizon. *Hague Journal on the Rule of Law* 14: 73–99. [CrossRef]

Bucholc, Marta. forthcoming. Legal governance of abortion: Interdependencies and centrifugal effects in the global figuration of human rights. *Historical Social Research*.

Cabral Grinspan, Maura. 2020. Paper presented at the 24th Congress of the World Association for Sexual Health and XII Congreso Nacional de Educación Sexual y Sexología, Building Bridges in Sexual Health and Rights, Ciudad de México, Mexico, October 12–15. Available online: https://gate.ngo/wp-content/uploads/2020/03/The-Road-to-Hell.-Intersex-People-Sexual-Health-and-Human-Rights.pdf (accessed on 3 April 2023).

Carpenter, Morgan. 2012. Researching Intersex Populations. Available online: https://ihra.org.au/research/ (accessed on 24 March 2023).

Christensen, Joel. 2023. The Conversation, Mothers' Lives in Ancient Greece Were Not Easy—But Celebrations of Their Love Have Survived across the Centuries. Available online: https://theconversation.com/mothers-lives-in-ancient-greece-were-not-easy-but-celebrations-of-their-love-have-survived-across-the-centuries-204449 (accessed on 24 March 2023).

Coen-Sanchez, Karine, Bassey Ebenso, Ieman Mona El-Mowafi, Maria Berghs, Dina Idriss-Wheeler, and Sanni Yaya. 2022. Repercussions of overturning *Roe v. Wade* for women across systems and beyond borders. *Reprod Health* 19: 184. [CrossRef] [PubMed]

Commissioner for Human Rights. 2011. *Discrimination on Grounds of Sexual Orientation and Gender Identity in Europe*. Strasbourg: Council of Europe Publishing, p. 132.

Conference Advancing the Human Rights of Intersex People. 2023. Iceland's Presidency of the Committee of Ministers. Available online: https://www.coe.int/en/web/sogi/-/advancing-the-human-rights-of-intersex-people (accessed on 10 April 2023).

Davaki, Konstantina. 2013. The Policy on Gender Equality in Greece, European Parliamentary Research Service (EPRS). Available online: https://policycommons.net/artifacts/1339977/the-policy-on-gender-equality-in-greece/1950059/ (accessed on 12 March 2023).

De Marcilla Musté, Mireia Garcés. 2022. You Ain't Woman Enough: Tracing the Policing of Intersexuality in Sports and the Clinic. *Social & Legal Studies* 31: 847–70. [CrossRef]

Elmatzoglou, Stella. 2021. Intersex Persons. Available online: https://3pointmagazine.gr/atoma-diafylika-i-allios-intersex/ (accessed on 10 April 2023). (In Greek).

European Commission. 2023. LGBTIQ Equality Strategy 2020–25. Available online: https://commission.europa.eu/strategy-and-policy/policies/justice-and-fundamental-rights/combatting-discrimination/lesbian-gay-bi-trans-and-intersex-equality/lgbtiq-equality-strategy-2020-2025_en (accessed on 12 March 2023).

Free & Equal UN. 2017. United Nations Human Rights Office of the High Commissioner. *United Nations for LGBT Equality, Fact Sheet: Intersex*.

Freedom House. 2022. Freedom in the World 2022: Greece. Available online: https://freedomhouse.org/country/greece/freedom-world/2022 (accessed on 22 March 2023).

Garland, Fae, and Mitchel Travis. 2022. *Intersex Embodiment*. Bristol: Bristol University Press.

Ghattas, Dan Christian. 2019. Protecting Intersex People in Europe: A Toolkit for Law and Policy Makers. Available online: https://www.oiieurope.org/wp-content/uploads/2019/05/Protecting_intersex_in_Europe_toolkit.pdf (accessed on 20 March 2023).

Greenberg, Julie A. 2012. *Intersexuality and the Law: Why Sex Matters*. New York: New York University Press.

Greenberg, Julie, Marybeth Herald, and Mark Strasser. 2010. Beyond the Binary: What Can Feminists Learn from Intersex Transgender Jurisprudence. *Michigan Journal of Gender & Law* 17: 13. Available online: https://repository.law.umich.edu/mjgl/vol17/iss1/2 (accessed on 3 May 2023).

Howe, Erin, Frazer Somjen, Dumont Melissa, and Zomorodi Gitta. 2017. *The State of Intersex Organizing (2nd Edition): Understanding the Needs and Priorities of a Growing but Under-Resourced Movement*. New York: American Jewish World Service, Astraea Lesbian Foundation for Justice and Global Action for Trans Equality.

Iefimerida. 2022. Plevris: He Announced a Provision for the Protection of Intersex Children—What It Will Include. May 10. Available online: https://www.iefimerida.gr/ellada/proaniggeile-diataxi-gia-tin-prostasia-ton-intersex-paidion (accessed on 10 May 2022). (In Greek).

InterAct. 2022. Intersex Support and Advocacy Groups. Available online: https://interactadvocates.org/resources/intersex-organizations/ (accessed on 22 March 2023).

Intersex Flower Greece. 2009. Available online: http://grintersex.blogspot.com/ (accessed on 17 March 2023). (In Greek).

Intersex Greece. 2021. Memorandum to the Drafting Committee of the National Strategy for the Equality of LGBTQI+. Available online: https://drive.google.com/file/d/1Gw2fublrw6qb38g0tb8jhoiYurgNpvhB/view (accessed on 1 April 2023).

Intersex Greece. 2022. A Historic Day for the Protection of the Human Rights of Intersex Children in Greece. Available online: https://intersexgreece.org.gr/en/2022/07/19/a-historic-day-for-the-protection-of-the-human-rights-of-intersex-children-in-greece/ (accessed on 5 August 2023).

Intersex Greece. 2023. Hate Speech against Intersex People in Greece. Available online: https://intersexgreece.org.gr/wp-content/uploads/2023/06/Hate-speech-against-intersex-people-in-Greece-report-EN_May23-2.pdf (accessed on 1 April 2023).

Jensen, Marisa, Jörg Schorer, and Irene R. Faber. 2022. How is the Topic of Intersex Athletes in Elite Sports Positioned in Academic Literature Between January 2000 and July 2022? A Systematic Review. *Sports Med—Open* 8: 130. [CrossRef]

Judgment Semenya v. Switzerland—Discrimination against International Level Athlete Who Was Not Afforded Sufficient Procedural Safeguards When Challenging World Athletics Regulations. 2023. Press Release. Available online: https://hudoc.echr.coe.int/eng-press#%7B%22itemid%22:[%22003-7701636-10631196%22]%7D (accessed on 29 April 2023).

Kaiafa-Kmpanti, Maria, Efi Kounougeri-Manoledaki, and Elisavet Simeonidou-Kastanidou. 2017. *Recognition of gender identity: In view of the Draft Law of the Legal Preparatory Committee of the Ministry of Justice*. Athens: Sakkoulas.

Kelley, Jonathan, Mariah D. R. Evans, and Bruce Headey. 1993. Moral reasoning and political conflict: The abortion controversy. *The British Journal of Sociology* 44: 589–612. [CrossRef] [PubMed]

Kuzemko, Irene. 2023. My Life Really Began When I Found Out I'm Intersex at 22. Available online: https://yearofthewomen.net/en/magazin/my-life-really-began-when-i-found-out-i-m-intersex-at-22?fbclid=IwAR1onJs-Aa57Kf7ItBauxC1JFi5d1QJnDn9MDIegzkWFO6dMhhKtbGPznZw (accessed on 24 March 2023).

Left. 2017. "Equality and Freedom Today": Reportage by Left.gr from the Event of SYRIZA for the Legal Recognition of Gender Identity. June 1. Available online: https://left.gr/news/isotita-kai-eleytheria-simera-reportaz-apo-tin-ekdilosi-toy-syriza-gia-ti-nomiki-katohyrosi-tis (accessed on 28 June 2023).

Malta Declaration. 2013. OII Europe. Available online: https://www.oiieurope.org/malta-declaration/ (accessed on 22 March 2023).

Maxouri, Aggeliki. 2022. Intersex Children: New Provision of the Bill Bans the Change of Their Sex Characteristics before 15 Years Old—The Message of Intersex Greece. *News4Health*, June 27. Available online: https://www.news4health.gr/politiki-ygeias/15204/interseks-paidia-nea-diataksi-nomosxediou-apagoreyei-tin-allagi-ton-xaraktiristikon-tous-prin-ta-15-tous-to-minyma-tis-intersex-greece (accessed on 27 June 2022).

Mestre, Yessica. 2022. The Human Rights Situation of Intersex People: An Analysis of Europe and Latin America. *Social Sciences* 11: 317. [CrossRef]

Monro, Surya, Morgan Carpenter, Daniela Crocetti, Georgiann Davis, Fae Garland, David Griffiths, Peter Hegarty, Mitchell Travis, Mauro Cabral Grinspan, and Peter Aggleton, eds. 2021. Intersex: Cultural and Social Perspectives. *Culture, Health & Sexuality* 23: 431–40. Available online: https://www.tandfonline.com/doi/epdf/10.1080/13691058.2021.1899529?needAccess=true&role=button (accessed on 1 July 2023).

Myers, Alicia D. n.d. Motherhood in the Greco-Roman World. Available online: https://www.bibleodyssey.org/people/related-articles/motherhood-in-the-greco-roman-world/ (accessed on 8 September 2023).

Mylonas, Harris. 2018. Greece: Political developments and data for 2017. *European Journal of Political Research Political Data Yearbook* 57: 121–28. [CrossRef]

National Commission on Human Rights. 2015. Transgender Persons and Gender Identity Report. September. Available online: https://www.nchr.gr/images/pdf/apofaseis/diakriseis/EKTHESI_Nomiki%20anagnorisi%20taytotitas%20fylou.pdf (accessed on 26 April 2023). (In Greek).

National Strategy for the Equality of LGBTQI+. 2021. Available online: https://www.primeminister.gr/wp-content/uploads/2021/06/ethniki_statigiki_gia_thn_isothta_ton_loatki.pdf (accessed on 26 April 2023). (In Greek).

OII Europe. 2022. Good Practice Map 2022. Available online: https://www.oiieurope.org/wp-content/uploads/2023/05/GPMap2022_web.pdf (accessed on 5 July 2023).

Papaioannou, Giorgos. 2022. The Testimonies of Intersex Persons Are Shocking: If the Bill Passes, It Will Be a “Historic” Moment. July 13. Available online: https://intersexgreece.org.gr/2022/07/13/sygklonizoun-oi-martyries-intersex-atomon-istoriki-stigmi-an-psifistei-to-nomoschedio/ (accessed on 13 July 2022). (In Greek).

Parliamentary Assembly, Resolution 2048. 2015. Discrimination against Transgender People in Europe. Available online: https://pace.coe.int/en/files/21736/ (accessed on 20 April 2023).

Parliamentary Assembly, Resolution 2191. 2017. Promoting the Human Rights of and Eliminating Discrimination against Intersex People. Available online: https://assembly.coe.int/nw/xml/XRef/Xref-XML2HTML-en.asp?fileid=24232/ (accessed on 20 April 2023).

Pikramenou, Nikoletta. 2019. *Intersex Rights. Living between Sexes*. Cham: Springer.

Pikramenou, Nikoletta. 2022a. Intersex Rights in Greece and in Europe (Presentation at the National School of Judges). June 10. Available online: https://www.academia.edu/96088185/%CE%A4%CE%B1_%CE%AF%CE%BD%CF%84%CE%B5%CF%81%CF%83%CE%B5%CE%BE_%CE%B4%CE%B9%CE%BA%CE%B1%CE%B9%CF%8E%CE%BC%CE%B1%CF%84%CE%B1_%CF%83%CF%84%CE%B7%CE%BD_%CE%95%CE%BB%CE%BB%CE%AC%CE%B4%CE%B1_%CE%BA%CE%B1%CE%B9_%CF%83%CF%84%CE%B7%CE%BD_%CE%95%CF%85%CF%81%CF%8E%CF%80%CE%B7_E%CE%B9%CF%83%CE%AE%CE%B3%CE%B7%CF%83%CE%B7_%CE%95%CE%A3%CE%94%CE%99_ (accessed on 10 June 2022).

Pikramenou, Nikoletta. 2022b. Prohibition of Intersex Genital Mutilation Procedures on Intersex Children, Intersex Greece. Available online: https://intersexgreece.org.gr/en/2022/07/25/3449/ (accessed on 7 July 2023).

Pikramenou, Nikoletta, and Simeonidou Rinio. 2022. Intersex persons in Greece and Article 16. *TA NEA*, July 5. Available online: https://www.tanea.gr/print/2022/07/05/greece/ta-interseks-lfatoma-lfstin-ellada-lfkai-to-lfarthro-16/ (accessed on 20 April 2023). (In Greek).

Romero, Margarita Sánchez, and Rosa Ma Cid López, eds. 2018. *Motherhood and Infancies in the Mediterranean in Antiquity*. Oxford: Oxbow Books. [CrossRef]

Rubin, David A. 2015. Provincializing Intersex: US Intersex Activism, Human Rights, and Transnational Body Politics. *Frontiers: A Journal of Women Studies* 36: 51–83. [CrossRef]

Simeonidou, Rinio. 2019. The Wonderful and Diverse Spectrum of Sex: Intersex Children and Unconditional Love. *EfSyn*. Available online: https://www.efsyn.gr/ellada/koinonia/199860_yperoha-poikilomorfo-fasma-toy-biologikoy-fyloy-intersex-paidia-kai-aney (accessed on 5 April 2023). (In Greek).

StopIGM. 2019. Genital Mutilation: How Malta’s Law Fails Intersex Children. Available online: https://stopigm.org/genital-mutilation-how-malta-law-fails-intersex-children/ (accessed on 25 April 2023).

StopIGM.org. 2014. Selective Intersex Abortions: XXY 74%, Indeterminate Sex 47%, Hypospadias 2%. Available online: https://stopigm.org/selective-intersex-abortions-hypospadias-intersex-xxy/ (accessed on 5 April 2023).

Strand, Cecilia, Jakob Svensson, Roland Blomeyer, and Margarita Sanz. 2021. *Disinformation Campaigns about LGBTI+ People in the EU and Foreign Influence*. Strasbourg: European Parliament.

Swarr, Amanda Lock, Sally Gross, and Liesl Theron. 2009. South African Intersex Activism: Caster Semenya’s Impact and Import. *Feminist Studies* 35: 657–62.

Tamney, Joseph B., Stephen D. Johnson, and Ronald Burton. 1992. The Abortion Controversy: Conflicting Beliefs and Values in American Society. *Journal for the Scientific Study of Religion* 31: 32–46. [CrossRef]

TedxTalks. 2018. Intersex Human Rights, Rinio Simeonidou, TedxLesvos. Available online: https://www.youtube.com/watch?v=FJo4Br_Ifd8 (accessed on 5 April 2023).

Thanopoulos, Vasilis. 2017a. Interview: Irene Simeonidou, Antivirus Magazine. Available online: https://avmag.gr/80506/ (accessed on 3 April 2023). (In Greek).

Thanopoulos, Vasilis. 2017b. Interview: Lakis Kandilis, Antivirus Magazine. Available online: https://avmag.gr/synentefxi-lakis-kandyllis/ (accessed on 26 March 2023). (In Greek).

The European Parliament. 2019. European Parliament Resolution of 14 February 2019 on the Rights of Intersex People (2018/2878(RSP)). Available online: https://www.europarl.europa.eu/doceo/document/TA-8-2019-0128_EN.html (accessed on 10 April 2023).

Tsouroufli, Maria. 2020. Gendered and classed performances of ‘good’ mother and academic in Greece. *European Journal of Women’s Studies* 27: 9–24. [CrossRef]

UNHCR, and Refworld. 2017. Freedom in the World 2017—Greece. Available online: https://www.refworld.org/docid/59c102fae.html (accessed on 22 May 2023).

Verde, Lena. 2017. A Collective Battle. No 1333. July. Available online: https://ergatiki.gr/article.php?id=18699&issue=1333 (accessed on 10 April 2023). (In Greek).

Written Individual Submission from Intersex Russia, Universal Periodic Review for Russia. 2018. Available online: https://www.upr-info.org/sites/default/files/documents/2018-04/ir_upr30_rus_e_main.pdf (accessed on 2 April 2023).

XY Spectrum. 2018. What Is It Like to Be Intersex in the Western Balkans. Available online: https://youtu.be/n6BLZHFbeL0?t=50 (accessed on 24 April 2023).

social sciences

Article

Cultural Awareness of Intersex in Malta: Invisibility, Stigma and Epistemic Injustice

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Abstract: In 2015, Malta introduced ground-breaking legal reform designed to protect the bodily integrity of intersex infants in Malta. Drawing on semi-structured interviews with healthcare professionals, lawyers, policy-makers and advocates, this article considers the extent to which this reform has improved the cultural visibility and recognition of intersex people in Malta. Engaging with literature on epistemic injustice, this article provides new evidence for a cultural silence around intersex bodies that operates not only at a level of public knowledge but also at the individual and institutional levels. Our findings relate to three categories of visibility: political, cultural and medical. While the political visibility of intersex was an important factor in the introduction and shape of law reform in Malta, our respondents felt that the legislation had had very little effect on public understandings and familiarity with intersex issues. Moreover, respondents felt that many intersex people would be unlikely to know that they were intersex due to the limited conceptual and critical resources available to them: issues such as stigma and shame further encourage the epistemic silencing of intersex issues. The lack of cultural and medical visibility has significantly limited both the intended and hoped-for effect of the legislation. The article considers the broader implications of these results beyond Malta for those seeking to use the law to improve the lived experiences of intersex people.

Keywords: intersex; variations of sex characteristics; DSD; epistemic injustice; Malta; law; cultural visibility

Citation: Bartolo Tabone, Claudia, Fae Garland, and Mitchell Travis. 2024. Cultural Awareness of Intersex in Malta: Invisibility, Stigma and Epistemic Injustice. *Social Sciences* 13: 150. https://doi.org/10.3390/socsci13030150

Academic Editor: Nigel Parton

Received: 26 January 2024
Revised: 28 February 2024
Accepted: 29 February 2024
Published: 6 March 2024

1. Introduction

In 2015, Malta introduced ground-breaking legal reform through its Gender Identity, Gender Expression and Sex Characteristics Act 2015 (GIGESCA) which was designed to protect the bodily integrity of intersex infants. In doing so, Malta became the first jurisdiction to introduce a legislative framework that ostensibly challenged medical practice by prohibiting unnecessary medical interventions on children without their consent. This article arises from the first small-scale qualitative study with policy-makers and healthcare professionals[1] to provide evidence uncovering the effect of this legislation on intersex rights. One of the hoped-for consequences of GIGESCA was not only to directly change medical practice, but to help bring about wider cultural visibility and recognition of intersex people in Malta (Garland and Travis 2018) and, in doing so, reduce stigma and experiences of epistemic injustice. This article examines the extent to which this legislation has brought about such change in Malta. Such examination is integral for a broader understanding of the efficacy of legal reform, as Malta's experience demonstrates how state failure to recognise and redress epistemic injustice through other mechanisms can render legislative reform ineffective.

Accordingly, we engage with literature on epistemic injustice (Fricker 2007, 2017; Merrick 2019; Carpenter 2018, 2023; Carpenter and Jordens 2022; Ziemińska 2020; Griffiths

2023) reflecting on the interaction between law, cultural invisibility and epistemic injustice. In this sense, we evaluate GIGESCA's ability to address two key forms of intersex epistemic injustice: testimonial injustice, where intersex voices are discredited as a result of their lived experience (Carpenter 2018); and hermeneutical injustice, where intersex people are "unable to make sense of their experience due to prevailing social norms." (Carpenter 2018, p. 459; Ziemińska 2020, p. 54). Invisibility arises from (and also contributes to) a lack of shared social resources for intersex or endosex people[2] to understand intersex lived experience. The result is further marginalisation which "perpetuates the lack of resources needed to understand those experiences" (Goldberg 2020, p. 37). We ask, how far has law reform in Malta been able to remedy such injustice and what can we learn from this experience?

Chiefly, although there has been some political recognition of intersex by policy-makers and through legislation, this article provides new evidence that a cultural silence remains around intersex bodies despite legislative reform. While GIGESCA attempts to redress testimonial injustice, there is nothing in GIGESCA or surrounding policy discussions and initiatives that specifically addresses hermeneutical injustice and may even contribute to it. Consequently, gains in political visibility have not been made elsewhere. Our respondents felt that the legislation had very little effect on cultural understandings and familiarity with intersex issues. Problems such as stigma and shame as well as conflation with trans concerns further encourage the epistemic silencing of intersex issues. Moreover, medical professionals continue to be limited by epistemic injustice and the difficulties that presents for intersex people and their parents who are navigating healthcare spaces. A hermeneutic justice gap thus remains which fundamentally hinders the efficacy of law reform in Malta, with evidence showing that people may not even realise that the rights available through GIGESCA apply to them. Unless the cycle of cultural invisibility is broken, legal reform may be rendered ineffective. While the law's ability to challenge epistemic injustice in Malta may be attributable to Malta's distinct cultural, political and medical context, there are some more general lessons to be learned from Malta's experience. Notably, states who wish to improve intersex lived experience must combine top-down initiatives such as introducing legislation with alternative mechanisms of regulation and education.

The article now outlines GIGESCA before turning to an overview of epistemic injustice specific to intersex people. We then set out the methodology used for our empirical project before setting out our findings relating to three categories of visibility: political visibility, cultural visibility and medical visibility. We then finally consider how to improve intersex visibility within and outside of Malta and ways in which we might overcome hermeneutical injustice in this arena.

2. An Overview of The Gender Identity Gender Expression and Sex Characteristics Act 2015

GIGESCA arose as a response to a legal case which centred on a trans womans' right to marry.[3] The case was intended to go to ECHR, but settlement was reached between Malta and the claimant whereby Malta promised to introduce a swathe of progressive LGBT reforms including a gender recognition act, now GIGESCA.[4] Although the outgoing Nationalist Party government recognised the need for legal reform to protect the rights of gender-diverse people, these were ultimately driven by a newly appointed Labour Government. However, GIGESCA was not initially designed to include intersex-specific provisions (Garland and Travis 2023). Rather, lobbying for the introduction of a Gender Identity Bill in Malta started in 2010 (Falzon 2010) but its first iteration was only addressed towards trans people. The first draft referred to the establishment of a 'Transgender Persons Register' which would be accompanied by a "procedure for the recognition of a person's gender." Policy-level engagement with international intersex organisations placed the need for legal reform on the agenda (Garland and Travis 2023). Significantly, the Third International Intersex Forum was held in Malta in 2013 with good engagement from policy-makers and led to the intersex provisions being added to the Bill by the time that it was first read in

Parliament in October 2014. The first draft of the Bill underwent a public consultation, and numerous organisations and institutions, both local and international, submitted their comments (Falzon 2010, p. 40). These submissions—unsurprisingly—emphasised the lack of cultural visibility as most made no reference to the intersex provisions and the few that did were either from international intersex organisations or were particularly concerned that the public still did not know the differences between intersex and trans.[5] Accordingly, the introduction of the intersex provisions within GIGESCA appeared to happen with little notice or attention from the public in Malta (Garland and Travis 2023) with the focus instead being held by debates around trans rights.

Despite the lack of attention, the provisions that were introduced were significant. Alongside equality laws that protect intersex people from discrimination and hate crimes, GIGESCA was the first piece of legislation which included a prohibition on non-consensual non-therapeutic surgeries prohibited "until the person to be treated can provide informed consent.' (s. 14(1)). The act also included criminal penalties for those that breached this prohibition[6] and instigated a raft of changes to healthcare provision for intersex people. GIGESCA also sought to improve intersex healthcare experiences. Under ss.14(4) and 14(5), GIGESCA also sought to establish an interdisciplinary team (IDT) charged with overseeing healthcare provision for intersex children.[7] Treatment could only be carried out if an agreement was reached between the parents and the interdisciplinary team. This provision appears to give equal authority to the parents and the group of experts; however, the Act does not address the possibility of an impasse or provide possible solutions for any disagreements between the parents themselves, or between the parents and the IDT. GIGESCA aspirationally introduced s.15(1) which states that individuals "seeking psychosocial counselling, support, and medical interventions relating to sex and gender should be given expert sensitive and individually tailored support…" and this support "should extend from the date of diagnosis or self-referral for as long as necessary." While not specifically addressed at intersex people, this section was also a step in the right direction. As opposed to the previous section, s.15 does not appear to address minors but rather any persons, whatever their age, should be able to seek psychosocial care when and for as long as they need it.

The sentiment of the intersex provisions in GIGESCA was certainly a positive one and was welcomed by intersex activists around the world (Garland and Travis 2018). Yet the Act itself was never intended to address the issue of intersex invisibility. Rather it was intended to grant specific rights and obligations to intersex people and medical practitioners. However, given that Fricker (2007, p. 154) states that silence within healthcare itself means that "the whole engine of collective social meaning [is] effectively geared to keeping [intersex experiences] out of sight", GIGESCA's focus on illuminating and changing medical protocols marks a potential shift towards greater cultural visibility. This article explores whether greater cultural visibility has followed GIGESCA. Understanding this, as the next section demonstrates, is crucial to understanding the efficacy of the legislation. If intersex remains culturally invisible outside of the legislative context, affected individuals will simply not know that rights and obligations will apply to them. Thus, the law's utility and the value of legislation will be limited.

3. Intersex People and Epistemic Injustice: The Need for State Action

In recent years, there has been increasing engagement with the notion of 'epistemic injustice'. Starting with Fricker, epistemic injustice has been characterised as a set of circumstances whereby an individual is "ingenuously downgraded and/or disadvantaged in respect of their status as an epistemic subject"(Fricker 2007, p. 53). Ballakrishnen and Lawsky further this by describing it as "refus[ing] to accept someone as a person who is capable of knowing things and of communicating that knowledge is to dehumanize them" (Ballakrishnen and Lawsky 2022, p. 1031). According to Fricker (2007), epistemic injustice includes both testimonial and hermeneutical injustice. The former refers to situations whereby the testimony of that person is devalued on account of an aspect of their identity

(Merrick 2019, p. 4433; Fricker 2007, p. 29). For example, intersex people's accounts of medical harms are often discredited owing to structural identityprejudice which depicts intersex people as 'less rational' or 'untrustworthy', particularly in comparison to medical practitioners who use this prejudice to refute such accusations of harm (Merrick 2019, p. 4433; Fricker 2007, p. 29). Indeed, Merrick explains that victims of testimonial injustice are often members of groups typically "barred from fully participating in the institutions tasked with generating the culturally dominant hermeneutical resources" (Merrick 2019, p. 4433). In the context of intersex people, there has been a historic exclusion of intersex voice both in "determining and evaluating medical care" (Merrick 2019, p. 4435), and the inappropriate pathologisation of intersex people demonstrates evidence of such testimonial injustice (Luzzi 2021, p. 4; Merrick 2019; Davis 2015). In this sense, then, the introduction of GIGESCA, legislation that has been actively designed to respond to the concerns of medical harm raised by the intersex community in the International Intersex Forum in 2013 in Malta, marks a state-led initiative to respond to testimonial epistemic injustice. This article considers whether GIGESCA has successfully redressed intersex testimonial injustice.

Moreover, epistemic injustice also arises in contexts where "a gap in collective interpretative resources puts someone at an unfair disadvantage when it comes to making sense of their social experience" (Fricker 2007, p. 1). This has been characterised as 'hermeneutical injustice' (Fricker 2007, p. 1). As Ziemińska explains, "hermeneutical injustice is a structural notion, and no agent perpetuates the injustice (even unintentionally). It is a structural vice of the social imagination" (Ziemińska 2020, p. 53), and, as Carpenter notes, it arises in situations where individuals have "no access to concepts and terms that can describe their experience" (Carpenter 2023, p. 4). Thus, in the context of GIGESCA, hermeneutical injustice can mean that *accessing* available rights in the law is not possible.

The concept of epistemic injustice has increasingly been used in relation to intersex people (Carpenter 2018, 2023; Carpenter and Jordens 2022; Ziemińska 2020; Griffiths 2023). General familiarity with the term intersex is low (Hegarty et al. 2021). The lack of epistemic and cultural knowledge about intersex people arises from a societal enforcement of the gender binary (Dreger 1998; Ziemińska 2020; Foucault 1980) and a medical establishment that has historically focused on secrecy around intersex variations (Hegarty and Chase 2000; Davis 2015; Carpenter 2023). As Carpenter notes:

> Non-disclosure or motivated disclosure of a diagnosis, and use of language that disconnects individuals from peer support, are widespread phenomena that leave individuals with significant gaps in understanding about their bodies and an inability to connect with others. These forms of disclosure mean that the authority of biomedical professionals is boosted, while the voices of community and parents are systematically marginalised in ways that limit agency and participation in decision-making. (Carpenter 2023, p. 15)

This article asks, then, whether in Malta, GIGESCA has been able to remedy this form of epistemic injustice and increase cultural visibility. Medical professionals and guidelines have been instrumental in denying intersex peoples' knowledge of their own variations and bodies and, in many ways, hindered the establishment of intersex communities, which can make it difficult for individuals to mobilise. Since at least 2006, professional medical guidance has rowed back from its position of secrecy towards dialogue with parents and intersex children. Nonetheless, healthcare's change in nomenclature from 'intersex' to 'DSD' (Disorders of Sex Development) has been seen by some as an intention to "wrest epistemic authority back from the nascent intersex movement" (Carpenter 2023, p. 8; Davis 2015) and as re-entrenching "clinical power to delineate and silence those marked by the diagnosis" (Holmes 2011).[8]

At the same time, since the early 1990s, intersex activists have worked with LGBT activists to create visibility and community space (Preves 2003). This has created a nascent but contrasting epistemology of intersex whereby it is characterised through the lenses of LGBT and increasingly non-binary embodiment (Garland and Travis 2023). As Griffiths explains, "Historically, there have been two dominant frameworks within which intersex has been made intelligible or recognizable: that of biomedicine, and that of gender and/or sexuality" (Griffiths 2023, p. 13). As Carpenter highlights, "The resulting hermeneutical injustices have material effects where, for example, the use of 'disorders of sex development' terminology in clinical settings, and the term 'intersex' in community, human rights and LGBTQ spaces has sometimes led to the construction of incommensurate and contradictory policy frameworks, as if referring to distinct populations" (Carpenter 2023, p. 6; see also Garland and Travis 2023). Framing intersex experiences through a singular framework can thus create its own form of "epistemic violence, whereby intersex demands, testimonies and politics are ignored in favour of more dominant narrative" (Griffiths 2023, p. 13).

Consequently, Ziemińska highlights that the cultural visibility of intersex people is "a structural problem" (Ziemińska 2020, p. 54), that we are "prisoners of the social imagination that is created by the whole society" (Ziemińska 2020, p. 60) and that intersex "voices cannot be understood in the public arena" (Ziemińska 2020, p. 54). To remedy this, Fricker suggests the need for more empirical data and to prioritise the voices of minority groups (Fricker 2007, p. 162), suggestions that are bolstered by interdisciplinary intersex studies (Monro et al. 2021) and that we seek to add to in our recommendations from this study.

The need for participation and voice echoes work that has been done in the spheres of equality and social justice. Sandra Fredman, for example, has made enhancing voice and participation one of the core tenets of her multi-dimensional approach to substantive equality, alongside the related notions of addressing stigma, stereotyping, prejudice and violence, and accommodating difference and achieving structural change (Fredman 2016, p. 713). Political visibility is thus a priority in redressing epistemic injustice. This is not only addressed through legislation but through ongoing opportunities to create meaningful dialogue between intersex people and the state. As Merrick (2019) states, combatting testimonial and hermeneutical injustice requires both societal and institutional remedies to neutralise prejudice against intersex people and "policy setting bodies must also cultivate this and correct for adverse dialogical effects due to hermeneutical marginalization" (Merrick 2019, p. 4434). Moreover, it may involve funding peer-support networks for intersex people to develop their own sense of community (Garland and Travis 2018).

Accordingly, for GIGESCA to mark a watershed moment in terms of legal rights, there must be an accompanying shift in epistemic injustice to ensure the possibility of participation. Unless individuals can articulate harms and access rights, legal reform is in danger of being a superficial response to the problematic medical responses in this area. We now turn to the results of our empirical project to examine whether the reform in Malta was accompanied by (or indeed led to) a change in epistemic and cultural knowledge about intersex.

4. Materials and Methods

This research was funded by the British Academy and sought to examine the impact of GIGESCA's intersex provisions on the Maltese intersex population. To do so, the authors conducted a systematic literature review of the following: relevant laws in place before and after GIGESCA was introduced; transcripts of parliamentary sittings during which the Bill was being discussed; newspaper articles, both local and international; and other local and international reports. Beyond this, the primary aim of our research was to analyse the social impact of this specific legal reform; a series of semi-structured interviews with a diverse cohort of stakeholders was planned. This exercise established the personal and social contexts that surrounded GIGESCA and allowed for deeper exploration of its aims and the impact of the changes that it introduced.

Requests for ethical review were successfully submitted to the University of Malta and the Maltese Health Ethics Committee. Since the intention was to interview Maltese nationals, documentation in both the Maltese and English languages was prepared. Notably, most Maltese nationals are bilingual, however it was felt that giving the option of replying in either language would enable respondents to choose the language they preferred. As one of the researchers is Maltese and can speak the language fluently, it was possible to offer the option of holding interviews in Maltese.

Recruitment was mainly done through an open invitation. Invitations were sent to professional associations and entities for distribution among their members. In some instances, respondents themselves recommended that invitations be sent to other individuals with experience in the area. Eleven professionals—two lawyers, three policy-makers; two involved in advocacy work, and four healthcare professionals (nursing, paediatric surgery, psychology and endocrinology)—sat for a semi-structured interview carried out over Zoom between 2022 and 2023. The transcripts were anonymized, and thematic analysis was carried out. Owing to Malta's population size, additional difficulties exist relating to anonymization, as it potentially means that there is more identifiable information which will need removal during the anonymisation process. To mitigate this, we not only anonymised respondents' details such as their name, but followed processes for small populations recommended by Saunders et al. (2015).[9] Data were analysed thematically (Braune and Clarke 2015), with themes generated around issues relating to cultural knowledge, visibility and epistemic injustice. Whilst the views of our respondents differed on a number of important topics, in relation to epistemic injustice and evaluating whether Malta had been a success in those terms, they were in consensus.

Unfortunately, no intersex persons or parents of intersex children accepted the invitation to be interviewed. Although the professionals' perspectives proved to be insightful, failure to obtain the intersex persons' experience is considered a major limitation of the study. In part, the reasons for this lack of recruitment may be explained through the discussion of epistemic injustice that we now turn to in this article. For example, some of our respondents held the opinion that many intersex people may not even realise that they are intersex or that this research was addressed to them. In Sections 5.2.2 and 5.2.3, we reflect on issues of stigma and lack of self-knowledge and their links to hermeneutical injustice within intersex experiences in more detail. This, coupled with the idea that stigma was perceived to be increased in Malta may have affected our ability to recruit. What this does mean, however, is that our conclusions are without reference to intersex people in Malta and thus are limited in terms of what we can learn. More research is needed, and careful thought as to how to engage participants must be given by researchers in the context of the hermeneutical injustice experienced by intersex people.

We now present our findings with regards to three themes: political visibility, cultural visibility and visibility in healthcare.

5. Results and Discussion

5.1. Theme 1: Political Visibility

Despite its track record for its Catholic conservativism and its historically restrictive approaches towards abortion and divorce, Malta introduced a swathe of progressive LGBT rights in the 2010s, making it one of the most progressive states in Europe in this regard. Notably, GIGESCA was a huge change in legislative engagement with intersex issues, not just within Malta, but globally (Garland and Travis 2018, 2023; Ní Mhuirthile 2018). The legislation was comprehensive and forward-thinking—seeking to both protect intersex people but also ensure access to support from healthcare professionals over the life course. The design of GIGESCA clearly benefitted from the participation and voices of intersex people. Several of our respondents noted the participation of Government Ministers at the Third International Intersex Forum held in Malta in 2013.

> *. . .the minister had the opportunity to meet a number of intersex activists from around the world when they had I think it was the second or the third international intersex forum that ILGA Europe was conducting in Malta. So the minister had this opportunity, you know, to listen to the stories of so many people and I think, from what I know, she felt compelled that she needs to do something about this. . . . think it was a big chance, a bit you know, pushing by the right people at the right time.* (Respondent 4—advocacy)

Malta's ability to introduce such progressive rights was attributed by our respondents to several individuals within the government having familiarity with intersex issues through their work with international LGBTI organisations.

> *. . .the Minister at the time was surrounded by two people who have done a lot of work around intersex persons globally*. (Respondent 4—advocacy)

> *. . .within the ministry at the time [there were] two people who had been chairing the International Intersex Forums on behalf of ILGA-Europe and ILGA, who therefore knew more and could drive that process.* (Respondent 2—policymaker)

Our respondents were keen to highlight, therefore, the fortuitous set of circumstances that led to intersex issues being included within the scope of GIGESCA. Here, the participation of individual actors and the Ministers' access to the testimonies of a range of international actors made a huge difference to the government's epistemic unfamiliarity with, understanding of, and commitment to these issues. Whilst Malta did not have a wide-reaching intersex-led NGO, the existence of these key actors and moments were crucial to driving forwards social change.

> *. . .in reality, intersex issues were relatively new to the movement at the time and so were not necessarily being pushed by the civil society organisations. But when the law was proposed, or rather, when political will was expressed in terms of passing the GIGESC Act from the political side, it was always intended to include intersex issues. So in this sense, that part of the law was more government- than society-led and mainly because there was not a lot of knowledge I would say of civil society on intersex issues.* (Respondent 2—policymaker)

At this level, then, the political climate within Malta was able to counter the testimonial injustice-induced credibility deficit that often pervades political and institutional responses to intersex experiences. Indeed, tribute to such political awareness can be found in GIGESCA's attempt to redress some testimonial injustice within the scope of the Act. The drafting of GIGESCA's intersex provisions used deliberate language to ensure that the Act's remit was wide, casting the right to be free from unnecessary physical interference without the express consent of the individual under s.14 broadly. Significantly, the legislation does not actually use or define the term 'intersex' but instead it prohibits "any sex assignment treatment and/or surgical intervention on the sex characteristics of a minor which treatment and/or intervention" rather than interventions on intersex minors. Section 2 further defines 'sex characteristics' as:

> *the chromosomal, gonadal and anatomical features of a person, which include primary characteristics such as reproductive organs and genitalia and, or in chromosomal structures and hormones; and secondary characteristics such as muscle mass, hair distribution, breasts and, or structure.*

The legislature's choice to use 'sex characteristics' instead of 'intersex' was intended to make the application of this legal right wide-reaching and avoid reliance on the medical institution to provide a diagnosis before an individual can invoke s.14, removing some of the barriers that perpetuate testimonial injustice. Legislators specifically wanted to avoid medical 'gatekeeping' of these rights by allowing them to determine whether an individual is or is not 'intersex' for the purposes of GIGESCA's protective provisions. As one respondent stated:

> *[policy-makers] wanted to make sure that minors would be protected even when they are not diagnosed as intersex because of course . . . there is a lack of awareness on what being intersex means and that includes the medical community. So if you have a minor that is not correctly diagnosed but is still recommended for surgical interventions on their sexual organs so on and so forth, they are still protected by this law. And that is what* [policy-makers] *wanted to do. So [they] did not want a law to be restricted to apply only when there is a DSD diagnosis.* (Respondent 5—Law)

In addition to this, the working group which was set up to review and develop the medical protocol regulating intersex care per s16(6) was to consist of an equal mix of human rights experts, psychosocial practitioners, and medical professionals. The inclusion of human rights professionals was specifically to ensure that the experiences of intersex individuals in terms of medical harm were taken seriously by the working group so that a model of best practice could be developed:

> *. . . an interdisciplinary panel that establishes treatment protocols . . . should try to look at issues beyond the beyond the medical. So, trying to have protocols that look at social issues, look at self-determination issues as well, issues which, as we mentioned before, medical practitioners might not be too ready to think about, or even accept immediately. So, to really bring in more than the just medical into the conversation.* (Respondent 11—Law)

While GIGESCA does not contain reference to the inclusion of patient groups or intersex individuals, it is a significant attempt to remedy testimonial injustice experienced by intersex people in relation to discussions about appropriate medical care. Indeed, the very nature of the intersex provisions is to redesign the provision of healthcare in a way that responds to intersex experiences, acknowledging that surgeries on infants amount to criminal harms.

However, post-implementation, this has not redressed testimonial injustice. In fact, there has been a huge delay in GIGESCA's implementation due to a lack of definitional and terminological consensus between human rights experts and medical experts. As a result, the protocol has not been finalized, and thus, the full remit of the act is not yet set. This schism between human rights narratives and medical narratives over intersex is well documented (see e.g., Carpenter 2018; Garland and Travis 2020a). In Malta, this divide is a pervasive issue relating to epistemic injustice, where healthcare practitioners often appear impervious to, or even dismissive of, claims of human rights violations in this arena from supranational bodies such as the UN and the European Court of Human Rights (Garland et al. 2022). In Malta, this debate has really centered on whether hypospadias[10] should or should not be included within the definition of 'intersex'.

> *. . . they're still discussing . . . the basic concept of the word intersex, because the way [medical professionals] see this category of people is, you know, this is a condition, a disorder of sex characteristics, and we're talking a very different language. And others are saying no it's not a disorder, but it's a difference, or it's a diversity. And they're [medical practitioners] thinking of, you know, what is the standard or kind of the golden standard of what a vagina and what a penis should look like, and what other intersex conditions should be considered as intersex conditions include the hypospadias, for example.* (Respondent 2—policymaker)

Accordingly, testimonial injustice pervades in the aftermath of legislative reform. It supports Merrick's assertion that "...the prevailing perspective or practical identity of a Western healthcare professional is not entirely well-suited for virtuously listening to patients or their non-medical advocates" (Merrick 2019, p. 4445). Accordingly, both Merrick and Fricker argue that to cultivate institutional testimonial justice, or what Merrick defines as being biomedical testimonial injustice, there must be greater "respect for a patient's epistemic agency and interpretive competence part of the practical identities of healthcare practitioners and providers" (Merrick 2019, p. 4445). Yet, there has not been the political capacity for this in Malta. While there has been some commendable political visibility, post-GIGESCA, it has been difficult to create the climate necessary to remove the prejudice attached to intersex narratives. Indeed, politically, several changes since GIGESCA's introduction in 2015 have diluted the efficacy of political visibility. As respondent 3 (advocacy) highlights:

> *Keep in mind that we've had a lot of political changes over the past few years in Malta, and every time there is a change in Minister, then any Ministry-appointed boards have to resign. It's a courtesy. They call it a courtesy but you have to resign in case the minister*

> *happens not to like you and doesn't want you on the board. The new minister, right. And* [Malta's] *had a few of those, you know, changes, over the past years we've had ministerial changes. That obviously doesn't help because everything is at a standstill until the new minister is in place and says yes ok, the board can continue at it was, or whatever.*

Political instability has, therefore, also contributed to the delays faced by the Working Group and, thus, the full implementation of GIGESCA. In the next section, we outline some of the issues around cultural visibility and how epistemic injustices have hindered the implementation of GIGESCA. In the absence of a strong alternative, it is perhaps not surprising that the medical profession has been able to continue to shape the epistemic direction of implementation.

Moreover, as discussed below, whilst political visibility was hugely successful in terms of introducing legislation, its attempt to address testimonial injustice may have actually exacerbated hermeneutical injustice through the absence of a clear relatable term such as intersex or even specific variations. This lack of language consensus contributes to hermeneutical injustice through a persistent misalignment between social, political and medical understandings of intersex. Without terminological consensus, medical framings of 'disorder' continue to dominate understandings of what intersex is. This dominant framing constructs intersex through a particular lens and, in many ways, prevents its mobilisation as an ontological category. Our argument here is not to suggest that any particular term is more or less preferrable—indeed, there is plenty of evidence to suggest that the avoidance of labels helps avoid inappropriate pathologisationand recognises the multiple experiences of individuals with intersex variations, many of whom do not wish to, nor realise that they may, come under the umbrella term 'intersex' (Topp 2013; Viloria 2017; Malatino 2019). However, as noted below, in the absence of clear cultural knowledge and understanding, a lack of clarity over just who may be protected by s.14 has not only led to stalling by the medical profession post-implementation, and a potential co-opting of this legislative space, but individuals may simply not realise that the Act is intended to protect them. The rights contained within the Act are rendered unintelligible because there is a lack of language for people who need or wish to apply it. Indeed, as part of the consultation process for GIGESCA, Organisation Intersex International Australia (now the Intersex Human Rights Australia IHRA) submitted a consultation response which suggested that "the proposed language around 'sex characteristics' would benefit from either the additional inclusion of a legal definition of 'intersex', or mention of 'people with intersex variations' to "promote legal and societal clarity about the full diversity of sex characteristics of people that arise in nature."[11] Some of our respondents also recognised that better oversight of definitions was needed or would have helped particularly around the inclusion of hypospadias.

This, combined with no visible third sector organisation pushing for this reform, means that much of the legislation around intersex seems to have gone unnoticed by the broader public including both endosex and intersex people allowing hermeneutical injustice to perpetuate. Thus, the implementation stages of GIGESCA have been affected in part due to a lack of intersex stakeholders capable of providing their voices to ensure the accountability and transparency of governance in this area.

5.2. Theme 2. Cultural (In)Visibility

Unlike political visibility, our focus on cultural visibility refers to the wider public awareness of intersex at the individual and interpersonal levels. In this sense, we analyse the discursive awareness of intersex and how far it still remains unintelligible within wider society (Butler 1990). While we are unable to draw from intersex voices, our respondents nevertheless provided insight into the hermeneutical progress made in this arena. Respondents reflected on how far these legal reforms had been able to infiltrate wider societal (and in Section 5.3 healthcare) discourse and remedy hermeneutical injustice.

5.2.1. Cultural Invisibility

Despite the growing political recognition of intersex and its effect on legislation, our respondents suggest that this was yet to translate to a general hermeneutical cultural awareness of intersex embodiment and its related issues. In keeping with general low levels of cultural awareness of intersex variations (Hegarty et al. 2021), respondent 10 (healthcare) stated that:

> *If you speak to lay persons and ask what do you know about intersex, what do you know about the intersex condition, or persons who have been diagnosed as intersex? No idea!*

One aspect of the limited visibility of intersex people was attributed to a lack of visible role models and community leaders. As respondent 4 (advocacy) notes:

> *Well, first of all, I think the lack of awareness and visibility is something that is still very much present, and. . . you know we're educating people out there about intersex conditions. But there isn't anyone visibly Maltese appearing on media and talking about their experience, unlike all of the other identities within the LGBTIQ community. So, I think that makes it quite difficult for other intersex persons to reach out, to be part of the Community and to have Community support.*

This is perhaps unsurprising, given that Malta is a small conservative Catholic jurisdiction which, as we discuss below, exaggerates the difficulties in speaking openly about being intersex. Yet, visible role models are an important aspect of recognising a community not just for the wider culture but, as will be discussed in the next section, for self-recognition. Not only were intersex people themselves not visible, but there was limited hermeneutic awareness of what intersex is. This supports the view that the issues that intersex people face are hermeneutically epistemic (Carpenter 2018, 2023; Carpenter and Jordens 2022; Ziemińska 2020; Griffiths 2023). Without the vocabulary and conceptual scaffolding to place intersex within the cultural schema, legislative change has been unable to increase cultural visibility. As respondent 5 (Law) explains:

> *Not many people pay a lot of attention to what's happening in Parliament. So, I would not be surprised that at the time they were not aware. Now I am hoping things changed, you know, 7 years after that. . . . I believe it was a case of law driving society forward and not vice versa. Sometimes you get society pushing for legal change. In this case I think it was very top-down approach, which is good in a sense because it needed to happen and it needed to happen fast, but at the same time you'd get this disconnect.*

Respondent 5 (Law) highlights that the pressing need for GIGESCA and its perceived time sensitivity meant that the legislation was largely dictated by a core group of 'experts' rather than stemming from a broader social movement. The speed with which intersex was included into GIGESCA and the political strategy around it meant that there was limited consciousness raising attached to intersex at the time of the Bill's passing contributing to the lack of attention paid to the need to remedy hermeneutical injustices. The lack of a social movement pushing for this legislation can also be explained through hermeneutical injustice, as discussed in the next section.

5.2.2. A Lack of Personal Awareness

Our respondents felt that intersex people within Malta would not have the conceptual or cultural resources to understand that they were intersex. This issue of hermeneutical injustice helps to potentially explain the difficulties in recruiting intersex people in this study. As respondent 1 explains, "I wouldn't be surprised if there were people out there who just didn't know they were intersex. Didn't know this [law] was meant for them." Our respondents felt that the cultural conditions within Malta (of conservativism, Catholicism, medical stigma) meant that it would be unlikely for intersex people to have the imaginative tools necessary to identify with intersex labels—a core tenant of hermeneutical injustice. As respondent 10 (healthcare) explains:

> *Also being a very small area geographically, and also being, from the social aspect, people are very much related and also go around everyday activities very much within the same people, you see, it's still a secret. It's a very secretive kind of thing. I think it's very much related, as well, to the erroneous idea of the Catholic culture being predominant in Malta.*

This secretive approach would go some way to explaining our difficulties with recruiting intersex Maltese people (and parents) to our study. It would similarly explain the very small minority of intersex people on the 'Working Group' set up as part of GIGESCA to oversee the creation of healthcare protocols related to intersex people informed by both healthcare and human rights approaches.

This hermeneutical injustice has material effects when considered in the context of GIGESCA. The 'success' of the legislation is dependent on its use. Whilst this may, for the most part be measured in terms of its deterrent effect on medical professionals it also presupposes the idea that its constituent population is aware enough of the legislation to utilise it. Our respondents felt that this was not the case:

> *What I can tell you . . . is that most of our clients know nothing of it [GIGESCA] . . .* (Respondent 10—healthcare)

> *Nothing. Zero . . . there haven't been any legal queries from any intersex person. Nothing. I mean, when you have all the conditions in place for a person to enjoy rights, speak to NGOs for advice and support, you know, and everything is in place favouring the situation, and there's still a lack of engagement, then . . . it goes to show how invisible, how disenfranchised, how disempowered, how afraid people are.* (Respondent 11—Law)

This is an important point, without the cultural awareness to use it, GIGESCA is, at least for intersex people, futile, particularly in a context whereby doctors claim the legislation does not apply to them. Moreover, the lack of visible intersex people creates broader problems—without community input, it is difficult to monitor the 'success' of this legislation or to consider whether different forms of interventions are necessary. Indeed, this research study and others indicates the difficult of recruiting much needed intersex voices.[12] As respondent 3 (advocacy) highlights: *"The largest one, for me, not necessarily for them, is complete invisibility. They are completely invisible. And if they're invisible, then we don't really know what their issues are. And we can't do anything, you know, to deal with whatever their issues are"*. The difficulties with visibility lead directly to a lack of participation and voice, which, in turn, prevents support for intersex people being led by their own desires and needs—hermeneutic justice becomes embedded and self-perpetuating.

Similarly, without self-recognition, it is difficult to build a wider network of community support. The hermeneutical injustices present in Malta (and elsewhere) have hindered the development of a visible and active intersex movement. This, for some of our respondents, was compounded by feelings of shame and stigma associated with intersex variations and is likely exacerbated by the lack of reference to intersex in the legislation.

5.2.3. Stigma/Shame

Our respondents felt that the lack of personal awareness of intersex variations was intensified by issues of shame and stigma within Maltese society. These feelings of shame led to parents deliberately withholding important facts about children's medical histories from them.

> *. . . we don't tell the kids themselves who have a right to information about themselves, we don't tell the relatives—God forbid we tell the relatives! Therefore, this whole thing becomes a shameful secret still.* (Respondent 10—healthcare)

> *. . . there is an element of shame in the parents for having failed to produce a 'perfect' boy or a 'perfect' girl, then being referred.* (Respondent 3—advocacy)

These reports are in keeping with general observations of parent's treatment of intersex variations—particularly prior to the 2006 Consensus Statement (see for example Hegarty and Chase 2000) and reflect the high rates of decisional regret that parents feel in these circumstances (Roen et al. 2023). Some respondents pointed towards the word ‘sex’ in both intersex and disorders of sex development as a source of shame for conservative and Catholic parents that stopped them from fully engaging with resources available on their child’s variation. The conceptual resources needed to combat hermeneutical injustice is thus stymied by cultural stigma and secrecy.

However, one respondent returned to themes of hermeneutical injustice, stating that, *“I would say there is a stigma but I don’t think I can even say that because it’s so unknown, even as a possibility, that I won’t even say there’s a stigma attached to it”.* The lack of awareness around intersex, for this respondent, prevented its being understood through a lens of stigma, or perhaps it might be better understood as a stigma for which those that experience it lack the epistemic knowledge to articulate. Here, we reflect on our own experiences with this project: the experience of stigma, shame and fear of being ‘outed’ may have further prevented people from participating in the research. Malta is a small conservative island community where anonymity is far more difficult to maintain.[13] The perceived risk of being ‘outed’ as intersex may have outweighed the research goals for potential participants.

5.2.4. Conflation of Trans and Intersex

Whilst our respondents felt that there was a cultural conceptual lack of awareness about intersex people, they felt that often this gap in knowledge was conflated with trans issues. This element of hermeneutical injustice was brought particularly to the fore in Malta, as GIGESCA predominantly dealt with trans issues and was, in many ways, a response to an ECHR case (that had been settled before a decision was made) that centered on trans people’s access to marriage (*Cassar v Malta* 36982/11, see also Garland and Travis 2023). As respondent 5 (Law) notes:

> *And in particular with Malta, the hype with this law was not about the intersex provisions, so when it was enacted in 2014, the hype was mainly around the transgender community. The intersex provisions were rarely mentioned in the press, or when politicians spoke about it. It was very, very rarely heard of. So that’s another issue in itself. . . .*

In some ways, this reflected the strategy of the politicians supporting the Bill. Whilst there was opposition to components related to trans equality, very little attention was paid to the intersex aspects of the provisions (Garland and Travis 2023). As a result, at least for intersex people, the Bill was able to sail under the radar. Whilst this was useful for ensuring that the Bill passed into legislation, it may have had the negative effect of diminishing the cultural visibility of it, of the need for such legislation, and of intersex people in general, inadvertently perpetuating epistemic injustice.

Moreover, the inclusion of intersex within GIGESCA may have led to some conceptual or schematic conflation between trans and intersex issues. As one respondent (policymaker) highlights, *“The issue is when it goes to the general public, I think. So perhaps the communication should make an explicit effort to distinguish the two issues”.* Unfortunately, this conceptual confusion is not uncommon (Griffiths 2023; Garland and Travis 2020b) and can lead to tensions between the trans and intersex communities.

Whilst the lack of public awareness around intersex is clear, the legislation was designed to foster cultural awareness within the medical profession. In the next section, we outline some of the difficulties that have been encountered in that space.

5.3. Theme 3. Visibility within Healthcare

Whilst there was some recognition of and knowledge pertaining to intersex issues at the political level, our respondents suggested that this, thus far, seemingly failed to transfer across to wider society within Malta. Our research also explored, however, how far healthcare professionals perpetuated or were themselves bound by epistemic injustice. Understanding this is key to this project, given that healthcare is the one institution that intersex individuals, particularly in infancy, and their family will encounter to discuss care. Even though several medical professionals were invited to participate in this research, many of those contacted stated that they could not take part, as they knew nothing about intersex, highlighting continuing levels of hermeneutical injustice in the very community the legislation was designed to target. This is confirmed by some of the respondents:

> *. . . not even healthcare professionals like nurses for example were aware that these people even exist. We don't see them much, somehow.* (Respondent 8—healthcare)

The fact that no medical protocol, no Interdisciplinary Team, and no specific Intersex Wellbeing Clinic have yet been set up, further perpetuates the invisibility of intersex people within the healthcare system and reinforces hermeneutical injustice. Those who were diagnosed in the past also seem to have been lost within the system, with no follow-ups and no long-term care.

> *Again, it's difficult in a sense to justify both sides of the coin when we know so little in terms of outcomes, when we cannot trace the impact that certain interventions have had on intersex people because they are completely invisible. This has been an issue . . .* (Respondent 2—policymaker)

Hermeneutical injustice thus also exacerbates poor healthcare practice for intersex people. The lack of follow-up care reinforces the idea that many intersex people in Malta may be unaware of their variation, or may not conceptualise it in terms of intersex. Again, this limits the effectiveness of GIGESCA, as people will be unaware that it applies to them. Lack of knowledge amongst healthcare professionals allows and enables the further marginalisation of intersex people by promulgating stigma and shame. Drawing on Fricker (2007, p. 154) as we noted above, silence within healthcare itself means that "the whole engine of collective social meaning [is] effectively geared to keeping [intersex experiences] out of sight". While investigating the impact GIGESCA had on knowledge about intersex within healthcare so far, we identified issues relating to medical terminology and medical awareness of law and legal obligations.

5.3.1. Medical Terminology

Indubitably, the language used by medical professionals can affect the way intersex people perceive themselves and how they are perceived by others. Terminology can create 'framing effects' that can prevent people from understanding their experiences in particular ways (Streuli et al. 2013; Garland and Travis 2023; Carpenter 2018; Davis 2015). Framing intersex as a disorder which can be 'fixed' by medical intervention prevents parents and intersex people from accessing the conceptual tools needed to think otherwise and is a strong driver of hermeneutical injustice. The use of 'disorders of sex development' (DSD) therefore, whilst not unusual in the healthcare sector, illustrates another method through which hermeneutical injustice is perpetuated and continues the cultural invisibility of intersex people.

> Interviewer: . . .*the word intersex, is that ever used in the clinical setting?*
>
> Respondent 7 (healthcare): *Not really.*

Yet NGOs and third sector organisations who are committed to supporting the same people use the term 'intersex'. DSD or the specific variation diagnosed, such as CAH or CAIS, are the terms more commonly used in the clinical setting in keeping with the general findings of Lundberg et al. (2021). International medical norms predominantly dictated by the Chicago Consensus Statement (Lee et al. 2006) had been largely untroubled by the presence of GIGESCA and medical professionals had largely failed to consider how GIGESCA might challenge their definitions and practices.

Despite GIGESCA's potential for an epistemic shift, the language used in the health sector continued to be 'medicalized,' and included terms such as disorders, symptoms, and signs. More shockingly, and in comparison to the absence of the term 'intersex', the term 'hermaphrodite' was still used, even though it has been largely condemned by both the intersex community and international medical protocols.

> *. . . the word hermaphrodite is still used, for example. If you tell them hermaphrodite they might click, and say, ah, a hermaphrodite, ok, now I understand. But intersex is still something which is not known.* (Respondent 8—healthcare)
>
> *. . .we're still discussing with a number of medical professionals even on the basic concept of the word intersex, because the way they see this category of people is, you know, this is a condition, a disorder of sex characteristics, and we're talking a very different language.* (Respondent 4—advocacy)

GIGESCA has not led to a paradigm shift in how intersex is conceptualised in the Maltese healthcare professional, and so it continues, in many ways, to reinforce hermeneutical injustice by failing to give intersex people and their families the conceptual tools to articulate the issues that they face. Even where healthcare professionals are engaged in dialogue regarding the development of medical protocols, they have consistently demonstrated a reluctance or perhaps inability to consult with intersex people on the development of guidelines.

5.3.2. Medical Awareness of Law and Legal Obligations

Further to this, when asked about their knowledge of GIGESCA, many of the respondents admitted that they either did not know much about the legislation, or nothing at all.

> Interviewer: *So, the law that we're interested in, do you know anything about the law, or anything about the political discussions in Malta?*
>
> Respondent 7 (healthcare): *Um, not really. . . . I've got second-hand information that there were discussions with the LGBTQ movement regarding pushing to avoid doing surgery in these patients until they are at an age that they can give consent themselves. I'm not sure if this is anything to do with the Law or if it's something else that is still coming up.*

There is a sense then that while many intersex people may not know GIGESCA applies to them, similarly where healthcare practitioners lack the language to discuss this phenomenon and understand how it relates to their work, they may also not realise that GIGESCA applies to them. This is a matter, then, of both protection and enforcement. There is yet no common understanding of what falls under the umbrella term 'intersex.'

> *No criteria that defines 'intersex'. . . evident that people, professionals, met people who are transgender but when it comes to intersex, people from (various clinics) recalled of meeting babies but only babies with ambiguous genitalia—that is what they understood by intersex.* (Respondent 8—healthcare)

Within the medical setting, DSD also means different things for different people – compared to other medical diagnoses such as cleft palate, in which corrective surgery is advocated routinely.

> *Hypospadias (is) quite common in Malta. When it's severe, like scrotal or perianal, they should work up for ambiguous genitalia but instead, if testes are present, then it has to be a boy and proceed with hypospadias repair.* (Respondent 7—healthcare)
>
> *From the respondents' comments, it is evident that there is no agreement on a common definition for intersex and for some, there is "not much of an understanding of the particularities of intersex versus the particularities of trans."* (Respondent 10—healthcare)

This is significant, given that medical knowledge regarding intersex people directly affects hermeneutical injustice. Medical practitioners not only determine healthcare pathways on their assessment of whether or not someone has an intersex variation, but they are often responsible for conferring the knowledge necessary for that individual to make sense of their own lived experience. In a small country like Malta, having the doctors on board would mean also pushing cultural as well as medical visibility. Most of the respondents were also unaware of any discussions held prior to the enactment of the law, particularly with the medical professions.

> *. . . remember consultations but not with medical personnel.* (Respondent 3—advocacy)
>
> *I don't believe that there was any consultation with the medical profession. . ..* (Respondent 4—advocacy)
>
> *. . . when the law was drafted, they never talked to any doctors. . ..* (Respondent 9—healthcare)

Although GIGESCA created more awareness for the trans community, both within the medical field and outside it, some of the respondents remarked that the same could not be said about the intersex community. Hoping that the law would bring about the same "momentum of change" for intersex people as it did for trans people, respondent 8 (healthcare) observed that ". . . it is useless making (sic) a law and then there is not awareness or training about it." While the general consensus is that many do not know much or enough about the law, some conflicting respondents still spoke of the increased amount of training that healthcare professionals were receiving about intersex and gender-related issues.

This highlights the hermeneutic difficulties with intersex issues. Despite legislation, healthcare professionals still lack the appropriate schematic tools to understand intersex variations outside the context of a disorder narrative (Garland and Travis 2023). More needs to be done to ensure that medical professionals understand the obligations placed upon them by GIGESCA. Reflection needs to be taken as to why the law has been so unsuccessful in interrupting medicines' conception of intersex as disorder. Nonetheless, Malta's stagnation supports Merrick's contention mentioned earlier that Western healthcare is ill-suited to listening to patient advocates. In this theme, a more general engagement with intersex people might create the environments needed to enable healthcare professionals to understand and make sense of intersex experiences.

6. Improving Intersex Visibility

Malta provides evidence for those considering law reform in this area. The small island community in Malta and its conservative climate mean that some of our concerns are specific to Malta, while others are perhaps indicative of issues relating to the laws' discursive powers more generally. It is clear from our findings that political visibility, while necessary for law reform, is insufficient to transform and improve intersex experiences. The entrenched systemic nature of hermeneutical injustice and identity prejudice means that more must be done by states to create the conditions of change. Specifically, an integral part of challenging medical practice and enhancing the rights of intersex people relies on increasing the cultural visibility of intersex people, in tandem with specific legal regulation of the medical profession. Learning from Malta's experience, Law reformers and policy-makers must be attentive to hermeneutical injustice, particularly biomedical hermeneutical injustice, when pursuing ways in which to improve the lived experiences of intersex people. Political visibility, while important, is not sufficient to remedy the hermeneutical injustice gap.

Moreover, Malta reveals the vast obstacle that the schism between human rights and medical narratives can create when implementing law. States must think carefully about *how* they engage with various stakeholders to mitigate this standoff, and also ensure that the medical narrative does not dominate discussions about implementation. To remedy the divide between human rights and medical narratives, medical professionals must reflect on their own epistemic primacy and the privileging that their views are granted. In order to combat both hermeneutic and testimonial epistemic injustice, priority must be given to the voices and testimony of intersex people.

Visibility, in cultural, political and healthcare terms, must be the chief priority of reformers and requires continued engagement with relevant stakeholders after the introduction of legislation. In part, this will come from thinking creatively about ways to legislate to improve intersex visibility, and therein, the possibility of future partnership. This will be easier in jurisdictions that have mobilised intersex organisations, support groups and communities. The lack of this in Malta necessitates more creative approaches. Medical treatment paradigms, as Merrick (2019) suggests, must be sufficiently informed by the testimony of intersex people, and this has proven to be challenging in Malta. Indeed, improving the visibility of intersex people was seen as a key priority for a number of our respondents. As Respondent 3 (advocacy) noted:

> *I would think that, one, we need to raise awareness, we need to raise a lot more awareness. We need to. . . As I said, most people—I'm not saying based on hard facts, but I would say that most people in Malta do not know what intersex is. They just don't know about it. So I think we would need to raise the awareness generally, and knowledge, so that it is not seen as something, such a taboo, such an out of the ordinary, extraordinary, a terrible place to be for somebody, but rather just part of life. Part of the diversity of life if you like. I would think that that would help, however I suspect that many, again completely off the top of my head, not based on any research or evidence, but I would think that people who are intersex may not think that that's a very good idea. Many people who are intersex, at the moment in Malta, who are living hidden lives, would, you know. . . I think they might find that very scary.*

Awareness-raising through educative programs was mentioned by a number of our respondents. This would have value in breaking through the epistemic barriers many intersex people face in knowing themselves as intersex, and its value extends beyond Malta to those jurisdictions wanting to implement meaningful change. Awareness-raising offers the conceptual tools needed for self-identification and consequently self-acceptance. Such an approach would need buy-in from a range of institutions, including the education system, schools and individual teachers engaging in a 'whole-school learning approach' that encompasses the classroom, home and the local community (Brömdal et al. 2021). Education, therefore, might form an important part of challenging hermeneutical injustice and may be something for policy-makers to consider alongside the development of intersex legislation. Another method for improving intersex visibility would be through the development of community spaces and resources that can challenge the epistemic primacy of the healthcare profession. How this is done may need to be different in alignment with differing social and political contexts. Broadly speaking, however, the design and development of resources aimed at parents, or the placement of people with intersex variations on the potential multidisciplinary team, might go some way to raising the visibility of intersex people within medical spaces—not least to other intersex people. There are challenges with this approach, however, created by the lack of 'out' intersex people in Malta, but this may be less of a challenge in other jurisdictions. Malta's experience demonstrates how hermeneutical injustice is self-perpetuating. More research is needed with intersex populations in Malta to delve into this issue in greater depth.

Linked to this is the need for intersex role models within the 'media' space, specifically in Malta; some other jurisdictions have already begun these processes. These would go a long way to offering people schematic familiarity with intersex people across society. Once again, however, this encounters difficulties with a lack of visible intersex people within Malta. These challenges have yet to be addressed by Maltese policy-makers, and it may be that social norms around gender are so entrenched that this limits the speed and degree in which change can occur. Unfortunately, we have identified a lapse in momentum following the successful introduction of GIGESCA:

> *I would say either there's no political effort because again there's no pressure coming from anywhere barring possibly MGRM*[14] *and people like us. So there isn't that political pressure from above to hurry things up or get going. It sort of feels like there was this rush to get laws through and then once the dust had settled, it's done now you know, let's chill for a bit. . . .there's a sense of apathy coming from other parts, so . . .* (Respondent 5—Law)

Again, this links back to the lack of a visible intersex-led organisation within Malta. The lack of existence of such an organisation, or indeed, any visible intersex stakeholders, has meant that there has been a lack of pressure on the Government to deliver on the promises contained within GIGESCA. Issues of heremenutic injustice continue to be cyclical and self-perpetuating, and intervention is desperately needed to break this cycle. Moreover, it points to the need to have an interconnected approach to challenge epistemic injustice that requires a clear road map that considers the various institutions that an individual may engage with across their lifetime. The recommendations that we make map onto one another: a successful education program may well lead to more role models and, in turn, greater community-building amongst intersex people who are given epistemic credibility about their concerns. Here, we highlight how gains in hermeneutic justice may eventually lead also to testimonial justice.

7. Conclusions

In conclusion, this article offers empirical evidence to the growing acknowledgment of the relationship between intersex people, law and epistemic injustice (Merrick 2019; Carpenter 2018, 2023; Carpenter and Jordens 2022; Ziemińska 2020; Griffiths 2023). Our research is the first to demonstrate that whilst there has been political consciousness around intersex issues in Malta culminating in GIGESCA, this has seemingly failed to translate through to wider society and in parts of the healthcare system. Despite the development of promising legislation, intersex people continue to face epistemic injustice, and particularly hermeneutical injustice, at several levels. Hermeneutically, within Maltese culture, this has been particularly problematic, as many intersex people and their parents lack the schematic tools needed to conceptualise themselves or their children as intersex. As such, there has been a lack of engagement by intersex people with GIGESCA: our respondents struggled to think of a singular instance where an intersex person had engaged with the legislation and we were unsuccessful in our attempts to speak with intersex people themselves.

These issues are reinforced by feelings of shame or stigma that our respondents felt were heightened by the Maltese (conservative, Catholic) context. Moreover, intersex issues were often conflated with people's recognition of trans issues—an issue perhaps, with the duality of GIGESCA and the visibility of its significance for the trans community, perpetuating hermeneutical injustice.

Similarly, in terms of hermeneutical injustice, the lack of self-awareness of intersex people has fed into a broader pattern of cultural invisibility. There is a severe lack of intersex role models or 'out' community organisers in Malta. As such, much of the awareness-raising work has been picked up by broader LGBT+ organisations. This lack of representation perpetuates the cycle of invisibility and has stagnated the creation of a recognisable intersex community within Malta. Additionally, it continues the conflation of intersex and trans identities in the cultural consciousness (Garland and Travis 2020b, 2023).

This hermeneutical injustice is compounded by a medical profession that continues to frame intersex variations through the lens and terminology of disorder. At the same time, healthcare professionals' awareness of GIGESCA and the roles and legal obligations it placed upon them was limited—similarly pointing to continuing levels of hermeneutical injustice in one of the key populations the legislation was designed to respond to. More training was needed to counter healthcare professional's understandings of, and duties to, people with intersex variations.

As a result, we recommend that Malta undertake an extensive education program in order to tackle hermeneutic injustice—not just for medical professionals but across society through the education system. It is hoped that this will create the knowledge, context and conceptual tools necessary for intersex persons, parents and allies to identify themselves as intersex and to allow their injustices to be recognised. In the future, this may break the cycle of cultural invisibility and allow for a greater engagement with the intersex community in the creation of legal regulation and healthcare practices that center on justice for intersex people at their core.

Our findings have implications beyond the Maltese context. More broadly, those seeking to introduce legal reform must be attentive to the fact that law, alone, is insufficient to change the conditions of hermeneutical injustice. Commitment to improving the lived experiences of intersex people requires an extensive effort to ensure that intersex voices are heard, and that individuals and community representatives are able to actively participate and be listened to by institutional actors responsible for implementation and change post-legislation. Similarly, reformers need to ensure that there is an interconnected approach to challenging hermeneutical injustice, beginning with education. This, of course, will require tailoring to the specific context of that jurisdiction and the varied ways in which individuals engage with different institutions. It will also require working with international and, where possible, local organisations, and committing the necessary resources (financial and time) to change. Where there are no local organisations or role models, it highlights the greater need for investment in educational initiatives. In the long term, this will dismantle hermeneutical injustices and lead to the enabling of the intersex community.

Our final comment is that more research is desperately needed to capture the voices of intersex people, especially in Malta. While our findings offer some insight into the effects of law, it is by no means determinative, and the absence of intersex voices in this project mean that we are limited in the claims we can make.

Author Contributions: Conceptualization, F.G. and M.T.; methodology, F.G.; formal analysis, C.B.T., F.G. and M.T.; investigation, C.B.T., F.G. and M.T.; data curation, C.B.T., F.G. and M.T.; writing—original draft preparation C.B.T., F.G. and M.T.; writing—review and editing, C.B.T., F.G. and M.T.; project administration, F.G.; funding acquisition, F.G. and M.T. All authors have read and agreed to the published version of the manuscript.

Funding: This research was funded by British Academy, grant number SRG19_190990.

Institutional Review Board Statement: The study was conducted in accordance with the Declaration of Helsinki, and approved by the University of Manchester Research Ethics Committee 3 (Study Ref: 2021-7452-21286 approved 14 December 2021) and also the Maltese Health Ethics Committee (Study Ref HEC05.22. approved 05 August 2022).

Informed Consent Statement: Informed consent was obtained from all subjects involved in the study.

Data Availability Statement: Data supporting reported results will be deposited in the UK Data ReShare Depositary.

Conflicts of Interest: The authors declare no conflicts of interest. The funders had no role in the design of the study; in the collection, analyses, or interpretation of data; in the writing of the manuscript; or in the decision to publish the results.

Notes

[1] The study was unable to recruit intersex people. While this is a significant limitation it also indicates the extensiveness of epistemic injustice within Malta. We reflect on this further throughout.

[2] Endosex is the term coined to refer to people without intersex traits. See Carpenter et al. (2022).

[3] *Joanne Cassar* v *Malta* Application no 36982/11.

[4] For a detailed overview on the passage of this piece of legislation, see Garland and Travis (2023).

[5] See e.g., the individual response by Nicholas Briffa available here https://meae.gov.mt/en/public_consultations/msdc/pages/consultations/gigesc.aspx (accessed on 8 November 2023).

[6] Gender Identity, Gender Expression And Sex Characteristics Act (https://www.gov.mt) (accessed on 8 November 2023).

[7] The composition of this team was not set within GIGESCA, but rather was to be "composed of those professionals whom the Minister considers as appropriate".

[8] We reflect more on the relationship between terminology and epistemic injustice in Section 5.1.

[9] e.g., we removed details such as familial relationships and living relationships, religious or cultural background.

[10] Hypospaidas is where the uretha opening is not at the tip of the penis.

[11] Their consultation response can be found here: https://meae.gov.mt/en/Public_Consultations/MSDC/Documents/2014%20-%20GIGESC/Organisation%20Intersex%20International%20Australia%20(OII%20Australia).pdf (accessed on 8 November 2023).

[12] Other projects have similarly encountered difficulties with recuritment and Ní Mhuirthile et al. (2022) have identified intersex as a 'hard-to-reach' population.

[13] We had taken measures to mitigate for the heightened risks with anonymity, following Saunders et al. (2015) for research conducted in small island communities.

[14] A Maltese based organisation devoted to achieving "full equality for LGBTIQ people in Maltese society". <maltagayrights.org>

References

Ballakrishnen, Swethaa, and Sarah B. Lawsky. 2022. Law, Legal Socializations, and Epistemic Injustice. Law & Social Inquiry, FirstView, 2022, forthcoming, UC Irvine School of Law Research Paper No. 2022-19. Available online: https://ssrn.com/abstract=4130483 (accessed on 1 September 2023).

Braune, Virginia Braun, and Victoria Clarke. 2015. Using Thematic Analysis in Psychology. *Qualitative Research in Psychology* 3: 77–101. [CrossRef]

Brömdal, Annette, Agli Zavros-Orr, Lisahunter, Kirstine Hand, and Bonnie Hart. 2021. Towards a wholeschool approach for sexuality education in supporting and upholding the rights and health of students with intersex variations. *Sex Education* 21: 568583. [CrossRef]

Butler, Judith. 1990. *Gender Trouble, Routledge Classics*. London: Routledge.

Carpenter, Morgan. 2018. The "Normalization" of Intersex Bodies and "Othering" of Intersex Identities in Australia. *Journal of Bioethical Inquiry* 15: 487–95. [CrossRef] [PubMed]

Carpenter, Morgan. 2023. Fixing Bodies and Shaping Narratives: Epistemic Injustice and the Responses of Medicine and Bioethics to Intersex Human Rights Demands. *Clinical Ethics* 115. [CrossRef]

Carpenter, Morgan, and Christopher F. C. Jordens. 2022. When Bioethics Fails: Intersex, Epistemic Injustice and Advocacy. In *Interdisciplinary and Global Perspectives on Intersex*. Edited by Megan Walker. Cham: Springer Nature Switzerland AG.

Carpenter, Morgan, Katharine B. Dalke, and Brian D. Earp. 2022. Endosex. *Journal of Medical Ethics* 49: 225–26. [CrossRef] [PubMed]

Davis, Georgiann. 2015. *Contesting Intersex: The Dubious Diagnosis*. New York: NYU Press.

Dreger, Alice. 1998. *Hermaphrodites and the Medical Invention of Sex*. Harvard: Harvard University Press.

Falzon, Neil. 2010. *A Proposed Gender Identity Act for Malta*. Available online: https://issuu.com/aditus/docs/a_proposed_gender_identity_act_for_malta_?mode=embed&layout=http://skin.issuu.com/v/light/layout.xml&showFlipBtn=true (accessed on 1 September 2023).

Foucault, Michel. 1980. *Herculine Barbin: Being the Recently Discovered Memoirs of a Nineteenth-Century French Hermaphrodite*. New York: Pantheon Books.

Fredman, Sandra. 2016. Substantive equality revisited. *International Journal of Constitutional Law* 14: 712–38. [CrossRef]

Fricker, Miranda. 2007. *Epistemic Injustice: Power and the Ethics of Knowing*. Oxford: Oxford University Press. ISBN 9780198237907.

Fricker, Marianne. 2017. Evolving concepts of epistemic injustice. In *Routledge Handbook of Epistemic Injustice*. Edited by Ian James Kidd, Jose Medina and Gaile Pohlhaus, Jr. Routledge Handbooks in Philosophy. London: Routledge, pp. 53–60. ISBN 9781138828254.

Garland, Fae, and Mitchell Travis. 2018. Legislating intersex equality: Building the resilience of intersex people through law. *Legal Studies* 38: 587–606. [CrossRef]

Garland, Fae, and Mitchell Travis. 2020a. Making the State Responsible: Intersex Embodiment, Medical Jurisdiction and State Responsibility. *Journal of Law and Society* 47: 298–324. [CrossRef]

Garland, Fae, and Mitchell Travis. 2020b. A Jurisprudence of the Body: Emergencies, Emergence, and Intersex Embodiment. In *A Jurisprudence of the Body*, 1st ed. London: Palgrave Macmillan Ltd.

Garland, Fae, and Mitchell Travis. 2023. *Intersex Embodiment Legal Frameworks beyond Identity and Disorder*. Bristol: Bristol University Press. ISBN 9781529217391.

Garland, Fae, Kay Lalor, and Mitchell Travis. 2022. Intersex Activism, Medical Power/Knowledge and the Scalar Limitations of the United Nations. *Human Rights Law Review* 22: ngac020. [CrossRef]

Goldberg, Daniel. 2020. Epistemic Injustice, Disability Stigma, and Public Health Law. In *Disability, Health, Law and Bioethics*. Cambridge: Cambridge University Press.

Griffiths, David Andrew. 2023. Georgina Somerset, British Intersex history, and the I in LGBTQI. *Journal of Homosexuality* 23: 1–24. [CrossRef]

Hegarty, Peter, and Cheryl Chase. 2000. Intersexed activism, feminism, and psychology: Opening a dialogue on theory, research, and practice. *Feminism & Psychology* 10: 117–32. [CrossRef]

Hegarty, Peter, Marta Prandelli, Tove Lundberg, Lih-Mei Liao, Sarah Creighton, and Katrina Roen. 2021. Drawing the line between essential and non-essential interventions on intersex characteristics with European healthcare professionals. *Review of General Psychology* 25: 101–14. [CrossRef]

Holmes, Morgan. 2011. "The Intersex Enchiridion: Naming and Knowledge". *Somatechnics* 1: 388–411. [CrossRef]

Lee, Peter A., Christopher P. Houk, S. Faisal Ahmed, Ieuan A. Hughes, and in collaboration with the participants in the International Consensus Conference on Intersex organized by the Lawson Wilkins Pediatric Endocrine Society and the European Society for Paediatric Endocrinology. 2006. Consensus Statement on Management of Intersex Disorders. *Pediatrics* 118: e488–e500. [CrossRef] [PubMed]

Lundberg, Tove, Katrina Roen, Carina Kraft, and Peter Hegarty. 2021. How young people talk about their variations in sex characteristics: Making the topic of intersex talkable via sex education. *Sex Education* 21: 1–16. [CrossRef]

Luzzi, Federico. 2021. Deception-Based Hermeneutical Injustice. *Episteme*, 1–9. [CrossRef]

Malatino, Hilary. 2019. *Queer Embodiment: Monstrosity, Medical Violence, and Intersex Experience*. Lincoln: Univesity of Nebraska Press.

Merrick, Teri. 2019. From 'Intersex' to 'DSD': A case of epistemic injustice. *Synthese* 196: 4429–47. [CrossRef]

Monro, Surya, Morgan Carpenter, Daniela Crocetti, Georgiann Davis, Fae Garland, David Griffiths, Peter Hegarty, Mitchell Travis, Mauro Cabral Grinspan, and Peter Aggleton. 2021. Intersex: Cultural and social perspectives. *Culture, Health & Sexuality* 23: 431–40. [CrossRef]

Ní Mhuirthile, Tanya. 2018. Malta. In *The Legal Status of Intersex Persons*. Edited by Jens Scherpe, Anatol Dutta and T. Helms. Cambridge: Intersentia, pp. 357–68. [CrossRef]

Ní Mhuirthile, Tanya, Maria Feeney, Mel Duffy, and Anthony Staines. 2022. *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*. Dublin: Dublin City Univesity, pp. 1–242.

Preves, Sharon. 2003. *Intersex and Identity: The Contested Self*. New Brunswick: Rutgers University Press.

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: 1089198. [CrossRef]

Saunders, Benjamin, Jenny Kitzinger, and Celia Kitzinger. 2015. Anonymising interview data: Challenges and compromise in practice. *Qualitative Research* 15: 616–32. [CrossRef]

Streuli, Jürg C., Effy Vayena, Yvonne Cavicchia-Balmer, and Johannes Huber. 2013. Shaping parents: Impact of contrasting professional counseling on parents' decision making for children with disorders of sex development. *The Journal of Sexual Medicine* 10: 1953–60. [CrossRef] [PubMed]

Topp, Sarah S. 2013. Against the quiet revolution: The rhetorical construction of intersex individuals as disordered. *Sexualities* 16: 180–94. [CrossRef]

Viloria, Hida. 2017. *Born Both: An Intersex Life*. Boston: Hachette.

Ziemińska, Renata. 2020. The Epistemic Injustice Expressed in 'Normalizing' Surgery on Children With Intersex Traits. *Diametros* 17: 52–65. [CrossRef]

social sciences

Article

The Universal Periodic Review and the Ban on Intersex Genital Mutilation in an African Context

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Abstract: The Universal Periodic Review (UPR) assesses the human rights records of all 193 UN Member States against the benchmark of the Universal Declaration of Human Rights and its core human rights treaties. To date, more than 100,000 recommendations have been provided to states under review (SUR) from peer Member States. Less than 1% address the rights of intersex persons. Western countries issue most of these cases, followed by the Latin American and Caribbean countries. African and Asian countries formulate a negligible number. This asymmetric data might mistakenly support the assumption that Western countries care more about the rights of intersex persons than non-Western countries. However, the recent groundbreaking Resolution on the Promotion and Protection of the Rights of Intersex Persons in Africa calls upon its states' parties to stop nonconsensual genital normalisation practices on intersex persons and considers these practices as mutilation. Intersex genital mutilation (IGM) stands as a profound human rights infringement experienced by intersex individuals, who undergo medical interventions often performed on their healthy bodies. The primary objective of such interventions is to enforce conformity to prevailing medical and sociocultural norms pertaining to binary genders. I argue that Member States formulating recommendations advocating for the ban on IGM should consider contextualised factors, especially with regards to "informed consent". This approach aims to enhance the persuasiveness of recommendations and increase the likelihood of their acceptance by SUR. Through the analysis of twenty-nine IGM-related UPR recommendations, this article addresses the effectiveness of the UPR in discussing intersex rights and the ban on IGM, with a focus on Africa.

Keywords: human rights; informed consent; intersex; intersex genital mutilation (IGM); Universal Periodic Review (UPR)

Citation: Ravesloot, Saskia Caroline Irene. 2024. The Universal Periodic Review and the Ban on Intersex Genital Mutilation in an African Context. *Social Sciences* 13: 349. https://doi.org/10.3390/socsci13070349

Academic Editors: Surya Monro, Tanya Ni Mhuirthile, Amets Suess-Schwend, Fae Garland, Daniela Crocetti, David Andrew Griffiths and Katrina Roen

Received: 3 March 2024
Revised: 31 May 2024
Accepted: 31 May 2024
Published: 28 June 2024

1. Introduction

This paper seeks to strengthen the effectiveness of efforts to eradicate intersex genital mutilation (IGM) within the Universal Periodic Review (UPR) by advocating for contextualised recommendations. IGM (Bauer et al. 2020, p. 726) is a human rights violation experienced by intersex individuals, many of whom undergo medical surgery often conducted against their will at a young age (UN Office of the High Commissioner for Human Rights 2019, p. 4). The UPR evaluates UN Member States' human rights records against the benchmark of the Universal Declaration of Human Rights (UN General Assembly 1948). While the international human rights framework is increasingly emphasising intersex rights (Zelayandia-Gonzalez 2023, p. 2) and the issue of intersex genital surgery (Jorge et al. 2021, p. 679), the UPR process only generates a few IGM-related recommendations, which are mainly provided by Western countries (Ravesloot 2022, p. 259). These cases share similarities in content and formulation, with most recommendations stressing "informed consent". While their current number is limited, and discussions surrounding IGM are still emerging within the UPR process, they are likely to increase in the future. I argue that current recommendations supporting the prohibition of IGM risk reflecting a predominantly Western perspective, which may prove ineffective in addressing IGM in non-Western contexts. This is particularly evident in the focus on informed consent which, within a Western framework, requires competent, informed, and voluntary decisions on IGM by parents or the intersex individual (Benson 2005). Such consent might not be obtained in a non-Western context as, for example, in certain African countries where community input may form part of that decision-making, due to the sociocultural environment that values collective interests over individual rights (Akpa-Inyang and Chima 2021, p. 15). To advance this argument, this article conducts a content analysis of twenty-nine recommendations related to IGM sourced from the Universal Human Rights Index (UN Office of the High Commissioner for Human Rights 2023). These recommendations, however, do not explicitly use the term IGM.[1] The article assesses the suitability of these recommendations with the doctrine of informed consent as outlined by Benson (2005, p. 36), particularly in non-Western contexts. It uses the African context as a case study to address the question: are UPR recommendations effective in ensuring competent, informed, and deliberate decisions about IGM?

The widely cited estimate of 1.7% for the prevalence of intersex individuals[2] originating from Faust-Sterling's seminal work (Fausto-Sterling 2000), raises more questions about its accuracy than about its origin. Calculated based on "a wide variety of populations" (Garland and Travis 2023, p. 4), it is unclear whether African populations are included. Moreover, the dearth of African research on the subject (Ellaithi et al. 2011, p. 267) further compounds the issue, highlighting a significant gap in our understanding of intersexuality beyond Western contexts. Likewise, most scholars denouncing the atrocities of IGM discuss intersexuality predominantly in Western countries. Critical scientific literature is growing in the West but remains sparse in Africa, where the literature is primarily situated in the clinical (medical) field on intersex issues. However, change is imminent, given the recent groundbreaking Resolution of the Human Rights Council (UN Human Rights Council 2024), and the landmark Resolution on the Promotion and Protection of the Rights of Intersex Persons in Africa (African Commission on Human and Peoples' Rights 2023). Both resolutions support banning harmful practices and stress informed consent, although in different terms. While utilising the term IGM deliberately and aligning with perspectives from critical analyses (Monro et al. 2021) opposing IGM, this article makes a dual contribution. Firstly, it enriches the UPR as a dialogue platform and bolsters its effectiveness by advocating for intersex rights through adequate recommendations to ban IGM. Secondly, while further exploring the use of the concept of informed consent, it offers new insights into a significantly under-researched domain: the rights of intersex individuals in Africa and how the concept of informed consent does not travel universally.

Defining informed consent in the African context is challenging because it stems from the Western liberal tradition (Akpa-Inyang and Chima 2021, p. 8). In African societies, community existence is fundamental, favouring collective rights over individualistic ideals prevalent in the West (Akpa-Inyang and Chima 2021, p. 2). Simply replicating existing UPR recommendations without questioning their effectiveness when addressed to non-Western countries risks undermining meaningful dialogue on the ban on IGM. If UPR recommendations disregard the community in seeking informed consent, efforts to ban IGM might be less effective. Decision-making processes on IGM that do not contextualise informed consent might even cause experiences of epistemic violence (Dotson 2011, p. 242), and more specifically testimonial smothering (Dotson 2011, p. 244), from the intersex person, silencing their own voice in favour of conforming with the community's decision.[3] Even when the community does not enforce a decision on the intersex person, there is the risk that the intersex person anticipates the group's desires, to the detriment of their own wishes. Therefore, while Western models may not fit directly, adaptation is necessary and possible for the African context, without dismissing the importance of informed consent (Akpa-Inyang and Chima 2021, p. 15).

To leverage UPR recommendations in advocating for the prohibition of IGM in an African context, the next section gives an overview of the literature on IGM and highlights the gaps this article aims to fill. The subsequent section on the materials and methods outlines the research approach. The results section shares findings on the limited and geographical asymmetric interest of the international community for intersex rights. It then applies the concept of informed consent to the twenty-nine IGM-related UPR recommendations. Next, the discussion section applies these findings to address the question: Are the UPR recommendations effective in ensuring competent, informed, and deliberate decisions about IGM in an African context? Finally, the article concludes by advocating for UPR recommendations that are contextualised and reduce the risks of epistemic violence for African intersex persons.

2. Context

2.1. Intersexuality in Africa

One of the few recent studies on the human rights situation of intersex persons in Africa states that "While countries outside Africa have been progressive when it comes to the rights of intersex persons, progress has been minimal in Africa", with South Africa and Kenya as exceptions and flag bearers in the protection of the rights of intersex persons (Centre for Human Rights 2022, p. 5). Clinical studies on the prevalence of intersexuality in Africa underscore the absence of data (Amolo et al. 2019, p. 1) and records (Ellaithi et al. 2011, p. 267). Ameyaw et al. (2019, p. 638) claim that their study in the Ashanti region of Ghana conducted in 2019 "is to our knowledge the first to provide an estimate of DSD incidence in infants born in sub-Saharan Africa."[4] The lack of reported cases may stem from the limited capabilities of many healthcare systems to diagnose, monitor, and report on instances of intersexuality (Warne and Raza 2008, p. 228). Country-specific factors—including poor healthcare facilities (Gnassingbe et al. 2009, p. 83), the lack of advanced examinations and diagnostic tools to identify the child's sex at hospitals (Warne and Raza 2008, p. 228), inadequately trained health service staff, including midwives (Ameyaw et al. 2019, p. 636), and the traditions of giving birth at home (Ameyaw et al. 2019, p. 638) rather than in a hospital—all create challenges to gather data and lead to an underrepresentation in the reported numbers of intersex infants. Furthermore, while "Many diagnoses have to be made by informed guesswork" (Warne and Raza 2008, p. 228), these diagnoses may occur only later in the life of the intersex child or adult (Gnassingbe et al. 2009, p. 83; Warne and Raza 2008, p. 234). Recent studies estimate the median age for the identification of an intersex person at around 6.5 years, and this identification may even occur during adolescence (Hansen et al. 2022, p. 189). While some studies highlight that "surgeries are a common practice" (Centre for Human Rights 2022, p. 8) in Africa, this delay in the identification of intersexuality supports the suggestion that surgical interventions at an early age are not a standardised medical procedure (Kraus 2013, p. 91).

The literature on the care and future prospects of intersex newborns in Africa is limited, especially from a cross-cultural perspective (Edgerton 1964, p. 1289). Warne and Raza (2008, p. 234), in their clinical analysis of intersexuality across resource-rich and resource-poor countries, acknowledge the diverse perspectives within African societies, in addition to various legal frameworks (Phele 2016, p. 55)[5] and cultural beliefs. They argue that poverty and the quality of social security, medical, and education systems have a greater impact on perceptions of intersexuality than sociocultural factors, such as religion or culture (Warne and Raza 2008, p. 234). Edgerton suggests that societies exhibit diverse responses to intersexuality. In his early anthropological examination of the responses to intersexuality of the Pokot in Kenya, he stresses that they view life in terms of physical sexuality, reproduction, and economic utility. He notes that intersex children were often killed, although in some cases they were allowed to survive (Edgerton 1964, p. 1298). In settings where the killing of intersex newborns persists, Behrens (2020, p. 2) argues that surgical intervention may be justifiable under certain conditions, to respect the best interest of the child and save the child's life. Conversely, it is essential to recognise that expensive medical interventions may not necessarily be the first concern for the parents of an intersex child; at times the child might even die before seeing a doctor (Warne and Raza 2008, p. 231). In rural communities, which are often resource-poor environments, families may first seek affordable alternative treatments or solutions and consult medical providers only as a last resort (Warne and Raza 2008, p. 230). Moreover, surgery itself is no guarantee of saving a child's life. In Africa, where paediatric surgery is not widely taught (Kraus 2013, p. 91) and only a few paediatricians operate (Gnassingbe et al. 2009, p. 83), surgical intervention on intersex children is no routine practice and "remains a life-threatening situation" (Kraus 2013, p. 91).

Due to limited financial resources and technical skills, Western paediatricians occasionally conduct the medical interventions. In her study in West Africa on hypospadias[6] treatment by French medical professionals, Kraus (2013, p. 91) stresses the strong impetus from Western doctors who apply their advanced techniques on intersex persons. Kraus' research highlights how surgeons can impact societal norms and beliefs about what is considered normal or acceptable in terms of ideals of sex, gender, and reproductive heterosexuality. She reports that since the mid-1990s, when the surgical missions became "popular", they have delivered quality surgical care and long-term follow-up for approximatively 160 "patients" per year (Kraus 2013, p. 85). She questions, however, whether patients would have visited the hospital without the French surgeons (Kraus 2013, p. 92). Gnassingbe et al. (2009, p. 83) report that African paediatric surgeons, with or without financial support from non-governmental organisations (NGOs), refer intersex persons to developed countries for treatment. They note that "At times NGOs also collaborate with their western partners to carry out benevolent health expeditions for local treatment of patients suffering from congenital abnormalities, including intersex in Africa." They report on a workshop held in a hospital in Togo in December 2006, which received a total of 107 participants: five French professors of paediatric surgery, sixty-two African paediatric surgeons, and forty African general surgeons (Gnassingbe et al. 2009, pp. 83–84). Intersex persons were invited to be operated on "free of charge" during the workshop, which introduced new (Western) technologies and transferred the accompanying knowledge to treat cases of intersexuality. Only one out of six "patients" did not give their consent and "refused to be feminised". Regarding the other "patients" it is merely assumed that they provided their consent in a competent, informed, and voluntary way, the three preconditions for informed consent, as will be explained below.

This overview of the limited literature on intersexuality and IGM within the African context touches upon the multifaceted dimensions that underpin the challenges faced by African societies in addressing intersexuality. Primarily, these challenges include diverse perspectives toward intersexuality, requiring the need for nuanced knowledge about both socio-economic factors (e.g., poverty, social welfare systems, education) and sociocultural dynamics (e.g., values, beliefs, religion, traditions) that influence a society's approach to intersexuality. Secondly, the literature suggests a critical need to assess the disparities in resources and the availability of medically skilled personnel, since a lack of resources and staff might increase the risk of Western support and practices, including harmful ones. These insights suggest that analysis of UPR recommendations targeting the prohibition of IGM should contextualize these recommendations according to both socio-economic and sociocultural factors, especially when intending to foster competent, informed, and deliberate decision-making on IGM. The subsequent section will delve into the concepts of informed consent, epistemic violence, and, in particular, testimonial smothering, as the latter is a potential negative experience of the intersex person, whereas informed consent is understood from a Western perspective.

2.2. Informed Consent and Epistemic Violence

A significant number of scholars address intersexuality through a human rights and ethical lens and establish a robust human rights-based argument against IGM (e.g., Bauer, Carpenter, Crocetti, Fox, Garland, Ghattas, Horowicz, Slokenberga, Thomson, Travis, and Truffer) (Monro et al. 2021, p. 432). Human rights frequently cited as at risk include: freedom from discrimination; protection from torture and other cruel, harmful or degrading treatment; and the right to health. An additional critical human right is the right to "informed consent". Zucker (1999, p. 2) highlights that some critics advocate for a suspension of surgery "until the status of previously treated patients are followed-up with greater precision." Beh and Diamond (2000, pp. 3–4) discuss the "doctrine of informed consent", focusing on parents' consent to perform surgery on their intersex child. Conversely, Carpenter (2018, p. 208) identifies the individual right to informed consent as a fundamental human right and defends the physical integrity of intersex children and adults, underscoring that the prohibition of medical interventions excludes essential, life-preserving procedures. Benson (2005, p. 36) scrutinises the rights of intersex persons under the "doctrine of informed consent". She stresses that informed consent should safeguard a patient's right to bodily integrity, self-determination, and the right to decline medical treatment deemed unwanted. Based on the legal concept of informed consent, Benson underscores three preconditions. Firstly, the decision to undergo IGM, or a parent's decision to subject a child to IGM, should be informed, including information about alternative solutions and relying on adequate information; next, this decision should be made (by the parents) in a voluntary way, without coercion; lastly, the decision should be made by the intersex person or the parents in a competent way, demonstrating an understanding of the nature, scope, and likely consequences of the consented action. Beauchamp and Childress (2001, pp. 69–74) stress that competent decisions include acknowledgement of the potential consequences and that "Inquiries about competence focus on whether patients or potential subjects are capable, psychologically or legally, of adequate decision-making." The conundrum, however, is that even when these requirements are completed, there is still a risk that the decision is not taken genuinely, due to the hidden process of testimonial smothering, a form of epistemic violence.

Epistemic violence, originally coined by Gayatri C. Spivak (Brunner 2021, p. 195), is further developed by Kristie Dotson (2011, p. 238), who defines that "Epistemic violence in testimony is a refusal, intentional or unintentional, of an audience to communicatively reciprocate a linguistic exchange owing to pernicious ignorance." In the context of intersex persons, epistemic violence might appear when the audience (medical staff and parents) refuses or avoids communicating with the knower (the intersex person) in a transparent manner. Disengaging from any transparent dialogue occurs intentionally or unintentionally and can be caused by a lack of appropriate knowledge by medical staff and parents regarding knowledge that is owned only by the intersex person. Epistemic violence might also occur when intersex persons are silenced, or unable to express their experiences or personal will, because the medical staff act on harmful biases relating to gender, age, or ethnicity. When doctors lack knowledge or diffuse harmful biases, there is a risk of miscommunication resulting in epistemic violence when the intersex person experiences damaging effects, including IGM.

One specific form of epistemic violence is coined by Dotson (2011, p. 238) as "testimonial smothering". Dotson (2011, p. 244) describes this form of epistemic violence as "the truncating of one's own testimony in order to ensure that the testimony contains only content for which one's audience demonstrates testimonial competence." From the perspective of the intersex person, self-censorship can occur if the person chooses to withhold their thoughts (an authentic decision about the consent), because they believe that their audience may not understand their true decision. In their recent book on intersex embodiment, Garland and Travis (2023, p. 45) share an example of an intersex child who believes that, by holding back, the child's parents will be spared from feeling incapable of understanding the child's authentic wishes: "When you are seven and you realize that your mother especially and also your father are very stressed, everybody is stressed and it has to do with your genitals, and then you consent out of wish to please or to take this stress away. Everybody knows that most children are doing things because they want to be accepted or liked or because they want to please their parents, and the doctors."

3. Materials and Methods

Qualitative research was conducted on the data retrieved from the Universal Human Rights Index (UN Office of the High Commissioner for Human Rights 2023). Out of a total of 101,132 UPR recommendations issued since 2008, 3835 cases related to the group "Lesbian, gay, bisexual and transgender and intersex persons (LGBTI)" were initially selected. These cases formed the basis for an additional selection based on a set of terms related to medical interventions[7], resulting in 216 cases. After removing duplicate recommendations, only 176 distinct UPR recommendations remained. The next step removed UPR recommendations that were not related to IGM. Cases that were excluded involved transsexual persons, legal recognition, the broader right to health and healthcare services, or self-determination of gender identity (mentioned independently). Maintaining a strict focus on IGM enabled comprehensive assessment of recommendations specifically targeting medical interventions for intersex individuals. The ultimate dataset comprised twenty-nine recommendations, involving twelve recommending states and eighteen states under review (SUR). Singular recommendations appeared in 2014 and 2018. In 2019, a notable increase occurred with ten recommendations, succeeded by two cases in 2020, seven in 2021, five in 2022, and three in 2023. This dataset served as the foundation for a content analysis of each recommendation, using the qualitative data analysis application Atlas.ti. I applied the legal concept of informed consent, as outlined by Benson (2005, p. 36), which requires the decision to be made in a competent, informed, and voluntary manner. The UPR recommendations were then further analysed regarding their potential to cause epistemic violence, based on Kristie Dotson's distinction of testimonial smothering as a form of epistemic violence in testimony (Dotson 2011, p. 244).

4. Results

The examination of all twenty-nine UPR recommendations concerning IGM reveals a predominant trend wherein none of the recommendations were issued by African countries. The absence of such recommendations is a crucial element to consider. These missing data underscore the dominant influence of Western countries in the discourse on IGM. Moreover, this absence prompts a critical examination of whose voices are heard and whose experiences are overlooked in discussions about IGM. With the anticipated increase in UPR recommendations on IGM, particularly considering the recent adoption of the two resolutions (UN Human Rights Council 2024; African Commission on Human and Peoples' Rights 2023), there is the potential that existing recommendations influenced by Western perspectives on informed consent may be merely replicated. This replication could occur without the necessary dialogue and without incorporating context-specific recommendations tailored to the diverse realities of African nations and would be less effective in offering protection from IGM.

As the data show in Figure 1, most recommendations were originated by and directed towards Western countries. Six cases were issued by countries from Latin America and the remaining twenty-three cases were formulated by Western countries. Malta[8] and Iceland[9] leading by example, each issued six recommendations. These two countries are among the first to draft legislation on protecting intersex children from nonconsensual medical interventions (Carpenter 2024, p. 14). On the receiving side, the analysis indicates that of the eighteen SUR, half of the recommendations were provided to four countries, namely Austria (four cases), Costa Rica (four cases), Finland (three cases), and Switzerland (three cases), directing the recommendations predominantly towards Western countries. Among the remaining recommendations (fifteen), only two were received by African countries (South Africa and Zimbabwe).

The data further indicate that among the few UPR recommendations that target the ban on IGM, several were identical. This is true for recommendations that advise states to "End harmful practices, including forced and coercive medical interventions, to ensure the bodily integrity of children with intersex variations". Two were issued by Iceland, one addressed to Austria and one to Australia in 2021, and one recommendation was received by South Africa in 2022. An additional identical case was issued by Iceland and addressed to Costa Rica in 2019 and by Malta to Austria in 2021: "Prohibit any practice that modifies a person's sex characteristics without irrefutable medical reasons and the full and informed consent of the person affected". A third identical recommendation was formulated by Malta and addressed in 2019 to Costa Rica and Slovenia, requiring the states to "Work towards ending protocols that aim to 'normalize' intersex bodies through harmful and medical practices including nonconsensual surgeries". Among the cited identical recommendations, it is noteworthy that only one recommendation was received by an African country (South Africa) and that all were issued by Western countries. These examples reveal the recurring pattern of duplicating existing recommendations and justify the concern that this practice could overlook specific contextual nuances in the future.

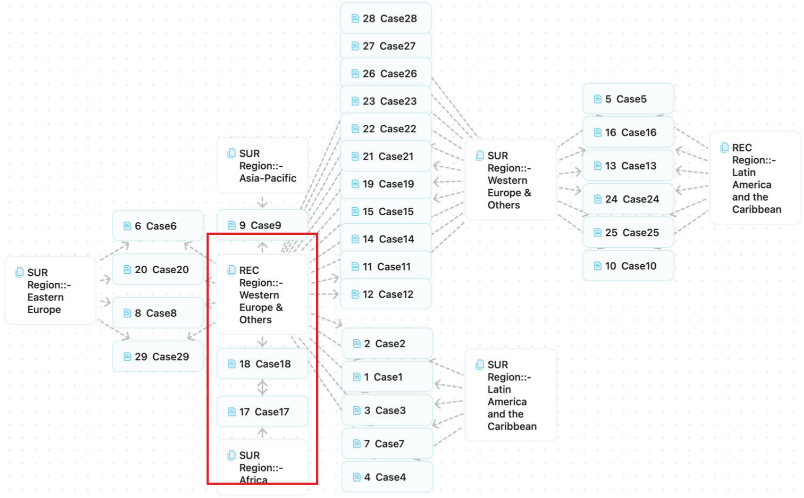

Figure 1. Provenance and destination of IGM-related UPR recommendations. Source: Own analysis using Atlas.ti, December 2023. SUR: state under review, REC: recommending state.

The content analysis of the twenty-nine UPR recommendations related to IGM resulted in thirty-nine observations across the entire dataset, as highlighted in Table 1. The findings were categorised into five groups. Group 1 covered recommendations that incorporated all three components (competent, informed, and voluntary). Group 2 related to recommendations including the "competent" and "informed" components. Group 3 highlighted recommendations that stressed the significance of the components "informed" and "voluntary". Finally, group 4 and group 5 referred to recommendations encompassing the components "voluntary" and "competent," respectively. These groups are briefly analysed below.

Table 1. Findings categorised into five groups.

	Group 1 (One Case)	Group 2 (Eight Cases)	Group 3 (One Case)	Group 4 (Eleven Cases)	Group 5 (Seven Cases)
Competent	X	X			X
Informed	X	X	X		
Voluntary	X		X	X	

Source: Own categorisation, December 2023.

Group 1: Only one recommendation covered all three components: competent, informed, and voluntary. Recommendation 147.229 issued by the Russian Federation and addressed to Spain in 2018, reads as follows: "Prohibit *non-consensual* medical interventions performed on intersex people *until the person in question is old enough* to grant their *free* and *informed consent*, unless the intervention is absolutely necessary for the development of their vital functions." (italics added).

Group 2: Eight recommendations mentioned the concepts "competent" and "informed". With respect to the component "competent", the cases highlighted that the consent should be "duly" given (one case) or "full" (two cases); that it should ensure (meaningful) participation in decision-making (three cases); and that it should not occur before they are able to give consent (two cases). As for references to the term "informed", the following wording was used: "that children and parents are informed about all options" (one case) and "informed consent" (seven cases).

Group 3: Only one recommendation emphasised the terms "informed" and "voluntary": "138.209 Adopt measures to guarantee the physical integrity and bodily autonomy of intersex people and prohibit unnecessary medical procedures without their *free* and *informed* consent" (italics added). In 2022, this recommendation was issued by Finland and addressed to Mexico.

Group 4: Eleven recommendations solely referred to the component "voluntary", encompassing various descriptions. The terminology mostly used is "non-consensual" (seven mentions), followed by "forced and coercive" (three mentions), and only one mentioned the term "involuntary". The latter was the case for recommendation 111.106 issued by Australia and addressed to Costa Rica in 2019: "Increase efforts to reduce the societal stigma faced by lesbian, gay, bisexual, transgender and intersex people and eradicate *involuntary* surgical procedures to 'normalize' the bodies of intersex people" (italics added).

Group 5: The last category comprised seven cases referencing the term "competent", in one form or another. Four of these forms refer to intersex children or minors and highlight the importance of "the manifestation of their gender identity", the age where they can consent", the "right to self-determination" (two cases), or "participation in decision-making". Another recommendation contains the expression "full consent".

Table 1 below summarises the references to competent, informed, and voluntary consent, organised by group. This summary indicates that most references included the components "competent" (sixteen observations), followed by "informed" (ten observations) and "voluntary" (thirteen observations). Only one recommendation encompasses all three required elements of informed consent.

The next section discusses the significance of these findings and strategies to ensure that informed consent truly represents the individual's intentions and can travel beyond a Western understanding.

5. Discussion

The discussion revolves around the implications of the findings: that only two African countries received recommendations related to IGM, and no African country issued an IGM-related recommendation. With the anticipated proliferation of UPR recommendations on IGM, mainly targeting the concept of informed consent risks replicating the Western ideation that will not succeed in protecting intersex persons from IGM in other contexts. As such, each component of informed consent is examined here, identifying its limitations when applied to a non-Western context, particularly the African context. Throughout this assessment, I will refer to the landmark Resolution on the Promotion and Protection of the Rights of Intersex Persons in Africa (African Commission on Human and Peoples' Rights 2023). I will also articulate the concern regarding the potential risk of self-censorship—a manifestation of epistemic violence labelled as testimonial smothering (Dotson 2011, p. 244). I start by reflecting on the person who gives informed consent.

5.1. Informed Consent

Focusing on the responsibility of the intersex person to provide consent assumes that the subaltern (the intersex person) *can* speak, to use the seminal words of Spivak (1988). When all criteria are fulfilled (competent, informed, and voluntary), the question remains: Whose consent is at stake? The Resolution on the Promotion and Protection of the Rights of Intersex Persons in Africa may provide guidance. Across the points of the Resolution, the mention of consent encompasses all three components. References to the components "voluntary" and "competent" appear in point 2 of the Resolution: "Stop *non-consensual* genital normalization practices on intersex persons, such as surgical, hormonal and sterilization procedures that alter the sexual characteristics of intersex persons and *ensure respect for their rights to make their own decisions* regarding their bodily integrity, physical autonomy and self-determination" (italics added). While point 2 does not make a reference to the intersex person's age, point 3 focuses on intersex minors and articulates that the consent needs to come from parents: "Ensure that any action concerning an *intersex minor* is carried out *with the permission of the parents* and after medical analysis, taking strict account of the best interests of the child" (italics added). Notwithstanding the reference to the best interest of the child, these two points lack clarity on whether consent should also come from the intersex child. In practice, genital surgery decisions involve parents but may not include the child's direct input (Warne and Raza 2008, p. 234; Swarr 2023, p. 149). Even when the child initially provides voluntary and competent consent, it is possible that, according to point 3, such consent may be overridden by the parents' non-consent. In the recommendation of group 1 (including all three components), the consent explicitly conditions that the intersex person be old enough to grant free and informed consent. This is an essential aspect to consider when formulating effective UPR recommendations on IGM.

5.2. Consent Given in a Competent Manner

The various references to consent given in a competent way, as highlighted for group 2 (competent and informed) and group 5 (competent), allow for the mitigation of some of the risks mentioned above. While the interpretations of "duly" given and "full" consent are subject to debate, a more precise approach to guaranteeing consent given in a competent way is by emphasising the subject's meaningful participation in decision-making processes about IGM. However, since practices for gender assignment vary across cultures (Edgerton 1964, p. 1298), sociocultural factors can compromise the right to meaningfully participate in decision-making. In Kenya, among the Pokot, the gender of a child is shared with the community from the moment of birth (Edgerton 1964, p. 1294). Conversely, in Ghana, parents have more time before the child's gender is revealed publicly (Ameyaw et al. 2019, p. 638). Overall, parents tend to reveal the gender of the child soon after birth. When parents decide to subject their child to IGM, they may infringe upon the child's rights, especially since newborns cannot meaningfully participate in such decisions (Monro et al. 2021, pp. 435–36). Recommendation 39.294, from Malta to Switzerland in 2023, suggests a way to ensure a child's meaningful participation in decision-making: "Consider explicitly prohibiting non-emergency, invasive and irreversible surgery or treatments with harmful effects on infants and children with variations in sex characteristics and ensure that these surgeries or treatments are postponed until the children can meaningfully participate in decision-making and give their informed consent" (italics added). References to the child's right to self-determination and gender identity, as in the recommendations 138.210 (Iceland to Finland in 2022)[10] and 111.107 (Portugal to Costa Rica in 2019)[11], provide another model to increase a child's meaningful participation in the decision to undergo IGM.

To mitigate the risk that the child's rights are violated during decision-making about medical interventions, the optimal measure is to delay this decision until the child can provide competent consent (Centre for Human Rights 2022, pp. 12–13). In a Kenyan study from 2019, intersex persons share their wish to postpone surgery until puberty, which allows them to review medical test results and interpret their dominant sex characteristics before consenting to any medical or surgical intervention (Amolo et al. 2019, p. 7). To ensure that the intersex child can participate meaningfully in decision-making, there needs to be an agreement on when a child is mature enough. While a child's age of maturity varies across cultures, there is still the risk that the family can overrule any individual decision regardless the child's age, maturity, or ability to decide. To counter this risk, additional reference to the protection of bodily integrity, autonomy, and self-determination are valuable, as in the recommendation 156.158, issued by Malta and addressed to Sweden in 2020: "Protect children's rights to *bodily integrity*, *autonomy* and *self-determination* by ensuring, by legislation or otherwise, that non-vital surgical or other medical procedures on intersex infants are not performed before they are able to provide their *informed consent*" (italics added). As such, there is a supplementary safeguard defending the child's own wishes while protecting the child against those of the wider community.

5.3. Consent Given in an Informed Way

The requirement to provide sufficient adequate information to the parents or to the intersex person frequently appears in the recommendations categorised under groups 2 (informed and voluntary) and 3 (voluntary). As highlighted above, achieving consent in Africa is often a collective process (Akpa-Inyang and Chima 2021, p. 15), i.e., a consensus among different parties who all need information about the treatments, possible outcomes, and alternatives. Occasionally, key stakeholders, such as the family and community leaders, postpone naming the child and assigning its gender until they have sufficient information to discuss how to ensure the infant's acceptance within the family and community (Ameyaw et al. 2019, p. 638). This raises a critical question: Who shares this information? The new Resolution provides insights and underscores this information's significance in two ways. First, point 7 stresses the importance of capacity building for healthcare personnel to deliver necessary and sufficient information to parents and children, especially with regard to prenatal counselling and support services, while "respecting the autonomy, psychological integrity and sexual characteristics of the intersex person". Second, point 9 (African Commission on Human and Peoples' Rights 2023) highlights the need to "Ensure intersex people's right to full information, including access to their own medical records and history". There is a shared concern that more skilled medical staff (Hansen et al. 2022, p. 191) and training centres are needed in Africa (Ameyaw et al. 2019, p. 638) to share adequate information.

More important, however, is the question of who produces this information. The competence of African doctors is doubted by Gnassingbe et al. (2009, p. 83) who note that, because there are only four paediatric surgeons per African country, intersex children "are treated most of the time by urologists, who are not competent in this regard". As illustrated in the articles of Kraus (2013, p. 85) and Gnassingbe et al. (2009, p. 83) knowledge and information from the Global North may be used. Enabling informed consent through the transfer of knowledge from the Global North to the Global South may be questionable in a context where local medical staff lack the technical know-how for appropriate medical interventions and knowledge about the consequences of IGM. This assertion holds even more validity in situations of knowledge sharing, as illustrated by the clinical workshop in Togo (Gnassingbe et al. 2009), where capacity building and training included IGM. Bridging knowledge gaps by using advanced technologies from the Global North, explained by Western (French) professors to African medics, focuses on optimising the surgical interventions. Such "surgical safaris" (Kraus 2013, p. 85) pose a problem, stressing the power relation between Western paediatrics (pioneering) and African medics (passive receivers of knowledge), creating an enabling environment for epistemic violence, and more specifically testimonial smothering experienced by African doctors and intersex persons.

Testimonial smothering may arise when Western specialists, collaborating with African medics, disregard, underestimate, or overlook the insights and expertise of African doctors, whether unintentionally or intentionally due to discriminatory biases. This may have negative consequences for the African doctors who, consequently, silence their own voices and disengage from the communication, allowing potential IGM to go unaddressed. Conversely, while interacting with Western paediatrics, African doctors may refrain from explaining features of African society, anticipating that such aspects are difficult to understand for doctors who are not familiar with a country's duties and traditions. This may result in flawed conversations about options and alternatives for medical interventions or surgery on intersex persons. In this scenario, the intersex individual may become a casualty of power dynamics, potentially abandoned to the care of a foreign doctor who lacks understanding of the local context, and more specifically of the interests and needs of the intersex individual. Moreover, medical interventions from foreign paediatricians may increase the knowledge gap between the doctor and the intersex person, depriving the patient or the patient's parents of a valid interlocutor. Intersex persons may find it more challenging to grasp information from someone who is unfamiliar with the intersex person's culture. Even more critical is the expectation that the intersex person—who may live in poverty and lack basic education and literacy skills—understands the meaning of the proposed medical intervention and can anticipate the consequences. This potential knowledge gap exacerbates existing unequal power relations between the intersex person and the medics, potentially creating conditions for testimonial smothering experienced by the intersex person, who might keep silent to conceal a lack of understanding of the options and consequences of medical interventions or surgery. Finally, the emphasis on medical interventions and surgery as the response to intersexuality excludes alternative solutions from the conversation between the intersex person and foreign medical staff.

Only one of the ten IGM-related recommendations referring to informed consent specifically mentions that alternative solutions must be provided. This is the case for Recommendation 57.162, provided by Chile to Ireland in 2021: "Develop a health-care protocol for intersex children, based on human rights, that ensures that children and parents are *informed about all options* and that children participate in decision-making, thus avoiding subjecting intersex children to irreversible interventions and medically unnecessary surgical procedures" (italics added). All the other cases simply mention informed consent, leaving the risks of testimonial smothering unaddressed. To mitigate these risks, I argue that UPR recommendations should stress the need for comprehensive and adequate information, including references to alternative solutions, when advocating for the prohibition of IGM. Furthermore, these recommendations should require such information to be provided by medical professionals who are trained and familiar with the specific context of the intersex individual.

5.4. Consent Given on a Voluntary Basis

Nonconsensual medical interventions occur in Africa (African Commission on Human and Peoples' Rights 2023). In her study in South Africa, Baird (2021, p. 373) finds that "These surgeries are performed without the consent of the child and at times without the consent of the parent/s and/or guardians, often resulting in life-long medical complications and mental trauma." In the fight against IGM, the Resolution (African Commission on Human and Peoples' Rights 2023) warns "that non-consensual and unnecessary surgical and other genital normalization procedures performed on intersex persons, in a medical or other setting, may cause them lifelong physical and psychological suffering, permanent sterility, incontinence, and loss of sexual pleasure". Point 2 of the Resolution (African Commission on Human and Peoples' Rights 2023) calls for a ban on nonconsensual IGM, where "State Parties to the African Charter have the obligation to recognize the rights, duties and freedoms guaranteed by the African Charter by adopting legislative or other measures to implement them". There are two layers at stake here for the intersex person in cases where their consent is requested before surgery: their duties towards their parents, and their duties those towards the community.[12] Both layers may result in testimonial smothering: children obeying their parents' will, and parents feeling pressured to conform to the sociocultural context and the will of the community. According to Warne and Raza (2008), traditional values and beliefs may hold significant influence across diverse cultures. While emphasising the scientific and technical complexity of intersexuality and arguing that local communities may struggle to grasp this complexity, decisions on medical interventions may become entangled with myths, misconceptions, and taboos, directing involved parties to faith healers, shrines, and sources of magic (Warne and Raza 2008, p. 230). Such an environment can disrupt communications among the community, parents, and the intersex person, who may silence their voice in favour of the will of the family and community. This, however, does not mean that the community will opt for any medical intervention. Nevertheless, there is a lack of clarity around the alternative solutions pursued and their potential to harm the intersex individual.

The salient role of the parents, family, and local communities has been stressed in most of the cited studies. In resource-poor environments, various aspects impact decisions regarding IGM, both for parents of intersex children and for intersex adults. These include lack of funds to finance medical interventions (Amolo et al. 2019, p. 7), the parents' preference for a boy (Hansen et al. 2022, p. 190), sociocultural pressure, and fear of discrimination (Warne and Raza 2008, p. 231). However, is parental consent for their intersex child to undergo a medical intervention, such as IGM, genuinely voluntary, when consent is given to comply with the prevailing sociocultural norms? Parents might constrain their choice and obey the expectations of the community, which overrules any "free" parental consent or consent from the intersex child. One might question how much free will remains for the intersex person in an African context to decide on their own bodily integrity.

None of the UPR recommendations claiming voluntary consent, as in group 3 (informed and voluntary) and 4 (voluntary), confront this risk. References to nonconsensual, forced, and coercive or involuntary consent are insufficient in an African context. For example, UPR recommendation 122.102, provided by New Zealand to Chili in 2019, does not specify who should give this consent: "Consider putting an end to non-consensual medical procedures which affect intersex persons". UPR recommendations should explicitly mention that the consent should come from the intersex person. Nevertheless, even when the intersex person consents, there is no guarantee that this consent truly reflects the preferences of the intersex person. To avoid testimonial smothering, UPR recommendations should refer to competent, informed, and voluntary consent given by the intersex person, while also recommending accompanying measures to raise awareness and build capacities. These measures should target the intersex persons, parents, families, and communities to create conditions for the intersex person to be able to make an authentic decision. This suggestion is backed by the Resolution, in point 11, i.e., "Raise awareness of intersex issues and the rights of intersex persons in society".

6. Conclusions

Based on the content analysis of the twenty-nine IGM-related cases, I argue that advocating for the respect of the universal human right of informed consent is a Western response to IGM that may not completely capture the priorities and requirements in non-Western settings; as such, it will consequently fail to achieve its objective: genuine informed consent. While this analysis is built on only a few cases, it opens up an area of inquiry moving forward, as more IGM-related recommendations will be formulated, particularly with the recent African Union Resolution (African Commission on Human and Peoples' Rights 2023) that explicitly highlights the ban on IGM. Future recommendations should capture the substantial needs of intersex children and adults, and ensure that genuine consent is given in a competent, informed and voluntary way. There is a risk that Western countries will continue to produce the majority of IGM-related UPR recommendations, which may create a perceived political skew and risks undermining the spirit of the UPR process, which is meant to be a dialogue. Additionally, countries with limited interest in the rights of intersex persons may disengage from the dialogue, while concealing human rights violations. Some human rights violations will be addressed, while others remain hidden, which may lead some to conclude that IGM is merely a Western concern. There is an urgent need to foster meaningful dialogue and develop recommendations that are sensitive to the unique sociocultural contexts of African countries, ensuring that the voices and needs of all stakeholders, including those of intersex individuals, are adequately represented and addressed.

In an African context, decisions regarding medical interventions for intersex children frequently exclude the intersex individual from the decision-making process. Decision-making often requires wide consultation among family members and the community. This collective process reduces the probability that the ultimate decisions about medical interventions and surgery represent the individual wish of the intersex person. This likelihood of obtaining genuine consent requires first that the decision is made in a competent way. This means that the (parents of the) intersex person understand the consequences and participate meaningfully in the decision-making process. A prerequisite for meeting this criterion is to delay decisions about medical interventions until the intersex child is old enough to make their own decisions. This approach rules out IGM for infants unless there is a life-threatening situation. In addition, decisions about medical interventions or surgery on intersex persons require adequate information that allows the intersex individual, or their parents, to understand the treatment and to assess alternative solutions. Capacity building is required for all parties involved, i.e., the medical staff, the parents, the extended family, and the community, to ensure appropriate knowledge sharing and transparent communication. Thirdly, decisions should be made on a voluntary basis. In an African context, however, free decisions about medical interventions or surgery are scarce, due to the importance of sociocultural context. Therefore, any UPR recommendation pursuing the ban on IGM should guarantee that the decision can be made in a competent, informed, and voluntary manner, while also recommending measures to safeguard the intersex person's ability to decide, and to ensure that this decision is respected by parents, families, and communities.

Funding: This research received no external funding.

Institutional Review Board Statement: The analysis presented in this article did not involve human or animal subjects; thus, an Institutional Review Board Statement is not applicable.

Informed Consent Statement: Not applicable.

Data Availability Statement: The original data presented in the study are openly available in the Universal Human Rights Index at https://uhri.ohchr.org/en, accessed date 3 March 2024. The dataset supporting the conclusions of this article will be made available by the author on request.

Acknowledgments: I would like to express my gratitude to Melanie Smith and the two anonymous reviewers for their comments and support.

Conflicts of Interest: The author declares no conflict of interest.

Notes

[1] An analysis of the terms found in IGM-related UPR recommendations (Ravesloot 2022) reveals that "normalising surgery", "gender-normalising surgery", or "medical interventions" are commonly mentioned.

[2] Diverse definitions of intersex contribute to varying estimates (Blackless et al. 2000).

[3] Both concepts are explained further in the text and build on the work of Kristie Dotson. She defines epistemic violence as "a failure of an audience to communicatively reciprocate, either intentionally or unintentionally, in linguistic exchanges owning to pernicious ignorance" (Dotson 2011, p. 242). Dotson identifies testimonial smothering as "the truncating of one's own testimony in order to insure that the testimony contains only content for which one's audience demonstrates testimonial competence." (Dotson 2011, p. 244).

[4] DSD stands for Disorders of Sex Development a medical term used to describe variations of sex characteristics, or intersex. I avoid using this term as it places intersexuality within a medical context. In contrast, intersex "allows for a greater discussion of the social and cultural understandings that are associated with the term, including issues around sex and gender (Garland and Travis 2023, p. 5).

[5] Phele (2016, p. 55) in Botswana explores the rights of intersex individuals, particularly concerning official documentation and notices that their rights are often neglected in laws and policies.

[6] According to (Cynthia Kraus 2013, p. 86), hypospadias is a variation of sex characteristic "in which the urethral opening is not located on the tip of the glans".

[7] Following terms were used: medical, surg (encompassing variations such as surgery, surgeries, or surgical), variation, harm, characteristic, norm (encompassing normalizing, or normalization), reassignment and sterilization.

[8] In 2015, Malta (n.d.) adopted The Maltese Gender Identity, Gender Expression and Sex Characteristics Act of 2015. ACT XI of 2015, as amended by Acts XX of 2015 and LVI of 2016 and XIII of 2018. The Act states in Article 14 that "It shall be unlawful

for medical practitioners or other professionals to conduct any sex assignment treatment and, or surgical intervention on the sex characteristics of a minor which treatment and, or intervention can be deferred until the person to be treated can provide informed consent: Provided that such sex assignment treatment and, or surgical intervention on the sex characteristics of the minor shall be conducted if the minor gives informed consent through the person exercising parental authority or the tutor of the minor."

[9] Iceland adopted in 2019 the Act on Gender Autonomy, No. 80/2019 as amended by Act No. 159/2019, No. 152/2020, and No. 154/2020 (Act on Gender Autonomy 2019). The Act states in Article 11 that "Permanent changes on genitals, gonads or other sex characteristics of persons 16 years or older are prohibited without their written consent."

[10] "138.210 Respect intersex children's right to self-determination and ban unnecessary surgeries."

[11] "111.107 Continue its efforts for the protection of the rights of lesbian, gay, bisexual, transgender and intersex persons, namely by recognizing the right of intersex persons to gender identity self-determination and gender expression, inter alia by prohibiting the performance of surgical or pharmacological interventions on children before the manifestation of their gender identity".

[12] The African Charter on Human and Peoples' Rights (ACHPR) precises in its article 27 that the (intersex) individuals are obligated to fulfil responsibilities to both their family and society and to exercise their rights and freedoms according to the prevailing morality and common interest (Organisation of African Union 1981).

References

Act on Gender Autonomy of 2019, No. 80/2019 as Amended by Act No. 159/2019, No. 152/2020, and No. 154/2020. 2019. Available online: https://www.government.is/library/04-Legislation/Act%20on%20Gender%20Autonomy%20No%2080_2019.pdf (accessed on 14 June 2024).

African Commission on Human and Peoples' Rights. 2023. Resolution on the Promotion and Protection of the Rights of Intersex Persons in Africa, ACHPR/Res.552 (LXXIV) 2023. Available online: https://achpr.au.int/en/adopted-resolutions/resolution-promotion-and-protection-rights-intersex-persons/ (accessed on 14 June 2024).

Akpa-Inyang, Francis, and Sylvester C. Chima. 2021. South African traditional values and beliefs regarding informed consent and limitations of the principle of respect for autonomy in African communities: A cross-cultural qualitative study. *BMC Medical Ethics* 22: 111. [CrossRef]

Ameyaw, Emmanuel, Serwah Bonsu Asafo-Agyei, Ieuan A. Hughes, Margaret Zacharin, and Jean-Pierre Chanoine. 2019. Incidence of disorders of sexual development in neonates in Ghana: Prospective study. *Archives of Disease in Childhood* 104: 636–38. [CrossRef]

Amolo, Prisca, Paul Laigong, Anjumanara Omar, and Stenvert Drop. 2019. Etiology and clinical presentation of disorders of sex development in Kenyan children and adolescents. *International Journal of Endocrinology* 2019: 2985347. [CrossRef] [PubMed]

Baird, Sophy. 2021. The silence of the 'I': Legal and social implications of intersex genital mutilation of children. *South African Journal on Human Rights* 37: 372–91. [CrossRef]

Bauer, Markus, Daniela Truffer, and Daniela Crocetti. 2020. Intersex human rights. *The International Journal of Human Rights* 24: 724–49. [CrossRef]

Beauchamp, Tom L., and James F. Childress. 2001. *Principles of Biomedical Ethics*. New York: Oxford University Press.

Beh, Hazel Glenn, and Milton Diamond. 2000. An emerging ethical and medical dilemma: Should physicians perform sex assignment surgery on infants with ambiguous genitalia. *Michigan Journal of Gender & Law* 7: 1–63.

Behrens, Kevin G. 2020. A principled ethical approach to intersex paediatric surgeries. *BMC Medical Ethics* 21: 108. [CrossRef]

Benson, Sara R. 2005. Hacking the gender binary myth: Recognizing fundamental rights for the intersexed. *Cardozo Journal of Law & Gender* 12: 31–63.

Blackless, Melanie, Anthony Charuvastra, Amanda Derryck, Anne Fausto-Sterling, Karl Lauzanne, and Ellen Lee. 2000. How sexually dimorphic are we? *Review and synthesis. The Official Journal of the Human Biology Association* 12: 151–66.

Brunner, Claudia. 2021. Conceptualizing epistemic violence: An interdisciplinary assemblage for IR. *International Politics Reviews* 9: 193–212. [CrossRef]

Carpenter, Morgan. 2018. Intersex variations, human rights, and the international classification of diseases. *Health and Human Rights* 20: 205–14. [PubMed]

Carpenter, Morgan. 2024. Fixing Bodies and Shaping Narratives: Epistemic Injustice and the Responses of Medicine and Bioethics to Intersex Human Rights Demands. *Clinical Ethics* 10: 3–17. [CrossRef]

Centre for Human Rights. 2022. *Study on the Human Rights Situation of Intersex Persons in Africa*. Pretoria: Faculty of Law, University of Pretoria. Available online: https://www.chr.up.ac.za/images/researchunits/sogie/documents/Intersex_Report/Intersex_report_Oct_Sept_2022.pdf (accessed on 14 June 2024).

Dotson, Kristie. 2011. Tracking epistemic violence, tracking practices of silencing. *Hypatia* 26: 236–57. [CrossRef]

Edgerton, Robert B. 1964. Pokot intersexuality: An East African example of the resolution of sexual incongruity. *American Anthropologist* 66: 1288–99. [CrossRef]

Ellaithi, Mona, Alaa A. Kamel, Osama Saber, and Olaf Hior. 2011. Consanguinity and disorders of sexual developments in the Sudan. *Sudan Journal of Medical Sciences* 6: 267–70.

Fausto-Sterling, Anne. 2000. *Sexing the Body: Gender Politics and the Construction of Sexuality*. New York: Basic Books.

Garland, Fae, and Mitchell Travis. 2023. *Intersex Embodiment: Legal Frameworks beyond Identity and Disorder*. Bristol: Bristol University Press.

Gnassingbe, Komla, S. da Silva-Anoma, G. K. Akakpo-Numado, A. H. Tekou, B. Kouame, C. Aguehounde, L. Coupris, R. B. Galifer, D. Aubert, and Y. Revillon. 2009. Transfer of surgical competences in the treatment of intersex disorders in Togo. *African Journal of Paediatric Surgery* 6: 82–84. [CrossRef] [PubMed]

Hansen, Erik, Eric Irungu, John Muma Nyagetuba, and Joyce MbogoJoyce. 2022. Management of differences in sexual development: Evolution of an approach for a resource-limited setting. *Annals of African Surgery* 19: 186–92. [CrossRef]

Jorge, Juan Carlos, Leidy Valerio-Pérez, Caleb Esteban, and Ana Irma Rivera-LassenIrma. 2021. Intersex care in the United States and international standards of human rights. *Global Public Health* 16: 679–91. [CrossRef] [PubMed]

Kraus, Cynthia. 2013. Hypospadias surgery in a West African context: The surgical (re-) construction of what? *Feminist Theory* 14: 83–103. [CrossRef]

Malta. n.d. The Maltese Gender Identity, Gender Expression and Sex Characteristics Act of 2015. ACT XI of 2015, as Amended by Acts XX of 2015 and LVI of 2016 and XIII of 2018. Available online: https://legislation.mt/eli/cap/540/eng/pdf (accessed on 14 June 2024).

Monro, Surya, Morgan Carpenter, Daniela Crocetti, Georgiann Davis, Fae Garland, David Griffiths, Peter Hegarty, Mitchell Travis, Mauro Cabral Grinspan, and Peter Aggleton. 2021. Intersex: Cultural and social perspectives. *Culture, Health & Sexuality* 23: 431–40.

Organisation of African Union. 1981. The African Charter on Human and Peoples' Rights (ACHPR). Available online: https://au.int/sites/default/files/treaties/36390-treaty-0011_-_african_charter_on_human_and_peoples_rights_e.pdf (accessed on 14 June 2024).

Phele, Keikantse Elizabeth. 2016. Law and Silence of Intersex Status: A Threat to Human Rights in Botswana. Ph.D. dissertation, University of Pretoria, Pretoria, South Africa.

Ravesloot, Saskia. 2022. Addressing intersex genital mutilation through the universal periodic review: An emerging opinio juris? In *Paz, Direitos e Novas Redes-III Conferência Internacional Ativismos em África*. Recife: UFPE, pp. 243–73.

Spivak, Gayatri Chakrovorty. 1988. Can the subaltern speak? In *Marxism and the Interpretation of Culture*. Edited by Cary Nelson and Lawrence Grossberg. London: MacMillan Education.

Swarr, Amanda Lock. 2023. *Envisioning African Intersex. Challenging Colonial and Racist Legacies in South African Medicine*. Durham: Duke University Press.

UN General Assembly. 1948. Universal Declaration of Human Rights, 217 (III) A. Available online: http://www.un.org/en/universal-declaration-human-rights/ (accessed on 10 December 2023).

UN Human Rights Council. 2024. Resolution Combating Discrimination, Violence and Harmful Practices against Intersex Persons, A/HRC/55/L.9. Available online: https://undocs.org/Home/Mobile?FinalSymbol=A/HRC/55/L.9&Language=E&DeviceType=Desktop&LangRequested=False (accessed on 21 March 2024).

UN Office of the High Commissioner for Human Rights. 2019. OHCHR Background Note on Human Rights Violations against Intersex People. Available online: https://www.ohchr.org/sites/default/files/Documents/Issues/Discrimination/LGBT/BackgroundNoteHumanRightsViolationsagainstIntersexPeople.pdf (accessed on 10 December 2023).

UN Office of the High Commissioner for Human Rights. 2023. Universal Human Rights Index. Available online: https://uhri.ohchr.org/en/search-human-rights-recommendations (accessed on 10 December 2023).

Warne, Garry L., and Jamal Raza. 2008. Disorders of sex development (DSDs), their presentation and management in different cultures. *Reviews in Endocrine and Metabolic Disorders* 9: 227–36. [CrossRef] [PubMed]

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

Zucker, Kenneth. 1999. Intersexuality and gender identity differentiation. *Annual Review of Sex Research* 10: 1–69. [CrossRef] [PubMed]

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Article

Boundaries of Parental Consent: The Example of Hypospadias Surgery

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Abstract: Human rights organisations raise concerns about medical interventions on children with intersex variations, particularly when these interventions impinge on the child's bodily autonomy and are without a sound biomedical basis. Psychosocial literature and legal literature have made very different contributions to thinking about the healthcare of people with intersex variations, but both literatures pay attention to the process of informing patients about elective interventions and the workings of consent. The present paper addresses the absence of dialogue across medical, legal, and psychosocial literatures on the surgical treatment of children with intersex variations. The analysis presented in this paper focusses on the assumptions underpinning the practice of allowing parents to consent on behalf of their children to elective surgery in the instance of hypospadias. In this paper, we (i) introduce consent from a medico-legal perspective, (ii) analyse selected documents (including medical, psychosocial, and human rights documents) in relation to the concept of parental consent on behalf of a child, and (iii) reconsider the current practice of inviting parents to give consent for elective genital surgery on infants. What emerges from our analysis is a picture of long-term relationships and interactions over time within which the consent process is located. The focus is not whether *consent* is granted, but whether *free and informed consent* is granted. This picture allows us to expand the understanding of "informed consent," highlighting the importance of producing ethical interactions between health professionals and patients with the view that these relationships last for years. Understanding consent as a process, considering information as dynamic, partial, and negotiated, and understanding the doctor–patient interaction as relational might enable us to imagine the kind of informed consent process that genuinely works for everyone concerned. Our examination of selected legal, medical, and psychosocial texts raises doubt about whether current hospital practice meets the requirement of informed parental consent on behalf of children undergoing hypospadias surgery.

Keywords: intersex; hypospadias; human rights law; psychosocial; penile surgery; parental consent; children

Citation: Roen, Katrina, and Rogena Sterling. 2023. Boundaries of Parental Consent: The Example of Hypospadias Surgery. *Social Sciences* 12: 677. https://doi.org/10.3390/socsci12120677

Academic Editors: Jenny Pearce and Peter Hopkins

Received: 10 August 2023
Revised: 27 October 2023
Accepted: 6 December 2023
Published: 8 December 2023

1. Introduction

Human rights organisations have noted concerns about medical interventions on children with variations in sex characteristics (also known as intersex variations) (Amnesty International 2017; United Nations Human Rights Council 2013; United Nations Human Rights Office of the High Commissioner 2023). These concerns arise particularly when the intervention (hormonal, surgical, or diagnostic) impinges on the child's bodily autonomy and is carried out for reasons that do not strictly have a biomedical basis. Reasons for intervention are sometimes described as appearance-altering or functional and are often explained as being important for psychosocial reasons. It is striking that psychosocial research looking to substantiate those rationales has failed to find evidence that "normalising" interventions on children's sex characteristics reliably produce the hoped-for psychosocial benefits for the child. Psychosocial research (e.g., Lundberg 2017; Roen 2019; Steers et al. 2021) and legal research (e.g., Greenberg 2017; McDonald 2015) stand alongside human rights organisations in raising concerns about elective medical interventions on children with variations in sex characteristics.

Psychosocial literature and legal literature have made very different contributions to thinking about the healthcare of people with variations in sex characteristics, but both literatures pay attention to the relative roles of children and caregivers, the process of informing patients about elective interventions, and the workings of consent. These bodies of literature are not necessarily used at all by health professionals who draw up guidelines for medical practice. Instead, there is a chasm of understanding where medical, legal, and psychosocial literatures all address the same topic, and few authors work across these literatures.

The present paper addresses the absence of dialogue across medical, legal, and psychosocial literatures on the surgical treatment of children with variations in sex characteristics. We approach this collaboration as Aotearoa New Zealand researchers with expertise in human rights law (RS) and psychosocial research (KR). We undertake this work at a time when the United Nations Committee on the Rights of the Child is charging Aotearoa New Zealand and other countries with abusing children's human rights because surgeons perform elective genital surgery on infants born with variations in sex characteristics (UNCRC 2016). The surgery is presumed to be carried out on the basis of parental consent. This paper focuses principally on the most common variation, hypospadias, and it tackles questions about parental consent. Hypospadias is an anatomical variation where the urethral opening appears somewhere other than the tip of the penis, such as the underside or base of the penis. In this paper, we systematically work with medical, legal, and psychosocial research with the aim of contributing to the current dialogue about parental consent in the context of elective surgical interventions on the genital and reproductive organs of children with variations in sex characteristics.

What assumptions underpin the practice of allowing parents to consent on behalf of their children to elective surgery in the instance of hypospadias? To address this question, we (i) introduce consent from a medico-legal perspective, (ii) analyse selected documents (including medical, psychosocial, and human rights documents) in relation to the concept of parental consent on behalf of a child, and (iii) reconsider the current practice of inviting parents to give consent for elective genital surgery on infants.

Hypospadias surgery to move the urethral opening to the tip of the penis is driven by a popular belief that it brings psychosocial benefit to the child, but psychosocial research has failed to show the hoped-for benefits (Schönbucher et al. 2008). Although many surgeons argue for the continuation of hypospadias surgery (Snodgrass and Bush 2016), other surgeons have brought the evidence into question, pointing to research limitations and surgical failures (Long and Canning 2016). There are questions about the ethics of early surgery (Weber et al. 2009), in a context where parental regret rates are as high as 39% (Ghidini et al. 2016). Further, parents are affected in their decision to consent to surgery by framing effects that they are unaware of (Streuli et al. 2013). Psychosocial research shows that health professionals, whose role it is to support parents' consent process, seem to underestimate the framing effect they bring to the conversation (Roen and Hegarty 2018). We conclude that parents may be unintentionally set up to "agree" to surgery on behalf of their infant before they have genuinely weighed the pros and cons.

2. Consent

The legal doctrine of informed consent derives from The Nuremberg Code ([1947] 1996). This mechanism was introduced to move medicine from a paternalistic ('doctor knows best') model to a new model with respect for patient autonomy (Katz 1998; Skowron and Angelos 2017). Although there is case law relating to consent, in Aotearoa New Zealand, consent in medical situations is based on the New Zealand Public Health and Disability Act (2000) and Right 7 of the Health and Disability Commissioner (Code of Health and Disability

Services Consumers’ Rights) Regulation (1996). Medical informed consent is essential to the medical professional’s ability to diagnose and treat patients as well as the patient’s right to accept or reject clinical evaluation, treatment, or both (Paterick et al. 2008). The informed consent process puts in place a patient–doctor relationship where each partner understands and accepts the degree of autonomy the patient desires in the decision-making process (Health and Disability Commissioner (Code of Health and Disability Services Consumers’ Rights) Regulation 1996, Right 7; Paterick et al. 2008). Such a process should have a greater impact on patients with intersex variations than it has given the emphasis on respect for autonomy and beneficence towards patients (Reis 2019).

Informed consent is an interactive process whereby the patient is informed about all options, including not having the treatment and the possible benefits and possible negative effects (Kumar 2013). There is relativity in the practice of informed consent, that is, more intimate or invasive examinations require more explicit consent (Kumar 2013).

Informed consent indicates a right to choose whether to have a particular medical treatment (including the right to refuse or withdraw consent) rather than demanding a particular treatment (Keenan and Dalziel 2016, p. 101). It implies that the patient knows what they are consenting to and the consequences of it. It strongly relies on the premise that patients are able to make treatment decisions based on a balanced and thorough understanding of the risks and benefits associated with available treatment alternatives (Lorenzo et al. 2012). The process of informed consent is meaningless unless consent is given on the basis of relevant information and advice (Rogers v Whitaker 1992, para. 14). That is, the patient requires all information they deem relevant, whether or not the medical professional considers it relevant. The law indicates that the one giving consent is entitled to information even beyond the knowledge of a particular medical professional to enable the correct decision (Rogers v Whitaker 1992, para. 14). This process involves an exchange of ideas where the patient indicates their situation and medical professionals answer their questions and provide information about risks and benefits connected with medical treatments (Paterick et al. 2008).

The decision must be voluntary and without duress; otherwise, consent is void (Keenan and Dalziel 2016; Skegg et al. 2015). As Right 2 of the Code states, any decision must be free from coercion or discrimination (Health and Disability Commissioner (Code of Health and Disability Services Consumers’ Rights) Regulation 1996). Informed consent infers agency or self-determination and upholding the patient’s human rights (Rogers v Whitaker 1992, para. 15). The law presumes competency unless proven otherwise. The test for incompetence involves the patient being unable to comprehend and retain the necessary information about the procedure or treatment and being unable to weigh the information, balancing risks, and needs to arrive at a choice (Keenan and Dalziel 2016). If the patient is deemed incompetent, a guardian gives or denies consent on their behalf. When it is in the child’s best interests, it is assumed that the child’s parent(s) or guardian can give or refuse consent on the child’s behalf (refer to the Health and Disability Commissioner (Code of Health and Disability Services Consumers’ Rights) Regulation (1996), for details).

Medical professionals must recognise that informed medical choice is an educational process, honestly providing all “necessary information that may influence treatment or advice” (Paterson 2003, p. 1), and it has the potential to affect the patient–doctor alliance to their mutual benefit (Paterick et al. 2008). The consent process should be the foundation of the fiduciary relationship between a patient and a physician (Paterick et al. 2008). When medical professionals and patients take medical informed consent seriously, the patient–doctor relationship becomes a true partnership with shared decision-making authority and responsibility for outcomes (Paterick et al. 2008).

Although there is an established body of literature informing medico-legal understandings of consent, it is not clear how this literature informs current medical interventions on variations in sex characteristics.

3. Analysis of Selected Texts

The current paper is based on a body of literature selected with the aim of investigating questions of parental consent in the case of infant genital surgery. Our interest in drawing together psychosocial, medical, human rights, and legal approaches to this issue guided our selection of literature for analysis. We drew texts from our existing bibliographic databases and from literature searching. We selected texts that:

- Have implications for the process by which parents come to consent to elective genital surgery on behalf of children;
- Have broad relevance to variations in sex characteristics and/or specific relevance to hypospadias;
- Are published in English.

Our goal was not to undertake an exhaustive review but, rather, to draw together texts that might underpin a rigorous discussion across the disciplines of interest. For this purpose, we have included some texts written by surgeons, some written by psychologists, and some written with a human rights focus, as shown in Table 1.

Table 1. Body of texts for analysis.

Disciplinary Perspective	Selected Texts
Surgical/clinical perspectives	Dodds, P. R., Batter, S. J., Shield, D. E., Serels, S. R., Gavafalo, F. A., and Maloney, P. K. (2008). Adaptation of adults to uncorrected hypospadias. *Urology, 71*(4), 682-685. doi:10.1016/j.urology.2007.07.078 Ghidini, F., Sekulovic, S., and Castagnetti, M. (2016). Parental Decisional Regret after Primary Distal Hypospadias Repair: Family and Surgery Variables, and Repair Outcomes. *The Journal of Urology, 195*(3), 720-724. Liao, L.-M., Wood, D., and Creighton, S. M. (2015). Parental choice on normalising cosmetic genital surgery: Between a rock and a hard place. *BMJ (Online), 351*, h5124. doi:10.1136/bmj.h5124
Psychosocial perspectives	Cools, M., Nordenström, A., Robeva, R., Hall, J., Westerveld, P., Flück, C., . . . on behalf of the Cost Action B. M. working group. (2018). Caring for individuals with a difference of sex development (DSD): a Consensus Statement. *Nature Reviews Endocrinology, 14*(7), 415-429. doi:10.1038/s41574-018-0010-8 Roen, K., and Hegarty, P. (2018). Shaping parents, shaping penises: How medical teams frame parents' decisions in response to hypospadias. *British Journal of Health Psychology, 23*(4), 967-981. doi:10.1111/bjhp.12333 Schönbucher, V. B., Weber, D. M., and Landolt, M. A. (2008). Psychosocial adjustment, health-related quality of life, and psychosexual development of boys with hypospadias: A systematic review. *Journal of Pediatric Psychology, 33*(5), 520-535. doi:10.1093/jpepsy/jsm098 Streuli, J. C., Vayena, E., Cavicchia-Balmer, Y., and Huber, J. (2013). Shaping parents: Impact of contrasting professional counseling on parents' decision making for children with disorders of sex development. *The Journal of Sexual Medicine, 10*(8), 1953-1960. doi:10.1111/jsm.12214
Legal and human rights perspectives	Mendez, J. E. (2013). *Report of the special rapporteur on torture, and other cruel, inhuman and degrading punishment*: 22nd Session of the UN Human Rights Council. Paterson, R. (2003). Informed consent in New Zealand: Medical myths. *New Zealand Medical Journal, 116*(1183). World Health Organisation. (2014). *Eliminating forced, coercive and otherwise involuntary sterilisation: An interagency statement OHCHR, UN Women, UNAIDS, UNDP, UNFPA, UNICEF and WHO.*

In the first stage of analysis, we each independently read the selected texts, making detailed notes that were structured with a series of analytic questions. These analytic questions concerned (i) what is understood and assumed about consent and the legal framing of consent within the given text, and (ii) how children, parents, and health professionals are figured in the text in relation to their respective roles in the decision-making and consenting processes. We then combined our separate sets of notes, alongside each analytic question, in our analytic table. By reading our combined notes, we began to develop a shared interpretation. We each contributed to the writing of this interpretation, with RS leading the writing about the conceptual and legislative framing of consent, and KR leading the writing about how the various parties are figured in the consent process.

3.1. How Consent Is Presented in the Selected Texts

What is consent, and what are the assumptions made about consent, according to the selected texts? Although legal and human rights documents focus in detail on the concept of consent, this is not the case in medical and other health literature, where it is often assumed that a consent process takes place unproblematically.

Medical consent is intended to protect the patient (Paterson 2003). The consent process is not intended as a tick-box exercise that might protect the medical professional from potential disciplinary action (Paterson 2003). Health professionals have a "duty to inform and obtain informed consent" (Paterson 2003, p. 1), with the understanding that consent can only be given by an informed patent (Health and Disability Commissioner (Code of Health and Disability Services Consumers' Rights) Regulation 1996, Rights 6, 7). It is envisaged that the informed consent process should be located in a context of trust and confidentiality between the patient and medical professionals (Cools et al. 2018).

Patients and/or parents/guardians should be thoroughly informed by the clinical team and, on the basis of being thoroughly informed, they may give consent (Cools et al. 2018). The person giving consent must consider that they understand the information (Paterson 2003). They must be "given the information that a reasonable patient, in that patient's circumstances, would expect to receive" (Paterson 2003, p. 2), and patients can only consent of their own free will (Paterson 2003).

Informed consent procedures are based on trust and confidentiality. Cools et al. explained that, to "build a trustful relationship, an open discussion of all available relevant medical data, including progressive information on any hitherto insufficiently communicated aspects of the condition, is crucial" (Cools et al. 2018, p. 419). When intersex children undergo "cosmetic and other non-medically necessary surgery" (World Health Organisation 2014, p. 2), the validity of the consent process has been called into question. As a result, such surgical procedures have been "recognized as human rights violations by international human rights bodies and national courts" (World Health Organisation 2014, p. 2).

It is often assumed that "counselling by medical clinicians" is sufficient to enable parents to prepare for surgery (Ghidini et al. 2016, p. 723), but current information management concerning DSD and the medical framing of variations may produce biased decisions, as demonstrated by Streuli et al.'s study (Streuli et al. 2013). With regard to genital-normalising surgery, the Special Rapporteur on torture has stated that consent for surgery must be given by the person concerned (Mendez 2013), not solely by their parent/guardian.

Our initial analysis suggests that some complexities of parental consent may be underexamined, especially in relation to elective genital surgery on children. Our analysis so far raises questions about the process of informing parents so they can reasonably consent on behalf of their children. Given that the consent process involves relationships of trust, communication, and shared understandings, we are interested in the key parties involved in these relationships: parents, children, and health professionals.

3.2. Parents

Parents/caregivers become positioned in very particular and interesting ways when the possibility of infant genital surgery arises. This part of our analysis sheds light on the informed consent process by examining how parents are figured in the context of psychomedical, human rights, and legal literature.

In the texts we analysed, key ways that parents are figured relate to their emotional state, their understandings and beliefs, the information and support they may be given, the decisions they face, and the potential for regretting their decision afterwards. Each of these aspects involves uncertainties and tensions that have some bearing on their role in consenting (or not) to surgery on their child.

Parents may be understood as being "in the difficult situation of having to decide whether their young son should undergo an operation that is not strictly necessary and carries a risk of complications" (Ghidini et al. 2016, pp. 720–21). Of the parents who participated in one study, 78% "reported they wished they had had more information on the condition preoperatively" (Ghidini et al. 2016, p. 723). This study reported that parents strongly desired more knowledge before making decisions (Ghidini et al. 2016, p. 723). Medical professionals who took part in another study described parents as almost always wanting surgery to go ahead during infancy, yet non-medical professionals who took part in the same study described how a shift seemed to take place when they had conversations with parents about nonsurgical options (Roen and Hegarty 2018). Talking about non-surgical options was sometimes described as a relief to parents (Roen and Hegarty 2018). From this, we see some tensions inherent in what parents want and in what health professionals think parents want.

With regard to their emotional state, parents report that being told about their child's diagnosis and treatment plans can be emotionally overwhelming (Cools et al. 2018). Clinical researchers point to the importance of providing parents with time and support, but this does not necessarily happen to a sufficient degree to offset the challenges parents face (Liao et al. 2015). Parents may feel "insurmountable pressure" in relation to social norms about genital appearance and may "find it impossible to delay surgery" (Liao et al. 2015, p. 2) because of the lack of a clear non-surgical pathway or protocol (Liao et al. 2015). Some psychomedical researchers argue that parents are not presented with real choices and are not given the time and psycho-educational input needed to properly engage with the information they are given (Liao et al. 2015). These statements about the psychological effect of norms and the absence of non-surgical healthcare options point to a situation where the possibility of meaningful parental consent is severely jeopardised.

One text describes various ways that parents might think about surgery and ways that they might engage in the consent process: they might be positioned to be responsible for deciding for or against a particular treatment; they might consider surgery as necessary and not requiring any decision at all; they often prefer not to wait until the child is old enough to contribute to the decision; they may be swayed by social pressures and norm-based attitudes; and they may be swayed by health professionals and the information they receive in healthcare contexts (Streuli et al. 2013). The focus of this paper is an empirical study demonstrating how the framing of healthcare information is likely to sway the decisions parents make about genital surgery.

The authors of one text explained that there is "no evidence that parents are given sufficient time to appreciate their child, effective psychosocial support to manage their emotional reactions, or help to slowly digest the highly complex medical information and implications" (Liao et al. 2015, p. 1). In the absence of this time and support, the consent process comes into doubt. Given that surgical techniques change and cannot be fully evaluated until adult outcomes are known, there is not a clear consensus about which surgical approaches work best, and most surgeons operate on children's genitalia without the outcomes of their work being evaluated. This means that parents are effectively "opting for experimental surgery on their children" (Liao et al. 2015, p. 1) without realising that this is what they are doing. These authors point to the high levels of parental regret after such surgery takes place, and they point to the parents' emotional state, suggesting that it "may not be optimal" for decision making (Liao et al. 2015). They also cite research showing that parents' decisions are likely to be influenced by the medicalised presentation of genital differences in ways they do not realise.

In this context, it is little surprise that follow-up studies after surgery find that a substantial number of parents express regret about their decision for the surgery to go ahead. Further, human rights literature raises the concern that surgery sometimes goes ahead without parental consent. This tallies with psychosocial literature, which reports instances of parents handing the decision over, not wanting to take responsibility for consenting to surgery and wanting this to be the responsibility of medical staff.

Reading across the different bodies of literature, we see a picture of parents that raises questions about the extent to which they are genuinely in a position to consent to surgery on behalf of their children. The way parents are figured across these texts suggests that they are not necessarily adequately informed, they do not necessarily feel sufficiently supported to take this responsibility on behalf of their children, and they are not routinely (if ever) given genuine options between at least two healthcare pathways, one of which involves surgery and the other of which does not.

3.3. Children

Children are central to the issue at hand. They are also, paradoxically, absent in the sense that their voice is absent, as adults make decisions on their behalf. This part of our analysis examines how children—particularly infants—are figured in the context of the selected psychomedical, human rights, and legal literature.

The tension running through these texts relates to whether it is advisable to carry out non-life-saving genital surgery as early as possible in the child's life, or whether it is advisable to wait until the child is old enough to be involved in any decision about a surgical intervention. That is, the absence of the child's voice is recognised as a problem.

Some explicitly advocate waiting until the child is old enough to be actively involved in treatment decisions whenever that is possible (Cools et al. 2018). The World Health Organisation also states, "if possible, irreversible invasive medical interventions should be postponed until a child is sufficiently mature to make an informed decision... and give full, free and informed consent" (World Health Organisation 2014, pp. 7–8).

Although some explicitly address urination issues that might be faced by a child growing up with a hypospadic penis, there is also acknowledgement that no studies actually assess the urination/voiding issues experienced by children with unoperated hypospadias (Ghidini et al. 2016, p. 723). It would seem that an assumption is made about what children experience without that being evidenced in research.

Many of the references to children throughout these texts are speculative and future-oriented, focused on how to best promote the quality of life of the child and speculating about how penile appearance and urine spraying might affect the child's quality of life. However, one text asserts that children "born with atypical sex characteristics are often subject to ... involuntary genital normalising surgery, performed without their informed consent, or that of their parents ... Causing severe mental suffering." (Mendez 2013, pp. 18–19). A review of the research evidence base suggests, however, that there is no clear evidence of hypospadias surgery contributing positively to children's psychosocial well-being; these authors suggest that affected children "might profit from psychosocial support... to better accept their penis" (Schönbucher et al. 2008, p. 531).

In some texts, the child is clearly figured as a focus of detailed medical examination and testing. That is, the child is not a subject with desires or agency but is a body undergoing medical examination. Other texts point to the attempts that some non-medical staff make to talk with parents in a way that actively figures the child as happy and lovable (Roen and Hegarty 2018). This may be a strategic move to help the parents see their child in a non-medical light and understand that surgery is not a prerequisite for happiness, well-being, or being loved (Roen and Hegarty 2018). One study sought to show how children can be figured variously as having a medical illness or as being part of a social world that can involve support (Streuli et al. 2013). This study suggests that different kinds of health professionals might foreground these different perspectives on the child (Streuli et al. 2013).

If one were to approach these texts naïvely and try to glean something about children through what is written, the resulting picture may well be quite patchy and unfocused. Just as the child does not clearly have a voice in this situation, they are not pictured as coherent subjects (agentic or otherwise) in the texts.

An interpretation that we could draw is that the very people at the centre of this work (i.e., children) are only understood in vague and partial terms. Each party involved in decision-making processes and healthcare has an idea about the child—an imagining, a speculation, and a wish—but no one knows the child yet. Not being able to clearly picture the subject at the centre of medical interventions raises questions about whether it might be possible for anyone to make decisions and give consent on behalf of this subject. Indeed, some argue that the child is a not-yet-subject in this context (Aspinall 2006; Roen 2009). Certainly, it is reasonable for adults to make life-saving decisions on behalf of the infant, but is it reasonable to make non-urgent decisions that presume knowledge of the child's own future experience of their body?

3.4. Health Professionals

Many of the texts we are examining have been written by health professionals, and the remainder of the texts comment on the work of health professionals. But how are health professionals figured in these texts? This question is important for examining health professionals' role in the informed consent process.

Across these texts, health professionals are featured as experts who work in multidisciplinary teams; as professionals who give one another advice about what is best practice; as people who have divergent views on infant genital surgery; as people who unwittingly sway parents' decisions through their medical framing of genital variations; and as professionals who are required to inform parents but who not legally required to ensure parents' understanding.

Clinicians undertake research and publish guidelines. They are also an intended audience for guidelines about the requirements of informed consent, such as the WHO statement that informs healthcare providers that any advice or information they give should enable individuals to make the best decisions for themselves and should be nondirective. "The guidelines that indicate the requirement of full, free and informed consent should be available and should be well understood by practitioners and the public" (World Health Organisation 2014, p. 9).

In some instances, health professionals themselves are the focus of research. Our sample of texts includes two studies addressing how health professionals might frame the information they give parents about infant genital surgery and the unintended consequences of this framing. This research opens up the possibility of different kinds of information-giving leading to different treatment decisions. Roen and Hegarty (2018), for example, distinguished between medical professionals who talk in ways that medicalise the child's body and psychologists who actively seek to demedicalise the child's genital variation. Health professionals who choose a demedicalising way of talking about genital variations might, for example, focus on the loving relationship between the parent and the child or other aspects of the social and support context that the child lives in. Streuli et al. (2013) demonstrated empirically how these different ways of talking can lead to different treatment decisions. The significant role that clinicians play when they talk with parents raises questions about the extent to which it is actually the parents making the decision. What does it actually mean to define infant genital surgery as occurring subject to "parental consent" (Roen and Hegarty 2018)?

It is interesting to read alongside one another the psychological texts, showing that medical professionals unwittingly influence parents' decisions due to the way they give "information", and the legal texts, pointing out that medical professionals' information-giving role is so limited that they are not even required to ascertain how well parents have understood the information. Advice directed towards health professionals makes it clear that any information should be given in a spoken and written form (World Health Organisation 2014). “The doctor needs to inform the patient about the potential risks and benefits of the proposed treatment and let the patient to know that his or her welfare is the paramount concern.” (Paterson 2003, p. 1). In addition, “doctors are required to facilitate understanding [the law does not require them to] guarantee patient understanding” (Paterson 2003, p. 2). Psychology and Law both make an important contribution to our thinking about “informed consent” on behalf of infants, and reading these different texts alongside one another serves to highlight the chasm that opens up between them. It is in this chasm of possibility and uncertainty that health professionals are working. There is a great deal of flexibility around the actual practice of “informing” parents prior to them giving “consent.” In this context, it is, perhaps, not surprising that parents repeatedly express confusion and/or regret. Some texts consider regrettable medical interventions as a reasonable basis for apology. The WHO, for instance, states that it is important to recognise “past or present policies, patterns or practices of coercive sterilisation, and issue statements of regret or apology to victims” (World Health Organisation 2014, p. 15).

It is not only historical practices that might give rise to regret and apology. Researchers continue to raise uncertainties about the outcomes of childhood genital surgery. Liao et al. wrote that “Paediatricians’ confidence in the ability to construct genital anatomies is to meet cultural expectations of appearance and function has not been borne out” (Liao et al. 2015, p. 1). Researchers who have reviewed outcome studies similarly express concern that “there is no empirical evidence that corrective surgery at the youngest possible age leads to a better psychological development” and conclude that “empirical results do not support the early surgical interventions, which paediatric urologists recommend” (Schönbucher et al. 2008, p. 530). We see here that clinicians’ publications serve as a forum for expressing divergent perspectives on infant genital surgery. It must be understood that the very context for informing parents and engaging them in a consent process is a context of debate and uncertainty. It is not clear that parents are informed about these uncertainties before being invited to consent to surgery on behalf of their children.

4. Discussion

Hypospadias surgery is routinely performed in many countries and is most likely presented to parents as a routine surgery. Hypospadias is presented to parents as a common condition that can be corrected with surgery (Starship 2019). The routine discussion of this process produces an illusion in which both the medical professional and patient/caregiver believe that “all risks, benefits, and alternatives” have been discussed and agreed upon (Skowron and Angelos 2017, p. 1). This is despite there being little evidence for surgical urgency, except in the rare instance of urinary blockage.

There is relatively high trust in medical professionals in hospitals, putting them in a position of power. In such a high-trust environment, parents with little knowledge of the situation and why such procedures are performed rely on the advice given by medical professionals. They seldom have other information sources in such stressful times. Though it is couched in terms of parental consent, the decision may largely be “induced precipitately and unconsciously by a health professional rather than emerging from a balanced, comprehensive, and thought-out process” (Streuli et al. 2013, p. 1958). In the remainder of this paper, we consider consent as a relational process and as a legal duty.

4.1. Consent as a Relational Process

Although medical professionals and parents do not necessarily agree on the treatment of a child (McDougall et al. 2016), they are often engaged in a consent process. What emerges from our analysis is a picture of long-term relationships and interactions over time within which the consent process is located. This picture allows us to expand the understanding of “informed consent” so that it is no longer a matter of merely “giving information" and "consenting", but, instead, it is a matter of producing ethical interactions between health professionals and patients with the aim of healthcare relationships lasting for years. Understanding consent as a process, understanding information as dynamic, partial, and negotiated, and understanding the doctor–patient interaction as relational might enable us to imagine the kind of informed consent process that genuinely works for everyone concerned. This means imagining a future where parents do not come away from these interactions feeling confused and overwhelmed, where any consent that is given does not reliably lead to regret, and where the child concerned is figured as an agentic subject who is part of this relational dynamic that persists over time.

4.2. Legal Duty of Consent

Informed consent is a legal duty and affords medical professionals to avoid liability when performed in accordance with appropriate clinical standards (Keenan and Dalziel 2016; Skegg et al. 2015; World Health Organisation 2014).

Medical professionals would acknowledge, when suggesting treatments such as hypospadias surgery, that they have a legal duty to obtain informed consent (Paterson 2003). Although concerns are raised about surgery going ahead without consent (Frommer et al. 2021; Sterling 2018), it would be very difficult to find that hypospadias surgery has not had consent granted. It is also recognised that hypospadias surgery and associated treatments would follow standard protocols. The focus is not whether *consent* is granted, but whether such hypospadias surgery has *free and informed consent* granted. Moreover, is the consent granted by parents or guardians valid? Several cases have determined that parents cannot decide on cases affecting children's ability to reproduce (Secretary 1992), yet this was held differently in the case of intersex surgery that was considered "therapeutic" (Re: Lesley (Special Medical Procedure) 2008, FamCA 1226).

Although, generally speaking, the law assumes that the person concerned is the one giving consent, when a person is under 16 years old, consent falls on the parent or guardian. This is a dwindling duty as the child's competency increases, following the Gillick principle (Gillick v West Norfolk and Wisbech AHA 1985, *UKHL 112*, pp. 113–14). As the child's understanding and intelligence develops, parental consent reduces, and it terminates when the young person has the capacity to make their own decisions (Gillick v West Norfolk and Wisbech AHA 1985). Therefore, with hypospadias surgery usually being carried out in infancy and sometimes in teenage years, parental consent can only be given when it is in the child's best interest, as per the parents' legal duty (Gillick v West Norfolk and Wisbech AHA 1985, p. 170; Care of Children Act 2004 (NZ)) or in teenage years with the child's consent with parental support, in alignment with the Gillick principle. Does the treatment improve the child's well-being, in particular given that hypospadias is not life-threatening (NHS Trust 2021)?

There are two critical components to be considered in consent for hypospadias surgery. The first is whether consent is freely given. The second is whether the person consenting is adequately informed. If either or both of these fail or are inhibited, then any consent becomes invalid. We address each of these components in turn.

When consent is freely given, this means there is no coercion or duress during the process of giving consent. This includes misrepresenting the necessity of the surgery. Stating that it "would be better off to have the operation than not to have it" does not meet the requirement of informed consent (Reibl v Hughes 1980, p. 925). Even if the medical professional may feel it is for the consumer's own good, the medical professional must not "misinterpret the nature or necessity of a procedure, or resort to any attempt to put undue pressure on a consumer to accept it" (Keenan and Dalziel 2016, p. 104).

The second core aspect of the legal duty of consent in the medical context is that the person consenting is adequately informed (Health and Disability Commissioner (Code of Health and Disability Services Consumers' Rights) Regulation 1996, Rights 6, 7). It is through being adequately informed and given time to contemplate and consult with others if desired that the person can give or refuse consent. Full disclosure concerning the treatment suggested must include the “state of medical knowledge at that time” (Rosenberg v Percival 2001, HCA 18, para. 67), recognising that knowledge is constantly evolving.

Being adequately informed legally indicates that a person has sufficient information to make a decision regarding whether or not to agree to a particular medical treatment (Keenan and Dalziel 2016, p. 109). Although information may never be perfect, “fully informed” consent requires the disclosure of all expected risks, side effects, benefits, and costs of each option. The test for disclosure includes any information that “a reasonable person in the patient’s position would be likely to attach significance to” (Montgomery (Appellant) v Lanarkshire Health Board (Respondent) (Scotland) 2015, para. 87). It also includes the likely consequence of not having treatment (Health and Disability Commissioner (Code of Health and Disability Services Consumers’ Rights) Regulation 1996, Rights 6, 7; Keenan and Dalziel 2016, p. 109). The patient is entitled to take into account all non-medical considerations when making decisions (Montgomery (Appellant) v Lanarkshire Health Board (Respondent) (Scotland) 2015, para. 83). All risks, no matter how infrequent, must be disclosed (Keenan and Dalziel 2016, p. 113; Montgomery (Appellant) v Lanarkshire Health Board (Respondent) (Scotland) 2015, p. 89).

The test is not what significance the medical professional attaches to risks and benefits, but what significance the person concerned might attach to those risks and benefits. Even if a court is satisfied that a reasonable person in the patient’s position would be unlikely to attach significance to a particular risk, the fact that the patient may ask questions means there is some significance and relevance to the question (Rogers v Whitaker 1992, para. 11).

5. Conclusions

Conversations between health professionals and parents have been presumed to provide the basis for the informed consent that underpins penile surgery on children with hypospadias. These conversations take place in a medical setting where parents are highly likely to trust medical professionals, perhaps to the extent that they may not consider that there is any option other than to go ahead with surgery. Psychosocial research demonstrates that parents’ interpretation of what they are told is strongly impacted by framing effects, which are likely to prompt them to opt for surgery when that course of action is presented to them by a medical professional. It is likely that non-surgical care pathways are not presented to parents and that non-medical professionals are not involved in talking with parents about their son’s healthcare, about penile variations, or about any concerns that might be relevant to parents soon after the birth of a child with hypospadias. In this context, it seems unlikely that conversations between medical professionals and parents can provide the basis for a valid consent process.

Human rights organisations have found the surgery carried out on children with variations in sex characteristics, including hypospadias, to be a breach of the rights of the child. Some medical professionals continue to argue for the benefits of this surgery on the assumption that it is consented to by parents or guardians. Psychosocial research brings into question the communication between medical professionals and parents that underpins the consent process. Our examination of selected legal, medical, and psychosocial texts raises significant doubt about whether current hospital practice meets the requirement of informed parental consent on behalf of children undergoing hypospadias surgery.

Author Contributions: Conceptualization, K.R. and R.S.; analysis, K.R. and R.S.; writing—original draft preparation, K.R.; writing—review and editing, R.S.; funding acquisition, K.R. All authors have read and agreed to the published version of the manuscript.

Funding: This research was funded by University of Waikato grant number ALPSS12Dec2019.

Institutional Review Board Statement: Not applicable.

Informed Consent Statement: Not applicable.

Data Availability Statement: No new data were created or analyzed in this study. Data sharing is not applicable to this article.

Conflicts of Interest: The authors declare no conflict of interest.

References

Amnesty International. 2017. *First Do No Harm: Ensuring the Rights of Children with Variations of Sex Characteristics in Denmark and Germany*. Available online: https://www.amnesty.org/en/documents/eur01/6086/2017/en/ (accessed on 26 October 2023).

Aspinall, Cassandra Louise. 2006. Do I make you uncomfortable: Refslections on using surgery to reduce the distress of others. In *Surgically Shaping Children: Technology, Ethics, and the Pursuit of Normality*. Edited by Erik Parens. Baltimore: Johns Hopkins University Press, pp. 13–28.

Care of Children Act 2004 (N.Z.). 2004. Available online: https://www.legislation.govt.nz/act/public/2004/0090/latest/DLM317233.html?src=qs (accessed on 26 October 2023).

Cools, Martine, Anna Nordenström, Ralitsa Robeva, Joanne Hall, Puck Westerveld, Christa Flück, Birgit Köhler, Marta Berra, Alexander Springer, Katinka Schweizer, and et al. 2018. Caring for individuals with a difference of sex development (DSD): A Consensus Statement. *Nature Reviews Endocrinology* 14: 415–29. [CrossRef]

Frommer, Michael, John Howell, Edward Santow, Susan Cochrane, and Bruce Alston. 2021. *Ensuring Health and Bodily Integrity: Towards a Human Rights Approach for People Born with Variations in Sex Characteristics*. Available online: https://humanrights.gov.au/intersex-report-2021 (accessed on 26 October 2023).

Ghidini, Filippo, Sasa Sekulovic, and Marco Castagnetti. 2016. Parental decisional regret after primary distal hypospadias repair: Family and surgery variables, and repair outcomes. *The Journal of Urology* 195: 720–24. [CrossRef] [PubMed]

Gillick v West Norfolk and Wisbech AHA. 1985. *UKHL* 112.

Greenberg, Julie A. 2017. Legal, ethical, and human rights considerations for physicians treating children with atypical or ambiguous genitalia. *Seminars in Perinatology* 41: 252–55. [CrossRef] [PubMed]

Regulation 1996) Health and Disability Commissioner (Code of Health and Disability Services Consumers' Rights) Regu-lation. 1996. (NZ). Available online: https://www.legislation.govt.nz/regulation/public/1996/0078/latest/whole.html (accessed on 26 October 2023).

Katz, Jay. 1998. Reflections on informed consent: 40 years after its birth. *Journal of the American College of Surgeons* 186: 466–74. [CrossRef] [PubMed]

Keenan, Rebecca, and Kathryn Dalziel. 2016. *Health Care and the Law*, 5th ed. Toronto: Thomson Reuters.

Kumar, Nandini K. 2013. Informed consent: Past and present. *Perspectives in Clinical Research* 4: 21–25. [CrossRef]

Liao, Lih-Mei, Dan Wood, and Sarah M. Creighton. 2015. Parental choice on normalising cosmetic genital surgery: Between a rock and a hard place. *BMJ* 351: h5124. [CrossRef]

Long, Christopher J., and Douglas A. Canning. 2016. Hypospadias: Are we as good as we think when we correct proximal hypospadias? *Journal of Pediatric Urology* 12: 196.e191–196.e195. [CrossRef]

Lorenzo, Armando J., Luis H.P. Braga, Bozana Zlateska, Bruno Leslie, Walid A. Farhat, Darius J. Bägli, and Joao L. Pippi Salle. 2012. Analysis of decisional conflict among parents who consent to hypospadias repair: Single institution prospective study of 100 couples. *The Journal of Urology* 188: 571–75. [CrossRef]

Lundberg, Tove Pernilla. 2017. Knowing Bodies: Making Sense of Intersex/DSD a Decade Post-Consensus. Doctoral thesis, University of Oslo, Reprosentralen, Norway. Available online: https://www.duo.uio.no/handle/10852/55654 (accessed on 26 October 2023).

McDonald, Elisabeth. 2015. Intersex people in Aotearoa New Zealand: The challenges for law and social policy: Part I: Critiquing gender normalising surgery. *Victoria University of Wellington Law Review* 46: 705–24. [CrossRef]

McDougall, Rosalind, Clare Delany, and Lynn Gillam. 2016. *When Doctors and Parents Disagree: Ethics, Paediatrics and the Zone of Parental Discretion*. Alexandria: Federation Press.

Mendez, Juan E. 2013. *Report of the Special Rapporteur on Torture, and Other Cruel, Inhuman and Degrading Punishment*. 22nd Session of the UN Human Rights Council. Available online: https://digitallibrary.un.org/record/793910?ln=en (accessed on 26 October 2023).

Montgomery (Appellant) v Lanarkshire Health Board (Respondent) (Scotland). 2015. UKSC 11. Available online: https://www.supremecourt.uk/cases/docs/uksc-2013-0136-judgment.pdf (accessed on 26 October 2023).

New Zealand Public Health and Disability Act. 2000. Available online: https://www.legislation.govt.nz/act/public/2000/0091/latest/DLM80051.html (accessed on 26 October 2023).

NHS Trust. 2021. Hypospadias Repair. NHS: The Leeds Teaching Hospitals. Available online: https://www.leedsth.nhs.uk/a-z-of-services/childrens-surgery/childrens-day-surgery/about-your-procedure/hypospadias-repair/ (accessed on 26 October 2023).

Paterick, Timothy J., Geoff V. Carson, Marjorie C. Allen, and Timothy E. Paterick. 2008. Medical informed consent: General considerations for physicians. *Mayo Clinic Proceedings* 83: 313–19. [CrossRef] [PubMed]

Paterson, Ron. 2003. Informed consent in New Zealand: Medical myths. *New Zealand Medical Journal* 116: 1183.

Re: Lesley (Special Medical Procedure). 2008. FamCA 1226; *Unreported*.

Reibl v Hughes. 1980. 2 S.C.R. 880. Available online: https://www.canlii.org/en/ca/scc/doc/1980/1980canlii23/1980canlii23.html (accessed on 26 October 2023).

Reis, Elizabeth. 2019. Did Bioethics Matter? A History of Autonomy, Consent, and Intersex Genital Surgery. *Medical Law Review* 27: 658–74. [CrossRef]

Roen, Katrina. 2009. Clinical intervention and embodied subjectivity: Atypically sexed children and their parents. In *Critical Intersex*. Edited by Morgan Holmes. Farnham: Ashgate, pp. 15–40.

Roen, Katrina. 2019. Intersex or diverse sex development: Critical review of psychosocial health care research and indications for practice. *The Journal of Sex Research* 56: 511–28. [CrossRef]

Roen, Katrina, and Peter Hegarty. 2018. Shaping parents, shaping penises: How medical teams frame parents' decisions in response to hypospadias. *British Journal of Health Psychology* 23: 967–81. [CrossRef] [PubMed]

Rogers v Whitaker. 1992. HCA 58; 175 CLR 479 Available online: www.paci.com.au/downloads_public/court/12_Rogers_v_Whitaker.pdf (accessed on 19 November 1992).

Rosenberg v Percival. 2001. HCA 18, P44/2000. Available online: http://eresources.hcourt.gov.au/showCase/2001/HCA/18 (accessed on 26 October 2023).

Schönbucher, Verena B., Daniel M. Weber, and Markus A. Landolt. 2008. Psychosocial adjustment, health-related quality of life, and psychosexual development of boys with hypospadias: A systematic review. *Journal of Pediatric Psychology* 33: 520–35. [CrossRef]

Secretary. 1992. Department of Health and Community Services v JMB and SMB (Marion's Case). *Family LR* 15: 392.

Skegg, Peter. D. G., Ron Paterson, and Jo Manning. 2015. *Health Law in New Zealand*. Toronto: Thomson Reuters.

Skowron, Kinga B., and Peter Angelos. 2017. Surgical Informed Consent Revisited: Time to Revise the Routine? *World Journal of Surgery* 41: 1–4. [CrossRef]

Snodgrass, Warren, and Nicol Bush. 2016. Primary hypospadias repair techniques: A review of the evidence. *Urology Annals* 8: 403–8. [CrossRef]

Starship. 2019. *Hypospadias*. Available online: https://starship.org.nz/guidelines/hypospadias (accessed on 1 August 2023).

Steers, Denise M., Georgia L. Andrews, Esko J. Wiltshire, Angela J. Ballantyne, Sunny C. Collings, and Maria H. Stubbe. 2021. Young people with a variation in sex characteristics in Aotearoa/New Zealand: Identity, activism and healthcare decision-making. *Culture, Health & Sexuality* 23: 457–71. [CrossRef]

Sterling, Rogena. 2018. Identity and Its Protection as the Aim and Purpose of International Human Rights Law: The Case of (Inter)Sex Identity and Its Protection. Doctoral thesis, The University of Waikato, Hamilton, New Zealand. Available online: https://hdl.handle.net/10289/11891 (accessed on 26 October 2023).

Streuli, Jürg C., Effy Vayena, Yvonne Cavicchia-Balmer, and Johannes Huber. 2013. Shaping parents: Impact of contrasting professional counseling on parents' decision making for children with disorders of sex development. *The Journal of Sexual Medicine* 10: 1953–60. [CrossRef] [PubMed]

The Nuremberg Code. 1996. *BMJ* 313: 1448. First published 1947. [CrossRef]

UNCRC. 2016. *Concluding Observations on the Fifth Periodic Report of New Zealand (CRC/C/NZL/CO/5)*; United Nations Human Rights Office. Available online: https://www.ohchr.org/en/documents/concluding-observations/crccnzlco5-concluding-observations-fifth-periodic-report-new (accessed on 26 October 2023).

United Nations Human Rights Council. 2013. Report of the Special Rapporteur on Torture and other Cruel, Inhuman or Degrading Treatment or Punishment, Juan E. Méndez (A/HRC/22/53). Available online: http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53_English.pdf (accessed on 26 October 2023).

United Nations Human Rights Office of the High Commissioner. 2023. *Human Rights Violations against Intersex People: A Background Note*; United Nations Human Rights Office. Available online: https://www.ohchr.org/sites/default/files/Documents/Issues/Discrimination/LGBT/BackgroundNoteHumanRightsViolationsagainstIntersexPeople.pdf (accessed on 26 October 2023).

Weber, Daniel Max, Verena B. Schönbucher, Rita M. Gobet, Andreas Ch Gerber, and Markus A. Landolt. 2009. Is there an ideal age for hypospadias repair? A pilot study. *Journal of Pediatric Urology* 5: 345–50. [CrossRef] [PubMed]

World Health Organisation. 2014. *Eliminating Forced, Coercive and Otherwise Involuntary Sterilisation: An Interagency Statement*; OHCHR, UN Women, UNAIDS, UNDP, UNFPA, UNICEF and WHO. Available online: https://www.who.int/publications/i/item/9789241507325 (accessed on 26 October 2023).

social sciences

Review

Revisiting the Claims of Past Medical Innocence and Good Intentions

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Abstract: Medical professionals usually reject critiques of deferrable treatments that alter the sex characteristics of infants and children without personal informed consent on the grounds that intersex adults' experiences reflect 'obsolete' practice. However, past practice is also protected from criticism by claiming 'good intentions', a commitment to the child's best interest and context-dictated constraints on medical practice. I first examine foundational literature of the Optimal Gender Policy to verify the presence of statements of interests or motives, I then collect affect displays to identify motives, and I observe attitudes to clitoridectomy. Affect displays point to motives that are relevant in interpretive sociology, as they allow access to cultural or institutional dispositions when justification talk has not been provided. While a statement of interest is absent from the foundational literature, I identify the following affect displays: (1) unease and disgust; (2) attachment to heteronormativity, as well as three kinds of gratification or pleasure rewards; (3) power pleasure; (4) surgical pleasure; (5) and cosmetic pleasure. As surgical action appeases some of these affects and nourish others, previous medical professionals had interests that were their own and not centred on the children. Examination of attitudes to clitoridectomy reveals that clinicians were aware of the (phallo)clitoris' importance to sexual pleasure but dismissed it, further invalidating claims that past practice was based on children's best interest.

Keywords: intersex; medical culture; motive; clitoridectomy; interpretive sociology

Citation: Bastien Charlebois, Janik. 2024. Revisiting the Claims of Past Medical Innocence and Good Intentions. *Social Sciences* 13: 1–19. https://doi.org/10.3390/socsci13060279

Academic Editors: Surya Monro, Tanya Ni Mhuirthile, Amets Suess Schwend, Fae Garland, Daniela Crocetti, David Andrew Griffiths and Katrina Roen

Received: 30 March 2024
Revised: 8 May 2024
Accepted: 14 May 2024
Published: 22 May 2024

1. Introduction

Medical professionals involved in bodily norm conformity of infants and children with innate variations of sex characteristics commonly reject criticism. Their treatment notably comprises deferrable surgical and hormonal treatments without personal informed consent, examinations, and pathologizing language. When these children get older and some manage to impart their lived experiences, question treatment, and demand human rights protection through a collectivized position of intersex subjects (Preves 2006; Bastien Charlebois 2019), they are dismissed or misrepresented (Chase 1998; Carpenter 2024). North American and European pediatric urology and pediatric endocrinology medical associations as well as authorities in the field claim that these intersex human rights-based perspectives are inapplicable to current management of what they now frame as Disorders of Sex Development diagnoses. Experiences and demands are deemed anecdotal, unrepresentative, biased, uninformed, or even harmful to today's children (Lee and Houk 2010; Mouriquand et al. 2014; Societies for Pediatric Urology et al. 2017; Subramaniam et al. 2020; Wolffenbuttel et al. 2018). Trauma and suffering are euphemized, cast as self-created fantasies, misinterpretations, "counterfactual thinking" (Lee and Houk 2010; Meyer-Bahlburg 2005; Money and Lamacz 1987; Sandberg et al. 2017, p. 492), or associated with outdated practices conducted by non-specialists 'many years ago' (Frimberger and Gearhart 2005; Mouriquand et al. 2014)[1]. Human rights approaches are resisted and framed as simplistic, non-scientific, illogical, unreasonable, polarizing, and a threat to parental rights (Mouriquand et al. 2014; Societies for Pediatric Urology et al. 2017; Subramaniam et al. 2020; Gardner and Sandberg 2018; Pediatric Endocrine Society 2020)[2].

According to medical professionals, current management would not produce significant negative consequences since it would now be considerate and profoundly improved, requiring but minute adjustments. As a case in point, the joint 2020 Consensus Statement on Management of Differences of Sex Development of the European Society for Paediatric Urology (ESPU) and the Societies for Pediatric Endocrinology (SPU) responded to increased human rights-based challenges from intersex actors and organizations, UN treaty bodies, human rights-based NGOs, and legislative bodies by insisting[3]

> We, physicians, who daily take care of children with a variety of congenital conditions. . . are committed to the current, as well as the future, health and well-being of all children entrusted to our care. . . . It is ironic that the current controversy occurs at a time when we have made great strides in medical and surgical advances. (Subramaniam et al. 2020)

Although this stressing of improved practice implies an awareness of the failings of previous practice, this does not translate into acceptance of it being critiqued either. Intersex adults' frustration over medical professionals' firm refusal to take stock of the damage endured and implement changes that would protect children from the harm of bodily violation does not find any more receptiveness even when the focus is shifted to historic management. Medical professionals attribute benevolent motivation or 'good intentions' to 'well-meaning' or 'well-intended' predecessors and stress or imply the impossibility of selecting alternatives to treatment standards (Blondin et al. 2017; Lee and Houk 2010; Thomas 2004; Lee et al. 2023): "Doctors, especially perhaps those in the paediatric disciplines, have always been motivated by the wish to do what they genuinely believe to be in the best interests of their young patients and their families" (Thomas 2004, p. 47). At a French Senate hearing, pediatric urologist Pierre Mouriquand lamented the criticism of past practice: "We very often receive criticism and come under attack for the decisions we made. I wish they would accept to understand the context of that time" (Blondin et al. 2017, p. 193, my translation). Additionally, past treatment approaches are elevated to the status of gold standard. They are presented as the best medical professionals could envision and apply at the time: "These [intersex] individuals may also fail to recognize that prior care was within the standard of care that existed at the time" (Lee and Houk 2010, p. 2). They refer to the approach established by famous pediatric endocrinologist Lawson Wilkins and his team at Johns Hopkins Medical University, who were instrumental in securing management of infants and children with innate variations of sex characteristics. This approach has since been designated as the Optimal Gender Policy (Meyer-Bahlburg 1998) and encompass gender assignment decisions, surgical and hormonal options, as well as parental, child information management.

Early medical figures who worked with or trained under Lawson Wilkins also bring up context-dictated constraints on treatment decisions when confronted with criticism at the end of their careers or after they retired. This is the case of gynecologist and surgeon Dr. Howard W. Jones (1910–2015), whose promotion of clitoridectomies was still accepted as late as 1974 (Jones 1974) and he is known to have reacted strongly to critique: "Dr. [Howard] Jones bridled at being criticized, long after the fact, for performing such surgery. 'You are doing what the conventional wisdom around that time said to do.'" (Hutter Epstein 2015, p. A1). Equally, Melvin M. Grumbach (1925–2016), a pediatric endocrinologist who trained under Lawson Wilkins, shared with the Johns Hopkins Bulletin:

> [C]linicians who have built careers on treating intersexuals advise against judging past events through "year 2000" glasses. "We look through the retrospectoscope and say, 'My God! How did we do that?'" says Mel Grumbach, a pediatric endocrinologist who was a fellow at Hopkins in the early 1950s. . . "It's not fair. A lot has changed since then. We must learn from the advances that have been

> made rather than point fingers." (Hendricks 2000, under "Because so much has changed")

Claims of constraints dictated by context suggest powerlessness over treatment protocol decisions. Under that perspective, past social norms and medical knowledge limitations made better treatment options impossible. This applies to clitoridectomies and clitoral amputations. Current practitioners claim predecessors ignored the importance of (phallo)clitoral sensitivity in sexuality (Hendren 1998) or imply it through the casual enunciation of medical progress in developing knowledge on the clitoris (Baskin et al. 1999; Lee and Houk 2014).

These motivation- and context-based defences of previous management decisions have been made for around 25 years. However, they do not exceed a few sentences and have never been the object of medical articles. Older clinicians who drew from their professional experience to discuss past dispositions and context did so very succinctly, as illustrated by the previous quotes from Dr. Howard Jones and Dr. Mel Grumbach, and newer medical generations make these defences without referring to specific sources or documentation.

Past benevolent motivation and context as grounds for rejection of critiques have been employed in other social groups dynamics. A recent example is the reaction of educators working at residential schools and participating in assimilation endeavours of Canadian Indigenous peoples, as well as comments from theologians, legislators, columnists, or members of the public (Gulliver 2021; Justice and Carleton 2021; Turnbull 2021). 'Good intentions' are a tool of image restoration, used in diverse situations (Benoit and Drew 1997; Van Dijk 1992). They are not only availed of by social actors subjected to criticism, but also by sympathizers. When medical professionals invested in intersex management are concerned, the good intention defence has an added dimension. It is also brought up by social actors criticizing their practice. Intersex activists, social scientists, journalists, and human rights organizations alike mention that they understand that past medical professionals were 'well-meaning' or had 'good intentions' (Intersex Society of North America 2004; de María Arana 2005; Feder 2011; Guterman 2012; Reis 2020; Cabral 2019; Horton 2023). That social actors feel that such a statement is required when submitting critiques to medical professionals reveals the degree to which our 'Western' cultures readily assume benevolent motivations behind their actions[4]. Failing to utter it would be perceived as unfair criticism of medical professionals and compromise the social acceptance of grievances.

Nevertheless, good intention and context defences are getting challenged in some areas. Social actors criticizing colonialism and racism underscore the importance of examining past statements before assuming benevolent motivations (Heath Justice and Carleton 2021; Gulliver 2021; Turnbull 2021): "Arguments that Canada's Indian Policy was well-intentioned and humanitarian in nature must be evaluated against the harsh, condescending, and, at times, self-interested statements of the individuals who framed and implemented that policy" (Truth and Reconciliation Commission of Canada 2015, p. 112). In the field of intersex management, Juan E. Méndez (2014), the UN Special Rapporteur on torture and other cruel, inhuman, or degrading treatment or punishment stated that intrusive, irreversible, non-consensual, and non-therapeutical practices on "patients from marginalized groups" constitute forms of torture or ill-treatment despite medical claims of good intention (p. xvii). Feder (2015) argues that medical professionals insisting on good intentions while refraining from repairing the harm they caused does additional wrong. Peck and Feder (2017) argue that institutional pressures on intersex management did not morally dispense medical professionals with examining the effect of their actions.

Social science literature on intersex management has submitted important insights into medical professionals' motivation for securing control of bodies whose sex characteristics they consider as unfit to be classified as male or female. Redick (2004, 2006) and Reis (2009), investigating the inception of the Optimal Gender Policy by pediatric endocrinologist Lawson Wilkins's team at Johns Hopkins, both uncovered how medical professionals grew increasingly uncomfortable at waiting for intersex individuals' confirmation of their gender in the 1930s and 1940s. They suspected that some of them may be homosexual and attempt to evade law enforcement by posing as a sex (gender) they were not[5]. For medical professionals to solve that uncertainty required that they develop a treatment approach that would allow them to intervene systematically on newborns. Examining management practice once it was institutionalized, Kessler (1990) has shed light on medical professionals' heteronormative lenses when reading of intersex(ed) bodies and treatment decisions. She later unveiled the intensity of disgust towards intersex genitalia but did not situate that discovery in a reflection on medical professionals' motivations (Kessler 1998). Feder (2011) did but focused exclusively on this affect "as a motivating force" for intersex management (p. 623). She came to question the assumption of good intentions after being confronted by expressions of disgust from medical professionals: ". . . [H]is disgust would disrupt my willingness to attribute good intentions not only to him, but to those physicians who continue to recommend and perform cosmetic genital surgeries" (p. 638). Her observations are mainly drawn from medical statements contemporary to her research. When interviewing medical professionals in the 2000s, Davis (2011) uncovered financial interest as one reason why some would resist intersex demands for self-determination. Although enlightening, these social science works did not have past motivations as the main objects of their research.

While researching an extensive amount of medical literature for a book project, I came across content complicating both claims of a practice guided by a commitment to a child's best interest, and the impossibility of considering other treatment options that would better serve them. This inspired me to bring this material together and add depth to motivation and context in the medical management of intersex children. Although both could be examined separately, they are closely related in medical discourse. Context defences are used to sustain the idea that past medical professionals centered their decisions on children's best interest as they had no better knowledge to base them on.

The main question I pursue is: whose interest did the previous management centre on? This entails illustrating the extent of motivations displayed and examining available knowledge for decision-making. Given that this last dimension could be broad, I will focus on knowledge and attitudes about clitoridectomy. This endeavour is heuristic or exploratory and does not aim at establishing quantified distribution of interests or motivations. It rather aims at documenting the range of motivations expressed at intersex management and examining whether these concurrent motivations are compatible or not with 'best interest.' This analysis of motivations will improve understanding of intersex management medical culture and the dispositions it allows or fosters.

2. Materials and Methods

Looking for intentions behind social subjects' actions has been the object of critique by researchers across various disciplines (Duranti 2006). Not only can "intention" be envisioned differently from one language to another (Duranti 2006, p. 34), but reflexivity, planning, or deliberateness cannot be presumed behind every action and discourse (Duranti 2006; Van Dijk 2006). While medical professionals' defence often draws on the "good intentions" figure of speech, we cannot presume that treatment decisions and protocol elaboration all stem from a reflexive stance. A common denominator would be motive, which can be open to grounds as much as to emotional force behind actions, to stated end goals as much as to initial impetus for action (Campbell 1996).

Although sociology has mainly abandoned this wider understanding of motives after Charles Wright Mills (1940) influential proposal to reduce it to the production and tailoring of justifications to the situations where they are anticipated or requested, Campbell (1996) argues for its relevance. He agrees with Weber's ([1922] 1947) position that motives are key to explain actions, as actions that look identical at first glance will be different in nature depending on the subjective meaning they have for the actors. Campbell (1996) reframes motive as "a complex of meaning and affect which serves to energize action" (p. 106). I consider it important for sociology not to discard motives or affect displays as irrelevant to analysis. If they are not met with reprobation and corrective measures from the institution within which they emanate, it indicates that this institution allows it. If they are expressed by social actors as they establish practices that are quickly adopted and become greatly influential within the institution, it indicates validation. Repetition of motives or affect displays from different social actors participating in this practice within the institution means a shared disposition, either as a subculture within a discipline or a discipline's culture itself. By ignoring them and solely focusing on rationales, though, we cut ourselves from a deeper understanding of social dynamics. This is especially the case when reasoned motivations, justification talk, or accounts from direct actors are absent or minimal, which applies to the dynamics at play in past medical management of intersex bodies.

Motives or affects are a delicate dimension to tease out of utterances. But, emotional investments being present even in dominant perspectives whose language is unmarked and incorrectly cast as neutral, I posit that it is possible to approach motives by extracting affect displays in speech acts. Emotions expressed towards a situation deemed undesirable and around actions undertaken to solve it can point to investments and motivations proper to the speaker—and others in his social or institutional group. Given the specific medical claim of serving the child's 'best interest', I will pay attention to who is the beneficiary of a medical professional's quelled or nurtured emotion in intersex management.

The emotional investments are those of clinicians active before public intersex critique. I carefully approach later declarations as they could be post hoc accounts, whereby past actions privately motivated by personal interest or prejudice or previous values are publicly justified by principles enjoying current social acceptability (Winchester and Green 2019). The first step of this analysis is to verify whether statements of intentions were part of the Optimal Gender Policy foundation or not. The sample material covers all documents published by Lawson Wilkins's team from Wilkins's (1950) seminal *The Diagnosis and Treatment of Endocrine Disorders in Childhood* through to the formal presentation and promotion of the driving principles and methodology of what will later be called the 'Optimal Gender Policy' in the *Bulletin of the Johns Hopkins Hospital* (Money et al. 1955) and *Pediatrics* (Wilkins et al. 1955), and ending with Money's Hermaphroditism chapter in the *Sexual Behaviour Encyclopedia* directed at social scientists (Money 1961)[6]. Since the rationale of an approach should be presented at its inception, this selection should suffice in locating the stated intention and its form. This should especially apply to invasive non-consensual treatments that do not aim at sustaining life yet produce fundamental and irreversible change.

The second step of this analysis is to look for affect displays from medical professionals involved in intersex management before intersex critique. This period spans from Wilkins' 1950 seminal book to 1994–1995, when the Intersex Society of North America (Intersex Society of North America 1994–1995) sent its first *Recommendations for Treatment pamphlet* after its foundation following Fausto-Sterling's (1993) essay in *Nature*. This examination does not encompass all material from that period, as the identification of alternative motivations suffices to provide a more adequate portrayal than the current one. Material includes medical literature, comments, editorials, speeches, medical reports and, since some affects are only expressed while discussing practice in general, interview excerpts or transcriptions of audiovisual recordings.

The third and last step addresses constraints on treatment options, most specifically the performance of clitoridectomies. It can be assessed through medical disagreements or hesitations towards the proposals of the Optimal Gender Policy. This can span again from Wilkins (1950) through to the presentation of the Reimer experimentation (Money and Ehrhardt 1972). This is based on Grumbach's statement, which claims the Optimal Gender Policy only found general acceptance after the presentation of the Reimer case (Colapinto [2000] 2006). For this three-step endeavour, I draw on extensive reading of the medical literature on intersex management since Wilkins's (1950) seminal book and close examination of the successive development and purchase of arguments supporting treatment aspects. The total intersex management medical literature read from the 1950 to 1993 period amounts to 126 publications.

Selection of quotes has obeyed the following principles. While I had to draw from the Lawson Wilkins team for stated interest, I took care of using quotes illustrating motivations or expressing views on clitoridectomy from clinicians who were well known or established in the field before public intersex criticism. Given the delicate nature of the observations I make and the frequent indirectness of motivations, I provide up to three examples for each. This limits the risks of these motivations being discounted as isolated and supports the idea that they are worthy of in-depth investigations, to the extent that such an endeavour is feasible. I have increased quote selection to five on awareness of the importance of the clitoris to compensate for the shorter exploration of context.

Given that this article examines published and public medical discourse on intersex management, it is no interventionary study. Protective ethical measures are not required in this context.

3. Results

3.1. An Absence of Stated Interest

When initiating and sharing the Optimal Gender Policy (1950–1961), the Lawson Wilkins team does not mention whose interests it serves. Treatment recommendations are first introduced with statements on sex/gender determination. While intersex individuals are eventually mentioned as recipients, in what regard these sex characteristics constitute a problem in need of a surgical and hormonal solution is cursorily raised in two articles. Nowhere is data submitted to the effect that people with atypical sex characteristics are generally suffering from their difference. Even when broadening the scope to objectives, we are left with rare, indirect, and vague statements. In the 1950–1961 period, only three passages allude to interest or objective. Two come from Wilkins and his colleagues when they present their protocol in Pediatrics:

Uncertainty, protective secrecy or social ostracism make it difficult for the child to adjust properly. . .

> It is obvious that unless there is a fairly well-developed phallus the patient cannot function as a male and will be subjected to constant humiliation and embarrassment throughout life. (Wilkins et al. 1955, pp. 287, 296)

Or again, by Hampson et al. (1956), after the formal launch of the Hopkins approach:

> Few would dispute that the ultimate objective in the treatment of any hermaphroditic patient is to ensure the establishment and maintenance of a stable and pervasive gender role. (p. 548)

Wilkins et al. (1955) bring up adjustment difficulties due to social ostracism (p. 287), and express worry at the potential of “humiliation and embarrassment” for men with an ‘underdeveloped phallus’ (p. 296). While Hampson et al. (1956) do mention an “ultimate objective” (p. 548). In both cases, however, treatment recommendations are not answering an assessment of mental health risk among intersex people. We already know from his thesis that Money (1952) was surprised to observe so little mental afflictions as well as the capacity to develop a feminine or masculine ‘gender role’ despite strongly atypical sex characteristics (Colapinto [2000] 2006)[7]. This was also repeated in the early writings of the Psychohormonal Research Unit, after they conducted additional interviews (Hampson 1955, p. 266; Money et al. 1956, p. 53). While penis size mentioned by Wilkins et al. (1955) is indeed associated with great anxiety among many men in our societies, they leave the male function and the ‘obviousness’ of failing at it unexamined. ‘Fairly well-developed’ remains eminently subjective, as both individual medical professional impression and standard imply judgment. What the intersex individual would make of this function and evaluation of ‘underdeveloped’ is not explored. It does not substantiate that fabricating a body, approximating female medical norms, without that individual’s express desire is ‘obviously’ in their best interest. Moreover, Wilkins et al. (1955)’s promotion of the protocol does not address all situations for which they deem invasive surgical and hormonal modifications imperative. For instance, nothing is mentioned of how amputation or clitoridectomy of (phallo)clitorises or performance of vaginoplasties on children they assign as girls would be in their interest.

In sum, statements of intentions are absent from most 1950–1961 literature and vaguely broached in two articles. Given that suffering to the point of needing systematic interventions without personal consent is not demonstrated, the idea that it is in intersex individuals' 'best interest' to be subjected to them is groundless. Furthermore, "Establishment and maintenance of a stable gender role" (Hampson et al. 1956, p. 548) lends itself no more to having the interest of the intersex individual in mind as to caring about the preservation of a heteronormative gender order. Some may still argue that the absence of assessment does not preclude treatment decisions founded on a desire to serve intersex individuals' best interests, even if left unstated. After all, Hampson et al. (1956) present their objective as obvious or taken for granted with "Few would dispute" (p. 548).

If 'interest' has the intersex individuals as recipients, however, it is solely determined by the team members' presumptions. Wilson's team has solicited no input from intersex individuals on what treatment approaches they consider to be in their best interest. In fact, at the very moment of its inception, the Optimal Gender Policy was met with protest from some distressed children. This is illustrated by Money et al.'s (1955) reaction to a three-year-old's acute distress at being subjected to a non-urgent surgery he did not consent to: "[H]e had grossly misconstrued his surgical experiences to signify that his penis was being mutilated..." (p. 298). Not only is this child's fright over what was done to his penis dismissed, but this article contains many passages ridiculing his response. His wish to preserve his penis is not accepted, as the team simply decides to postpone the other operations.

In the absence of direct claims, determining whether medical professionals were motivated by children's best interest or other interests will better be answered by documenting and examining affect displays throughout the period preceding intersex critique (1950–1993). These affects emerge when describing intersex bodily difference and conjecturing on their future social, sexual, or love life, as well as when discussing treatment and surgery. As they only are expressed by medical professionals, it cannot be surmised that they are shared by intersex individuals. Moreover, many of these affects follow mentions of actions only medical professionals execute. As such, actions undertaken by medical professionals are susceptible to quell or feed these affects.

I have identified five affect display types that can be independent of caring for an intersex individual's well-being or serving their interest. I have observed (1) unease and disgust; (2) commitment to gender norms, as well as three kinds of gratification or pleasure rewards: (3) power pleasure, (4) surgical pleasure, (5) and cosmetic pleasure. I have selected some quotes as illustrations for each of these affect types.

3.2. A Motivation to Quell Unease and Disgust

Unease and disgust have already been exposed by Kessler (1998). While significant, the list she submitted is not exhaustive, thus illustrating the importance of this affect. Here is a selection:

> Diseased nature oftentimes breaks forth in strange eruptions. (King Henry IV, Act III, Scene I, line 27, quoted in the preface to Jones and Scott 1958)
>
> The excision of a hypertrophied clitoris is to be preferred over allowing a disfiguring and embarrassing phallic structure to remain. (Gross et al. 1966, p. 300)
>
> Failure to [proceed with surgery] will leave a button of unsightly tissue. (Kogan et al. 1983, p. 748)

The disgust and unease expressed at atypical sex characteristics belong to the medical professionals and not the intersex individuals. In Lawson Wilkins's famous surgeons Jones and Scott's (1958) case, the quote has particular significance. It precedes the introduction to a book designed to instruct fellow practitioners in the surgical standards and approaches they developed and applied, thus broadcasting what sentiment drives their practice. Their attribution of 'diseased nature' to sex characteristics is more than framing them as a pathology, that is an undesirable state that must be altered. It imbues them with tragedy and presents them as a trouble for normalcy, 'erupting' as they do into expected naturalness. This quote is no objective, dispassionate description. The surgical approaches and techniques Jones and Scott presented are meant to deal with the tragic existence of atypical sex characteristics, to counter the trouble they cause.

The intensity of unease is manifest in other passages where disgust is openly expressed. Gross et al. (1966) and Kogan et al. (1983) present atypical sex characteristics as utterly undesirable to their eyes. The affects in these passages are not externalized and attributed to other social actors or intersex individuals but emanating from medical actors. The most generous interpretation would be to allow for an omission based on a purported obviously shared affect among all social actors. What reveals medical professionals' proper investment, however, is their perceived imperative of immediate surgical modifications trumping recipients' own consideration of what would be in their best interest. Abstaining from performing surgery would be a failure. Not intervening would be allowing undesirability, sexual freakiness, or unsightliness. The urgent performance of deferrable surgery without personal informed consent is considered by these medical professionals as a necessary response to the repulsion they experience when seeing atypical sex characteristics. In essence, surgery treats their disgust.

3.3. A Motivation to Preserve Gender Order or Heteronormativity

After the turn of the 1940–1950s, where Reis (2009) and Redick (2004, 2006) observed a wish for the systematization of intersex management stemming from doubt about self-declared gender identity, motivation to preserve gender order has been present in further texts. These are manifest from the inception of the Optimal Gender Policy up to the latest publications preceding intersex critique. In her groundbreaking work arising out of interviews with leading medical professionals in the field of intersex management, Kessler (1990) identified heteronormativity at play in treatment format and decisions. I also identified further examples.

> Dr. LAWSON WILKINS: Now, what should we do with those intersexes?
>
> (under "Discussion" section of Joan Hampson 1956, p. 130, proceedings from a symposium held on the 3–4 September 1954)

One of the few fundamental aspects of life is that of sex. Its normal functioning is vital to the survival of our race. . .

> [An intersex child] conjures up visions of a hopeless psychological misfit doomed to live always as a sexual freak in loneliness and frustration. (Dewhurst and Gordon 1969, pp. vii, 1)

> Perhaps the most traumatic failure to meet our expectations of normalcy is presented by sex errors of the body. Genital abnormalities, in particular, challenge the basic tenets of our identities as men or women. We regard the sex we are as an eternal verity. It lies at the core of our being and is therefore sacrosanct. One of the great mysteries of creation, it is not to be tampered with, explored, analyzed, explained, or questioned. To do so is to debase it. This mystification of sex leaves no room for doubt, no place for ambiguity. The first thing asked of every new human being is whether it is a boy or a girl. It must be one or the other. There are no additional categories. (Louis Gooren 1994, preface author in Money 1994, p. ix)

Motivation to preserve gender order is implicit. It appears when we observe medical professionals lamenting over being unable to agree on the proper "sex" of a child or—as is the case with Wilkins (Hampson 1956, under "Discussion" section, p. 129) and some peers—not being able to dictate the proper sex at birth (see note 7 above). That atypical sex characteristics cannot be left as they are denotes how medical professionals see them as unsuitable with strong notions they hold of sex, gender, and sexuality. Wilkins's "what should we do with those intersexes?" (Hampson 1956, under "Discussion" section, p. 130), which he uttered during a talk with colleagues at a symposium before the formal announcement of the Optimal Gender Policy, follows not a presentation on why intersex individuals would need having their sex characteristics modified without their consent, but simply a mention that their bodies are not readily classifiable in a male/man or a female/woman sex/gender. This is said in a context where Wilkins does not ignore that previous clinicians would wait until puberty to confirm an individual's gender and where he prefers a protocol that would systematize management at infancy. Flexibility is undesirable to him and to some peers. Furthermore, the fact that he and his team would have assignment standards that follow strict heterosexual norms of penovaginal sex (i.e., Wilkins et al. (1955)'s "serviceable vagina" (p. 296) or '(non-)fairly well-developed phallus') is an indication of his and their investment in maintaining heteronormative sex/gender.

A few years later, Dewhurst and Gordon (1969) depict the risk of not managing intersex people by evoking boundless threats. Their stressing of how the "normal functioning of sex" is "vital" for the "survival" of humanity draws from heteronormative dread of queer sex whose marginal existence could topple the collective capacity for reproduction. Threat is also implied with the 'misfit' categorization. While worry about the intersex individuals' future is present, it is mingled with strong affect regarding the impact of their existence on society. The 'sexual freak' depiction conjures up danger and unease. In what sense that individual would be a sexual freak is left unsaid. In that context, it could be the haunting trouble of homosexuality with bodies too similar with one another for heteronormative comfort. It could be objects as recipients of desire with fetishism, so-called active–passive roles, sex work, sexual acts, or even invasive behaviour. It also is a mystery how purported loneliness would allow sexual activity. All this reflects unformed thoughts and further strong affect from these professional medicals. The imperative of sexual normalcy also serves to appease these medical professionals' fear of disorder.

Invited by Money to write the foreword to the second edition of his *Sex Errors of the Body* (1994), professor emeritus and endocrinologist Dr. Gooren offers a flowery statement over the preciousness of conventional sex convictions: "eternal verity", "core of our being", "sacrosanct", "one of the great mysteries of creation" whose questioning would "debase it" (p. ix). It is a further illustration of how medical professionals can hold sex, gender, and sexual norms dear. Sexual ambiguity should have no place and its existence is an affront to the sacrosanct nature of sex and the great mysteries of creation. While he does not call out for surgeries, his statement as well as the fact that it introduces Money's second edition of a book on intersex management implies their execution. Ambiguity is to be erased, as its presence risks the questioning of norms, which is not to be allowed or tolerated.

3.4. A Motivation to Experience the Pleasure of Power

The pleasure of power is hinted at occasionally. Overtly stating that we love to exercise power over other people's lives goes counter to shared cultural expectations. Still, one can find examples of older medical professionals who have expressed delight at having the possibility to impact intersex bodies so profoundly. Two of these examples are retrospective, but still relevant given that it lends itself to critique and thus does not indicate self-censorship:

> Nothing in medicine is more spectacular and gratifying than the prevention or control of virilization in female pseudohermaphrodites which resulted from the discovery in 1950 that virilizing adrenal hyperplasia can be suppressed by physiologic doses of cortisone (Wilkins 1957, pp. 214–15)
>
> Doctors were very influenced by the twin experience... That's powerful. That's really powerful... This case was used to reinforce the fact that you can really do anything. You can take a normal XY male and convert it into a female in the neonatal period, and it won't make any difference. (Grumbach, interviewed by Colapinto [2000] 2006, p. 76, emphasis in the original)

> REPORTER JACKIE POU: "The criticism is always, these doctors are playing God."
>
> Dr. TERY HENSLE: "No. I used to. And I really liked it. [laughs:] But it wasn't the right thing to do." (ABC News Nightline and Pou 2015, 5:28–5:38 min)

Wilkins's (1957) quote illustrates that he relished the spectacular changes the treatment he devised managed to produce in people's bodies, not as an answer to their wishes, but guided by his belief that the presence of a uterus dictates a female gender. Traditionally and for decades to come in some cultures, many individuals of this variation were assigned male and had developed a male identity. Having and exerting the power to produce this high degree of change is gratifying, that is, it gives pleasure and satisfaction. Grumbach, who trained under Wilkins, also illustrates the pleasure of being able to do "anything" (interviewed by Colapinto [2000] 2006, p. 76) to an intersex individual, implying the availability of a range of options that medical professionals get to pick. Although he veils his own affect behind a collective "you" (p. 76), he does not exclude himself from it. He implies a shared disposition with colleagues. In this context, his stressing and repeating of "powerful" (p. 76) involves more than strictly being convinced by the Reimer twins experiment of Money. It indicates enthusiasm at the actions medical professionals can undertake with that knowledge, that is, again, determining something as decisive and far-reaching as one's body and one's gender, with the expectations and treatment they will be subjected to in all areas of social and intimate life. Dr. Tery Hensle, pediatric urologist and professor emeritus at Columbia University, first reacts with a "no" to reporter Jackie Pou's mentioning of the 'doctors are playing God' critique. He quickly relents and says that it had been the case, locating it in the past. He adds that he liked it[8]. Since 'playing God' is a metaphor, it cannot be construed as an avowal of seeing oneself as God. It nonetheless indicates an enjoyment of the decisive power one can exert over another person's life and body.

Wilkins' "Now, what should we do with those intersexes?" (Hampson 1956, under "Discussion" section, p. 130) also involves power. From the outset, the sentence casually communicates medical authority. Medical professionals benefit from the leeway to secure management of intersex bodies/individuals and exclusively decide how it is devised, while taking that privilege for granted and obvious. The State has not requested the establishment of a protocol, nor did civil society, parents, or intersex individuals themselves. 'What should we do' convokes medical peers to joint deliberation, where they enjoy the authority of considering approaches without the pressure of accountability. In contrast, 'those intersexes' announces intersex individuals as distant, otherized, and passive figures. Their powerlessness is obvious, but that does not make medical professionals pause over this imbalance. Even if this is part of a medical paternalism deeply ingrained at the time, the cultural context cannot deny the pleasure derived from exerting so much power over intersex individuals' lives.

3.5. *A Motivation to Experience the Pleasure of Surgery*

Then comes the pleasure of surgery. Though not expressed in the original Optimal Gender Policy literature, I postulate that surgical practice in pediatrics is not isolated from general surgical culture. One would expect appreciation of surgical practice to get into surgical specializations. Here are quotes from two surgeons who achieved fame in intersex surgery before the emergence of intersex criticism and one from another who is head of a surgeon association:

> As reconstructive surgeons, often excited by what progressively appears in our hands, we are tempted to focus mainly on the immediate outcome of the surgical procedure rather than on the long-term results (Passerini-Glazel 1999, p. 1592)
>
> And after having, I would say, the pleasure—and let us not take it superficially–of the achievement, as one would say in English, of realizing with our hands the [surgical] project we have conceived. . .

> (Nihoul-Fékété, interviewed by Dubosc 2009, 10:30–10:46 min)
>
> I love to cut. Many a resident has heard me say. . . "I can't believe somebody is paying me to do this.". . . At some time in your education, you were injected with the addicting drug called "surgery". You had and/or developed panache. You have become a very successful surgeon, which affords you job security, financial comfort, great respect in your community, and daily personal interactions that are profound and fulfilling. Best of all, when you go to work, you get to cut. (Thirlby 2007, p. 429)

Thirlby (2007), a president of a US medical association, portrays his relationship to surgery in such a way that he expects his eagerness and excitement to be a shared affect among surgeons. He does surgery because he loves it. Although pleasure at work activities is idealized and not problematic per se, it becomes complicated when the surgical practice one is trained in comprises or mainly consists of deferrable operations done on individuals without their informed consent. This enthusiasm seems to be general and applies to intersex management surgeons themselves. Surgeon Passerini-Glazel (1999), creator of a popular vaginoplasty technique, alludes to shared excitement among peers about their surgical practice to explain their tendency to negate the relevance of critique coming from people who testify it has harmed them. Eminent and retired French surgeon Nihoul-Fékété (Dubosc 2009) talks about her relationship to surgical practice and underscores the pleasure she draws from surgical practice. Considering that pediatric urology was developed in good part around intersex management, I surmise that these medical professionals would have an interest in having access to that important source of pleasure. In that regard, I agree with Iain Morland's (2005) assessment: "In the conventional medical approach to intersex, the subject is the surgeon, and the patient the tool of his professional desire" (p. 338). Older pediatric surgeons' interest in experiencing surgical pleasure enters into conflict with intersex individuals' best interest, as they also have a personal interest in promoting a surgical plan to parents.

3.6. A Motivation to Experience the Pleasure of Seeing Desirable Genitalia

Finally, there is the gratification felt when achieving 'pleasant-looking genitalia.' This one is the most controversial observation. I heard it being discussed in the community in informal contexts, but to my knowledge it has not been written publicly.

> The anterior wedge excision results in a more delicate feminine glans clitoris. (Newman et al. 1992, p. 647)
>
> Most pediatric urologists believe that the surgical procedures they currently use result in cosmetically pleasing external genitalia and a clitoris that has the potential to retain both sensory and erectile function. (Aaronson 2001, p. 190)
>
> When I turned 25 years old, I asked for my medical records.

The medical report said that if my clitoris was removed, it would be more beautiful and feminine. It was even written: This intervention made a very pleasing cosmetic effect (Holmes, interviewed by Radio-Canada.ca Zone Société 2017, italics in original to highlight English quotation, translation mine)

Expression of medical satisfaction towards cosmetic results of surgery appears in pre-intersex critique literature or in later old-timer surgeons' assertions. Describing the result of clitoral reduction as a 'delicate' clitoris draws from a sexualized lexical repertoire, as do 'cosmetically pleasing genitalia' and 'very pleasing cosmetic effect'. These comments cannot be discounted as coming from untrained clinicians unrelated to the medical professionals who specialized in intersex management. The surgeon who performed the amputation of Professor Morgan Holmes in 1975 when she was seven is Robert Douglas Jeffs (Holmes 2015), hailed as a founding father of North American pediatric urology. Aaronson's (2001) comment also indicates that he considers his affect towards cosmetic results to be shared by colleagues. It remains that even when surgeons abstain from using words denoting sexual appreciation, what they consider to be 'cosmetically pleasing genitalia' cannot escape their own sexual taste. External genitalia must be pleasing to the eye while females/women assigned must satisfy surgeons' sexual ideals of penetrability.

3.7. An Examination of the Constraints of Context

Despite claims of past practice being constrained by context, one can find through Wilkins's teams' literature different allusions or even direct answers to opposing views on intersex management. The Optimal Gender Policy first was a response to an 'idiosyncrasy' of approaches—from the wording of Money himself—preceding and existing at its inception. Although many medical professionals were swayed by Lawson Wilkins' authority and prestige after its formal launch, it still was met with doubt, specifically regarding the necessity of early and definitive gender assignment. It was expressed from Cappon et al. (1959), Armstrong (1966), Zuger (1970) or, to a lesser extent, Grumbach (interviewed by Colapinto [2000] 2006), but they did not gain ground because they were severely rebuked by Money and his followers, whom he had gained since his association with Lawson Wilkins.

Specific reservations about clitoridectomy can also be found in the literature since the very early days of the protocol. Even though the structure of the (phallo)clitoris has been little investigated for several decades, there already was knowledge of its importance for erotic sensation. Freudian prejudice relegating it to a secondary role in sexual development did circulate but would not erase that knowledge. Here is a selection of discussions on the advisability or not of clitoridectomies—emphases are mine:

> There should be a complete extirpation of both corpora cavernosa and not merely amputation which will leave a hard stump. Although some workers object to this procedure on the grounds that it may deprive the patient of future sexual gratification, the writer believes that it is justified because it removes some of the tensions and problems which cause serious difficulties. (Wilkins 1950, p. 224, emphasis mine)
>
> Dr. ROBERT J. McKAY Jr.: Anatomic studies have shown that the nerve endings responsible for erotic sensation in the genital area of the female are located in the labia minora and the foreskin of the clitoris. Therefore, if clitoridectomy is to be done, the cavernous portion of the clitoris should be removed, leaving the skin intact. (under "Discussion" section of Joan Hampson 1956, p. 134, emphasis mine)
>
> Although the importance of the clitoris to the female for satisfactory erotic stimulation during active sexual life is not settled, there is some evidence that it may be necessary (Bongiovanni 1963, p. 68, emphasis mine),
>
> ...certainly not advisable unless there is a definite indication. However, it is questionable whether the clitoris is essential to normal adult sexual life. Kroger and Freed state, "In the child the clitoris gives sexual satisfaction, while in the emotionally mature woman the vagina is supposed to be the principal sexual organ." (Platt 1963, p. 152, emphasis mine)
>
> Whilst in theory preservation of the glans has some thing to commend it, the results of amputation appear satisfactory (Dewhurst and Gordon 1969, p. 41, emphasis mine)

As early as 1950, in his first edition of his seminal book, Wilkins evokes objections to clitoral amputation from colleagues—'workers'—on the grounds that it is crucial for sexual pleasure. Removal of an individual's (phallo)clitoris would go so far as to deprive them of that experience. Wilkins's (1950) answer to their objection means they are significant enough for him to feel the need to justify his approach. His justification for such a surgical approach and its concomitant gender assignment, however, was of acute vagueness: "removes some of the tensions and problems which cause serious difficulties" (p. 224). Nowhere in his book does he expand upon it. That such triple vagueness (tension–problem–serious difficulties) failing at coalescing into reasoned thought sufficed to caution infringement on children's bodily integrity is additional illustration of the immense authority enjoyed by medical professionals. This authority would transmute individual and amorphous subjective conviction into scientific truth. In 1955, in a discussion between peers involving Wilkins, who promotes the approach he and his team developed, Dr. McKay Jr. (under "Discussion" section of Joan Hampson 1956, p. 134) voices his concerns over amputation. Although he is mistaken in reducing sensitivity to labia or foreskin, he nonetheless brings up the risk of compromising erotic sensation with this type of surgery. Wilkins' team member Joan Hampson's (1955) work on the supposed non-prejudicial effect of clitoridectomy on sexual pleasure is then brought up in that conversation as an attempt to assuage his fears. While Wilkins' team concludes thus, they did initiate that research as a response to apprehension from peers.

Hesitation remains even after the establishment of the Optimal Gender Policy. The importance of the clitoris for sexual pleasure is first mentioned or hinted at, but then cast aside through an 'it's-important-but-not' rhetorical dance, as we observe in statements from Bongiovanni (1963), Platt (1963), and Dewhurst and Gordon (1969). All hints at possessing arguments without producing any, or are content with superficial answers, like evoking the capacity for sexual pleasure of African women who were subjected to clitoridectomy (Gross et al. 1966). Contrary to the claim of past ignorance, older medical professionals did have an idea of the clitoris's importance for sexual pleasure but decided against it.

While we cannot claim with certainty that every critique of the Optimal Gender Policy would reject treatments without personal consent, the hesitation of some was in line with the previous practice of waiting until puberty to confirm sex assignment and perform any modifications. There was room for treatment decisions that would have better protected intersex individuals' integrity and sexual pleasure.

4. Discussion

4.1. Self-Centred Motivations as Negations of the Child's Best Interest

Although one would rarely if ever read statements to the effect that a given medical or health-related protocol is initiated with 'good intentions', one could deduce intentions, interest, or motivations and their benevolent character through the presentation of the problem or suffering the protocol is meant to solve. While some problems or sufferings may seem obvious enough not to need a presentation, problematization that is *centred around care about a subject's suffering* would be committed to understanding its specific dimensions and submit them as the starting point of treatment development. In the case of the institutionalization of intersex management, problematization has been scarce, vague, ambiguous, and brief. No data were brought up to demonstrate a state of suffering among intersex adults that needed a systematic solution involving invasive bodily modifications in infancy. We do have previous studies (Redick 2004, 2006; Reis 2009), however, of mid-20th century medical professionals' attitudes towards intersex adults that shed a light on whose interest they focused on. The suspicion about intersex individuals' own gender affirmation has been a major motivation behind securing and systematizing control over intersex children's bodies and gender as early as possible in their lives. Fear of intersex individuals getting away with homosexuality is not centred on the intersex individual's (best) interest, but on medical professionals' own investments in heterosexuality and its concomitant requisite of separate and 'complementary' gender roles. Though motivations and interests could theoretically shift with time, the period spanning manifestations of this attitude and the inception of the Optimal Gender Policy is too short for it to apply.

In addition to this context, affects expressed through what clinicians said of intersex bodies and their clinical practice included motivations unrelated with benevolent dispositions towards intersex individuals. These affects emanate from key actors of the Optimal Gender Policy and are repeated in the community of medical professionals invested in intersex management. None of these have been subjected to critique by peers. This indicates that they are not unrelated to, but are a part of this community's culture. The affects that are part of this culture reflect a desire to preserve heteronormative gender order, which is consistent with the initial suspicion of homosexuality. This investment is deeply anchored in the clinicians' stance, as they express affects of great intensity with their revulsion and disgust towards bodies that are incompatible with their heteronormative sexual standards. Conforming these bodies to heteronormativity through surgery and hormonal therapy is a way for clinicians to appease their revulsion and disgust. Experiencing pleasure from the power to radically change an individual's bodily, gender, and sexual destiny is also compatible with the investment in heteronormativity and dominant gender norms. A clinician can draw satisfaction from being able to work as a bulwark against the disorder intersex misfits could cause in these norms with their intact bodies. This satisfaction is further fed from pediatric and urologist surgeons' enjoyment in producing conforming bodies despite the absence of the individual's consent. Surgeon investment in heteronormativity can go so far as being centred on their own relationship to sexually desirable female bodies, producing genitalia that is pleasurable to them. In all these cases, these affects are centred on the medical professionals and the actions they motivate serve their interest. The fundamental question is whether these interests are compatible or not with an intersex individual's best interest.

While some would argue that a clinician could be invested in heteronormativity but still draw pleasure from knowing he has the potential to drastically improve individuals' lives, this perspective overlooks the prerequisites of 'best interest.' Serving an individual's best interests implies that all actions directed at that individual be undertaken with their interests as a priority. Given that intersex individuals were not granted a say in what would be in their best interest, there is no way for them to set limits on differing interests. Postulating that intersex children's best interest would happen to be compatible with these other interests is denying their humanity. Their distinct personhood is dissolved into other social actors who enjoy more acknowledgement than they do. This is obvious when Thomas (2004) claims that management was undertaken with children's and parents' best interest in mind. Taking parents' interests into account means that a child's interest must yield when they conflict.

4.2. Past Medical Innocence and Good Intentions Claims as Revealers of Current Medical Culture

How medical professionals envision predecessors' affects and motivations is informative. Current defence of past clinicians indicates identification with them and their practice. This identification is even more obvious considering that the constant and heavy emphasis on distinguishing current practices from previous ones never turns into a disavowal of the latter. Acknowledgement that non-consensual treatments can be damaging is restricted to the past but still euphemized. Past practice will be inserted in previous '(gold) standards of practice' and removed from the field of objects that can be targeted by criticism, frustration, and anger—including from individuals who have had their humanity negated and have deeply suffered from them. For all the insistence on distinction of current practice from the past, it still rests on the foundations laid by the Optimal Gender Policy. Examining medical professionals' protection of predecessors and previous practice is as relevant to understanding current practice as are the motivations behind securing control over intersex management.

When one mobilizes 'standard of the times' to allow for damage caused by actions claimed to be undertaken in the name of vulnerable individuals' or social groups' 'best interest,' they expect that mere wish and presumption to know what is best will be considered as satisfactory substitutes for inquiry into what recipients wish for themselves. They also veil decision-making processes behind unavoidability and powerlessness. At the heart of acting "in the name of" lies the dehumanization of an individual or group whose perspectives are not considered relevant enough or credible enough to be consulted. It may have been difficult for actors of past contexts to behave otherwise. But, refraining from acknowledging how their actions were damaging because they were purportedly driven by 'good intentions' when in fact they were built on a dehumanizing relationship to vulnerable subjects means that medical professionals holding on to the 'good intentions' rationale fail to see how this relationship is dehumanizing as much as they fail to see how it still applies in today's context. In the end, insisting on 'good intentions' cannot expurgate conflict, as these assertions originate from a power dynamic whereby a dominant group has imposed treatment on a marginalized group.

Current medical professionals' reduction of past motivation to 'good intentions' and 'best interest' could indicate that they are unaware of the earlier complexity of affects, which would reflect limited exposure in training to the history and early literature of intersex management. That they would nonetheless project good intentions despite this limitation indicates an investment in preserving predecessors' images. Combined with the defence of the successive standards of practice for being what past medical professionals considered the best approaches and protocols, this reveals the continued importance of protecting medical authority and self-regulation privileges. Acknowledging past practice as severely harmful and not centred on recipients' best interest undermines current authority. Acknowledging that "best interest" must be founded on social actors and individuals' own understanding of what it consists of—especially when treatment offered for children is non-life threatening—also does.

If current medical professionals are aware of the existence of potential alternative treatment but still consider them improbable, it indicates a normalization of credibility excess granted because of medical team prestige instead of examination and replication of claims. It would also be a normalization of dominant teams' scornful rebukes of dissenting views. The same applies to clitoridectomy. Former medical professionals' ignorance cannot be claimed given that they felt it necessary to defend it against the awareness that the (phallo)clitoris could be important in sexual pleasure. It is prejudice and not ignorance that made medical professionals willing to discard it with shallow arguments.

4.3. Concluding Remarks

This narrative has a functional purpose for current practice. We would gain from probing what motivates medical practitioners to resist intersex critiques and frustration and how they conclude that predecessors were being motivated by "good intentions" and could not envision treatment alternatives. We would also gain from exploring what it means to them to defend these predecessors. In their adaptation to medical intersex management of Card's philosophical reflections on institutional evils, Peck and Feder (2017) hypothesize that medical resistance to apology over past practice could stem from misunderstanding the different degrees of responsibility. While my observations indicate more motivations, this dimension is worth investigating. The 'good intentions' defence should be examined as part of a conversation on power, accountability, and reflexivity in medicine and other institutions. It should also spur a reflection on how we proceed to identify our intentions, motivations, and interests as citizens or professionals.

Funding: This research received no external funding.

Institutional Review Board Statement: Not applicable.

Informed Consent Statement: Not applicable.

Data Availability Statement: No new data were created.

Acknowledgments: I want to thank the reviewers for their comments and April Dawn Duncan for the linguistic proofreading. Some sentences have been added afterwards.

Conflicts of Interest: The author declares no conflicts of interest.

Notes

[1] Incidentally, Peter A. Lee and Christopher P. Houk are the first authors of the Consensus Statement on Management of Intersex Disorders, which was broadcast as a more sensible and respectful approach to children with intersex variations (Lee et al. 2006). It has been criticized by intersex activists for its vagueness, its absence of commitment to stop normative surgeries, and its adoption of pathologizing Disorders of Sex Development nomenclature (Christian-Ghattas 2019; Holmes 2011; Carpenter 2016).

The exclusionary practices of medical professionals towards intersex activists in the drafting of the Consensus have also been subjected to critique (Karkazis 2008).

[2] Some of these references have medical professionals as authors but represent medical association statements.

[3] Carpenter (2024) points out that medical "claims about change" have been a useful political tool in hindering legislative regulation of medical management of people with innate variations of sex characteristics (p. 7).

[4] My putting 'Western' between parentheses stems from the fact that the word has its failings, as it does not adequately reflect geographical positions. I nonetheless use it to avoid universalizing observations made in European, North American, and Oceanic contexts. I do not presume they are absent from other contexts; my knowledge is simply insufficient to draw conclusions about them.

[5] In France, fear of "sex errors" in assigning gender to children drove famous medical professionals to push for legislation that would grant them the authority of assignment at birth. They stressed how laypeople's mistakes could introduce danger in segregated spaces and institutions, as well as create same-sex marriages (Houbre 2014).

[6] Ulrike Klöppel's thorough historical research has allowed finding informal discussions preceding presentations of the Optimal Gender Policy, which I included in my sample (Klöppel 2010).

[7] I have read Money's thesis, but it is forbidden to quote it directly (see Money 1952). Since Colapinto mentioned it before the introduction of this interdiction, I use his account.

[8] This exchange is discussed in Feder (2015). Dr Tery Hensle started his pediatric urology practice at the end of the 1970s.

References

Aaronson, Ian A. 2001. The Investigation and Management of the Infant with Ambiguous Genitalia: A Surgeon's Perspective. *Current Problems in Pediatrics* 31: 168–94. [CrossRef] [PubMed]

ABC News Nightline, and Jackie Pou. 2015. Intersex Children: Waiting to Decide on Sex Surgery? *ABC News*. March 5. Available online: https://www.youtube.com/watch?v=5dJduGC3HyQ (accessed on 27 March 2024).

Armstrong, C. N. 1966. Treatment of Wrongly Assigned Sex. *The British Medical Journal* 2: 1255–56. [CrossRef] [PubMed]

Baskin, Laurence S., Ali Erol, Ying Wu Li, Wen Hui Liu, Eric Kurzrock, and Gerald R. Cunha. 1999. Anatomical Studies of the Human Clitoris. *The Journal of Urology* 162: 1015–20. [CrossRef] [PubMed]

Bastien Charlebois, Janik. 2019. On Our Own Terms and in Our Own Words: The Value of First-Person Accounts of Intersex Experience. In *#MyIntersexStory: Personal Accounts by Intersex People Living in Europe*. Berlin: Organisation Intersexe International-OII-Europe, pp. 75–109. Available online: https://www.oiieurope.org/wp-content/uploads/2019/11/testimonial_broch_21-21cm_for_web.pdf (accessed on 27 March 2024).

Benoit, William L., and Shirley Drew. 1997. Appropriateness and Effectiveness of Image Repair Strategies. *Communication Reports* 10: 153–63. [CrossRef]

Blondin, Maryvonne, Corinne Bouchoux, and Sénat de France. 2017. *Rapport d'information fait au nom de la délégation aux droits des Femmes et à l'égalité des chances entre les hommes et les femmes (1) sur les variations du développement sexuel: Lever un tabou, lutter contre la stigmatisation et les Exclusions*. Rapport sénatorial n. 441. Session ordinaire de 2016–2017. Paris: Sénat de France. Available online: https://www.senat.fr/rap/r16-441/r16-4411.pdf (accessed on 27 March 2024).

Bongiovanni, Alfred M. 1963. Editorial Comment: Female Adrenogenital Syndrome: Early Surgical Repair, Louis Platt and Jerrold M. Becker, 1963. *The Journal of Pediatrics* 62: 68.

Cabral, Mauro. 2019. The Road to Hell: Intersex People, Sexual Health & Human Rights. Keynote lecture presented at Building Bridges in Sexual Health and Rights. Paper presented at 24th Congress of the World Association for Sexual Health and XII Congreso Nacional de Educación Sexual y Sexología, World Trade Center, Mexico City, Mexico, October 12–15; Available online: https://gate.ngo/knowledge-portal/publication/the-road-to-hell-intersex-people-sexual-health-human-rights-document/ (accessed on 27 March 2024).

Campbell, Colin. 1996. On the Concept of Motive in Sociology. *Sociology* 30: 101–14. Available online: https://www.jstor.org/stable/42857839 (accessed on 27 March 2024). [CrossRef]

Cappon, Daniel, Calvin Ezrin, and Patrick Lynes. 1959. Psychosexual Identification (Psychogender) in the Intersexed. *Canadian Psychiatric Association Journal* 4: 90–106. [CrossRef] [PubMed]

Carpenter, Morgan. 2016. The Human Rights of Intersex People: Addressing Harmful Practices and Rhetoric of Change. *Reproductive Health Matters* 24: 74–84. [CrossRef] [PubMed]

Carpenter, Morgan. 2024. Fixing Bodies and Shaping Narratives: Epistemic Injustice and the Responses of Medicine and Bioethics to Intersex Human Rights Demands. *Clinical Ethics* 19: 3–17. [CrossRef]

Chase, Cheryl. 1998. Hermaphrodites with Attitude: Mapping the Emergence of Intersex Political Activism. *A Journal of Gay and Lesbian Studies* 4: 189–211. [CrossRef]

Christian-Ghattas, Dan. 2019. *Protecting Intersex People in Europe: A Toolkit for Law and Policymakers*. Berlin: OII-Europe and ILGA-Europe. Available online: https://oiieurope.org/wp-content/uploads/2019/05/Protecting_intersex_in_Europe_toolkit.pdf (accessed on 28 March 2024).

Colapinto, John. 2006. *As Nature Made Him: The Boy Who Was Raised as a Girl*. Reprinted with P.S. New York. Toronto: Harper Perennial. First published 2000 by HarperCollins.

Davis, Georgiann. 2011. "DSD Is a Perfectly Fine Term": Reasserting Medical Authority through a Shift in Intersex Terminology. In *Sociology of Diagnosis, Advances in Medical Sociology*. Edited by P. J. McGann and David J. Hutson. New York: Emerald Group Publishing, pp. 155–82.

de María Arana, Marcus. 2005. *A Human Rights Investigation into the Medical 'Normalization' of Intersex People*. Report of a public hearing. San Francisco: Human Rights Commission of the City & County of San Francisco. Available online: https://ihra.org.au/wp-content/uploads/2009/03/sfhrc_intersex_report.pdf (accessed on 30 March 2024)Report of a public hearing.

Dewhurst, Christopher J., and Ronald R. Gordon. 1969. *The Intersexual Disorders*. London: Baillière Tindall & Cassell.

Dubosc, Patrice dir. 2009. Bioéthique et soin: Entretien avec Claire Nihoul-Fékété. In *DVD Bioéthique et soin*. vol. Hors-série/9. Directed by Patrice Dubosc. L'Espace éthique de l'Assistance publique—Hôpitaux de Paris. Available online: https://www.youtube.com/watch?v=O1hkWXPJu2I (accessed on 28 March 2024).

Duranti, Alessandro. 2006. The Social Ontology of Intentions. *Discourse Studies* 8: 31–40. [CrossRef]

Fausto-Sterling, Anne. 1993. The Five Sexes: Why Male and Female Are Not Enough. *The Sciences* 33: 20–25. [CrossRef]

Feder, Ellen K. 2011. Tilting the Ethical Lens: Shame, Disgust, and the Body in Question. *Hypatia* 26: 632–50. [CrossRef]

Feder, Ellen K. 2015. Beyond Good Intentions. *Narrative Inquiry in Bioethics* 5: 133–38. [CrossRef]

Frimberger, Dominic, and John P. Gearhart. 2005. Ambiguous Genitalia and Intersex. *Urologia Internationalis* 75: 291–97. [CrossRef] [PubMed]

Gardner, Melissa, and David E. Sandberg. 2018. Navigating Surgical Decision Making in Disorders of Sex Development (DSD). *Frontiers in Pediatrics* 6: 339. [CrossRef] [PubMed]

Gooren, Louis. 1994. Foreword. In *Sex Errors of the Body and Related Syndromes: A Guide to Counseling Children, Adolescents, and Their Families*, 2nd ed. Baltimore: P.H. Brookes Pub. Co, p. ix.

Gross, Robert E., Judson Randolph, and John F. Crigler. 1966. Clitorectomy for Sexual Abnormalities: Indications and Technique. *Surgery* 59: 300–8. [PubMed]

Gulliver, Trevor. 2021. Denying Racism in Canada's Residential School System. *Citizenship Education Research Journal/Revue de Recherche sur L'éducation à la Citoyenneté* 9: 1–12. Available online: https://ojs-o.library.ubc.ca/index.php/CERJ/article/view/453/497 (accessed on 28 March 2024).

Guterman, Lydia. 2012. Why Are Doctors Still Performing Genital Surgery on Infants? *Open Society Foundations*. January 29. Available online: https://www.opensocietyfoundations.org/voices/why-are-doctors-still-performing-genital-surgery-on-infants (accessed on 28 March 2024).

Hampson, Joan. 1955. Hermaphroditic Genital Appearance, Rearing and Eroticism in Hyperadrenocorticism. *Bulletin of the Johns Hopkins Hospital* 96: 265–73. [PubMed]

Hampson, Joan. 1956. Hermaphroditic Genital Appearance, Rearing and Eroticism in Hyperadrenocorticism. In *Adrenal Function in Infants and Children: A Symposium [held on 3-4 September 1954]*. Edited by Lytt I. Gardner. Syracuse: Grune & Statton, pp. 119–36.

Hampson, Joan, John Money, and John Hampson. 1956. Hermaphroditism: Recommendations Concerning Case Management. *Journal of Clinical Endocrinology and Metabolism* 16: 547–56. [CrossRef]

Hendren, Hardy W. 1998. Surgical Approach to Intersex Problems. *Seminars in Pediatric Surgery* 7: 8–18. [CrossRef] [PubMed]

Hendricks, Melissa. 2000. In the Hands of Babes. *Johns Hopkins Magazine*. Available online: http://pages.jh.edu/jhumag/0900web/babes.html (accessed on 28 March 2024).

Holmes, Morgan. 2011. The Intersex Enchiridion: Naming and Knowledge. *Somatechnics* 1: 388–411. [CrossRef]

Holmes, Morgan. 2015. When Max Beck and Morgan Holmes Went to Boston. *Intersex Day*. October 17. Available online: https://intersexday.org/en/max-beck-morgan-holmes-boston-1996/ (accessed on 28 March 2024).

Horton, Adrian. 2023. "We Are Literally Erased": What Does It Mean to Be Intersex? *The Guardian*. June 28. Available online: https://www.theguardian.com/film/2023/jun/28/intersex-documentary-every-body-what-does-it-mean (accessed on 28 March 2024).

Houbre, Gabrielle. 2014. Un «sexe indéterminé»: L'identité civile des hermaphrodites entre droit et médecine au XIXe siècle. *Revue d'histoire Du XIXe Siècle—La Société de 1848* 1: 63–75. [CrossRef]

Hutter Epstein, Randi. 2015. Howard W. Jones Jr., a Pioneer of Reproductive Medicine, Dies at 104. *The New York Times*, July 31, p. A1. Available online: https://www.nytimes.com/2015/08/01/science/howard-w-jones-jr-a-pioneer-of-reproductive-medicine-dies-at-104.html(accessed on 28 March 2024).

Intersex Society of North America. 1994–1995. *ISNA's Recommendations for Treatment. Organisation*. Rohnert Park: Intersex Society of North America. Available online: https://web.archive.org/web/20010818083755/http://isna.org/library/recommendations.html (accessed on 28 March 2024).

Intersex Society of North America. 2004. *What's Wrong with the Way Intersex Has Traditionally Been Treated?* Rohnert Park: Intersex Society of North America. Available online: https://isna.org/faq/concealment/ (accessed on 28 March 2024).

Jones, Howard W. 1974. Surgical Construction of Female Genitalia. *Clinics in Plastic Surgery* 1: 255–69. [CrossRef] [PubMed]

Jones, Howard W., and William Wallace Scott. 1958. *Hermaphroditism, Genital Anomalies and Related Endocrine Disorders*. Baltimore: The Williams and Wilkins Company.

Justice, Daniel Heath, and Sean Carleton. 2021. Truth before Reconciliation: 8 Ways to Identify and Confront Residential School Denialism. *The Conversation*. August 5. Available online: http://theconversation.com/truth-before-reconciliation-8-ways-to-identify-and-confront-residential-school-denialism-164692 (accessed on 28 March 2024).

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

Kessler, Suzanne J. 1990. The Medical Construction of Gender: Case Management of Intersexed Infants. *Signs* 16: 3–26. [CrossRef]

Kessler, Suzanne J. 1998. *Lessons from the Intersexed*. New Brunswick: Rutgers University Press.

Klöppel, Ulrike. 2010. *XX0XY Ungelöst: Hermaphroditismus, Sex Und Gender in Der Deutschen Medizin: Eine Historische Studie Zur Intersexualität*. Bielefeld: Transcript Verlag.

Kogan, Stanley J., Paul Smey, and Selwyn B. Levitt. 1983. Subtunical Tonal Reduction Clitoroplasty: A Safe Modification of Existing Techniques. *The Journal of Urology* 130: 746–48. [CrossRef] [PubMed]

Lee, Peter A., and Christopher P. Houk. 2010. The Role of Support Groups, Advocacy Groups, and Other Interested Parties in Improving the Care of Patients with Congenital Adrenal Hyperplasia: Pleas and Warnings. *International Journal of Pediatric Endocrinology* 2010: 563640. [CrossRef] [PubMed]

Lee, Peter A., and Christopher P. Houk. 2014. Commentary to "Evidence Regarding Cosmetic and Medically Unnecessary Surgery on Infants". *Journal of Pediatric Urology* 10: 7. [CrossRef]

Lee, Peter A., Christopher P. Houk, Faisal Ahmed, and Ieuan A. Hughes. 2006. Consensus Statement on Management of Intersex Disorders. *Pediatrics* 118: e488–500. [CrossRef]

Lee, Peter A., Tom Mazur, and Christopher P. Houk. 2023. DSD/Intersex: Historical Context and Current Perspectives. *Journal of Pediatric Endocrinology and Metabolism* 36: 234–41. [CrossRef]

Meyer-Bahlburg, Heino F. L. 1998. Gender Assignment in Intersexuality. *Journal of Psychology & Human Sexuality* 10: 1–21. [CrossRef]

Meyer-Bahlburg, Heino F. L. 2005. Book Reviews Intersex: Fact or Fiction? *Journal of Sex Research* 42: 175–81. [CrossRef]

Méndez, Juan E. 2014. Introduction. In *Torture in Healthcare Settings: Reflections on the Special Rapporteur on Torture's 2013 Thematic Report*. Washington, DC: Center of Human Rights & Humanitarian Law (Washington College of Law, American University), pp. xv–xix.

Mills, C. Wright. 1940. Situated Actions and Vocabularies of Motive. *American Sociological Review* 5: 904. [CrossRef]

Money, John. 1952. Hermaphroditism: An Inquiry into the Nature of a Human Paradox. Ph.D. dissertation, Harvard University, Cambridge, MA, USA.

Money, John. 1961. Hermaphroditism. In *The Encyclopaedia of Sexual Behaviour*. Edited by Albert Ellis and Albert Abarbaniel. New York: Hawthorn Books, vol. 1, pp. 472–84.

Money, John. 1994. *Sex Errors of the Body and Related Syndromes: A Guide to Counseling Children, Adolescents, and Their Families*, 2nd ed. Baltimore: P.H. Brookes Pub. Co.

Money, John, and Anke A. Ehrhardt. 1972. *Man & Woman, Boy & Girl: The Differentiation and Dimorphism of Gender Identity from Conception to Maturity*. Baltimore: Johns Hopkins University Press.

Money, John, and Margaret Lamacz. 1987. Genital Examination and Exposure Experienced as Nosocomial Sexual Abuse in Childhood. *The Journal of Nervous and Mental Disease* 175: 713–21. [CrossRef] [PubMed]

Money, John, Joan Hampson, and John Hampson. 1955. Hermaphroditism: Recommendations Concerning Assignment of Sex, Change of Sex, and Psychologic Management. *Bulletin of the Johns Hopkins Hospital* 97: 284–300. [PubMed]

Money, John, Joan Hampson, and John Hampson. 1956. Sexual Incongruities and Psychopathology: The Evidence of Human Hermaphroditism. *Bulletin of the Johns Hopkins Hospital* 98: 43–57. [PubMed]

Morland, Iain. 2005. "The Glans Opens Like a Book": Writing and Reading the Intersexed Body. *Continuum: Journal of Media & Cultural Studies* 19: 335–48. [CrossRef]

Mouriquand, Pierre, Anthony Caldamone, Peter Malone, J. D. Frank, and Piet Hoebeke. 2014. The ESPU/SPU Standpoint on the Surgical Management of Disorders of Sex Development (DSD). *Journal of Pediatric Urology* 10: 8–10. [CrossRef]

Newman, Kurt, Judson Randolph, and Kathryn Anderson. 1992. The Surgical Management of Infants and Children with Ambiguous Genitalia: Lessons Learned from 25 Years. *Annals of Surgery* 215: 644–53. [CrossRef]

Passerini-Glazel, Giacomo. 1999. Editorial: Feminizing Genitoplasty. *The Journal of Urology* 161: 1592–93. [CrossRef]

Peck, Eliana, and Ellen K. Feder. 2017. Institutional Evils, Culpable Complicity, and Duties to Engage in Moral Repair. *Metaphilosophy* 48: 203–26. [CrossRef]

Pediatric Endocrine Society. 2020. *Position Statement on Genital Surgery in Individuals with Differences of Sex Development (DSD)/Intersex Traits*. McLean: Pediatric Endocrine Society. Available online: https://pedsendo.org/wp-content/uploads/2020/10/44-DSD-paperPosition-Statement-DSD-SIG.pdf (accessed on 28 March 2024).

Platt, Louis. 1963. 'Editorial Comment: Female Adrenogenital Syndrome'. *The Journal of Pediatrics* 62: 152. Available online: https://www.jpeds.com/article/S0022-3476(63)80087-6/pdf (accessed on 28 March 2024).

Preves, Sharon E. 2006. Out of the O.R. and into the Streets: Exploring the Impact of Intersex Media Activism. *Cardozo J.L. & Gender* 12: 247–88. [CrossRef]

Radio-Canada.ca Zone Société. 2017. I comme Intersexe, professeure, mère, activiste et comme MorganL'acronyme LGBTQ+. *ICI.Radio-Canada, ICI Toronto*. June 23. Available online: https://ici.radio-canada.ca/nouvelle/1041093/intersexe-lgbtq-morgan-holmes-professeure (accessed on 28 March 2024).

Redick, Alison. 2004. American History XY: The Medical Treatment of Intersex, 1916–1955. Ph.D. dissertation, New York University, New York, NY, USA, September.

Redick, Alison. 2006. What Happened at Hopkins: The Creation of the Intersex Management Protocols. *Cardozo J.L. & Gender* 12: 289–96.

Reis, Elizabeth. 2009. *Bodies in Doubt: An American History of Intersex*. Baltimore: Johns Hopkins University Press.

Reis, Elizabeth. 2020. A Historic Intersex Awareness Day. *The Hastings Center*. October 26. Available online: https://www.thehastingscenter.org/a-historic-intersex-awareness-day/ (accessed on 28 March 2024).

Sandberg, David E., Vickie Pasterski, and Nina Callens. 2017. Introduction to the Special Section: Disorders of Sex Development. *Journal of Pediatric Psychology* 42: 487–95. [CrossRef] [PubMed]

Societies for Pediatric Urology, American Association of Clinical Urologists, American Association of Pediatric Urologists, Pediatric Endocrine Society, Society of Academic Urologists, The Endocrine Society, and The North American Society for Pediatric and Adolescent Gynecology (NASPAG). 2017. *Physicians Recommend Individualized, Multi-Disciplinary Care for Children Born "Intersex"*. Available online: https://spuonline.org/HRW-interACT-physicians-review/ (accessed on 28 March 2024).

Subramaniam, Ramnath, Konrad Szymanski, Alexander Springer, Earl Cheng, Richard Rink, Katja P. Wolffenbuttel, and Piet Hoebeke. 2020. *ESPU—SPU Consensus Statement 2020: Management of Differences of Sex Development (DSD)*. European Society for Paediatric Urology and The Societies for Pediatric Urology. Available online: https://www.espu.org/members/documents/383-espu-spu-consensus-statement-2020-management-of-differences-of-sex-development-dsd (accessed on 28 March 2024).

Thirlby, Richard C. 2007. The Top 10 Reasons Why General Surgery Is a Great Career. *Archives of Surgery* 142: 423–29. [CrossRef]

Thomas, David F. 2004. Gender Assignment: Background and Current Controversies. *British Journal of Urology* 93: 47–50. [CrossRef] [PubMed]

Truth and Reconciliation Commission of Canada. 2015. *Canada's Residential Schools: The History, Part 1 Origins to 1939*. Vol. 1. 6 vols. The Final Report of the Truth and Reconciliation Commission of Canada. Montreal, London, and Chicago: McGill-Queen's University Press. Available online: https://publications.gc.ca/collections/collection_2015/trc/IR4-9-1-1-2015-eng.pdf (accessed on 28 March 2024).

Turnbull, Ryan. 2021. When "good Intentions" Don't Matter: The Indian Residential School System. *The Conversation*. August 2. Available online: http://theconversation.com/when-good-intentions-dont-matter-the-indian-residential-school-system-165045 (accessed on 28 March 2024).

Van Dijk, Teun A. 1992. Discourse and the Denial of Racism. *Discourse and Society* 3: 87–118. [CrossRef]

Van Dijk, Teun A. 2006. 'Ideology and Discourse Analysis'. *Journal of Political Ideologies* 11: 115–40. [CrossRef]

Weber, Max. 1947. *The Theory of Social and Economic Organization*. Translated by A. M. Henderson, and Talcott Parsons. New York: Oxford University Press. First published 1922.

Wilkins, Lawson. 1950. *The Diagnosis and Treatment of Endocrine Disorders in Childhood and Adolescence*. Springfield: Charles C. Thomas.

Wilkins, Lawson. 1957. Presidential Address. *The Endocrine Society* 61: 206–16. [CrossRef]

Wilkins, Lawson, Melvin Grumbach, Judson J. Van Wyk, Thomas H. Shepard, and Constantine Papadatos. 1955. Hermaphroditism: Classification, Diagnosis, Selection of Sex and Treatment. *Pediatrics* 16: 287–302. [CrossRef] [PubMed]

Winchester, Daniel, and Kyle D. Green. 2019. Talking Your Self into It: How and When Accounts Shape Motivation for Action. *Sociological Theory* 37: 257–81. [CrossRef]

Wolffenbuttel, Katja P., Piet Hoebeke, and the European Society for Pediatric Urology. 2018. Open Letter to the Council of Europe. *Journal of Pediatric Urology* 14: 4–5. [CrossRef] [PubMed]

Zuger, Bernard. 1970. A Critical Review of the Evidence from Hermaphroditism. *Psychosomatic Medicine* 32: 449–63. [CrossRef]

social sciences

Article

Human Rights-Based Intersex Healthcare: Using Hospital Data to Quantify Genital and Reproductive Surgery on Children in Aotearoa New Zealand

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Abstract: Medical intervention in the context of variations in sex characteristics (intersex variations) has been addressed by many academic disciplines, including medical research, human rights law, and psychosocial research, but few studies bring these diverse disciplines into substantive dialogue. Recent years have seen an increase in human rights statements about the indefensibility of some surgical interventions carried out on children with variations in sex characteristics. This has prompted attempts in some jurisdictions to move towards human rights-based healthcare for people with intersex variations. Such a move will require better dialogue across legal and health-related disciplines, as well as a clearer overview of which and how many surgical interventions are at issue. The present paper initiates the dialogue across disciplines and quantifies surgical interventions carried out on the sexual and reproductive organs of minors in Aotearoa New Zealand, over a five-year period. We suggest that, for the purpose of monitoring any shift towards human rights-based healthcare, national healthcare data will need to more clearly identify diagnoses and interventions relating to minors with variations in sex characteristics.

Keywords: intersex; variations in sex characteristics; human rights; psychosocial; hospital data; genital surgery; children

Citation: Roen, Katrina, Claire Breen, and Ashe Yee. 2023. Human Rights-Based Intersex Healthcare: Using Hospital Data to Quantify Genital and Reproductive Surgery on Children in Aotearoa New Zealand. *Social Sciences* 12: 660. https://doi.org/10.3390/socsci12120660

Academic Editor: Nigel Parton

Received: 1 August 2023
Revised: 20 September 2023
Accepted: 24 November 2023
Published: 28 November 2023

1. Introduction

Research relating to intersex healthcare consists of discrete bodies of literature that show little dialogue between them. Medical research, human rights research, and psychosocial research all address questions about the healthcare of people with intersex characteristics, but more dialogue across this literature is required to improve healthcare. The present paper works across these bodies of literature, specifically considering medical practice in Aotearoa New Zealand. This paper is guided by three questions. (1) What understanding can be achieved by working across medical, human rights, and psychosocial literature on intersex healthcare? (2) What empirical evidence is there of surgical procedures on minors with variations in sex characteristics in Aotearoa New Zealand? (3) How might a human rights approach to the healthcare of people with variations in sex characteristics impact health service data?

2. Medical Practices and Psychosocial Critiques

People with variations in sex characteristics are diagnosed and treated with a view not only to addressing biomedical issues but also to masculinise or feminise sex anatomy. The most common surgical intervention intended to produce normative male genitalia is hypospadias surgery, and a substantial body of medical literature focuses on this surgery. Less literature focuses on feminising interventions, which can include clitoral surgery and vaginal construction and gonadectomy. We consider the literature on each of these types of surgery.

2.1. Hypospadias Surgery

Hypospadias surgery involves moving the urethral opening from the underside to the tip of the penis and is typically carried out on the healthy tissue of an infant's penis. In a substantial percentage of cases, this surgery produces ongoing medical problems, some of which necessitate further surgery.

This surgery is driven by the belief that a child with a penis that is different from others will suffer in social situations. That is, hypospadias surgery is carried out for psychosocial reasons. Parents are required to consent to hypospadias surgery on behalf of their children, but it is not clear that the consent given is fully informed (Roen 2022). Research suggests that men who are used to living with hypospadias do not tend to seek penile surgery (Dodds et al. 2008, p. 682), and parents who initially consent to hypospadias surgery on behalf of their sons often regret that decision later (Vavilov et al. 2020).

Outcome studies suggest complication rates ranging from 10% to 54%, depending on the degree of hypospadias and the length of follow-up (Lucas et al. 2020; Pfistermuller et al. 2015; Schneuer et al. 2015). The most frequent complications include lower urinary tract symptoms (LUTS), urethral stricture, urethral fistula, meatal stenosis, and urinary tract infection (Hoy and Rourke 2016; Pfistermuller et al. 2015). Urologists specialising in this surgery raise concerns about the rate of failure and the need for repeat surgery to repair problems caused by the initial operation (Long and Canning 2016; Long et al. 2017). Some children undergo multiple repeat operations throughout their childhood for this reason. Each repeat operation carries a higher likelihood of failure than the previous operation (Snodgrass et al. 2014).

2.2. "Feminising" Interventions

Some variations in sex characteristics prompt "feminising" interventions such as clitoral reduction, vaginal construction, and gonadectomy. International research viewing long-term outcomes of this surgery often focuses on specific diagnostic groups such as CAH and AIS.

A review of surgical outcome studies reports on 29 studies (1178 patients) following genital surgery in relation to congenital adrenal hyperplasia (CAH) and identifies concerns about clitoral sensitivity, difficulties with vaginal penetration, and vaginal stenosis (Almasri et al. 2018). One concern quantified across 14 studies was vaginal stenosis (at a rate of 0.27; 95% CI 0.15 to 0.41). Another concern quantified across eight studies was urinary incontinence (at a rate of 0.04; 95% CI, 0.0 to 0.10). The three studies (combined sample size N = 102) reporting whether participants were able to have comfortable intercourse found that this was only possible for 48% of respondents. Three different studies (combined sample size N = 98) reported that almost 20% of respondents reported pain during intercourse. These are examples of the concerns about feminising genital surgery sometimes carried out on people too young to consent or understand the long-term implications of the surgery.

A study of long-term outcomes for people with AIS reported on 63 people who had undergone surgery, including 62 gonadectomies and 12 instances of vaginal surgery (Duranteau et al. 2020). A further nine had undergone vaginal dilation without surgery. Substantial numbers of participants (up to 62%) reported pain and bleeding in relation to intercourse, and this was true for those who had had vaginal interventions and for those who had not. Table 1 distils data on sexual complaints most frequently reported by people with AIS.

The high rate of complaints related to vaginal surgery is reflected in other studies, too (Duranteau et al. 2020). Given this recent evidence that the available interventions do not reliably produce good outcomes for adults, it is questionable to carry out such interventions on minors.

Table 1. Frequently reported sexual complaints.

	During Intercourse	**After Intercourse**
Participants who had vaginal interventions	pain: 62% bleeding: 47%	pain: 38% bleeding: 20%
Participants who did not have vaginal interventions	pain: 55%	pain: 25%

(Data from Duranteau et al. 2020).

2.3. Gonadectomy

When a person with internal gonads is found to have a Y chromosome, it was historically standard practice to remove the gonads during childhood. In the case of complete androgen insensitivity syndrome (CAIS), gonadectomy was standard practice soon after diagnosis (Deans et al. 2012), but this has changed over time. For people living as girls/women, gonadectomy was understood both to reduce cancer risk and to align the sexed anatomy with the gender identity of the person concerned. Both of these rationales for removing the gonads have come into question. Recent research documents the "negative impact of gonadectomy" in the lives of people with AIS (Duranteau et al. 2020, p. 4). Some people with relevant diagnoses (such as Androgen Insensitivity Syndrome and Swyers Syndrome) now retain their gonads, which are beneficial in terms of bone development and maintaining hormonal balance. In at least some instances, it now seems that the risk of cancer is lower than previously thought. Based on "data, and in line with demands from advocacy groups to restrict surgery. . . many DSD centres gradually adopted a policy of postponing prophylactic gonadectomy to late adolescence in individuals with CAIS" (Cools and Looijenga 2017, p. 176).

Giving more opportunities for young people in some centres to have a say about their healthcare has produced a generation of girls who have grown up with CAIS and, in some instances, are choosing not to undergo gonadectomy as adults (Cools and Looijenga 2017). While leading centres may have a policy of gonad retention until late adolescence, it is not clear how widespread this approach is outside leading centres.

2.4. Psychosocial Research

Psychosocial rationales are often put forward to explain surgery on the sexual and reproductive organs of children with variations in sex characteristics. There is now a growing body of psychosocial research literature highlighting the flaws in the assumption that such surgery will lead to better psychosocial outcomes for children.

Psychosocial research points to problems with the attempt to surgically "normalise" the sexed anatomy of people with variations in sex characteristics. We highlight three types of problems: (1) flawed assumptions underpinning surgery; (2) problematic communication and decision-making around the surgery; and (3) troubling outcomes from the surgery. We consider the literature addressing each of these concerns.

Surgical interventions to produce more normative-looking genitalia have long been based on psychosocial assumptions about child well-being. Assumptions revolve around heteronormative expectations (creating genitalia that will facilitate penis–vagina intercourse) and gender-specific expectations, such as the idea that a boy must be able to stand to urinate. Studies that have sought to assess the validity of assumptions about the psychosocial benefits that people experience as a result of childhood genital surgery have failed to support these assumptions (e.g., Schönbucher et al. 2008). Some have underscored approaches that avoid or work critically with these assumptions (e.g., Alderson et al. 2018; Liao 2007). It seems that the psychosocial assumptions used to justify normalising surgery during childhood are based on the personal beliefs of the adults making decisions on behalf of children, not on psychosocial research evidence.

Surgical interventions on children's genitalia have been considered justifiable on the basis of parental consent. Researchers now bring the informed consent process into question, pointing to persistent communication difficulties that arise in the hospital setting. Psychosocial research shows that parents find hospital-based communication about their child's variation in sex characteristics confusing (Boyse et al. 2014), fails to take their concerns into account (Chivers et al. 2017; Lundberg et al. 2017), and leaves them feeling they cannot genuinely make a decision about the proposed surgery (Freda et al. 2015). These communication issues undermine the validity of (parental) consent.

Even if valid informed parental consent was obtained and the assumptions underpinning normalising genital surgery were accurate, the troubling outcomes of surgery cannot be ignored. In addition to unintended outcomes involving surgical complications (pain, bleeding, and infection) are unintended psychosocial outcomes of surgery and the genital examinations necessitated by surgery. Over decades, intersex people have told psychologists about the inappropriate level of genital examination they experience and the distress this causes (Kessler 1998; Tosh 2020). Psychosocial research points to the stigma, shame, disempowerment, and anger that result from genital surgery and examinations (Meyer-Bahlburg et al. 2017; Sanders et al. 2017), comparing this to the psychological effects of sexual abuse (Schützmann et al. 2009; Tosh 2020). Given that genital surgery cannot be carried out without genital examinations and the likelihood of repeat surgery, the issues raised here are unlikely to be resolved in a context where childhood genital surgery continues at current levels.

3. Human Rights Literature

The heightened focus on surgeries on individuals with variations in sex characteristics in medicine and psychosocial research has led to an examination of such surgeries within human rights law. The current study builds on prior work that considers medical interventions on intersex children from human rights and ethical perspectives (Bauer et al. 2020; Carpenter 2016; Garland et al. 2021, 2022; Monro et al. 2017; Zelayandia-Gonzalez 2023).

In global terms, the right to be protected from degrading treatment (UNGA 1948, art 5; 1966a, art 7; 1984, art 16) was extended to healthcare settings when the UN Special Rapporteur Against Torture called upon states to repeal any law allowing genital-normalising surgery to be enforced or administered upon any person without their free and informed consent (UNHRC 2013). The right to health (UNGA 1948, art 25; 1966b, art 12), which includes sexual and reproductive health (WHO 2015), is also violated when states fail to take steps to prevent medically unnecessary, irreversible, and involuntary surgery and treatment (CESCR 2016). As with all human rights, these human rights are underpinned by the right to be free from discrimination (OHCHR 2021).

Articles 23 and 24 of the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP) state that Indigenous people have the right to the enjoyment of the highest attainable standard of physical and mental health (UNGA 2007). The right to health is a central component of Indigenous peoples' right to self-determination. The principle of free, prior, and informed consent, as an integral element of the right to self-determination, means that Indigenous peoples have the right to be actively involved in the development and administration of a health programme. However, Indigenous people commonly experience discrimination and interpersonal and structural racism that frequently leads to their marginalisation or exclusion (UNHCR 2016). The rights of minorities are also recognised in international law (UNGA 1966a, art 27), which has implications for Pacifica in Aotearoa New Zealand.

Within the UN Convention on the Rights of the Child 1989 ("the Convention"), the matter of unconsented surgeries on children with variations in sex characteristics is regarded as a harmful practice (CRC 2015) contravening the child's right to be free from violence (UNCRC 2011; UNGA 1989, art 19). A children's rights perspective requires a more nuanced approach to determinations of necessity and consent. Article 3 of the UNCRC requires that the child's best interests are a primary consideration in a decision affecting the child. This means that an adult's judgement of a child's best interests cannot override the obligation to respect the child's rights under the Convention (UNCRC 2011). The child's best interests also means that the question of valid consent must include consideration of whether the treatment would be medically justifiable, a decision that should be made by a multidisciplinary team of professionals (UNCRC 2013). The child's right to have their voice heard (UNGA 1989, art 12) also plays a key role, meaning that it should be presumed that a child has the capacity to form their own views and the right to express them in healthcare proceedings. The right to be heard for all children means that information about proposed treatments and their effects and likely outcomes should be provided in a child-appropriate way, with properly trained staff (CRC 2009). Article 18 of the Convention also recognises that parents are primarily responsible for the upbringing and development of their child, which provides the basis for parental authority and capacity to provide consent (that must be informed by their child's best interests). The exercise of parental responsibility must also be considered in light of the evolving capacities of the child (UNGA 1989, art 5). Together, these provisions mean that, ultimately, the child is potentially competent to consent to medical treatment irrespective of the views of their parents (UNCRC 2003).

The Convention's prohibition of discrimination (UNGA 1989, art 2), along with its particular recognition of the rights of Indigenous and minority children (UNGA 1989, art 30), underpins States' obligations to effectively realise the rights of their intersex children, some of whom will experience multiple forms of discrimination. As an aspect of their right to health, Indigenous children must have access to culturally appropriate health services (UNCRC 2009). The UNDRIP also calls for particular attention to the rights and special needs of Indigenous youth and children (UNGA 2007). Similarly, the Expert Mechanism on the Rights of Indigenous Peoples has noted that the varying challenges experienced by Indigenous children may be compounded by intersecting vulnerabilities, including being intersex (UNHCR 2016; UNHRC 2021).

The human rights provisions outlined above have implications for the design and delivery of healthcare to Pacifica intersex children, though there is no clear evidence of this being taken into account in current health service delivery in Aotearoa New Zealand.

Domestic Law in Aotearoa New Zealand Echoes International Human Rights Law

Section 11 of the New Zealand Bill of Rights Act 1990 (NZBORA 1990) states that everyone has the right to refuse medical treatment. Section 19 of the Act states that everyone has the right to be free from discrimination, a right that includes the prohibition of discrimination on the grounds of sex (HRA 1993, s 21(1)(a); NZHRC 2020). The NZBORA also recognises the rights of minorities (NZBORA 1990, s 20).

The Health and Disability Commissioner Act 1994 establishes that no healthcare procedure shall be carried out without informed consent (HDCA 1994, s 20(1)(a)). The Code of Health and Disability Services Rights 1996 contains the right to be fully informed and to be able to make an informed choice and give informed consent. The provision of consent is a matter of competence to be determined by the health professional (HDC 1996). Such determinations are not age-related, with the focus being on the competence of the individual child to consent (van Rooyen et al. 2015; Wood 1998). Questions of the competency and fitness of health practitioners are governed by the Health Practitioners Competency Assurance Act 2003.

There is no legally defined age at which any person is deemed competent to consent to medical treatment. The Care of Children Act 2004 (COCA 2004) sets some parameters for such decision-making. The welfare and best interests of the child or young person are the first and paramount consideration in all decision-making affecting the child (COCA 2004, s 4), and the child must be protected from harm (COCA 2004, s 5(a)). The child must be given reasonable opportunities to express their views on any matters affecting them, and such views must be taken into account (COCA 2004, s 6). Parents have the primary responsibility for the child's development and upbringing (COCA 2004, s 5(b)), whilst their duties, powers, rights, and responsibilities include helping the child to decide on important matters affecting them, such as non-routine medical treatment (COCA 2004, 16(1), (2)).

In Aotearoa New Zealand, there is a further bicultural dimension to the aforementioned legal and policy framework that stems from the country's founding document, namely the Treaty of Waitangi Te Tiriti o Waitangi 1840 (Treaty of Waitangi Te Tiriti o Waitangi 1840). Current responses to intersex variations have been criticised for overlooking Indigenous cultural constructs and understandings (Kerekere 2017; Steers et al. 2021), reflecting only binary Western constructions of gender that categorise individuals as either male or female (NZHRC 2018). Similar findings have been made in relation to Pacifica (Thomsen et al. 2021).

Since the late 1990s, advocates have consistently campaigned on the human rights implications of surgery on intersex children at the international level (SOGII 2013; UNHRC 2018, 2019). At the domestic level, in 2008, the New Zealand Human Rights Commission (NZHRC) stated that intersex children should not be operated on and that an independent advocate should represent the interests of the child where delaying surgery was not possible (NZHRC 2008). It subsequently recommended the development of legislative safeguards for children in light of the right to bodily integrity and the right to refuse medical treatment contained in the New Zealand Bill of Rights Act 1990. The Commission has also called for a child-centred approach requiring a central role for young intersex people and their families/whānau in policy development, legislative changes, and medical developments (NZHRC 2016).

In effect, for most Aotearoa New Zealand children with variations in sex characteristics, the decision concerning potential medical intervention may be deferred to when the child is of sufficient age and maturity to have a well-reasoned, culturally informed view on whether or not to have that intervention.

The matter of surgery on intersex children was discussed by Aotearoa New Zealand's delegation and the UN Committee on the Rights of the Child in 2016. The view of the delegation was that there was no legally binding system to prevent genital normalisation surgeries in children, and neither were there plans to introduce such legislation. In a follow-up to the delegation's statement that there was no surgery related to "gender assignment" in New Zealand since 2006, the government clarified that the government had provided funding for genital normalisation surgeries outside of Aotearoa New Zealand. It was subsequently revealed that one to two operations within the country had been undertaken upon children on an annual basis (UNCRC 2016b). The CRC Committee subsequently recommended the creation of a child rights-based healthcare protocol for intersex children, and that medical and psychological professionals be trained on the range of biological and physical sexual diversity and on the consequences of unnecessary surgical and other medical interventions on intersex children (UNCRC 2016a). In response to these recommendations, as well as domestic advocacy, the Child and Youth Intersex Clinical Reference Group produced a guideline for health professionals involved immediately following the birth of a child with a genital variation (Starship 2020). Unfortunately, this guideline goes little further than encouraging health professionals to avoid stigmatising language and suggesting that surgery should not be considered as a first option. Aotearoa New Zealand has been asked to provide further information on the establishment of the rights-based healthcare protocol for intersex children, as well as data on the number of intersex children who have undergone surgery or treatment related to their sex characteristics (UNCRC 2020).

4. Empirical Study

To document any shift towards human rights-informed medical practices, it is necessary to collect data on how many surgical procedures are undertaken on minors with diagnoses related to variations in sex characteristics (diagnoses of sex development). A move towards human rights-informed healthcare should be marked by a reduction in surgery on the genital and reproductive organs of children who are too young to consent. The current study begins this process of documentation, presenting data over the 5-year period to 2019.

We report on hospital data from Aotearoa New Zealand and address two questions: (1) What surgery is carried out on the genital or reproductive organs of children and young people in Aotearoa New Zealand? (2) What are the human rights implications of this surgery for children and young people with variations in sex characteristics in Aotearoa New Zealand?

5. Methods

This study is based on aggregate hospital discharge data published online annually by New Zealand's Ministry of Health[1]. These data include the annual number of diagnoses given and surgical procedures undertaken within New Zealand's publicly funded health system, with a breakdown by age, sex, and ethnicity. We searched for diagnoses and surgical interventions that are or may be related to variations in sex characteristics. New Zealand hospital data are reported using ICD terms.

We organised and interpreted the data following four steps. First, identifying which ICD terms are most likely to relate to people with variations in sex characteristics. Second, identifying which of these were applied to minors during the five years of interest. Third, tabulating all the data for the relevant ICD terms and age groups. Fourth, clustering the ICD terms under relevant headings and producing pie charts and histograms for each cluster of interventions or diagnoses.

6. Findings

The use of ICD terms becomes problematic when interpreting the data. Hospital surgery data breaks down genital and reproductive surgery into categories that cannot simply be interpreted or mapped onto specific genital variations because the labelling makes generic reference to incision, excision, repair, or categories such as "other procedures". The interventions indicated by these terms may or may not have been carried out on a person with a variation in sex characteristics. There are records of surgical interventions on the penis, urethra, testes, vas deferens, vagina, vulva, perineum, and clitoris of children, and these are the focus of our analysis.

Reporting all these data, with the knowledge that some of them may have no bearing on children with variations in sex characteristics, is useful at this stage because we envisage that there should be a change over time in the frequency of these interventions as health professionals in Aotearoa New Zealand shift to a human rights-based way of working. We also propose a shift in record-keeping to help monitor changes to the healthcare of people with variations in sex characteristics.

We report the analysis of hospital discharge data on diagnoses and surgical interventions under four subheadings: (i) diagnoses, (ii) hypospadias, (iii) gonadectomy, and (iv) surgery on children's clitoris, vagina, vulva, and perineum.

6.1. Diagnoses

By far, the largest number of diagnoses falling under the umbrella of interest relate to hypospadias. More than 200 minors are diagnosed with hypospadias each year in New Zealand (with a population of just over 5 million[2]), while other categories likely to relate to variations in sex characteristics are far less numerous, as shown in Figure 1. Because of the way some diagnoses related to sex development are clustered and labelled and because most cases are simply documented as "other," it is very difficult to get a clear picture of how many minors with variations in sex characteristics are diagnosed in New Zealand hospitals each year.

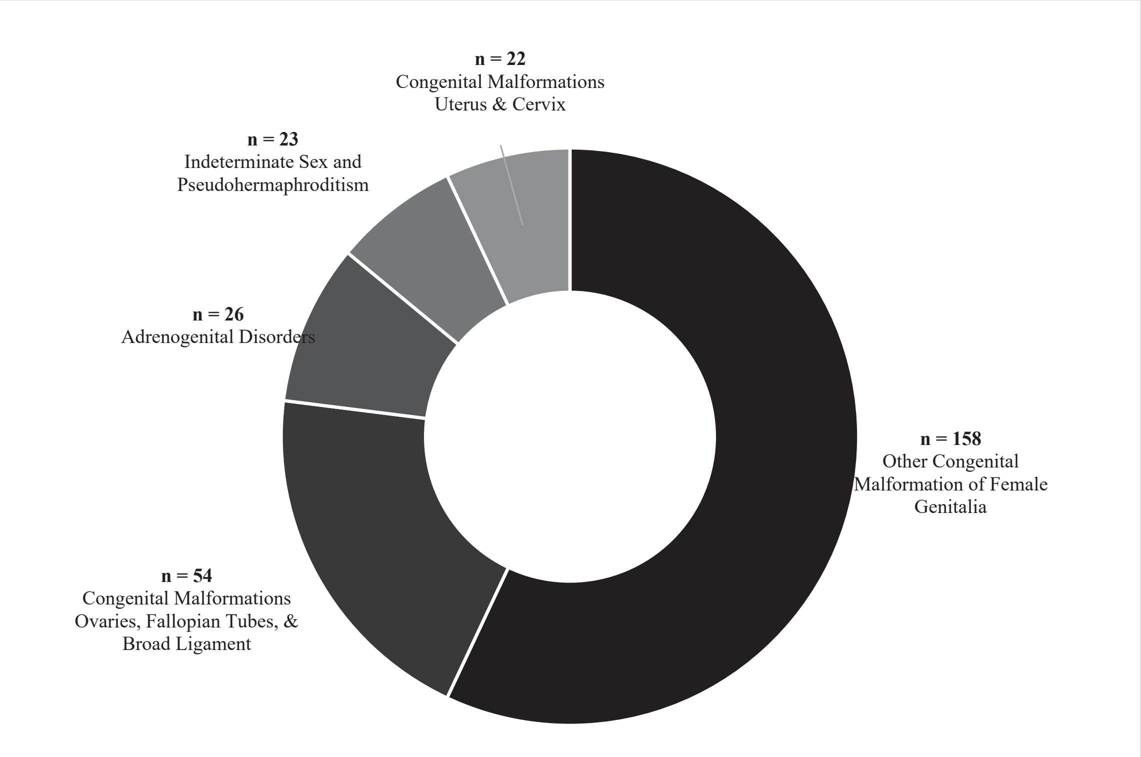

Figure 1. Diagnoses that may be associated with surgery on the genital or reproductive organs of minors with VSC, sum over 5 years.

Figure 1 shows the 5-year sum of people aged 0–19 years who were given a range of diagnoses that could fall under the umbrella of variations in sex characteristics and be associated with surgery on genital and reproductive organs.

Public hospital data classifies most of these variations in genital or reproductive organs broadly as "congenital malformations", thereby obscuring the many diagnostic groupings that fall under the umbrella of variations in sex characteristics. It is not possible to know how many of the minors who received these diagnoses might have undergone surgery on their genital or reproductive organs.

The diagnostic group that does appear clearly in the dataset but is not considered in Figure 1 is hypospadias.

6.2. *Hypospadias*

Unlike other diagnostic groups, there is clear documentation of how many surgical procedures take place each year on children diagnosed with hypospadias. Based on the number of surgical procedures documented (Table 2), it appears that the majority of people diagnosed with hypospadias undergo at least one surgical procedure between the ages of 0 and 4 years. As shown in Figure 2, a substantial number of these surgical procedures are carried out on Indigenous Māori and Pacifica children.

Table 2. Hypospadias diagnoses and surgical procedures on minors.

	Age	2014/15	2015/16	2016/17	2017/18	2018/19
Hypospadias diagnosis	0 to 4	258	258	222	241	196
	5 to 9	20	25	12	16	13
	10 to 14	6	9	11	5	5
	15 to 19	4	2	7	3	2
	Total	**288**	**294**	**252**	**265**	**216**
Hypospadias surgery	0 to 4	194	200	176	175	133
	5 to 9	25	33	22	17	12
	10 to 14	8	7	13	11	3
	15 to 19	2	2	4	3	0
	Total	**229**	**242**	**215**	**206**	**148**

6.3. Gonadectomy

Gonadectomy may be performed for a number of reasons, including torsion of the testis, undescended testis, infection, cancer, injury, or in the context of a variation in sex characteristics such as androgen insensitivity syndrome. It is not possible to know, on the basis of publicly available data, which instances of gonadectomy relate to a variation in sex characteristics and which gonadectomies might have been delayed until the child was old enough to have a meaningful say in the decision. Figure 3 clusters together procedures that involve the removal of ovaries and/or testes. To better monitor surgical practices that impinge on the human rights of people with variations in sex characteristics, it would be necessary to maintain clearer records relating to gonadectomy, which can shed more light on the issue of necessity and consent.

6.4. Surgery on Children's Clitoris, Vagina, Vulva, and Perineum

Over the years studied, minors in Aotearoa New Zealand underwent hundreds of operations per year on their vagina, vulva, or perineum. Public hospital discharge data classifies most of this surgery under broad categories of excision, incision, repair, and other, which gives no way of knowing which procedures are related to variations in sex characteristics and which could have been delayed until the person was old enough to consent. Given the high number of procedures and the relatively low incidence of variations that impact on vaginal anatomy, we presume that most of the procedures indicated in the data do not relate to variations of sex characteristics but are carried out for some other reason.

Figure 4 presents the total number of surgical procedures each year broken down by age and ethnicity.

Figure 5 shows the total number of procedures carried out on the "female" organs of 0–19 year olds over the 5-year period studied. This pie chart demonstrates the extremely vague terms used in the presentation of data about surgical procedures on genitalia labelled as female. Based on the terms used, it is impossible to know which interventions are carried out on children and young people with variations in sex characteristics. In order to assess whether there is any reduction in the number of feminising genital procedures on minors in Aotearoa New Zealand, the data collected would need to be coded more clearly than is currently the case.

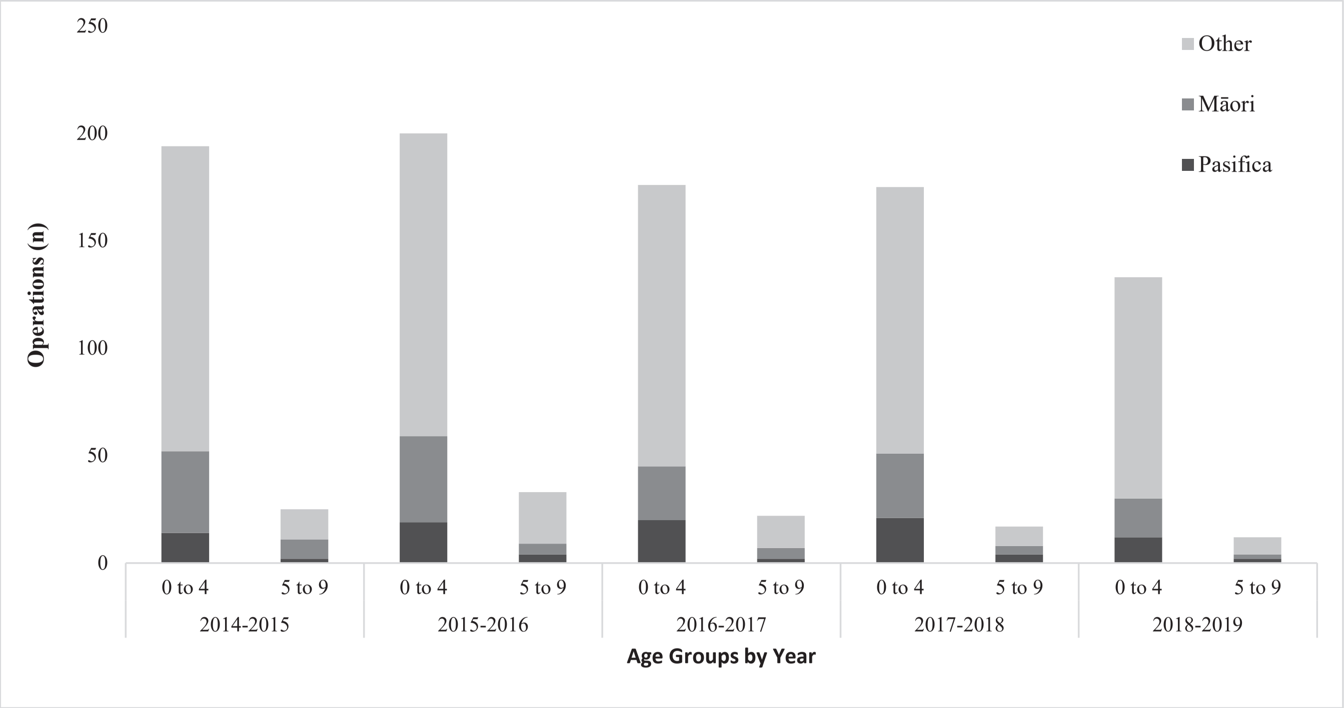

Figure 2. Hypospadias operations on children under 10 years of age.

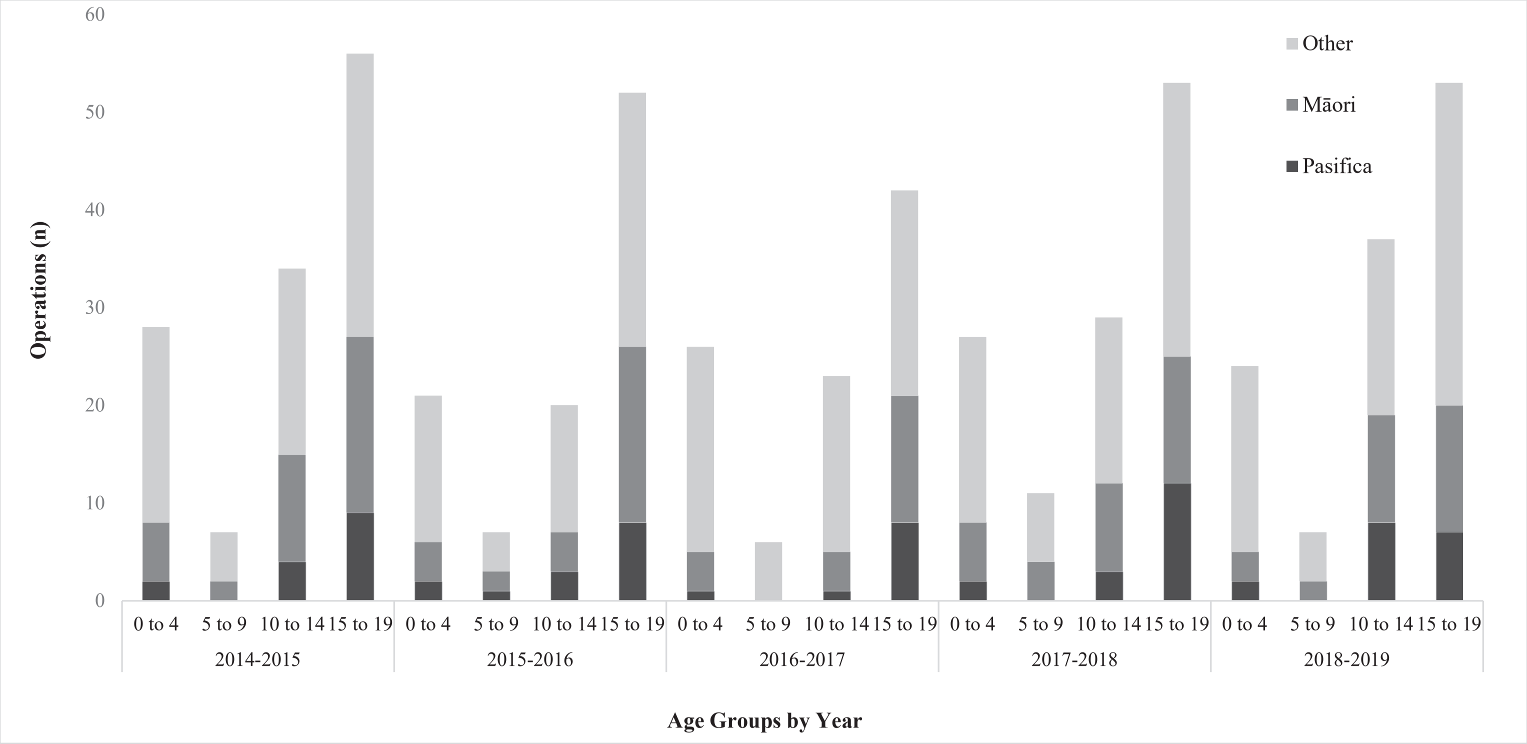

Figure 3. Orchidectomy, oophorectomy, and salpingo-oophorectomy.

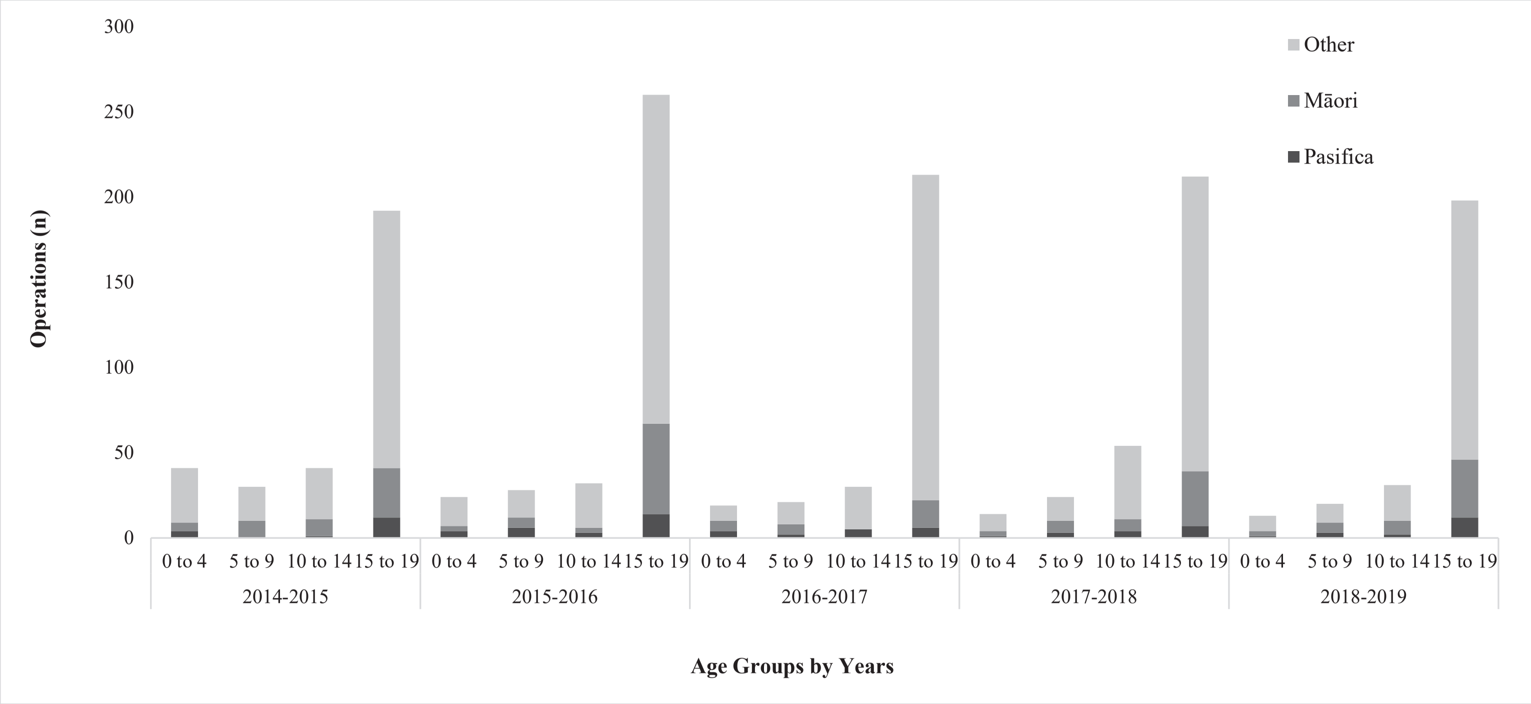

Figure 4. Excision, incision, and repair procedures on the vagina, vulva, or perineum.

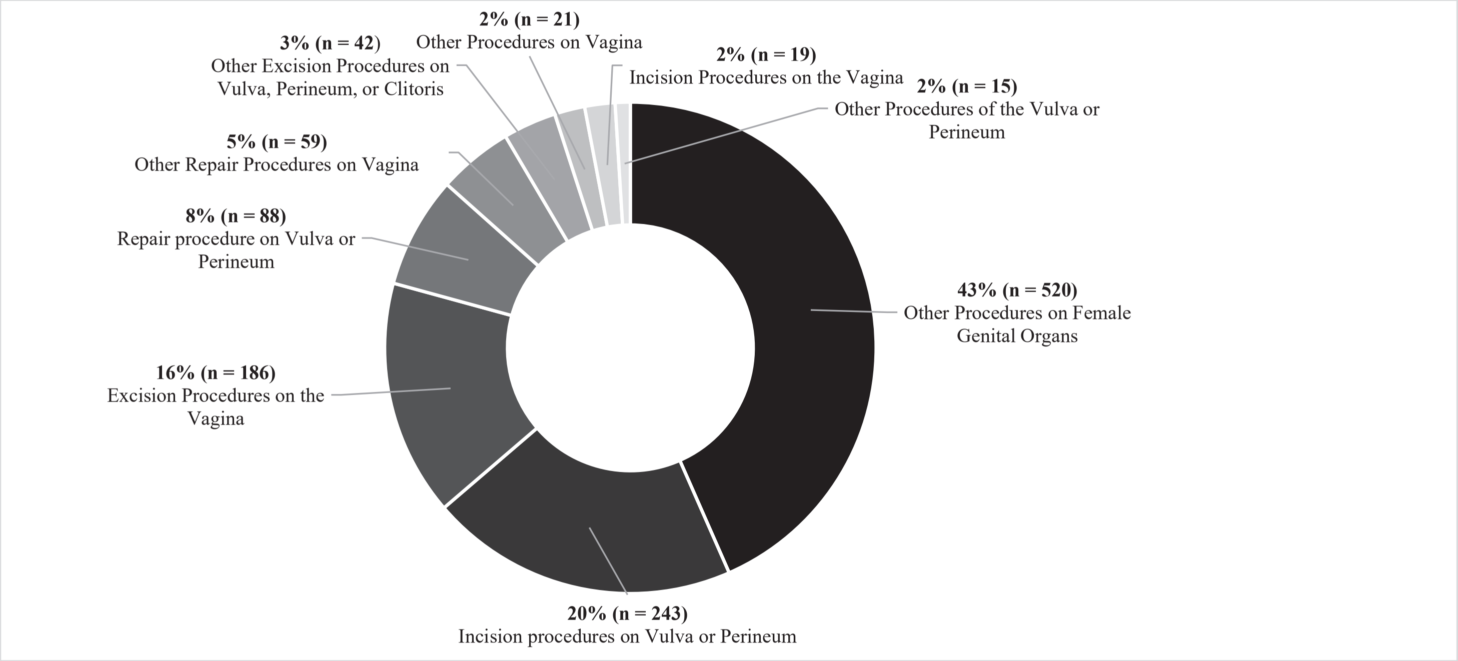

Figure 5. Operations on the vagina, vulva, or perineum 2014–2019.

6.5. Overview of Procedures across Age Groups

Table 3 documents the number of surgical interventions undertaken on the genital and reproductive anatomy of people aged 0 to 19 years over the 5-year period studied. While not all of these interventions were carried out in the context of a variation in sex characteristics, it is reasonable to assume that many were.

Table 3. Surgical procedures on the genital and reproductive organs of people aged 0–19 years.

Procedures	2014–2015	2015–2016	2016–2017	2017–2018	2018–2019
Hypospadias Repair	229	242	215	206	148
Orchidectomy	88	63	60	75	77
Oophorectomy[3]	37	37	37	45	44
Surgical Procedures on the Urethra	133	117	137	101	111
Testis, Vas Deferens, Epididymis, and Spermatic Cord Interventions	70	63	71	67	59
Surgical Procedures on the Vagina, Vulva, or Perineum	170	170	153	169	158

7. Discussion

Some medical interventions carried out on children and young people with variations in sex characteristics raise human rights issues. The current analysis focuses on surgical interventions recorded in national hospital discharge data. It is important that future research address interventions that are not the focus here, including hormonal treatments, medical examinations, and other diagnostic procedures.

National hospital discharge data made publicly available in Aotearoa New Zealand documents the surgical interventions carried out on the sexual and reproductive anatomies of children and young people, including hypospadias repair, orchidectomy, oophorectomy, and surgical procedures on the urethra, vagina, and vulva. For many of these interventions, it is not possible to know (on the basis of the publicly available aggregate data) whether the intervention was carried out in the context of a variation in sex characteristics. Other reasons for some of the surgical procedures identified could include gender-affirming surgery for young trans people or repair surgery following an injury.

It is not clear from hospital discharge data which of the procedures documented would be delayed or stopped in the context of a move to human rights-informed healthcare of minors with variations in sex characteristics. There are questions to be asked about procedures occurring on younger children. What are these interventions? Could they have been delayed until the child was old enough to meaningfully consent? On what basis did the child's caregivers consent to the surgery? More detailed data would be needed to consider any human rights implications of these procedures on the reproductive organs of minors, including a substantial minority of Indigenous Māori children, as well as Pacifica children.

7.1. Genital Surgery on Indigenous Māori and Pacifica Children

A substantial minority of the operations documented in our study are carried out on Indigenous Māori and Pacifica children. In the context of Aotearoa New Zealand, where Te Tiriti o Waitangi sets out binding agreements about the obligations of the State to protect and promote the well-being of Māori people, this should mean that Indigenous communities are consulted and Indigenous health principles are applied to the healthcare of these children. There is no evidence of this occurring, and we have not been able to find documentation of Indigenous perspectives being sought or expressed in relation to the specific kinds of surgery considered in this paper. Given the long-standing failure to adequately serve Indigenous populations in mainstream health services, it seems unlikely that all caregivers responsible for Indigenous children give genuinely informed consent for the surgical interventions that these children undergo.

The obligation to recognise the rights of minorities in domestic (NZBORA 1990, s 20) and international law (UNGA 1966a, art 27; 1989, art 30) has implications for the design and delivery of healthcare to Pacifica children; again, there is no evidence of this occurring.

The UNCRC 1989 stipulates that Indigenous children must have access to culturally appropriate health services (UNCRC 2009), and the UNDRIP 2007 underscores the rights of Indigenous people in relation to health. Taking a human rights-based approach to the healthcare of children and young people with variations in sex characteristics would, therefore, mean establishing what constitutes culturally appropriate responses to intersex bodies. Given that Māori and Pacifica models of health emphasise a holistic perspective, not a medicalising or compartmentalising approach, it seems likely that intersex advocates' calls for respecting bodily integrity (Black et al. 2017) could sit well with Māori models (Durie 1985, 1999), and Pacifica models (Kapeli 2021) of health. It is time for work to be done on articulating Māori and Pacifica approaches to intersex health and well-being (Roen and Oliver 2022) and for those understandings to contribute to healthcare practices.

7.2. Penile, Vaginal and Vulval Surgery

In Aotearoa New Zealand, an average of 175 surgical procedures are carried out per year on children aged 0 to 4 in relation to hypospadias. The United Nations Committee on the Rights of the Child has recommended that non-essential surgical procedures on the genitalia of infants and children too young to consent in Aotearoa New Zealand do not continue (UNCRC 2016a). Discontinuing hypospadias surgery, in most or all cases, should, therefore, be a priority for shifting to a human rights-based healthcare approach for children with variations in sex characteristics. Hypospadias surgery is questionable from a human rights perspective because hypospadias surgery is not biomedically necessary. Rather, it tends to be undertaken for psychosocial reasons that are increasingly being challenged. Hypospadias surgery can necessitate subsequent surgeries to correct problematic surgical outcomes. Evidence of parental regret (Vavilov et al. 2020) and the lived experience of adults with hypospadias raises questions about consent, which has legal implications. A human rights-based approach would mean delaying surgical intervention at least until the person concerned can meaningfully consent to the surgery or freely opt not to have surgery.

The long-term effects of vaginal and vulval surgery impact the person's sexual experience in ways that cannot necessarily be taken into account by health professionals and caregivers deciding to go ahead with surgery on children. For decades, intersex people have raised concerns about this kind of surgery (e.g., Chase 1998; Holmes 2002a, 2002b), and so have health professionals (e.g., Creighton and Minto 2001; Crouch et al. 2008; Minto et al. 2001). Recent clinical research echoes these concerns (Almasri et al. 2018; Duranteau et al. 2020). Given that feminising genitoplasty is typically carried out for psychosocial reasons (founded on the popular beliefs that a girl must grow up with typical-looking genitalia and that all females want to participate in penis–vagina intercourse) and not on biomedical grounds, these surgical interventions can be delayed until the person concerned is old enough to decide for themselves whether or not they want surgery. In cases where menstruation might be obstructed prior to surgery, this can be managed through medication until surgery occurs.

Medical evidence cataloguing high levels of poor outcomes with feminising genitoplasty ought to prompt more data collection on this type of surgery on children with genital variations; the failure to do so raises questions around the extent to which the human rights (NZBORA 1990, s 11; UNGA 1989, art.s 19, 24) of children with vaginal variations are protected in Aotearoa New Zealand. The challenge ahead is to establish a nonsurgical healthcare pathway that includes enough support for affected whānau/families to raise a child with genital variation and enough support for children and young people so they can genuinely be involved in a consent process if, one day, surgery becomes a possibility for them.

7.3. Prophylactic Gonadectomy

The question of gonadectomy on minors with variations in sex characteristics is more complicated than the other surgical interventions considered here. Some gonadectomy, for some diagnostic groups and age groups, is medically necessary and can be lifesaving. The complicated questions relate to which groups, at which ages, and based on what information. Here, we set out some key understandings from recent clinical research with a view to informing a human rights-based approach to gonadectomy.

Gonadectomy impinges on fertility, hormone production, and bone health and is, therefore, of particular concern (Weidler et al. 2019). Living without gonads necessitates hormone replacement therapy, which can be hard to manage, potentially leading to years of debilitating problems. The dilemma faced by clinicians and by people who agree to this surgery (for themselves or on behalf of their children) is that it may not be easy to weigh the health risks associated with gonadectomy against the cancer risks associated with some internal gonads. This dilemma is twofold: first, new research continues to emerge informing the assessment of cancer risk, and second, the very mention of cancer can be so emotive that it may be difficult for caregivers to accurately assess risk. In some instances when gonads are removed, parents are unaware of the choices open to them (such as retaining the gonads until at least after puberty), and parents and young people do not have access to good data about the actual level of risk of malignancy given their specific circumstances.[4]

A gonad-sparing approach is now taken in some centres internationally, based on low malignancy rates during childhood, depending on diagnosis (Steinmacher et al. 2021). This gonad-sparing approach involves an assessment of tumour risk based on molecular diagnosis, but the difficulty of rolling out this approach more widely is that most patients do not have a molecular diagnosis (Steinmacher et al. 2021). Some clinician–researchers have proposed a biannual screening program for women who choose to retain their gonads into adulthood (Döhnert et al. 2017), and some have set out a protocol for gonad preservation based on the principle of shared decision-making and watchful waiting (Weidler et al. 2019). While “testicular germ cell tumours are increasingly believed to be quite rare with rates as low as 0% in molecularly confirmed individuals with AIS” (Weidler et al. 2019, p. 605), there is currently no way of reliably detecting the development of malignancy (Cools and Looijenga 2017; Weidler et al. 2019).

For variations in sex characteristics where gonadectomy might once have been routine, human rights-based healthcare would involve taking a gonad-sparing approach whenever possible. The latest research suggests that decisions should be informed by molecular diagnostic tools and the principle of shared decision-making. This area of intersex healthcare is changing at some pace as new technologies become available to identify cases where gonadectomy is necessary for saving life and to distinguish those from cases where gonadectomy impinges on the rights of a minor. A greater understanding of the medical risks and health benefits of delaying gonadectomies in children should presumably lead to a downward trend in gonadectomies, but the variability of the data across the years suggests either that instances of gonadectomies remain the same despite the changing knowledge or current data reporting fails to discern progress that is being made. Either way, the data raise questions for the right to health, which requires States to provide trained and skilled health personnel who can perform a full range of sexual and reproductive healthcare services as well as scientific and medically appropriate and up-to-date evidence-based information (CESCR 2000, 2016).

8. Conclusions

This paper highlights the disjuncture between medical practice and human rights principles. Concerns about a range of surgical interventions on children with variations in sex characteristics are articulated in medical literature, pointing to problematic surgical outcomes and the likelihood of parental regret. Psychosocial research points to communication and decision-making problems that bring the consent process into question and highlights long-term psychosocial distress resulting from clinical intervention. Human rights literature states that some surgical interventions on the genital and reproductive organs of minors are indefensible in relation to international human rights agreements and domestic human rights and healthcare legislation in Aotearoa New Zealand. The present data show clearly that surgery continues on minors with variations in sex characteristics in Aotearoa New Zealand.

Our research raises questions about the statement of the Aotearoa New Zealand delegation to the UN Committee on the Rights of the Child that no surgery relating to gender assignment had taken place in Aotearoa New Zealand from 2006, and the subsequent revelation that, annually, one to two surgeries had taken place upon children with variations of sex characteristics in Aotearoa New Zealand (UNCRC 2016b).

If Aotearoa New Zealand is to meet its legal obligations then many of the surgical interventions addressed in this paper must be brought into question. If a human rights-based approach to intersex healthcare is implemented in Aotearoa New Zealand, we would expect to see three key changes: (1) a reduction in the number of surgical operations performed on the genital and reproductive organs of minors in New Zealand's public hospitals; (2) procedures for documenting medical diagnoses and interventions on children with variations in sex characteristics more clearly than is currently the case; and (3) the development and implementation of a nonsurgical and culturally meaningful alternative care pathway.

Author Contributions: Conceptualization, K.R. and C.B.; methodology, K.R.; analysis, A.Y., K.R. and C.B.; data curation, A.Y.; writing—original draft preparation, K.R.; writing—review and editing, C.B. and A.Y.; funding acquisition, C.B. and K.R. All authors have read and agreed to the published version of the manuscript.

Funding: This research received no external funding but was supported by an ALPSS Interdisciplinary Collaboration Grant (2021), University of Waikato.

Institutional Review Board Statement: Not applicable.

Data Availability Statement: Data available in a publicly accessible repository that does not issue DOIs via Aotearoa New Zealand's Ministry of Health website. Publicly available datasets were analyzed in this study. This data can be found here: https://www.health.govt.nz/nz-health-statistics/health-statistics-and-data-sets/publicly-funded-hospital-discharges-series (accessed on 23 November 2023).

Conflicts of Interest: The authors declare no conflict of interest.

Notes

[1] https://www.health.govt.nz/nz-health-statistics/health-statistics-and-data-sets/publicly-funded-hospital-discharges-series/publicly-funded-hospital-discharges-series/publicly-funded-hospital-discharges-series (accessed on 23 November 2023).

[2] New Zealand's population was reported as 5,126,300 in September 2021: https://www.stats.govt.nz/indicators/population-of-nz (accessed on 23 November 2023).

[3] Based on the sum of oophorectomy procedures plus salpingo-oophorectomy procedures.

[4] Concerns about inadequate communication of choices about retaining gonads are documented by intersex youth who have spoken out in recent years, including young people from North America (e.g., https://www.facebook.com/watch/?v=10154742737199605 accessed on 23 November 2023); Europe (e.g., https://interactadvocates.org/i-discovered-im-intersex-from-the-buzzfeed-video/ accessed on 23 November 2023); and Aotearoa New Zealand (e.g., https://www.renews.co.nz/im-intersex-and-i-wish-doctors-had-left-my-body-alone/ accessed on 23 November 2023).

References

Alderson, Julie, Katrina Roen, and Miriam Muscarella. 2018. Psychological care and evaluation in pediatric and adolescent gynecology practice. In *Pediatric and Adolescent Gynecology: A Problem-Based Approach*. Edited by Sarah M. Creighton, Adam Balen, Lesley Breech and Lih-Mei Liao. Cambridge: Cambridge University Press, pp. 150–57.

Almasri, Jehad, Feras Zaiem, Rene Rodriguez-Gutierrez, Shrikant U. Tamhane, Anoop Mohamed Iqbal, Larry J. Prokop, Phyllis W. Speiser, Laurence S. Baskin, Irina Bancos, and M. Hassan Murad. 2018. Genital Reconstructive Surgery in Females With Congenital Adrenal Hyperplasia: A Systematic Review and Meta-Analysis. *The Journal of Clinical Endocrinology and Metabolism* 103: 4089–96. [CrossRef]

Bauer, Markus, Daniela Truffer, and Daniela Crocetti. 2020. Intersex human rights. *The International Journal of Human Rights* 24: 724–49. [CrossRef]

Black, Eve, Kylie Bond, Tony Briffa, Morgan Carpenter, Candice Cody, and Alex David. 2017. Darlington Statement: Joint Consensus Statement from the Intersex Community Retreat in Darlington, March 2017. Available online: https://darlington.org.au/statement/ (accessed on 23 November 2023).

Boyse, Kyla L., Melissa Gardner, Donna J. Marvicsin, and David E. Sandberg. 2014. "It was an overwhelming thing": Parents' needs after infant diagnosis with congenital adrenal hyperplasia. *Journal of Pediatric Nursing* 29: 436–41. [CrossRef]

Carpenter, Morgan. 2016. The human rights of intersex people: Addressing harmful practices and rhetoric of change. *Reproductive Health Matters* 24: 74–84. [CrossRef] [PubMed]

CESCR. 2000. General Comment No. 14: The Right to the Highest Attainable Standard of Health (Art. 12) E/C.12/2000/4. Available online: https://www.ohchr.org/en/resources/educators/human-rights-education-training/e-general-comment-no-14-right-highest-attainable-standard-health-article-12-2000 (accessed on 23 November 2023).

CESCR. 2016. General Comment No. 22 (2016) on the Right to Sexual and Reproductive Health (Article 12) E/C.12/GC/22. Available online: https://docstore.ohchr.org/SelfServices/FilesHandler.ashx?enc=4slQ6QSmlBEDzFEovLCuW1a0Szab0oXTdImnsJZZVQfQejF41Tob4CvIjeTiAP6sGFQktiae1vlbbOAekmaOwDOWsUe7N8TLm%252BP3HJPzxjHySkUoHMavD%252Fpyfcp3Ylzg (accessed on 23 November 2023).

Chase, Cheryl. 1998. Surgical Progress is Not the Answer to Intersexuality. *The Journal of Clinical Ethics* 9: 385–92. [CrossRef] [PubMed]

Chivers, Clare, Jan Burns, and Martha D. Collado. 2017. Disorders of sex development: Mothers' experiences of support. *Clinical Child Psychology and Psychiatry* 22: 675–90. [CrossRef] [PubMed]

COCA. 2004. Care of Children Act 2004 (N.Z.). Available online: https://www.legislation.govt.nz/act/public/2004/0090/latest/DLM317233.html (accessed on 23 November 2023).

Cools, Martine, and Leendert Looijenga. 2017. Update on the Pathophysiology and Risk Factors for the Development of Malignant Testicular Germ Cell Tumors in Complete Androgen Insensitivity Syndrome. *Sexual Development* 11: 175–81. [CrossRef]

CRC. 2009. General Comment No. 12: The Right of the Child to be Heard CRC/C/GC/12. Available online: https://www2.ohchr.org/english/bodies/crc/docs/advanceversions/crc-c-gc-12.pdf (accessed on 23 November 2023).

CRC. 2015. Concluding Observations on the Combined Second to Fourth Periodic Reports of Switzerland CRC/C/CHE/CO/2-4. Available online: https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbolno=CRC/C/CHE/CO/2-4&Lang=En (accessed on 23 November 2023).

Creighton, Sarah, and Catherine Minto. 2001. Managing Intersex: Most Vaginal Surgery in Childhood Should be Deferred. *British Medical Journal* 323: 1264–65. [CrossRef]

Crouch, Naomi S., Lih M. Liao, Christopher R. J. Woodhouse, Gerard S. Conway, and Sarah M. Creighton. 2008. Sexual function and genital sensitivity following feminising genitoplasty for congenital adrenal hyperplasia. *The Journal of Urology* 179: 634–38. [CrossRef]

Deans, Rebecca, Sarah M. Creighton, Lih-M. Liao, and Gerard S. Conway. 2012. Timing of gonadectomy in adult women with complete androgen insensitivity syndrome (CAIS): Patient preferences and clinical evidence. *Clinical Endocrinology* 76: 894–98. [CrossRef]

Dodds, Peter R., Stephen J. Batter, Dennis E. Shield, Scott R. Serels, Francis A. Gavafalo, and Paul K. Maloney. 2008. Adaptation of adults to uncorrected hypospadias. *Urology* 71: 682–85. [CrossRef]

Döhnert, Ulla, Lutz Wünsch, and Olaf Hiort. 2017. Gonadectomy in Complete Androgen Insensitivity Syndrome: Why and When? *Sexual Development* 11: 171–74. [CrossRef]

Duranteau, Lise, Marion Rapp, Tim C. van de Grift, Angelica L. Hirschberg, Agneta Nordenskjöld, and dsd-LIFE group. 2020. Participant- and clinician-reported long-term outcomes after surgery in individuals with complete androgen insensitivity syndrome. *Journal of Pediatric and Adolescent Gynecology* 34: 168–75. [CrossRef]

Durie, Mason H. 1985. A Maori perspective of health. *Social Science & Medicine* 20: 483–86. [CrossRef]

Durie, Mason H. 1999. Te Pae Māhutonga: A model for Māori health promotion. *Health Promotion Forum of New Zealand Newsletter* 49: 2–5.

Freda, Maria F., Francesca Dicé, Maria Auricchio, Mariacarolina Salerno, and Paolo Valerio. 2015. Suspended sorrow: The crisis in understanding the diagnosis for the mothers of children with a disorder of sex development. *International Journal of Sexual Health* 27: 1–13. [CrossRef]

Garland, Fae, Kay Lalor, and Mitchell Travis. 2022. Intersex Activism, Medical Power/Knowledge and the Scalar Limitations of the United Nations. *Human Rights Law Review* 22: 1–22. [CrossRef]

Garland, Fae, Michael Thomson, Mitchell Travis, and Joshua Warburton. 2021. Management of 'disorders of sex development'/intersex variations in children: Results from a freedom of information exercise. *Medical Law International* 21: 116–46. [CrossRef]

HDC. 1996. The Health and Disability (Code of Health and Disability Services Consumers' Rights) Regulation. Available online: https://www.hdc.org.nz/your-rights/about-the-code/code-of-health-and-disability-services-consumers-rights/ (accessed on 23 November 2023).

HDCA. 1994. Health and Disability Commissioner Act 1994 (N.Z.). Available online: https://www.legislation.govt.nz/act/public/1994/0088/latest/DLM333584.html (accessed on 23 November 2023).

Holmes, Morgan. 2002a. Queer Cut Bodies. In *Queer Frontiers: Millennial Geographies, Genders, and Generations*. Edited by J. A. Boone, Martin Dupuis, Martin Meeker, Karin Quimby, Cindy Sarver, Debra Silverman and Rosemary Weatherston. Madison: The University of Wisconsin Press, pp. 84–110.

Holmes, Morgan. 2002b. Rethinking the meaning and management of intersexuality. *Sexualities* 5: 159–80. [CrossRef]

Hoy, Nathan Y., and Keith F. Rourke. 2016. Better defining the spectrum of adult hypospadias: Examining the effect of childhood surgery on adult presentation. *Urology* 99: 281–86. [CrossRef] [PubMed]

HRA. 1993. Human Rights Act 1993 (N.Z). Available online: https://www.legislation.govt.nz/act/public/1993/0082/latest/DLM304212.html (accessed on 23 November 2023).

Kapeli, Sarah A. 2021. A latent profile analysis of Pacific health values. *Pacific Health Dialog* 21: 531–44. [CrossRef]

Kerekere, Elizabeth. 2017. *Part of the whānau: The Emergence of takatāpui identity—he whāriki takatāpui*. Wellington: Victoria University of Wellington. Available online: http://researcharchive.vuw.ac.nz/bitstream/handle/10063/6369/thesis_access.pdf?sequence=1 (accessed on 23 November 2023).

Kessler, Suzanne J. 1998. *Lessons from the Intersexed*. New Brunswick: Rutgers University Press.

Liao, Lih M. 2007. Towards a clinical-psychological approach to address the heterosexual concerns of intersexed women. In *Out in Psychology: Lesbian, Gay, Bisexual, Trans and Queer Perspectives*. Edited by Victoria Clarke and Elizabeth Peel. Hoboken: John Wiley & Sons, pp. 391–408.

Long, Christopher J., and Douglas A. Canning. 2016. Hypospadias: Are we as good as we think when we correct proximal hypospadias? *Journal of Pediatric Urology* 12: 196.e1–196.e5. [CrossRef] [PubMed]

Long, Christopher J., David I. Chu, Robert W. Tenney, Andrew R. Morris, Dana A. Weiss, Aseem R. Shukla, Arun K. Srinivasan, Stephen A. Zderic, Thomas F. Kolon, and Douglas A. Canning. 2017. Intermediate-term follow-up of proximal hypospadias repair reveals high complication rate. *The Journal of Urology* 197: 852–58. [CrossRef] [PubMed]

Lucas, Jacob, Tyler Hightower, Dana A. Weiss, Jason Van Batavia, Simonna Coelho, Arun K. Srinivasan, Aseem R. Shukla, Steven A. Zderic, Thomas F. Kolon, Mark R. Zaontz, and et al. 2020. Time to complication detection after primary pediatric hypospadias repair: A large, single center, retrospective cohort analysis. *Journal of Urology* 204: 338–43. [CrossRef] [PubMed]

Lundberg, Tove, Anders Lindström, Katrina Roen, and Peter Hegarty. 2017. From knowing nothing to knowing now: Parents' experiences of caring for their children with Congenital Adrenal Hyperplasia. *Journal of Pediatric Psychology* 42: 520–29. [CrossRef]

Meyer-Bahlburg, Heino F. L., Jananne Khuri, Jazmin Reyes-Portillo, and Maria I. New. 2017. Stigma in medical settings as reported retrospectively by women with congenital adrenal hyperplasia (CAH) for their childhood and adolescence. *Journal of Pediatric Psychology* 42: 496–503. [CrossRef]

Minto, Catherine L., Sarah Creighton, and Christopher Woodhouse. 2001. Long Term Sexual Function in Intersex Conditions with Ambiguous Genitalia. *Journal of Pediatric and Adolescent Gynecology* 14: 141–42. [CrossRef]

Monro, Surya, Daniela Crocetti, Tray Yeadon-Lee, Fay Garland, and Mitch Travis. 2017. *Intersex, Variations of Sex Characteristics, and DSD: The Need for Change*; Huddersfield: University of Huddersfield Press. Available online: http://eprints.hud.ac.uk/id/eprint/33535/ (accessed on 23 November 2023).

NZBORA. 1990. New Zealand Bill of Rights Act 1990 (N.Z.). Available online: https://www.legislation.govt.nz/act/public/1990/0109/latest/DLM224792.html (accessed on 23 November 2023).

NZHRC. 2008. *To Be Who I Am, Kia Noho Au Ki Tōku Anō: Report of the Inquiry into Discrimination Experienced by Transgender People He Pūrongo mō te Uiuitanga mō Aukatitanga e Pāngia ana e ngā Tangata Whakawhitiira*. Wellington: NZHRC.

NZHRC. 2016. *Intersex Roundtable Report 2016: The Practice of Genital Normalisation on Intersex Children in Aotearoa New Zealand*. Wellington: NZHRC.

NZHRC. 2018. *Intersex Roundtable Report 2017: Ending the Practice of Genital Normalisation on Intersex Children in Aotearoa New Zealand*. Wellington: NZHRC.

NZHRC. 2020. PRISM: Human Rights Issues Relating to Sexual Orientation, Gender Identity and Expression, and Sex Characteristics (SOGIESC) in Aotearoa New Zealand. Available online: https://www.hrc.co.nz/files/9215/9253/7296/HRC_PRISM_SOGIESC_Report_June_2020_FINAL.pdf (accessed on 23 November 2023).

OHCHR. 2021. The Core International Human Rights Instruments and Their Monitoring Bodies. Available online: https://www.ohchr.org/EN/ProfessionalInterest/Pages/CoreInstruments.aspx (accessed on 23 November 2023).

Pfistermuller, Katherine L. M., Andrew J. McArdle, and Peter M. Cuckow. 2015. Meta-analysis of complication rates of the tubularized incised plate (TIP) repair. *The Journal of Pediatric Urology* 11: 54–59. [CrossRef] [PubMed]

Roen, Katrina. 2022. Hypospadias surgery: Understanding parental emotions, decisions and regrets. *International Journal of Impotence Research* 35: 67–71. [CrossRef]

Roen, Katrina, and Eli Oliver. 2022. Decolonising and demedicalising intersex research. *Feminism & Psychology* 32: 281–90. [CrossRef]

Sanders, Caroline, Zoe Edwards, and Kimberley Keegan. 2017. Exploring stakeholder experiences of interprofessional teamwork in sex development outpatient clinics. *Journal of Interprofessional Care* 31: 376–85. [CrossRef]

Schneuer, Francisco J., Andrew J. A. Holland, Gavin Pereira, Carol Bower, and Natasha Nassar. 2015. Prevalence, repairs and complications of hypospadias: An Australian population-based study. *Archives of Disease in Childhood* 100: 1038–43. [CrossRef]

Schönbucher, Verena B., Daniel M. Weber, and Markus A. Landolt. 2008. Psychosocial adjustment, health-related quality of life, and psychosexual development of boys with hypospadias: A systematic review. *Journal of Pediatric Psychology* 33: 520–35. [CrossRef]

Schützmann, Karsten, Lisa Brinkmann, Melanie Schacht, and Hertha Richter-Appelt. 2009. Psychological distress, self-harming behavior, and suicidal tendencies in adults with disorders of sex development. *Archives of Sexual Behaviour* 38: 16–33. [CrossRef] [PubMed]

Snodgrass, Warren, Carlos Villanueva, and Nicol Bush. 2014. Primary and reoperative hypospadias repair in adults: Are results different than in children? *Journal of Urology* 192: 1730–33. [CrossRef] [PubMed]

SOGII. 2013. Submission from the Aotearoa New Zealand's Sexual Orientation, Gender Identity and Intersex (SOGII) UPR Coalition 2013. Available online: https://uprdoc.ohchr.org/uprweb/downloadfile.aspx?filename=294&file=CoverPage (accessed on 23 November 2023).

Starship. 2020. *Differences of Sex Development—Atawhai Taihemahema*; Auckland: Starship Child Health. Available online: https://starship.org.nz/guidelines/differences-of-sex-development-atawhai-taihemahema/ (accessed on 23 November 2023).

Steers, Denise M., Georgia L. Andrews, Esko J. Wiltshire, Angela J. Ballantyne, Sunny C. Collings, and Maria H. Stubbe. 2021. Young people with a variation in sex characteristics in Aotearoa/New Zealand: Identity, activism and healthcare decision-making. *Culture, Health & Sexuality* 23: 457–71. [CrossRef]

Steinmacher, Sahra, Sara Y. Brucker, Andrina Kolle, Bernhard Kramer, Dorit Scholler, and Katharina Rall. 2021. Malignant Germ Cell Tumors and Their Precursor Gonadal Lesions in Patients with XY-DSD: A Case Series and Review of the Literature. *International Journal of Environmental Research and Public Health* 18: 5648. [CrossRef]

Thomsen, Patrick, Sarah Mclean-Osborn, Hollyanna Ainea, and Allyssa Verner-Pula. 2021. Examining the State of Health Research on Pacific Rainbow Communities in New Zealand; Literature Review. *Pacific Health Dialog* 21: 449–57. [CrossRef]

Tosh, Jemma. 2020. Intersex Youth: Non-consensual surgeries and nosocomial sexual abuse. In *Therapeutic Rape Culture*, 1st ed. London: Routledge, pp. 20–35. [CrossRef]

Treaty of Waitangi Te Tiriti o Waitangi. 1840. Available online: https://waitangitribunal.govt.nz/treaty-of-waitangi/meaning-of-the-treaty/ (accessed on 23 November 2023).

UNCRC. 2003. General Comment No. 4: Adolescent Health and Development in the Context of the Convention on the Rights of the Child CRC/GC/2003/4. Available online: https://docstore.ohchr.org/SelfServices/FilesHandler.ashx?enc=6QkG1d%252FPPRiCAqhKb7yhsiQql8gX5Zxh0cQqSRzx6ZfAICbDzm5DUreYo1tlYOkZcPE%252BQh98dgWJaknr%252BF7jm9%252BkvHmi4ctJTvJ1CPTUqN7%252F4K3R8rTOQIXpWvhMbx0f (accessed on 23 November 2023).

UNCRC. 2009. General Comment No. 11: Indigenous Children and Their Rights under the Convention CRC/C/GC/11. Available online: https://docstore.ohchr.org/SelfServices/FilesHandler.ashx?enc=6QkG1d%252FPPRiCAqhKb7yhsqIkirKQZLK2M58RF%252F5F0vHfIzasSO0EEdqdWmq9j7BREhPNv8rsqw5s1P9yZnbT0%252BVCtG7gTjfUoMHKWMhfZjxkzJvW8MwfhHmnb02XKphT (accessed on 23 November 2023).

UNCRC. 2011. General Comment No. 13: The Right of the Child to Freedom from All Forms of Violence CRC/C/GC/13. Available online: https://www2.ohchr.org/english/bodies/crc/docs/crc.c.gc.13_en.pdf (accessed on 23 November 2023).

UNCRC. 2013. General Comment No. 14 on the Right of the Child to Have His or Her Best Interests Taken as a Primary Consideration (Art. 3, Para. 1) CRC/C/GC/14. Available online: https://www2.ohchr.org/english/bodies/crc/docs/gc/crc_c_gc_14_eng.pdf (accessed on 23 November 2023).

UNCRC. 2016a. Concluding Observations on the Fifth Periodic Report of New Zealand CRC/C/NZL/CO/5. Available online: https://documents-dds-ny.un.org/doc/UNDOC/GEN/G16/236/30/PDF/G1623630.pdf?OpenElement (accessed on 23 November 2023).

UNCRC. 2016b. New Zealand Government Response to Questions from the United Nations Committee on the Rights of the Child. Available online: https://tbinternet.ohchr.org/Treaties/CRC/Shared%2520Documents/NZL/INT_CRC_AIS_NZL_25497_E.pdf (accessed on 23 November 2023).

UNCRC. 2020. List of Issues Prior to Submission of the Sixth Periodic Report of New ZealandCRC/C/NZL/QPR/6. Available online: https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbolno=CRC%252FC%252FNZL%252FQPR%252F6&Lang=en (accessed on 23 November 2023).

UNGA. 1948. Universal Declaration of Human Rights UNGA Res 217 A(III)). Available online: https://www.ohchr.org/en/universal-declaration-of-human-rights (accessed on 24 November 2023).

UNGA. 1966a. International Covenant on Civil and Political Rights. United Nations Treaty Series, 999, 171. Available online: https://www.ohchr.org/en/instruments-mechanisms/instruments/international-covenant-civil-and-political-rights (accessed on 23 November 2023).

UNGA. 1966b. International Covenant on Economic, Social and Cultural Rights. United Nations Treaty Series, 993, 3. Available online: https://www.ohchr.org/en/instruments-mechanisms/instruments/international-covenant-economic-social-and-cultural-rights (accessed on 23 November 2023).

UNGA. 1984. Convention Against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (UNCAT). United Nations Treaty Series, 1465, 85. Available online: https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-against-torture-and-other-cruel-inhuman-or-degrading (accessed on 23 November 2023).

UNGA. 1989. Convention on the Rights of the Child. United Nations Treaty Series, 1577, 3. Available online: https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-rights-child (accessed on 23 November 2023).

UNGA. 2007. United Nations Declaration on the Rights of Indigenous Peoples A/RES/61/295. Available online: https://www.un.org/development/desa/indigenouspeoples/wp-content/uploads/sites/19/2018/11/UNDRIP_E_web.pdf (accessed on 23 November 2023).

UNHCR. 2016. Right to Health and Indigenous Peoples with a Focus on Children and Youth: Study by the Expert Mechanism on the Rights of Indigenous Peoples A/HRC/33/57. Available online: https://www.ohchr.org/en/documents/thematic-reports/ahrc3357-right-health-and-indigenous-peoples-focus-children-and-youth (accessed on 23 November 2023).

UNHRC. 2013. Report of the Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment A/HRC/22/53. Available online: https://www.ohchr.org/sites/default/files/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53_English.pdf (accessed on 23 November 2023).

UNHRC. 2018. Summary of Stakeholders' Submissions on New Zealand Report of the Office of the United Nations High Commissioner for Human Rights A/HRC/WG.6/32/NZL/3. Available online: https://documents-dds-ny.un.org/doc/UNDOC/GEN/G18/342/40/PDF/G1834240.pdf?OpenElement (accessed on 23 November 2023).

UNHRC. 2019. Report of the Working Group on the Universal Periodic Review: New Zealand A/HRC/41/4. Available online: https://documents-dds-ny.un.org/doc/UNDOC/GEN/G19/087/77/PDF/G1908777.pdf?OpenElement (accessed on 23 November 2023).

UNHRC. 2021. Efforts to Implement the United Nations Declaration on the Rights of Indigenous Peoples: Indigenous Peoples and the Right to Self-Determination: Draft Report of the Expert Mechanism on the Rights of Indigenous Peoples. Available online: https://documents-dds-ny.un.org/doc/UNDOC/GEN/G21/100/89/PDF/G2110089.pdf?OpenElement (accessed on 23 November 2023).

van Rooyen, Amanda, Tineke Water, Shayne Rasmussen, and Kate Diesfeld. 2015. What Makes a Child a 'Competent' Child. *The New Zealand Medical Journal* 128: 88–95.

Vavilov, Sergey, Grahame Smith, Malcolm Starkey, Peter Pockney, and Aniruddh V. Deshpande. 2020. Parental decision regret in childhood hypospadias surgery: A systematic review. *Journal of Paediatrics and Child Health* 56: 1514–20. [CrossRef]

Weidler, Erica M., Maria E. Linnaus, Arlene B. Baratz, Luis F. Goncalves, Smita Bailey, S. Janett Hernandez, Veronica Gomez-Lobo, and Kathleen van Leeuwen. 2019. A Management Protocol for Gonad Preservation in Patients with Androgen Insensitivity Syndrome. *Journal of Pediatric and Adolescent Gynecology* 32: 605–11. [CrossRef] [PubMed]

WHO. 2015. *Sexual Health, Human Rights and the Law*. Geneva: World Health Organization.

Wood, B. 1998. *Consent in Child and Youth Health: Information for Practitioners*; Tokyo: Ministry of Health.

Zelayandia-Gonzalez, Ernesto. 2023. The growing visibility of intersex demands as the United Nations: A review of the treaty bodies' concluding observations. *Social Sciences* 12: 73. [CrossRef]

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Article

Uncertain Knowledge: The Medicalisation of Intersex People and the Production of Ignorance

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Abstract: Ignorance is produced through mechanisms related to power relations and socio-cultural context. This article examines whether the theoretical conceptualisation of agnotology may be useful when exploring intersex and the way it has been erased socially and physically. Specifically, based on the work of a PhD in Sociology and History of Science, it proposes categorising three types of mechanisms of ignorance production—cultural, epistemological and physical—with the aim of providing a greater understanding of how medicine, science and technology participate in a continuous process of erasing intersex bodies and lived experiences. Using medical literature, interviews and observations, the article focuses on a specific area of biomedical knowledge and intervention: the prenatal 'treatment' of Congenital Adrenal Hyperplasia (CAH) with dexamethasone or 'prenatal DEX'. It shows how this procedure was pioneered by French doctors and how it continues to be practised in France despite numerous uncertainties and controversies inside and outside of the medical sphere.

Keywords: biomedicine; gender; intersex; prenatal diagnosis; controversy; ignorance; hormones; France; epistemology; body

Citation: Raz, Michal. 2024. Uncertain Knowledge: The Medicalisation of Intersex People and the Production of Ignorance. *Social Sciences* 13: 385. https://doi.org/10.3390/socsci13080385

Academic Editors: Surya Monro, Tanya Ni Mhuirthile, Amets Suess-Schwend, Fae Garland, Daniela Crocetti, David Andrew Griffiths and Katrina Roen

Received: 2 April 2024
Revised: 11 July 2024
Accepted: 19 July 2024
Published: 24 July 2024

1. Introduction

> 'Knowledge is possible only through the systematic "social construction of ignorance"'. (Rayner 2012, p. 111)

Ignorance is not only the absence of knowledge but a gendered and racialised (Mills [1997] 2022) active process that has a 'complex political and sexual geography' (Proctor and Schiebinger 2008, p. 2). Several scholars have shown how some parts of the body, especially parts perceived as female (e.g., the clitoris) or gender non-conformity, have been the stage of an 'epistemology of ignorance' (Tuana 2004), subjected to mechanisms of invisibilisation. Knowledge is very entangled with power relations and is, therefore, dependent on what is considered to be, in different cultures and times, legitimate subjects of scientific production (Foucault [1976] 1988).

The pioneers of agnotology, Robert Proctor and Londa Schiebinger, showed how ignorance is produced through several "mechanisms, such as deliberate or inadvertent neglect, secrecy and suppression, document destruction, unquestioned tradition, and myriad forms of inherent (or avoidable) culturopolitical selectivity" (Proctor and Schiebinger 2008, p. vi). Following a sociological perspective of agnotology (Funkenstein and Steinsaltz 1987; Gross and McGoey 2022), this article focuses on how these mechanisms apply to intersex variations. It analyses 'the modes of oversight and invisibility'[1] (Fillion and Torny 2016, p. 49) of certain knowledge about different aspects concerning intersex people.[2]

Since the 1950s, most intersex people have been medicalised and undergone hormonal and/or surgical interventions during childhood and/or adolescence (Fausto-Sterling 2000; Karkazis 2008; Kessler 1998; Holmes 2008). Scholars in critical intersex studies (Holmes 2009) showed that intersex people, whose very existence unsettles longstanding convictions around sex binarism and dominant gender norms, have been subjected to forms of erasure (Holmes 2008; Kennedy 2020; Monro et al. 2024; Morrison et al. 2021). Despite the abundance of medical publications on the issue of intersex, this erasure can be understood as a mechanism of ignorance production. This mechanism mainly concerns how scientific knowledge and technologies concerning intersex are related to power and hierarchies between normative and non-normative bodies.

This paper examines the way the theoretical conceptualisation of agnotology may be useful when exploring the medicalisation of intersex people. It aims to explore the mechanisms of ignorance production—categorised into three types—since the development of Johns Hopkins' biomedical protocol by looking at the French context and its relationship to global debates. In a nutshell, this protocol, developed by a multidisciplinary staff in the 1950s at the Johns Hopkins Hospital in the United States, called for the early detection and medicalisation of intersex children. Doctors and psychologists suggested deciding on the child's gender assignment as soon as possible and medically intervening (ideally before the child was 3 years old) to make the body conform to the assigned gender, advising parents to keep the medical assignment a secret. I will argue that the epistemological considerations around ignorance production in science are entangled with practices of erasure, which attempt to make intersex lives impossible, echoing Viviane Namaste's findings on the 'invisible lives' of transgender people in our societies, in discourse, and in everyday life institutions (Namaste 2000).

To illustrate how some of these mechanisms apply in practice, as well as their consequences in intersex people's (and their parents') lives, I will analyse a specific area of current biomedical knowledge and intervention in detail: prenatal 'treatment'[3] for Congenital Adrenal Hyperplasia (CAH).[4] With treatment pioneered in France in 1980, CAH is the only group of genetic conditions and the only intersex variation for which prenatal hormonal 'treatment' is prescribed. My analysis will reveal that biomedical knowledge, technologies and practices concerning intersex people all belong to a specific 'regime of truth' (*régime de verité*, Foucault [1976] 1995), whose premises and consequences are unquestioned. Although professionals justify their protocols with science, the data produced resembles what I propose to call *uncertain knowledge*, even in the eyes of scientific experts themselves. My analysis will also show how 'uncomfortable knowledge' (Rayner 2012) is quickly sidelined in order to preserve the apparent consensus around controversial practices of 'normalisation' of 'atypical' sex, such as the prescription of prenatal hormones to avoid the 'masculinisation' of 46,XX chromosome foetuses with CAH (Dreger et al. 2012). By unravelling the mechanisms of ignorance production, a paradox emerges: increasing biomedical knowledge and techniques seems to produce new questions, dilemmas and debates.

2. Materials and Methods

This paper presents one aspect of a larger research project on medical practices on intersex people during the second half of the 20th century and the beginning of the 21st century, mainly in France and Israel. It is primarily a development of a chapter in my PhD dissertation, which is focused on the French context (Raz 2019, available in French in open access), where I used qualitative sociological and historical methods to analyse medical archives, interviews and observations. The historical materials included scientific and institutional literature between 1950 and 2022 and oral history via interviews. The medical literature sampling, via PubMed, consisted of researching articles published by French doctors in French and English using keywords (Congenital Adrenal Hyperplasia; Hermaphrodism; Hermaphroditism; Pseudo-hermaphroditism; Ambiguous Genitalia; Disorder of Sex Development; Micropenis; Hypospadias). Approximately 420 articles and 30 books/dissertations were identified, from which the most relevant were analysed in depth (about 80). Publications that were not focused on intersex aspects (i.e., only concentrated on biochemical aspects of CAH, genetics, tumours, etc.) were not included in the analysis presented here. Publications from nationally recognised French journals were given priority (for example, *Pédiatrie*, *Annales pédiatriques*, *Annales d'endocrinologie*, *Archives* *françaises de pédiatrie, Chirurgie pédiatrique, Gazette médicale de France, Journal de génétique humaine, La revue du Praticien, L'Année endocrinologique, La Presse médicale*, *Revue française de gynécologie et d'obstétrique*) especially for the 1950s to 1990s timeframe. In the section of the present article concerning prenatal 'treatment' for CAH, I also use international biomedical and bioethical publications. These were complemented by French institutional documents, such as official protocols and reports. Every (online) document coming from a French hospital or public health institution concerning CAH was collected.

Besides the literature review, I carried out semi-structured interviews with biomedical practitioners (19) and parents of intersex children with CAH (7) between 2012 and 2015. The interviews were recorded with the knowledge and consent of the interviewees, and all data were anonymised. All of the names that appear, other than from published sources, are pseudonyms. Participants were informed of the subject of the interview and had the opportunity to refuse to reply to certain questions, especially parents, for whom there was a possible emotional impact since the interview addressed intimate issues. To avoid this potential negative impact, the interview was conducted following general questions, avoiding intrusion and letting the interviewees narrate the story they wanted to tell in their own words. All participants received an electronic copy of the final result of the research (the PhD dissertation). Two interviews were conducted by phone due to geographical distance. All interviews were analysed using a qualitative thematic method: the content was analysed manually, identifying major repeated themes and then focusing particularly on less documented topics, such as prenatal diagnosis of intersex variation. Indeed, I was struck by the absence of this topic in social science published work. Other data used in the study came from my in situ observations of national and local hospital staff meetings (five specialised multidisciplinary meetings discussing 'patients' categorised as having 'Disorders of Sex Development' (DSD)) and observations from international and French medical conferences (4) that took place in 2013–2015. French conferences were open to the public (upon application) and were co-organised by the parents' association, which was informed about my research. I consider official presentations during these conferences to be almost-public data. These observations helped me acquire a firm understanding of both official medical presentations and unofficial conversations and remarks during breaks, as well as non-public discussions between medical colleagues. I also collected data from documents belonging to a CAH parents' association with the permission of the association's president. These documents included the association's bulletin (2004–2015) as well as information on regional-level meetings between parents and medical staff (2008–2012) and on an online discussion forum (2005–2018). As the in-depth research data were mainly collected before 2018, the findings may not be entirely applicable to current days. The debates and medical practices might have changed since then. Nevertheless, I have been paying careful attention to the subject, and no significant official changes involving new recommendations or new practices have been published in the meantime. Also, for this article, more recent data and publications were used, affirming the relevance of the results to 2024.

I started research on this topic in 2009 as a young non-French endosex (i.e., non-intersex) person living in France, and tried to develop an ethically situated position taking into account the difficulties for intersex people to exist as a collective and to make their voice heard in the then-current context in France where research and activism were almost non-existent. As ignorance production mechanisms lie at the heart of my research, they had to be taken into consideration not only as a theoretical tool used for analysing the materials but also as a reflexive reminder of my own position in this field of research. My research approach was to cast a critical feminist gaze on the processes by which biomedical science aims to reverse the traditional subject–object power relations. Intersex people have been an object of scientific interest for centuries. Accordingly, positioning my research by focusing on legitimate, dominant social actors—mainly doctors—was the methodological and ethical position I was most comfortable taking. This decision prioritised the study of the powerful rather than reiterating the objectification of the dominated population.

3. Intersex People and the Mechanisms of Ignorance Production

> 'If we are to fully understand the complex practices of knowledge production and the variety of features that account for why something is known, we must also understand the practices that account for not knowing, that is, for our lack of knowledge about a phenomenon' (Tuana 2004, pp. 194–95).

The mechanisms of ignorance production about intersex are deployed consciously to a greater or lesser extent. They include, among others, the following: cultural invisibilisation, secrecy and lack of medical information, division among variations of sex characteristics, social biases in scientific studies and insufficient robust data. The mindset of erasure behind processes of ignorance production has had serious repercussions on intersex people. A better understanding of these processes should help to improve knowledge about intersex and the negative consequences of ignorance.

In this context, the first section of this paper proposes a categorisation of how ignorance is produced in order to help analyse how medicine, science and technology participate in a continuous process of erasing intersex bodies and lived experiences (Monro et al. 2021). This categorisation is possible thanks to the large amount of data now available on intersex people and my own research experience over the last 15 years. I suggest distinguishing three types of social erasure as they apply to intersex: cultural erasure, epistemological erasure and physical erasure. We will look at these three elements in detail below.

1. Cultural erasure

   First, on a general level, ignorance is produced by removing the existence of intersex variations from the collective awareness and by allowing the biomedical sphere to monopolise it. Many social actors participate in this process, mainly state institutions, cultural content producers, medical staff and education professionals. Modern Western culture has established, deep in our perceptions, a sense of obviousness of sex binarism that intersex or other bodies that do not conform to norms risk destabilising (King 2016; Laqueur 1990).

   Throughout history, 'hermaphrodites',[5] as a scientific category, have been positioned between visibility and invisibility, depending on the cultural context and power relations in place. In modern history (Daston and Park 1995), considerable scientific resources have been invested in the search for the 'true sex' (Foucault 1980).[6] For example, at the end of the 19th and beginning of the 20th centuries, intersex people were publicly exposed, exoticised and dehumanised in the West during Circus shows (De Herder 2020). With the arrival of modern science (starting from the 16th century), intersex bodies, especially the genitals, have often been published in medical books and were super-visible in a dehumanising way. As Amato put it: 'Ironically, it is this heightened visibility of intersex bodies that entails their invisibilisation' (Amato 2016, p. 49).

   During most of the 20th century, intersex people were progressively invisiblised and confined almost exclusively to the medical sphere as 'syndromes' of 'sexual ambiguity'. Consequently, they were absent from popular culture, arts and school curricula (King 2016; Sterling 2021) and were excluded from collective activities such as Olympic sports (Bohuon 2015). This had severe consequences on intersex lives. The title of an article written by Sarita Vincent Guillot, a French intersex activist, illustrates this reality: '*Intersex: not having the right to say what no one told us we were*' (Guillot 2008, p. 37, author's translation). A change occurred at the beginning of the 21st century with the development of 'intersex intelligibility in the cultural imaginary' (Amato 2016, p. 22). This led to intersex people appearing increasingly more often in books, movies and television, as well as in some educational programs. This fundamental shift was made possible by the creation of movements who fought for intersex people to be socially recognised, not as rhetorical or symbolic figures, but as embodied human beings fighting for their rights. This increasing visibility has been slower to develop in France than in anglophone countries (Raz 2023).

2. Epistemological erasure

   The second type of social erasure is epistemological, that is to say, the scientific production of ignorance, whereby access to information and data such as personal files (solicited by individuals) or medical archives (solicited by scholars) is restricted or partial. Many physicians interpreted Johns Hopkins' biomedical protocol as a recommendation to conceal information from concerned people and sometimes also from their parents (Meoded-Danon and Yanay 2016). In practice, this involved advising parents to hide all details about a child's intersex variation in order to prevent any potential 'doubt' children might have about their sex and gender (Karkazis 2008). This mechanism legitimises ignorance by promoting it as something for one's own good (Funkenstein and Steinsaltz 1987). However, frequent silence and/or secrecy surrounding their bodies and medical history has negative repercussions on intersex people (Monro et al. 2024). Access to personal files is denied or restricted for many intersex people. Other obstacles to acquiring their own personal files include the financial cost and long waiting periods (Holmes 1994). Many are told that archive files have disappeared, been destroyed or lost. Sometimes, retrieved files are partial; for example, information is missing about medical interventions performed on them when they were young[7]. Some of these old practices, such as diffusing false information or denying access to medical files, were challenged during the 2005 'Consensus Conference' in Chicago, but they have not entirely stopped: individuals are still receiving partial and mainly pathologised information about their variation and past medical interventions. This production of a subjective ignorance of one's own body and history hinders the capacity of intersex people to produce their own knowledge. The consequence is that certain information is denied, and medical knowledge is positioned as the only legitimate form of knowledge. The subjectivation process of recovering one's 'stolen word' (*parole volée*, Guillot 2008, p. 47) implicates the need for intersex people to struggle against 'epistemic injustice' (Fricker 2007) of knowledge being withheld from them (Bastien-Charlebois 2017). As a result of this 'wrong' which is done to them, 'specifically in their capacity as a knower', they are prevented from 'collective interpretive resources', which would enable them to make sense of their own social experience (Fricker 2007, p. 1).

   Terminology issues are indeed very important. While many doctors present the current medical paradigm, which uses the DSD[8] nomenclature as neutral, intersex scholars argue that, on the contrary, it contributes to the stigmatisation and the erasure of intersex variations using a strategy of divide and rule (Davis 2015; Lundberg 2017; Aegerter 2022). More specifically, they believe that it concentrates on biomedical issues, such as diagnosis and genetics, so as to exclude an increasingly larger number of variations from the umbrella category of intersex (e.g., hypospadias, Turner or Klinefelter syndromes, and even CAH).

   Up to the present day in France, only authorised medical staff have access to data such as the number of intersex (or DSD) 'patients', the number and types of surgeries conducted or hormonal 'treatments' initiated and the age of the intersex person at the time of these interventions. These are the same people who promote the protocol itself. Indeed, a French Senate report indicated that even the Minister of Health admitted to having no data on the interventions and management of intersex variations (Blondin and Bouchoux 2017). This is still the case, though a report with data on the number of operations is to be published soon as directed by a law passed in 2021. The obstacles that non-medical scholars face in trying to access medical archives and data in France hinder the possibility for anyone other than medical practitioners to conduct intersex research. Since doctors and psycho-medical employees in hospitals are the only persons with access to these data, they are both the judge and jury—evaluating their own practices (Raz 2016). The inaccessibility to medical data, even for 'patients' themselves (and therefore persons for whom doctor–patient confidentiality does not apply), not only produces ignorance at the individual and collective levels but also difficulties in developing intersex studies in France.

3. Physical erasure
   The third type of erasure in the context of intersex people is physical obliteration. Embodied and concrete, it uses physical modifications to 'repair' or 'normalise' intersex bodies. It is related to a more general tendency to necropolitics (Mbembé 2003), whereby intersex lives are considered unworthy, attested to by degraded mental health, suicide attempts (Rosenwohl-Mack et al. 2020) and infanticide (Carpenter 2020; Behrens 2020), practices we may qualify as eugenic. Here, we especially think about voluntary interruptions of pregnancy that take place in different countries. That is attested by several scholars (Hashiloni-Dolev 2006; Jeon et al. 2012), open European data (Eurocat, *European surveillance of congenital anomalies*) and my own research in Israel (Raz 2015) and France (Raz 2019), where several doctors said they try to avoid these selective abortions but that they do occur in some centres. In the West, physical modifications to intersex persons, often without their consent, are widespread and commonplace. They consist of biomedical interventions which aim to erase any gap between social and medical norms. They include invasive non-reversible surgical operations (e.g., gonadectomies, vaginal creation or extension, cosmetic alteration of penile appearance, clitoris reduction or ablation, mastectomies), post-operation acts such as vaginal dilatations and hormonal prescriptions (in order to enlarge the penis, reduce the clitoris or body hair, replace physiological hormones that were stopped by gonad ablations, etc.) and laser epilation prescriptions. Some of these practices have evolved over time. Gonadectomies, for example, are not systematically conducted during a child's first years of life, but no proof exists to this day that 'normalisation' interventions have stopped or diminished in France. Many of the debates surrounding intersex people concentrate on the physical mutilation of bodies already born; few mention other types of erasure of bodily variations in the prenatal phase, such as pregnancy interruptions of intersex foetuses and hormonal intervention aiming to prevent the 'virilisation' of the foetus. I will detail this particular practice in the next part of this paper.

The three categories described above are related and intertwined. Epistemological erasure is always entangled with concrete practices of obliteration or regulation of bodies. The various processes of erasing intersex have enabled the illusion of a natural, exclusively binary sex to be maintained. This illusion serves as the postulate, the justification and the result of intersex 'normalisation' practices. In this sense, the production of ignorance about intersex stems from the belief that the existence of intersex people might disturb the cognitive bases of a society (Funkenstein and Steinsaltz 1987). In the following section, I will concentrate on a specific case study of these mechanisms situated in the biomedical sphere: the prenatal regulation of intersex bodies, mainly through the controversy surrounding prenatal hormonal 'treatment' for Congenital Adrenal Hyperplasia (CAH). Prenatal medicine is a field inherently filled with uncertainties, giving rise to numerous technical and ethical debates. My example aims to illustrate the way mechanisms of ignorance production apply in real-world settings.

4. Case Study: Uncertain Knowledge and the Controversy Surrounding Prenatal 'Treatment'

4.1. The Erasure of CAH Girls: A Short History

The history of the medicalisation of CAH illustrates the three types of erasure, particularly the physical and epistemological ones. CAH is related to the production of hormones by the adrenal glands. Already in the 1930s, doctors knew that there was a relationship between the hormonal activity of the adrenal glands and the 'masculinisation' of genitals in XX chromosome individuals. Salt-losing CAH is one of the several CAH variations and can be life threatening. It was only in 1949 that Lawson Wilkins, the founder of paediatric endocrinology, discovered that cortisone was an effective substance in reducing androgen production in a baby being treated at the Johns Hopkins Hospital (Eder 2010).

Wilkins claimed that children with XX chromosomes should be assigned as female, irrespective of their phenotype. This recommendation was revolutionary since many individuals with CAH were historically raised as boys before CAH diagnosis and the new protocol were introduced. The medicalisation of birth, new genetic technologies and other social and technological transformations made it appear obvious to physicians like Wilkins that people with XX-CAH are 'true' girls. Following the introduction of the Johns Hopkins protocol and the increasing 'technological imperative' (Koenig 1988), early interventions (i.e., hormonal therapy and surgery) to 'feminise' genitals via clitoridectomy and vaginoplasty were promoted and became routine practice typically between one and four years of life (Karkazis 2008).

Wilkins also promoted the idea that CAH variations must be distinguished from other intersex variations since the children were 'authentic girls' (Bernard et al. 1962). As it was related to a chronic endocrine condition, this variation was defined as a distinctive category with, supposedly, no relation to gender issues once the 'virilised girls' were 'normalised' (i.e., once all signs of what could be considered to be their 'ambiguous' sex characteristics were obliterated). This erasure transformed the way intersex people and their parents understood and experienced CAH; specifically, it made it difficult for them to relate their experience to the larger intersex reality of medical invalidation, thus exemplifying cultural erasure as well as epistemological and physical erasure. Due to the lack of cultural representations and social existence of the intersex category, CAH physical erasure could not be apprehended by concerned people as a social rather than a medical process.

Most parents were, and still are, influenced by this paradigm of erasure. The French parents of intersex children association *Surrénales* (the Adrenals) endorses medical discourse and practice. One of the mothers I interviewed who was a member of this association had a 14-year-old daughter with CAH. She described her understanding of her daughter's condition—probably because that is how it was explained to her—as follows: "*There is a malformation of the genitals because she didn't have... a vagina. So, they had to build all this and, well, after... we all agree that it's a girl and that there is absolutely no doubt about it*."[9] Thus, girls with CAH undergo physical and epistemological erasure by the medical and discursive removal of anything that might raise 'doubt' about their sex.

4.2. The Birth of Prenatal DEX

The physical erasure of intersex traits has taken place mostly after birth but also prenatally. This new temporality—even before a child is born and has a social existence—helped reinforce the three types of erasure: physical, of course, but also epistemological and cultural. More specifically, the erasure of the 'virilisation' of CAH girls that has mainly operated through postnatal biomedical interventions starts during pregnancy. From the late 1960s to the end of the 1970s, various research projects sought to find a means to identify intersex people prenatally. Throughout these 10 years or so, several attempts were made to find a marker for a specific genetic diagnosis, but all resulted in failure (Frasier et al. 1975). Elsewhere, in 1965, British researchers (led by gynaecologist Thomas Norman Jeffcoate) suggested the possibility of Prenatal Diagnosis (PND) of congenital adrenal hyperplasia through an analysis of steroids in amniotic fluid. From the beginning, the stated goals of this research were to improve postnatal care and to find a prenatal 'treatment' (Merkatz et al. 1969). At that time, it was still impossible to put this into practice. In the following years, efforts were made to elucidate biological mechanisms by genetically locating intersex variations and, at the same time, proposing ways of applying this knowledge to PND.

In 1969, a team of physicians in New York published the results of their study to test the validity of hormone sampling techniques during pregnancy (Merkatz et al. 1969). Between 1974 and 1977, studies identified the genetic link causing this variation, allowing a more precise biological diagnosis. In 1979, the prenatal diagnosis of CAH using amniocentesis became a reality in two French laboratories: one in Paris and the other in Lyon (Floret et al. 1980). This hormonal-based diagnosis technique spread in the 1980s, both in France, as illustrated by a retrospective study listing 274 pregnancies monitored for CAH in Lyon between 1979 and 1993 (Forest et al. 1993), and internationally.

In the early 1980s (i.e., shortly after their discovery of the hormonal-based technique for prenatal diagnosis in 1979), the same scientific team in Lyon made another discovery concerning hormonal intervention during pregnancy to reduce the 'masculinisation' of foetuses with CAH. Specifically, paediatrician Michel David and endocrinologist Maguelone Forest experimented with giving hydrocortisone to pregnant persons with a history of CAH to investigate the substance itself and its effects (David and Forest 1984). Despite the high cost of this 'virilisation' treatment, administering hormones to pregnant persons progressively became the norm in families considered 'at risk'. Although the procedure itself is technically quite simple, its timing is important: the aim is to start 'treatment' as soon as possible, even before one had diagnosed whether the foetus actually has CAH or not. Results for the first six treated cases were published in 1984. One of the doctors involved recounted to me in an interview:

> "We gave a fairly large dose of hydrocortisone, and then we still did an amniocentesis at mid-gestation to measure 17OHP in the amniotic fluid to know if it worked. Well, the hormone was very high, so we said to ourselves that it's not enough, so we increased the dose, and the child was born almost normal. She just had a clitoris a little bit big, but she's never had surgery, she's never had any problems, and things have always gone well in this family"[10].

Clearly, the goal of this intervention is the birth of a child considered 'normal' and the physical erasure of intersex traits. In the words of one of the specialists involved in the first PND treatment, it aimed to 'restrain' the virilisation (Ibid.) of XX foetus' genitals, mainly the formation of the vagina, and to avoid having a clitoris judged too large. Initially conceived as a tool to fight against 'serious' and 'incurable' diseases, as French law puts it,[11] prenatal diagnosis in intersex persons became a field where sex and gender were regulated. The purpose of this prenatal 'treatment' was not to prevent the metabolic risks linked to the CAH condition. From the outset, it was used explicitly as a tool to avoid and erase 'atypical' sex. The results presented in the aforementioned study in 1984 suggest that it was thanks to the prenatal intervention that things had 'always gone well in this family'. Indeed, the medical literature on PND DEX 'treatment' often emphasises its alleged benefits: genitals are less virilised, and therefore, surgery is sometimes considered unnecessary (Xu et al. 2020). A French retrospective study of foetuses who received DEX found that the majority of foetuses with CAH who received DEX at an early stage of gestation 'had normal external genitalia at birth', thus indicating that 'early DEX initiation is [essential] to prevent any surgery' (Tardy-Guidollet et al. 2014).

After these early experiments, this practice of administering hydrocortisone to pregnant persons at risk using a molecule called dexamethasone (DEX) began to extend to other countries. As Dreger states, "*'at-risk' mothers-to-be throughout the world started being offered prenatal dexamethasone*" (Dreger 2015, p. 361). For example, in New York, a clinical team led by Dr. Maria New started to experiment with this procedure in 1986, leading to the centre she led becoming the largest centre of prenatal hormonal intervention worldwide for women at risk for CAH. Interestingly, back in France, Paris's largest paediatric hospital—Necker-Enfants Malades—did not immediately provide this service. Dr. Bonnet was a surgeon practising there at the time. According to her, some endocrinologists were reticent about the 'treatment', fearing *'complications'*. However, she considered that the idea of prenatal 'treatment' "*is very good. If we can suppress androgens, we will have a much smaller clitoris at birth*".[12] The history of the invention and extension of the prenatal DEX show how mechanisms of physical erasure of intersex traits were implemented. This erasure stems from an epistemological and cultural perception expressed by physicians who consider intersex bodies (here, a large clitoris) unacceptable. The epistemological erasure also concerns producing ignorance about this 'treatment', a process I will detail in the next section.

4.3. International Controversy: Sidelining Uncomfortable Knowledge

While this 'treatment' was generally considered by doctors as something positive, 'to avoid surgery',[13] they gave no consideration to potential physical side effects to the pregnant person or the foetus or to ethical issues of the procedure. This section aims to illustrate how these mechanisms of ignorance production were activated, paying special attention to epistemological erasure and its consequences.

The fear of harmful effects (on the pregnant person and/or the foetus) was present from the beginning of DEX therapy. However, all criticism was quickly dismissed by the pioneering doctors, who asserted that "*there is no substantial evidence of foetal effects of high doses [. . .] or low doses of glucocorticoid therapy in human pregnancy*" (David and Forest 1984, p. 799). One of the members of the original French team also stated to me during an interview that psychological and physical studies were conducted on the first cases to verify that there were no adverse effects and that nothing was found to validate the fear of such effects.[14]

The assertion that no harmful side effects were found in the early years was supposed to reassure critics. Nevertheless, the logic behind the defence of prenatal DEX is based on the idea that we must prove that a 'treatment' is harmful after its use instead of proving that it is not harmful before its use. Hence, the absence or quasi-absence of well-founded knowledge about the long-term effects did not hold back the use of the procedure. It seems, therefore, that epistemological erasure, via scientific production of ignorance, is a central part of prenatal DEX.

DEX 'treatment' started to become controversial by the end of the 1990s, when it began to be criticised both from inside and outside the medical sphere itself. This controversy, which continues today, does not call into question the effectiveness of DEX, which is measured in terms of the 'feminisation' of the genitals. Rather, it is based on two criticisms: the first regards ethical, sociological and political concerns about the legitimacy of this 'treatment' (whose main goal was to 'normalise' bodies); the second regards its potential harmfulness.

The first criticism came from activist groups and social science researchers who warned about the ethical consequences of the prenatal erasure of intersex variations. From a bioethical point of view (Dreger et al. 2012; Dreger 2015), some persons oppose the very idea of wanting to 'devirilise' foetus genitals. This viewpoint affirms that even if the 'treatment' is not harmful, it should be questioned since it is an intervention that does not alleviate a vital danger but instead 'normalises' bodies by trying to erase not only intersex physical traits but also their social and cultural existence (Holmes 2008). This criticism does not find much support in the medical sphere, which considers that DEX 'treatment' helps to avoid painful surgery. This argument ignores the fact that there is also an alternative route with no DEX and no surgery. Thus, prenatal erasure of intersex is justified by medical claims of avoiding physical postnatal erasure that is never questioned.

The second criticism came from the fields of biomedicine and bioethics and specifically concerns the benefit/risk ratio. Stakeholders felt there could be significant adverse effects of the 'treatment' on foetuses, most of which are unaffected by the condition.[15] Another element of this criticism was the issue of insufficient data or missing data of good scientific quality on the long-term follow-up of children and adults exposed to DEX 'treatment'.

For more than twenty years now, doctors have been increasingly warning and arguing that the safety of this intervention has not been proven. The controversy began in the late 1990s with the publication of articles by Walter L. Miller, a paediatrician endocrinologist and professor at the University of California (Seckl and Miller 1997). In the conclusion of an article from 1999, he warned that: "*the ethics of needlessly subjecting 7 of 8 foetuses to an experimental therapy with unknown long-term consequences remain unresolved because the long-term safety and outcome have not been established*" (Miller 1999, p. 538). He also stated that "*therefore, prenatal treatment of CAH remains experimental*" (*Ibid*., p. 538). Potential harmful effects could affect all foetuses exposed to DEX: growth retardation, hypertension and effects on 'emotionality'.[16] Miller did not initially recommend prohibiting the 'treatment' but suggested framing it with safety measures in mind because "*it is important to be cautious now so that we do not have regrets later*" (*Ibid*., p. 538). In his opinion, prenatal DEX should only be used in large specialised centres that collect cases and establish a research protocol. Additionally, he claimed that physicians should obtain written, informed consent from the pregnant women concerned. In 2008, Miller reiterated his criticism and maintained that "*this experimental treatment is not warranted and should not be pursued, even in prospective clinical trials*" (Miller 2008, p. 17).

Other criticisms of prenatal DEX in the last twenty years highlight the production of ignorance, including the absence of studies, whether animal- or human-based, and determining whether or not foetal dexamethasone is harmful (McCann-Crosby et al. 2018). Indeed, several animal studies on in utero exposure to corticosteroids have raised questions about the safety of this 'treatment' (Hirvikoski et al. 2008). As for human studies, besides the Lyon research team's publication of their safety results in 1993 (Forest et al. 1989, 1993), a Swedish team was the primary force accentuating the debate in the 2000s, with different publications on a follow-up study of their 'patients'. They argued that their methodology was more scientifically rigorous than previous ones. As a precaution, and because of the possibility of long-term consequences, they only used DEX within the framework of a well-controlled clinical trial that started in 1999 (Hirvikoski et al. 2007). Their studies constitute the first short- and long-term neuropsychological assessments of children and adolescents treated in utero based on children's self-reports. In 2007, the first results were published and suggested that exposure to DEX in utero would have effects on brain development, with problems linked to verbal and visuospatial working memory, moderate behavioural abnormalities (shyness, strong emotionality, low self-esteem and poor academic performance), as well as defects in growth and psychomotor development.

Armed with these results, the team addressed the regional ethics committee in Stockholm in 2010, saying that it would be more prudent to interrupt recruiting 'patients' for their study, pending results from larger and more conclusive studies worldwide. The Swedish team, with its relatively small samples, continues to publish and speak at international conferences, saying that their study results to date are contradictory or unreliable and require further exploration (Hirvikoski et al. 2007; Lajic et al. 2018). In a 2014 interview, Dr. Dupuy asserted that, unlike the Swedish team, the Lyon team conducted large and reliable studies on their 'patients':

> "The problem is that the Swedes, they had, I don't know, 9, 10, 12 cases, while I had 50 or 60 antenatal diagnoses of hyperplasia with the treatment. I don't know how many I have done, more than a hundred. [. . .] And each time I have done a study after 5 years, 10 years, to review our patients, to review everything that we thought we had to follow. I've done that several times, eh, and I've always published our work on it. No, we didn't find anything salient."[17]

In terms of studies with relatively large samples, two suggested that there may be long-term harmful cognitive effects (New et al. 2001; Meyer-Bahlburg et al. 2012) and that more comprehensive studies need to be implemented (Forest et al. 1998). However, follow-up studies in large medical centres struggled to find and recruit 'patients' for the follow-up questionnaire, an aspect which also makes the results unreliable (Dreger 2015). One of these studies—conducted in New York—attempted to evaluate the long-term outcome of women and children exposed in utero. However, only half of the families included in the study actually responded (72 out of 154 questionnaires sent) (Speiser et al. 2010). In short, "*the medical-scientific literature was utterly devoid of well-controlled studies of efficacy and long-term safety of prenatal dexamethasone for intersex prevention*" (Dreger 2015, pp. 228–29). These various points highlight that knowledge about the adverse effects of prenatal DEX is still insufficient and uncertain.

A lack of scientific knowledge about the safety of prenatal DEX 'treatment' must not be perceived as a coincidence: the relative ignorance about this 'treatment' is part of an ignorance production mechanism related to the epistemological erasure of intersex. We see that science does not impose its truth in a linear and homogeneous manner and that physicians choose to position themselves differently in relation to the controversy: the way of presenting the risks and evaluating them largely depends on the point of view adopted by the individual physician and the staff concerned. More specifically, some doctors who administered prenatal DEX—notably Maria New—put forward a double discourse. In front of parents, they promoted the 'treatment' as effective and safe; in front of the authorities, they sought funding to carry out follow-up studies on their own 'patients', claiming that the effects of the drug had not yet been determined (Dreger 2015). In other words, on the one hand, they were promoting the practice of administering DEX by attempting to ignore uncertainties; on the other hand, they were working at promoting research that would resolve these same uncertainties, which were ignored in clinical practice.

Alice Dreger, a researcher and former member of the Intersex Society of North America (ISNA), which was the first intersex activist group in the world, joined forces with health professionals to fight against the use of DEX. She distributed information about the potential harmfulness of prenatal DEX, demanded a stop to its use and called for an investigation by (American) federal authorities, explaining—with the support of others—that it violated the fundamental principles of clinical medical research. In her 2015 book, Dreger recounts this fight, which included standing up to doctors during international congresses, including in January 2010 when she confronted Maria New. In the French context, promoters of prenatal DEX were very aware of this growing public opposition worldwide. Dr. Dupuy recalls: "*I was attacked at conferences, and I always said thank you; I never argued*".[18]

The numerous alerts on prenatal DEX right from the outset gave rise to new international recommendations. As early as 2002, the *Paediatric Endocrine Society* and the *European Society for Paediatric Endocrinology* issued a joint consensus statement. In 2010, the *Endocrine Society* issued a warning following a report affirming that '*the evidence regarding foetal and maternal sequelae [. . .] is of low or very low quality due to methodological limitations and sample sizes*'. That report recommended that prenatal DEX should be used only in clinical trials and that parents had to be informed about the possible risks of the 'treatment'. Other countries issued the recommendation that '*the administration of dexamethasone for prenatal treatment of CAH only take place as part of research projects that have ethics approval and patient follow-up protocols*'.[19]

The above paragraphs, focusing on the substantial international controversy surrounding prenatal DEX 'treatment' over the last twenty years, highlight that doctors and health institutions have been well aware all along that they have been using a molecule whose safety has not been verified scientifically. Indeed, the poor quality of the available data reproduces mechanisms of ignorance and uncertain knowledge production. It seems like this ignorance production was motivated by a larger aim to physically erase intersex as early as possible, thus socially and culturally erasing the existence of intersex people.

The current use of DEX is controversial and considered experimental by the latest international guidelines (Speiser et al. 2018). Its use is not well documented, but a European medical study provides some data attesting that prenatal DEX continues to be used in France: from 2002 to 2011, about 154 foetuses were subjected to prenatal DEX in the French participating centres (Nowotny et al. 2022).

4.4. France and the Maintenance of a Policy of Ignorance

The epistemological erasure of intersex, as evidenced by the absence of official data about medical practises, is reinforced by the dismissal of existing knowledge. As described above, prenatal DEX was invented in France and then spread internationally during the 1990s. From the outset, '*France is the country that has used it the most*'[20] as one of the Lyon team asserted in a 2009 meeting. Despite a great deal of international criticism (see above), French doctors continue to use prenatal DEX, thereby participating in a general logic of erasure of 'atypical' sex culturally, epistemologically and physically. This use is reflected in an information note from the Parisian hospital Robert Debré, published in 2013 and still available on the hospital website in 2024 (see Appendix A). The management recommendations on CAH published by the HAS (French High Authority of Health) in 2011, mentioning the possibility of prescribing prenatal DEX, is still in effect in 2024.[21] Furthermore, the head of the national expertise centre in Lyon, Dr. Pierre Mouriquand, publicly confirmed this French approach during a French Senate special committee meeting:

> "This treatment is very controversial because the side effects can be serious [. . .]." Dr. Pierre Mouriquand
>
> "These are the reasons why certain countries—Sweden or the United States—have abandoned these hormonal treatments." Maryvonne Blondin
>
> What about in France?
>
> "We continue to prescribe them."[22] Dr. Pierre Mouriquand

French promoters of prenatal DEX consider the controversy to be a foreign one that does not concern them; as one such promoter said: "*the American criticisms are not very valid*".[23] The first promoters of prenatal DEX from France and the US are now retired, and a new generation of practitioners has emerged, aware of the international controversy surrounding the 'treatment'. Some continue to advocate the procedure, echoed in the words of a French gynaecologist–endocrinologist: "*we see couples, we offer treatment, we are for it. The benefit is greater than the risks*".[24]

Given the risks involved, some French doctors remain cautious and express more nuanced points of view. During a conference titled 'Congenital Adrenal Hyperplasia' organised by *Surrénales* on 5 April 2013, an important French paediatric endocrinologist spoke publicly and conceded that "*there is a debate, not enough data, methods not well-founded enough, without a control group*". However, despite these reservations, the staff at the hospital continues to prescribe prenatal DEX in certain cases.

When talking about DEX 'treatment' for a case during a staff meeting, Dr. Schapiro, a geneticist at another Parisian hospital, said: "*sometimes it works, sometimes it doesn't. And when it works, we don't really know the collateral effects*".[25] But this attitude of uncertainty did not lead to a direct condemnation of this 'treatment'; rather, it led to the proposal of a preventive approach using pre-implantation diagnosis and '*to only re-implant the boys*' (Ibid.). In other words, in order to protect CAH boys from being exposed to a potentially harmful intervention, these medics suggested pre-selecting embryos by erasing all of the XX ones in advance, hence making the prenatal DEX unnecessary. The pre-implantation procedure is an invasive, exhausting medical procedure for (to be) pregnant persons.

The above examples highlight the fact that while some French doctors question the use of DEX, they do not go so far as to condemn it. The well-being of pregnant persons is rarely mentioned or taken into account during discussions about prenatal DEX. As far as pregnant persons are concerned, doctors generally state that '*the impact of the treatment on the mother seems minor*'[26] even though the national protocol mentions that there are side effects, and in particular, '*excessive weight gain, stretch marks, maternal discomfort, sleep disorders, high blood pressure*'.[27] Basically, doctors consider the effects of the 'treatment' to be marginal compared to the ultimate objective, in other words, what they see as the 'benefits'.

4.5. Parents' Experience and Medical (Dis)information

The goal of erasing intersex justifies, in the view of some medics, the dismissal of physical risk to the pregnant person. However, the experience of pregnant persons highlights that the impact of prenatal DEX on their health is a major cause for concern that is frequently ignored. This section continues to explain how the three types of erasure are entangled and related to ignorance production mechanisms that do not directly concern intersex but, more broadly, parents' and children's bodies.

The potential long-term risks and negative side effects for pregnant persons and their children lead many women to wonder about taking prenatal DEX. For example, research contributor Annie's experience brings to light a complex reality and highlights the importance of considering not only medical reasoning but also the consequences on pregnant bodies in any evaluation of the 'treatment'. Coming from the Paris region, her first affected daughter was born in 2004 and diagnosed with CAH at birth. A year later, she became pregnant again and immediately began prenatal DEX. Although she was being followed by a major Parisian paediatric hospital, she said she was not warned of the side effects of taking DEX during pregnancy, effects which she experienced severely. In addition to very significant weight gain, she said:

> "I had water retention, I had a beard; most of it went away after giving birth. I wasn't sleeping. I was a bundle of nerves; I vacuumed all the time. I wasn't well. [. . .] I asked if I could stop it or reduce [the 'treatment'] and I was told no, and I had to continue for a month after the birth."[28]

When I asked her if she would take the 'treatment' if she had to do it again, she said no. The *Surrénales* Association (see above) supports prenatal hormonal intervention and encourages parents to trust what doctors tell them. In an online forum created by the association, some members express their disagreement and their fear of the procedure. They speak about the dilemma they face and the lack of clear information given to them.

Following international criticism and recommendations, the current French use of prenatal DEX gives key importance to the issue of information (i.e., A Parisian hospital's note Appendix A). Doctors are now obliged to inform parents of the potential risks of this prenatal hormonal intervention as part of a new 'therapeutic alliance', a concept based on the promotion of the informed choice of medical care users who must have all the information necessary for their decision, and the freedom to choose what suits them. However, several studies in social sciences have underlined that this therapeutic alliance is not between equals because, currently, the doctor–user relationship is entangled in the dynamics of power and authority (Alderson 2001; Vassy 2006). This alliance is, therefore, a fiction of autonomy since it is structured by strong pressures from doctors (Press and Browner 1997). As Annie and other parents who contributed to my research affirmed, information about the state of the science of prenatal DEX is not always clear or complete; some indicated that the potential adverse effects on the foetus were not even mentioned to them. Furthermore, unconscious representations influence the way parents imagine having an intersex child, so the verbal and non-verbal language used by doctors affects their perception and acceptance of intersex people and of prenatal DEX (Streuli et al. 2013).

In the context of prenatal DEX, health professionals, for the most part, inform parents of potential side effects for the pregnant persons and the child but use strategies to convince them that despite these risks, 'treatment' is almost obligatory. This is highlighted in the testimonies I collected a few years back—this may have changed since—where parents declared they were put under a lot of pressure by doctors to agree to 'treatment', the latter insisting on the so-called benefits instead of the disadvantages or risks. This strategy reduced the pregnant person's agency and engendered a feeling of helplessness in the face of this pressure. In this way, medical professionals placed the responsibility on pregnant persons who, if they refused the 'treatment', might feel guilty for not having acted to prevent the 'virilisation' of their daughters. Pregnant persons were faced with the dilemma of having to choose between the desire to follow the medical advice of prenatal erasure of intersex traits and that of protecting themselves and their future child from side effects.

All of these testimonies confirm that in France, prenatal DEX is not only strongly recommended by the medical profession but that parents are sometimes pressured into accepting it. Parents' ignorance is produced by the way information is conveyed or concealed, the uncertain context, and a timeline that puts pressure on them to decide and which does not leave space for them to seek further information. This ignorance is a mechanism that is not only cognitive but also emotional, as it produces negative feelings such as anxiety and guilt. The lack of concealment of information from parents in order to promote prenatal

DEX exemplifies the epistemological erasure not only of intersex but of the general health of non-intersex family members. It illustrates the importance given to the physical and cultural erasure of intersex altogether.

5. Discussion

The internal tension contained in the expression 'uncertain knowledge' in the title of this article underlines that all scientific knowledge, technologies and medical practices on intersex belong to a specific regime of truth whose premises and consequences are left unquestioned, thereby generating a regime of ignorance. The latter continues to function in France today despite numerous uncertainties and controversies inside and outside the medical sphere.

The context of prenatal DEX allows us to reflect on the way in which certain medical practices are maintained despite criticism and uncertainty. It also reveals how biomedical practices that claim to be based on consensual knowledge are embedded in a local framework. Why do French doctors sideline criticism of this 'treatment' or even ignore it? This approach follows similar French public health scandals surrounding the iatrogenic effects of hormones (growth hormones, contraceptive pills, etc.). It is remarkable that prenatal DEX was introduced in the 1980s, a period when it was discovered that administering hormones to pregnant persons could have serious consequences, mainly after the scandal around diethylstilbestrol (DES) in the 1970s (another synthetic oestrogen given to pregnant persons which had serious risks) (Bonah and Gaudillière 2007; Fillion and Torny 2016)[29]. The denial of potential harm is somewhat incoherent with the highly preventive biomedicine and injunctions to pregnant persons concerning, for example, alcohol or smoking ('zero risk').

It is unsettling to observe the similarities between DEX use, the mechanisms of ignorance around DES, and the kind of intentional blindness or historical amnesia that accompanied it. Furthermore, in France, there is a quasi-absence of public controversies about hormonal use in general: the contraceptive pill or replacement menopausal 'treatment'. This is due in part to the way feminist movements have thought about issues related to the body and medicine and, more generally, to the relatively high trust women have in the French medical system and technological apparatus, which is often seen as emancipatory for women (Löwy and Gaudillière 2004). The reaction time of the French medical profession in the face of alarm signals was very long, and a change only occurred when the women directly concerned managed to make it a public scandal in France.

The maintenance of such practices despite the continued scientific debate regarding the safety of DEX testifies to a denial, not only of history but also of current published data: dismissing ethical and scientific criticism allowed French specialists to reproduce the erasure of intersex. French doctors' resistance to criticism also indicates the importance given by the erasure of intersex variations, which, in our specific context, concerns the 'virilisation' of the genitals of XX-CAH. This goal, taken for granted by doctors, seems so important to them that they are willing to promote a 'treatment' which is, at best, understudied and, at worst, harmful to exposed foetuses, mostly non-CAH babies. Accordingly, preventing 'atypical' sex would appear to have a much higher priority than the well-being of pregnant persons and their future children. Knowledge about prenatal DEX, which is uncertain and insufficient, is sidelined so as not to infringe on the assumed benefits of this 'treatment': erasing intersex from bodies and minds.

Overall, the case study provided allowed me to examine the mechanisms by which biomedical science not only produces knowledge but ignores or excludes knowledge that contradicts its paradigm. Several dimensions of 'uncomfortable knowledge' appear to be deliberately excluded because they threaten a pre-existing system. Hence, the establishment of practices considered acceptable or even taken for granted is inseparable from processes minimising uncertainty.

This ignorance points to a larger effort to erase intersex and demonstrates how the three types of erasure are linked and form a circular system that justifies and maintains itself: physical erasure is enabled by the cultural erasure of intersex and the incapacity to socially accept and represent intersex bodies and experiences. But this physical prenatal or postnatal erasure also reproduces cultural ignorance of intersex lives. This becomes possible because several epistemological mechanisms of erasure are used: producing ignorance impedes intersex people and their parents from conceiving alternatives to the medicalised path of physical obliteration; concealing or dismissing data and information on prenatal DEX also enables the maintenance of the system of erasure by putting 'normalisation' as a higher goal than physical integrity, diversity or general health. Thus, ethical issues around it are minimised and considered to be marginal within the larger process of erasing intersex.

6. Conclusions

This paper examined how medicine, science and technology participate in a continuous process of erasing intersex variations by practices of invisibilisation. In turn, this logic of erasure reveals a larger logic of ignorance production. The case study of the use of prenatal DEX illustrates the three types of erasure presented at the beginning of this paper, cultural, epistemological and physical, and the way they are entangled and co-produce each other to maintain the system of medicalising intersex bodies. The social difficulty of conceiving a body with a large clitoris in relation to binary categories underlies the origin of medical justifications for erasure. It is thus related to the cultural erasure regarding any variation of the female/male normative binarism. It also demonstrates epistemological erasure by illustrating how biomedical science sidelines certain data and minimises uncertainty or long-term risks such as side effects. Finally, the use of DEX is directly connected to physical erasure since it aims to obliterate the existence of intersex traits by medically intervening as early as possible on intersex children's genitals.

By unravelling mechanisms of ignorance production, a new paradox emerges: the increase in biomedical knowledge and techniques also produces many dilemmas and debates. The questions left unanswered are whether the production of ignorance is necessarily conscious and whether it stems from an intention to hide information or whether it is a social process, largely unintentional, which can be observed by examining precisely what knowledge is left unknown, which facts are minimised and which realities do not interest science. It is important to bring to light the epistemological and political consequences of this *regime of ignorance* and its paradoxes in order to build an alternative field of knowledge about intersex lives and represent other paths than early medicalisation and erasure of intersex.

Funding: This research received no external funding.

Institutional Review Board Statement: Ethical review and approval were waived for this study due to French research context at the time, where this approval was not demanded by my PhD institution.

Informed Consent Statement: Informed consent was obtained from all subjects involved in the study.

Data Availability Statement: The data presented in this study are available on request from the corresponding author due to privacy reasons.

Conflicts of Interest: The authors declare no conflict of interest.

Appendix A. Author's Translation

> "INFORMATION NOTE FOR COUPLES AT RISK Document from the Robert Debré hospital, read online on the Parisian hospitals' network APHP website on 7 November 2023.

The aim of this document is to discuss the advantages and disadvantages of a treatment that can be started from the start of pregnancy to avoid or limit the malformation of the external genitalia in girls who have congenital adrenal hyperplasia.

Appendix A.1. Principles of Treatment

The treatment is administered to the mother. Dexamethasone is a synthetic corticosteroid marketed in the form of Dectancyl tablets. This medication passes the placenta, it will slow down the production of male hormones in the foetus and prevent masculinisation of the external genitalia of girls who have congenital adrenal hyperplasia.

To be effective, treatment must be started before the formation of the external genitalia (i.e., at best before the 7th week of pregnancy). It must be taken daily until delivery, and should only be discontinued on justified medical advice. Monitoring this treatment requires regular consultations and blood tests, 15 days after the start of treatment and then throughout the pregnancy [. . .].

Appendix A.2. Efficiency

When this treatment is given adequately and is regularly monitored, the effectiveness in preventing malformations of the genital organs is complete or almost complete. Girls who received treatment in utero (during pregnancy) have normal genitalia or at most an isolated increase in clitoral size. If left untreated, there is a risk of significant malformation of the genital organs requiring one or more complex reconstructive surgical procedures.

Appendix A.3. Side Effects of Antenatal Treatment

In the mother, this treatment may have undesirable effects, especially in the event of prolonged treatment throughout pregnancy leading to significant weight gain, mood changes, increased blood pressure, oedema and stretch marks during the 2nd and the 3rd trimester of pregnancy. In some cases, sugar intolerance or diabetes may develop. All these parameters will be monitored during monthly consultations by an obstetrician specialised in this type of treatment.

In children, the administration of glucocorticoids (cortisone equivalents) via their mother does not cause any known adverse side effects. However, this treatment is recently introduced (the first treatments began in 1984) and no study has precisely evaluated its long-term effect on the development of the child, both in the case of transitional treatments stopped around the 11th week (unaffected foetus) and in the case of prolonged treatments until the end of pregnancy. The studies currently underway give contradictory results and cast doubt on possible memory problems in certain children who have received antenatal treatment.

Appendix A.4. Conclusions

[. . .] The aim of this note is to raise questions from parents faced with this difficult choice which the entire team of paediatric endocrinologists, surgeons, geneticists and obstetricians will endeavour to answer.”

Notes

[1] Author’s translation. Original expression: ‘les formes d’oubli et d’invisibilité’.

[2] Intersex people, or individuals with sex development variations, present inborn sex characteristics that do not fit the social and medical norms of male/female binarism. The term intersex can also refer to individuals who have experienced medical and social invalidation of their bodies.

[3] Some terms (treatment, normalisation, virilisation, atypical sex, ambiguous sex, etc.) are put into quotation marks since their use is a borrowed one: they are used in medical papers or discourse and suggest that intersex is a pathology. The quotation marks signify that the author does not endorse this approach.

[4] CAH is related to variations in the production of hormones by the adrenal glands. It is a rare genetic condition with a recessive heredity mechanism. In people with XX chromosomes, it often creates intersex traits such as a bigger-than-average clitoris, labial fusion, and/or a vagina considered too small.

[5] Intersex people were named «hermaphrodites» during many periods of history, mainly in medical publications, considering it as a monstrosity or a pathology. The use of this mythological term has been criticised by concerned people since the 1990s as stigmatising and should, therefore, be employed only for historical purposes.

[6] In 1980, Michel Foucault wrote a text as a preface to the English edition of Abel/Herculin Barbin's memoirs. In this text, he reminds the scientific context of medical perception of intersex people in the 19th century. The dominant approach, "age of gonads", as it was called by Alice Dreger (1998), was to consider that doctors should determine the 'true' sex of intersex people by looking inside their bodies, and especially by examining their gonads during internal surgery. The idea of a gonadal sex as the 'true sex' did not completely disappear, but other components of sex were taken into account, maintaining, for many doctors, the illusion of a 'true sex' for each intersex person.

[7] On this topic, see a recent press investigation about French intersex people and their struggle to obtain their medical files: Pepy, Lilas. Personnes intersexes: des mutilations tenues au secret. *La Déferlante*, May 2024.

[8] The DSD nomenclature distinguishes intersex people into categories of 'syndromes' mostly following their sex chromosomes.

[9] Interview with Charlotte, February 2014. All of the names given to interviewees are pseudonyms.

[10] Interview with Dr. Dupuy, pediatric endocrinologist, May 2014.

[11] It is said that 'The voluntary interruption of a pregnancy may, at any time, be performed if two doctors attest, after examination and discussion, that the continuation of the pregnancy seriously endangers the woman's health or that there is a strong probability that the unborn child will suffer from a particularly serious condition of particular gravity recognised as incurable at the time of diagnosis' (L.162-12, law n°75-17 of 17 January 1975, art. 5).

[12] Interview with Dr. Bonnet, pediatric surgeon, April 2014.

[13] Interview with Dr. Rousseau, pediatric endocrinologist, March 2014.

[14] See note 10 above.

[15] DEX may be potentially given to any 'at risk' pregnant persons who already had an affected child before knowing if the foetus is affected by CAH and before knowing its chromosomes. However, CAH is a recessive genetic condition, which means only 1 of 4 foetuses will actually be affected. Furthermore, since only XX chromosomes foetuses are targetted, they only represent half of the foetuses, which can be potentially treated (hence 1 of 8).

[16] As early as 1995, a study suggested that these children were shyer and more sensitive than the control group (Trautman et al. 1995).

[17] Interview with Dr. Dupuy, May 2014.

[18] See note 17 above.

[19] Recommendation no 6.27 from the Second Report '*Involuntary or coerced sterilisation of intersex people in Australia*', 25 October 2013, Senate Standing Committees on Community Affairs, Commonwealth of Australia 2013.

[20] Minutes of a meeting of the association *Surrénales*, June 2009.

[21] These recommendations are available (in French) here: https://www.has-sante.fr/upload/docs/application/pdf/2011-05/ald_hors_liste_-_pnds_sur_lhyperplasie_congenitale_des_surrenales.pdf (consulted on 21 May 2024).

[22] Dr. Pierre Mouriquand, head of a department in Lyon and coordinator of the Expertise national Centre of genital development (DEVGEN). Exerpt of his presentation in a Senate commission (Blondin and Bouchoux 2017, p. 23).

[23] Interview with Dr. Rousseau, February 2014.

[24] Interview with Dr. Guez, gynaecologist, January 2015.

[25] Interview with Dr. Schapiro, geneticist, December 2014.

[26] Information meeting of the association *Surrénales*.

[27] National Protocol of Diagnosis and Care (PNDS) on Congenital Adrenal Hyperplasia, published in April 2011 by the High Authority of Health (HAS).

[28] Interview with Annie, June 2014.

[29] DES is a synthetic estrogen which has been prescribed to pregnant persons. Its use was called into question in 1953 because it was suspected of leading to vaginal and cervical cancer in girls exposed to it in utero. Following the protest movement, DES was contraindicated for pregnant persons in 1977.

References

Aegerter, Audrey. 2022. Enjeux et controverses quant à la participation d'activistes intersexes au Consensus de Chicago (2005). *Santé Publique* 34: 59–67. [CrossRef] [PubMed]

Alderson, Priscilla. 2001. Down's Syndrome: Cost, Quality and Value of Life. *Social Science & Medicine* 53: 627–38. [CrossRef]

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

Bastien-Charlebois, Janik. 2017. Les sujets intersexes peuvent-ils (se) penser?. Les empiétements de l'injustice épistémique sur le processus de subjectivation politique des personnes intersex(ué)es. *Socio. La nouvelle revue des sciences sociales* 9: 143–62. [CrossRef]

Behrens, Kevin G. 2020. A Principled Ethical Approach to Intersex Paediatric Surgeries. *BMC Med Ethics* 21: 108. [CrossRef] [PubMed]

Bernard, Raymon, J. Coignet, J. P. Dageville, and Giraud F. Maestraggip. 1962. Pseudohermaphrodisme féminin avec macrogénitosomie succédant à un syndrome de Debré-Fibiger méconnu. *Archives françaises de pédiatrie* 19: 538–44. [PubMed]

Blondin, Maryvonne, and Corinne Bouchoux. 2017. Variations du Développement Sexuel: Lever un Tabou, Lutter Contre la Stigmatisation et les Exclusions. *Senate Information Report* n° 441. Available online: https://www.senat.fr/rap/r16-441/r16-441.html (accessed on 10 July 2024).

Bohuon, Anaïs. 2015. Gender Verifications in Sport: From an East/West Antagonism to a North/South Antagonism. *International Journal of the History of Sport* 32: 965–79. [CrossRef]

Bonah, Christian, and Jean-Paul Gaudillière. 2007. Faute, accident ou risque iatrogène? *Revue Française Des Affaires Sociales* 3: 123–51. [CrossRef]

Carpenter, Morgan. 2020. The OHCHR Background Note on Human Rights Violations against Intersex People. *Sexual and Reproductive Health Matters* 28: 13–16. [CrossRef] [PubMed]

Daston, Lorraine, and Katharine Park. 1995. The Hermaphrodite and the Orders of Nature: Sexual Ambiguity in Early Modern France. *GLQ: A Journal of Lesbian and Gay Studies* 1: 419–38. [CrossRef]

David, Michel, and Maguelone G. Forest. 1984. Prenatal treatment of congenital adrenal hyperplasia resulting from 21-hydroxylase deficiency. *The Journal of Pediatrics* 105: 799–803. [CrossRef]

Davis, Georgiann. 2015. *Contesting Intersex: The Dubious Diagnosis*. New-York: NYU Press.

De Herder, Wouter W. 2020. Clémentine Delait (1865–1934), the Most Famous Bearded Lady on the Continent in the 20th Century. *Gynecological Endocrinology* 36: 213–17. [CrossRef] [PubMed]

Dreger, Alice. 1998. A History of Intersexuality: From the Age of Gonads to the Age of Consent. *Journal of Clinical Ethics* 9: 345–55. [CrossRef] [PubMed]

Dreger, Alice. 2015. *Galileo's Middle Finger: Heretics, Activists, and One Scholar's Search for Justice*. New York: Penguin Books.

Dreger, Alice, Ellen K. Feder, and Anne Tamar-Mattis. 2012. Prenatal Dexamethasone for Congenital Adrenal Hyperplasia. *Journal of Bioethical Inquiry* 9: 277–94. [CrossRef] [PubMed]

Eder, Sandra. 2010. The Volatility of Sex: Intersexuality, Gender and Clinical Practice in the 1950s. *Gender & History* 22: 692–707. [CrossRef]

Fausto-Sterling, Anne. 2000. *Sexing the Body: Gender Politics and the Construction of Sexuality*. New York: Basic Books.

Fillion, Emmanuelle, and Didier Torny. 2016. Un précédent manqué: Le Distilbène® et les perturbateurs endocriniens. Contribution à une sociologie de l'ignorance. *Sciences Sociales et Santé* 34: 47–75. [CrossRef]

Floret, D., H. Plauchu, F. Berlin, H. Betuel, and M. Forest. 1980. Diagnostic prénatal de l'hyperplasie congénitale des surrénales. Déficit en 21-hydroxylase. *La Nouvelle presse médicale* 9: 1960–961. [PubMed]

Forest, Maguelone G., Hervé Bétuel, and Michel David. 1989. Prenatal Treatment in Congenital Adrenal Hyperplasia Due to 21-Hydroxylase Deficiency: Up-Date 88 of the French Multicentric Study. *Endocrine Research* 15: 277–301. [CrossRef] [PubMed]

Forest, Maguelone G., Michel David, and Yves Morel. 1993. Prenatal diagnosis and treatment of 21-hydroxylase deficiency. *The Journal of Steroid Biochemistry and Molecular Biology* 45: 75–82. [CrossRef]

Forest, Maguelone G., Yves Morel, and Michel David. 1998. Prenatal Treatment of Congenital Adrenal Hyperplasia. *Trends in Endocrinology & Metabolism* 9: 284–89.

Foucault, Michel. 1980. *Herculine Barbin: Being the Recently Discovered Memoirs of a Nineteenth-Century French Hermaphrodite*. New York: Vintage Books.

Foucault, Michel. 1988. *The History of Sexuality*. New York: Vintage Books. First published 1976.

Foucault, Michel. 1995. La Fonction Politique de l'intellectuel. In *Dits et Écrits, Tome II*. Paris: Gallimard, vol. 184, p. 109. First published 1976.

Frasier, S. D., I. Thorneycroft, B. Weiss, and R. Horton. 1975. Letter: Elevated amniotic fluid concentration of 17 alphahydroxyprogesterone in congenital adrenal hyperplasia. *The Journal of Pediatrics* 86: 310–12. [CrossRef]

Fricker, Miranda. 2007. *Epistemic Injustice: Power and the Ethics of Knowing*. Oxford: Oxford University Press.

Funkenstein, Amos, and Adin Steinsaltz. 1987. *The Sociology of Ignorance*. Tel Aviv: Israeli Ministry of Defense. (In Hebrew)

Gross, Matthias, and Linsey McGoey, eds. 2022. *Routledge International Handbook of Ignorance Studies*, 2nd ed. London: Routledge. [CrossRef]

Guillot, Vincent. 2008. Intersexes: Ne pas avoir le droit de dire ce que l'on ne nous a pas dit que nous étions. *Nouvelles Questions Féministes* 27: 37–48. [CrossRef]

Hashiloni-Dolev, Yael. 2006. Genetic Counseling for Sex Chromosome Anomalies (SCAs) in Israel and Germany: Assessing Medical Risks According to the Importance of Fertility in Two Cultures. *Medical Anthropology Quarterly* 20: 469–86. [CrossRef]

Hirvikoski, Tatja, Anna Nordenström, Torun Lindholm, Frank Lindbald, Martin Ritzén, and Svetlana Lajic. 2008. Long-term follow-up of prenatally treated children at risk for congenital adrenal hyperplasia: Does dexamethasone cause behavioural problems? *European Journal of Endocrinology* 159: 309–16. [CrossRef] [PubMed]

Hirvikoski, Tatja, Anna Nordenström, Torun Lindholm, Frank Lindbald, Martin Ritzén, Anna Wedell, and Svetlana Lajic. 2007. Cognitive functions in children at risk for congenital adrenal hyperplasia treated prenatally with dexamethasone. *The Journal of Clinical Endocrinology and Metabolism* 92: 542–48. [CrossRef]

Holmes, Morgan. 1994. Medical Politics and Cultural Imperatives: Intersexuality beyond Pathology and Erasure. Unpublished Master's thesis, York University, Toronto, ON, Canada.

Holmes, Morgan. 2008. *Intersex: A Perilous Difference*. Plainsboro Township: Associated University Presse.

Holmes, Morgan, ed. 2009. *Critical Intersex*. Farnham: Ashgate.

Jeon, Kwon Chan, Lei-Shih Chen, and Patricia Goodson. 2012. Decision to Abort after a Prenatal Diagnosis of Sex Chromosome Abnormality: A Systematic Review of the Literature. *Genetics in Medicine* 14: 27–38. [CrossRef]

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

Kennedy, Aileen. 2020. Fixed at birth: Medical and legal erasures of intersex variations. *University of New South Wales Law Journal* 39: 813–42. [CrossRef]

Kessler, Suzanne J. 1998. *Lessons from the Intersexed*. New Brunswick: Rutgers University Press.

King, Brian W. 2016. Becoming the Intelligible Other: Speaking Intersex Bodies against the Grain. *Critical Discourse Studies* 13: 359–78. [CrossRef]

Koenig, Barbara A. 1988. The Technological Imperative in Medical Practice: The Social Creation of a "Routine" Treatment. In *Biomedicine Examined*. Edited by Margaret Lock and Deborah Gordon. Dordrecht: Springer, pp. 465–96. [CrossRef]

Lajic, Svetlana, Leif Karlsson, and Anna Nordenström. 2018. Prenatal Treatment of Congenital Adrenal Hyperplasia: Long-Term Effects of Excess Glucocorticoid Exposure. *Hormone Research in Paediatrics* 9: 362–71. [CrossRef] [PubMed]

Laqueur, Thomas. 1990. *Making Sex—Body & Gender from the Greeks to Freud*. Cambridge: Harvard University Press.

Löwy, Ilana, and Jean-Paul Gaudillière. 2004. Controverses sur le traitement hormonal de la ménopause. *Mouvements* 32: 32–39. [CrossRef]

Lundberg, Tove P. 2017. Knowing Bodies: Making Sense of Intersex/DSD a Decade Post-Consensus. Doctoral dissertation, University of Oslo, Oslo, Norway. Available online: https://www.duo.uio.no/handle/10852/55654 (accessed on 10 July 2024).

Mbembé, Achille. 2003. Necropolitics. *Public Culture* 15: 11–40. [CrossRef]

McCann-Crosby, Bonnie, Frank Placencia, Oluyemisi Adeyemi, Jennifer Dietrich, Rachel Wills, Sheila Gunn, Marni Axelrad, Duong Tu, David Mann, Lefkothea Karaviti, and et al. 2018. Challenges in Prenatal Treatment with Dexamethasone. *Pediatric Endocrinology Reviews* 16: 186–93. [CrossRef] [PubMed]

Meoded-Danon, Limor, and Niza Yanay. 2016. Intersexuality: On Secret Bodies and Secrecy. *Studies in Gender and Sexuality* 17: 57–72. [CrossRef]

Merkatz, Irwin R., Maria I. New, Ralph E. Peterson, and Mary P. Seaman. 1969. Prenatal diagnosis of adrenogenital syndrome by amniocentesis. *The Journal of Pediatrics* 75: 977–82.

Meyer-Bahlburg, Heino F. L., Curtis Dolezal, Rita Haggerty, Michael Silverman, and Maria I. New. 2012. Cognitive outcome of offspring from dexamethasone-treated pregnancies at risk for congenital adrenal hyperplasia due to 21-hydroxylase deficiency. *European Journal of Endocrinology* 167: 103–10. [CrossRef]

Miller, Walter L. 1999. Dexamethasone treatment of congenital adrenal hyperplasia in utero: An experimental therapy of unproven safety. *The Journal of Urology* 162: 537–40. [CrossRef] [PubMed]

Miller, Walter R. 2008. Prenatal Treatment of Classic CAH with Dexamethasone: Con. *Endocrine News*, April. pp. 16–18.

Mills, Charles W. 2022. *The Racial Contract*. Ithaca: Cornell University Press. First published 1997.

Monro, Surya, Morgan Carpenter, Daniela Crocetti, Georgiann Davis, Fae Garland, David Griffiths, Peter Hegarty, Mitchell Travis, Mauro Cabral, and Peter Aggleton. 2021. Intersex: Cultural and social perspectives. *Culture, Health & Sexuality* 23: 431–40.

Monro, Surya, Sean Saifa Wall, and Kate Wood. 2024. Intersex equality, diversity and inclusion and social policy: Silences, absences, and erasures in Ireland and the UK. *Critical Social Policy* 44: 3–22. [CrossRef]

Morrison, Tessalyn, Alexis Dinno, and Taurica Salmon. 2021. The Erasure of Intersex, Transgender, Nonbinary, and Agender Experiences Through Misuse of Sex and Gender in Health Research. *American Journal of Epidemiology* 190: 2712–17. [CrossRef]

Namaste, Viviane. 2000. *Invisible Lives: The Erasure of Transsexual and Transgendered People*. Chicago: University of Chicago Press.

New, Maria I., Ann Carlson, Jihad Obeid, Ian Marshall, Monina Cabrera, Amanda Goseco, Karen Lin-Su, Andrea Putnam, Qing Wei, and Robert Wilson. 2001. Extensive Personal Experience: Prenatal Diagnosis for Congenital Adrenal Hyperplasia in 532 Pregnancies. *Journal of Clinical Endocrinology & Metabolism* 86: 5651–57.

Nowotny, Hanna, Uta Neumann, Véronique Tardy-Guidollet, S. Faisal Ahmed, Federico Baronio, Tadej Battelino, Jérôme Bertherat, Oliver Blankenstein, Marco Bonomi, Claire Bouvattier, and et al. 2022. Prenatal Dexamethasone Treatment for Classic 21-Hydroxylase Deficiency in Europe. *European Journal of Endocrinology* 186: 17–24. [CrossRef]

Press, Nancy, and Carole Browner. 1997. Why Women Say Yes to Prenatal Diagnosis. *Social Science & Medicine* 45: 979–89. [CrossRef]

Proctor, Robert N., and Londa Schiebinger, eds. 2008. *Agnotology: The Making and Unmaking of Ignorance*. Stanford: Stanford University Press, pp. 1–33.

Rayner, Steve. 2012. Uncomfortable Knowledge: The Social Construction of Ignorance in Science and Environmental Policy Discourses. *Economy and Society* 41: 107–25. [CrossRef]

Raz, Michal. 2015. Médecins israéliens face au diagnostic prénatal des fœtus intersexués. *Sciences Sociales et Santé* 33: 5–34. [CrossRef]

Raz, Michal. 2016. Qualité de vie et fertilité dans les études de suivi des personnes intersexuées. *Cahiers du Genre* 60: 145–68. [CrossRef]

Raz, Michal. 2019. La production des évidences sur l'intersexuation Savoirs et pratiques médicales autour de l'hyperplasie congénitale des surrénales (France, 1950–2018). Ph.D. dissertation, EHESS, Paris, France. Available online: https://hal.science/tel-02863019v1/document (accessed on 10 July 2024).

Raz, Michal. 2023. *Intersexes: Du pouvoir médical à l'autodétermination*. Paris: Le Cavalier Bleu.

Rosenwohl-Mack, Amy, Suegee Tamar-Mattis, Arlene B. Baratz, Katharine B. Dalke, Alesdair Ittelson, Kimberly Zieselman, and Jason D. Flatt. 2020. A National Study on the Physical and Mental Health of Intersex Adults in the U.S. *PLoS ONE* 15: e0240088. [CrossRef] [PubMed]

Seckl, Jonathan R., and Walter L. Miller. 1997. How safe is long-term prenatal glucocorticoid treatment? *JAMA: The Journal of the American Medical Association* 277: 1077–79. [CrossRef]

Speiser, Phyllis W., Ricardo Azziz, Laurence Baskin, Lucia Ghizzoni, Terry Hensle, Deborah Merke, Heino Meyer-Bahlburg, Walter Miller, Victor Montori, Sharon Oberfield, and et al. 2010. A Summary of the Endocrine Society Clinical Practice Guidelines on Congenital Adrenal Hyperplasia due to Steroid 21-Hydroxylase Deficiency. *International Journal of Pediatric Endocrinology* 2010: 494173. [CrossRef]

Speiser, Phyllis W., Wiebke Arlt, Richard J. Auchus, Laurence S. Baskin, Gerard S. Conway, Deborah P. Merke, Heino F. L. Meyer-Bahlburg, Walter L. Miller, M. Hassan Murad, Sharon E. Oberfield, and et al. 2018. Congenital Adrenal Hyperplasia Due to Steroid 21-Hydroxylase Deficiency: An Endocrine Society Clinical Practice Guideline. *The Journal of Clinical Endocrinology & Metabolism* 103: 4043–88. [CrossRef]

Sterling, Rogena. 2021. Intersex People and Educating for the Development of Personality. *Sex Education* 21: 614–27. [CrossRef]

Streuli, Jurg C., Effy Vayena, Yvonne Cavicchia-Balmer, and Johannes Huber. 2013. Shaping parents: Impact of contrasting professional counseling on parents' decision making for children with disorders of sex development. *Journal of Sexual Medicine* 10: 1953–60. [CrossRef] [PubMed]

Tardy-Guidollet, Véronique, Rita Menassa, Jean-Marc Costa, Michel David, Claire Bouvattier-Morel, Clarisse Baumann, Muriel Houang, Françoise Lorenzini, Nicole Philip, Sylvie Odent, and et al. 2014. New Management Strategy of Pregnancies at Risk of Congenital Adrenal Hyperplasia Using Fetal Sex Determination in Maternal Serum: French Cohort of 258 Cases (2002–2011). *The Journal of Clinical Endocrinology and Metabolism* 99: 1180–88. [CrossRef] [PubMed]

Trautman, Paul D., Heino F. Meyer-Bahlburg, Jill Postelnek, and Maria New. 1995. Effects of early prenatal dexamethasone on the cognitive and behavioral development of young children: Results of a pilot study. *Psychoneuroendocrinology* 20: 439–49. [CrossRef] [PubMed]

Tuana, Nancy. 2004. Coming to Understand: Orgasm and the Epistemology of Ignorance. *Hypatia* 19: 194–232. [CrossRef]

Vassy, Carine. 2006. From a Genetic Innovation to Mass Health Programmes: The Diffusion of Down's Syndrome Prenatal Screening and Diagnostic Techniques in France. *Social Science & Medicine* 63: 2041–51. [CrossRef]

Xu, Lizhen, Wei Lin, Liangchun Cai, Huibin Huang, Jixing Liang, Liantao Li, Liyao Zong, Nengying Wang, Junping Wen, and Gang Chen. 2020. Efficacy and Safety of Prenatal Dexamethasone Treatment in Offspring at Risk for Congenital Adrenal Hyperplasia Due to 21-Hydroxylase Deficiency: A Systematic Review and Meta-Analysis. *Clinical Endocrinology* 92: 109–23. [CrossRef]

social sciences

Review

Intersex Epistemologies? Reviewing Relevant Perspectives in Intersex Studies

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Abstract: Over the last decades, intersex studies has achieved increasing development as a field of critical knowledge, in tight collaboration with discourses developed by intersex activism and human rights bodies. This paper proposes a self-reflexive review of epistemological perspectives in intersex studies within broader discursive fields, through a thematic analysis and comparative framing analysis. This analysis is based on a narrative literature review of academic contributions, activist declarations, and documents issued by human rights bodies conducted over the last decade as a work-in-progress project. Furthermore, it includes results of a scoping review of recent knowledge production in intersex studies carried out in Scopus within the subject area 'social sciences'. This paper focuses on the analysis of the following epistemological perspectives: human rights frameworks, legal perspectives and citizenship theories, reflections on biopolitics, medicalization and iatrogenesis, sociology of diagnosis framework, depathologization perspective, respectful health care models, and reflections on epistemological, methodological, and ethical aspects. The literature review raises questions about the existence of specific intersex epistemologies in intersex studies, their interrelation with discourses contributed by intersex activism and human rights bodies, and the opportunities for a contribution of theory making in intersex studies to the human rights protection of intersex people.

Keywords: intersex studies; epistemologies; human rights; biopolitics; medicalization; depathologization; epistemic injustice

Citation: Suess-Schwend, Amets. 2024. Intersex Epistemologies? Reviewing Relevant Perspectives in Intersex Studies. *Social Sciences* 13: 298. https://doi.org/10.3390/socsci13060298

Academic Editor: Nigel Parton

Received: 20 March 2024
Revised: 21 April 2024
Accepted: 23 April 2024
Published: 31 May 2024

1. Introduction

According to Foucault ([1969] 1972), "The conditions necessary for the appearance of an object of discourse, the historical conditions required if one is to 'say anything' about it, and if several people are to say different things about it, (. . .) as we can see, these conditions are many and imposing. Which means that one cannot speak of anything at any time" (pp. 44–45).

Over the last decades, intersex studies has emerged as a field of knowledge, contributing critical reflections in tight interaction with discourses of intersex activism and human rights bodies. This paper aims at reviewing relevant epistemological perspectives in intersex studies, intersex activism, and human rights discourses.

From academic and academic–activist perspectives, several authors have published edited books focused on critical analyses of intersex-related medical practices and legal regulations, reviews of the history of intersex activism, and narratives about the social situation of intersex people, among them Dreger (1999), Fröhling (2003), Cabral Grinspan (2009), Holmes ([2009] 2016), Barth et al. (2013), Thomas et al. (2013), Haller et al. (2022), and Laura-Inter and Alcántara (2023). Without always explicitly mentioning the term 'intersex studies', these anthologies can be read as contributions to the process of establishing intersex studies as a field of knowledge in the intersection between different theoretical perspectives, backgrounds, and languages.

Furthermore, intersex authors and allies have contributed definitions and conceptualizations of intersex studies, describing its characteristics and scope. Carpenter ([2012] 2023) indicates: “Intersex studies is an interdisciplinary and growing field, frequently involving collaboration with intersex-led organisations, and also involving academics with lived experience” (s.p.). Monro et al. (2021) highlight: “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” (p. 431).

In ‘Intersex Studies: A Systematic Review of International Health Literature’, T. Jones (2018) uses a different strategy to delimit intersex studies. The author identifies different “theoretical lenses” in studies on intersex issues, differentiating between “expert-centered, patient-centered, group-centered, or theory-centered” lenses, and mentioning “Critical Intersex Studies” within “[c]ommunity-group centered” lenses (T. Jones 2018, p. 4). “Critical Intersex Studies lenses” are defined as “focused on human rights and bodily autonomy for intersex as a specific group” (T. Jones 2018, p. 5).

Within this paper, I conceptualize intersex studies as an interdisciplinary field of knowledge developed by intersex authors and allies from diverse theoretical and academic–activist perspectives that contribute critical reflections on intersex-related clinical practices, legal frameworks, social inequities, and forms of knowledge production. Unlike T. Jones (2018), I do not include intersex-related clinical literature within the scope of intersex studies but instead focus on critical reflections about intersex-related clinical and social practices.

From the awareness that terminology is a contested aspect in the field (Monro et al. 2021), I will give preference to the term ‘intersex’ throughout the text, according to its use in intersex activism, intersex studies, and human rights discourses, and following the definitions contributed by OII Europe/ILGA Europe (Ghattas 2019)[1] and the United Nations (UN 2019).[2] When referring to previous historical moments or other cultural contexts, I will use the term ‘variations of sex characteristics’.[3]

The emergence of intersex studies can be analyzed within the broader framework of an historical development of conceptualizations and regulations of variations of sex characteristics. Over the last century, in the Western world the medical gaze has achieved a dominant position in conceptualizing, categorizing and diagnosing intersex bodies and lives (Cleminson and Vázquez García 2009, 2018; Dreger [1998] 2003, 1999, 2018; Eckert [2009] 2016, 2017; Foucault [1978] 1980; García López 2015, 2018; Gregori Flor 2013; Gregori Flor et al. 2018; Griffiths 2018; Karkazis 2008; Kennedy 2016; Reis 2005, 2019). This medical gaze is described as historical and Western-centered, and the reviewed authors highlight the existence of other forms of conceptualizing and regulating variations of sex characteristics in previous centuries (Cleminson and Vázquez García 2009, 2018; Foucault [1978] 1980; García López 2015; Kennedy 2016; Reis 2005, 2019) and diverse cultural contexts (Eckert [2009] 2016, 2017; Swarr 2023).

In other knowledge fields that contribute critical reflections on medical practices and epistemological power structures, such as trans studies, crip studies, deaf studies, or mad studies, I identified reflections on “trans* epistemology” (Radi 2019, p. 43), “crip-istemologies” (Johnson and McRuer 2014, p. 127), “Deaf Epistemologies” (De Clerck 2016), and “Mad Epistemologies” (LeFrançois and Voronka 2022, p. 105), raising questions about the existence and characteristics of specific intersex epistemologies in the field of intersex studies.

Based on previous reflections on intersex studies as a knowledge field, this paper focuses on the review of epistemological frameworks in intersex studies, intersex activism, and international and regional human rights bodies, aimed at enhancing the awareness of theoretical perspectives and contributing to the development of strategies for supporting the human rights of intersex people.

2. Methods and Ethics

This analysis is based on a narrative literature review of epistemological, methodological, and ethical reflections in intersex and trans studies that I have conducted over more than ten years as a work-in-progress project. In previous publications (Suess-Schwend 2014, 2020, 2022, 2023),[4] I identified several relevant epistemological perspectives in intersex studies that I will analyze in more detail in this paper.

As a second step, I conducted a scoping review of intersex-related articles, books, and book chapters in the subject area 'social sciences' in Scopus published between 2013–2022, combining the keyword 'intersex' with keywords related to the theoretical frameworks I found in the previous narrative review. I identified 341 publications in Scopus, with 329 in English, 5 in Spanish, 4 in Portuguese, 1 in French, 1 in Italian and 1 in German. After removing duplicates, non-related entries, or entries in other formats, I applied the following non-eligibility criteria to 332 publications:

- Focus on LGBTI, not intersex (n = 184)
- Pathologizing perspectives (n = 5)
- Other ethical concerns (n = 3)

Finally, I selected 140 publications for an in-depth review.

Taking into account the limitation of the selection to highly indexed publications mainly in English, I completed the scoping review with the narrative review conducted previously and during the elaboration of the paper, including 93 papers, book chapters, books, and reports in English, Spanish, French, Portuguese and German from the field of intersex studies. I also reviewed 22 intersex activist documents, among them 16 international and regional declarations, and 18 intersex-related strategic human rights documents, including 17 documents issued by international and regional human rights bodies, and the Yogyakarta Principles plus 10, developed by an international expert group (YP+10 2017) (in the following, indicated as 'human rights documents').

Within the selected publications, I analyzed the epistemological frameworks by means of a thematic analysis (Braun and Clarke 2022), identifying the following relevant themes:

- Human rights frameworks, legal perspectives, and citizenship theories
- Critical perspectives on clinical practices
- Disability/crip theories
- Theories on embodiment, sex/gender non binarism, and bodily diversity
- Reflections on social inequities, intersectionalities, and social justice
- Educational perspectives
- Reflections on epistemological, methodological, and ethical aspects

This thematic analysis was combined with a framing analysis (Johnston 2002), comparing terminologies and framing strategies in the field of intersex studies with those used in the reviewed activist declarations and human rights documents.

I followed ethical principles relevant for literature reviews, such as an adequate and meaningful selection, representation, and citations (Suri 2008), as well as a practice of reflexivity (Olmos-Vega et al. 2023). I developed this review as an ally of intersex activism, being aware of the ontological complexity of this ally position, committed to the human rights protection of intersex people, and aimed at not repeating dynamics of epistemic injustice (Fricker 2007).

3. Results and Discussion

In the following section, I will present and discuss selected results of the literature review, focusing specifically on the mention of epistemological perspectives related to each theme in intersex studies, intersex activism, and documents published by international and regional human rights bodies. I will mention some of the reviewed themes and authors without reproducing the complete literature review.

The following analysis focuses on human rights frameworks, legal perspectives and citizenship theories, critical perspectives on clinical practices, as well as reflections on epistemological, methodological, and ethical aspects.

3.1. Human Rights Frameworks, Legal Perspectives, and Citizenship Theories

3.1.1. Human Rights Frameworks

The literature review identifies human rights perspectives as a core framework in the reviewed publications. These findings coincide with previous analyses that indicate human rights as a central focus of intersex studies (Monro et al. 2021; T. Jones 2018). Within this shared human rights focus, I identified different themes and perspectives.

The reviewed authors question the human rights violations that intersex people face, denouncing the practice of non-consensual surgeries on the sex characteristics of intersex newborns, children, and adolescents (Ammaturo 2016b; Bastien-Charlebois and Guillot 2018; Bauer et al. 2020; Cabral Grinspan 2006, 2009, 2022; Cabral Grinspan and Benzur 2005; Cabral Grinspan and Carpenter 2018; Carpenter 2016, 2018a, 2018b, 2020; Crocetti et al. 2020a; Davidian [2011] 2013; Ghattas 2013; Guillot 2018; Mestre Martínez 2022; Monro et al. 2019; O'Brien 2015; Paechter 2021; Suess-Schwend 2014, 2020, 2022, 2023; Winter Pereira 2022; Zelayandía-González 2023). Furthermore, they identify a lack of adequate health care throughout their lifespan (Berry and Monro 2022; Crocetti et al. 2020b; Crocetti et al. [2023] 2024), as well as dynamics of social discrimination and exclusion in different contexts (Carpenter 2020; Sterling 2021; Winter Pereira 2022).

Intersex studies also provides a review of the historical development of local, regional, and international human rights-based intersex activism over the last decades in different world regions (Astraea Lesbian Foundation for Justice 2016; Bauer et al. 2020; Chase 2013; Crocetti et al. 2020a; Davidian [2011] 2013; Davis 2015; Haller et al. 2022; Karkazis 2008; Rubin 2017, 2019; Suess-Schwend 2022, 2023; von Wahl 2021; Winter Pereira 2022). The reviewed authors analyze the demands of regional and international intersex networks, identifying the protection of the right to bodily integrity and cessation of non-consensual surgeries performed on the sex characteristics of intersex newborns, children, and adolescents as main demands (Ammaturo 2016b; Bastien-Charlebois and Guillot 2018; Bauer et al. 2020; Carpenter 2016, 2018a, 2018b, 2020; Crocetti et al. 2020a, 2020b; Davidian [2011] 2013; Grabham 2007; Guillot 2018; Mestre Martínez 2022; Monro et al. 2019; O'Brien 2015; Paechter 2021; Sterling 2021; Suess-Schwend 2014, 2020, 2022, 2023; von Wahl 2021; Winter Pereira 2022; Zelayandía-González 2023). Furthermore, they review the lobbying activities of intersex activist groups and networks in international and regional human rights bodies (Bauer et al. 2020; Rubin 2019; Winter Pereira 2022).

The reviewed authors describe the engagement of regional and international human rights bodies with intersex issues, such as the UN, the Council of Europe, the European Parliament, or the Inter-American Commission on Human Rights, analyzing their resolutions and recommendations (Bauer et al. 2020; Carpenter 2020; Garland and Travis 2022; Garland et al. 2022; Pikramenou 2019; Ravesloot 2021; Sterling 2021; Travis 2015; Winter Pereira 2022; Zelayandía-González 2023). They also review the implementation of their recommendations in national contexts (Carpenter 2018b; Duggan and McNamara 2021; Garland and Travis 2022; Ní Mhuirthile et al. 2022; von Wahl 2021).

Several authors highlight binary biases in international human rights law and national legislations (O'Brien 2015; Paechter 2021; Pikramenou 2019), as well as analogies between female genital mutilation (FGM) and intersex genital mutilation (IGM) (Rubin 2019; Svoboda 2013). Carpenter (2016) reviews advancements and challenges in the response of the international human rights system to the demands of the intersex movement, highlighting that "[s]tructural change is needed to end the pathologisation and stigmatisation of healthy intersex bodies" (pp. 79–80).

The reviewed human rights-based publications also reflect a discussion about terminologies, including a critical review of their historical development, Western and clinical precedence, and frequently pathologizing connotations. On the other hand, the reviewed authors identify strategies of resignification and reappropriation. They show a preference for using 'intersex' and 'variations of sex characteristics (VSC)' instead of terms such as 'hermaphrodite', 'DSD, Disorders of Sex Development', 'dsd, differences of sex development' or specific diagnostic codes (Cabral Grinspan 2009; Carpenter 2018b; Crocetti et al.

2020b; Davis 2015; Delimata et al. 2018; Feder and Karkazis 2008; Hegarty et al. 2021; Lundberg et al. 2019; Machado 2006; Merrick [2017] 2019; Monro et al. 2021; Topp 2013; Zelayandía-González 2023).

Furthermore, some of the reviewed authors contribute reflections on the specific human rights-related epistemological framings used by intersex activist networks, human rights bodies, and policy makers, comparing their use and discussing their applicability and limitations (Bauer et al. 2020; Crocetti et al. 2020a; Zelayandía-González 2023).

Bauer et al. (2020) provide an in-depth review of framing strategies used by International Human Rights Mechanisms (IHRMs) and intersex activists, outlining "some of the most significant Human Rights frameworks that have been applied to IGM, and intersex in general, by different IHRMs" (p. 730).

In reviews of UN Universal Periodic Review documents (Ravesloot 2021) and UN treaty body documents (Zelayandía-González 2023), both authors coincide in observing the absence of references to the term DSD or dsd. Zelayandía-González (2023) identifies only one mention of the term 'Intersex Genital Mutilation' (IGM) in the reviewed treaty body documents, raising the question of whether this low mention "might be an indication of a 'compromise' position that recognise this harmful practice as a human rights violation but is not ready yet to grant 'mutilation status' such as the one given to FGM" (p. 11).

Crocetti et al. (2020a) interviewed "intersex activists, patient associations advocates, policy representatives and medical professionals", examining "shared aims and areas of tension in naming aspects of intersex medical treatment human rights abuses" (p. 591). They conclude: "Our analysis indicates that tension does not rest as much on the rights claims in-of-themselves, but rather on the tactic of appealing to IHRBs and the strong emotional register of human rights terms such as 'harmful practice', 'torture', 'inhuman or degrading treatment' and 'violence'" (Crocetti et al. 2020a, p. 591).

Following these previous analyses and framing analysis methods developed in social movement theory (Johnston 2002), I reviewed the terminologies and frameworks used to mention intersex-related human rights violations in human rights-based publications identified in the narrative and scoping review, international and regional intersex activist declarations and human rights documents.

I found a relatively broad overlap in the identified human rights violations, with partially different terminologies and framings between academic publications, activist declarations, and human rights documents. To describe non-consensual medical interventions performed on intersex minors, the term 'human rights violations' or similar wordings are used in the three reviewed fields.[5] The term 'harmful practices' or related wordings (such as 'harmful cultural practices', 'harmful social and cultural practices' or 'harmful medical practices') can be observed in several of the reviewed academic and human rights documents, but only in three activist declarations.[6] The term 'harmful practices' is also used in other activist reports (Ghattas 2015, p. 21, 2019, p. 19). Furthermore, two of the reviewed academic publications refer to the concept 'iatrogenic harm' (Reis-Dennis and Reis 2017, p. 825; Suess-Schwend 2020, p. 799, 2022, p. 97).

The three reviewed document types frame intersex-related medical interventions with similar concepts, such as 'normalizing',[7] 'non-consensual',[8] and 'medically unnecessary',[9] and related terms. The term 'intersex genital mutilation', mentioned in several of the reviewed contributions from intersex studies and human rights documents, together with related terms (such as 'genital mutilation', 'infant genital mutilation' or 'genital cutting'), is only included in three of the reviewed activist declarations.[10] On the other hand, this concept is also used by other intersex activist organizations, such as Iranti-org (2016), OII Europe/ILGA Europe (Ghattas 2019, p. 11) and StopIGM.org/Zwischengeschlecht (2023, s.p.). Furthermore, authors from the field of intersex studies, intersex activism and human rights bodies apply concepts such as 'cruel, inhuman and degrading treatment' or similar wordings,[11] and authors from the field of intersex studies refer to terms such as "physical torture" (Guillot 2018, c.a.), "gendered forms of torture and ill-treatment" (Cabral

Grinspan and Carpenter 2018, p. 184), or “crimen contra la humanidad” (“Crime against humanity”,[12] García López 2018, p. 244).

The reviewed academic publications, activist declarations, and human rights documents also use other terms to describe the human rights violations that intersex people are exposed to. The terms ‘discrimination’[13] and ‘pathologization’[14] are frequently mentioned in all three types of documents. The reviewed academic publications and human rights documents use the term ‘violence’, and variants such as ‘medical violence’, ‘systemic violence’, or ‘institutional violence’, among others. The term ‘violence’ only is included in one of the reviewed activist documents.[15] On the other hand, several of the reviewed activist declarations allude to ‘infanticide and honor killings of intersex people’ or similar terms. The term ‘infanticide’ is also brought up in the reviewed academic literature, but only by three of the reviewed human rights documents.[16] The three reviewed fields also mention ’sterilization’,[17] ‘preimplantation genetic diagnosis’, and terms related to prenatal interventions.[18]

Intersex studies, intersex activism, and human rights bodies also contribute affirmative concepts to frame the human rights of intersex people. Again, I compared the terminologies and framings used in the reviewed academic literature, international and regional activist declarations, and human rights documents. I observed a related high coincidence, especially for concepts such as ‘bodily integrity’,[19] ‘bodily autonomy’,[20] ‘self-determination’,[21] and related terms in all three document types. I also found a mention of the ‘right to health’,[22] and ‘health needs’.[23] Academic, activist and human rights documents highlight the need for ‘access to health care’, ‘access to social services’ and ‘access to psychosocial and peer support’,[24] as well as the relevance of training.[25] The reviewed documents also refer to ‘informed consent’,[26] ‘right to truth’, ‘right to information’ and ‘access to medical records’.[27] Furthermore, all three document types include concepts such as ‘anti-discrimination’,[28] ‘depathologization’,[29] ‘access to justice’ and ‘reparations, redress, and compensations’,[30] with differentiated frequency according to the field.

The reviewed activist declarations do not mention the term ‘best interest of the child’,[31] a term used both in academic literature and human rights documents. This lack of use in activist contexts may be related to the observation of a use of the concept to justify non-consensual interventions, as critically reviewed in intersex studies (Paechter 2021). The Yogyakarta Principles plus 10 (YP+10 2017) indicate: “Ensure that the concept of the best interest of the child is not manipulated to justify practices that conflict with the child’s right to bodily integrity” (p. 10).

Within the reviewed human rights discourses, I identified a high level of dialogue between academia, activism, and human rights bodies, with some differentiated terminology uses, such as regarding the use of the IGM concept or the term ‘best interest of the child’. These differentiated terminologies and framings may be related to differentiated field-specific interests or strategic decisions according to the political and institutional context, as mentioned by previous authors (Bauer et al. 2020; Crocetti et al. 2020a; Zelayandía-González 2023). Their analyses invite us to engage in a critical and self-reflexive review of opportunities and limitations in their use in different fields, including academia, activism, human rights bodies, law, health care, and education.

3.1.2. Legal Analyses

The reviewed academic publications also contribute legal analyses on the human rights of intersex people and their implementation in countries of Africa, Asia, Europe, Latin America, and Oceania, including comparative studies.[32]

Some of the reviewed legal publications mention explicitly the epistemological perspectives they use, among them ‘vulnerability theory’, ‘jurisdictional analysis’, and ‘legal geography’. They also use approaches such as ‘doctrinal and socio-legal methodology’, ‘analysis of bioethical arguments’, ‘shared-decision-making approach’, and ‘doctrine of informed consent’.[33]

Furthermore, they refer to framings that inform their legal analyses, among them 'legal embodiment', 'intersex embodiment', 'intersex equality', 'formal equality', 'substantive equality', and 'scalar limitations'. I also identified a mention of diverse other framings, among them 'social justice', 'gender justice', 'hospitality rules', 'biopolitics, bioethics and biolaw' and 'depathologization and human rights perspective'.[34]

The reviewed authors also analyze the process of implementation and impact of juridical advancements on intersex people. Garland and Travis (2018) review "the practical impact that law has had on the lives and experiences of intersex embodied people" (p. 587), developing strategies for moving from "formal equality" towards "substantive equality" (pp. 605–6). Garland et al. (2022) analyze the limitations that intersex-related UN recommendations face in their local implementation, specifically the prohibition of non-consensual surgeries and other medical treatment on intersex minors, framing them as "Scalar Limitations" (p. 1). Travis (2015) reviews the protection of intersex rights in EU anti-discrimination law.

The reviewed legal literature includes analyses of the intersections between medicine and law in constructing binary sex/gender categories (Kennedy 2016), as well as legal third sex/gender options (Botha 2018; Cabral Grinspan and Carpenter 2018; Carpenter 2018b; Carpenter and Jordens 2022; Cossutta 2018; Garland and Travis 2018; Schotel and Mügge 2021; Travis 2015; von Wahl 2021).

On the other hand, the reviewed intersex activist declarations question the understanding of intersex people as a third sex/gender. They recommend intersex children to be registered as female or male, as long as sex assignment at birth is compulsory, and to facilitate administrative options for modifying this assignment, if wished (African Intersex Movement 2017, 2019, 2023; Asian Intersex Movement 2018; Australian and Aotearoa/New Zealand Intersex Community Organisations 2017; Conferencia Regional Latinoamericana y del Caribe de Personas Intersex 2018; International Intersex Forum 2013; Intersex Asia 2023).

> Reject any notion and labelling of intersexuality as a "third sex", "third gender", "indefinite sex", "non-determined sex", "ambiguous sex" or similar ones at birth, along with the practice of leaving blank the box corresponding to sex assignment after birth, because these categories do not reflect the diversity of the bodies we inhabit and violate our right to privacy.
>
> (Conferencia Regional Latinoamericana y del Caribe de Personas Intersex 2018, s.p.)

> Regarding sex/gender classifications, sex and gender binaries are upheld by structural violence. Additionally, attempts to classify intersex people as a third sex/gender do not respect our diversity or right to self determination. These can inflict wide-ranging harm regardless of whether an intersex person identifies with binary legal sex assigned at birth or not.
>
> (Australian and Aotearoa/New Zealand Intersex Community Organisations 2017, s.p.; bold removed)

Various declarations suggest removing 'sex' or 'gender' as a legal category on birth certificates, identity cards, or passports in the future (African Intersex Movement 2017, 2019, 2023; Australian and Aotearoa/New Zealand Intersex Community Organisations 2017; Conferencia Regional Latinoamericana y del Caribe de Personas Intersex 2018; International Intersex Forum 2013).

Some of the reviewed declarations question the sex/gender binary (Australian and Aotearoa/New Zealand Intersex Community Organisations 2017; European Intersex Meeting 2014) and suggest making non-binary options available in the administrative process to modify gender/sex markers for people able to consent (African Intersex Movement 2017, 2019, 2023, s.p.; Asian Intersex Movement 2018; Australian and Aotearoa/New Zealand Intersex Community Organisations 2017; First European Intersex Community Event 2017; Intersex Asia 2023).

The OII Europe/ILGA Europe Legal Toolkit recommends: “the third option must be used only on a voluntary, personal basis”, “be available to all people” and “parents must not be obliged to have their intersex child registered with the third option” (Ghattas 2019, p. 32; bold removed).

The reviewed resolutions of European human rights bodies recommend establishing flexible birth registration and gender recognition procedures (CoE 2017; European Parliament 2019). The Council of Europe resolution also suggests to: “ensure, when gender classifications are in use by public authorities, that a range of options are available for all people, including those intersex people who do not identify as either male or female” and “consider making the registration of sex on birth certificates and other identity documents optional for everyone” (CoE 2017, s.p.).

In the reviewed legal analyses contributed within intersex studies, I noted a frequent focus on third sex/gender categories, a focus that does not seem to match with the priorities of intersex activist groups. This interest seems not to be limited to the legal literature. Reviewing anthropological literature, Holmes (2004) questions “[t]he anthropological fascination with cultures incorporating more than male and female sex categories into their symbolic classification schemes” (p. 2).

Several of the reviewed authors echo these critiques and debates, discussing critically the role, limitations, and contradictions of legal third sex/gender categories (Botha 2018; Cabral Grinspan and Carpenter 2018; Carpenter 2018b; Carpenter and Jordens 2022; Cossutta 2018; Garland and Travis 2022; Schotel and Mügge 2021; Travis 2015; von Wahl 2021). Cabral Grinspan and Carpenter (2018) highlight that “assigning intersex people to a third sex category purifies the standard gender framework of non-standard embodiments, rendering them as an abject ‘other’, distinguished from endosex men and women” (p. 192) and conclude: “Ultimately, we hope for a future where legal gender markers are irrelevant, or no longer legally required at all” (p. 196).

3.1.3. Citizenship Theories

Some of the reviewed authors also contribute reflections related to citizenship studies, contributing a discussion of the characteristics of “intersex citizenship” (Grabham 2007, p. 29; Monro et al. 2019, p. 780), “intersex infant and children’s citizenship” (Monro et al. 2019, p. 783), or “intersex/variations of sex/characteristics and DSD citizenship” (Monro et al. 2019, p. 780).

Furthermore, they analyze the contribution of the concept as a specific epistemological perspective (Grabham 2007; Monro et al. 2019). Monro et al. (2019) argue that “a citizenship approach may be useful internationally in supporting the human rights of intersex people and those with VCS, because it offers analysis that addresses the full range of factors and processes that impede or support these human rights”, identifying “a large gap in citizenship studies regarding intersex and VSC” (p. 780). Grabham (2007) highlights: “As long as intersex issues are defined by medically disciplining techniques, there remains a need to think critically about how citizenship norms are constructed through responses to corporeality” (p. 29).

The authors review the contribution of different related theories to intersex citizenship, such as ‘children’s citizenship’, ‘health citizenship’, ‘sexual citizenship’, ‘sexual and gendered citizenship’, ‘gender citizenship’, or ‘multisexual citizenship’. They also refer to approaches such as ‘feminist citizenship’, ‘reproductive citizenship’, ‘intimate citizenship’, ‘biocitizenship’, ‘consumer citizenship’, ‘legal citizenship’, and ‘national and trans-national citizenship’.[35]

While human rights discourses and legal approaches are central in the three reviewed knowledge fields, the citizenship concept seems to be less used in intersex activism and human rights discourses. I only found a mention of ‘citizenship rights’ in some of the reviewed activist declarations, and no mention of the citizenship concept in the reviewed human rights documents apart from a use of the term “citizenship card” related to the administrative procedure of modifying sex markers (UN 2023, p. 19).

This limited or absent mention of the citizenship concept in the reviewed activist declarations and human rights documents raises the question about a potential future contribution of citizenship theories to intersex activism and human rights work, taking into account contemporary discussions regarding the opportunities, limitations, and complexities of the concept (Leydet 2023).

3.2. Critical Perspectives on Clinical Practices

As a relevant focus in intersex studies, I could identify the critical review of clinical practices. Intersex authors and allies use different epistemological perspectives to analyze clinical practices, among them biopolitics, medicalization and iatrogenesis, the sociology of diagnosis framework, and the depathologization perspective. Furthermore, they contribute proposals for respectful clinical practices.

3.2.1. Biopolitics, Medicalization, and Iatrogenesis

Foucault ([1976] 2020) describes biopolitics and biopower as new forms of power that emerged in the 19th and 20th centuries. He defines the society of control as characterized by an interrelation between control, knowledge, and power, highlighting that "[t]he old power of death that symbolised sovereign power was now carefully supplanted by the administration of bodies and the calculated management of life" (Foucault [1976] 2020, pp. 139–40). According to his analysis, "[a]nother consequence of this development of bio-power was the growing importance assumed by the action of the norm, at the expense of the juridical system of the law" (Foucault [1976] 2020, p. 144). Furthermore, Foucault ([1963] 1973) analyzes the historical development of medicine and medicalization over the last centuries. He establishes an analogy between different forms of examination in the judicial, clinical, and research fields (Foucault [1963] 1973, [1975] 1977), exploring its biopolitical character, in the sense of both producing and regulating knowledge. In the Introduction of 'Herculine Barbin', Foucault ([1978] 1980) analyzes the transition from a juridical towards a medical regime in conceptualizing and regulating people considered as "hermaphrodites" within the framework of the historical development from a disciplinary towards a biopolitical society, under the question "Do we *truly* need a *true* sex?" (p. 1).

Agamben ([2003] 2005) refers to the concept 'state of exception', indicating: "The state of exception is not a special kind of law (like the law of war); rather, insofar as it is a suspension of the juridical order itself, it defines law's threshold or limit concept" (p. 4). Agamben ([2003] 2005) understands the "inmediately biopolitical significance of the state of exception as the original structure in which law encompasses living beings by means of its own suspension" (p. 3).

The concept of 'medicalization' has been explored by Conrad (1992), who affirms that "Medicalization consists of defining a problem in medical terms, using medical language to describe a problem, adopting a medical framework to understand a problem, or using a medical intervention to 'treat' it" (p. 211).

Illich (1975) discusses the term "Clinical Iatrogenesis" (p. xi), indicating that "clinical iatrogenic disease comprises all clinical conditions for which remedies, physicians, or hospitals are the pathogens, or 'sickening' agents" (p. 18). Illich (1975) also refers to "social iatrogenesis" to describe "various symptoms of social overmedicalization" (p. 24) and "cultural iatrogenesis", in the sense of "the paralysis of healthy responses to suffering, impairment, and death" (p. 25).

The reviewed publications from the field of intersex studies use the frameworks of biopolitics, biopower, state of exception, medicalization, and iatrogenesis to reflect on intersex-related clinical practices from different theoretical perspectives, observing an historical process of medicalization imposed on intersex bodies and its consequences and establishing a comparison with other medicalization practices (Balocchi 2014; Cabral Grinspan 2006; Cabral Grinspan and Carpenter 2018; Carpenter 2018b; Davis and Murphy 2013; Davis et al. 2016; García López 2015, 2018; C. Jones 2022; Kirjava 2022; Reis-Dennis and Reis 2017; Preves 2002; Repo 2013; Rubin 2017, 2021; Suess-Schwend 2023; Vázquez García 2013).

Cabral Grinspan (2006) identifies aspects that "sitúan la intersexualidad como cuestión esencialmente biopolítica" ("situate intersexuality as an essentially biopolitical issue", p. 49) (see Note 12), highlighting an "incesante tensión biopolítica entre lo propio y lo ajeno, lo hospitalario y lo hostil, lo monstruoso y lo humano, l*s extranjer*s y la ciudad" ("incessant biopolitical tension between the self and the other, the hospitable and the hostile, the monstrous and the human, foreigners and the city", p. 62).

Referring to non-consensual surgeries on intersex children, Repo (2013) postulates "The Biopolitical Birth of Gender", noting that "gender was invented in the 1950s as a new sexual apparatus of biopower" (p. 228).

Davis and Murphy (2013) use the concept of biopower and Agamben ([2003] 2005)'s concept 'state of exception' to analyze medical interventions on intersex bodies, indicating that "intersex traits (. . .) directly threaten the normalization of male and female as the only sex characteristics", and "[m]edical experts (. . .) effectively exercise biopower through the administration of medical technologies, and through the medical gaze" (p. 133). According to their analysis, "intersex bodies *are* the site where technical practices perform what becomes a state of exception, with the result of a permanently modified body" (Davis and Murphy 2013, p. 135).

Vázquez García (2013) critically reviews the transhistorical use of the Foucauldian concepts of biopower and biopolitics in contemporary reflections on intersex-related clinical practices. Within a historical review of the treatment of intersex bodies, he differentiates between two different forms of biopolitics, classic liberal biopolitics and new biopolitics. According to Vázquez García (2013), the work of John Money and colleagues is characteristic for this new biopolitics, combining "biopoder disciplinario" ("disciplinary biopower", p. 91) by means of surgical interventions with "biopoder regulador" ("regulatory biopower", p. 91) through family supervision and counselling.

With reference to Arendt and Agamben, García López (2018) postulates that the figure of the refugee and the intersex body suppose "The End of All Rights: the Living Body as Threshold of Democracy" (p. 223). García López (2018) analyzes the argument of psychosocial urgency in the performance of early surgeries as a form of exception converted in norm, applying Agamben ([2003] 2005)'s concepts 'state of exception' and 'bare life' to the situation of intersex people, using the term "el bio-estado de excepción y la nuda vida intersex" ("the bio-state of exception and the intersex bare life", p. 234). In a previous paper, the author describes the intersex body as "un mapa de cicatrices, una cartografía biopolítica que muestra cómo se ejecuta la heterosexualidad dominante, la heteronormatividad" ("a map of scars, a biopolitical cartography that shows how dominant heterosexuality, heteronormativity, is executed", García López 2015, p. 55).

Rubin (2017) analyzes "intersex treatment, activism and theory" as "particular examples to rethink the biopolitics and geopolitics of intersex in specific contexts that have far-reaching consequences" (pp. 15–16). In another publication, Rubin (2021) proposes the concept "*biopolitical* protest" as "a politic that contests the regulation of human life through the medicalization and pathologization of intersex, trans, and gender-nonconforming bodyminds and to expose the administration of sexual dimorphism and binary gender as tactics of racial capitalism" (p. 987).

Davis et al. (2016) compare "Intersex and Trans Medicalization Practices", concluding that "[p]roviders for intersex people are inclined to approach intersex as an emergency that necessitates medical attention, whereas providers for trans people attempts to slow down their patients' urgent requests for transitioning services" (p. 490). Balocchi (2014) explores forms of "medicalization of intersex/uality" (p. 12) in a qualitative study involving intersex people and medical providers. Carpenter (2018b) highlights: "Claims that medicalization saves intersex people from 'othering,' or that legal othering saves intersex people from medicalization, are contradictory and empty rhetoric" (p. 487). Kirjava (2022) reviews "[p]arallels in the medicalization of people who are intersex and people who are deaf" (p. 1). C. Jones (2022) analyzes loneliness as a consequence of the medicalization of intersex bodies.

Finally, some of the reviewed authors use the concept of "iatrogenic harm" (Reis-Dennis and Reis 2017, p. 825) and "iatrogenic consequences" (Preves 2002, p. 530) when referring to non-consensual and not clinically necessary surgeries performed on intersex children.

The reviewed international and regional intersex activist declarations do not mention explicitly the concepts biopolitics, medicalization, and iatrogenesis. Some of the declarations include descriptions of the clinical practices that intersex people are exposed to that coincide with the situations described in intersex studies as forms of biopolitics, medicalization, and iatrogenesis (African Intersex Movement 2017, 2019, 2023; Asian Intersex Movement 2018; Australian and Aotearoa/New Zealand Intersex Community Organisations 2017; European Intersex Meeting 2014; Intersex Asia 2023).

Additionally, the San José de Costa Rica Statement (Conferencia Regional Latinoamericana y del Caribe de Personas Intersex 2018) questions the colonial character of intersex-related clinical discourses and practices.

> With the collective strength of this space today we expose all the ways in which our experiences have been historically and repeatedly colonized, from the invasion of our lands to that of our bodies.
>
> (Conferencia Regional Latinoamericana y del Caribe de Personas Intersex 2018, s.p.)

Some of the reviewed authors refer to these colonial dynamics, as well as decolonial perspectives (Eckert [2009] 2016, 2017; Lewis 2022; McRuer [2009] 2016; Swarr 2023).

Without explicitly using the concepts of biopolitics and iatrogenesis, the reviewed human rights reports and declarations describe harmful medical practices and their consequences on the health and well-being of intersex people (CoE 2015; EC 2012; IACHR 2015, 2016, 2020, 2023; UN 2016, 2017, 2019). The Council of Europe Report (CoE 2015) dedicates a chapter to the "Medicalisation of intersex people" (pp. 19–26).

While the use of theoretical frameworks such as biopolitics, medicalization, and iatrogenesis seem to be mostly limited to the academic field, I could identify the description of related situations in activist and human rights documents, creating the opportunity for a dialogue about strategies to overcome their harmful consequences.

3.2.2. Sociology of Diagnosis

The sociology of diagnosis perspective is used to analyze the cultural roles and consequences of diagnostic processes in the contemporary Western society, as well as practices of contestation (Brown 1990; Jutel 2009; Jutel and Nettleton 2011).

> Within the context of Western biomedicine diagnosis: validates what counts as disease; offers explanations and coheres patients' symptoms; legitimates illness, enabling patients to access the sick role; provides a means to access resources and facilitates their allocation; and forms the foundation of medical authority. But close scrutiny reveals that the picture is not a simple one. Medical diagnoses are also contested, socially created, framed and/or enacted.
>
> (Jutel and Nettleton 2011, p. 793)

Applying the sociology of diagnosis framework to the experiences of intersex people, Jenkins and Short (2017) explore the "relationship between social diagnosis and (de)medicalization" (p. 91) in intersex-related diagnosis processes, identifying "key actors and structures in the intersex debate, and their contributions to (de)medicalization processes" and "highly complex negotiations between social actors over the pathologization of this condition" (p. 93). They observe that "social actors can engage with social structures to both contribute and resist the framing of a condition like intersex as pathological" (Jenkins and Short 2017, p. 93).

The reviewed intersex activist declarations and human rights documents do not explicitly mention the sociology of diagnosis framework. Several of the activist declarations include the demand of depathologizing diagnostic classifications.

> To depathologise variations in sex characteristics in medical practices, guidelines, protocols and classifications, such as the World Health Organisation's International Classification of Diseases.
>
> (African Intersex Movement 2017, s.p., 2019, s.p., 2023, s.p.; Asian Intersex Movement 2018, p. 3; International Intersex Forum 2013, s.p.; Intersex Asia 2023, p. 9)

An international working group coordinated by GATE (2014, 2017) contributes detailed suggestions for modifying intersex-related diagnostic codes in the ICD-10, International Classification of Diseases 10th Revision (WHO [1990] 2019).

The UN (2019) and the European Parliament (2019) mention the need for modifying diagnostic codes.

In the reviewed activist declarations and human rights documents, I observed a critical discussion on diagnostic practices and classifications that is in line with the sociology of diagnosis framework without mentioning this perspective explicitly.

3.2.3. Depathologization Perspective

Over the last 15 years, the depathologization perspective has achieved an increasing relevance in trans activism and studies, aimed at questioning dynamics of pathologization and psychopathologization (Suess-Schwend 2014, 2020, 2022, 2023; Suess-Schwend et al. 2014).

> Pathologization can be understood as the conceptualization of bodily characteristics, habits, practices, gestures, people and groups of people as mentally disordered, ill, abnormal or malformed. The demand for depathologization is a response to multiple forms of pathologization of trans and intersex people in different social fields, including social, familial, educational, academic, labor, clinical and legal contexts.
>
> (Suess-Schwend 2020, p. 800)

In the field of intersex studies, intersex activism, and intersex-related human rights documents, an increased use of the concepts of pathologization and depathologization can be observed.

A broad range of the reviewed authors use the concept 'pathologization' or related verbal forms to question intersex-related medical terminologies, diagnostic classifications, and clinical discourses and practices. Some of the reviewed activist declarations also refer to 'pathologization' or related verbal forms in relation to intersex bodies and terminology use. Several of the reviewed human rights documents include the term 'pathologization' or related verbal forms in reference to current conceptualizations of intersex bodies, language use, diagnostic codes, and medical practices (see Note 14).

Some of the reviewed authors also use the concept 'depathologization' or related verbal forms and terms (such as 'non-pathologization') to refer to intersex people and narratives (see Note 29). In the anthology 'Inter*Pride', Cabral Grinspan (2022) contributes an extensive reflection on intersex depathologization in a chapter titled 'Advancing Intersex Depathologization—Die Entpathologisierung von Intergeschlechtlichkeit voranbringen' (p. 161). Bastien-Charlebois and Guillot (2018) highlight that "[s]ince its establishment in the early 1990s the intersex movement has been attempting to enforce the respect for intersex children's human rights to physical integrity and self-determination, as well as the non-pathologization of intersexuality" (p. 257). I refer to the "depathologization and human rights perspective" (Suess-Schwend 2022, p. 92).

Several of the reviewed activist declarations demand the depathologization of medical guidelines, protocols, and classifications, training from depathologizing and human rights perspectives, and non-pathologizing psycho-social and peer support (see Note 29).

> All training should be provided from a depathologizing and human rights perspective.
>
> (First European Intersex Community Event 2017, s.p.)

> In view of ensuring the bodily integrity and well-being of intersex people, autonomous non-pathologising psycho-social and peer support be available to intersex people throughout their life (as self-required), as well as to parents and/or care providers.
>
> (African Intersex Movement 2017, s.p., 2019, s.p., 2023, s.p.; Asian Intersex Movement 2018, p. 4; International Intersex Forum 2013, s.p.)

Furthermore, they claim “supportive, safe and celebratory environments” (Asian Intersex Movement 2018, p. 4; International Intersex Forum 2011, s.p., 2012, s.p., 2013, s.p.; Intersex Asia 2023, p. 11). Other activist groups also demand a depathologization of intersex bodies (Iranti-org 2016; OII Europe 2023). For the Intersex Awareness Day 2023, OII Europe (2023) launched a campaign titled “Depath Intersex. Depathologize Intersex”, including a detailed description of different aspects related to depathologization, under the following objective: “we want to help people gain an understanding of what pathologizing intersex means, why it has to stop and how we can start depathologizing intersex” (s.p.).

Several of the reviewed human rights documents refer to the term ‘depathologization’ and related verbal forms (see Note 29). Among others, the European Parliament resolution (2019) “calls on the Member States to ensure the depathologisation of intersex people” (s.p.), and the UN Background Note refers to the “need to depathologize intersex traits, and bodily diversity in general” (UN 2019, p. 57).

I found an expanding use of the terms pathologization and depathologization in all three reviewed knowledge fields. The increasing relevance of the depathologization perspective within intersex-related discourses may provide an opportunity for a dialogue with other knowledge fields that analyze dynamics of pathologization, such as trans studies, disabilities/crip studies, or mad studies.

3.2.4. Respectful Health Care Approaches

At the same time as questioning pathologizing medical models, the reviewed academic, activist and human rights documents refer to the right to health (see Note 22) and health needs (see Note 23) of intersex people.

The reviewed authors from the field of intersex studies identify barriers in accessing health care, especially for older intersex people (Berry and Monro 2022; Crocetti et al. 2020b, [2023] 2024), recommending the provision of appropriate health care across the lifespan, as well as access to psychosocial and peer support (see Note 24). Some of the reviewed authors contribute proposals for a “Human Rights-Based Intersex Healthcare” (Roen et al. 2023, p. 1), “humanistic healthcare approach” (Meoded Danon and Schweizer 2020, p. 441), “[a]gency-based approaches” (Crocetti et al. 2020b, p. 500), and “a trauma-informed approach to care” (Haghighat et al. 2023, p. 1), highlighting the relevance of professional training (see Note 25).

Several of the reviewed intersex activist declarations demand access to necessary and appropriate health care, social services, psychosocial and peer support (see Note 24), as well as training opportunities for health professionals (see Note 25). Two of the reviewed activist declarations underline the relevance of ‘universal health coverage’ (GATE et al. 2019, s.p.; Intersex Asia 2023, p. 6). Furthermore, the Darlington Statement proposes “the implementation of advisory bodies to develop human rights-based, lifetime, intersex standards of care with full and meaningful participation by intersex community representatives and human rights institutions” and “the implementation of adequate clinical transition pathways from paediatric to adult services” (Australian and Aotearoa/New Zealand Intersex Community Organisations 2017, s.p.; bold removed).

The reviewed human rights documents mention the importance of an access to health care, including psychosocial and peer support (see Note 24), and training of health professionals (see Note 25), as well as the implementation of a “holistic and patient-centred approach" (CoE 2017, s.p.), and the elaboration of "comprehensive healthcare protocols" (IACHR 2020, s.p.). The Inter-American Commission on Human Rights calls on providing "access to support as well as to medical services that respond to their specific health needs and are based on non-discrimination, informed consent and respect for their fundamental rights" (IACHR 2016, s.p.).

The three reviewed knowledge fields contribute proposals for respectful health care approaches that may open the way towards future clinical practices based on the recognition of the right to bodily integrity, the ban of non-consensual surgeries and other treatments, and the relevance of respectful and non-discriminatory communication.

3.3. Reflections on Epistemological, Methodological, and Ethical Aspects

In several previous publications, I reviewed epistemological, methodological, and ethical reflections in intersex studies and activism (Suess-Schwend 2014, 2020, 2022, 2023). In these previous publications, as well as in the current literature review, I identified reflections on epistemic injustice as a central issue both in academic publications and academic–activist recommendation documents, including suggestions for working towards epistemic justice, such as practices of reflexivity, collaborative research methodologies, and human rights-based ethics. The reviewed human rights documents do not provide recommendations related to research, apart from mentioning the need for further research on the human rights situation of intersex people (CoE 2013, 2015) and the request for a report "examining in detail discriminatory laws and policies, acts of violence and harmful practices against persons with innate variations in sex characteristics, in all regions of the world, and their root causes, and also examining best practices" (UN 2024, par. 1).

Fricker (2007) provides a detailed analysis of the concept of "epistemic injustice", differentiating between two forms of epistemic injustice, "testimonial injustice" and "hermeneutical injustice" (p. 1), and describing examples in diverse social contexts. According to her analysis, "[t]estimonial injustice occurs when prejudice causes a hearer to give a deflated level of credibility to a speaker's word; hermeneutical injustice occurs at a prior stage, when a gap in collective interpretive resources puts someone at an unfair disadvantage when it comes to making sense of their social experiences" (p. 1). Fricker (2007) also indicates the possibility of working towards "testimonial justice" (p. 92) and "hermeneutical justice" (p. 174).

Regarding epistemology of knowledge, Sedgwick (1994) highlights that "ignorance is ignorance of a knowledge" and "ignorances (. . .) are produced by and correspond to particular knowledges and circulate as part of particular regimes of truth" (p. 25). According to Tuana (2004), "[a]n important aspect of an epistemology of ignorance is the realization that ignorance should not be theorised as a simple omission or gap but is, in many cases, an active production" (p. 195).

In the field of intersex studies, several of the reviewed authors denounce dynamics of epistemic injustice and epistemology of ignorance that intersex people are exposed to in clinical practices, policy making, and research (Bastien-Charlebois 2016, 2017, 2019; Cabral Grinspan and Benzur 2005; Merrick [2017] 2019; van Heesch [2009] 2016).

Merrick ([2017] 2019) analyzes "the 2005 Consensus Conference as a failed attempt to extend epistemic justice to intersex patients and advocacy groups" (p. 3).

Based on the question "Can Intersex subjects reflect (upon themselves)?" (s.p.), Bastien-Charlebois (2017) reviews the impact of testimonial and hermeneutical injustice on the political subjectivation of intersex people, and their opportunities to emerge as "sujet-acteur" ("subject–actor", s.p.). In another publication, Bastien-Charlebois (2016) analyzes, with reference to the concept "epistemic injustice," "[h]ow medical discourse dehumanizes intersex people," identifying as forms "[i]nstituting absence of participation by intersex people", "[t]reating intersex people as mere sources of information" and "[t]reating intersex people's voices to a range of dismissive comments" (s.p.).

Referring to Miranda Fricker, Carpenter (2016) stresses that "[f]or intersex people, this hermeneutical injustice arises in two distinct ways: through clinical secrecy and terminology, and through societal discourse on identity" (p. 79).

Several authors reflect on the ambivalence of the testimonial role that intersex people are associated with. Bastien-Charlebois (2019) highlights the relevance and lack of recognition of "first person accounts" (p. 78) by medical practitioners.

> Each have different outlooks on first person accounts and value them differently. Medical practitioners mainly invalidate them as "anecdotal", human rights specialists considers each instance as relevant when examining human rights violations, and legislators often hesitate between medical authority and human rights obligations.
>
> (Bastien-Charlebois 2019, p. 78)

Cabral Grinspan (in Cabral Grinspan and Benzur 2005) refers to the ambivalence of the testimony role for intersex people, for being considered "pacientes, es decir, sujetos de una tradicional escucha menguada, mutilada" ("patients, this is, subjects of a traditional diminished, mutilated listening", p. 298).

Cabral Grinspan (2009) also identifies another dimension of discursive exclusion: the identification of intersex experiences with narratives in English and from the Global North. The anthology 'Interdicciones', edited by Cabral Grinspan (2009) with contributions in Spanish and Portuguese, most of them from the Global South, aims at producing an "*inversión* geopolítica" ("geopolitical *inversion*", p. 6).

In relation to the concept of epistemology of ignorance, van Heesch ([2009] 2016) describes experiences of withholding information about diagnoses and surgical interventions from intersex people.

From intersex academic–activist perspectives, several recommendation documents contribute suggestions for overcoming epistemic injustice and epistemology of ignorance, especially highlighting the need for reflexivity and awareness of the own positionality and motivation for researching intersex-related issues, as well as providing methodological suggestions.

In 'Suggested Guidelines for Non-Intersex Individuals Writing about Intersexuality and Intersex People', Koyama (2002) mentions various recommendations aimed at avoiding epistemic injustice, among them:

> I Recognize that you are not the experts about intersex people, intersexuality, or what it means to be intersexed; intersex people are. (. . .)
>
> II Critically approach writings by non-intersex 'experts' such as doctors, scientists, and academics about intersexuality or intersex people if you decide to quote or cite them. (. . .)
>
> III Do not write about intersex existence or the concept of intersexuality without talking about the lives and experiences of intersex people as well as issues they face. (. . .)
>
> IV Do not judge the politics and narratives of intersex people or movement based on how useful they are to your political agenda (or agendas). (. . .)
>
> (Koyama 2002, p. 1)

In their recommendations for respectful intersex-related research, RéFRI, Réseau francophone de recherche sur l'intersexuation (2020) invites researchers to critically review their own motivation to research intersex-related topics: "Pourquoi je me suis intéressé·e à ce sujet? Quel rapport (ou non) avec mon vécu personnel? Qu'est-ce qui m'a attiré vers la question inter?" ("Why am I interested in this topic? What does this have to do (or not) with my personal experience? What drew me to the intersex issue?", s.p.). Furthermore, the RéFRI recommendations suggest that researchers avoid pathologizing and stigmatizing terminologies, inform themselves about the demands of intersex associations, avoid the exoticization of intersex people, and: "Penser à inverser le regard: ne pas étudier seulement les intersexués comme objet mais objective les dominants: médicins, psys, etc." ("Think about reversing the focus: don't just study intersex people as objects, but objectivize the dominant ones: medics, psys, etc.", RéFRI 2020, s.p.; bold removed).

The Darlington Statement highlights the importance of "community input" and refers to the need for avoiding medical photography of children with intersex variations (Australian and Aotearoa/New Zealand Intersex Community Organisations 2017, s.p.).

In a recommendation document published by Intersex Human Rights Australia, Carpenter ([2012] 2023) calls for "community-based participatory research", ensuring "the survey is relevant and meaningful", "accessible" and "trauma-informed" (s.p.).

In the same document, recommendations are provided regarding inclusive sex/gender categories in quantitative research, aimed at avoiding a misrepresentation of intersex people, such as "supporting *multiple choice answers* for questions on sex or gender", "[a]n open field for gender" and "[s]eparating intersex from a question on sex and/or gender" (Carpenter [2012] 2023, s.p.).

Based on previous ethical recommendations, I constructed principles for an "ethics of depathologization", "as a work in process concept open to further developments" (Suess-Schwend 2022, p. 111), including principles related to epistemic justice and reflexivity. I understand "[e]thics of depathologization" "as a research practice based on the depathologization and human rights perspective, developed in the field of trans and intersex studies, but applicable to different research topics, knowledge fields and situation of structural violence and epistemic injustice" (Suess-Schwend 2022, p. 111).

Koyama (2002) closes the 'Suggested Guidelines' with a call for political commitment: "No writings about intersexuality or intersex people should make light of the immediate crisis: five children are being mutilated every day in the United States alone. Think about what you can do to help stop that" (p. 2).

The contribution of broad epistemological, methodological, and ethical reflections and recommendations in intersex studies raises the question about how to enhance their application in intersex-related research and other research fields.

3.4. Limitations and Future Research Interests

This literature review aims at providing a general panoramic view about epistemological perspectives in intersex studies, intersex activism, and human rights documents during the moment of writing. This strategy entails several methodological limitations.

The panoramic scope facilitates a general overview of the current discursive production but limits an in-depth exploration of each of the mentioned themes, opening potential areas of interest for future studies. The necessary selection of authors includes risks such as being perceived as unfair or biased.

I conducted the review from the understanding of intersex studies as a critical field of knowledge that questions dominant clinical, legal, and social practices. My decision to focus on critical discourses informs necessarily both the scoping and narrative review.

The scoping review conducted using Scopus is reduced to high-indexed publications, mainly in English. I tried to balance this bias by including publications in other languages that I identified in the previous narrative review. In future scoping reviews, additional databases, including databases in other languages, could be included. I also limited the comparative review of activist and human rights documents to international and regional activist declarations, as well as selected documents of international and regional human rights bodies (and the Yogyakarta Principles plus 10), leaving out local activist declarations and reports, other UN treaty body documents or country-specific human rights documents.

Furthermore, the interest in focusing on epistemological perspectives relevant for intersex studies, intersex activism, and human rights bodies entails a difficulty—the used epistemological perspectives or framing strategies are often not explicitly mentioned.

The literature review on epistemological perspectives in intersex studies presented in this paper also allows for the identification of potential future research interests.

In the reviewed literature, I found several analyses on the history of intersex activism, focusing frequently on the history of US-based intersex activism (Davis 2015; Karkazis 2008;

Rubin 2017, 2019), but also including the history of intersex activism in other countries and continents (Astraea Lesbian Foundation for Justice 2016; Haller et al. 2022; von Wahl 2021). It could be interesting to analyze the historical and political contexts in which contemporary intersex studies has emerged in different world regions and how these contexts have informed epistemological perspectives.

As mentioned above, for this paper I selected some of the epistemological perspectives identified in the literature review, leaving other relevant themes out, among them theories on embodiment, sex/gender non binarism and bodily diversity, disability/crip theories, reflections on social inequities, intersectionalities and social justice, or educational perspectives. A review of these epistemological perspectives could be developed in future publications.

Some of the reviewed authors analyze intersex studies and activism in relation to other knowledge fields, including a comparison between dynamics of medicalization related to intersex and trans people (Davis et al. 2016), intersex and deaf people (Kirjava 2022), or crip and intersex discourses (Orr 2022). Based on these previous analyses, a future project could focus on comparing epistemological reflections in different knowledge fields and activist discourses related to the experiences of dynamics of medicalization, pathologization, and epistemic injustice in clinical and research contexts.

4. Conclusions

The literature review presented in this paper aims at reviewing epistemological perspectives in intersex studies, intersex activism, and intersex-related human rights documents.

Reviewing the field of intersex studies, intersex activism, and intersex-related human rights documents throughout more than a decade by means of a work-in-progress project, I became aware of the expanding knowledge production in the mentioned fields. I constantly observe the publication of new contributions in the academic, activist, and human rights field. During the review process of this paper, the first UN resolution on intersex rights was passed (UN 2024). This process may indicate a move from a situation of invisibility and hermeneutical injustice towards a moment in which "[t]he conditions necessary for the appearance of an object of discourse" (Foucault [1969] 1972, p. 44) seem to emerge in the public sphere. At the same time, it is important to be aware of the continued human rights violations intersex people face, as well as backlashes and new threats.

From the positionality as an ally of intersex activism, I would like to stress the awareness of the specific ethico-political responsibility of portraying these multiple and expanding fields.

The literature review shows a tight relationship between the discourses contributed by intersex studies, intersex activism, and human rights bodies, especially regarding human rights frameworks. The discussion includes a review of human rights-based frames and their applicability for activism and policy making. In this sense, the reflections on epistemological perspectives in intersex studies are not limited to the academic field but can be related to strategies in intersex activism and human rights bodies. At the same time, in some specific topics, I identified differentiated priorities and terminology uses between academia on the one hand, and activism and human rights bodies on the other hand, including self-reflexive thoughts in academic contributions regarding the potential impact of these differences. An ongoing dialogue between the three fields could contribute to supporting socially committed and human rights-based knowledge production.

As indicated above, other knowledge fields mention the development of specific epistemologies in their fields, raising the question: Can we talk about specific intersex epistemologies in the field of intersex studies and activism?

I can observe an application of already existing frameworks to the field of intersex studies and/or intersex activism, such as reflections on human rights, biopolitics, medicalization, iatrogenesis, and epistemic injustice. At the same time, the experience of human rights violations and pathologization of intersex bodies raises specific epistemological reflections on the right to bodily integrity, protection from harmful practices, and depathologization that can be considered as specific contributions of intersex studies and activism—perhaps shared with other knowledge fields constituted by an experience of human rights violations in clinical and research contexts.

I would like to finish by highlighting the importance of engaging in a discussion about how reflections on epistemologies and theory making in intersex studies can contribute to political action, and the role of academic–activist authors in this process, aimed at identifying and developing framing strategies to support the protection of the human rights of intersex people and research practices based on epistemic justice.

Funding: This research received no external funding. I would like to acknowledge the contribution of the discussions on intersex studies shared in the INIA: Intersex—New Interdisciplinary Approaches project, funded by the European Commission (MSC-ITN 859869), in which I participate as a member of the consortium team and PhD co-supervisor.

Institutional Review Board Statement: The analysis presented in the manuscript did not involve humans or animals throughout the course of the literature review; therefore, the Institutional Review Board Statement is not applicable.

Informed Consent Statement: Not applicable.

Data Availability Statement: The analysis presented in this manuscript is a literature review; therefore, no new data were created or analyzed and data sharing is not applicable.

Conflicts of Interest: The author declares no conflicts of interest.

Notes

[1] "Intersex individuals are born with sex characteristics (sexual anatomy, reproductive organs, hormonal structure and/or levels and/or chromosomal patterns) that do not fit the typical definition of male or female" (Ghattas 2019, p. 6).

[2] "Intersex people are born with physical sex characteristics (such as sexual anatomy, reproductive organs, hormonal patterns and/or chromosomal patterns) that do not fit typical definitions for male or female bodies" (UN 2019, p. 4).

[3] According to The Yogyakarta Principles plus 10 (YP+10 2017), the term "'sex characteristics'" refers to "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" (p. 6).

[4] I have published reflections on epistemological, methodological, and ethical reflections in intersex and trans studies since 2011, including my PhD thesis. In order to reduce self-citation, in this paper I only refer to some selected recent publications that include references to previous works.

[5] Framing of intersex-related medical interventions as 'human rights violations', or related terms in the reviewed academic publications (Baird 2021, p. 372; Bastien-Charlebois 2017, s.p.; Cabral Grinspan and Carpenter 2018, p. 183; Carpenter 2020, p. 13; Ghattas 2013, p. 7; Hart and Shakespeare-Finch 2022, p. 912; Machado 2008, p. 36; Smith and Hegarty 2021, p. 548; Suess-Schwend 2023, p. 31), activist declarations (Asian Intersex Movement 2018, p. 2; Australian and Aotearoa/New Zealand Intersex Community Organisations 2017, s.p.; Conferencia Regional Latinoamericana y del Caribe de Personas Intersex 2018, s.p.; European Intersex Meeting 2014, s.p.; Intersex Asia 2023, p. 10), and human rights documents (ACHPR 2023, s.p.; CoE 2015, p. 10; EC 2012, p. 83; European Parliament 2019, para. B; FRA 2015, p. 5; IACHR 2015, p. 114, 2016, s.p.; UN 2016, s.p., 2017, p. 1, 2019, title, 2023, p. 1). The page indication corresponds to the first mention in the text, idem in the following notes.

[6] Framing of intersex-related medical interventions as 'harmful practices', or related terms (among others 'harmful cultural practices', 'harmful social and cultural practices', or 'harmful medical practices') in the reviewed academic publications (Baird 2021, p. 372; Bauer et al. 2020, pp. 724, 735; Cabral Grinspan and Carpenter 2018, p. 191; Carpenter 2016, p. 74, 2018a, p. 205, 2020, p. 14; Swarr 2023, pp. 145, 149), activist declarations (Australian and Aotearoa/New Zealand Intersex Community Organisations 2017, s.p.; Intersex Asia 2023, p. 3; International Intersex Forum 2014, p. 1) and human rights documents (ACHPR 2023, preamble; IACHR 2016, s.p.; UN 2016, s.p., 2017, p. 1, 2019, p. 2, 2024, p. 2).

[7] Framing of intersex-related medical interventions as 'normalizing', or related terms in the reviewed academic publications (Ammaturo 2016b, p. 591; Cabral Grinspan 2006, p. 59; Cabral Grinspan and Benzur 2005, p. 289; Cabral Grinspan and Carpenter 2018, p. 186; Crocetti et al. 2020b, p. 500; Cuadra et al. 2022, p. 1; Davidian [2011] 2013, c.a.; Dreger 2018, c.a.; García López 2015, p. 57, 2018, p. 244; Ghattas 2013, p. 35; Horowicz 2017, p. 183; Machado 2008, p. 31; Meoded Danon and Schweizer 2020, p. 1562; Pikramenou 2019, b.a.; Reis-Dennis and Reis 2017, p. 826; Swarr 2023, p. 140), activist declarations (African Intersex Movement 2017, 2019, 2023, s.p.; Asian Intersex Movement 2018, pp. 2, 3; Intersex Asia 2023, p. 9; International Intersex Forum 2011, s.p., 2012, s.p., 2013, s.p.) and human rights documents (ACHPR 2023, preamble; CoE 2015, p. 9, 2017, para. 7.1.1.; European Parliament 2019, para. 2; FRA 2015, p. 1; IACHR 2015, p. 114; UN 2019, p. 22). The abbreviation c.a. refers to chapter abstract and b.a. to book abstract listed in Scopus, idem in the following notes.

[8] Framing of intersex-related medical interventions as ‘non-consensual’, ‘involuntary, ‘forced’, ‘coercive’, or related terms in the reviewed academic publications (Bastien-Charlebois 2017, s.p.; Bauer et al. 2020, p. 730; Carpenter 2018b, p. 487; Duggan and McNamara 2021, p. 272; Harper 2020, b.a.; Hart and Shakespeare-Finch 2022, p. 883; Tosh 2019, b.a.; Suess-Schwend 2014, p. 134, 2020, p. 799, 2023, p. 26), activist declarations (European Intersex Meeting 2014, s.p.; Intersex Asia 2023, p. 4), and human rights documents (ACHPR 2023, preamble; UN 2019, p. 6).

[9] Framing of intersex-related medical interventions as ‘medically unnecessary’, or related terms in the reviewed academic publications (Bastien-Charlebois 2017, s.p.; Hart and Shakespeare-Finch 2022, p. 883; Swarr 2023, p. 18), activist declarations (Conferencia Regional Latinoamericana y del Caribe de Personas Intersex 2018, s.p.; First European Intersex Community Event 2017, s.p.; Intersex Asia 2023, p. 4), and human rights documents (ACHPR 2023, preamble; CoE 2013, s.p., 2015, p. 9, 2017, para. 7.1.1; European Parliament 2019, para. 6; FRA 2015, p. 5; IACHR 2015, pp. 116–18, 2023, s.p.; UN 2016, s.p., 2017, p. 1, 2024, p. 2, preamble).

[10] Framing of intersex-related medical interventions as ‘intersex genital mutilation’, or related terms (among others ‘genital mutilation’, ‘infant genital mutilation’, or ‘genital cutting’) in the reviewed academic publications (Baird 2021, p. 372; Bauer et al. 2020, p. 726; Cabral Grinspan 2006, p. 59; Cabral Grinspan and Benzur 2005, p. 293; Davidian [2011] 2013, c.a.; García López 2015, p. 54, 2018, p. 236, Guillot 2018, c.a.; Machado 2008, p. 26; Rubin 2019, c.a.; Suess-Schwend 2022, p. 97; Svoboda 2013, p. 237; Swarr 2023, p. 136; Winter Pereira 2022, p. 181), activist declarations (First European Intersex Community Event 2017, s.p.; International Intersex Forum 2014, p. 1; Intersex Asia 2023, p. 13), and human rights documents (CoE 2015, pp. 16, 31; European Parliament 2019, para. D, L; FRA 2015, s.p.; IACHR 2015, p. 116; UN 2019, p. 17).

[11] Framing of intersex-related medical interventions as ‘cruel, inhuman and degrading treatment’, or related terms in the reviewed academic publications (Bauer et al. 2020, p. 724; García López 2015, p. 68), activist declarations (European Intersex Meeting 2014, s.p.; First European Intersex Community Event 2017, s.p.), and human rights documents (CoE 2015, p. 25; UN 2019, p. 9).

[12] If not indicated otherwise, translations into English are mine.

[13] Use of the concept ‘discrimination’, or related terms in the reviewed academic publications (Amos et al. 2022, p. 833; Cabral Grinspan and Carpenter 2018, p. 184; Ghattas 2013, p. 7; Husakouskaya 2013, p. 10; Mestre Martínez 2022, p. 1; Sampaio Oliveira Lima et al. 2019, c.a.; Sperling 2021, p. 584; Suess-Schwend 2020, pp. 799, 803, 2022, p. 97; Swarr 2023, p. 93), activist declarations (Asian Intersex Movement 2018, p. 2; Australian and Aotearoa/New Zealand Intersex Community Organisations 2017, s.p.; First European Intersex Community Event 2017, s.p.; International Intersex Forum 2013, s.p., 2014, s.p.; Intersex Asia 2023, p. 3), and human rights documents (ACHPR 2023, para. 5; CoE 2015, p. 7, 2017, title, paras. 4, 5; European Parliament 2019, paras. B, E, K, 10, 11; FRA 2015, p. 1, 2020, p. 51; IACHR 2016, 2020, 2023, s.p.; UN 2016, s.p., 2017, p. 1, 2019, p. 4, 2023, p. 1, 2024, title, preamble, para. 3; YP+10 2017, p. 10).

[14] Use of the concept ‘pathologization’, or related verbal forms (‘pathologize’, ‘pathologized’, ‘pathologizing’, in American and British spelling) in the reviewed academic publications (Bastien-Charlebois 2017, s.p.; Bastien-Charlebois and Guillot 2018, pp. 258, 262; C. Jones 2022, pp. 42, 44; Carpenter 2016, pp. 77, 79, 80, 2018a, pp. 205–8; Crocetti et al. 2020b, p. 500, 506, 507; Eckert [2009] 2016, 2017, b.a.; García López 2015, p. 61; Ghattas 2013, p. 14; Hart and Shakespeare-Finch 2022, p. 912; Jenkins and Short 2017, p. 91; Kehrer and Balocchi 2022, p. 98; Kirjava 2022, p. 1, 4; Machado 2008, p. 16; Malatino 2013, p. 241; Meoded Danon 2018, p. 569; Meoded Danon and Schweizer 2020, p. 441; Monro et al. 2021, pp. 433, 435; O’Brien 2015, pp. 11, 16; Rubin 2021, p. 987; Sperling 2021, p. 584; Suess-Schwend 2020, p. 799, 2022, pp. 93, 97, 2023, p. 32; Swarr 2023, p. 2; Topp 2013, p. 180), activist declarations (Australian and Aotearoa/New Zealand Intersex Community Organisations 2017, s.p.; Conferencia Regional Latinoamericana y del Caribe de Personas Intersex 2018, s.p.; First European Intersex Community Event 2017, s.p.), and human rights documents (CoE 2015, pp. 9, 23; EC 2012, pp. 5, 15; European Parliament 2019, para. 7, 8; FRA 2015, p. 2, 2020, pp. 52, 53; IACHR 2015, pp. 118–19, 2016, s.p.; UN 2016, s.p., 2019, pp. 4, 52).

[15] Use of the concept ‘violence’, or related terms (among others ‘family violence’, ‘domestic violence’, ‘gender-based violence’, ‘interphobic violence’, ‘medical violence’, ‘institutional violence’, ‘social and systemic violence’, or ‘sexual violence’) in the reviewed academic publications (Bauer et al. 2020, p. 730; C. Jones 2022, p. 39; Cabral Grinspan and Carpenter 2018, p. 186; García López 2015, p. 67, 2018, p. 236; Ghattas 2013, p. 7; Mestre Martínez 2022, p. 1; Pikramenou 2020, p. 62; Rubin 2021, p. 987; Sampaio Oliveira Lima et al. 2019, c.a.; Suess-Schwend 2020, p. 803, 2022, p, 97; Swarr 2023, p. 4; Tosh 2019, c.a.; Winter Pereira 2022, pp. 182, 185), activist declarations (Intersex Asia 2023, p. 3, 10), and human rights documents (CoE 2015, p. 44; European Parliament 2019, paras. B, E; FRA 2020, p. 51; IACHR 2015, p.114, 2016, s.p., 2020, s.p., 2023, s.p.; UN 2016, s.p., 2017, p. 2, 2019, p. 5, 2023, p. 1, 2024, title, preamble, paras. 1–3).

[16] Use of the concepts ‘infanticide’, ‘honor killings’, or related terms in the reviewed academic publications (Carpenter and Jordens 2022, p. 110; Ghattas 2013, p. 42; Machado 2008, p. 30; Suess-Schwend 2020, p. 803; 2022, p. 97; Swarr 2023, p. 145), activist declarations (African Intersex Movement 2017, s.p., 2019, s.p., 2023, s.p.; Asian Intersex Movement 2018, p. 5; Intersex Asia 2023, pp. 9, 10; International Intersex Forum 2011, s.p., 2012, s.p., 2013, s.p.), and human rights documents (ACHPR 2023, preamble; UN 2019, p. 4, 2023, p. 1).

[17] Use of the concept ‘sterilization’, or related terms in the reviewed academic publications (Bauer et al. 2020, p. 730; Cabral Grinspan and Carpenter 2018, p. 187; Ghattas 2013, p. 36; Suess-Schwend 2014, p. 134, 2020, p. 803, 2022, p. 97; Swarr 2023, p. 140), activist declarations (African Intersex Movement 2017, s.p., 2019, s.p., 2023, s.p.; Asian Intersex Movement 2018, p. 3;

International Intersex Forum 2013, s.p.), and human rights documents (ACHPR 2023, para. 2; CoE 2015, p. 9, 2017, para. 7.1.1.; FRA 2015, p. 5; IACHR 2015, pp. 114–15, 2016, s.p., 2020, s.p., 2023, s.p.; UN 2016, s.p., 2017, p. 2, 2019, p. 6).

[18] Use of the concepts 'prenatal implementation diagnosis', 'prenatal interventions', or related terms in the reviewed academic publications (Jenkins and Short 2017, p. 95; Orr 2019, c.a.; Suess-Schwend 2014, p. 134, 2020, p. 803), activist declarations (Asian Intersex Movement 2018, p. 3; International Intersex Forum 2013, s.p.; Intersex Asia 2023, p. 9; International Intersex Forum 2011, s.p., 2012, s.p.), and human rights documents (CoE 2015, p. 30; UN 2019, p. 31).

[19] Use of the concept 'bodily integrity', 'physical integrity', or related terms in the reviewed academic publications (Ammaturo 2016b, p. 591; Bauer et al. 2020, pp. 729–31; Bastien-Charlebois and Guillot 2018, c.a.; Cabral Grinspan and Carpenter 2018, p. 192; Carpenter 2016, p. 77, 2018a, p. 205, 2018b, p. 487, 2020, p. 516; Crocetti et al. 2020a, p. 943; García López 2015, p. 68, 2018, p. 236; Ghattas 2013, p. 34; Hegarty et al. 2021, p. 25; Lewis 2022, p. 255; Machado 2008, p. 36; Pikramenou 2019, b.a.; Rajam and Banerjee 2022, p. 130; Suess-Schwend 2014, p. 134, 2023, p. 26; Swarr 2023, p. 140), activist declarations (African Intersex Movement 2017, s.p., 2019, s.p., 2023, s.p.; Asian Intersex Movement 2018, p. 2; Australian and Aotearoa/New Zealand Intersex Community Organisations 2017, s.p.; European Intersex Meeting 2014, s.p.; First European Intersex Community Event 2017, s.p.; International Intersex Forum 2011, s.p., 2012, s.p., 2013, s.p.; Intersex Asia 2023, p. 4), and human rights documents (ACHPR 2023, para. 2; CoE 2013, s.p., 2015, pp. 7, 14; EC 2012, pp. 17, 71; European Parliament 2019, para. 6; FRA 2015, p. 5; IACHR 2020, s.p., 2023, s.p.; UN 2017, p. 1, 2019, pp. 4, 15, 2023, p. 1; YP+10 2017, p. 10).

[20] Use of the concepts 'bodily autonomy', 'physical autonomy', or related terms in the reviewed academic publications (Carpenter 2016, p. 74, 2020, p. 516; Carpenter and Jordens 2022, p. 121; Crocetti et al. 2020a, p. 943; García López 2015, p. 62; Lewis 2022, p. 255; lisahunter et al. 2022, p. 1047; Machado 2008, p. 37; Meoded Danon 2018, p. 569; Meoded Danon and Schweizer 2020, p. 441; Suess-Schwend 2014, p. 134; Svoboda 2013, p. 237; Swarr 2023, p. 140), activist declarations (African Intersex Movement 2017, s.p., 2019, s.p., 2023, s.p.; Asian Intersex Movement 2018, p. 2; Australian and Aotearoa/New Zealand Intersex Community Organisations 2017, s.p.; First European Intersex Community Event 2017, s.p.; International Intersex Forum 2013, s.p.; Intersex Asia 2023, p. 4), and human rights documents (ACHPR 2023, para. 2; CoE 2013, s.p., 2015, p. 31, 2017, para. 7.1.; European Parliament 2019, para. 6; IACHR 2016, s.p.; UN 2019, p. 21, 2023, p. 1; YP+10 2017, p. 10).

[21] Use of the concept 'self-determination', or related terms in the reviewed academic publications (Bastien-Charlebois and Guillot 2018, c.a.; Cabral Grinspan and Carpenter 2018, p. 192; Carpenter 2016, p. 77, 2018b, p. 487; Carpenter and Jordens 2022, p. 121; Crocetti et al. 2020a, p. 943; Ghattas 2013, p. 45; Hegarty et al. 2021; Pikramenou 2019, b.a.; Schotel and Mügge 2021, p. 981; Suess-Schwend 2014, p. 134; Swarr 2023, p. 140; Woweries 2018, b.a.), activist declarations (African Intersex Movement 2017, 2019, 2023, s.p.; Asian Intersex Movement 2018, p. 2; Australian and Aotearoa/New Zealand Intersex Community Organisations 2017, s.p.; First European Intersex Community Event 2017, s.p.; International Intersex Forum 2011, s.p., 2012, s.p., 2013, s.p.; Intersex Asia 2023, p. 9), and human rights documents (ACHPR 2023, para. 2; CoE 2013, s.p., 2015, p. 9, 2017, paras. 7.1.2., 7.3.2.; EC 2012, p. 71; European Parliament 2019, paras. J, 6, 9; UN 2019, p. 35; YP+10 2017, p. 10).

[22] Mention of the 'right to health', or related terms in the reviewed academic publications (Bauer et al. 2020, p. 730; Swarr 2023, p. 85), activist declarations (Asian Intersex Movement 2018, p. 2; GATE et al. 2019, s.p.), and human rights documents (CoE 2015, p. 25; European Parliament 2019, para. 7; IACHR 2016, s.p., 2020, s.p.; UN 2017, p. 1, 2019, pp. 12, 59, 2023, p. 1, 2024, p. 2).

[23] Mention of 'health needs', or related terms in the reviewed academic publications (Berry and Monro 2022, p. 51; Crocetti et al. 2020b, p. 500, [2023] 2024, p. 332; lisahunter et al. 2022, p. 1047), activist declarations (Asian Intersex Movement 2018, p. 4; Australian and Aotearoa/New Zealand Intersex Community Organisations 2017, s.p.; First European Intersex Community Event 2017, s.p.; GATE et al. 2019, s.p.; Intersex Asia 2023, p. 6) and human rights documents (ACHPR 2023, s.p.; FRA 2020, p. 52; UN 2016, s.p., 2017, pp. 2, 3, 2019, p. 29, 2023, pp. 6, 12).

[24] Mention of 'access to health care', 'access to social services', 'access to psychosocial and peer support', or related terms in the reviewed academic publications (Amos et al. 2022, p. 833; Gregori Flor et al. 2018, p. 1; Hart and Shakespeare-Finch 2022, p. 912; Swarr 2023, pp. 77, 136), activist declarations (African Intersex Movement 2017, s.p., 2019, s.p., 2023, s.p.; Asian Intersex Movement 2018, p. 4; Australian and Aotearoa/New Zealand Intersex Community Organisations 2017, s.p.; First European Intersex Community Event 2017, s.p.; GATE et al. 2019, s.p.; International Intersex Forum 2012, s.p., 2013, s.p.), and human rights documents (CoE 2015, pp. 9, 43, 2017, para. 7.1.4.; IACHR 2016, s.p.; UN 2016, s.p., 2017, p. 1, 2019, pp. 29, 60, 2023, p. 2).

[25] Mention of the relevance of training for health professionals in the reviewed academic publications (Haghighat et al. 2023, p. 1; Meoded Danon and Schweizer 2020, p. 4; Swarr 2023, p. 140), activist declarations (African Intersex Movement 2017, s.p., 2019, s.p., 2023, s.p.; Asian Intersex Movement 2018, s.p.; Conferencia Regional Latinoamericana y del Caribe de Personas Intersex 2018, s.p.; First European Intersex Community Event 2017, s.p.; Intersex Asia 2023, p. 6; International Intersex Forum 2012, s.p.; Intersex Asia 2023, p. 9), and human rights documents (ACHPR 2023, para. 7; European Parliament 2019, para. 14; IACHR 2016, s.p., 2020, s.p.; UN 2017, p. 2, 2019, p. 57).

[26] Mention of the 'right to informed consent', or related terms in the reviewed academic publications (Amos et al. 2022, p. 833; Cabral Grinspan and Carpenter 2018, p. 187; Carpenter and Jordens 2022, p. 114; García López 2015, p. 61, 2018, p. 235; Ghattas 2013, p. 14; Gregori Flor et al. 2018, p. 1; Lowry 2018, p. 321; Machado 2008, p. 36; Pikramenou 2019, b.a.; Suess-Schwend 2014, p. 134; Swarr 2023, p. 149; Woweries 2018, c.a.), activist declarations (Australian and Aotearoa/New Zealand Intersex Community Organisations 2017, s.p.; Conferencia Regional Latinoamericana y del Caribe de Personas Intersex 2018, s.p.; European Intersex

Meeting 2014, s.p.; First European Intersex Community Event 2017, s.p.; International Intersex Forum 2011, s.p., 2012, s.p.), and human rights documents (CoE 2015, p. 8, 2017, paras. 7.1.2., 7.5.; EC 2012, p. 84; European Parliament 2019, para. D; FRA 2015, p. 2; IACHR 2015, p. 119; IACHR 2016, s.p., 2020, s.p.; UN 2016, s.p., 2019, pp. 6, 9, 13, 2023, p. 2, 2024, preamble; YP+10 2017, p. 15).

[27] Mention of the 'right to truth', 'access to information', 'access to medical records', or related terms in the reviewed academic publications (Carpenter 2020, p. 516; Ghattas 2013, p. 15), activist declarations (African Intersex Movement 2017, s.p., 2019, s.p.,2023, s.p.; Asian Intersex Movement 2018, p. 5; Conferencia Regional Latinoamericana y del Caribe de Personas Intersex 2018, s.p.; First European Intersex Community Event 2017, s.p.; International Intersex Forum 2012, s.p., 2013, s.p.; Intersex Asia 2023, p. 10), and human rights documents (ACHPR 2023, para. 9; CoE 2015, pp. 9, 25, 2017, para. 7.1.5.; European Parliament 2019, para. 6; IACHR 2020, s.p., 2023, s.p.; UN 2016, s.p., 2019, pp. 14, 15, 2023, p. 2).

[28] Mention of the 'right to anti-discrimination', and related terms in the reviewed academic publications (Bauer et al. 2020, p. 730; Carpenter 2016, pp. 77–78, 2020, p. 516; Garland and Travis 2018, p. 587; lisahunter et al. 2022, p. 1047; Lundberg et al. 2019, p. 354; O'Brien 2015, p. 1; Pikramenou 2019, b.a.; Suess-Schwend 2020, p. 808; Swarr 2023, p. 98; Travis 2015, p. 180), activist declarations (ACHPR 2023, para. 5; African Intersex Movement 2017, 2019, 2023, s.p.; Asian Intersex Movement 2018, p. 2; European Intersex Meeting 2014, s.p.; First European Intersex Community Event 2017, s.p.; Intersex Asia 2023, p. 5), and human rights documents (CoE 2015, pp. 16, 43; UN 2016, s.p., 2019, p. 4, 2023, p. 1; YP+10 2017, p. 10).

[29] Use of the concept 'depathologization', related verbal forms ('depathologize', 'depathologizing', in American and British spelling) and related terms (such as 'non-pathologisation') in the reviewed academic publications (Bastien-Charlebois and Guillot 2018, c.a.; Cabral Grinspan 2022, p. 161; Frank 2018, p. 127; Ghattas 2013, p. 11; Haghighat et al. 2023, p. 1; Suess-Schwend 2014, p. 134, 2020, pp. 799, 803, 2022, pp. 91–93, 2023, pp. 30, 32), activist declarations (African Intersex Movement 2017, s.p., 2019, s.p., 2023, s.p.; Asian Intersex Movement 2018, pp. 3, 4; First European Intersex Community Event 2017, s.p.; International Intersex Forum 2013, s.p.; Intersex Asia 2023, p. 9), and human rights documents (European Parliament 2019, paras. 7, 8; FRA 2020, p. 52; UN 2019, p. 57).

[30] Mention of the 'right to access justice', 'reparations, redress, and compensations', and related terms in the reviewed academic publications (Bauer et al. 2020, p. 730; Cabral Grinspan and Carpenter 2018, p. 196; Suess-Schwend 2014, p. 134, 2020, p. 803; Swarr 2023, p. 151; Zelayandía-González 2023, p. 2), activist declarations (Asian Intersex Movement 2018, p. 5; Australian and Aotearoa/New Zealand Intersex Community Organisations 2017, s.p.; First European Intersex Community Event 2017, s.p.; International Intersex Forum 2013, s.p.; Intersex Asia 2023, p. 10), and human rights documents (ACHPR 2023, para. 10; CoE 2015, pp. 5, 8, 33, 49, 2017, para. 7.5.1.; EC 2012, p. 64; European Parliament 2019, para. 10; IACHR 2020, s.p., 2023, s.p.; UN 2017, p. 2, 2019, pp. 4, 42, 57, 2023, p. 1, 2024, preamble; YP+10 2017, p. 15).

[31] Use of the concept 'best interest of the child', and related terms in the reviewed academic publications (Baird 2021, p. 372; García López 2015, p. 62; Horowicz 2017, p. 183; Paechter 2021, p. 844), and human rights documents (ACHPR 2023, para. 3; CoE 2015, pp. 19, 20, 33; YP+10 2017, p. 10).

[32] Geographic context of the reviewed legal analyses: Africa (Baird 2021; Botha 2018; Pikramenou 2019; Rubin 2019), Asia (Rajam and Banerjee 2022; Pikramenou 2019), Europe (Botha 2018; Cossutta 2018; Dietz 2018; García López 2015, 2018; Garland and Travis 2018, 2020a, 2020b, 2022; Garland et al. 2022; Mestre Martínez 2022; Ní Mhuirthile et al. 2022; Pikramenou 2019; Rubin 2019; Schotel and Mügge 2021; Suess-Schwend 2018; Travis 2015; von Wahl 2021), Latin America (Davidian [2011] 2013; Mestre Martínez 2022; Pikramenou 2019; Rubin 2019), North America (Davidian [2011] 2013; Lowry 2018; Pikramenou 2019; Rubin 2019), Oceania (Carpenter 2018b; Cossutta 2018; Duggan and McNamara 2021; Garland and Travis 2018, 2022; Kennedy 2016; Pikramenou 2019; Rubin 2019), including comparative studies (Botha 2018; Cossutta 2018; Davidian [2011] 2013; Garland and Travis 2018, 2022; Mestre Martínez 2022; Pikramenou 2019; Rubin 2019).

[33] Epistemological perspectives in the reviewed legal analyses: "vulnerability theory" (Garland and Travis 2018, p. 588; 2020a, p. 298), "jurisdictional analysis" (Garland and Travis 2020a, p. 298), "legal geography" (Garland et al. 2022, p. 1), "doctrinal and socio-legal methodology", "analysis of bioethical arguments", and "shared-decision-making approach" (Horowicz 2017, p. 183), and "doctrine of informed consent" (Lowry 2018, p. 321).

[34] Framings in the reviewed legal analyses: "legal embodiment" (Dietz 2018, p. 185), "intersex embodiment" (Garland and Travis 2018, p. 587, 2020a, p. 298, 2020b, c.a.), "intersex equality", "formal equality", and "substantive equality" (Garland and Travis 2018, p. 587), "scalar limitations" (Garland et al. 2022, p. 1), "social justice" (Garland and Travis 2018, p. 587), "gender justice" (Lowry 2018, p. 321), "hospitality rules" (Cabral Grinspan and Carpenter 2018, p. 183), "biopolítica, bioética y bioderecho", ("biopolitics, bioethics and biolaw", García López 2018, p. 224), and "perspectiva de despatologización y derechos humanos" ("depathologization and human rights perspective", Suess-Schwend 2018, p. 97).

[35] Contributions of other citizenship theories to intersex citizenship: "children's citizenship" (Monro et al. 2019, p. 783), "health citizenship" (Monro et al. 2019, p. 780), "sexual citizenship" (Grabham 2007, p. 29; Monro et al. 2019, p. 785), "sexual and gendered citizenship", "gender citizenship", and "multisexual citizenship" (Ammaturo 2016a, b.a.), "feminist citizenship" (Monro et al. 2019, p. 784), "reproductive citizenship" (Monro et al. 2019, p. 782), "intimate citizenship" (Grabham 2007, p. 29; Monro et al. 2019, p. 785), "biocitizenship" (King 2021, p. 519), "consumer citizenship" (Grabham 2007, p. 29; Rubin 2019), "legal citizenship" (Monro et al. 2019, p. 785), and "national and trans-national citizenship" (Ammaturo 2016a, b.a.).

References

ACHPR, African Commission on Human and Peoples' Rights. *Resolution on the Promotion and Protection of the Rights of Intersex Persons in Africa—ACHPR/Res.552 (LXXIV) 2023*. Banjul: African Commission on Human and Peoples' Rights. Available online: https://achpr.au.int/en/adopted-resolutions/resolution-promotion-and-protection-rights-intersex-persons (accessed on 19 April 2024).

African Intersex Movement. 2017. *Public Statement by the African Intersex Movement*. Available online: https://www.astraeafoundation.org/stories/public-statement-african-intersex-movement/ (accessed on 19 April 2024).

African Intersex Movement. 2019. *African Intersex Movement—Africa's Regional Intersex Network—Established*. Available online: https://www.astraeafoundation.org/stories/african-intersex-movement-network-founded-in-kenya/ (accessed on 19 April 2024).

African Intersex Movement. 2023. *The 3rd African Intersex Movement Statement. Theme: Reconnecting and Shaping our Narrative*. Available online: https://intersexnigeria.org/wp-content/uploads/2023/02/3rd-African-Intersex-Movement-Statement-2023.pdf (accessed on 19 April 2024).

Agamben, Giorgio. 2005. *State of Exception*. Chicago: University of Chicago Press. First published 2003.

Ammaturo, Francesca Romana. 2016a. *European Sexual Citizenship: Human Rights, Bodies and Identities*. London: Palgrave Macmillan.

Ammaturo, Francesca Romana. 2016b. Intersexuality and the 'Right to Bodily Integrity': Critical Reflections on Female Genital Cutting, Circumcision, and Intersex 'Normalizing Surgeries' in Europe. *Social and Legal Studies* 25: 591–610. [CrossRef]

Amos, Natalie, Bonnie Hart, Adam O. Hill, G. J. Melendez-Torres, Ruth McNair, Marina Carman, Anthony Lyons, and Adam Bourne. 2022. Health Intervention Experiences and Associated Mental Health Outcomes in a Sample of LGBTQ People with Intersex Variations in Australia. *Culture, Health and Sexuality* 25: 833–46. [CrossRef] [PubMed]

Asian Intersex Movement. 2018. *Public Statement*. Available online: https://intersexasia.org/wp-content/uploads/2019/08/IA-Stat_English_pages.pdf (accessed on 19 April 2024).

Astraea Lesbian Foundation for Justice. 2016. *We Are Real: The Growing Movement Advancing the Human Rights of Intersex People*. New York: Astraea Lesbian Foundation for Justice.

Australian and Aotearoa/New Zealand Intersex Community Organisations. 2017. *Darlington Statement*. Available online: https://darlington.org.au/statement/ (accessed on 19 April 2024).

Baird, Sophy. 2021. The Silence of the 'I': Legal and Social Implications of Intersex Genital Mutilation of Children. *South African Journal on Human Rights* 37: 372–91. [CrossRef]

Balocchi, Michela. 2014. The medicalization of intersexuality and the sex/gender binary system: A look on the Italian case. *LES Online* 6: 65–78.

Barth, Elsa, Ben Böttger, Dan Christian Ghattas, and Ina Schneider, eds. 2013. *Inter: Erfahrungen intergeschlechtlicher Menschen in der Welt der zwei Geschlechter*. Berlin: NoNo Verlag.

Bastien-Charlebois, Janik. 2016. *How Medical Discourse Dehumanizes Intersex People*. Altona: IHRA, Intersex Human Rights Australia, in collaboration with Brújula Intersexual: Available online: https://intersexday.org/en/medical-discourse-bastien-charlebois/ (accessed on 19 April 2024).

Bastien-Charlebois, Janik. 2017. Les sujets intersexes peuvent-ils (se) penser? Les empiétements de l'injustice épistémique sur le processus de subjectivation politique des personnes intersex(ué)es. *Socio* 9: 143–62. [CrossRef]

Bastien-Charlebois, Janik. 2019. 'On our own terms and in our own words': The value of first person accounts of intersex experience. In *#MyIntersexStory. Personal Accounts by Intersex People Living in Europe*. Edited by Dan Christian Ghattas, Ins A. Kromminga, Irene Kuzemko, Kitty Anderson and Audrey Aegerter. Berlin: OII Europe, pp. 75–109.

Bastien-Charlebois, Janik, and Vicent Guillot. 2018. Medical Resistance to Criticism of Intersex Activists: Operations on the Frontline of Credibility. In *Normed Children: Effects of Gender and Sex Related Normativity on Childhood and Adolescence*. Edited by Erik Schneider and Christel Baltes-Löhr. Bielefeld: Transcript Verlag, pp. 257–69.

Bauer, Markus, Daniela Truffer, and Daniela Crocetti. 2020. Intersex Human Rights. *International Journal of Human Rights* 24: 724–49. [CrossRef]

Berry, Adeline W., and Surya Monro. 2022. Ageing in obscurity: A critical literature review regarding older intersex people. *Sexual and Reproductive Health Matters* 30: 2136027. [CrossRef] [PubMed]

Botha, Henk. 2018. Beyond Sexual Binaries? The German Federal Constitutional Court and the Rights of Intersex People. *Potchefstroom Electronic Law Journal* 21: 1–26. [CrossRef]

Braun, Virginia, and Victoria Clarke. 2022. *Thematic Analysis: A Practical Guide*. London: SAGE Publishing.

Brown, Phil. 1990. The Name Game: Towards a Sociology of Diagnosis. *The Journal of Mind and Behavior* 11: 385–406.

Cabral Grinspan, Mauro. 2006. *El cuerpo en el cuerpo*. Una introducción a las biopolíticas de la intersexualidad. *Orientaciones. Revista de las homosexualidades* Extra11: 47–64.

Cabral Grinspan, Mauro. 2022. Advancing Intersex Depathologization—Die Entpathologisierung von Intergeschlechtlichkeit voranbringen. In *Inter* Pride. Perspektiven aus einer weltweiten Menschenrechtsbewegung*. Edited by Paul Haller, Luan Pertl and Tinou Ponzer. Hiddensee: W_orten & meer, pp. 161–74.

Cabral Grinspan, Mauro, and Gabriel Benzur. 2005. Cuando digo *intersex*. Un diálogo introductorio a la *intersexualidad*. *Cadernos Pagu* 24: 284–304.

Cabral Grinspan, Mauro, and Morgan Carpenter. 2018. Gendering the Lens: Critical Reflections on Gender, Hospitality and Torture. In *Gender Perspectives on Torture. Law and Practice*. Edited by Center for Human Rights & Humanitarian Law, Washington College of Law and American University. Washington, DC: American University, pp. 183–96.

Cabral Grinspan, Mauro, ed. 2009. *Interdicciones. Escrituras de la intersexualidad en castellano*. Córdoba: Anarrás Editorial.

Carpenter, Morgan. 2016. The human rights of intersex people: Addressing harmful practices and rhetoric of change. *Reproductive Health Matter* 24: 74–84. [CrossRef] [PubMed]

Carpenter, Morgan. 2018a. Intersex Variations, Human Rights, and the International Classification of Diseases. *Health and Human Rights* 20: 205–14.

Carpenter, Morgan. 2018b. The 'Normalization' of Intersex Bodies and 'Othering' of Intersex Identities in Australia. *Bioethical Inquiry* 15: 487–95. [CrossRef] [PubMed]

Carpenter, Morgan. 2020. The OHCHR Background Note on Human Rights Violations against Intersex People. *Sexual and Reproductive Health Matters* 28: 1–4. [CrossRef] [PubMed]

Carpenter, Morgan. 2023. *Researching Intersex Populations*. Altona: IHRA, Intersex Human Rights Australia. First published 2012. Available online: https://ihra.org.au/research/ (accessed on 19 April 2024).

Carpenter, Morgan, and Christopher F. C. Jordens. 2022. When Bioethics Fails: Intersex, Epistemic Injustice and Advocacy. In *Interdisciplinary and Global Perspectives on Intersex*. Edited by Megan Walker. Cham: Palgrave Macmillan, pp. 107–24.

Chase, Cheryl. 2013. Hermaphrodites with Attitude: Mapping the Emergence of Intersex Political Activism. In *The Transgender Studies Reader*. Edited by Susan Stryker and Stephen Whittle. London and New York: Routledge, pp. 300–14.

Cleminson, Richard, and Francisco Vázquez García. 2009. *Hermaphroditism, Medical Science and Sexual Identity in Spain, 1850–1960*. Cardiff: University of Wales Press.

Cleminson, Richard, and Francisco Vázquez García. 2018. *Sexo, Identidad y Hermafroditas en el Mundo Ibérico, 1500–1800*. Madrid: Cátedra.

CoE—Council of Europe. 2013. *Resolution 1952(2013). Children's Right to Physical Integrity*. Strasbourg: Council of Europe. Available online: https://assembly.coe.int/nw/xml/XRef/Xref-XML2HTML-en.asp?fileid=20174 (accessed on 19 April 2024).

CoE—Council of Europe. 2015. *Human Rights and Intersex People*. Strasbourg: Council of Europe Publishing.

CoE—Council of Europe. 2017. *Resolution 2191(2017). Promoting the Human Rights of and Eliminating Discrimination against Intersex People*. Strasbourg: Council of Europe. Available online: https://assembly.coe.int/nw/xml/XRef/Xref-XML2HTML-en.asp?fileid=24232 (accessed on 19 April 2024).

Conferencia Regional Latinoamericana y del Caribe de Personas Intersex. 2018. *Declaración de San José de Costa Rica/San José de Costa Rica Statement*. Available online: https://brujulaintersexual.org/2018/04/02/declaracion-de-san-jose-de-costa-rica/ (accessed on 19 April 2024).

Conrad, Peter. 1992. Medicalization and Social Control. *Annual Review of Sociology* 18: 209–32. [CrossRef]

Cossutta, Carlotta. 2018. Linguistic Traps: Identity and Differences through Institutions. In *Law, Politics and the Gender Binary*. Edited by Petr Agha. London and New York: Routledge, pp. 45–60. [CrossRef]

Crocetti, Daniela, Adeline Berry, and Surya Monro. 2024. Navigating the complexities of adult healthcare for individuals with variations of sex characteristics: From paediatric emergencies to a sense of abandonment. *Culture, Health & Sexuality* 26: 332–45. First published 2023. [CrossRef] [PubMed]

Crocetti, Daniela, Elisa A. G. Arfini, Surya Monro, and Tray Yeadon-Lee. 2020a. 'You're Basically Calling Doctors Torturers': Stakeholder Framing Issues around Naming Intersex Rights Claims as Human Rights Abuses. *Sociology of Health and Illness* 42: 943–58. [CrossRef] [PubMed]

Crocetti, Daniela, Surya Monro, Valentino Vecchietti, and Tray Yeadon-Lee. 2020b. Towards an Agency-Based Model of Intersex, Variations of Sex Characteristics (VSC) and DSD/dsd Health. *Culture, Health and Sexuality* 23: 500–15. [CrossRef]

Cuadra, Magali, Ricardo Baruch, Andrea Lamas, María E. Morales, Armando Arredondo, and Doris Ortega. 2022. *Normalizing* Intersex Children through Genital Surgery: The Medical Perspective and the Experience Reported by Intersex Adults. *Sexualities* 27: 533–52. [CrossRef]

Davidian, Alison. 2013. Beyond the Locker Room: Changing Narratives on Early Surgery for Intersex Children. In *Sexuality and Equality Law*. Edited by Suzanne B. Goldberg. London and New York: Routledge, pp. 405–27. First published 2011. [CrossRef]

Davis, Georgiann. 2015. *Contesting Intersex. The Dubious Diagnosis*. New York: New York University Press.

Davis, Georgiann, and Erin L. Murphy. 2013. Intersex Bodies as States of Exception: An Empirical Explanation for Unnecessary Surgical Modification. *Feminist Formations* 25: 129–52. [CrossRef]

Davis, Georgiann, Jodie M. Dewey, and Erin L. Murphy. 2016. Giving Sex: Deconstructing Intersex and Trans Medicalization Practices. *Gender and Society* 30: 490–514. [CrossRef]

De Clerck, Goedele A. M. 2016. *Deaf Epistemologies, Identity, and Learning: A Comparative Perspective*. Washington, DC: Gallaudet University Press.

Delimata, Natalie, Margaret Simmonds, Michelle O'Brien, Georgiann Davis, Richard Auchus, and Karen Lin-Su. 2018. Evaluating the Term 'Disorders of Sex Development': A Multidisciplinary Debate. *Social Medicine* 11: 98–107.

Dietz, Chris. 2018. Governing Legal Embodiment: On the Limits of Self-Declaration. *Feminist Legal Studies* 26: 185–204. [CrossRef]

Dreger, Alice D. 2003. *Hermaphrodites and the Medical Invention of Sex*. Cambridge and London: Harvard University Press. First published 1998.

Dreger, Alice D. 2018. 'Ambiguous Sex'—Or Ambivalent Medicine?: Ethical Issues in the Treatment of Intersexuality. In *Women, Medicine, Ethics and the Law*. Edited by Susan Sherwin and Barbara Parish. London and New York: Routledge, pp. 225–36. [CrossRef]

Dreger, Alice D., ed. 1999. *Intersex in the Age of Ethics*. Hagerstown: University Publishing Group.

Duggan, Keely, and Donna McNamara. 2021. The Blurred Distinction between Therapeutic and Non-Therapeutic Medical Interventions for Intersex Children in Australia. *Australian Journal of Human Rights* 27: 272–92. [CrossRef]

EC—European Commission. 2012. *Trans and Intersex People. Discrimination on the Grounds of Sex, Gender Identity and Gender Expression*. Luxembourg: Office for Official Publications of the European Union.

Eckert, Lena. 2016. 'Diagnosticism': Three Cases of Medical Anthropological Research into Intersexuality. In *Critical Intersex*. Edited by Morgan Holmes. London and New York: Routledge, pp. 41–72. First published 2009.

Eckert, Lena. 2017. *Intersexualization: The Clinic and the Colony*. London and New York: Routledge. [CrossRef]

European Intersex Meeting. 2014. *Statement of Riga*. Available online: https://www.oiieurope.org/statement-of-riga/ (accessed on 19 April 2024).

European Parliament. 2019. *European Parliament Resolution of 14 February 2019 on the Rights of Intersex People (2018/2878(RSP))*. Strasbourg: European Parliament. Available online: https://www.europarl.europa.eu/doceo/document/TA-8-2019-0128_EN.html (accessed on 19 April 2024).

Feder, Ellen K., and Katrina Karkazis. 2008. What's in a Name? The Controversy over 'Disorders of Sex Development'. *Hasting Center Report* 38: 33–36. [CrossRef] [PubMed]

First European Intersex Community Event. 2017. *Vienna Statement of the First European Intersex Community Event*. Available online: https://www.oiieurope.org/statement-1st-european-intersex-community-event-vienna-30st-31st-march-2017/ (accessed on 19 April 2024).

Foucault, Michel. 1972. *The Arqueology of Knowledge and The Discourse on Language*. New York: Pantheon Books. First published 1969.

Foucault, Michel. 1973. *Birth of the Clinic: An Archaeology of Medical Perception*. London and New York: Routledge. First published 1963.

Foucault, Michel. 1977. *Discipline and Punish*. New York: Pantheon Books. First published 1975.

Foucault, Michel. 1980. *Herculine Barbin: Being the Recently Discovered Memoirs of a Nineteenth-Century French Hermaphrodite*. New York: Pantheon Books. First published 1978.

Foucault, Michel. 2020. *The History of Sexuality: 1: The Will to Knowledge*. London: Penguin Books. First published 1976.

FRA, European Union Agency for Fundamental Rights. 2015. *The Fundamental Rights Situation of Intersex People*. Luxembourg: Publications Office of the European Union.

FRA, European Union Agency for Fundamental Rights. 2020. *EU-LGBTI II. A Long Way to Go for LGBTI Equality*. Luxembourg: Publications Office of the European Union.

Frank, Sarah E. 2018. Intersex and Intimacy: Presenting Concerns about Dating and Intimate Relationships. *Sexuality and Culture* 22: 127–47. [CrossRef]

Fricker, Miranda. 2007. *Epistemic Injustice: Power and the Ethics of Knowing*. Oxford: Oxford University Press.

Fröhling, Ulla, ed. 2003. *Leben zwischen den Geschlechtern. Intersexualität—Erfahrungen in einem Tabubereich*. Berlin: Ch. Links Verlag.

García López, Daniel J. 2015. La intersexualidad en el discurso médico-jurídico. *Eunomía: Revista en Cultura de la Legalidad* 8: 54–70.

García López, Daniel J. 2018. El fin de todos los derechos: El cuerpo viviente como umbral de la democracia. *Anales de la Cátedra Francisco Suárez* 52: 223–47. [CrossRef]

Garland, Fae, and Mitchell Travis. 2018. Legislating Intersex Equality: Building the Resilience of Intersex People through Law. *Legal Studies* 38: 587–606. [CrossRef]

Garland, Fae, and Mitchell Travis. 2020a. Making the State Responsible: Intersex Embodiment, Medical Jurisdiction, and State Responsibility. *Journal of Law and Society* 47: 298–324. [CrossRef]

Garland, Fae, and Mitchell Travis. 2020b. Temporal Bodies: Emergencies, Emergence, and Intersex Embodiment. In *A Jurisprudence of the Body. Palgrave Socio-Legal Studies*. Edited by Chris Dietz, Mitchell Travis and Michael Thomson. Cham: Palgrave Macmillan, pp. 119–47. [CrossRef]

Garland, Fae, and Mitchell Travis. 2022. *Intersex Embodiment. Legal Frameworks beyond Identity and Disorder*. Bristol: Policy Press.

Garland, Fae, Kay Lalor, and Mitchell Travis. 2022. Intersex Activism, Medical Power/Knowledge and the Scalar Limitations of the United Nations. *Human Rights Law Review* 22: ngac020. [CrossRef]

GATE. 2014. *Intersex Issues in the International Classification of Diseases: A Revision*. Buenos Aires and New York: GATE. Available online: https://gate.ngo/wp-content/uploads/2015/10/GATE_Intersex-Issues-in-the-ICD_2014.pdf (accessed on 19 April 2024).

GATE. 2017. *Submission by GATE to the World Health Organization: Intersex Codes in the International Classification of Diseases (ICD) 11 Beta Draft*. Buenos Aires and New York: GATE. Available online: https://gate.ngo/wp-content/uploads/2024/02/GATE_Intersex-codes-in-the-ICD-11-Beta-Draft_2017.pdf (accessed on 19 April 2024).

GATE, IHRA, Intersex Human Rights Australia, Justicia Intersex, AIS Support Group Australia, Kimberly Saviano, AIS-DSD Support Group, Bilitis Resource Center Foundation, Brújula Intersexual, Brújula Intersexual Argentina, and et al. 2019. *Joint Statement on the International Classification of Diseases 11*. Available online: https://ihra.org.au/35299/joint-statement-icd-11/ (accessed on 19 April 2024).

Ghattas, Dan Christian. 2013. *Human Rights between the Sexes. A Preliminary Study on the Life Situations of Inter* Individuals*. Berlin: Heinrich Böll Stiftung.

Ghattas, Dan Christian. 2015. *Standing Up for the Human Rights of Intersex People—How Can You Help*. Brussels and Berlin: ILGA Europe and OII Europe. Available online: https://www.oiieurope.org/wp-content/uploads/2016/02/How-to-be-a-great-intersex-ally-A-toolkit-for-NGOs-and-decision-makers-December-2015.pdf (accessed on 19 April 2024).

Ghattas, Dan Christian. 2019. *Protecting Intersex People in Europe: A Toolkit for Law and Policymakers*. Berlin and Brussels: OII Europe, ILGA Europe.

Grabham, Emily. 2007. Citizen Bodies, Intersex Citizenship. *Sexualities* 10: 29–48. [CrossRef]

Gregori Flor, Nuria. 2013. Utopías dicotómicas sobre los cuerpos sexuados. *Arbor Ciencia, Pensamiento y Cultura* 189: a071. [CrossRef]

Gregori Flor, Nuria, Silvia García Dauder, and Inma Hurtado García. 2018. Bioethics and Intersex: "Time Out". A Paradigm Shift on Intersex Management in the Spanish Context. *Athenea Digital* 18: e1899. [CrossRef]

Griffiths, David A. 2018. Diagnosing sex: Intersex surgery and 'sex change' in Britain 1930–1955. *Sexualities* 21: 476–95. [CrossRef] [PubMed]

Guillot, Vicent. 2018. Sex/gender Normativity and Intersex Bodies: Intersex and Human Rights. In *Normed Children: Effects of Gender and Sex Related Normativity on Childhood and Adolescence*. Edited by Erik Schneider and Christel Baltes-Löhr. Bielefeld: Transcript Verlag, pp. 245–55.

Haghighat, Darius, Tala Berro, Lilian Torrey Sosa, Kaya Horowitz, Bria Brown-King, and Kimberly Zayhowski. 2023. Intersex people's perspectives on affirming healthcare practices: A qualitative study. *Social Sciences & Medicine* 329: 116047. [CrossRef] [PubMed]

Haller, Paul, Luan Pertl, and Tinou Ponzer, eds. 2022. *Inter* Pride. Perspektiven aus einer weltweiten Menschenrechtsbewegung*. Hiddensee: W_orten & meer.

Harper, Catherine. 2020. *Intersex*. London and New York: Routledge.

Hart, Bonnie, and Jane Shakespeare-Finch. 2022. Intersex Lived Experience: Trauma and Posttraumatic Growth in Narratives. *Psychology and Sexuality* 13: 912–30. [CrossRef]

Hegarty, Peter, Lois Donnelly, Paul Francis Dutton, Sara Gillingham, Valentino Vecchietti, and Kaz Williams. 2021. Understanding of Intersex: The Meanings of Umbrella Terms and Opinions about Medical and Social Responses among Laypeople in the United States and United Kingdom. *Psychology of Sexual Orientation and Gender Diversity* 8: 25–37. [CrossRef]

Holmes, Morgan. 2004. Locating Third Sexes. *Transformations. Journal of Media, Culture & Technology* 8: 1–13.

Holmes, Morgan, ed. 2016. *Critical Intersex*. London and New York: Routledge. First published 2009.

Horowicz, Edmund M. 2017. Intersex Children: Who are we really Treating? *Medical Law International* 17: 183–218. [CrossRef]

Husakouskaya, Nadzeya. 2013. Rethinking Gender and Human Rights through Transgender and Intersex Experiences in South Africa. *Agenda: Empowering Women for Gender Equity* 27: 10–24. [CrossRef]

IACHR—Inter-American Commission on Human Rights. 2015. *Violence against LGBTI Persons*. Washington, DC: OAS—Organization of the American States.

IACHR—Inter-American Commission on Human Rights. 2016. *Intersex Awareness Day—End Violence and Harmful Medical Practices on Intersex Children and Adults, UN and Regional Experts Urge*. Washington, DC: IACHR. Available online: https://www.oas.org/en/iachr/media_center/PReleases/2016/153.asp (accessed on 19 April 2024).

IACHR—Inter-American Commission on Human Rights. 2020. *On International Intersex Awareness Day, the IACHR Calls on States to Protect the Right to Health of Intersex Persons*. Washington, DC: IACHR. Available online: https://www.oas.org/en/iachr/media_center/PReleases/2020/259.asp (accessed on 19 April 2024).

IACHR—Inter-American Commission on Human Rights. 2023. *IACHR Calls to Guarantee the Rights of Intersex Older Persons*. Washington, DC: IACHR. Available online: https://www.oas.org/en/IACHR/jsForm/?File=/en/iachr/media_center/PReleases/2023/250.asp (accessed on 19 April 2024).

Illich, Ivan. 1975. *Medical Nemesis: The Expropriation of Health*. Milan: KKIEN Publishing International.

International Intersex Forum. 2011. *Media Release. First Ever International Intersex Forum*. Available online: https://ihra.org.au/14340/first-international-intersex-forum/ (accessed on 19 April 2024).

International Intersex Forum. 2012. *Second International Intersex Forum*. Stockholm, 9–11 December 2012. Available online: https://ilga.org/news/second-international-intersex-forum-stockholm-9-11-december-2012/ (accessed on 19 April 2024).

International Intersex Forum. 2013. *Malta Declaration*. Available online: https://www.oiieurope.org/malta-declaration/ (accessed on 19 April 2024).

International Intersex Forum. 2014. *Fourth International Intersex Forum—Media Statement*. Available online: https://www.oiieurope.org/wp-content/uploads/2017/04/EDITED-FINAL-FINAL-FINAL-PressRelease4thForum.pdf (accessed on 19 April 2024).

Intersex Asia. 2023. *Asian Intersex Statement 2023*. Available online: https://intersexasia.org/wp-content/uploads/2023/12/Asian_statement_2023_Official_27Dec.pdf (accessed on 19 April 2024).

Iranti-org. 2016. *Ending Pathological Practices against Trans and Intersex Bodies in Africa*. Johannesburg: Iranti-org. Available online: https://iranti.org.za/wp-content/uploads/2019/04/Ending-Pathological-Practices-Against-Trans-And-Intersex-Bodies-in-Africa-Toolkit-2017.pdf (accessed on 19 April 2024).

Jenkins, Tania M., and Susan E. Short. 2017. Negotiating Intersex: A Case for Revising the Theory of Social Diagnosis. *Social Science and Medicine* 175: 91–98. [CrossRef]

Johnson, Merri Lisa, and Robert McRuer. 2014. Cripistemologies: Introduction. *Journal of Literary & Cultural Disability Studies* 8: 127–47.

Johnston, Hank. 2002. Verification and Proof in Frame and Discourse Analysis. In *Methods of Social Movement Research*. Edited by Bert Klandersmans and Suzanne Staggenborg. Minneapolis and London: University of Minnesota Press, pp. 62–91.

Jones, Charlotte. 2022. The Harms of Medicalisation: Intersex, Loneliness and Abandonment. *Feminist Theory* 23: 39–60. [CrossRef] [PubMed]

Jones, Tiffany. 2018. Intersex Studies: A Systematic Review of International Health Literature. *SAGE Open* 8: 1–22. [CrossRef]

Jutel, Annemarie. 2009. Sociology of diagnosis: A preliminary review. *Sociology of Health & Illness* 31: 278–99.

Jutel, Annemarie, and Sarah Nettleton. 2011. Towards a sociology of diagnosis: Reflections and opportunities. *Social Science & Medicine* 73: 793–800.

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

Kehrer, Ino, and Michela Balocchi. 2022. Invisibilizzazione e cancellazione delle variazioni intersex in Italia tra sistema medico e giuridico. *Salute e Societa* XXI: 98–113. [CrossRef]

Kennedy, Aileen. 2016. Fixed at birth: Medical and legal erasures of intersex variations. *University of New South Wales Law Journal* 39: 813–42.

King, Brian W. 2021. Engaging Peers and Future Parents, Creating Future Turbulence: Activist Biocitizenship Practices and Intersex Transgression in the Classroom. *Sex Education* 21: 519–34. [CrossRef]

Kirjava, S. A. 2022. Parallels in the medicalization of people who are intersex and people who are deaf. *Ethics, Medicine and Public Health* 24: 100814. [CrossRef]

Koyama, Emi. 2002. *Suggested Guidelines for Non-Intersex Individuals Writing about Intersexuality & Intersex People*. Available online: https://isna.org/pdf/writing-guidelines.pdf (accessed on 19 April 2024).

Laura-Inter, and Eva Alcántara, eds. 2023. *Brújula. Voces de la intersexualidad en México*. Serie Habitaciones Nueve. Ciudad de México: Editorial 17, Instituto de Estudios Críticos.

LeFrançois, Brenda A., and Jijian Voronka. 2022. Mad Epistemologies and Maddening the Ethics of Knowledge Production. In *Unravelling Research. The Ethics & Politics of Research in the Social Sciences*. Edited by Teresa Macías. Halifax and Winnipeg: Fernwood Publising, pp. 105–30.

Lewis, Mel Michelle. 2022. Intersex Justice Pedagogy. *Transgender Studies Quarterly* 9: 255–63. [CrossRef]

Leydet, Dominique. 2023. Citizenship. In *The Stanford Encyclopedia of Philosophy*. Edited by N. Zalta and Uri Nodelman. Stanford: Stanford University, s.p.

lisahunter, Agli Zavros-Orr, Annette Brömdal, Kirstine Hand, and Bonni Hart. 2022. Intersex Awareness and Education: What Part can Health and Physical Education Bodies of Learning and Teaching Play? *Sport, Education and Society* 28: 1047–67. [CrossRef]

Lowry, Caroline. 2018. Intersex in 2018: Evaluating the Limitations of Informed Consent in Medical Malpractice Claims as a Vehicle for Gender Justice. *Columbia Journal of Law and Social Problems* 52: 321–56.

Lundberg, Tove, Ingrid Dønåsen, Peter Hegarty, and Katrina Roen. 2019. Moving Intersex/DSD Rights and Care Forward: Lay Understandings of Common Dilemmas. *Journal of Social and Political Psychology* 7: 354–77. [CrossRef]

Machado, Paula S. 2006. Intersexuality and the 'Chicago Consensus': The vicissitudes of nomenclature and their regulatory implications. *Revista Brasileira de Ciências Sociais* 23: 109–23. [CrossRef]

Machado, Paula S. 2008. O sexo dos anjos: Representações e práticas em torno do gerenciamento sociomédico e cotidiano da intersexualidade. Ph.D. thesis, Universidade Federal do Rio Grande do Sul, Porto Alegre, Brazil.

Malatino, Hilary. 2013. The Waiting Room: Ontological Homelessness, Sexual Synecdoche, and Queer Becoming. *Journal of Medical Humanities* 34: 241–44. [CrossRef] [PubMed]

McRuer, Robert. 2016. Afterword: The Future of Critical Intersex. In *Critical Intersex*. Edited by Morgan Holmes. London and New York: Routledge, pp. 245–50. First published 2009.

Meoded Danon, Limor. 2018. Intersex Activists in Israel: Their Achievements and the Obstacles they Face. *Journal of Bioethical Inquiry* 15: 569–78. [CrossRef] [PubMed]

Meoded Danon, Limor, and Katinka Schweizer. 2020. Psychosocial Approaches and Discursive Gaps in Intersex Healthcare: Findings from an Israeli–German Action Research Study. *Culture, Health and Sexuality* 23: 441–56. [CrossRef] [PubMed]

Merrick, Teri. 2019. From 'Intersex' to 'DSD': A Case of Epistemic Injustice. *Synthese* 196: 4429–47. First published 2017. [CrossRef]

Mestre Martínez, Yessica. 2022. The Human Rights Situation of Intersex People: An Analysis of Europe and Latin America. *Social Sciences* 11: 317. [CrossRef]

Monro, Surya, Daniela Crocetti, and Tray Yeadon-Lee. 2019. Intersex/variations of Sex Characteristics and DSD Citizenship in the UK, Italy and Switzerland. *Citizenship Studies* 23: 780–97. [CrossRef]

Monro, Surya, Morgan Carpenter, Daniela Crocetti, Georgiann Davis, Fae Garland, David Griffiths, Peter Hegarty, Mitchell Travis, Mauro Cabral Grinspan, and Peter Aggleton. 2021. Intersex: Cultural and Social Perspectives. *Culture, Health & Sexuality* 23: 431–40. [CrossRef]

Ní Mhuirthile, Tanya, Maria Feeney, Mel Duffy, and Anthony Staines. 2022. *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*. Dublin: Dublin City University.

O'Brien, Wendy. 2015. Can International Human Rights Law Accommodate Bodily Diversity? *Human Rights Law Review* 15: 1–20. [CrossRef]

OII Europe. 2023. *Depath Intersex. Depathologize Intersex*. Berlin: OII Europe. Available online: https://campaigns.oiieurope.org/depath/ (accessed on 19 April 2024).

Olmos-Vega, Francisco M., Renée E. Stalmeijer, Lara Varpio, and Renate Kahlke. 2023. A practical guide to reflexivity in qualitative research: AMEE Guide No. 149. *Medical Teacher* 43: 241–51. [CrossRef]

Orr, Celeste E. 2019. (Liberatory) Reproductive Technologies and (Eugenic) Interphobic Selection. In *Connecting, Rethinking and Embracing Difference*. Edited by Anthony Gambrell, Debora Osborne and Lawrence Buttigieg. Leiden: Brill, pp. 87–102.

Orr, Celeste E. 2022. *Cripping Intersex*. Chicago: University of British Columbia Press.

Paechter, Carrie. 2021. The Rights and Interests of Trans and Intersex Children: Considerations, Conflicts and Implications in Relation to the UNCRC. *Journal of Gender Studies* 30: 844–54. [CrossRef]

Pikramenou, Nikoletta. 2019. *Intersex Rights: Living between Sexes*. Chan: Springer.

Pikramenou, Nikoletta. 2020. Intersex Athletes: Invisible Victims in the Language of Gender-Based Violence. *Agenda* 34: 62–70. [CrossRef]

Preves, Sharon E. 2002. Sexing the Intersexed: An Analysis of Sociocultural Responses to Intersexuality. *Signs* 27: 523–56. [CrossRef]

Radi, Blas. 2019. On Trans* Epistemology: Critiques, Contributions, and Challenges. *Transgender Studies Quarterly* 6: 43–63. [CrossRef]

Rajam, Shardha, and Atreyo Banerjee. 2022. Right to Genital Integrity: Law, Limbo and The Status of Intersex Children in India. *Columbia Journal of Gender & Law* 42: 130–82.

Ravesloot, Saskia. 2021. The Universal Periods Review beyond the binary—Advancing the rights of persons with variations in sex characteristics. Paper presented at 8th International Conference of Gender & Women Studies 2021, Singapore, July 29; ISBN 978-624-5892-02-0.

Reis, Elizabeth. 2005. Impossible Hermaphrodites: Intersex in America, 1620–1960. *The Journal of American History* 92: 411–41. [CrossRef]

Reis, Elizabeth. 2019. Did Bioethics Matter? A History of Autonomy, Consent, and Intersex Genital Surgery. *Medical Law Review* 27: 658–74. [CrossRef] [PubMed]

Reis-Dennis, Samuel, and Elizabeth Reis. 2017. Are Physicians Blameworthy for Iatrogenic Harm Resulting from Unnecessary Genital Surgeries? *AMA Journal of Ethics* 19: 825–33. [CrossRef]

Repo, Jemima. 2013. The Biopolitical Birth of Gender: Social Control, Hermaphroditism, and the New Sexual Apparatus. *Alternatives: Global, Local, Political* 38: 228–44. [CrossRef]

RéFRI—Réseau francophone de recherche sur l'intersexuation. 2020. *Recommandations pour une recherche respectueuse sur l'intersexuation*. Available online: https://refri.hypotheses.org/recommandations-aux-chercheur%C2%B7e%C2%B7s (accessed on 19 April 2024).

Roen, Katrina, Claire Breen, and Ashe Yee. 2023. Human Rights-Based Intersex Healthcare: Using Hospital Data to Quantify Genital and Reproductive Surgery on Children in Aotearoa New Zealand. *Social Sciences* 12: 660. [CrossRef]

Rubin, David A. 2017. *Intersex Matters. Biomedical Embodiment, Gender Regulation, and Transnational Activism*. New York: State University of New York.

Rubin, David A. 2019. Provincializing Intersex: U.S. Intersex Activism, Human Rights, and Transnational Body Politics. In *Reproductive Justice and Sexual Rights: Transnational Perspectives*. Edited by Tanya Saroj Bakhru. London and New York: Routledge, pp. 229–52.

Rubin, David A. 2021. Anger, Aggression, Attitude: Intersex Rage as Biopolitical Protest. *Signs* 46: 987–1011. [CrossRef]

Sampaio Oliveira Lima, Isabel María, Andréa Santana Leone de Souza, Jamille Guimarães, and Ana K. Canguçu-Campinho. 2019. Intersexuality and Discrimination: Silence as Family Violence. In *Sexuality, Oppression and Human Rights*. Edited by Júlia Tomás and Nicol Epple. Oxford: Inter-Disciplinary Press, pp. 101–12. [CrossRef]

Schotel, A. L., and L. M. Mügge. 2021. Towards Categorical Visibility? The Political Making of a Third Sex in Germany and the Netherlands. *Journal of Common Market Studies* 59: 981–1024. [CrossRef]

Sedgwick, Eve K. 1994. *Tendencies*. London and New York: Routledge.

Smith, Annette, and Peter Hegarty. 2021. An Experimental Philosophical Bioethical Study of how Human Rights are Applied to Clitorectomy on Infants Identified as Female and as Intersex. *Culture, Health and Sexuality* 23: 548–63. [CrossRef] [PubMed]

Sperling, Jenny. 2021. Comprehensive Sexual Health Education and Intersex (in)Visibility: An Ethnographic Exploration Inside a California High School Classroom. *Sex Education* 21: 584–99. [CrossRef]

Sterling, Rogena. 2021. Intersex People and Educating for the Development of Personality. *Sex Education* 21: 614–27. [CrossRef]

StopIGM.org/Zwischengeschlecht. 2023. *What is Intersex Genital Mutilation (IGM)?* Zurich: StopIGM.org/Zwischengeschlecht. Available online: https://stopigm.org/what-is-igm/what-are-igm-practices/ (accessed on 19 April 2024).

Suess-Schwend, Amets. 2014. Cuestionamiento de dinámicas de patologización y exclusion discursiva desde perspectivas trans e intersex. *Revista de Estudios Sociales* 49: 128–43. [CrossRef]

Suess-Schwend, Amets. 2018. Derechos de las personas trans e intersex: Revisión del marco legislativo en el context español desde una perspectiva de despatologización y derechos humanos. *Revista Derecho y Salud* 28: 97–115.

Suess-Schwend, Amets. 2020. Questioning Pathologization in Clinical Practice and Research from Trans and Intersex Perspectives. In *The SAGE Handbook of Global Sexualities*. Edited by Zowie Davy, Ana Cristina Santos, Chiara Bertone, Ryan Thoreson and Saskia E. Wieringa. London: SAGE Publications, vol. 2, pp. 798–821.

Suess-Schwend, Amets. 2022. Constructing an Ethics of Depathologization: Epistemological, Methodological and Ethical Reflections in Trans and Intersex Studies. In *Rethinking Transgender Identities: Reflections from Around the Globe*. Edited by Petra L. Doan and Lynda Johnston. London and New York: Routledge, pp. 91–123.

Suess-Schwend, Amets. 2023. The clinical gaze on gender and bodily diversity in childhood and adolescence: Critical perspectives. In *Child-Friendly Perspectives on Gender and Sexual Diversity. Beyond Adultcentrism*. Edited by José Antonio Langarita, Ana Cristina Santos, Marisela Montenegro and Mojca Urek. London and New York: Routledge, pp. 26–46.

Suess-Schwend, Amets, Karine Espineira, and Pau Crego Walters. 2014. Depathologization. *TSQ, Transgender Studies Quarterly* 1: 73–77. [CrossRef]

Suri, Harsh. 2008. Ethical considerations in synthesising research—Whose representations? *Qualitative Research Journal* 8: 63–73. [CrossRef]

Svoboda, J. Steven. 2013. Promoting Genital Autonomy by Exploring Commonalities between Male, Female, Intersex, and Cosmetic Female Genital Cutting. *Global Discourse* 3: 237–55. [CrossRef]

Swarr, Amanda Lock. 2023. *Envisioning African Intersex. Challenging Colonial and Racist Legacies in South African Medicine*. Durham: Duke University Press.

Thomas, Maud-Yeuse, Karine Espineira, and Arnaud Alessandrin, eds. 2013. *Identités intersexes: Identités en débat*. Paris: L'Harmattan.

Topp, Sarah S. 2013. Against the Quiet Revolution: The Rhetorical Construction of Intersex Individuals as Disordered. *Sexualities* 16: 180–94. [CrossRef]

Tosh, Jemma. 2019. *The Body and Consent in Psychology, Psychiatry, and Medicine: A Therapeutic Rape Culture*. London and New York: Routledge.

Travis, Mitchell. 2015. Accommodating Intersexuality in European Union Anti-Discrimination Law. *European Law Journal* 21: 180–99. [CrossRef]

Tuana, Nancy. 2004. Coming to Understand: Orgasm and the Epistemology of Ignorance. *Hypatia* 19: 194–232. [CrossRef]

UN—United Nations, Human Rights Council. 2024. *Resolution Adopted by the Human Rights Council on 4 April 2024. 55/41. Combating Discrimination, Violence and Harmful Practices against Intersex Persons. A/HRC/RES/55/14*. Geneva: Human Rights Council. Available online: https://documents.un.org/symbol-explorer?s=A/HRC/RES/55/14&i=A/HRC/RES/55/14_1714553310612 (accessed on 11 May 2024).

UN—United Nations, Office of the United Nations High Commissioner for Human Rights. 2016. *Intersex Awareness Day—Wednesday 26 October*. Geneva: Office of the United Nations High Commissioner for Human Rights. Available online: https://www.ohchr.org/en/press-releases/2016/10/intersex-awareness-day-wednesday-26-october (accessed on 19 April 2024).

UN—United Nations, Office of the United Nations High Commissioner for Human Rights. 2017. *Fact Sheet Intersex*. Geneva: Office of the United Nations High Commissioner for Human Rights. Available online: https://www.unfe.org/sites/default/files/download/Intersex-English.pdf (accessed on 19 April 2024).

UN—United Nations, Office of the United Nations High Commissioner for Human Rights. 2019. *Background Note on Human Rights Violations against Intersex People*. Geneva: Office of the United Nations High Commissioner for Human Rights. Available online: https://www.ohchr.org/sites/default/files/Documents/Issues/Discrimination/LGBT/BackgroundNoteHumanRightsViolationsagainstIntersexPeople.pdf (accessed on 19 April 2024).

UN, United Nations, Office of the United Nations High Commissioner for Human Rights. 2023. *OHCHR Technical Note on the Human Rights of Intersex People: Human Rights Standards and Good Practices*. Geneva: Office of the United Nations High Commissioner for Human Rights. Available online: https://www.ohchr.org/sites/default/files/2023-11/ohchr-technical-note-rights-intersex-people.pdf (accessed on 19 April 2024).

van Heesch, Margriet. 2016. Do I Have XY Chromosomes? In *Critical Intersex*. Edited by Morgan Holmes. London and New York: Routledge, pp. 123–45. First published 2009.

Vázquez García, Francisco. 2013. Más allá de la crítica de la medicalización. Neoliberalismo y biopolíticas de la identidad sexual. *Constelaciones—Revista de Teoría Crítica* 5: 76–102.

von Wahl, Angelika. 2021. From Object to Subject: Intersex Activism and the Rise and Fall of the Gender Binary in Germany. *Social Politics* 28: 755–77. [CrossRef]

WHO—World Health Organization. 2019. *ICD-10, International Statistical Classification of Diseases and Related Health Problems 10th Revision*. Geneva: World Health Organization. First published 1990.

Winter Pereira, Luisa. 2022. Intersex legal activism. United Nations on the human rights of intersex people. *Age of Human Rights Journal* 18: 181–97. [CrossRef]

Woweries, Jörg. 2018. Categories: Who has a Disorder? Who Gets to Decide? In *Normed Children: Effects of Gender and Sex Related Normativity on Childhood and Adolescence*. Edited by Erik Schneider and Christel Baltes-Löhr. Bielefeld: Transcript Verlag, pp. 95–112.

YP+10—The Yogyakarta Principles Plus 10. 2017. *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*. Available online: https://yogyakartaprinciples.org/wp-content/uploads/2022/02/021522-Principios-de-Yogyakarta-mas-10.pdf (accessed on 19 April 2024).

Zelayandía-González, Ernesto. 2023. The growing visibility of intersex demands at the United Nations: A review of the treaty bodies' concluding observations. *Social Sciences* 12: 73. [CrossRef]

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Article

The Power of Phenomenology

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Abstract: Hermeneutic phenomenology's aim is to bring forth that which needs to be thought about. It is an invitation to think. To articulate thinking, one needs to listen in the corners and the shadows of the lived experience(s) of the phenomenon being investigated. The method simultaneously holds numerous perspectives and adopts an embodied approach to embracing experiential knowledge. This paper explores the power of hermeneutical phenomenology, as a methodological approach for understanding what it means to be intersex. Intersex people have bodies that are born different to typical male-female ones. Intersex is an umbrella term that includes more than thirty ways the human body may differ according to its sex characteristics (i.e., genitalia, hormones, chromosomes, sex organs). From interviews with intersex people, we confirm that employing a hermeneutic phenomenological approach did not just answer our research questions, but also became a powerful and empowering means through which some participants were effectively able to navigate, share and 'own' their personal story. Indeed, the method's person-centred and ethical underpinnings permitted some to engage in the research in ways that became empowering and transformational.

Keywords: intersex; lived experience; sharing stories; other; knowledge of self; empower; hermeneutic phenomenology

Citation: Duffy, Mel, and Tanya Ní Mhuirthile. 2024. The Power of Phenomenology. *Social Sciences* 13: 442. https://doi.org/10.3390/socsci13090442

Academic Editor: Barbara Fawcett

Received: 5 July 2024
Revised: 15 August 2024
Accepted: 20 August 2024
Published: 24 August 2024

1. Introduction

This paper draws on data that were gathered from the stories people shared with the authors as part of the study 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. This was an exploratory study and the first of its kind in Ireland. As noted in the study title, we intended to 'map' what it means to be intersex in Ireland. Using hermeneutical phenomenology as our methodological approach, this study sought to understand the lived experience of what it means to be intersex from the perspectives of three distinct groups: (1) intersex people, (2) their families and partners and (3) healthcare professionals who work in this field. Data from these three groups generated the lay and professional knowledge we expected to use to inform the development of appropriate law and policy in Ireland to ensure the rights of the intersex community are protected and upheld in Irish society. This paper emanates from our experiences of doing hermeneutic phenomenology with our intersex respondents. The phenomenon in question is the experience of being intersex. We were interested in how intersex people experience living their lives. This paper does not seek to examine the legal and policy aspects of the Mapping Study, but rather is focused on the experience of doing and using the methodology.[1] Prior to discussing the power of hermeneutic phenomenology in enabling people to reveal their experience of a particular phenomenon, we consider it necessary to explore what intersex might mean as the use of language to describe intersex is a very important issue within the intersex community (Lundberg et al. 2018; Davis 2014).

Intersex is an umbrella term that includes more than thirty ways the human body differs according to its sex characteristics—specifically, its chromosomes, hormones, genitalia and sex organs. Intersex people are born with sex characteristics (including genitals, gonads and chromosome patterns) that do not fit typical binary notions of male or female bodies (United Nations for LGBT Equality n.d.). Sometimes, this is referred to as having Variation(s) of Sex Characteristics (VSC) or Atypical Sex Characteristics. Many medical and health professionals are familiar with the term Disorders of Sex Development (DSD) (Lee et al. 2006). Before we proceed, we believe the intersex nomenclature merits brief discussion.

Debate abounds within the medical community, and beyond, and even within the intersex community itself, about the use of terminology and what ought to be considered under the ‘intersex’ umbrella (Monro et al. 2017; Reis 2007). Historically, the word hermaphrodite was used to describe an intersex person, but this is considered by some to be a harmful slur, “outdated and pejorative” (van Lisdonk 2014, p. 15), demeaning (Reis 2007) and offensive (Rubin 2015).

The umbrella term intersex is widely used and accepted internationally (Bauer et al. 2020). In fact, two significant calendar days use this word: Intersex Awareness Day (October 26th) and Intersex Solidarity Day (November 8th). While the word intersex is not without criticism, the general consensus is that intersex is widely accepted globally and is more favourable than other more medical terms, such as Disorders of Sex Development (DSD) (Davis et al. 2016)—the latter being problematic because it pathologises bodily differences (Monro et al. 2017), is stigmatising (Cresti et al. 2018) and has the potential to imply that different or disordered bodies need to be fixed or repaired (Reis 2007; Carpenter 2018a). To counter the pathologising effects of the word ‘disorder’, Reis (2007) advocated for the use of Divergence of Sex Development. Another variant is Difference(s) of Sex Development. Still, some medics find it best to use the term Atypical Gonadal/Genital Development (AGD) given the “confusion and discomfort” associated with previous terminology (Gorduza et al. 2018, p.45).

Not all people, including those who are intersex, use the term intersex. Significant variation exists among those who are intersex in terms of how they use terminology. Van Lisdonk’s research demonstrates that

> interviews with active members of patient organisations and persons with intersex/dsd revealed that they mostly do not use either term themselves. Instead, they generally tend to use the condition-specific term, such as ‘men with Klinefelter syndrome’ or ‘women with x y chromosomes’. Some of those interviewed were actually found to be entirely unfamiliar with the terms intersex and dsd. (van Lisdonk 2014, p. 25)

Greater general acceptance exists around the fact that a person’s choice of terminology ought to be respected. Some intersex people, such as Rose (2020), argue for intersex to be understood as a broad and inclusive spectrum that will permit acceptance of multiple and diverse experiences and such a belief sits within our hermeneutical phenomenological approach where the person and their lived experience are front and centre. We are in full agreement with Rose (2020), and we appreciate Lundberg et al.’s comment “that the debate on terminology is not yet settled” (Lundberg et al. 2018, p. 163), and so, for the remainder of this article, we use the word intersex as an umbrella term. This is in keeping with the use of the word by the EU Agency for Fundamental Rights in their 2015 focus paper on human rights for intersex people (European Union Agency for Fundamental Rights 2015) and subsequent report on LGBTI equality (European Union Agency for Fundamental Rights 2020).

Finally, it is important to note that such bodily variations are not to be confused with a person’s sexual/gender identity, which is why some previously used terms, such as intersexual and intersexuality, are deemed “socially undesirable” (van Lisdonk 2014, p. 25). While the ‘I’ in LGBTQI+ represents intersex, only some intersex people identify under the LGBTQI+ umbrella.

2. Methodology

Intersex people have long been the object of scientific research (Raz 2024). The literature reveals that the impact of research has been negative, and that intersex people report feeling 'objectified' by researchers (Preves 2003; Kessler 1998; Fausto-Sterling 1993). This sense of objectification is further compounded as intersex people articulate that they are not believed when they report their experiences. Carpenter draws on Fricker's (Fricker 2007) concept of testimonial injustice to argue that "the credibility of intersex voices is diminished, even where they speak about personal lived experience, and even though contrary perspectives lack evidence" (Carpenter 2018b, p. 459). Charlebois goes further, arguing that intersex people are, thus, hermeneutically marginalised (Charlebois 2017). She eloquently summarises the difficult process of overcoming obstacles of objectivity to claim their own agency. Facilitating the emergence of subject-actors requires a reimagining of how research is undertaken.

To allow intersex voices to join the community of thinkers, and thus gain full humanity, it will be necessary to reflect not only on the conditions of knowledge production, but also on the modes of assessment and the validation criteria used (Charlebois 2017).

In keeping with the legitimacy of foregrounding the voices of intersex people, we chose hermeneutic phenomenology as our methodological approach. We sought to understand the lived experience of intersex people in a manner which returned to them their agency and power over how the research and interviewing process would proceed. In so doing, we discovered that those who shared their stories with us had a lot to say about both their lives and the experience of being interviewed in this manner. This paper reports those insights.

Through interviews, the voices of intersex people can be heard, offering us an insight into their "ideas, thoughts and memories in their own words rather than in the words of the researcher" (Reinharz 1992, p. 9). In doing this, we seek the meaning(s) and understandings(s) that participants gave to their experiences. Hermeneutic phenomenology aims to bring forth that which needs to be thought about. As Charlebois notes, it is the epistemological injustice inherent in the systemic structures surrounding intersex which subjugates intersex people such that it is difficult for them to come to a knowing of themselves (Charlebois 2017). This methodology creates a space for unencumbered reflection. It is an invitation to think. To articulate thinking, one needs to listen in the corners and the shadows of the lived experience(s) of the phenomenon being investigated. The method "embraces multi-perspectival, embodied and experiential ways of knowing" (Dibley et al. 2020, p. 7). Smythe et al. articulate that there are no set of steps or a step-by-step guide, rather each hermeneutic phenomenological researcher enacts a process that centres on reflection, writing, re-writing and thinking (Smythe et al. 2008).

Meanings and understandings are social products, which are not created in isolation; they are products of interpretations of the actions through a process of reflecting on the actions. Individuals give meaning to the situation in which they find themselves; this is informed by both cultural norms and expectations. Therefore, a similar interaction in a different culture may lead to different meanings (Cuff et al. 2006).

Giorgi (2005) suggests that the goal of phenomenological analysis is centred on the clarification of the meanings given to a phenomenon. By voicing their experiences, participants give clarity to their lived state, which can lead to change, as there can be a discrepancy between what we think we live and/or how we experience life, and the reality of the actual living and/or experience. "A discovery of this difference and its correction can lead to more authentic living and interaction with others and thus a better world" (Giorgi 2005, p. 77). By articulating their lived experience of being intersex, our participants gain a deeper understanding of their lived experience, which can change their reality and their understanding of what it means to be human. Phenomenological studies recognise that in any culture, multiple realities of the same phenomena may exist, and that groups and/or communities share in these realities. It facilitates the position that a number of simultaneous meanings can be given to the same experience. These meanings may or may not be shared by others.

Ethical approval was granted for the study by the DCU Research Ethics Committee (REC) in 2019. The COVID-19 pandemic restrictions meant we had to conduct interviews online using zoom and/or telephone. Our submission to the DCU REC for an amendment to facilitate this was approved in May 2020. We knew our intersex sample were a vulnerable group. We also knew our interviews could have a trigger effect and cause upset in our participants. In order to safeguard our participants' welfare, we established a follow-up procedure. We engaged with a counsellor who had expertise in working with sexual minority clients. This counsellor had also completed master's-level research on the subject of intersex lives. We had business/contact cards printed with the counsellor's details on them. These would be given to participants at the end of each interview. The study paid for the first two sessions that any participant chose to attend. When face-to-face interviews were impossible to conduct due to COVID-19-related restrictions, we provided the counsellor's contact details to participants in an email. We can confirm the counsellor's services were used following interviews, but preserving patient confidentiality, we were not informed which participants availed themselves of this follow-up procedure.

A total of seven intersex people participated in the interviews. The small sample size is typical of this type of hermeneutic phenomenological investigation (Dibley et al. 2020). At interview, participants were simply asked to talk about their experience of (being) intersex. This open approach is deliberately designed to give all control of the interview and the direction of the conversation to the interviewee. It does not demand of the participant responses to particular questions, rather, the comfortability of the participant is always reflected in the richness of the story that emerges (Dibley et al. 2020). Further questions arose from the interviewees' responses, giving rise to the prompt or probe questions, which invited clarity where necessary. Interviews ranged in duration from 60 min to 150 min, although some participants requested more than one interview to enable them to tell their story in full. This was a unique aspect of the study which was not anticipated at the outset. Being human in the world of intersex experience is complex and the telling of their story was never a short conversation. Rather, it was a profoundly reflective practice whereby the participant unravelled their story in their own time. Indeed, some participants re-engaged with us for second and third interviews to clarify aspects of their original telling of their story or to share more about themselves. This suggests that the first interview may have been used to establish trust between the storyteller and listener. The storytellers came to understand that they could trust us to hold their stories and honour their lives. Trust was not sought but freely given. Three members of the research team, the authors and our post-doctoral researcher on the project, conducted interviews. Interviews were recorded, then transcribed using pseudonyms, which are the names attributed to storytellers reported throughout this article.

The Mapping Study was designed with participants from the intersex community, thus fulfilling an engaged research approach. The authors of this paper are both Irish and cisgender, one heterosexual, the other a lesbian, ranging in age from the 40s to 60s and both are parents. Thus, the study established a steering committee to ensure that intersex inclusion remained at its centre. The steering committee was made up of national and international members who are either academics, activists or both from the intersex community, thus adhering to the intersex community principle of "nothing about us, without us". As researchers, we constructed ourselves as "researchers in the middle" (Breen 2007, p. 163). The researchers own positions in this research are as follows: (1) being lesbian, through her academic work and own lived experience understanding the nuances of marginalisation by society, and (2) through her earlier work with intersex people having gained an understanding of the institutions of society and how they knowingly or unknowingly are the cause of oppression.

This paper seeks to articulate the power of hermeneutic phenomenology in affording a space where the self and the experience of the self can be revealed. Hermeneutic phenomenology is underpinned by the philosophy of Heidegger (1962), as he was concerned with being *in* the world.[2] The essence of Heidegger's hermeneutic phenomenology is

'Dasein', which he explains as the human being in the world. "The 'essence' of Dasein lies in its existence" (Heidegger 1962, p. 67). The human being is always involved in the world as they experience it. Johnson suggests that Heidegger views the human being as "always involved in the practical world of experience" (Johnson 2000, p. 136). Heidegger indicates that "Being-in-the-world is a basic state of Dasein" (Heidegger 1962, p. 86). Relating this to the participants in this study, being-in-the-world (Dasein) as intersex people can be seen as active participation in that world, creating meaning and understanding to being themselves in a world that may not recognise or speak to them. This paper explores the stories of intersex people as being in the world of intersex experiences. As researchers using hermeneutic phenomenology, we seek to understand the meaning that participants give to their experiences.

Hermeneutic phenomenology is both a philosophy and a methodology that many balk at as it appears to have no criteria or steps to completion. From the outside looking in, this might appear to be so, but hermeneutic phenomenology does have avenues towards completion, albeit in non-conventional ways. Crowther et al. state that hermeneutic phenomenology "challenges pre-determined rules and research procedures" (Crowther et al. 2016, p. 827) resulting in the researcher being liberated from the conventional ideas of what is the "right" and "wrong" way of doing things. It is both a philosophy and methodology centred on the task of thinking.

> We come to know what it means to think when we ourselves try to think. If the attempt is to be successful, we must be ready to learn thinking. (Heidegger 1976, p. 3)

Our participants' observations reflect Heidegger's remarks that thinking creates a road of discovery of who we are as well as the nature of our Being (Gray 1976). This is in keeping with the method as it requires us to think, to uncover and to bring forth that which needs to be thought about. Through the interviews, thinking brings forth shared meaning(s) and understanding(s) of how the phenomenon of being intersex emerges from the participants' evolving knowing. A few participants in our study returned to their story a second and a third time. In returning to the story, the participant reflected upon what they had shared and, in some cases, sought to clarify, adding to their story. The going back and forth of the participants is akin to Heidegger's hermeneutic circle. While the hermeneutic circle is commonly articulated as the method chosen as

> analysis [it] is a continuous circular and reflexive process where themes emerge, and the researcher returns to the data and starts to re-read it. (Dibley et al. 2020, p. 127)

3. Story Telling

At the heart of our study was an invitation to people to tell us their story of being intersex. We ask one question: Can you please tell me your experience of being intersex? This is the creation of a space by which the person is free to tell their story about being them. There are no preconceived ideas or notions entailed in the question. There are no questions that we seek or require to be answered. It is a free canvas through which the storyteller paints their own picture—their reality for the listener. For many of us, we are never really asked: Who are you? Tell me about yourself? We may indeed be familiar with the question: Who do you think you are? But to be genuinely interested in the person as they present themselves to us is the central aspect of hermeneutic phenomenology. Grey states

> For him [Heidegger] the spoken word is greatly superior to the written. (Gray 1976, p. vi)

It is within the spoken word that the nuances of life are articulated. The listener is welcomed into the life of the storyteller, where the hidden is revealed precisely through the way it is spoken. The listener, that is the interviewer, navigates the teller's journey with the teller, traversing the highways and byways of their life. As researchers, we immerse ourselves in the story as told of the lived experience of the phenomena under investigation. Later, the interviewer will reflect upon the story and transform it for wider public consumption while remaining true to the storyteller.

4. Invitation to Speak

We received an email from a participant at a conference on a presentation about this methodology relating to intersex experiences. We had raised the question 'What is it like to be human?'. Commenting on their own life, they wrote

> This has been one of the challenges for me; how to express what it's like to be me. [correspondent]

In the context of being human, the correspondent continues

> Throughout my life including my encounters with the medical world I was never asked, "How do you feel?" or "Tell me about yourself ". It seems almost too obvious to miss this critical question because our inner world is as important as our physical outer world. [correspondent]

Indeed, few are asked in a medical setting to reveal who they are from their perspective. In other settings, we may upon greeting someone ask them: How are you? If the person begins to respond, they may have broken the social norms of greeting. The response in an Irish setting may be to say, "I am doing fine" or "Great, thank you" but never revealing the true nature of how we are. But a detailed response is not what is socially expected. We have social cues for interaction. There are some settings where these cues are not relevant; for example, when a doctor asks, "How are you?", there is an expectation that the patient/client will respond relating to the reason why they are in a consultation in the first place. Heidegger regarded language

> As that sphere in which man can dwell alright and make clear to himself who he is. (Heidegger (1962), in Gray 1976, p. vii)

It is through language that we articulate who we are. The correspondent suggests that they were never invited in a healthcare setting, or indeed any other setting, to articulate who they were. Through this, the self is never revealed to the other, but more importantly, as Heidegger (1962) suggests that it is in the articulation that we come to know ourselves, neither is the self ever revealed to oneself. It is the negation or the unrevealing of the self when it really matters that leads to a hiddenness of the truth of who we are to both ourselves and others. Indeed, in a healthcare setting, when the healthcare provider does not ask how the patient experiences the condition that they are presenting with, it removes the possibility for the healthcare provider to review, reflect, and, through thinking, make changes in how they as professionals engage with intersex people or indeed any other person they encounter in their practice. This level of engagement is something that our correspondent would have welcomed.

5. Participant's Engagement

We suggest that some participants in our study engaged in their own hermeneutic circle through a reflective process, returning to their story, further sharing their understanding(s) and meaning(s) with us. They dwelled with the story they had shared to add illumination later. For example, Darcy returned to their story twice with a few emails in between. Prior to the ending of the third interview, they were asked if there was anything else they wished to further explore. They stated:

> No, I can't really think of anything. I think I am good. I have covered everything. But that really is everything now. I don't think there is anymore that I can possibly tell you but if there is I will come back to you and tell you but thank you for giving me the opportunity to come back and tell more of it. [Darcy]

It is in the dwelling with the story of the self that Darcy could make clear to themselves who they are. This experience reflects Charlebois' point that intersex people are required to negotiate the tension between the impact of non-consensual medical interventions and the subsequent internalisation of a deficient vision of oneself in order to become active subjects with full agency (Charlebois 2017). In the telling of Darcy's story, the reflective process opened up avenues through which the self was explored and shared. It gave meaning and understanding to their life as an intersex person; meaning and understanding as they had come to know it through the articulation of this life.

While Darcy had come to tell their story in their own way and in parts, there was also an underlying reason why they felt they could come back

> Part of the reason why I am committed to doing this and doing it so fully is because I appreciate the fact that you guys want to do it for fully and you are being led by intersex people. I have never done a research study that is so led by intersex people like myself and that is why I am happy to do it. [Darcy]

Participants returning to the story reflected the trust that was placed in us to reveal their story to others in ways that were true to their meanings and understandings. We are in effect "bearing witness to their stories" (Crowther et al. 2016, p. 2) through the opportunity to "review, reflect and inspire new thinking" (Crowther et al. 2016, p. 2).

6. Building Trust Leads to Understanding

The study was developed through partnership and built with the intersex community in the development of the research programme. This led to trust relationships being built with participants prior to our meeting.

> Being aware of one's population is very important; being sensitive to the concerns of others and listening to their fears, needs and desires for their own personal safety emanates from an ethical standpoint. (Dibley et al. 2020, p. 81)

Being comfortable with the process and subsequent interview lends itself to the revealing of the self by the participants. Alan reflected on his experience of being different during his teenage years:

> I would probably answer by asking you the question, how does a teenager hide a variation in genital anatomy in a compulsory shower with 20 other fellas after PE? My answer to that is you could only hide by being in plain sight. There was no option of hiding. [Alan]

Saving oneself from the gaze of the Other as a teenager can be difficult at the best of times. The taken-for-granted situation of the communal shower amongst boys is the expectation of the 'sameness' of bodies. It is here that Alan discovers his difference or rather comes to the knowing that Others can expose his difference. In this situation, Alan found that one can hide in plain sight. He further states:

> No, again that is before the age of the internet and before the age of, I don't believe, I didn't have access and no one else would have access to pictures, descriptions, diagrams, terminology etc either. That anyone else could pick it up readily. I do remember the PE teacher looking but never went as far as saying anything. So, the obvious thing for me was as quickly as possible to shower without ever drawing attention to myself. Cause there was another chap in the class like that was even more self-conscious than I was and he became a target. So the two together was the absolute proof that you do not be visible by being, the best way to be invisible to be completely visible. By showing no signs, showing nothing. [Alan]

Even though Alan's PE teacher may have noticed his difference, nothing was said. He, the PE teacher, was the external observer of Alan's body. The non-recognition of his status led to the reinforcements that silence prevailed about his body. This reflects Sartre's notion of the body, that it is through the body that I experience myself but also it is through the body that I experience the Other (Moran 2000). There were silence and unknowables as access to information about bodies like Alan's was unavailable. Alan responded by not drawing attention to himself. Alan's experience of the showers was a situation that "threatens the integrity of the self" (Giddens 1992, p. 54). Whatever mechanisms that were built over time to protect the self were dismantled, and the validity of himself was never questioned but cast aside by that one look.

Being self-conscious could lead to being 'targeted' and Alan did not bring that attention to himself. Not drawing attention to himself became a strategy for his life:

> Very good at hiding in plain sight but I spent my life hiding. [Alan]

Alan had learnt how to act, react and behave to exist within the spaces he found himself in, which was crafted and became a way of life during his teenage years. In Goffman's terms, Alan made himself "into something that others can read and predict from" (Goffman 1971, p. 11). Every time he had PE, Alan is confronted with himself, the reality that he is different from other boys. He exists within the reality of what a normative male body 'looks' like and knows that he does not fit. Alan never reveals the truth of his situation, neither did he develop trust relations with others as he spent all his life hiding in plain sight. Giddens suggests that an individual will have a stable sense of self-identity if there is:

> a feeling of biographical continuity which she is able to grasp reflexively and, to a greater or lesser degree, communicate to others. That person also, through early trust relations, has established a protective cocoon which 'filters out', in the practical conduct of day-to-day life, many of the dangers which in principle threaten the integrity of the self. Finally, the individual is able to accept that integrity as worthwhile. (Giddens 1991, p. 54)

Alan did not communicate to others who he was, which led to the fact that acceptance of himself as a worthwhile human being was never realised to his satisfaction. His worth, value and understanding of who he was in the world was undermined as, Giddens (1991) suggests, by necessity these traits are developed through early trust relations, which were not available to Alan. Alan's "every-day skill of coping" (Draucker 1999, p. 361) was hiding. In effect, Alan became a shadow. He was not casting a shadow as we all do in twilight, which gives a sense of self. I can see myself through my shadow and I know I exist. Casting a shadow is something my body does, but to be cast as a shadow is to have something thrust upon you by the Other. Alan's image of the shadow does not denote positivity, rather, it casts him into darkness, a shadow in the corner, whereby the Other does not acknowledge his existence, as he does not exist within their realm of normative bodies. Alan cannot be seen or is not seen, which he recognises. This is very different from Sartre's suggestion of:

> My possibility of hiding in the corner becomes the fact that the Other can surpass it towards the possibility of pulling me out of concealment, of identifying me, of arresting me. (Sartre 1969, p. 264)

From a Sartrean perspective, the possibility of hiding in the corner is my choosing of concealing myself. However, Alan was placed in the corner by the Other through non-recognition. He has no possibility of being discovered, as the Other does not recognise his existence. He has become the outsider (Becker 1963), looking in but with no say in what is happening. He is alienated from the world as Alan knows it and from himself through the actions of the Other. Alan's own possibility becomes the possibility of the Other to declare who he is: a non-entity.

7. Hiding Loss, Hiding Pain

This study revealed lives that were deeply entangled in mistrust, unknowns and unknowables, but centred on the vision that others had of what bodies should be and the consequences for not having that desired body. What our study revealed was the power of parents, teachers and medical personnel to make pronouncements and claims about the body, thus imputing meanings and understandings on the body. The study also exposed how power was used from the perspective of the power holder, rather than the person who experienced the inferences of the power holder.

> It is in the reality of everyday life that the Other appears to us, and his probability refers to everyday reality. (Sartre 1969, p. 253)

People living with intersex bodies confront the reality of being intersex in the most unexpected places. They exist within a world with normative bodily expectations. Institutions, such as family, education, hospitals and GP services, not only reflect this normalisation but have no perception of bodies outside of that norm.

The truth of their situation (intersex people) may be hidden from them, and coming to the understanding of their difference may be a difficult experience, as revealed by Frankie:

> I was 12 that is when I realised there was something different about me because like all kids went through the change of life and I stayed the same of when I was like a child. [Frankie]

Through her friendships, Frankie realised that there was something different about her. This difference was centred in and on her body—her body was not similar to other girls' bodies; unlike her friends' bodies, Frankie's body was not changing. As she traversed her teenage years, there were many interactions with doctors to unravel why she was not developing in accordance with what is expected as she made the journey from childhood to teenagerhood to adulthood.

> And then when I was older, I kept going to the doctors to find out why I wasn't growing, and they said, well, when you are 13 we are going to try medication because if you are on medication you should go through the changes of life. [Frankie]

Healthcare provision was not an option for Frankie as her father refused to pay for it. However, later, through the discovery of a Rainbow Resource Centre, Frankie did discover what was blocking her developing. When a member of the centre asked her if she understood her medical papers, her reply affirms how she perceived herself:

> I just know that I was born a mistake. [Frankie]

Through her interaction with family and the medical professionals, Frankie had learnt that she was a "mistake", but that "fact" had never been unpacked for her. Her difference was flaunted in front of her by family members as not being the "norm" of social expectation. Her body was examined by others and declarations were made on who she was:

> And he [doctor] checked me in the same way that my dad would check me or whatever and he was like 'I can't believe how she didn't grow properly' and he [father] was like 'well what does this mean?' And the doctor said 'well, it is kind of like she is trans but she is not'. 'Well can it have kids? Because that is the only thing that I want' [father] and the doctor said 'no, she can't have kids'. And he [father] was like 'well what use is she to me then?' And he's [doctor] like 'she can adopt kids', 'and like what, she can have two people that are mentally retarded in the house? No thanks.' [father]

For Frankie, no opportunity was provided by the medical personnel or her father to discuss the truth of her situation with them. Medical examination was carried out on her without her consent and the revelations announced without discussion. Frankie found herself within a

> Context of discourse and interaction position persons in systems of evaluation and expectations which often implicate their embodied being; the person experiences herself as looked at in certain ways, described in her physical being in certain ways, she experiences the bodily reactions of others to her, and she reacts to them. (Young 2005, p. 17)

Frankie was placed into systems of evaluation and interaction through her body being different by being examined by a healthcare professional who could make judgements about her. While doctors do evaluate, assess and care for patients, Frankie experienced the revelation of the kind of being she was, being evaluated and assessed and rendered without care. The revelation was unfinished and unsatisfactory. Frankie was left with the understanding that she was different, incomplete, a non-trans, trans-like person; thus, she was unfinished and unsatisfactory. There was nothing to be done, she was not the emerging woman that the medical profession expected her to be or that society expected as the declarations by her father made clear to her. What Frankie did not expect, in the examination of her body, was that the totality of the self was exposed for Others to see and evaluate, in accordance with the values and belief systems of those caring for her within the culture within which she resided. The truth of herself was mediated by Others (Sartre 1969). Heidegger suggests that

> To every being as such there belongs identity, the unity with itself. (Heidegger 1969, p. 26)

Through the declarations of others in her life, Frankie's 'unity of the self' became unravelled and unknown to her as she did not fit what was thought of as an emerging adolescent and later adult woman. She was rendered with no identity.

From a Giddens' point of view, one could suggest that Frankie could not develop a biographical continuity whereby she could recount her life story and recognise the self in that story (Giddens 1991). To achieve a biographical continuity Frankie would first have to be able to communicate to herself who she is before she could communicate it to Others. Like Frankie, Alan also experienced this never happening as he chose to live his life on his own as the sharing of that life is too painful for him. The development of trust relationships whereby people can be themselves with themselves and Others, thus establishing a comfort in their life, can be difficult to achieve for intersex people.

Frankie is devalued as a human being. Her worth, value and understandings of who she is in the world were undermined:

> It is only through being object that we can be given a value, assigned a worth, some "thing" that can be assessed. (Howard 2002, p. 59)

She is not measured in accordance with her own bodily integrity but measured against the general expectation of the integrity of certain genitalia that belong or are assigned to either female or male bodies, by the community of the assessor, that is the healthcare provider. Within this measurement, she becomes a non-entity and is, according to her father, a being of 'no use'.

Sartre suggests that "shame of self; it is the recognition of the fact that I am indeed that object which the Other is looking at and judging" (Sartre 1969, p. 261). It disrupts the sense of self, the taken-for-granted knowledge of knowing who I am. In Frankie's case, that knowing was negative.

> So, I grew up thinking that everybody was supposed to hate me. [Frankie]

She became the object of this judgement. The world within which Frankie lives is alien to her; she was alienated from that world and, by extension, alienated from herself. Frankie discovered the two-fold result of the uncovering of the truth of the self; she was alienated from the self and there was no possibility of self-recovery either now or in the future. Once you uncovered and acknowledged your difference, there was no belonging, no safe space, no feeling of being one with the Other. Were you really the person you were before you discovered who you are? You cannot undo what you now know, but equally you cannot accept the definition of who you are as being told by others who do not want to know who you really are. Frankie sat in the midst of power relations as a child to a father, as a patient to a healthcare provider, as a worker to an employer and as a road user to those who did not want the person she is to be in that space. Power shaped her perception of herself and her place in the world.

8. Conclusions

The power of hermeneutic phenomenology is that through interviews, we bear witness to the experiences of people sharing their stories, in this case, their experiences of being intersex. Through listening to their stories being told, we sometimes hear about a life that has been hidden or supressed. Crucially, their stories expose to us the damaging or destroying effect of being unseen as a whole person. Alan's story reveals how others, namely, his family, hid the reality of who he was from him and how that affected his education and, later, his life. In the telling of her story, Frankie reveals how her father viewed having a female child. Her value and worth to him was solely as the provider of the next generation. But not being what he wanted, she was rendered useless and less than human and, indeed, less than woman. The power and perception of her body communicated by the medical professionals reinforced this perspective.

However, Frankie's story points to the fact that a community did exist whereby she could find acceptance of herself as the whole person she is, a whole person with a particular body and who needs a community (acceptance) to be whole. This, for her, was the Rainbow Resource Centre. Alas, Alan did not find such a community. On the other hand, Darcy informs us that being presented with an opportunity to tell one's story is a way of being oneself in the world.

Through the uncovering of the lived experience, an important contribution to knowledge is made. These stories demonstrate that true expertise of being intersex in the world is held by those who embody intersex experience. Hermeneutic phenomenology, as both a philosophy and a method, highlights how research can be carried out which centres the experiences of the person, empowering them through the sharing of their stories. In this way, they become agents of their own lives rather than being rendered objects of academic curiosity and research.

It is through the non-directed rambling along the highways and byways of their own lives that their stories emerged in a manner that was meaningful for each storyteller. In sharing their stories, as they wished, Darcy, Alan and Frankie came to new insights and understandings of the lives they have experienced. They found the sharing empowering. Through reflection, they were able to review and plan how their next encounter with the Other may enable them to obtain a better outcome. As Alan said:

> They had all the power, I had nothing. I had no information. I had no ground to stand on. All I could do was just react to what was being said to me. I was so much on the back foot I couldn't catch up and that would have been a major part of the difficulty. Again, it goes back to if you don't even know enough of your own story to be able to say it. [Alan]

Author Contributions: Conceptualization, M.D. and T.N.M.; methodology, M.D. and T.N.M.; validation, M.D. and T.N.M.; formal analysis, M.D. and T.N.M.; investigation M.D. and T.N.M.; resources M.D. and T.N.M.; data curation, M.D. and T.N.M.; writing—original draft preparation, M.D. and T.N.M.; writing—review and editing, M.D. and T.N.M.; project administration, M.D. and T.N.M.; funding acquisition, M.D. and T.N.M. All authors have read and agreed to the published version of the manuscript.

Funding: This study was funded by the Irish Research Council, IRC Coalesce 2019/156.

Institutional Review Board Statement: The study was conducted in accordance with the Declaration of Helsinki and approved by the Dublin City University Research Ethics Committee (protocol code DCUREC/2019_119 and 28 June 2019).

Informed Consent Statement: Informed consent was obtained from all subjects involved in the study.

Data Availability Statement: No new data were created or analyzed in this study. Data sharing is not applicable to this article.

Acknowledgments: The authors would like to thank our intersex participants who shared their stories with us. They gave freely of their time and we are grateful for the trust they placed in us by sharing their stories of being intersex. Without your generosity, we would never have been able to do this work. Sincerest thanks are owed to Maria Feeney, who was our Postdoctoral Researcher on the Mapping Study for her invaluable contribution.

Conflicts of Interest: The authors declare no conflicts of interest. The funders had no role in the design of the study; in the collection, analyses, or interpretation of data; in the writing of the manuscript; or in the decision to publish the results.

Notes

[1] Further work by the authors is forthcoming that does examine these aspects of the Mapping Study.

[2] The contributions of this author to scholarship in the field of hermeneutic phenomenology are indisputable; however, we do acknowledge the controversy that surrounds Heidegger's engagement with National Socialism. As Wolin notes "It would be foolish to suggest that, as a result of Heidegger's concerted, short-lived engagement on behalf of the Nazi regime, he would somehow forfeit his status as a significant contributor to the legacy of Western thought." (Wolin 1993, p. vii).

References

Bauer, Markus, Daniela Truffer, and Daniela Crocetti. 2020. Intersex Human Rights. *The International Journal of Human Rights* 24: 724–49. [CrossRef]

Becker, Howard Saul. 1963. *Outsiders; Studies in the Sociology of Deviance*. New York: Free Press.

Breen, Lauren. 2007. The Researcher 'in the Middle': Negotiating the Insider/Outsider Dichotomy. *The Australian Community Psychologist* 19: 163–74.

Carpenter, Morgan. 2018a. Intersex Variations, Human Rights, and the International Classification of Diseases. *Health and Human Rights* 20: 205–14. [PubMed]

Carpenter, Morgan. 2018b. The 'Normalisation' of Intersex Bodies and 'Othering' of Intersex Identities. In *The Legal Status of Intersex Persons*. Edited by Anatol Dutta, Jens M. Scherpe and Tobias Helms. Cambridge: Intersentia, pp. 445–514. [CrossRef]

Charlebois, Janik Bastien. 2017. Les sujets intersexes peuvent-ils (se) penser? *Socio. La Nouvelle Revue des Sciences Sociales* 9: 143–62. [CrossRef]

Cresti, Matteo, Elena Nave, and Roberto Lala. 2018. Intersexual Births: The Epistemology of Sex and Ethics of Sex Assignment. *Journal of Bioethical Inquiry* 15: 557–68. [CrossRef] [PubMed]

Crowther, Susan, Pamela M. Ironside, Elizabeth Smythe, and Deborah G. Spence. 2016. Crafting Stories in Hermeneutic Phenomenology Research: A Methodological Device. *Qualitative Health Research* 27: 826–35. [CrossRef] [PubMed]

Cuff, Edward C., Wes W. Sharrock, D. W. Framcis, A. J. Dennis, and Dave W. Francis. 2006. *Perspectives in Sociology*, 5th ed. London: Routledge. [CrossRef]

Davis, Georgiann. 2014. The Power in a Name: Diagnostic Terminology and Diverse Experiences. *Psychology & Sexuality* 5: 15–27. [CrossRef]

Davis, Georgiann, Jodie M. Dewey, and Erin L. Murphy. 2016. Giving Sex: Deconstructing Intersex and Trans Medicalization Practices. *Gender & Society* 30: 490–514. [CrossRef]

Dibley, Lesley, Suzanne Dickerson, Mel Duffy, and Roxanne Vandermause. 2020. *Doing Hermeneutic Phenomenological Research: A Practical Guide/Lesley Dibley, Suzanne Dickerson, Mel Duffy, Roxanne Vandermause*. Los Angeles: SAGE.

Draucker, Claire Burke. 1999. The Critique of Heideggerian Hermeneutical Nursing Research. *Journal of Advanced Nursing* 30: 360–73. [CrossRef] [PubMed]

European Union Agency for Fundamental Rights. 2015. *FRA Focus Paper: The Fundamental Rights Situation of Intersex People*. Vienna: (FRA) European Agency for Fundamental Rights.

European Union Agency for Fundamental Rights. 2020. *A Long Way to Go for LGBTI Equality*. Luxembourg: Publications Office of the European Union.

Fausto-Sterling, Anne. 1993. The Five Sexes: Why Male and Female Are Not Enough. *The Sciences*, 20–25. [CrossRef]

Fricker, Miranda. 2007. *Epistemic Injustice: Power and the Ethics of Knowing*. Oxford: Oxford University Press.

Giddens, Anthony. 1991. *Modernity and Self-Identity: Self and Society in the Late Modern Age*. Oxford: Oxford Polity Press.

Giddens, Anthony. 1992. *The Transformation of Intimacy Sexuality, Love, and Eroticism in Modern Societies*. Oxford: Oxford Polity Press.

Giorgi, Amedeo. 2005. The Phenomenological Movement and Research in the Human Sciences. *Nursing Science Quarterly* 18: 75–82. [CrossRef] [PubMed]

Goffman, Erving. 1971. *The Presentation of Self in Everyday Life*. London: Pelican Books.

Gorduza, Daniela B., Charmian A. Quigley, Anthony A. Caldamone, and Pierre D. E. Mouriquand. 2018. Surgery of Anomalies of Gonadal and Genital Development in the 'Post-Truth Era'. *Urologic Clinics of North America, Pediatric Urology* 45: 659–69. [CrossRef] [PubMed]

Gray, J. Glenn. 1976. Introduction. In Heidegger, Martin. 1976. In *What Is Called Thinking?* Translated by J. Glenn Gray. New York: Harper Perennial, pp. vi–xvi.

Heidegger, Martin. 1962. *Being and Time*. Translated by John Macquarrie, and Edward Robinson. New York: Harper and Row Publishers Incorporated.

Heidegger, Martin. 1969. *Identity and Difference*. New York: Harper and Row Publishers Incorporated.

Heidegger, Martin. 1976. *What Is Called Thinking?* Translated by J. Glenn Gray. New York: Harper Perennial.

Howard, Peggy Ann. 2002. "The Look" in Teacher's Performance Evaluation. In *Writing in the Dark: Phenomenological Studies in Interpretive Inquiry*. Edited by Max van Manen. London, ON: The Althouse Press, pp. 50–60.

Johnson, Mary E. 2000. Heidegger and Meaning: Implications for Phenomenological Research. *Nursing Philosoph* 1: 134–46. [CrossRef]

Kessler, Suzanne J. 1998. *Lessons from the Intersexed*. New Brunswick: Rutgers University Press.

Lee, Peter A., Christopher P. Houk, S. Faisal Ahmed, and Ieuan A. Hughes. 2006. Consensus Statement on the Management of Intersex Conditions. *Pediatrics* 118: e488. [CrossRef] [PubMed]

Lundberg, Tove, Peter Hegarty, and Katrina Roen. 2018. Making Sense of 'Intersex' and 'DSD': How Laypeople Understand and Use Terminology. *Psychology & Sexuality* 9: 161–73. [CrossRef]

Monro, Surya, Daniela Crocetti, Tray Yeadon-Lee, Fae Garland, and Mitch Travis. 2017. Intersex, Variations of Sex Characteristics, and DSD: The Need for Change. Huddersfield, UK. Available online: http://eprints.hud.ac.uk/id/eprint/33535/1/Intersex%20Variations%20of%20Sex%20Characteristics%20and%20DSDreportfinal.pdf (accessed on 15 November 2023).

Moran, Demotee. 2000. *Introduction to Phenomenology*. London: Routledge.

Preves, Sharon E. 2003. *Intersex and Identity: The Contested Self*. New Brunswick: Rutgers University Press.

Raz, Michal. 2024. Uncertain Knowledge: The Medicalisation of Intersex People and the Production of Ignorance. *Social Sciences* 13: 385. [CrossRef]

Reinharz, Shulamit. 1992. *Feminist Methods in Social Research*. New York: Oxford University Press.

Reis, Elizabeth. 2007. Divergence or Disorder?: The Politics of Naming Intersex. *Perspectives in Biology and Medicine* 50: 535–43. [CrossRef] [PubMed]

Rose, Maddie. 2020. Is MRKH Intersex? Ask a Different Question Instead. Available online: https://interactadvocates.org/is-mrkh-intersex/ (accessed on 15 November 2023).

Rubin, David A. 2015. Provincializing Intersex: US Intersex Activism, Human Rights, and Transnational Body Politics. *Frontiers: A Journal of Women Studies* 36: 51–83. [CrossRef]

Sartre, Jean-Paul. 1969. *Being and Nothingness: An Essay on Phenomenological Ontology*. Translated by Hazel E Barnes. London: Routledge.

Smythe, Elizabeth, Pamela M. Ironside, Sharon L. Sims, Melinda M. Swenson, and Deborah G. Spence. 2008. Doing Heideggerian Hermeneutic Research: A Discussion Paper. *International Journal of Nursing Studies* 45: 1389–97. [CrossRef] [PubMed]

United Nations for LGBT Equality. n.d. Fact Sheet Intersex. Available online: https://www.unfe.org/wp-content/uploads/2017/05/UNFE-Intersex.pdf (accessed on 15 February 2022).

van Lisdonk, Jantine. 2014. *Living with Intersex/DSD: An Exploratory Study of the Social Situation of Persons with Intersex/DSD*. The Hague: The Netherlands Institute for Social Research.

Wolin, Richard. 1993. *The Heidegger Controversy—A Critical Reader*. Cambridge: The MIT Press.

Young, Iris Marion. 2005. *On Female Body Experience: "Throwing Like a Girl" and Other Essays*. Oxford: Oxford University Press.

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Article

"These Researchers Think They Come From Heaven with Analytical Superpowers When They Don't": A Qualitative Analysis of Research Experiences in Intersex-Related Studies

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Abstract: This article explores diverse ethical considerations related to the study of vulnerable population groups to produce meaningful project outcomes that avoid harm to the involved communities. In the specific context of the intersex community, previous analyses have encountered various challenges, including the medicalization of intersex people's bodies, the use of pathologizing language, and misrepresentation of the population's needs. The article explores some of the beliefs, experiences, and tools that experts in research ethics, researchers, and intersex research participants consider most important regarding research ethics in intersex-related studies. The article is based on original empirical research; semi-structured interviews were conducted with 21 participants, recruited through email and snowball sampling methods, and the data were examined using thematic analysis. It moves from issues related to the research design (positionality, researcher preparation, framing intersex within the LGBT acronym) to experiences related to the research development (ethical approval, informed consent process, language use, relationship of trust). The article describes some of the major concerns and raises discussions that could be relevant for the development of future research under human rights-based perspectives. The findings are aimed to be useful beyond the field of intersex-related studies, as they can be relevant to research about other communities that have endured violations of their human rights during research.

Keywords: intersex; human rights-based approach; positionality; qualitative research

Citation: Mestre-Martínez, Yessica. 2024. "These Researchers Think They Come From Heaven with Analytical Superpowers When They Don't": A Qualitative Analysis of Research Experiences in Intersex-Related Studies. *Social Sciences* 13: 421. https://doi.org/10.3390/socsci13080421

Academic Editors: Surya Monro, Tanya Ni Mhuirthile, Amets Suess-Schwend, Fae Garland, Daniela Crocetti, David Andrew Griffiths and Katrina Roen

Received: 25 March 2024
Revised: 18 July 2024
Accepted: 29 July 2024
Published: 12 August 2024

1. Introduction[1]

Studies about vulnerable populations have led to the development of research projects to access these communities and understand their issues, raising complex ethical considerations regarding research practices (Hugman et al. 2011). In the pursuit of knowledge and the advancement of scientific understanding, researchers have the ethical responsibility to conduct studies that uphold the well-being of all participants involved (Beauchamp and Childress [1979] 2019). This ethical imperative is considered especially relevant in studies involving vulnerable communities, where cognitive, institutional, medical, social, or economic disparities can magnify the ethical challenges faced by researchers (Kipnis 2001). In this sense, "vulnerability, in the context of research, should be understood to be a condition, either intrinsic or situational, of some individuals that puts them at greater risk of being used in ethically inappropriate ways in research" (NBAC 2001, p. 85). From a broader perspective within social sciences, there is sometimes a disconnect between the "goals of science" and ethical considerations (Fisher 1999, p. 29). Researchers conducting studies with vulnerable populations often find themselves navigating these complex ethical challenges, drawing "upon their own moral compass, the advice of colleagues, and recommendations of institutional review boards (IRBs)" (Fisher 1999, p. 29). The decisions made in this regard "have immediate and possibly long-term impact on participants, their families, and the communities they represent" (Fisher 1999, p. 29).

Recognizing the potential ethical dilemmas inherent in such research dynamics, various ethical frameworks have been developed to offer guiding principles. Key among these are (i) the Nuremberg Code (International Military Tribunal 1946), (ii) the Declaration of Helsinki (WMA [1964] 2013), (iii) the Belmont Report (The National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research 1979), (iv) the Guidelines for Research Ethics in the Social Sciences and the Humanities (NNREC 2021), and (v) the Ethics in Social Sciences and Humanities (EC 2021).

These guidelines are essential as they provide a framework for protecting the rights of participants engaged in social science research. As such, several ethical principles outlined in this article, including obtaining fully informed consent and assent, utilizing appropriate language, and understanding the community's history, have been selected, considering the parameters established in these guidelines.

The first three regulations offer an ethical framework for the essentiality of informed consent, the management of risk, the necessity of the study, and the benefit that particularly vulnerable groups will obtain as a result of the research (International Military Tribunal 1946; The National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research 1979; WMA [1964] 2013). The latter two guidelines, specific to the social science field, underscore the importance of additional considerations in research involving vulnerable populations. Given the historical context of "abuses of power and unethical research" against vulnerable groups, there is a recognition that members of these groups "may wish not to be subjects of research, for instance, for fear of stigmatization or other negative consequences. At the same time, excessive protection of weak and vulnerable groups is inappropriate" (NNREC 2021, p. 29). Thus, the NNREC (2021) considers it advisable to implement additional measures to make the research as respectful as possible, "gaining knowledge about and respect the local context and social relations" of the group involved (p. 30).

In alignment with this perspective, the European Commission recommends the researcher: "Make sure you do not exacerbate people's vulnerability through your research or research participation" (EC 2021, p. 12). The EC guidelines also highlight various scenarios where research may pose greater risks, including "research involving sensitive topics and those which might cause psychological stress, anxiety or humiliation" (EC 2021, p. 19).

Fricker (2007) introduces the concept of epistemic injustice, illustrating instances where individuals, especially from marginalized communities, are not acknowledged as credible sources of knowledge. Fricker (2007) highlights how societal power dynamics systematically undermine the credibility and recognition of certain voices. Other scholars, such as Kristie Dotson (2011) and José Medina (2013), have further expanded the understanding of how epistemic violence or epistemic injustice manifests and perpetuates misrepresentation. While their perspectives may not be explicitly focused on research, their work holds ethical dimensions that are inherently relevant to the study of issues related to vulnerable communities.

Dotson (2011) discusses the idea of "[e]pistemic violence in testimony" (p. 238), which refers to situations where someone's words are not taken seriously or respected by others. This happens when people refuse to listen or respond to what someone is saying because they do not understand or do not wish to understand. Dotson (2011) calls this "pernicious ignorance," which means "any reliable ignorance that, in a given context, harms another person (or set of persons)" (p. 238). This concept highlights how not being heard or acknowledged can be damaging and unfair to the person trying to communicate (Dotson 2011). From here, she develops two important concepts: "testimonial quieting," which "occurs when an audience fails to identify a speaker as a knower" (Dotson 2011, p. 242), and "testimonial smothering" (Dotson 2011, p. 244). The author gives different meanings to this latter concept; one of them is "when an audience demonstrates testimonial incompetence with respect to the content of potential testimony" (Dotson 2011, p. 245). In this case, the speaker is rendered silent, not necessarily through explicit censorship, but rather through a lack of social recognition and receptiveness to their testimony (Dotson 2011).

Similarly, Medina's (2013) elucidation of "hermeneutical gaps" (p. 75) contributes to a comprehensive interpretation of the multifaceted ways in which marginalized voices are suppressed and distorted in research contexts. He discusses a gap in the collective understanding or conceptual resources of a community, which may lead to the inability to articulate or include certain experiences (Medina 2013). Medina's (2013) emphasis on hermeneutical gaps highlights how certain groups, often those at the margins of society, face challenges in having their experiences intelligibly expressed and comprehended. When dominant cultural frameworks lack the conceptual tools to make sense of the experiences of marginalized groups, it creates a gap in understanding that contributes to their exclusion and misrepresentation (Medina 2013).

Applying the reviewed reflections on epistemic injustice (Fricker 2007; Medina 2013) or epistemic violence (Dotson 2011) to the field of research practices, acknowledging and rectifying epistemic injustices in research becomes an ethical imperative, particularly concerning vulnerable communities. Understanding these ethical and epistemological challenges, this article aims to present and give voice to the narratives and research experiences of one of the communities that have suffered violations of their human rights during research, the intersex population, as well as to researchers and experts in research ethics with experience in the field of intersex-related research.

Intersex babies, children, and adults continue to face a series of human rights violations (Ghattas 2015; UN 2019) because of their physical characteristics. These include "violations of their rights to be free from torture and ill-treatment, to health and physical integrity, and to equality and non-discrimination" (UN 2019, p. 4). This is highly problematic and is due to a lack of recognition of intersex people, as Ghattas (2015) explains:

> In a world where the overwhelming majority of people and governments only know and accept two sexes ('male' and 'female'), the existence of intersex people and their bodies is not recognized. Instead, healthy intersex bodies are considered to be a 'medical problem' and a "psychosocial emergency" that needs to be fixed by surgical, hormonal, other medical, and sometimes psychological means. (Ghattas 2015, p. 9; reference removed)

According to a publication of the European Union Agency for Fundamental Rights (FRA 2015, quoted in Ghattas 2015, p. 9), within the European Union, surgeries aimed at 'normalizing' intersex children are performed in at least 21 Member States.

In the case of intersex-related studies, health professionals acquired a position of power under the name of science due to the ownership that medicine has taken of intersex bodies (Karkazis 2008). This sense of entitlement amongst medical practitioners implies decision-making processes about what is best for intersex people without them actively participating. It produces an atmosphere where only medical knowledge and experiences are taken into consideration; disregarding the experiences and knowledge that the community itself can propose for its own well-being which is a violation of their self-determination and constitution of the mentioned epistemic injustice within intersex-related studies (Bastien-Charlebois 2016).

Scholars from the field of intersex studies and activists have exemplified and contextualized the ways in which the experiences of intersex people have been disregarded and marginalized (Cabral Grinspan 2009; Carpenter [2014] 2019; Carpenter and IHRA 2018). This includes exposing instances where researchers wield privilege in the production and access of knowledge while emphasizing testimonial injustices and dehumanizing treatments endured by intersex individuals (Bastien-Charlebois 2017). The work of authors from the field of intersex studies underscores the need for a paradigm shift in knowledge creation, advocating for a more inclusive approach that considers the nuanced context surrounding intersex experiences (Bastien-Charlebois 2017; Carpenter and IHRA 2018).

From an activist perspective, members and organizations of the intersex community have raised their voices regarding the violation of human rights within research. For instance, Koyama (n.d.), ISNA (n.d.), and interACT (2023) have created different guidelines aiming to advise researchers to center the participants' voices, think critically, and avoid creating harm or re-traumatization. From an academic standpoint, Lundberg (2021) and Jones (2022) have conducted analyses on reflexivity concerning the ethical and methodological aspects of studying intersex-related topics. Jones (2022) contends that conducting research with intersex individuals demands heightened ethical sensitivity given the history of institutional power abuses (especially in medical contexts) coupled with social stigma and marginalization. She emphasizes the importance of employing methodologies that empower participants and do not perpetuate existing power imbalances. Similar reflections have been developed from the perspective of trans studies (Adams et al. 2017; Vincent 2018).

In 2023, I conducted a narrative literature review aimed at examining methodological research approaches and ethical considerations in studies related to intersex people (Mestre Martínez 2023a). While the majority of papers reviewed adhered to general ethical standards such as signed informed consent and data management information, some exhibited concerning practices (Mestre Martínez 2023a). That study formed a foundation for this article, as it revealed an absence of qualitative studies exploring the perspectives of experts in research ethics, researchers, and intersex research participants together. This article seeks to address this gap.

The results are categorized into two primary research stages: research design and research development. These stages were chosen due to the distinct ethical and epistemological considerations they entail. Participants contributed a variety of perspectives throughout both stages, unveiling their experiences with research and articulating concerns significant to them. This approach aims at establishing a platform for dialogue and improvement within the broader research community, and holding significance for the intersex population by giving voice to the human rights violations experienced by these individuals during research.

2. Materials and Methods

This research has a qualitative design involving a series of semi-structured interviews conducted in 2022 as part of the European research project 'INIA: Intersex—New Interdisciplinary Approaches.' Potential research participants were contacted by sending invitation emails to international and national intersex organizations, academic networks, and individual persons. In addition, a snowball technique was used. The research fulfils the parameters stated in the General Data Protection Regulation (Regulation (EU) 2016/679) (GDPR), and the Spanish legislation on data protection (Ley Orgánica 3/2018, de 5 de Diciembre, de Protección de Datos Personales y garantía de los derechos digitales).

The selection criteria for participants were having experience in the field of qualitative research on intersex issues as ethical experts, researchers, or intersex research participants, and residing in the European Continent, the American Continent, or Oceania. The study included 21 participants: 2 ethical experts, 17 researchers, and 2 research participants. However, within the ethical experts and the researchers' groups, a total of 9 people (who identified as intersex people) had also, at some point, had experience as research participants of intersex-related studies, which means they could offer a double perspective for the research purposes. Given the limited number of people involved in the field of intersex studies, demographic details about all three groups of participants, such as their region of residence, discipline, and career stage, will not be published to ensure confidentiality.

The semi-structured interviews allowed research participants to express their experiences regarding the development of research related to intersex issues and to engage in a reflexive exercise. The interview process tried to follow a human rights-based approach, which means research that prioritizes not only the study objectives but also how they are achieved, with a commitment to upholding human rights principles throughout the project (Smith 2018). Participants received an information sheet about the project, an informed consent form, and an explanation of their rights. They had the opportunity to review the information provided in the interview and the possibility to withdraw their interview at any time before the results were published. In order to avoid people feeling pressured to participate, the interviewing process always offered alternatives, such as not answering questions that the person did not feel comfortable with. During the interviews, the use of a depathologizing language was important in order to provide the participants with a comfortable environment for them to express their thoughts and therefore minimize the risk of possible re-traumatization. The project offered two funded psychotherapeutic sessions for intersex participants and access to a support organization contact sheet upon request.

Each interview took place remotely, was recorded, and lasted approximately one hour. The interviews were carried out from April 2022 to October 2022. The interview information was transcribed and imported into secured digital spaces along with the audio files. A thematic analysis was conducted, following Braun and Clarke's (2006) methodology. The data were organized using five initial codes, according to the structure of the interview script: background of the participant, experiences before the interviews, experiences during the interviews, experiences after the interviews, ethical insights, and recommendations/feelings. Thereafter, relevant themes mentioned by various participants were identified, related mainly to experiences before and during the interviews.

This article primarily aims at delineating the themes underscored by participants, by means of a descriptive approach. These themes can serve as a catalyst for fostering new dialogues within the area of intersex research. Consequently, the results section is dedicated to amplifying the voices of the participants, elucidating their experiences and recommendations related to the research design (positionality, researcher preparation, framing intersex within LGBT), and the experiences related to the research development (ethical approval, informed consent process, language use, relationship of trust).

Following the reflections on research methodology contributed by other scholars (Garland and Travis 2023; Monro et al. 2021), this research does not intend to speak for the intersex communities and, therefore, refrains from interpreting the participants' experiences. Instead, it aims to engage in dialogue with them for the purpose of knowledge development (Garland and Travis 2023). This overview addresses the contentious areas articulated by participants earlier. It is imperative to note that the sources of knowledge underpinning this article extend beyond scientific and academic research, incorporating activist perspectives and non-governmental reports. These sources were included to engage and recognize the different ways of knowledge production and existing contributions to the development of intersex-related studies.

As a non-intersex (or endosex) individual, my interest in intersex studies has developed closely in the last seven years alongside my work in public policy with other communities that have also experienced human rights violations during research, such as the trans and Indigenous communities. Through my involvement in the INIA Project as a Marie Curie Researcher, I have been dedicated since 2021 to studying the history, struggles, injustices, oppression, and marginalization faced by the intersex community.

3. Results

3.1. Experiences Related to Research Design

3.1.1. Positionality

Throughout the semi-structured interviews, most participants raised concerns related to researcher positionality. They pointed out the challenges associated with the internal personal processes and self-reflection that researchers undergo when studying a population that has experienced human rights violations, such as intersex individuals. A particular concern was voiced regarding researchers who are not intersex persons. Participants noted that the legitimacy of their involvement is assessed by both themselves and the intersex community.

For instance, from a researcher's perspective, Participant No. 15 (Researcher)[2] mentioned the ethical dilemmas that she went through during the publication of findings as an endosex person. The legitimacy of the research was always a topic of consideration because it made her feel that she was occupying a place that did not correspond to her.

Other researchers agreed with this internal discussion of legitimacy and doubting of their research. Participant No. 13 illustrates:

> [. . .] I think with time, it's been always a question of the legitimacy of me working on this issue, but that something, I mean, what helped me was going to meet intersex people that told me that, like, thank you for doing your research, and it's important that there are people doing it. So, it's kind of keeping in mind that if what I do can also serve their knowledge of intersex people and their rights [. . .] if you're not intersex, I think it's really complicated to do research with intersex people about their history and experience, but I guess you have to especially like try to do what your positionality in it, it's complex. So always remind, you know, yourself and the others what from what kind of point of view you're doing this research. (Researcher. P13)

Emphasizing the significance of scrutinizing internal motivations for conducting the research, participants underscored the importance of self-reflection in navigating these complexities. Particularly, researchers who are endosex showed more concern regarding their positionality and legitimacy in the research.

3.1.2. Researcher Preparation

According to the participants in this research, intersex individuals have endured experiences characterized by medicalization and human rights violations. Throughout the interviews, the interviewed endosex researchers highlighted the importance of educating themselves and taking part in training about research ethics previous to the research design. This emphasis aims to better comprehend the life experiences that individuals will share and, importantly, to prevent misconceptions.

Some of the researchers were aware of the problems; for example, Participant No. 6 (Researcher) stated that "[. . .] researchers will use intersex people to get information, but then they consider themselves as experts." This researcher mentioned how some researchers do not give the same value to the activist experience in comparison to the scientific experience.

Other participants who hold the position of researchers and have been participants of intersex-related research mentioned:

> I feel like quite comfortable talking about these issues where I know the researcher understands the population and that's what they're talking about, but it's incredibly frustrating when they clearly don't, they confuse it with trans issues all the time. [. . .] I think it could be quite confronting if you're talking to researchers who don't quite understand the population and like your issues. (Researcher—Participant. P17)

> [. . .] the researcher is coming from outside and you have to respect that this person understands their lived experience better than anybody else. These researchers think they come from heaven with analytical superpowers when they don't. (Researcher—Participant. P21)

The majority on the people interviewed commented at some point on the importance of researchers receiving previous training that creates an awareness of intersex people's experiences and makes them understand better the issues that they face and how future projects could help to solve them.

3.1.3. Framing Intersex within the LGBT Acronym

The research participants discussed approaches to research design, including framing intersex within the LGBT acronym, and emphasized the potential impact of this on the representation of the community's identity and priorities. Many participants expressed concerns about possible misrepresentations that could occur with the framing of intersex within LGBT, particularly when intersex issues are portrayed solely as gender or sex identification issues rather than acknowledging the violence they endure.

Participants mentioned possible reasons for this framing. Participant No. 9, who is a researcher, indicated that in some instances, it is easier to obtain ethical approval when the frame of the study is LGBT+ and therefore "[. . .] that creates a problem, because it means that it's pushing researchers towards this LGBT framing of intersex and not a medicalized of intersex because it's easier to get the data here." Another researcher, participant No. 4, states that some academics write about intersex people having an LGBT background, which could limit their focus, mentioning that "[. . .] gay people are not mutilated, so mutilation is not on their radar and then they focus on what they know, like discrimination, hate, hate speech and stuff like this, [. . .]."

Other perspectives came from people who have been researchers and participants. Some of them explained how this LGBT framing could remove the attention from real concerns that are specific to intersex people. Some of them stated the following:

> [. . .] if you had to draw one comparison, it would be more with victims of incest or victims of pedocriminality, like how you treat the people who are sharing the testimonies with you, how you can, I think often people would assume that is a question of identity or question of body, but it's not, it is about the experience of violence since you are very young, [. . .]. (Researcher–Participant. P11)

> [. . .] what is that doing to people who are cisgender heterosexual because I know they exist and they're part of my community? They tend not to become part of many intersex groups who are very LGBT focused. And sadly, that kind of pushes them. I mean, the only spaces that some of those people feel comfortable in is medicalized spaces because at least those spaces are not trying to tell them they are something that they don't feel they are, so it's a difficult situation. (Researcher—Participant. P1)

The framing of intersex-related studies within LGBT is a topic that created different opinions among participants. However, some of them agreed on the idea that to avoid misleading of locating intersex people's issues within LGBT research, it is necessary to consult the community in the research design so they can have a voice in what is important to them.

3.2. Experiences Related to Research Development

3.2.1. Ethical Approval

The process of securing ethical approval for the research projects emerged as a recurrent issue mentioned by the participants. They expressed concerns regarding the necessity of ethics approval, the composition of ethics committees, and the overall utility of the approval process for the research. A prevalent and shared concern was the expertise of the board members concerning the challenges faced by the intersex population. The opinions of some participants were as follows:

> The problem is that many of those boards are not familiar with the population. So many of much of the bad practice that I've talked about has been approved by an ethics review board that really has just not understood the population. (Researcher—Participant. P1)

> [. . .] passing a research ethics committee guarantees that the research is ethical, no, for a very clear reason, because first, because ethics committees as they are organized today, there are people who brutally ignore the realities, so they are approving things they have no idea about. (Researcher. P15. Own Translation)

A common opinion among some of the participants was that beyond the formality, ethics committees may not understand the realities and struggles of the people involved in the research.

3.2.2. Informed Consent Process

A crucial aspect and focal point of discussion during the interviews was the informed consent process—its formalities, scope, and utility post-interview. Participants employed various approaches related to the informed consent process and voiced concerns, particularly regarding the terminology used in the consent forms and the assurance of their rights throughout the research once they signed the forms.

Some of the participants who are researchers agreed on the idea that the importance of this lies in what happens after the informed consent has been signed, and the integrity that the researcher will have afterwards. Another point highlighted by one of the researchers was the way in which the consent forms were written. Participant No. 6 (Researcher) advised, "[. . .] you need consent forms that are accessible, they can explain in a very simple way, all the steps, and also provide an alternative in case that you don't like your research, the research, you can withdraw, but also mentioned a complaint mechanism or something, or someone to contact an organization to contact, something."

Other people emphasized the process that comes along with informed consent; one of them said the following:

> Maybe say things like, 'So would you like to know why I'm doing this research? What the objectives are? If you have any questions in that regard I would be happy to answer them' and to present the objective and what participation consists of; if there are any questions at all regarding the components of the research, feel free to ask and what I think would still be important may be that they are knowledgeable of consent forms but not everyone is knowledgeable about research and what it consists of [. . .]. (Researcher–Participant. P10)

The majority of the participants, especially those involved in research roles, emphasized the importance of viewing informed consent as a dynamic process. This process involves a series of actions that demonstrate respect for participants' rights and provide them with a safe space to express any concerns regarding the study.

3.2.3. Language Use

Several challenges disclosed by participants, especially within the researchers' group, became apparent during the interviews, particularly regarding the creation and development of the interview process. Some researchers encountered difficulties with language use, and interview partners with experience as research participants recounted instances where the misuse of language could compromise the trust in the relationship. One of them advised the following:

> [. . .] maybe use vocabulary at first that is as neutral as possible, interventions that you were subjected to, start with that and adjust regarding how the person describes them; I mean, I know I am using for myself human rights violations, at first I was using non-consensual interventions, I know that it is still considered a hot topic, it is shocking blurting out human rights violations and even for intersex people, they don't want to use 'genital mutilation,' others will, or 'sex mutilation' or 'sexual mutilation,' not just concentrated on genitals, because there might be different reasons a person doesn't want to hear 'genital mutilation,' and we can't just push people, it's a very sensitive thing [. . .]. (Researcher–Participant. P10)

A few individuals interviewed who are researchers and have been research participants commented on the mistrust that they have when somebody talks to them with a pathologizing language. Others emphasized the importance of using the preferred language of the person, even if it is medicalized. For instance, Participant No. 20 (Researcher-Participant) said, "[. . .] if you speak with a patient or organizer or whatever, and they only use their own variation and say syndrome, and don't use intersex. Don't say this intersex person, it's not like correct, but if I say I'm intersex, don't go and say, oh, this person with this syndrome because it's not the way I want." Overall, most of the people interviewed came to the conclusion that the language used plays a fundamental role in the development of a relationship of trust between researcher and participant.

3.2.4. Relationship of Trust

In the qualitative research process, participants underscored the significance of sustaining a relationship of trust with their research counterparts across all stages of the study, not solely limited to the interview process. Within this framework, some participants conveyed their discomfort, describing instances where they felt utilized solely as sources of data. This discomfort hindered their willingness to engage in subsequent research participation.

> [. . .] it is a feeling I think Yessica, a growth feeling valued. If you don't feel valued, it doesn't work because being valued and having trust, I think, is paramount key. In any research. You don't trust someone, then you may as well say no. [. . .] I think, if you feel that the interviewer, researcher, give something of themselves, not seeing anything deep or really dramatic, I think it always gives permission for the person being interviewed to give something of themselves, it becomes reciprocal, if that makes sense. (Participant. P5)

Some of the researchers interviewed in the study agreed upon the idea that building a relationship of trust is something that cannot be pushed because it requires time for the people to trust in the researcher's intentions and the position that he/she/they have of certain intersex issues. Participant No. 9 (Researcher) commented: "[. . .] in a way you are as a researcher to try to explain how you stay in that field, and you're not taking people's data or doing something horrible or creating intersex as a third gender [. . .]."

Participants of each group gave different perspectives on the relationship of trust and how it can develop. Nevertheless, consistency in the researcher's actions and time to build a relationship were two positive factors present in some of the answers. One of the researchers highlighted the importance on human connection to allow the relationship to grow:

> [. . .] for me, trust is something that arises from that relationship, and we can work on things beforehand to allow it to emerge, but it is, above all, something that will emerge if we are really capable of connecting humanly and if we are not capable of connecting humanly, it does not even emerge, it doesn't emerge, and it's possibly very good that it doesn't emerge because there's probably a protection from the other part and that is very appropriate. (Researcher. P14. Own Translation)

This study addressed results across a range of topics, including the significance of internal reflections such as positionality, the necessity of thorough researcher preparation, and the importance of consulting the community when framing topics under the LGBT umbrella. Additionally, the study highlighted the requirements for ethical approval and the process of informed consent, the correct use of language, and the value of fostering a trusting relationship between the researcher and the participants.

4. Discussion

These qualitative findings show a range of concerns and contribute to an open discussion about research on intersex issues. This discussion section addresses issues of legitimacy, epistemological violence, intersex-specific research methodology concerns and guidelines, the construction of an intersex identity, language use, and general issues concerning research with marginalized populations.

Although some of the topics mentioned during the interviews were not explicitly formulated as questions, the participants consistently and prominently introduced them into the conversation. An unexpected revelation emerged during the researchers' self-reflection process, particularly among those who do not identify as intersex. Initially, this theme was not identified as a separate category. However, researchers consistently referenced this topic, discussing their struggles in their positionality throughout their research project, especially those who are not intersex individuals themselves.

Many of the researchers involved in the qualitative study found themselves questioning their legitimacy within research projects and pondering the extent of responsibility associated with speaking and writing about a community that has long grappled for recognition. This self-reflection is understandable considering the history of epistemic injustice that the population has faced, mainly within medical research, including pathologizing classifications of their bodies (Merrick 2019).

Through the analysis of the interviews, most of the interviewed researchers were keen to constantly think of measures to avoid subjecting their studies to a framework of epistemic injustice concerning the intersex community. As mentioned above, the epistemic injustice frames a determined group in a defenseless stereotype (Fricker 2007), and the discreditation of their voices with the presence of "[e]pistemic violence in testimony" (Dotson 2011, p. 238) could occur in different contexts, among them research.

This study contributes to existing scholarship on intersex-related research. From a perspective of intersex studies, Janik Bastien-Charlebois (2017) explains extensively how epistemic injustice develops within the field of intersex-related research and the negative consequences it has brought for intersex people. She states that "the combined effect of hermeneutical marginalization and testimonial injustice can create credibility deflation. [. . .] It is impossible to produce comprehensive empirical investigations into the effects of non-consensual body modification when the medical profession has exclusive access to the records [. . .]" (Bastien-Charlebois 2017, n.p.; own translation). Following Medina's (2013) framework of hermeneutical gaps, Ziemińska (2020) highlights that for intersex people, "[i]t is not only a problem that intersex voices have a deflated level of credibility, but it is also a structural problem that is easy to miss: their voices cannot be understood in the public arena, as the public binary notion of two sexes makes too little space for these voices. The intersex experience is closed behind hospital doors" (p. 54).

Within the participants' responses during the interviews, several comments were directed toward the researchers' attitudes. It was emphasized that researchers should value the activist knowledge and experiences of the participants and not diminish them in comparison to scientific knowledge. These comments align with the report published in 2014 by the organization GATE—Global Action for Trans Equality; the report addressed intersex issues in the International Classification of Diseases, including an epistemological analysis (GATE 2014). While this epistemological analysis is primarily centered on clinical research, its insights are crucial for comprehending the broader epistemological context in intersex-related research. It highlights the detrimental outcomes that arise when a researcher relies on their "own judgment as intrinsically better than the judgments of persons with intersex variations" (GATE 2014, p. 14). In this context, GATE (2014) has made observations such as: "Power-dynamics influence data-collection" and "[r]esearchers interpret their own results, often in their own hospitals, assessing the outcomes of their own treatment paradigms; there is selection and sampling bias" (p. 15; references removed).

The findings of this research revealed a consensus among some researchers regarding the historical challenges intersex individuals have faced due to objectification in research. They emphasized that current research on intersex-related topics should prioritize the voices and experiences of intersex individuals throughout the study's development. In this sense, Bartolo Tabone et al. (2024) suggest that "[t]o remedy the divide between human rights and medical narratives, medical professionals must reflect on their own epistemic primacy and the privileging that their views are granted. In order to combat both hermeneutic and testimonial epistemic injustice, priority must be given to the voices and testimony of intersex people" (p. 15).

To avoid the discussed objectivization, Koyama (n.d.) has elaborated guidelines for non-intersex researchers who decide to write about intersex issues, including the following suggestions: "Recognize that you are not the experts about intersex people, intersexuality, or what it means to be intersexed; intersex people are. When writing a paper about intersexuality, make sure to center voices of intersex people" and "[d]o not write about intersex existence or the concept of intersexuality without talking about the lives and experiences of intersex people as well as issues they face. Do not use intersex people merely to illustrate the social construction of binary sexes" (n.p., bold removed). These principles appeal to a human rights-based research framework that centers on voices and experiences and tries to produce research that recognizes the community's struggles.

Following along with the trajectory of these research dynamics, in the context of intersex-related studies, the findings of this study showed that the three interviewed groups emphasized the necessity for researchers to possess profound insights into the historical and present concerns of intersex individuals. Similar assertions have been made previously. For example, participants in an Amnesty International study emphasized the significance of researchers acknowledging the community's research context, which has historically been marked by severe human rights violations (Amnesty International 2017). These violations stem from the perception of intersex people's bodies as bodies that need to be 'normalized' in their sex characteristics to fit the gender binary categories, leading to a pathologizing experience for them and the perception of a need for their bodies to be corrected (Amnesty International 2017).

Gaining a comprehensive understanding of intersex issues extends beyond studying their history; it involves an examination of the sources contributing to this knowledge and the manner in which researchers articulate it. The Intersex Society of North America (ISNA n.d.) advises researchers to "[t]hink critically about all texts that deal with intersex" (n.p.). This involves asking pertinent questions about authors' or speakers' affiliations and the origins of their knowledge. Additionally, this organization suggests that when writing about intersex, researchers should strive to demonstrate a nuanced understanding and sensitivity towards the experiences and challenges faced by intersex individuals (ISNA n.d.).

Moving on with the theme of acquiring knowledge about the community's experiences and diversity previous to the development of a project (research design stage), the analysis of my research findings revealed another significant theme—the fundamental role of constructing an intersex identity. As an illustrative example, participants mentioned the inclusion of intersex-related studies into LGBT studies, initiating a dialogue that underscores the complexity of the relationship and its potential impact. This inclusion, for instance, plays a significant role in shaping or misrepresenting the identity of the intersex community.

Carpenter (2022) expressed similar concerns regarding the possible dismissal that it can create of intersex people's voices, indicating that "other reports suggest that people with innate variations of sex characteristics do not feel connected to an LGBTQ+ community [. . .]. It is vital to acknowledge the impact of misconceptions about intersex in LGBTQ+ and policy spaces, and a widespread ignorance of distinctly different community characteris-tics and demands" (p. 5). Similarly, Garland and Travis's (2023) research discusses the meaning of LGBT embodiment for the intersex community. They present diverse perspectives on this contentious topic, including: "Such alliances are an integral strategy for many intersex activists to ensure that intersex falls inside rather than outside law's protective sphere. They help politicize intersex, giving visibility" (Garland and Travis 2023, p. 83). Additionally, they highlight that sometimes LGBT organizations could have totally different priorities than intersex people's issues, creating consequences such as "misrepresent intersex-specific issues as relating to identity rather than bodily autonomy" (Garland and Travis 2020, p. 176, quoted in Garland and Travis 2023, p. 83). The authors also mentioned that within their qualitative study, some of their participants "felt that this was a product of organizations only including the 'I' to increase their chances of funding" (Garland and Travis 2023, p. 86).

Lastly, within the LGBT sphere, some participants in the qualitative research considered that situating intersex-related studies within LGBT research could enhance the likelihood of obtaining ethical approval. This perspective prompts an exploration into the impact and relevance of research ethics committees. While I could not identify a dedicated line of inquiry on this topic within intersex studies, the outcomes and functioning of research ethics committees as reviewing entities that look for the production of ethical research seem to be an open discussion in a broader academic context (Coleman and Bouësseau 2008). Critics are concerned about the tendency to focus more on the formalities rather than on the substance, the knowledge, diversity, and training that the committee members have of the research topic, the possible conflict of interests, and the enforceability of their decisions generate the question of their real impact (Coleman and Bouësseau 2008).

Transitioning to the domain of project development, according to the results of the interviews, informed consent plays a central role in intersex-related research, linked to the history of human rights violations, as well as the importance of agency and bodily autonomy for intersex people. The interview participants expressed the opinion that informed consent should be considered as a process rather than as a formal requirement. General ethical recommendations have been created to support the crafting of research protocols that adhere to minimal ethical standards (International Military Tribunal 1946; The National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research 1979; WMA [1964] 2013). Among these standards, the informed consent form is regarded as a critical component for participants involved in research projects, particularly within social sciences (EC 2021; NNREC 2021). Individuals interviewed in this study expressed discomfort when the informed consent process is reduced to a mere formality; some mentioned feeling objectified in previous projects. For intersex-related studies, the sensitive nature of the ethics surrounding informed consent stems from historical circumstances wherein intersex individuals have lacked agency over their bodies, leading to medical interventions being conducted without their voluntary and well-informed consent (FRA 2015).

Illustrating the various historical instances where intersex individuals have been deprived of adequate informed consent processes, Bastien-Charlebois (2016) asserts that "[i]ntersex people are a textbook case of what comprises being treated as 'mere sources of information' [. . .] we were very far from being considered as beings that should be asked for their thoughts and judgments" (n.p.). Regarding intersex-related research, interACT (2023) highlights that "studies must meet the highest standards of informed consent (and informed assent for children); respect the autonomy, dignity, and privacy of intersex participants and (where applicable) their families; avoid subjecting participants to unnecessary risks; and responsibly address questions relevant to the well-being of individuals with variations in their sex characteristics" (n.p.).

The considerations concerning informed consent go beyond the act of signing an informed consent agreement; they also touch on how information is presented. For instance, in the previously mentioned narrative literature review of qualitative and quantitative research on intersex issues I conducted in 2023, the inclusion of images in research publications emerged as a contentious issue (Mestre Martínez 2023a). In the review, I noted that "although it is not possible to recognize the participant, it may evoke a sensation of discomfort and pain to view these pictures, prompting the question: How does the participant feel about the public nature of these images and their right to privacy? Was it explicitly outlined in the informed consent form what types of pictures would be published?" (Mestre Martínez 2023a, p. 53).

Another issue that emerged from the research findings concerned how the information is presented. Participants interviewed in this research emphasized the significance and challenges of employing inclusive language in research and how language becomes one of the pillars for the establishment of a relationship of trust. The use of inclusive language is crucial for intersex-related studies, given the violations of bodily integrity experienced by intersex individuals (Carpenter and IHRA 2018). Lundberg et al. (2018) underscore the importance of language in shaping intersex individuals' identities, emphasizing that the lack of precise terminology can contribute to dehumanization and further marginalization. Given the influence of language on the medicalization of intersex individuals, Davis (2011) contends that the use of pathologizing language has reinforced the authority of medicine over intersex people's bodies.

Various intersex scholars, activists, and allies aim to generate awareness by stressing the existence of these pathologizing practices (Battaglino 2019; Cabral Grinspan 2009; Holmes 2008; Suess Schwend 2014, 2022). Similar reflections have been developed in research with other communities that have suffered marginalization. For instance, Vincent (2018), from a perspective of trans studies, mentions the connection between language and history, highlighting the importance of implementing a research methodology that is language-appropriate to avoid pathologization. Also, Adams et al. (2017) frame different issues related to research with trans individuals, which intersex people have also experienced. This highlights the importance of the researcher's linguistic choices during the interviews and dissemination of data (Adams et al. 2017).

To be consistent with the use of appropriate language and respect for trans people's rights within research, the European Professional Association for Transgender Health—EPATH and the World Professional Association for Transgender Health—WPATH have created Language Guidelines to advise researchers in the presentation and publication of results (Bouman et al. [2016] 2017). Furthermore, EPATH (2019) has launched a Research Policy to provide recommendations for research on trans issues.

It is noteworthy that the campaign 'Depath Intersex,' launched by OII Europe (2023), seeks to give visibility to pathologizing behaviors that can significantly impact the lives of intersex individuals by "creating and legitimizing stigma" (n.p.). The OII Europe initiative proposes recommendations, such as incorporating non-pathologizing information about intersex in educational materials and implementing human rights-based information and training for professionals, especially within the health care system (OII Europe 2023). Amets Suess Schwend (2022) has delved into an "ethics of depathologization," understanding the approach as "a research practice based on the depathologization and human rights perspective" (p. 111). Among other principles, Suess Schwend (2022) advocates for "[r]efraining from pathologizing language, using and promoting respectful, affirmative, and non-pathologizing conceptualizations and terminologies," and "[a]bstaining from a use of pathologizing images in publications or presentations" (p. 111).

The final aspect of research ethics that the participants emphasized is the importance of a relationship of trust during the execution of the project. One of them made a deep reflection on the importance of creating a human connection to establish a genuine relationship with intersex people. Costas Batlle and Carr (2021) noted this point, commenting that creating a genuine human connection is especially vital at this stage to truly capture the viewpoints of the participants, understanding this as a sharing relationship as valuable for the research as the other stages of the project. Therefore, following the line of thoughts of Costas Batlle and Carr (2021), it would be important to consider the creation of this relationship as an essential moment of the research process, particularly if the research topic involves the sharing of vulnerable aspects of the participants' lives.

5. Conclusions

The analysis of the fieldwork has opened avenues for new discussions and brought attention to existing gaps in intersex-related studies. Throughout the interview process, I encountered a variety of issues that were previously unseen (such as the important reflections around legitimacy, particularly for endosex people), and their identification was made possible through the experiences shared by the participants. One recurring issue that resonated closely with both the research participants and myself was the exploration of positionality. Internal struggles and self-reflection were consistently present, particularly among non-intersex researchers. A set of questions revolving around legitimacy, knowledge control, respect for intersex people's voices, and the establishment of trust were crucial for them (and for me) in determining the scope and relevance of research projects.

The engagement of research with a community that has faced human rights violations in certain aspects of their lives implies a commitment to studying their concerns comprehensively. This commitment is crucial to avoid overlooking essential elements that could contribute to defining the project's significance and coherence.

The interview quotes underscored the significance of establishing an authentic human connection between the researchers and the participants. This connection is vital not only for the advancement of intersex-related studies but also for research involving any population group that has experienced human rights violations. There is a historical wound of distrust, and a genuine human connection could aid in the healing process, ultimately enhancing the production of research results.

This study includes several limitations. Throughout the fieldwork, a recurring limitation was the challenge of accessing individuals with variations in sex characteristics who do not identify as intersex. The research project and informed consent documents were crafted using intersex terminology, posing difficulties in engaging with individuals who identify differently. For instance, someone identifying as having a Disorder of Sex Development (DSD) may choose not to associate with an intersex project. This challenge also extended to researchers; efforts were made to connect with those who had conducted qualitative research within the medical field involving DSD participants. However, upon sharing information, some researchers hesitated to participate in research framed under the intersex spectrum.

Funding: The research forms part of the project INIA. Intersex—New Interdisciplinary Approaches. This project has received funding from the European Union's Horizon 2020 Research and Innovation Programme under the Marie Skłodowska-Curie grant agreement No. 859869. This paper reflects only the views of the author and the Agency is not responsible for any use that may be made of the information it contains.

Institutional Review Board Statement: The study was approved by the Research Ethics Committee of the University of Granada (Comité de Ética en Investigación de la Universidad de Granada), Spain (protocol code 2450/CEIH/2021, certificate issued on 11 January 2022).

Informed Consent Statement: Informed consent was obtained from all subjects involved in the study.

Data Availability Statement: The data presented in this study are available on request from the corresponding author due to privacy reasons.

Conflicts of Interest: The author declares no conflicts of interest.

Notes

[1] Some lines of the introduction have been previously published in two reports. See: Mestre Martínez (2023a, 2023b).

[2] "Researcher," "Participant", or "Researcher—Participant" refers to the experiences and roles of the interview partner. "P15", etc., refer to the participation in the current research project. This academic article does not include quotes from experts on research ethics.

References

Adams, Noah, Ruth Pearce, Jaimie Veale, Asa Radix, Danielle Castro, Amrita Sarkar, and Thom Kai Cheng. 2017. Guidance and Ethical Considerations for Undertaking Transgender Health Research and Institutional Review Boards Adjudicating this Research. *Transgend Health* 2: 165–75. [CrossRef] [PubMed]

Amnesty International. 2017. First, Do No Harm: Ensuring the Rights of Children with Variations of Sex Characteristics in Denmark and Germany. Available online: https://www.amnesty.org/en/documents/eur01/6086/2017/en/ (accessed on 17 September 2023).

Bartolo Tabone, Claudia, Fae Garland, and Mitchell Travis. 2024. Cultural Awareness of Intersex in Malta: Invisibility, Stigma and Epistemic Injustice. *Social Sciences* 13: 150. [CrossRef]

Bastien-Charlebois, Janik. 2016. How Medical Discourse Dehumanizes Intersex People. Available online: https://intersexday.org/en/medical-discourse-bastien-charlebois/ (accessed on 12 September 2023).

Bastien-Charlebois, Janik. 2017. Les sujets intersexes peuvent-ils (se) penser? Les empiétements de l'injustice épistémique sur le processus de subjectivation politique des personnes intersex(ué)es. *Socio* 9: 143–62. [CrossRef]

Battaglino, Lorena. 2019. Intersexualidad: Un análisis crítico de las representaciones socioculturales hegemónicas de los cuerpos y las identidades. *Methaodos Revista de Ciencias Sociales* 7: 1. [CrossRef]

Beauchamp, Tom, and James Childress. 2019. *Principles of Biomedical Ethics*, 8th ed. Oxford: Oxford University Press. First published 1979.

Bouman, Walter Pierre, Amets Suess Schwend, Joz Motsman, Adam Smiley, Joshua D. Safer, Madeline B. Deutsch, Noah J. Adams, and Sam Winter. 2017. Language and trans health. *International Journal of Transgenderism* 18: 1–6. First published 2016. [CrossRef]

Braun, Virginia, and Victoria Clarke. 2006. Using Thematic Analysis in Psychology. *Qualitative Research in Psychology* 3: 77–101. [CrossRef]

Cabral Grinspan, Mauro, ed. 2009. *Interdicciones. Escrituras de la Intersexualidad en Castellano*. Córdoba: Anarrés Editorial.

Carpenter, Morgan. 2019. Intersex: Intersectionality, Epistemic Injustice and Structural Violence. Available online: https://morgancarpenter.com/intersectionality-epistemic-structural/ (accessed on 2 February 2023). First published 2014.

Carpenter, Morgan. 2022. Ambivalent Attention and Indeterminate Outcomes: Constructing Intersex and DSD in Australian Data. Available online: https://morgancarpenter.com/wp-content/uploads/2022/05/MNC-publication-version-aihw-paper.pdf (accessed on 19 September 2023).

Carpenter, Morgan, and IHRA (Intersex Human Rights Australia). 2018. Submission to the Australian Human Rights Commission on Protecting the Rights of People Born with Variations in Sex Characteristics in the Context of Medical Interventions. Available online: https://ihra.org.au/wp-content/uploads/2018/09/IHRA-submission-AHRC.pdf (accessed on 27 February 2024).

Coleman, Carl, and Marie-Charlotte Bouësseau. 2008. How Do We Know That Research Ethics Committees Are Really Working? The Neglected Role of Outcomes Assessment in Research Ethics Review. *BMC Medical Ethics* 9: 6. [CrossRef] [PubMed]

Costas Batlle, Ioannis, and Sam Carr. 2021. Trust and Relationships in Qualitative Research. In *Temporality in Qualitative Inquiry: Theories, Methods and Practice*. Edited by Bryan C. Clift, Julie Gore, Stefanie Gustafsson, Sheree Bekker, Ioannis Costas Batlle and Jenny Hatchard. London: Routledge, pp. 158–71.

Davis, Georgiann. 2011. "DSD is a Perfectly Fine Term": Reasserting Medical Authority through a Shift in Intersex Terminology. In *Sociology of Diagnosis. Advances in Medical Sociology, Vol. 12*. Edited by P. J. McGann and David Hutson. Leeds: Emerald Group Publishing Limited, pp. 155–82. [CrossRef]

Dotson, Kristie. 2011. Tracking Epistemic Violence, Tracking Practices of Silencing. *Hypatia* 26: 236–57. [CrossRef]

EC (European Commission). 2021. *Ethics in Social Science and Humanities*. Brussels: EC.

EPATH (European Professional Association for Transgender Health). 2019. Research Policy December 2019. Available online: https://epath.eu/wp-content/uploads/2020/02/EPATH-Research-Policy.pdf (accessed on 25 May 2024).

Fisher, Celia. 1999. Relational Ethics and Research with Vulnerable Populations. In *Reports on Research Involving Persons with Mental Disorders That May Affect Decision-Making Capacity*. Edited by NBAC (National Bioethics Advisory Commission). Rockville: NBAC, pp. 29–40.

FRA (EU Agency for Fundamental Rights). 2015. *The Fundamental Rights Situation of Intersex People*. Vienna: FRA. Available online: https://fra.europa.eu/en/publication/2015/fundamental-rights-situation-intersex-people (accessed on 16 March 2024).

Fricker, Miranda. 2007. *Epistemic Injustice: Power and the Ethics of Knowing*. Oxford: Oxford University Press.

Garland, Fae, and Mitchell Travis. 2020. Queering the queer/non-queer binary: Problematizing the "I" in LGBTI+. In *The Queer Outside the Law: Recognising LGBTIQ People in the United Kingdom*. Edited by Senthorun Raj and Peter Dunne. Cham: Palgrave Macmillan, pp. 165–86.

Garland, Fae, and Mitchell Travis. 2023. *Intersex Embodiment, Legal Frameworks beyond Identity and Disorder*. Bristol: Bristol University Press.

GATE (Global Action for Trans Equality). 2014. Intersex Issues in the International Classification of Diseases: A Revision. Available online: https://gate.ngo/knowledge-portal/publication/intersex-issues-in-icd-document/ (accessed on 4 March 2023).

Ghattas, Dan Christian. 2015. *Standing Up for the Human Rights of Intersex People—How Can You Help?* Berlin: OII Europe. Available online: https://www.oiieurope.org/standing-up-for-the-human-rights-of-intersex-people-how-can-you-help/ (accessed on 12 March 2023).

Holmes, Morgan. 2008. *Intersexuality: A Perilous Difference*. Cranbury: Associated University Press.

Hugman, Richard, Eileen Pittaway, and Linda Bartolomei. 2011. When 'do No Harm' Is Not Enough: The Ethics of Research with Refugees and Other Vulnerable Groups. *British Journal of Social Work* 41: 1271–87. [CrossRef]

interACT (Advocates for Intersex Youth). 2023. InterACT Policy Statement on Participation in Research. Available online: https://interactadvocates.org/interact-policy-on-participation-in-research/ (accessed on 28 August 2023).

International Military Tribunal. 1946. *The Nuremberg Code. Trials of War Criminals before the Nuremberg Military Tribunals under Control Council Law No. 10*; Washington, DC: U.S. Government Printing Office, vol. 2.

ISNA (Intersex Society of North America). n.d. Suggestions for Writing about Intersex. Available online: https://isna.org/node/977/ (accessed on 15 February 2023).

Jones, Charlotte. 2022. 'This Is What I Am and Who I Am': Exploring Authorship and Ethics in Intersex Research and Reflective Diaries. In *Interdisciplinary and Global Perspectives on Intersex*. Edited by Megan Walker. Cham: Palgrave Macmillan Switzerland, pp. 89–105. [CrossRef]

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

Kipnis, Kenneth. 2001. Vulnerability in Research Subjects: A Bioethical Taxonomy. In *Ethical and Policy Issues in Research Involving Human Participants*. Edited by NBAC (National Bioethics Advisory Commission). Bethesda: NBAC, vol. II, pp. G-1–G-13.

Koyama, Emi. n.d. Suggested Guidelines for Non-Intersex Individuals Writing about Intersexuality and Intersex People. Available online: https://isna.org/pdf/writing-guidelines.pdf (accessed on 7 March 2024).

Lundberg, Tove. 2021. Becoming 'Unstuck' Among Positionalities, Terms and Disciplines via Conversation (With Myself) Exploring Potentials for Affective Reflexivity in Critical Intersex Studies. In *The Politics and Ethics of Representation in Qualitative Research. Addressing Moments of Discomfort*. Edited by The Critical Methodologies Collective. London and New York: Routledge, pp. 9–29.

Lundberg, Tove, Peter Hegarty, and Katrina Roen. 2018. Making sense of 'Intersex' and 'DSD': How laypeople understand and use terminology. *Psychology & Sexuality* 9: 161–73. [CrossRef]

Medina, José. 2013. *The Epistemology of Resistance: Gender and Racial Oppression, Epistemic Injustice, and Resistant Imaginations*. Oxford: Oxford University Press.

Merrick, Teri. 2019. From 'Intersex' to 'DSD': A Case of Epistemic Injustice. *Synthese* 196: 4429–47. [CrossRef]

Mestre Martínez, Yessica. 2023a. D5.2.2 Report on review of methodologies and ethical frameworks in recent studies related to intersex issues. In *eReport on Law, Ethics and Human Rights, INIA: Intersex New Interdisciplinary Approaches*. Edited by Tanya Ní Mhuirthile and Amets Suess Schwend. Dublin: DCU, Dublin City University, pp. 14–56. Available online: https://doras.dcu.ie/28680/ (accessed on 7 March 2024).

Mestre Martínez, Yessica. 2023b. D5.2.3 Report providing results of the review of existing ethical principles in intersex studies and related fields. In *eReport on Law, Ethics and Human Rights, INIA: Intersex New Interdisciplinary Approaches*. Edited by Tanya Ní Mhuirthile and Amets Suess Schwend. Dublin: DCU, Dublin City University, pp. 59–81. Available online: https://doras.dcu.ie/28680/ (accessed on 7 March 2024).

Monro, Surya, Morgan Carpenter, Daniela Crocetti, Georgiann Davis, Fae Garland, David Griffiths, Peter Hegarty, Mitchell Travis, Mauro Cabral Grinspan, and Peter Aggleton. 2021. Intersex: Cultural and social perspectives. *Culture, Health & Sexuality* 23: 431–40. [CrossRef]

NBAC (National Bioethics Advisory Commission). 2001. *Ethical and Policy Issues in Research Involving Human Participants: Report and Recommendations of the National Bioethics Advisory Commission*. Bethesda: NBAC, vol. 1.

NNREC (The Norwegian National Research Ethics Committees). 2021. Guidelines for Research Ethics in the Social Sciences and the Humanities. Available online: https://www.forskningsetikk.no/globalassets/dokumenter/4-publikasjoner-som-pdf/guidelines-for-research-ethics-in-the-social-sciences-and-the-humanities.pdf (accessed on 5 March 2023).

OII Europe. 2023. Depath Intersex. Available online: https://campaigns.oiieurope.org/depath/ (accessed on 28 February 2023).

Smith, Rhona. 2018. Human Rights Based Approaches to Research. In *Research Methods in Human Rights*. Edited by Lee McConnell and Rhona Smith. London and New York: Routledge.

Suess Schwend, Amets. 2014. Cuestionamiento de dinámicas de patologización y exclusión discursiva desde perspectivas trans e intersex. *Revista de Estudios Sociales* 49: 128–43. [CrossRef]

Suess Schwend, Amets. 2022. Constructing an Ethics of Depathologization. Epistemological, Methodological and Ethical Reflections in Trans and Intersex Studies. In *Rethinking Transgender Identities. Reflections from Around the Globe*. Edited by Petra L. Doan and Lynda Johnston. London and New York: Routledge, pp. 91–123.

The National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. 1979. *Belmont Report: Ethical Principles and Guidelines for the Protection of Human Subjects of Research*; Washington, DC: Department of Health, Education, and Welfare, United States. Available online: https://www.hhs.gov/ohrp/sites/default/files/the-belmont-report-508c_FINAL.pdf (accessed on 28 February 2023).

United Nations, and Office of the High Commissioner for Human Rights (OHCHR). 2019. *Background Note on Human Rights Violations against Intersex People*. Geneva: OHCHR. Available online: https://www.ohchr.org/en/documents/tools-and-resources/background-note-human-rights-violations-against-intersex-people (accessed on 23 January 2024).

Vincent, Benjamin William. 2018. Studying trans: Recommendations for ethical recruitment and collaboration with transgender participants in academic research. *Psychology & Sexuality* 9: 102–16. [CrossRef]

WMA (World Medical Association). 2013. *Declaration of Helsinki: Ethical Principles for Medical Research Involving Human Subjects*. Ferney-Voltaire: World Medical Association. Available online: https://www.wma.net/policies-post/wma-declaration-of-helsinki-ethical-principles-for-medical-research-involving-human-subjects/ (accessed on 3 March 2023). First published 1964.

Ziemińska, Renata. 2020. The Epistemic Injustice Expressed in 'Normalizing' Surgery on Children with Intersex Traits. *Diametros* 17: 52–65. [CrossRef]

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Tel.: +41 61 683 77 34

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ISBN 978-3-7258-2620-9