



## 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



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## 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](#))<sup>1</sup> and the United Nations ([UN 2019](#)).<sup>2</sup> When referring to previous historical moments or other cultural contexts, I will use the term ‘variations of sex characteristics’.<sup>3</sup>

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),<sup>4</sup> 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.<sup>5</sup> 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.<sup>6</sup> 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’,<sup>7</sup> ‘non-consensual’,<sup>8</sup> and ‘medically unnecessary’,<sup>9</sup> 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.<sup>10</sup> 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,<sup>11</sup> 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”,<sup>12</sup> 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’<sup>13</sup> and ‘pathologization’<sup>14</sup> 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.<sup>15</sup> 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.<sup>16</sup> The three reviewed fields also mention ‘sterilization’,<sup>17</sup> ‘preimplantation genetic diagnosis’, and terms related to prenatal interventions.<sup>18</sup>

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’,<sup>19</sup> ‘bodily autonomy’,<sup>20</sup> ‘self-determination’,<sup>21</sup> and related terms in all three document types. I also found a mention of the ‘right to health’,<sup>22</sup> and ‘health needs’.<sup>23</sup> 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’,<sup>24</sup> as well as the relevance of training.<sup>25</sup> The reviewed documents also refer to ‘informed consent’,<sup>26</sup> ‘right to truth’, ‘right to information’ and ‘access to medical records’.<sup>27</sup> Furthermore, all three document types include concepts such as ‘anti-discrimination’,<sup>28</sup> ‘depathologization’,<sup>29</sup> ‘access to justice’ and ‘reparations, redress, and compensations’,<sup>30</sup> with differentiated frequency according to the field.

The reviewed activist declarations do not mention the term ‘best interest of the child’,<sup>31</sup> 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.<sup>32</sup>

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’.<sup>33</sup>

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’.<sup>34</sup>

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’.<sup>35</sup>

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 “immediately 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 extranjero\*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 body-minds 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 Organizations 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” (Roén 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: médecins, psys, etc.” (“Think

about reversing the focus: don't just study intersex people as objects, but objectivize the dominant ones: medics, psys, etc.", [ReFRI 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 de-

pathologization 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.

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## Notes

- <sup>1</sup> “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).
- <sup>2</sup> “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).
- <sup>3</sup> 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).
- <sup>4</sup> 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.
- <sup>5</sup> 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.
- <sup>6</sup> 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).
- <sup>7</sup> 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.astraeaafoundation.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.astraeaafoundation.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](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(u)ées. *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 Monroe. 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, Giorgiann. 2015. *Contesting Intersex. The Dubious Diagnosis*. New York: New York University Press.
- Davis, Giorgiann, 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, Giorgiann, 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, Giorgiann 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.oii-europe.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](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'. *Hastings 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.oii-europe.org/statement-1st-european-intersex-community-event-vienna-30st-31st-march-2017/> (accessed on 19 April 2024).
- Foucault, Michel. 1972. *The Archeology 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](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](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.oieurope.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. *Athena 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](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](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](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.oieurope.org/malta-declaration/> (accessed on 19 April 2024).
- International Intersex Forum. 2014. *Fourth International Intersex Forum—Media Statement*. Available online: <https://www.oieurope.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](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 Klandermans 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 Società* 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 Publishing, 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.oiiueurope.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. *Crippling 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 Maria, 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](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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