



Intersectional perspectives on poverty, activism, advocacy and community health:

Protecting the human rights of intersex people

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Background and methods

- Own background
- INIA: Intersex – New Interdisciplinary Approaches project, funded by the European Commission (MSCA-ITN 859869)
- Methods: Literature and document review, developed as a work-in-progress project



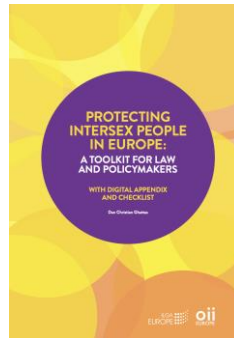
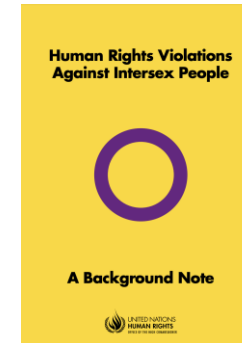
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Intersex people: Current situation

Intersex people

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)



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.
(OII Europe: Ghattas 2019, p. 6)

- DSD, Disorders of Sex Characteristics
- Specific diagnostic codes
- VSC, Variations of Sex Characteristics

Current situation

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- Frequent exposure to non-consensual and not clinically necessary surgical interventions and other treatments during childhood and adolescence
- Frequent impact of early interventions on health and wellbeing
- Lack of access to needed and ongoing health care, specially in adulthood
- Lack of access to medical records
- Situation of discrimination and stigmatization
- Structural inequities in access to education and employment
- Situations of poverty
- Epistemic injustice and lack of recognition of intersex experiences

African Intersex Movement 2017, 2019, 2023; Asian Intersex Movement 2018; Australian and Aotearoa/New Zealand Intersex Community Organisations 2017; European Intersex Meeting 2014; Ghattas 2013, 2015, 2019; Intersex Asia 2023.

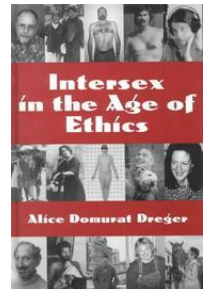
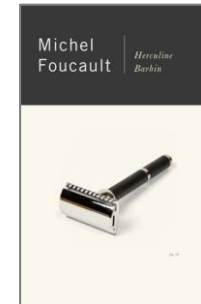
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Historical development: Clinical model



- **Global North**

- ✓ In different historical moments: Persecution and legal regulation
- ✓ From the 19th century on: Clinical gaze and medicalization of intersex bodies
- ✓ From the 1950s on: Model of early surgical intervention
- ✓ 2006: publication of the Chicago Consensus Statement (Update 2016)



- **Global South and East**

- ✓ Situation of cultural recognition and marginalization
- ✓ Colonialist views on diverse bodies
- ✓ Import of Western clinical diagnostic codes and clinical models



Structural inequities and poverty

- Increasing interphobic discrimination and violence
- Child abandonment and infanticide
- Poverty, unemployment and homelessness



Socially intersex persons and their families face extreme social rejection and violence from their communities. Owing to fear of stigmatisation by the community, some parents go the extent of abandoning their children.^[footnote]
(Mamhare et al. 2022, p. 15)



A higher proportion of intersex respondents reported experiencing discrimination, such as when looking for work (31 %) in 2023 than in 2019 (27 %), or when looking for housing to rent or buy in 2023 (28 %) than in 2019 (20 %). (...)
6 % of intersex respondents report having to sleep rough in a public space at least once in their life compared with 0.2 % of the general population.
(FRA 2024, p. 16, 23)

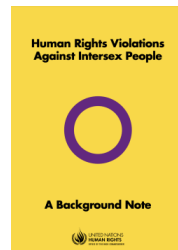
Ghattas 2019; Mamhare et al. 2022; Russel et al. 2023; Singh and Chiu 2020.

Alcántara Zavala 2009; Laura-Inter and Alcántara Zavala 2023; Carpenter 2024; T. Jones et al. 2016; Viera 2023; Zeeman and Aranda 2020.

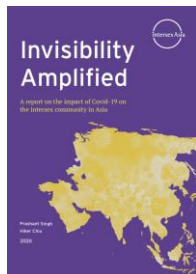
CIDH 2015; Council of Europe 2017; FRA 2015, 2020, 2024; UN 2017, 2019, 2023.

Structural inequities and poverty

- Impact of early surgeries and discrimination on educational and employment opportunities
- Inequities in the access to health care
- Impact of the COVID-19 pandemic on social vulnerabilities



The available data show that intersex people may have high rates of poverty, associated with high rates of early school leaving, stigmatization and discrimination.
(UN 2019, p. 38)



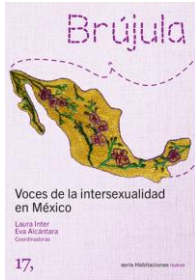
Even in the best of times, intersex people face legal and social vulnerabilities in areas such as employment, education, healthcare, housing, etc.^[footnote]
With Covid-19, people who were already part of a marginalized group find it even more difficult to cope with the situation, and this, in turn, affects their livelihood.
(Singh and Chiu 2020, p. 6)

Ghattas 2019; Mamhare et al. 2022; Russel et al. 2023; Singh and Chiu 2020.

Alcántara Zavala 2009; Laura-Inter and Alcántara Zavala 2023; Carpenter 2024; T. Jones et al. 2016; Viera 2023; Zeeman and Aranda 2020.

CIDH 2015; Council of Europe 2017; FRA 2015, 2020, 2024; UN 2017, 2019, 2023.

Structural inequities and poverty



- **Intersex people in rural and socially disadvantaged areas**

- ✓ Reduced exposure to non-consensual surgeries
- ✓ Lack of access to general health care services
- ✓ Health risks due to a lack of access to needed health care
- ✓ Difficulties to access support and activist groups



- **Intersectionality perspective and social determinants of health approach**



Ghattas 2019; Mamhare et al. 2022; Russel et al. 2023; Singh and Chiu 2020.

Alcántara Zavala 2009; Jenkins and Short 2017; Laura-Inter and Alcántara Zavala 2023; Suess-Schwend 2014; Viera 2023.

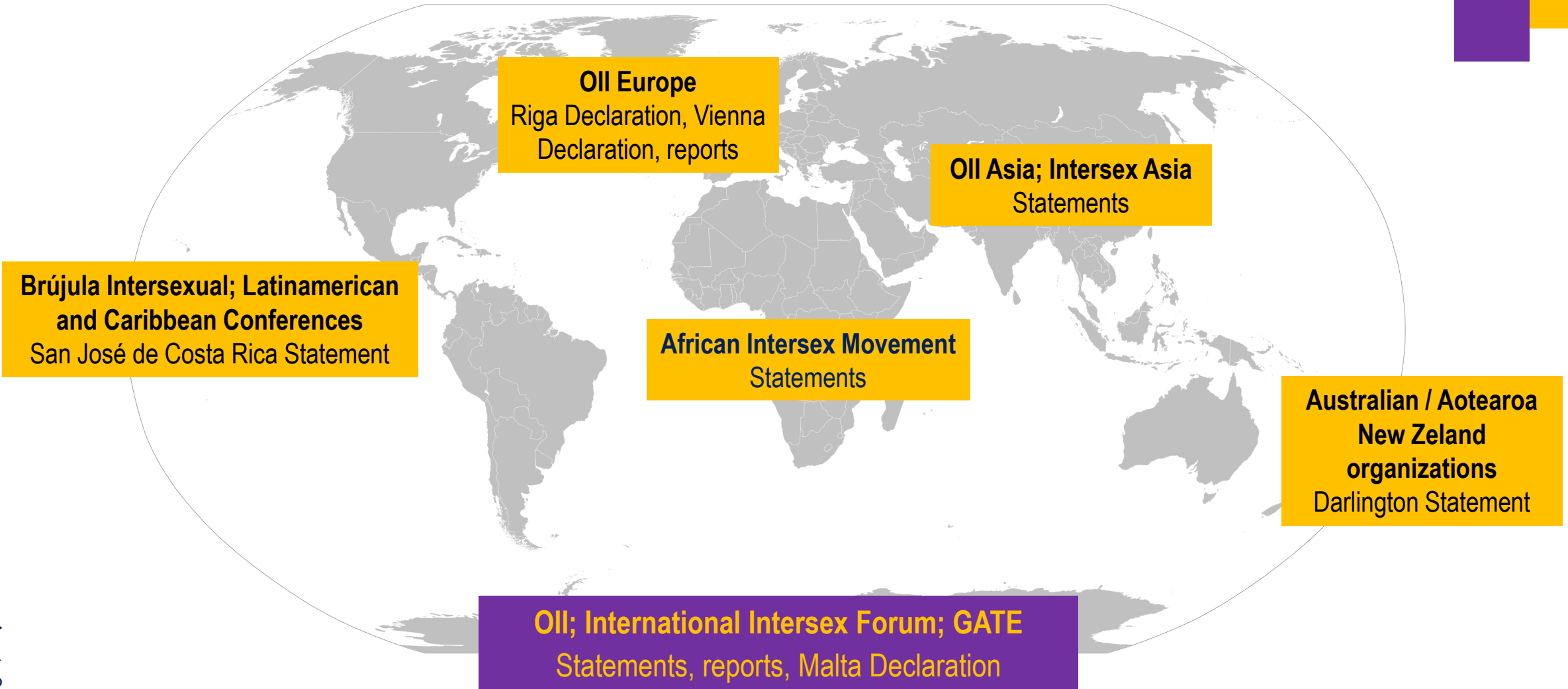
FRA 2020, 2024.

Intersex activism

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- **Since 1980:** Local and regional intersex support and activist groups
- **Over the last decade**
 - ✓ Emergence of international and regional networks
 - ✓ International and regional declarations
 - ✓ Lobbying activities in international and regional human rights bodies
- **Analyses from social movement theories, human rights and depathologization perspectives**

Intersex activism



African Intersex Movement 2017, 2019, 2023; Asian Intersex Movement 2018; Astraea Lesbian Foundation for Justice 2016; Australian and Aotearoa/New Zealand Intersex Community Organisations 2017; Conferencia Regional Latinoamericana y del Caribe de Personas Intersex 2018; European Intersex Meeting 2014; First European Intersex Community Event 2017; GATE 2015, 2017; GATE et al. 2019; International Intersex Forum 2011, 2012, 2013, 2014; Intersex Asia 2023; Iranti-org 2016; OII s.a.; OII Europe 2023.

Source of the image: Wikimedia Commons. 2006. BlankMap-World.svg. <https://commons.wikimedia.org/wiki/File:BlankMap-World.svg>

Intersex activism

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- **Main demands**
 - ✓ Cessation of non-consensual surgeries and other treatments
 - ✓ Cessation of preimplantation genetic diagnosis, infanticide and non-consensual sterilization
 - ✓ Access to medical records
 - ✓ Access to needed health care
 - ✓ Depathologization of terminologies in the ICD, International Classification of Diseases
 - ✓ Birth registration and opportunities to modify the legal sex/gender, abolition of sex/gender markers in identification documents
 - ✓ Access to justice, reparation and redress
 - ✓ Support spaces

Human rights framework

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- **Over the last decade:**
 - ✓ Inclusion of intersex issues in the agenda of international and regional human rights bodies
 - ✓ Reports, recommendations and resolutions
- **Analyses from human rights and legal perspectives**

Human rights framework



Recent developments



- UN resolution 2024
- Laws prohibiting non-consensual and not clinically necessary surgeries on intersex children
- Human rights-based health care models

- Inclusion of the term 'Disorders of Sex Development' in the ICD-11
- Continued clinical practices based on early surgical interventions

Recent developments



- **Good practice maps 2022 and 2023 – OII Europe**
 - ✓ Legal ban of non-consensual and not clinically necessary surgeries
 - ✓ Legal protection against hate crime and speech
 - ✓ Human rights-based research
 - ✓ Awareness raising
 - ✓ Arts and culture
 - ✓ Training for midwives

[Good Practice Map 2022](#)

[Good Practice Map 2023](#)



Community health: Recommendations and strategies

Recommendations and strategies

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- Health needs
- Rights to health, bodily integrity and autonomy, truth, informed consent and protection from discrimination
- Access to necessary and adequate health care (ongoing, affirmative, human rights-based, depathologizing, people-centered, agency-based, community-owned and trauma-informed)
- Access to psychosocial and peer support
- Professional training from human rights and depathologization perspectives

African Intersex Movement 2017, 2019, 2023; Asian Intersex Movement 2018; Astraea Lesbian Foundation for Justice 2016; Australian and Aotearoa/New Zealand Intersex Community Organisations 2017; Conferencia Regional Latinoamericana y del Caribe de Personas Intersex 2018; European Intersex Meeting 2014; First European Intersex Community Event 2017; GATE 2015, 2017; GATE et al. 2019; International Intersex Forum 2011, 2012, 2013, 2014; Intersex Asia 2023; Iranti-org 2016; OII Europe 2023, 2024[2018].

ACHPR 2023; Council of Europe 2013, 2015, 2017; EC 2012; European Parliament 2019; FRA 2015, 2020; IACHR 2015, 2016, 2020, 2023; UN 2017, 2019, 2023, 2024; UN et al. 2016.

Amos et al. 2022; Bastien-Charlebois and Guilot 2018; Bauer et al. 2020; Berry and Monro 2022; Cabral Grinspan 2022; Cabral Grinspan and Carpenter 2018; Cabral Grinspan and Carpenter 2018; Carpenter 2016, 2018a, 2018b, 2020, 2024; Carpenter and Jordens 2020; Crocetti et al. 2020a, 2020b, 2024[2023]; Frank 2018; García López 2015, 2018; Ghattas 2013; Gregori Flor et al. 2018; Haghghat et al. 2023; Hart and Shakespeare-Finch 2022; Lewis 2022; lisahunter et al. 2022; Lovry 2018; Machado 2008; Meoded Danon and Schweizer 2020; Pikramenou 2019; Rajam and Banerjee 2022; Roen et al. 2023; Suess-Schwend 2014, 2020, 2021, 2022, 2023a, 2023b, 2024; Swarr 2023; Woweries 2018.

Recommendations and strategies

The title is centered at the top. Below it are two horizontal lines, one purple and one yellow. To the right of the title area, there are two overlapping squares: a yellow one on top and a purple one on the bottom.

- **Role of community health**
 - ✓ Providing ongoing health care
 - ✓ Taking into account the social and cultural context
 - ✓ Providing non-pathologizing counseling for intersex people and families
 - ✓ Offering information regarding sexual and reproductive health
 - ✓ Conducting health education based on a recognition of bodily diversity
 - ✓ Collaborating with intersex groups in the development of guidelines and good practices

Recommendations and strategies



- Prioritize bodily integrity and autonomy and ensure informed consent
- Use respectful and non-pathologizing language
- Respect and recognize names and pronouns
- Provide non-pathologizing information, counseling and support
- Use a trauma-informed approach
- Avoid gendered language about bodily characteristics
- Offer contact information about intersex groups
- Develop human rights-based and collaborative research practices
- Reflect critically on own biases and knowledge gaps
- Support the human rights protection of intersex people



Conclusions

Conclusions



- Exposure of intersex people to non-consensual and not clinically necessary interventions, discrimination, social inequities and poverty worldwide
- Relevance of intersex advocacy and activism
- Support of international and regional human rights bodies
- Relevant role of community health
- Social transformation
 - ✓ Respect, recognition and celebration of bodily diversity
 - ✓ Right to bodily integrity and autonomy

References

For references please see

Suess-Schwend, Amets. 2024. Intersex Epistemologies? Reviewing Relevant Perspectives in Intersex Studies. *Social Sciences* 13(5): 298. doi: 10.3390/socsci13060298.

Some specific readings related to structural inequities, poverty, intersectionality and community health

Akhtar, Anis, Paul Dutton, Sara Gillingham, Charlotte Jones, Rachel Purtell, Magda Rakita, et al. 2022. *Fertility, relationships and intimacy. A guide to offering support to an adult with a variation in sex characteristics*. Exeter: University of Exeter, Wellcome Centre Cultures + Environments of Health, ReproFutures.

Alcántara Zavala, Eva. 2009. Pobreza y condición intersexual en México: reflexiones y preguntas en torno al dispositivo médico. Edited by Mauro Cabral Grinspan. *Interdicciones. Escrituras de la intersexualidad en castellano*. Córdoba, Argentina: Anarrás Editorial, pp. 16-30.

Berry, Adeline W., and Surya Monro. 2022. Ageing in obscurity: A critical literature review regarding older intersex people. *Sexual and Reproductive Health Matters* 30: 2136027. doi: 10.1080/26410397.2022.2136027.

Cabral Grinspan, Mauro. *Interdicciones. Escrituras de la intersexualidad en castellano*. Córdoba, Argentina: Anarrás Editorial.

Carpenter, Morgan. 2021. *Health and wellbeing*. IHRA, Intersex Human Rights Australia.

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

Crocetti, Daniela, Adeline Berry, and Surya Monro. 2024[2023]. Navigating the complexities of adult healthcare for individuals with variations of sex characteristics: From paediatric emergencies to a sense of abandonment. *Culture, Health & Sexuality* 26: 332–45. doi: 10.1080/13691058.2023.2208194. First published 2023.

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. doi: 10.1111/1467-9566.13072.

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. doi: 10.1080/13691058.2020.1825815.

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.

FRA, European Union Agency for Fundamental Rights. 2024. *LGBTIQ at a crossroads: progress and challenges*. Luxembourg: Publications Office of the European Union.

Ghattas, Dan Christian. 2016. *Standing up for the human rights of intersex people*. Berlin, Brussels: OII Europe, and ILGA Europe.

References



- Ghattas, Dan Christian. 2019. *Protecting intersex people in Europe: a toolkit for law and policymakers*. Berlin: OII Europe, 2019.
- 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. doi: 10.1016/j.socscimed.2023.116047.
- IGLYO, OII Europe, and EPA. 2018. *Supporting your intersex child*. Brussels, Berlin: IGLYO, OII Europe, and EPA.
- Intersex Asia, Prashant Singh, and Hiker Chiu. 2020. *Invisibility Amplified. A report on the impact of Covid-19 on the intersex community in Asia*. Intersex Asia.
- interAct, and Lambda Legal. 2018. *Providing Ethical and Compassionate Health Care to Intersex Patients. Intersex-Affirming Hospital Policies*.
- Jones, Charlotte, Anis Akhtar, Paul Dutton, Sara Gillingham, Rachel Purtell, Magda Rakita, et al. 2022a. *Supporting the reproductive and psychosocial needs of people with variations in sex characteristics. Reprofutures final project report*. Exeter: University of Exeter, Wellcome Centre Cultures + Environments of Health, Reprofutures.
- Jones, Charlotte, Anis Akhtar, Paul Dutton, Sara Gillingham, Rachel Purtell, Magda Rakita, et al. 2022b. *Supporting the reproductive and psychosocial needs of people with variations in sex characteristics. Policy and practice recommendations*. Exeter: University of Exeter, Wellcome Centre Cultures + Environments of Health, Reprofutures, 2022b.
- Jones, Tiffany, Bonnie Hart, Morgan Carpenter, Gavi Ansara, William Leonard, y Jayne Lucke. 2016. *Intersex: stories and statistics from Australia*. Cambridge: Open Book Publisher.
- OII Europe. 2023. *Good Practice Map 2022*. <https://www.oieurope.org/good-practice-map-2022/>
- OII Europe. 2024. *Good Practice Map 2023*. <https://www.oieurope.org/good-practice-map-2023/>
- Russell, Cianán B., Irene Amoroso, Jana Hugo, Ins A. Kromminga. 2023. *Intersections. Diving into the FRA LGBTI II Survey Data. Intersex Briefing*. Berlin, Brussels: OII Europe, ILGA Europe.
- Mamhare, Tapiwa. 2022. *Study on the human rights situation of intersex persons in Africa*. Pretoria: University of Pretoria, Centre for Human Rights.
- Swarr, Amanda Lock. 2023. *Envisioning African Intersex. Challenging Colonial and Racist Legacies in South African Medicine*. Durham: Duke University Press.
- 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.
- UNDP, United Nations Development Programme, and Intersex Society of Zambia. 2023. *Being Intersex in Zambia. A Legal and Policy Review*. New York, Lusaka: UNDP, Intersex Society of Zambia, 2023.
- Viera, Amiel Modesto. 2023. Trilhas para a Intersexofobia. *Caderno Espaço Feminino* 36: 110–137. doi: 10.14393/CEF-v36n1-2023-7.
- Viera, Amiel Modesto, Anacely Guimarães Costa, Barbara Gomes Pires, and Marina Cortez. 2021. Intersexualidade: desafios de gênero. *Periódicus* 16: 01-20.
- Zeeman, Laetitia, and Kay Aranda. 2020. A Systematic Review of the Health and Healthcare Inequalities for People with Intersex Variance. *Int J Environ Res Public Health* 18:6533. doi: 10.3390/ijerph17186533.

Thank you and questions



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