

APPENDIX II

THE STATE OF INTERSEX ORGANIZING

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GLOBAL
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PROJECT





APPENDIX II. STATE OF INTERSEX ORGANIZING CASE STUDIES

CASE STUDY 1

United Nations Intersex Resolution

On April 4, 2024, the Human Rights Council (HRC) at the United Nations in Geneva adopted a resolution calling its member states “to enhance efforts to combat discrimination, violence and harmful practices against intersex people” and “to address the root causes, such as stereotypes, spread of misconceptions and inaccurate information, stigma, and taboo.” This was the first time in history that intersex issues were explicitly addressed in an HRC resolution, and the resolution’s depathologizing language on variations of sex characteristics represented a major victory for intersex activists worldwide.

Intersex activists had started their engagement with the UN 20 years before; it took those long two decades of relentless advocacy to move intersex issues from civil society spaces to a positive resolution within the international human rights system.

Over those 20 years, intersex activists organized to overcome significant obstacles, including the widespread lack of knowledge about intersex issues among many UN agencies, mechanisms, and experts, as well as among many diplomatic missions. They had to overcome the generalized assumption that intersex issues were “naturally” represented in absentia by LGBTI and other human rights organizations. And they had to overcome the structural lack of funding to fully support their meaningful engagement, including, for example, travel costs. Overcoming those obstacles required intersex activists to combine several strategies: the constant elaboration of tailored briefings, glossaries, and trainings; the sustained expansion of collaboration across world regions; the construction of strong intersectional coalitions; the dedication to an unfunded program of work on top of their paid jobs inside or outside intersex activism; and the affirmation of their right to represent themselves in all international forums.

Intersex activists have been quite successful at reporting to UN Treaty Bodies, including the Committee on the Elimination of Discrimination Against Women (CEDAW), the Human Rights

Committee (HRC), the Committee on Economic, Social and Cultural Rights (CESCR), the Committee on the Rights of the Child (CRC), the Committee Against Torture (CAT), and the Committee on the Rights of Persons with Disabilities (CRPD) among others. As a result, those mechanisms have issued more than 500 observations, expressions of concern, and recommendations to states addressing human rights violations perpetrated against intersex people. Moreover, intersex in-person and virtual engagement with Treaty Bodies have decisively contributed to identifying those abuses as “harmful practices” and put into question its root causes and consequences.

Growing over the years, intersex advocacy with the UN Office of the High Commissioner for Human Rights (OHCHR) resulted in substantive achievements—starting with the 2015 Intersex Fact Sheet produced by Free & Equal, which has become a key resource in the introduction of intersex issues in the United Nations. In 2015, OHCHR organized the first Expert Meeting on Intersex Issues, in Geneva, including a delegation of activists from different regions. Afterward, OHCHR released a comprehensive report titled *Background Note on Human Rights Violations Against Intersex People*. In 2023, OHCHR released its *Technical Note on Human Rights of Intersex People: Human Rights Standards and Best Practices*.

The introduction and articulation of intersex issues at the United Nations has required activists to explore different conceptual and normative frameworks. For example, intersex issues have been addressed in the context of the protection against medical abuses, in the context of the protection against torture or cruel treatment, and in the context of violence against women. Intersex activists have also established the connection between intersex “normalizing” interventions and gender stereotypes, homophobia, lesbophobia, transphobia, genital mutilation, ableism, and racism. In 2017, the *Yogyakarta Principles Plus 10* made a decisive contribution to mainstream the notion of “sex characteristics;” since then, the UN has become increasingly open to addressing human rights violations against intersex people based on their “sex characteristics” to identify sex characteristics as a ground for specific protections, and to depathologize its understanding of intersex people, defining them as “people born with variations of sex characteristics.”

The HRC Resolution passed in April 2024 includes several follow-up steps, and all of them will require intersex activists to participate in providing technical support and political leadership to the process. While the 20 years of intersex organizing at the UN have built a diverse, expert, and committed movement, access to funding for international work remains a challenging obstacle, and the same goes for autonomous intersex access to the UN. To date, no intersex organization has obtained ECOSOC status.

Additional information

- ILGA World Database. database.ilga.org
- Resolution *Combating discrimination, violence and harmful practices against intersex persons*. A/HRC/55/L.9, 21 March 2024. documents.un.org/doc/undoc/ltd/g24/048/06/pdf/g2404806.pdf
- *Yogyakarta Principles (2007) and Yogyakarta Principles Plus 10 (2017)*: yogyakartaprinciples.org
- OHCHR (2023) *Technical Note on Human Rights of Intersex People: Human Rights Standards and Best Practices*.
- ECOSOC Status: Civil society organizations (CSOs) interested in participating in the work of the UN can apply to the Economic and Social Council (ECOSOC) to get their official accreditation (or ECOSOC status). It can be a long and difficult process, as applications can be deferred for several years due to the action of states opposing the application. CSOs without ECOSOC status depend on accredited allies to fully engage with the UN.

CASE STUDY 2

Building and Mobilizing Knowledge

In 1993, an intersex activist from the United States submitted a letter to *The Sciences*. The journal had published an article by biologist Anne Fausto Sterling titled “The Five Sexes,” which critically addressed medical dogmas on intersexuality. The respondent was Cheryl Chase, the pen name of Bo Laurent and founder of the Intersex Society of North America (ISNA). Her letter provided insider knowledge on intersex experiences and encouraged intersexual people to reach out to ISNA, where they were “assembling a support group and documenting our lives.” This intervention went around the world and started a global movement.

Since those very beginnings, intersex activists have been committed to building and mobilizing knowledge in deeply transformational ways—from collecting data and producing solid analysis on intersex communities and the issues affecting them to designing tool kits and guidelines for policymakers; from mapping laws and regulations to expanding social understanding of intersex people, bodies, and lives; from initiating conversations into their own language to translating intersex words into multiple languages; from providing guidance for adequate support to documenting intersex histories for posterity.

The Organisation Intersex International Europe (OII Europe), founded in 2012, has produced multiple resources for diverse audiences over more than a decade. For example, the different tool kits produced by OII Europe are respectively aimed at parents of intersex children and youth, intersex asylum seekers and refugees, legislators, policymakers, and allies. The network has also put together a detailed map identifying bans on intersex genital mutilation (IGM) and a curated list of indicators to identify good medical practices. During and after the pandemic of COVID-19, OII Europe produced a comprehensive report about intersex people in Europe and Central Asia and a 2022 follow-up survey. Operating in a multilingual region, ensuring access to information in different languages becomes a key political issue; on its website, OII Europe includes materials translated into 12 languages.

Intersex Asia, founded in 2018, has made critical contributions to increasing global knowledge about intersex people in the region. The network published the report *Invisibility Amplified: A report on the impact of COVID-19 on intersex people in Asia*, offering a detailed account of the pandemic and its consequences among intersex communities. More recently, Intersex Asia published four reports, respectively, focused on the state of intersex people's human rights in India, Bangladesh, Nepal, and Pakistan.⁴³

Intersex organizations working at the national level also dedicate their resources and efforts to building and mobilizing knowledge. Founded in 2013, *Brújula Intersexual* (BI) is a knowledge-building powerhouse. Based in México, BI has radically contributed to increasing the production and circulation of information on intersex issues in the Spanish-speaking world. Their approach includes the systematic translation of key documents from English to Spanish, giving many intersex activists in Latin America, Spain, and other regions of the world a real opportunity to keep track of global conversations. It also includes providing Spanish-speaking intersex people (as well as family members and allies) a digital platform to share their experiences, perspectives, and expectations. BI has also led and/or participated in the elaboration of guidelines focused on specific issues and has recently published the book *Brújula: Voces de la intersexualidad en México*, which includes more than 30 contributions.⁴⁴

Intersex Human Rights Australia (IHRA), founded in 2009, has published informative and analytic briefings on a wide range of issues (such as COVID-19, demographics, and intersectionality), guidance for data collection, and research and clinical guidelines. Since 2019, IHRA has also hosted and supported the periodic publication *YOUth&I*, which shares stories written by young intersex people.⁴⁵

43 intersexasia.org/resources/publications

44 diecisiete.org/portadas/brujula-voces-de-la-intersexualidad-en-mexico

45 youthandi.org

Created in 2020, the Consortium INIA—New Interdisciplinary Approaches—supported 10 early-stage researchers in obtaining a doctorate focusing on intersex issues; several of those researchers were also intersex activists themselves. Additionally, an advisory board integrated by senior intersex activists contributed to the synergy between academic and advocacy goals.

By including sex characteristics in its global map, ILGA World made a key contribution to expanding global knowledge on intersex issues. The same can be said of the publication of ILGA World’s groundbreaking *Intersex Legal Mapping Report* (2023), presenting the outcomes of a global survey on legal protections for people born with variations of sex characteristics.⁴⁶

Since Cheryl Chase’s letter to *The Sciences*, intersex activists have built undeniable expertise not only on intersex issues but also in many different strategies to build and mobilize knowledge about them, such as technical and creative writing, conceptual analysis, visual communications, translation, and trainings both in-person and virtual. While their role as producers of knowledge is still frequently diminished, ignored, or denied due to pervasive endosexism, intersex activists remain steadfast in their belief in the power of their individual and collective knowledge to transform the world.

Additional Information

- Brújula Intersexual. brujulaintersexual.org
- ILGA World. ilga.org
- Intersex Asia. intersexasia.org
- Intersex Human Rights Australia (IHRA). ihra.org.au
- Intersex New Interdisciplinary Approaches (INIA). intersexnew.co.uk
- Intersex Society of North America. isna.org
- OII Europe. oiieurope.org
- Endosexism is the “system of beliefs, attitudes, and structures that claim that being endosex is better, more natural, more normal, and more common than being intersex. Endosexism erases and stigmatizes intersex people.”
Source: plannedparenthoodaction.org/glossary

46 ilga.org/intersex-legal-mapping-report

CASE STUDY 3

An International Movement

Intersex activism has usually started small. Sometimes, it has started with just one intersex person telling their story to a journalist, sharing information on social media, or joining a Pride demonstration with an intersex flag. Many times, intersex activism has remained small for a long time; countries and even regions have depended on just a few people to build an entire movement. One of the key components of these individuals' success in expanding their impact has been their capacity to meet and work with other intersex activists at national, regional, and international convenings.

Between 2011 and 2015, the movement convened in four international intersex forums (IIF) in Brussels, Stockholm, Malta, and The Netherlands. The *Malta Declaration* was produced at the 2013 IIF, and it is still recognized as the foundational text for the intersex movement at the global level. Since then, a series of regional convenings and documents have contributed to building the movement forward.

Intersex organizations and activists from Australia and Aotearoa/New Zealand met for the first time in 2017 and adopted a joint consensus statement called the *Darlington Statement*. It was reaffirmed in 2018 during the second Australian-Aotearoa/New Zealand intersex retreat. A third Darlington retreat expanded the movement's reach in the region, recognizing its intrinsic intersectionality by supporting the Uluru Statements from the Heart, the *Yogyakarta Principles Plus 10*, and the *Canberra Statement* on forcibly displaced persons. The signers of the *Darlington Statement* became a consortium, bringing together intersex-led organizations, their allies, and community members engaged in implementing the *Statement*. Since 2021, the consortium has awarded "The Darling" award for intersex allies—received by the Queensland Council for LGBTI Health (2021), Working it Out (2022), and the Office of LGBTIQA+ Affairs at the Australian Capital Territory (2023).

In Latin America, the movement had its first regional meeting in Costa Rica in 2018; at that convening, activists adopted the *Declaration of San José de Costa Rica*. In 2020, just before the COVID-19 pandemic shutdown, the Latin American movement met in Buenos Aires for its second regional meeting.

In Europe, the first community event organized by OII Europe in 2017 adopted the *Vienna Statement*. The movement also met in Zagreb in 2019 and Paris in 2023, including for the first time several intersex families.

The first African intersex meeting occurred in South Africa in 2017; activists gathered there and produced the *Public Statement of the African Intersex Movement*. Over that foundation, a second meeting took place in Kenya, and in that context, the regional network African Intersex Movement was created.

In Asia, the first Asian intersex Forum was held in Thailand in 2018; the activists who gathered there produced a *Public Statement* and announced the creation of Intersex Asia.

The different declarations and statements collectively elaborated by intersex activists share similar calls to ban “normalizing” interventions, change standards of care and medical protocols, and provide adequate information and support to intersex people and their families. These documents also addressed specific needs and challenges faced by intersex communities in each region and built their demands on regional commitments to human rights. Both their similarities and differences illuminate the reality of a truly global movement, able to articulate universal perspectives and specific local calls for justice.

Despite their success, intersex convenings are still rare due to the extreme scarcity of funds available to afford them. Intersex activists have continued building their movement by engaging actively with regional and international conferences organized by endosex-led organizations. For example, intersex pre-conferences at ILGA World and regional ILGA conferences have become a key opportunity for activists to meet, share, analyze information, and build collective strategies. Other international convenings, such as Outright International Summits, AWID Forums, International AIDS Conferences, and WPATH Symposiums, provide additional key meeting opportunities. However, participation in all these spaces still depends on very limited access to grant funding.

Over the past few years, international LGBTIQ+ organizations have opened dedicated positions to address intersex issues. ILGA World, for example, counts on a program officer position focused exclusively on sex characteristics. Outright International initiated a senior advisor position focused on global intersex rights in 2023. Continuing the work initiated by GATE in 2014, a new global initiative focused on intersex depathologization was launched in 2024 under the coordination of Intersex Human Rights Australia.

Additional Information

- *Darlington Statement* (2017). darlington.org.au
- *Declaration of San José de Costa Rica* (2018). intersexday.org/en/san-jose-costa-rica-statement

- The Darling (2023). darlington.org.au/category/the-darling
- GATE (2018). gate.ngo/knowledge-portal/article/intersex-variations-human-rights-the-icd
- ILGA World. ilga.org/gender-identity-gender-expression-sex-characteristics
- IHRA (2024). ihra.org.au/40714/welcoming-mauro-cabral-grinspan
- *Malta Declaration* (2013). oiiurope.org/malta-declaration
- Outright (2023). outrightinternational.org/insights/welcome-kimberly-zieselmann
- *Public Statement of the African Intersex Movement* (2019). transintersexhistory.africa/june-2019-the-birth-of-the-african-intersex-movement-aim-kenya
- *Public Statement Intersex Asia* (2023). intersexasia.org/resources/publications/asian-intersex-statement
- *Vienna Statement* (2017). oiiurope.org/statement-1st-european-intersex-community-event-vienna-30st-31st-march-2017

CASE STUDY 4

Building and Mobilizing Knowledge on Anti-Gender Movements

Intersex people have been consistently medicalized since the 19th century. In other words, their very existence has been assumed as “naturally” belonging to medicine. In some cases, intersex medicalization has been produced by scientific institutions in some Global North and West countries; in many others, it was imposed by colonialism and imperialism around the world. One of the most pervasive consequences of intersex medicalization has been the widespread understanding of “normalizing” interventions as acceptable medical treatments for innate variations of sex characteristics. Such acceptance becomes evident when comparing massive outrage against practices such as female genital mutilation (FGM), discussed as rooted in “irrational” and “traditional” beliefs, with the equally massive indifference when it comes to being about practices such as intersex genital mutilation (IGM), as rooted in medicine as a “rational” and “modern” system.

Since its inception, the intersex movement has focused on identifying, addressing, denouncing, and dismantling both medicalization and its consequences in individual and collective

life—from the medical classifications, protocols, and treatments aimed to “normalize” innate variations of sex characteristics to the seemingly uncontested capacity of medicine to operate beyond human rights standards. However, the goal of emancipating intersex lives also required intersex activists to focus on another key area of social and institutional life: the law.

Advocacy focused on legal reform has required drastically increased intersex organizing in different areas: following and engaging with legislative work, monitoring electoral processes, building the capacity of law and policymakers, identifying and mobilizing allies, and engaging in effective coalition-building. It has also required activists to develop their expertise on legal issues, including informed consent, parental rights, and medical practice regulations.

Malta was the first country in the world to pass a law banning interventions performed on intersex people without a clear medical necessity. The Maltese *Gender Identity, Gender Expression and Sex Characteristics Act*, passed in 2015, opened the door for change in several other countries, where intersex activists and their allies organized toward legal reform.

In 2018, Portugal passed its *Law on the Right to Self-Determination of Gender Identity and Gender Expression and Protection of Everyone’s Sex Characteristics*; in 2020, Iceland passed its Law 154, amending the *Law on Sexual Anatomy*; in 2021, Germany adopted the *Law on the Protection of Children with Variants of Sex Development*; in 2022, Greece adopted the *Law on Medically Assisted Reproduction Reforms*; also in 2022, Kenya adopted the *Children Act*; in 2023 Spain passed the *Law for the Full and Effective Equality of Transgender People and for the Guarantee of LGBTI Rights*; in 2023, the Capital Territory of Australia passed the *Variations in Sex Characteristics (Restricted Medical Treatment) Bill*.

Intersex activists and their allies have also brought issues of innate variations of sex characteristics to strategic litigation processes. In Canada, for example, EGALE and several intersex plaintiffs filed an application in 2021 at the Ontario Superior Court of Justice, challenging the constitutionality of exceptions in the Criminal Code. Such exceptions permit “normalizing” aesthetic surgeries on intersex infants and children and “violate Charter-protected rights to liberty, security of the person, equality, and freedom from cruel and unusual treatment.” In India, the Srishti Madurai Educational Research Foundation approached the Delhi High Court in 2021, requesting a ban on “normalizing” surgeries; in 2022, the Court ordered the Delhi government to ban medical interventions on intersex infants except in life-threatening situations. In 2023, in Belgium, the Brussels Court of Appeals ruled against the Children’s

Hospital Queen Fabiola in a case of a 2010 nonconsensual surgery performed on an intersex teen.

Advances have also been made through administrative procedures; for example, that has been the case of the ministries of health of Albania, Chile, and Brazil. In other cases, governmental agencies and congressional bodies have called for legal reform; that has been the case, for example, in Austria (Equal Treatment Committee and National Council, 2021) and Belgium (House of Representatives, 2021).

While legislative, judicial, and administrative reforms are contributing to increasing legal protections for intersex people, more work is needed. More work is necessary, for example, to repeal regressive laws allowing “normalizing interventions” and to address and solve protection gaps affecting people born with certain sex characteristics excluded from otherwise progressive laws and policies. It is necessary to ensure that those laws and policies are properly implemented by monitoring and evaluating their implementation. It is also necessary to expand legal frameworks to enable them to address not only intersex issues in the present and the future but also in the past. That is the case, for example, with the *Bill on the Comprehensive Protection of Sex Characteristics* in Argentina and its call for the establishment of a truth commission to investigate human rights violations against intersex people in the country, allow victims’ access to reparations, and ensure that abuses perpetrated in the past are remembered by all and never repeated.

Additional information

- ILGA World Maps (2024). ilga.org/ilga-world-maps
- ILGA (2023) *Intersex Legal Mapping Report*. ilga.org/intersex-legal-mapping-report
- IGM (2023). oieurope.org/igm
- SHRM (2019) The right to truth for intersex people. srhm.org/news/the-right-to-truth-and-intersex-people