



Astraea LESBIAN FOUNDATION FOR JUSTICE

WE ARE REAL

The Growing Movement
Advancing the Human Rights
of Intersex People



Acknowledgements

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Astraea Lesbian Foundation for Justice is the only philanthropic organization working exclusively to advance LGBTQI human rights around the globe. We support grantee partners in the U.S. and internationally who challenge oppression and seed social change. We work for racial, economic, social, and gender justice, because we all deserve to live our lives freely, without fear, and with dignity.

Astraea's **Intersex Human Rights Fund** supports organizations, projects and campaigns led by intersex activists working to ensure the human rights, bodily autonomy, physical integrity and self-determination of intersex people worldwide. The Intersex Fund responds to the significant gap in funding for intersex issues by resourcing intersex-led activism, building the capacity of intersex groups, raising visibility about intersex human rights, and driving resources to the intersex movement.

FORWARD FROM THE INTERSEX HUMAN RIGHTS FUND ADVISORY BOARD

Thank you for taking the time to read this report. Inside, you will discover the amazing work being done by intersex activists around the globe.

For many years, we have worked tirelessly to confront the violence, discrimination and stigma that often surrounds intersex children and adults. We have dedicated many hours, often for free, to be there for our peers, to build organizations and networks, to provide advice and support to parents, to confront and educate doctors, to advocate before national, regional and international institutions, and to forge and expand alliances with other movements.

We have been at the frontlines telling our stories at a time when no one would listen to them and showing our scars at places where no one would see them. We have created pieces of art that have expanded cultural boundaries, and have produced critical and transformative knowledge that is changing the landscape of intersex rights for good.

This Fund is partnering with intersex activists around the world to support our goals, our work, and our visibility—to support us.

With funding from seed donors Kobi Conaway and Andrew Owen, the Arcus Foundation and other private donors, the Astraea Intersex Human Rights Fund is facilitating the growth of the intersex movement worldwide.

Join us in building a bright and dynamic intersex future.

Mauro Cabral	Natasha Jiménez
Morgan Carpenter	Nthabiseng
Hiker Chiu	Mokoena
Dan Christian	Sean Saifa Wall
Ghattas	

FRIENDS,

Worldwide, we find ourselves in a moment of increased visibility and rights for people with non-normative genders, sexualities and bodies. However, many in our communities still face incredible levels of violence, discrimination and isolation. The rights of intersex people are often forgotten or ignored. They are either dismissed as the concerns of a very small minority, or thoughtlessly tacked-on to the end of the LGBT acronym. It is time for LGBT rights, women's rights and all human rights funders to mindfully cast a wider net and ensure that we create truly inclusive solutions.

Intersex people exist. They face discrimination and human rights violations, primarily because their bodies do not conform to "typical" notions of male and female. They are subjected to non-consensual, harmful and unnecessary medical interventions, stigmatized by social norms that view intersex variations as abnormal, and made invisible by legacies of secrecy and shame. Further, intersex issues are starkly underfunded. In 2013, the median annual budget for intersex-led groups was less than USD \$5,000.

It is against this backdrop that intersex activists are leading the fight for justice and recognition of their human rights around the world.

Intersex activists are raising unprecedented levels of visibility about the violations they face, and their demands are being heard by national, regional and international institutions (see the Malta Declaration, pp.34-35). In 2015, Malta became the first country in the world to ban medically unnecessary surgeries on intersex infants and children, and several countries are poised to follow suit. Everyday, intersex activists are reaching new community members, educating new stakeholders, and fighting to end the harmful and unjust practices that they have personally endured.

This report is intended to help funders understand the scope of the problems intersex activists seek to address, and recommend ways to provide effective support to the intersex movement. Many of the examples of resilience, creativity and growth come from intersex groups that Astraea supports through the *Intersex Human Rights Fund*. Launched in 2015, the Fund was created to address the dearth of support for intersex activists and communities, and this report has been created with and for many of those activists leading the charge.

As a feminist, social justice and LGBTQI funder, Astraea is proud to release this report, furthering our core commitment to justice and liberation for all people. We call upon all donors to consider how you can support intersex human rights within your mandate. Whether your funding addresses LGBT rights or disability rights, civil rights or women's rights, health rights or children's rights, intersex issues are relevant to your work. Join us in reading, learning and expanding support for this incredible human rights movement.

In solidarity,



J. Bob Alotta

Executive Director
Astraea Lesbian Foundation for Justice

EXECUTIVE SUMMARY

Intersex issues lie at the intersection of many human rights concerns. If your work touches on health rights, sexual and reproductive rights, social justice or civil rights, it is connected to the human rights of intersex people. If you are focused on the human rights of women, children, people with disabilities or LGBT people, you are already working on the issues that concern intersex people. It's time to explicitly recognize these connections and support intersex activists' struggles to affirm their rights.

Activists for the rights of intersex people have had to break through a powerful veil of stigma and social exclusion that has made intersex people and their concerns invisible for too many years. The medicalization of intersex bodies and lives has kept intersex issues largely out of public discourses. Because of this, the human rights violations intersex people face were, for years, hidden or ignored. A growing awareness of these rights abuses has come primarily through the efforts of a small but growing number of intersex advocates, intersex scholars and their allies.

Many United Nations human rights bodies have recognized that medically unnecessary, non-consensual surgeries and other interventions on intersex children amount to human rights violations. The rights at stake are no less than the right to life, liberty and security of the person; the right of the child to protection; the right to the highest attainable standard of health; and the right to freedom from torture or cruel, inhuman or degrading treatment, among others. Several countries around the world, from Malta to Australia to Chile, have recognized these rights and taken important steps to protect them.

Intersex activists now call upon funders to engage with intersex organizations and support them in the struggle for visibility, to help increase their capacity, and to affirm the human rights of intersex people. Given the clear need for investment in the intersex movement and the flourishing opportunities for new partnerships, funders are encouraged to:

1. Fund organizations and projects led by and for intersex people.
2. Provide groups with flexible funding, including and especially core support.
3. Support intersex-led groups to pursue a range of

strategies, including direct service provision, research, and advocacy. More specifically, funders should support organizations to:

- Provide information, safe spaces and assistance to intersex people and parents of intersex children.
 - Gather quantitative and qualitative information about the situation of intersex people in various parts of the world.
 - Raise awareness and educate the public and key stakeholders regarding the existence of intersex people and their concerns.
 - Advocate for actions to respect, protect and fulfill the human rights of intersex people at the local, national, regional and international levels.
4. Fund and connect organizations to opportunities for capacity strengthening.
 5. Support movement building.
 6. Help groups promote the recognition of intersecting oppressions and develop partnerships and alliances with other human rights NGOs.
 7. Promote organizational and movement sustainability through strategies to address the safety, security and well-being of activists.
 8. In collaboration with intersex activists, help raise awareness and build capacity among other funders and stakeholders to foster greater understanding and advance the human rights of intersex people.

INTRODUCTION

“What is intersex?”

“Do intersex people really exist? I don’t know anyone who is intersex.”

“Isn’t this a medical issue? What does this have to do with human rights?”

“Intersex—is that like trans*?”

“What does intersex have to do with my work?”

These are the kinds of questions that intersex people encounter daily. Little known, often misunderstood, and frequently conflated with questions of sexual orientation and gender identity, the rights of intersex people are gaining new ground thanks to the work of intersex advocates, intersex scholars, intersex-led organizations and their allies around the globe—most of whom operate with little to no funding.

Intersex people exist. They face discrimination and human rights violations on different grounds, but especially because their bodies do not conform to typical male or female anatomies. They have been and continue to be subject to non-consenting and unnecessary medical interventions, and constantly face their negative consequences. They are stigmatized by medicalized and social norms that view intersex variations as abnormal, and they are made invisible by legacies of secrecy and shame. These issues impact the daily lives of intersex individuals, often from birth and throughout their entire lifetime.

A growing global movement led by intersex activists is seeking to challenge all of this. Intersex activists have made incredible strides in raising awareness of the lived realities of intersex people and the specific human rights violations they face. Working at local, national, regional and international levels—often simultaneously—intersex organizations are defending intersex people’s rights to self-determination, bodily autonomy and physical integrity, and to be free from stigma, discrimination and violence. They are promoting a more inclusive and celebratory understanding of bodily diversity and challenging the pathologization of intersex bodies. They are allying with children’s rights, patients’

rights, feminist, LGBTQ and disability rights movements to address shared concerns. They are creating safe spaces for intersex people and the parents of intersex children to connect with one another and access accurate, non-stigmatizing and non-pathologizing information. Through advocacy efforts, they are gaining legal protections and demanding justice for human rights abuses.

Remarkably, intersex activists and intersex-led organizations are doing this work with few resources and startlingly little access to funding. This holds true across the diversity of regions in which intersex-led groups are operating, in both high- and low-income countries. Relying primarily on volunteer efforts, many face challenges to their organizational sustainability, yet have been able to grow their reach and make an astounding amount of progress. New groups and networks are emerging every year, determined to overcome the isolation and silence that have characterized intersex lives for too long.

Because of their efforts, the human rights of intersex people are gaining a new and much-needed level of attention. **By recognizing and connecting to intersecting human rights concerns, such as children’s rights, disability rights and LGBTQ rights, more partners and funding will enable this vibrant movement to build upon its achievements, increase its impact and accelerate the potential for change.** This report is intended to help human rights donors and actors understand the scope of the problems intersex activists and intersex-led organizations seek to address, the intersections among human rights issues, and ways to provide effective support to strengthen intersex organizing.



A Note on this Report's Limitations

The aim of this report is to highlight the state of the intersex movement and provide recommendations for funders and other actors to support it.

We formulated this report by doing desk research, particularly reviewing documents produced by intersex activists, and conducting interviews with the Intersex Fund's international advisors. The report does not delve into the rich

academic research by intersex scholars. For reasons of space as well as language limitations, it does not detail all the achievements by intersex individuals and organizations in the last 30 years. We are aware that a number of important cases, laws, policies and initiatives are only briefly touched upon or possibly not even mentioned.

We hope that this report serves as another stepping-stone towards further research, resourcing and recognition of this growing and vibrant movement.



Intersex Island at Pride Photo credit: Intersex Island

SPEAKING OF SEX

When talking about the human rights of intersex people, we first have to recognize how our understandings of sex, gender and sexuality shape our views of the world. This is critical because the stigma, discrimination and violence that intersex people face are rooted in the ways that these powerful and socially-constructed concepts are understood and employed.

Gender: The attitudes, feelings and behaviors that a given culture associates with a person's biological sex. Behavior that is compatible with cultural expectations is referred to as *gender-normative*; behaviors that are viewed as incompatible with these expectations constitute *gender variance* or *gender non-conformity*.¹

Gender identity: A person's deeply felt internal and individual experience of gender, which may or may not correspond with the sex assigned at birth. This includes the personal sense of the body (which may involve, if freely chosen, modification of bodily appearance or function by medical, surgical or other means) and other expressions of gender, including dress, speech and mannerisms - usually understood as *gender expression*.²

Sexual orientation: A person's capacity for profound emotional, affectional and sexual attraction to, and intimate and sexual relations with, individuals of a different gender or the same gender or more than one gender.³

Sex/sex characteristics: A person's biological characteristics that are typically categorized as male or female. There are a number of characteristics of biological sex, including sex chromosomes, gonads, internal reproductive organs and external genitalia.⁴ Sex is typically assigned at birth. The choice of categorization and definitions of male and female bodies are based on social expectations and social needs.

In most parts of the world, medically grounded notions of what constitutes a "normal" man or woman hold sway. Holmes (2009) argues that "the management of both the children's bodies and the language to describe them secured the position of doctors as arbiters of knowledge, and helped to maintain the coherence of the standard sex categories: male and female", with the expectations that they are socialized to perform corresponding fixed gender behaviors.⁵ However, we are more complicated than that. Human beings can be born with a range of sex characteristics—chromosomal, hormonal, genital and other physical features—that do not always fit tidily into these two sex categories and their expected gender expressions.⁶

"Our diversity—the differences between our experiences and perspectives, as well as the shapes of our bodies—is something that we should celebrate and protect, in all its forms."

— Zeid Ra'ad Al Hussein, the UN High Commissioner for Human Rights, at the Expert Meeting on ending human rights violations against intersex persons, September 16, 2015⁷

Intersex is most commonly used to refer to a person's sex characteristics. These include primary characteristics, such as reproductive organs and genitalia, and/or chromosomal structures and hormones; and secondary characteristics, such as muscle mass, hair distribution, breasts and/or stature.⁸

People with intersex variations do not share a common sexual orientation or gender identity. They may identify as lesbian, gay, bisexual, queer, heterosexual or asexual, among other possibilities. They may identify as male or female, both or neither. Some intersex people also identify as trans*,⁹ and some add intersex as key qualifier in their gender presentation as, for example, intersex man or intersex woman. Some people adopt intersex as their personal and/or political identity, as a way of making visible their life experiences as intersex people, while other people with intersex variations do not identify as intersex.

Both intersex and trans* individuals may face discrimination related to perceived transgressions of societal expectations related to their sex and gender. A key difference is that intersex people are often subjected to unwanted medical and surgical treatments to "normalize" their bodies to fit within accepted categories and normative notions of male and female, while trans* people often face barriers in accessing gender affirming procedures, including surgeries and hormones.

Sex is a continuum, not a dichotomy. The lack of recognition of this reality leads to denying the existence of naturally occurring bodily diversity across the world.

FREQUENTLY ASKED QUESTIONS



What does intersex mean?

Intersex is an umbrella term used to describe people who are born with genetic, hormonal, genital or other sex characteristics that do not align with stereotypical definitions of male or female bodies. An individual may possess biological traits considered to belong to both sexes or lack some of the features often believed necessary to define someone as one or the other sex.¹⁰

Some intersex variations may be visible at birth—for example, when an infant’s genitalia does not fit medical standards of male or female anatomy. Some may not be discovered until puberty or later. Some intersex people lack an official medical diagnosis or are unaware of their variation because they experienced “normalizing” medical interventions as infants and their intersex status was kept from them because of the shame and taboo associated with it. As Fund Advisor and Co-Chair of OII Europe Dan Christian Ghattas explains, “An intersex person might have been told that they had surgery for ‘cancer.’ That person might believe this for decades, and suffer the fear of the cancer coming back, when in fact their healthy gonads were removed. This is how human rights breaches happen: without the person even knowing that they occurred or that they happened due to the person being intersex.”

There are many intersex variations, perhaps as many as 40, and in up to 80 percent of cases there is no exact diagnosis.¹¹ Variations that fall under the intersex umbrella include Androgen Insensitivity Syndrome (AIS), Congenital Adrenal Hyperplasia (CAH), Klinefelter Syndrome, Rokitansky-Küster-Hauser Syndrome (MRKH), Swyer Syndrome, Partial Gonadal Dysgenesis, Ovo-Testes, Turner Syndrome, and 5-Alpha Reductase Deficiency, among others.

With the exception of the very few intersex variations that can pose medical issues, most intersex people do not have inherent health problems related to being intersex. Intersex characteristics are simply a naturally occurring expression of human bodily diversity.¹²

What human rights violations do intersex people face?

Since their bodies do not conform to medical and societal expectations, intersex people face violations of their fundamental human rights. These violations include medically unnecessary and irreversible surgeries and other invasive procedures on intersex babies and children. Intersex infanticides have also been reported.¹³ Intersex people also face life-long stigma, discrimination and violence — in education, employment, health, sports, accessing public services, birth registration and obtaining identity documents.

Until recently, these human rights breaches received little attention. They are still rarely investigated and seldom prosecuted, meaning that harmful practices and discrimination remain widespread and intersex people’s access to justice and redress are severely limited.

The stigma associated with intersex bodies is resulting in increasing the number of intersex variations excluded by genetic de-selection, the number of pre-natal treatments to “normalize” intersex fetuses, and the number of selective abortions associated with intersex.¹⁴

How common are intersex variations? How many intersex people are there in the world?

It is difficult to say with certainty how many people are intersex. There is no systematic data collection, and estimates depend upon which intersex variations are included. Estimates of the percentage of the population born with intersex traits range from 1 in 1,500 or 2,000 births, and up

to four percent; however, oft-cited research recommends a figure of 1.7 percent.¹⁵ It should be noted that this research does not encompass all of the many intersex variations in existence or take into account differences in prevalence among populations around the world.

Are there other words for intersex?

Intersex people have received different names across cultures and throughout history. Some of those names still survive, as “güevedoce” in the Dominican Republic, “turnims” in Papua New Guinea, and “xuxana” in Malta. In the nineteenth century, medical practitioners began to use the words “hermaphrodite” and “pseudohermaphrodite” to describe intersex people. The term “intersex” came into use in the early twentieth century as a more scientific terminology, to replace “hermaphroditism” and its mythological connotations.

Both terms, “hermaphrodite” and “intersex,” have been re-appropriated, re-signified and politicized by intersex activists since the mid-1990s. Some intersex people have reclaimed hermaphrodite or “herm” as a means of empowerment, while intersex has become a key political identity.

In 2006, a group of medical practitioners decided to abandon the term intersex and replace it with “disorders of sex development” or “DSD” in a clinical consensus statement. While the statement describes the rationale as seeking to decrease the stigma associated with “intersex,” many intersex advocates reject DSD terminology as pathologizing, reaffirming of medical authority over intersex bodies, and justifying “normalizing” treatments to “fix” intersex people.

At the same time, for some activists, using DSD terminology is a strategic choice to facilitate engagement with the medical establishment and to reach out to intersex people who have a medicalized understanding of themselves. In an effort to avoid the pathologizing connotations of “disorder,” some use DSD to stand for “differences of” or “diverse” sex development.

“Sex characteristics” or “intersex traits” are terms used when referring to the features that make a person intersex; those terms have also been used in national legislation to protect the rights of intersex people. In some places, “inter*” is used to denote the diversity of intersex realities and bodies.



Intersexioni members convening, Italy. Photo credit: Intersexioni

A GLOBAL MOVEMENT

Activists for the rights of intersex people have had to break through a powerful veil of stigma and social exclusion that has made intersex people and their concerns invisible for too many years. The medicalization of intersex bodies and lives has kept intersex issues largely out of public discourses. Because of this, the human rights violations intersex people faced were, for years, hidden or ignored. A growing awareness of the rights abuses experienced by intersex people has come primarily through the efforts of a small but growing number of intersex advocates, intersex scholars and their allies.

Beginning in the 1990s and expanding rapidly within the last ten years, intersex activists have become increasingly organized and effective in their advocacy to reject the pathologization of intersex bodies and to promote recognition of the human rights of intersex people. As with many social movements, organizing began with affected individuals and their supporters coming together: as self-help or patient support groups, and as activist groups to raise public awareness and call for recognition of the human rights violations they faced. Among these first organizations were Androgen Insensitivity Syndrome Support Group Australia (AISSGA) formed in 1985, Intersex Society of North America (ISNA, now defunct) formed in 1993, the Arbeitsgruppe gegen Gewalt in der Pädiatrie und Gynäkologie (Working Group Against Violence in Pediatrics and Gynecology) founded in Germany in 1995, the Intersex Trust Aotearoa New Zealand (ITANZ) established in 1996, the Escrita en el Cuerpo/CBA formed in Argentina in 1999 and Intersex South Africa founded in 2000.

The number and visibility of groups working for the human rights of intersex people continues to grow. For example, the Organisation Intersex International (OII), a loose network founded 2003, now has affiliates led by intersex individuals in 27 countries spanning the globe. Recent years have seen a veritable explosion of intersex activism. In the period between 2012 and 2014, intersex activists founded more than 10 new groups, including the 2012 creation of OII Europe, an umbrella organization dedicated to campaigning at the European level. Organizations led by intersex people, or that have the meaningful participation of intersex activists, now exist in Africa, in Asia, in Oceania, across Europe, and in South and North America.

The ever-increasing visibility of intersex rights activism has encouraged and enabled more intersex individuals to step forward. The diversity of voices represented in the 2015

“I can’t remember so many people disclosing their status, sharing their stories. Just seeing people’s faces in photographs associated with events and articles. That visibility has never existed before.”

international Intersex Awareness Day serves as a striking example. As Fund advisor and OII Australia’s Co-Chair Morgan Carpenter observed, “I can’t remember so many people disclosing their status, sharing their stories. Just seeing people’s faces in photographs associated with events and articles. That visibility has never existed before.”

By virtue of the relatively small community of intersex activists, many have placed an emphasis on networking and promoting the leadership development of others, supporting them to start self-help groups, to connect to other activists, and to develop resources and programs. As Fund advisor Saifa Wall described it, “There is a small, but growing network of activists worldwide who are in communication with one another, borrowing tools and research to advance the larger premise of bodily integrity.” A key early moment is 2005, when the trans and intersex program of the Latin America and Caribbean office of OutRight Action International (formerly known as IGLHRC), then coordinated by Fund Senior Advisor Mauro Cabral, organized the first training institute for trans and intersex activists in Latin America and the Caribbean.¹⁶

Collaboration with and support from other human rights organizations and movements has also helped to strengthen intersex activism. **Recognition of intersecting and shared forms of oppression has enabled vital partnerships for**

intersex rights groups, most notably with LGBTQ and children's rights organizations, but also with feminist and disability rights organizations. They are connecting around issues of physical integrity, bodily autonomy, sexual and reproductive rights, experiences of discrimination based upon sex and gender norms, and the medicalization of intersex and disabled bodies. These partnerships can help elevate the voices and concerns of intersex people. For example, raising intersex issues as part of UN LGBT advocacy allowed Mauro Cabral to participate in the crafting of the *Yogyakarta Principles* in 2006 and to include intersex issues under Principle 18 on medical abuses. In Australia, OII Australia, along with AISSGA, developed a relationship with People with Disabilities Australia; this led to the extension of a Senate inquiry on involuntary or coerced sterilization—originally limited to people with disabilities—to include the situation of intersex people in 2014.¹⁷ These kinds of collaboration are building the base of support for the human rights of intersex people and highlighting the deep connections that marginalized communities share.

Following many years of intersex advocacy at ILGA¹⁸ conferences, the adoption of intersex as a central issue for

ILGA in 2008 provided new spaces and a new level of support for international intersex organizing. Since 2011, ILGA in collaboration with ILGA-Europe has facilitated three international intersex fora organized and led by intersex activists. These convenings—held in Belgium (2011), Sweden (2012), and Malta (2013)—have provided invaluable opportunities for intersex activists from around the globe to come together, identify shared areas of work, and strategize collectively. The 2013 meeting, which brought together 34 activists representing 30 intersex organizations, led to the creation of the public statement known as the Malta Declaration, a key document which outlines demands to end discrimination against intersex people and ensure their rights of bodily integrity, physical autonomy and self-determination. The declaration is used by intersex activists and allies worldwide as a reference point for intersex rights advocacy. In 2014, ILGA formally established an Intersex Secretariat and the Costa Rican organization Mulabi, led by intersex activist and Fund Advisor Natasha Jiménez, was elected to the post. Through intersex pre-conferences at regional meetings, ILGA has continued to provide activists with much-needed opportunities to bring in emerging leaders, develop skills and identify strategies to realize the *Malta Declaration*.

OII Europe & ILGA-Europe

Following ILGA's decision to include intersex in its mandate in 2008, the European region of ILGA - ILGA-Europe - ramped up its commitment to intersex activism by conducting internal education on intersex issues and identifying ways to integrate those issues into the organization's programs. It increased its collaboration with European intersex organizations and began supporting their capacity development based on jointly identified needs. Perhaps most important, as a well-established organization, ILGA-Europe helped to open doors for intersex-led advocacy at the European level.

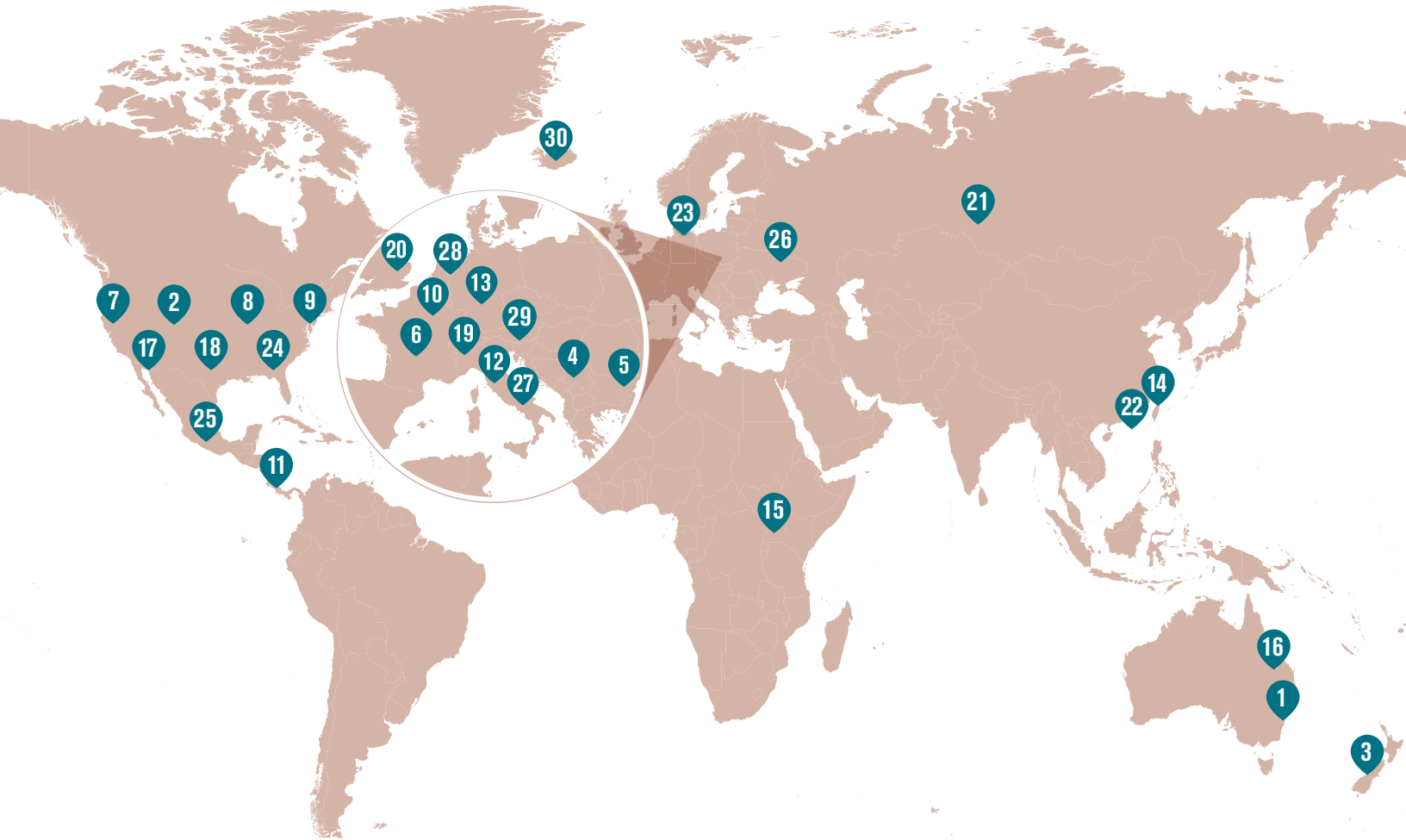
This kind of support has been vital, particularly to groups like OII Europe, which was founded during the second international intersex forum in 2012. OII Europe is the first and only intersex-led pan-European organization. It strives to raise public awareness and educate political stakeholders within the European Union (EU) and the Council of Europe (CoE), working toward legal change and the inclusion of intersex in European and national anti-discrimination legislation.

With the support of ILGA-Europe and OII Europe's strategic engagement, European government officials now seek OII Europe's expertise on intersex issues and view the group as a valued partner. These relationships have enabled the organization to play a key role in the development of several groundbreaking documents, including the Parliamentary Assembly of the Council of Europe's (PACE) Resolution 1952, which addresses the bodily integrity of intersex children, as well as a detailed issue paper on human rights and intersex people published by the Council of Europe (CoE) Commissioner for Human Rights and the European Union Agency for Fundamental Rights' Position Paper.^{19 20} OII Europe was also instrumental in the drafting process of the Malta's Gender Identity, Gender Expression and Sex Characteristics Act, which is a milestone in the recognition of intersex people. In 2014, in partnership with ILGA-Europe, OII Europe convened the first European intersex meeting and building upon the demands formulated at the 3rd international intersex forum, the groups at this meeting developed common advocacy objectives to advance intersex people's human rights in Europe.



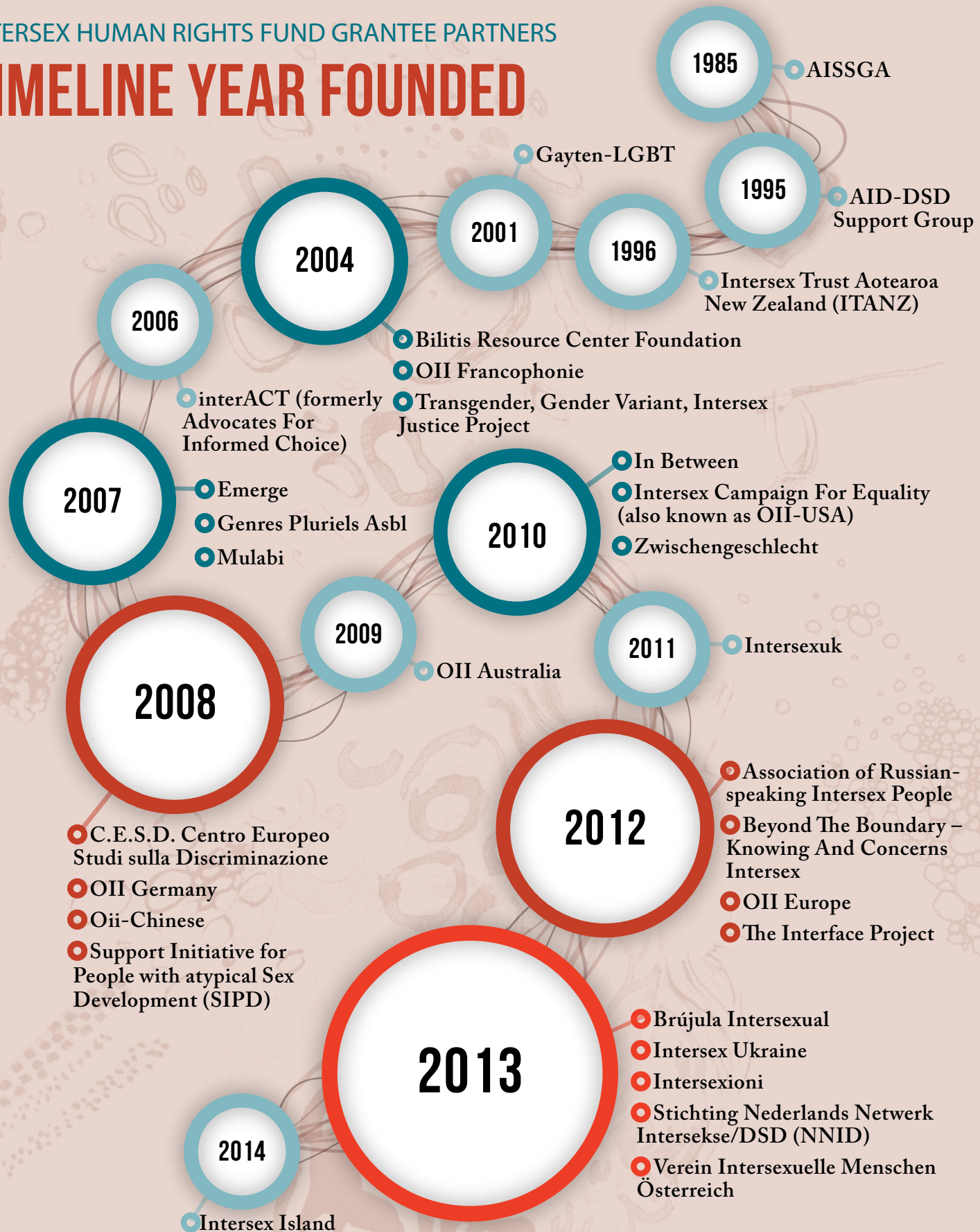
INTERSEX HUMAN RIGHTS FUND

2015 GRANTEE PARTNERS



- 1 AISSGA
- 2 AID-DSD Support Group
- 3 Intersex Trust Aotearoa New Zealand (ITANZ)
- 4 Gayten-LGBT
- 5 Bilitis Resource Center Foundation
- 6 OII Francophonie
- 7 Transgender, Gender Variant, Intersex Justice Project
- 8 interACT (formerly Advocates For Informed Choice)
- 9 Emerge
- 10 Genres Pluriels Asbl
- 11 Mulabi
- 12 C.E.S.D. Centro Europeo Studi sulla Discriminazione
- 13 OII Germany
- 14 Oii-Chinese
- 15 Support Initiative for People with atypical Sex Development (SIPD)
- 16 OII Australia
- 17 In Between
- 18 Intersex Campaign For Equality (aka OII-USA)
- 19 Zwischenengeschlecht
- 20 Intersexuk
- 21 Association of Russian-speaking Intersex People
- 22 Beyond The Boundary – Knowing And Concerns Intersex
- 23 OII Europe
- 24 The Interface Project
- 25 Brújula Intersexual
- 26 Intersex Ukraine
- 27 Intersexioni
- 28 Stichting Nederlands Netwerk Intersekse/DSD (NNID)
- 29 Verein Intersexuelle Menschen Österreich
- 30 Intersex Ísland

TIMELINE YEAR FOUNDED



HUMAN RIGHTS ISSUES

The idea that all bodies should fit neatly into mutually exclusive categories of “male” and “female” sexes ignores the diversity among us and perpetuates the stigma associated with being intersex. Such convictions are used to justify non-consensual and cosmetic medical interventions to make intersex bodies conform to societal and medical norms. They also underlie the discrimination that intersex people face in various aspects of daily life. Due to the dominance of the medical discourse, such harmful practices have only recently begun to be recognized as human rights violations. Only a few countries have explicit legal protections for intersex people, which means that abuses continue to this day and reparations or access to justice remain rare.

Around the world, intersex people face widespread and life-long violations of human rights recognized in the Universal Declaration of Human Rights; the International Covenant on Civil and Political Rights; the International Covenant on Economic, Social and Cultural Rights; the Convention Against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment; the Convention on the Rights of the Child; and the Convention on the Rights of Persons with Disabilities. These include:

- The right to life, liberty and the security of person
- The right to recognition as a person before the law
- The right to freedom from discrimination
- The right of the child to protection
- The right of the child to preserve his or her identity
- The right to the highest attainable standard of health
- The right to freedom from torture or to cruel, inhuman or degrading treatment or punishment, including non-consensual medical experimentation
- The right to privacy
- The right to marry and found a family

- The right to take part in cultural life
- The right to access justice, redress and compensation

Medicalization and Pathologization of Intersex Bodies

Many of the challenges intersex people face stem from the medical categorization of intersex variations as pathological. This perspective—that intersex traits are to be fixed and are disorders to be treated and repaired—has led to the widespread practice of harmful, unnecessary and non-consensual treatments conducted during infancy and childhood to “normalize” intersex bodies.²¹ These procedures violate individuals’ rights to self-determination, bodily integrity and physical autonomy. They come into conflict with children’s rights—to protection, to preserve their own identity, and to express their views about matters that affect them. In 2013, the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, Juan E. Mendez, issued a statement condemning non-consensual surgical interventions on intersex people as a form of torture, as did other human rights bodies after that.²²



While some procedures could be needed on the basis of concrete health risks, most are conducted based primarily on social concerns, paying no or minimal attention to evidence of their long-lasting consequences.²³ These procedures include genital surgeries, the surgical removal of reproductive tissues, and steroid or sex hormone treatments to “feminize” or “masculinize” intersex bodies. Such interventions are irreversible and can have serious and lifelong impacts like loss of sexual sensation, sterility, chronic pain, scarring, bleeding, chronic infections, osteoporosis, depression and trauma.²⁴ Many individuals undergo multiple or repeated surgeries and invasive, often unnecessary associated procedures such as visual recording through pictures or videos, repeated physical examinations and mechanical dilations. Despite the harmful psychological and physical impacts, there is a general lack of follow up care and research regarding intersex people’s quality of life after undergoing these interventions.

Where parents have the legal right to provide informed consent on behalf of their child, they often do not receive the information, time and psychosocial support needed to make well-informed decisions. Frequently, these decisions are made under pressure, without information about the various and potentially harmful implications of surgeries, and without the opportunity to talk with intersex adults and their families. In some cases, a decision is made even before a child is born, where fetuses with intersex traits may be subjected to prenatal “normalizing” treatments or selected for abortion.^{25 26} In places where access to medical care is more limited and beliefs about intersex are deeply negative, the choices made can also be extreme; intersex rights groups report that in parts of Uganda and rural China, intersex infants may be abandoned or killed.^{27 28}

For many intersex people, interactions with the medical system are continually fraught. Intersex individuals who have undergone non-consensual “normalizing” treatments, as well as those who have not, describe the fear, mistrust and discomfort they experience when it comes to accessing health services. In seeking care, they risk becoming objects of curiosity, harassed and subjected to breaches of medical privacy. In addition to these deterrents to seeking routine or emergency care, intersex people face difficulties accessing treatments that meet their specific needs. They may be denied access to services, medication or insurance coverage under health care schemes that fail to recognize the needs of individuals whose bodies do not conform to stereotypical definitions of male and female; for example, where policies make certain treatments (e.g. breast cancer screening) available to individuals registered as one sex, but the individual seeking it is registered as another sex.²⁹ These are clear violations of the right to the highest attainable standard of health.

The medicalization of intersex bodies also serves to make them socially stigmatized. The notion that intersex traits can be medically “repaired” implies that intersex bodies are inherently problematic and that “fixing” them requires erasing the problematic sex characteristics. This attitude casts a shadow of stigma and shame upon intersex people and their families. Intersex activists describe medical professionals who misrepresent or conceal the truth of their diagnosis from intersex patients; parents who have been advised not to speak openly with their intersex children about their bodies or to discuss the issue with others; and intersex individuals told they will never meet another person like them, who struggle with self-acceptance in silence and isolation. The sense of bearing shameful traits that merit erasing prevents many intersex people from seeking support or redress for the harms done to them. Moreover, evidence of these violations can be hard to recover; intersex individuals describe difficulties accessing medical records or discovering that their files have been altered or destroyed to conceal their history from them.³⁰

Discrimination Related to Legal Identity

Most countries require a child’s sex to be legally registered shortly after birth, typically within 30 days. The decision regarding the sex of a child is reflected in their identity documents (e.g. birth certificate, national ID and/or passport), which are needed in order to access services and participate in countless aspects of daily life. Therefore, the requirement of sex/gender assignment is used to prompt and justify “normalizing” interventions in infancy. For intersex individuals who identify with their assigned sex, this does not necessarily pose a challenge—though some intersex people experience violations related to *not* being recognized as their legal sex. For those who feel that the sex they were assigned at birth is incorrect or that the categories of male and female do not describe them, however, changing their legally registered sex or gender marker may prove difficult or impossible.

In many places, the barriers intersex people encounter in amending their legal sex/gender identification are similar to those that trans* people face. The laws governing these processes are often discriminatory and restrictive, including requirements such as a court order, psychological and medical examination, or confirmation from a medical expert that they have lived for a certain period of time in the gender role corresponding to the sex marker they are seeking. Because intersex status is not recognized or understood in many countries, intersex people may find themselves excluded by laws that only address the ability of trans* people to alter their official documents. In New

Zealand, for example, trans* individuals can change the gender indicated on their passports via simple declaration and have the option to select M (male), F (female) or X (indeterminate/unspecified); however, the law does not state that intersex individuals can access this process. Sometimes the requirements for changing legal identification, such as a mental health diagnosis or surgical and hormonal interventions, refer only to trans* people and do not apply to intersex individuals.

In most countries, male and female remain the only legal gender categories; for intersex individuals who identify as in between male and female, as both or neither, there is no option that recognizes them. Calls for the creation of “third gender” categories to include intersex people have been controversial. The danger of a third gender category is that, if it is only open to intersex and/or trans* people or made mandatory for them, it will reinforce the exclusion of those who do not fit within the sex binary. Australia provides an example of an opt-in framework: any intersex or gender diverse person can select an “X” gender marker on their passport if they can obtain certification from a doctor or psychologist. Complications remain regarding whether other countries recognize such passports and the possible harassment of those who carry them. Germany provides a different example: a law passed in 2013 mandates that infants who cannot be assigned to the male or female sex must have the gender entry left blank on their birth certificates. This was hailed inaccurately in the media as a “third gender option.” Rather than a choice made by parents or the concerned individual, the law leaves authority in the hands of doctors. Instead of offering protections, the blank entry may make intersex children more vulnerable to stigma and discrimination. Many intersex activists fear that the law will forcibly out intersex children and increase, rather than reduce, the likelihood of sex assignment surgeries on newborns, because parents will not want their children to lack a legal gender. Until such time that sex is no longer recorded on birth certifications, most intersex activists will continue to advocate for assigning the sex of an intersex infant on the basis of the best information available at the time and allowing for the possibility that the child may identify differently as they grow up.

The *Malta Declaration* calls for all adults to be able to amend their sex or gender classification through simple administrative procedures and to be able to choose among female, male, non-binary or multiple options. Ultimately, however, the vision is to remove sex or gender as a category on birth certificates and identification documents, as has been the case with race and religion.

When an intersex individual’s legal identity is considered incongruent with their chromosomes, genitalia, reproductive anatomy and/or hormones, they are vulnerable to discrimination. For example, they may face barriers to marriage or the adoption of children, in violation of the right to marry and form a family. Some of the most visible acts of discrimination concern the participation of intersex individuals in sports. Several international sports bodies, including the International Olympic Committee, use sex verification guidelines to determine whether athletes should be banned from competition. The case of Caster Semenya, a champion Olympic runner forced to undergo “gender testing,” received worldwide attention. But there are dozens of other women athletes who have experienced similar violations. Medical journals have documented, for example, the case of four young women athletes whose high levels of testosterone flagged them for medical examination and who were subsequently diagnosed as intersex. All four athletes consented to the medically unnecessary surgeries proposed by the doctors—the partial removal of their clitorises and the removal of their gonads—in order to return to competition.^{31 32}

Lack of Legal Protections and Redress

For the most part, violations of the human rights of intersex people have been hidden from public view. Laws or policies to prevent harmful interventions on intersex children are few and far between, and less than a handful of places offer protections to intersex people. It is often assumed that anti-discrimination protections on the ground of “sex” cover intersex as well, but in these laws, sex is generally equated with gender, not sex characteristics. While protections increasingly specify sexual orientation or gender identity, few include “intersex status” or “sex characteristics.”

This means that intersex people often lack protections or recourse for violations of their human rights. Access to justice and redress remains a major concern. Only a few cases have gone to court to challenge abuses of human rights experienced by intersex people. The *Malta Declaration* calls for the provision of “adequate acknowledgement of the suffering and injustice caused to intersex people in the past, and provide adequate redress, reparation, access to justice and the right to truth,” and as advocate Arvind Narrain argues, “a future free of discrimination on grounds of intersex status cannot emerge, if the injustices of the past are not fully redressed. The issue of what has been done to intersex infants around the world is one of which raises questions of truth, justice, reparation and guarantees of non-recurrence.”³³ Thanks to the work of intersex activists, processes to promote accountability for past malpractices and reparations for violations are beginning to advance.

INTERSEX IS EVERYWHERE

Intersex issues lie at the intersection of many human rights concerns. If your work touches on health rights, sexual and reproductive rights, social justice or civil rights, then it is connected to the human rights of intersex people. If you are focused on the human rights of women, children, people with disabilities, or LGBT people, then you are already working on the issues that concern intersex people. It's time to explicitly recognize these connections. Many of the abuses intersex people experience are shared with other marginalized communities and are rooted in similar discriminatory beliefs and attitudes. When we recognize these intersections, we can create a broader, more united front for change.



Small Luk, founder of Beyond the Boundary –
Knowing and Concerns Intersex Hong Kong.
Photo credit: School of Journalism and
Communication, CUHK

The sex binary and beliefs regarding “normal” bodies underpin the stigma, discrimination and violence that intersex people face. In most cultures, a person’s assigned sex is tied to expectations regarding their gender identity and expression and their sexuality, i.e. a person assigned “female” at birth is expected to act in feminine ways and to be sexually attracted to men. These deeply held heteronormative beliefs and values oppress and circumscribe the lives of women, gay and lesbian, trans* and gender nonconforming individuals, and intersex people. The price of transgressing these expectations is often violence and discrimination—in many different, but frequently shared, forms.

The intersex rights movement is premised on the fundamental right of all individuals to self-determination, bodily integrity and physical autonomy. This includes the ability to make decisions about sexual and reproductive health free from violence or coercion, and to have safe and pleasurable sexual experiences. The issue of consent about decisions affecting their bodies, as well as two specific and harmful practices, link the intersex community intimately to those fighting for the **rights of women and girls, trans* people, and people with disabilities**.

The first is the practice of non-consenting, medically unnecessary genital surgery on intersex children (for example, clitoridectomies). When conducted on non-intersex girls, these procedures are condemned as female genital mutilation and recognized as a form of violence and harmful practice that violates human rights principles of equality and nondiscrimination on the basis of sex, and the right to freedom from torture or cruel, inhuman or degrading treatment or punishment.³⁴ The second is forced/coerced sterilization. Human rights bodies have recognized that, in addition to contravening the right to freedom from torture, forced sterilization violates the right to form a family. Around the

world, intersex people and women and girls with disabilities experience sterilization without their consent.³⁵ In many places, trans* people are also subjected to sterilization and other surgical interventions as a requirement for legal recognition of their name and gender.

Intersex issues are also, very simply, **children’s rights issues**. Normalizing surgeries and treatments carried out on intersex children who are unable to give informed consent contravene several articles of the Convention on the Rights of the Child, including those concerning the best interests of the child, their right to be heard and take part in decisions affecting them, and their rights to be protected from physical or psychological violence and against traditional practices prejudicial to the health of children.

Medicalization and pathologization also cut across the experiences of intersex and other communities. Intersex individuals and people with disabilities are both marginalized by a medical perspective that frames difference as deficit and views atypical bodies as social liabilities rather than an expression of bodily diversity. For both groups, issues of medical abuse and violations of patients’ rights abound. They struggle to access health care that meets their needs, including health care professionals that understand their concerns and treat them with respect.

Medicalization masks the cultural biases, sexism, transphobia and homophobia that can underlie responses to the birth of an intersex child. Parents and doctors may fear that without intervention, the child will experience “gender confusion” or will not be heterosexual. Normalizing surgeries are often based on sexist and cisheteronormative assumptions about sexuality and what male and female bodies should look like.

GROWING RECOGNITION OF INTERSEX PEOPLE AND THEIR RIGHTS



Despite the uphill battle activists face, there are reasons for optimism. Due in large part to pioneering work by intersex-led organizations and their allies, there is growing awareness—among civil society organizations, governments, and international and regional human rights bodies—of the human rights violations intersex people face. Several countries have passed groundbreaking legislation or created inclusive policies to recognize intersex people and protect them from discrimination. There is also a small but growing body of jurisprudence related to the rights of intersex people.

Over the past few years, there has been a growing realization of the need to better understand, investigate and take action to address the human rights of intersex people. In 2013, intersex activists testified at the first-ever hearing on intersex issues held by the **Inter-American Commission on Human Rights**. The Commission has since created a rapporteurship to monitor the human rights situation of lesbian, gay, bisexual, trans, and intersex persons in the region. Also in 2013, the **Organization of American States** adopted a resolution on human rights, sexual orientation, and gender identity that urged member states to provide protections for intersex people and ensure that medical practices are consistent with human rights standards.³⁶ More recently, the Inter-American Commission called for a legal prohibition on surgeries or unnecessary medical interventions on intersex people without their informed consent.³⁷

In 2011, the **UN Committee Against Torture**, in its review of Germany, condemned and called for investigation of non-consensual medical treatment of intersex people.³⁸ In just the past year, the Committee has made strong recommendations to Austria, China, Denmark, Hong Kong and Switzerland, calling on states to take necessary measures to guarantee respect for the physical integrity and autonomy

of intersex persons and to ensure that no one is subjected during infancy or childhood to unnecessary medical procedures. These recommendations were reiterated by the **UN Committee on the Rights of Persons with Disabilities** in its review of Germany in 2015.³⁹ That was also the first year that the committee held a thematic briefing specifically regarding the human rights of intersex people, in which several intersex activists testified.

The **Council of the European Union** has adopted guidelines which affirm the rights of intersex people under existing international human rights law.⁴⁰ In 2014, the **European Parliament** called for action to mainstream issues specific to intersex people throughout relevant EU policies, ensure that equality bodies are trained on issues related to intersex people, and address the lack of research and legislation on the human rights of intersex people.⁴¹ Both the Council of Europe's Commissioner for Human Rights and the European Union's Fundamental Rights Agency (FRA) launched reports in 2015, expressing concerns regarding violations of intersex people's rights to self-determination and bodily autonomy. The Commissioner's paper, "Human Rights and Intersex people," provides an in-depth analysis of European legislation and policies affecting intersex people

while, the FRA focus paper examines the legal situation of intersex people from a fundamental rights perspective.^{42 43}

Many international human rights bodies are now paying specific attention to the rights of intersex children and the need to prevent harmful medical interventions. The **UN High Commissioner for Human Rights**, in a groundbreaking 2011 submission to the Human Rights Council, highlighted that intersex children are routinely subject to discrimination and medically unnecessary surgery, performed without their consent or that of their parents.⁴⁴ The **Parliamentary Assembly of the Council of Europe**, in 2013, adopted Resolution 1952 on children's right to physical integrity, addressing the issue of bodily integrity of intersex children for the first time.⁴⁵ In 2014, the UN High Commissioner for Human Rights, Navi Pillay, again stressed that “irreversible surgeries and sterilizations continue to be performed on intersex children without their informed consent, causing lifelong harm.”⁴⁶ In the last two years, the **UN Committee on the Rights of the Child (CRC)** has urged a number of countries, including Switzerland, Chile, France and Ireland to uphold intersex children's rights to bodily integrity, autonomy and self-determination, prevent unnecessary medical or surgical treatment, and provide families of intersex children with adequate counselling and support.⁴⁷ In 2015, **seven UN bodies**, including some that had not previously spoken out on intersex issues, released an interagency statement describing non-consensual, cosmetic and other non-medically necessary surgeries that result in sterilization of intersex infants as human rights violations.⁴⁸ At the 30th session of the Human Rights Council in 2015, the UN High Commissioner for Human Rights Zeid Ra'ad Al Hussein called attention to the discrimination and rights abuses that intersex people face, and pledged to identify steps that governments and others can take to end these violations.^{49 50} In September 2015, the Office of the High Commissioner for Human Rights (OHCHR) convened an international experts' meeting - the first of its kind - on intersex issues, which brought together UN representatives and intersex advocates to identify current challenges and gaps in addressing human rights violations faced by intersex people.⁵¹

Progressive Laws and Policies

Momentum to change national laws and policies is also growing. In 2015, Malta became the first country in the world to ban medically unnecessary surgeries on intersex infants and children. **Malta's Gender Identity, Gender Expression and Sex Characteristics Act**, creates a protected right of bodily integrity and physical autonomy for all

and makes it illegal to conduct any medical intervention on the sex characteristics of a person without informed consent.⁵² The law mandates that everyone should have access to psychosocial support as well as peer counselling for as long as necessary. Malta's law also establishes a right of gender identity for all people, as well as the ability to legally change gender. Currently, Argentina, Denmark, Malta and Ireland are the only countries in which any adult has the ability to change their recorded gender without proof of genital surgery, hormonal therapies, psychosocial or medical treatment.

In addition, the Malta law specifies “sex characteristics” as a protected ground and defines them in detail. Only two other countries have comparable protections. The first-ever such legislation was **South Africa's equality law**, which originally included “sex” is a prohibited ground of discrimination and was amended in 2005 to include “intersex” due to the efforts of Intersex South Africa and the South Africa Human Rights Commission. In 2013, **Australia's Sex Discrimination Amendment (Sexual Orientation, Gender Identity and Intersex Status) Act** was the first to include intersex status as a stand-alone prohibited ground of discrimination, defined as “the status of having physical, hormonal or genetic features that are neither wholly female nor wholly male; or a combination of female and male; or neither female nor male.” The Act also enables intersex people to make complaints to the Australian Human Rights Commission if they believe they have been discriminated against. In 2016, the Chilean Ministry of Health issued a protocol to stop normalizing surgeries on intersex children, making it the first health ministry to initiate such a step.⁵³

Emerging Jurisprudence and Calls for Justice

Few cases regarding the human rights of intersex people have gone to court, but in those that have, there have been several important rulings. The **Constitutional Court of Colombia** issued a series of decisions—in 1995, 1999, and 2008—that began to set boundaries on informed consent to genital normalizing surgery and acknowledged children's rights to bodily autonomy and the free development of their personal identity. The court established that parental consent was not enough to allow surgery on a child; parents had to understand the risks and possible alternatives to surgery, and their consent must be consistent and sustained over time. It further ruled that children five years of age and older have developed a sense of their gender identity and have the right to decide against surgery.

A 2014 ruling by the **High Court of Kenya** also established the rights of intersex children and called for the Kenyan government to take action. In the case of the intersex Baby “A,” the judge affirmed the right of every child to legal recognition and identity through the issuance of a birth certificate as well as the right of intersex children to access health services and not suffer discrimination related to their intersex status. Recognizing the lack of policies to address intersex-related concerns, the judge directed the Kenyan government to research and develop an appropriate legal framework on issues regarding intersex children.⁵⁴

In terms of reparation or compensation for harms done to intersex people, there are few precedents. In 2008, Christiane Völling successfully brought a lawsuit against the surgeon who removed her reproductive organs when she was 18 years old, essentially performing sex reassignment surgery, without her prior or informed consent. The **Regional Court of Cologne, Germany** concluded that there was no health risk that necessitated this irreversible surgery and, in 2009, she was awarded €100,000 in damages.⁵⁵ This was the first known civil suit to hold a surgeon accountable for non-consensual surgery on an intersex person.

Since then, human rights and medical ethics bodies have proposed exploring various methods of redress. In its 2011 review of Germany, the **UN Committee against Torture** recommended that the country investigate the non-consenting medical treatment of intersex people and adopt legal provisions in order to provide compensation to victims.⁵⁶ The **German Ethics Council** followed suit in a 2012 opinion that called for the establishment of a fund to recognize and assist intersex individuals “who have undergone pain, personal suffering, difficulties and permanent restriction of their quality of life due to treatments which... are based on discriminatory social concepts of sexual normality.”⁵⁷ The **Swiss National Advisory Commission on Biomedical Ethics** has also called for public acknowledgement of the suffering of intersex individuals as a result of past practice and recommended possible criminal sanctions to address unlawful medical interventions on intersex children. The **Argentinian National Institute Against Discrimination** launched a policy paper in 2015 addressing intersex issues from a human rights perspective and recommending the revision of care and treatment protocols, access to inclusive healthcare, stopping unnecessary treatments and surgeries, provision of parental and peer support, inclusion of intersex in educational programs, and respect for the privacy of intersex people and their families.⁵⁸

STRATEGIES FOR CHANGE

Intersex-led groups are utilizing a variety of strategies to build community, raise public awareness and advance the human rights of intersex people. They are working at the local as well as national, regional and international levels, often simultaneously, and with far too little resources.

Reaching and Empowering Intersex People

Many intersex people recount being told by medical professionals that they will never meet anyone like them. The stigma and shame projected onto intersex bodies, simply because of their difference, creates a silence and isolation that can be difficult to breach. Because of this, activists are using a range of tactics to reach intersex people and their families with empowering information and to create spaces where individuals can share their experiences.

One of the most powerful tactics activists use to overcome the problem of invisibility is coming out and sharing their own stories publically.

In many places, intersex-led groups have relationships with patient groups that may have a more medicalized and less advocacy-based perspective. The internet is also a key tool. Groups have created websites and blogs, and are using Facebook and other social media platforms, to provide non-medical, non-pathologizing information about intersex bodies and lives. Because so much information regarding intersex variations is only available in English, groups are translating resources into local languages, creating new, non-pathologizing vocabulary in local terms, and creating their own culturally-relevant materials. Given the limited number of intersex-led groups in existence, organizations that provide information in languages such as Chinese, Spanish, or Russian become a critical source of information for audiences in dozens of countries.

Intersex Ísland (Intersex Iceland)



Intersex Island members marching.
Photo credit: Intersex Island

Intersex Ísland was founded in 2014 to provide a safe space for intersex individuals, to educate the public about intersex issues, and to advocate for the principles outlined in the Malta Declaration. Among their first tasks was addressing the invisibility of intersex people in Iceland. An attitude of secrecy encouraged by the medical establishment and a lack of information in Icelandic language made “intersex” an almost unheard-of term. At the time of the organization’s founding, there existed only five pieces of writing on intersex issues in Icelandic and that were easily accessible to the public. This meant that Iceland had almost no non-medical discourse on intersex issues and that intersex people and their families felt disempowered to discuss their needs in the local language, often resorting to English. Intersex Ísland worked with a team of linguistic experts to develop a language base of non-pathologizing intersex terminology and, through public education and political advocacy, has been shaping an alternative discourse around intersex in the Icelandic language.

In a remarkably short time, the organization has been able to engage Iceland’s political parties, parliamentarians, and key government ministers, some of whom have spoken out publically against non-consensual surgeries on intersex children. Because of Intersex Ísland’s efforts, intersex information is now included in educational materials that go to all schools in the Reykjavik area and are accessible to all schools in the country.

Intersex-led groups are creating forums—both online and in person—where intersex people are able to share their stories and meet others like them. For many individuals, this is their first opportunity to connect with another intersex person, someone who understands and can relate to their experiences. In places where geography or other factors make it difficult to meet in person, or for intersex people who don't wish to be publically visible, online meet ups can provide an invaluable source of support.

Intersex groups are also providing spaces for specific constituencies, like intersex youth or parents of intersex children, in recognition of their different needs. For example, in the United States, **interACT**'s youth program is run by and for intersex youth to cultivate a sense of pride and develop leadership among young intersex people. It provides a platform for them to share their stories and to develop educational and advocacy materials from a youth perspective—for other young people, but also for parents and doctors. Many groups also help to connect parents of intersex children with intersex adults who have the same variation so that they can hear alternative perspectives from those often voiced by physicians. This kind of contact can have a huge influence on the decisions parents make regarding their child's welfare.

In addition to community building work, intersex activists are often called upon to provide one-on-one counseling or to support individual advocacy, for example, by helping an intersex individual to access their medical records or accompanying them in the process to change their legal name or gender. They are also linking intersex people to trusted service providers, including non-pathologizing doctors and psychosocial professionals, as well as legal aid. In all of these efforts, groups aim to develop self-acceptance and self-love, and to foster well-being and pride in the intersex community.

Ending Invisibility and Creating Knowledge

Public education and awareness raising is a huge part of intersex-led organizations' work. Many are proactively engaging the media and holding public events to provide information about intersex issues, share the real life experiences of intersex people, and call for the respect of intersex people's rights. They are training other civil society organizations and engaging religious institutions. One of the most powerful tactics activists use to overcome the problem of invisibility is coming out and sharing their own stories publically. This can be a risky and emotionally draining proposition; in some places, these intersex leaders are the only "out" intersex people in their country.

Oii-Chinese 關於



Oii-Chinese Founder, Hiker Chiu with schoolchildren. Photo credit: Oii-Chinese

Established in 2008, Oii-Chinese aims to provide Chinese-speaking communities with information created by intersex people, to bring intersex people together for peer support, and to advocate for their human rights. After creating a website to serve as an informational hub, the organization's founder, Hiker Chiu, decided to come out publicly—becoming the first intersex person to disclose their status and share intersex issues in a positive way in Chinese-speaking societies. In 2010, he/she launched the "Global Free Hugs with Intersex Movement" at the 8th Taipei Pride Parade as an awareness-raising strategy. The initiative led to Hiker sharing his/her story in more than 150 lectures, primarily in Taiwan, and receiving diverse mass media coverage. Hiker's visibility has encouraged intersex people from Taiwan, Hong Kong and China to contact the organization which provides one-on-one psychosocial support and facilitates online community forums, including groups for intersex teenagers and for mothers of intersex children.

The Oii-Chinese website continues to serve as a unique and valuable online repository of information, generating resources in Chinese and translating stories about intersex people and news of global intersex organizing into Chinese. It has received more than 50,000 visitors since 2011. With this experience, Oii-Chinese is dedicated to supporting the leadership development of other intersex individuals in Asia, including and beyond Chinese-speaking countries. In 2015, Oii-Chinese organized the first-ever intersex Asia gathering as a pre-conference to the ILGA-Asia conference in Taiwan. It brought together activists from East and Southeast Asia, seven of whom participated in the Taipei Pride Parade.

In addition to engaging traditional media outlets, groups are creating new media to celebrate intersex lives, challenge misperceptions about intersex people, and shine a light on human rights violations. They are doing so through video or written testimonies online, by producing documentary films, staging theatrical performances, and creating visual art. For example, New Zealand-based **ITANZ** teamed up with a filmmaker to produce the documentary *intersexion* which shares the narratives of intersex people from around the world and has been selected as an official training resource at the UN. Similarly, the **Interface Project**'s website features testimonies from intersex people that illustrate both the diversity and the resilience of the intersex community. It serves as a resource for parents, clinicians, and intersex people alike. Mauro Cabral's edition *Interdiciones* - a collection of essays and conversations on the experience of intersex people in Latin America and Spain - provides space for intersex voices to be heard while highlighting the different discourses and narratives around intersex bodies.⁵⁹

Intersex-led organizations are addressing the major lack of information on intersex realities by advocating for research engages the intersex community meaningfully in the process. Several intersex-inclusive organizations, like **Gayten-LGBT** in Serbia and **Bilitis Resource Center Foundation** in Bulgaria, are beginning to conduct their own research to understand current medical practices in their countries and use the information to engage medical professionals and families of intersex people about the implications of normalizing surgeries on intersex infants. Others are gathering data on the forms of discrimination intersex people face in order to inform advocacy efforts.

Alongside broader public awareness raising efforts, intersex organizations are targeting specific stakeholders for education and training. Parents are a primary target for many groups. The **Intersex Campaign for Equality (ICE)**, also known as OII-USA) has created a brochure to ease parents' concerns about their intersex children and provide comprehensive information about the implications of surgical "normalization," including medical studies. This resource is being used by healthcare professionals throughout the U.S.

Medical professionals are another key audience. Groups are engaging a range of practitioners, including surgeons, endocrinologists, psychologists, midwives, nurses as well as medical students in through formal trainings, as guest lecturers and through one-on-one engagement. The **Androgen Insensitivity Syndrome Support Group-USA**, has developed a medical education program which it runs in conjunction with its yearly member convening. This set up provides the opportunity for intersex people

Support Initiative for People with atypical sex Development (SIPD)



Julius Kagawa, executive director of SIPD.
Photo credit: Julius Kagawa

Since 2008, SIPD has been working to promote the human rights of intersex children and adults in Uganda. Because of limited access to health care, few infants born with intersex traits receive a medical assessment. Some are abandoned or killed soon after birth because of traditional beliefs that view atypical sex characteristics as a curse; others are hidden because of shame and fear. SIPD uses a variety of approaches to raise awareness and provide direct support to intersex people, including media campaigns, training community outreach workers, and facilitating support groups for families with intersex children.

SIPD has also been conducting outreach to 18 schools, mainly secondary schools, to provide support to intersex youth and cultivate a sympathetic climate where students can be comfortable coming out to each other or to school staff. SIPD reports that they have been approached by anywhere between six to fifteen intersex students in each school, many of whom want their peers to better understand intersex issues. SIPD is working with these schools to integrate intersex issues into pre-existing programs that focus on sexual development and life skills. They hope this will create greater understanding and acceptance, reduce the number of intersex students who drop out of school, and create a safe space for intersex youth.

and their parents to share their perspectives directly with medical professionals. Through these interactions and more targeted advocacy efforts, groups are promoting rights-based, non-pathologizing health care protocols and cultivating allies in the medical field willing to speak out against harmful practices. In Switzerland, the group **Zwischengeschlecht** played a key role in influencing the opinion published by the Swiss National Advisory Commission on Biomedical Ethics in 2012.⁶⁰ This groundbreaking report was among the first to acknowledge the harm inflicted by previous medical practices and recommend deferring surgery until the person concerned can make their own decisions.

Because students seldom learn about intersex variations in school, some groups are engaging their ministries of education and calling for the inclusion of information on intersex in national educational curricula. Several have taken on the task of education themselves by providing trainings for teachers and conducting workshops at secondary schools and universities, mainly in the context of sexual and reproductive health programs.

Building Legal Frameworks and Strengthening Human Rights Approaches

At the local and national levels, intersex groups are educating policy makers and advocating for laws and policies that recognize and protect the human rights of intersex people. The primary aim of many activists is to achieve a ban on non-consensual, medically unnecessary surgeries and treatment, using the Malta law as a model. To address the real and immediate health needs of intersex people, activists are also lobbying for access to health services and health insurance coverage. They are urging governments to include rights-based intersex information in health protocols and guidelines for physicians and other health workers.

Activists are also lobbying for the explicit inclusion of intersex (or sex characteristics) in anti-discrimination policies. In addition to targeting legislatures and ministries, groups are engaging other national bodies, such as equality and national human rights commissions, to promote recognition of intersex rights. In Hong Kong, for example, the organization **Beyond the Boundary—Knowing and Concerns Intersex** advocated successfully to the country's Equal Opportunities Commission to include intersex in its review of discrimination legislation and feasibility study on the possible creation of new protected characteristics. Some intersex groups are working to promote the right to gender identity, seeking greater provisions for intersex—and all people—to change their legal gender by advocating for

interACT (formerly known as Advocates for Informed Choice)



interACT activists at Pride.
Photo credit: interACT

interACT (formerly Advocates for Informed Choice) is based in the United States. This year, interACT is celebrating ten years of advocating for the human rights of children born with intersex traits

interACT Law & Policy uses innovative legal and other strategies, such as research and medical advocacy, to change laws and policies that discriminate against and harm intersex youth. interACT represents young people in institutional settings such as healthcare settings and schools, among others.

interACT puts an emphasis on youth leadership development and keeps children and youth at the heart of the organization's decision-making. **interACT Youth** is a powerful group of young people in their teens and twenties developing leadership skills and raising their individual and collective voices to raise intersex visibility and successfully change hearts and minds. Echoes of interACT Youth voices can be heard in media like the popular MTV television show, *Faking It*; during presentations at universities, medical schools, conferences; and at UN events.

interACT provides the opportunity for intersex people to be heard. Through media contacts and well-cultivated partnerships, **interACT Media** provides a venue for include the voices of intersex in various media to raise awareness about intersex issues. Espousing the belief that the only ones telling intersex stories should be intersex people, personal narratives and well-reasoned discussion are the hallmarks of interACT Media.

changes in policy or pursuing individual cases to amend identification documents. Groups have recently begun exploring strategic litigation as a strategy to advance some of these priorities. One such example is that of Dana Zzyym from **OII USA / Intersex Campaign for Equality**, who is suing the U.S. State Department for the right to have their gender accurately represented as neither male nor female on their passport.⁶¹

Many organizations are utilizing country review processes through the UN, using shadow reports and partnering with other civil society organizations to highlight the concerns of intersex people and bring pressure on their national governments. These include the Universal Periodic Review of the Human Rights Council as well as reviews by UN treaty bodies like the Committee on the Rights of the Child, the Committee against Torture, the Committee on the Rights of Persons with Disabilities, and the Committee on the Elimination of Discrimination against Women. Many of these efforts have resulted in strong recommendations to states to uphold the rights of bodily integrity, autonomy and self-determination, require informed consent, and pursue

investigation of non-consenting treatments. By engaging regional and international bodies, intersex groups are bringing visibility and a sense of urgency to these spaces. Most of the signs of progress at these levels—statements condemning violations of intersex children’s rights, calls for the development of legal frameworks—are a direct result of advocacy by intersex activists and their allies.

At the global level, the movement for intersex depathologization is closely monitoring the process of revision and reform of the International Classification of Diseases (ICD) at the World Health Organization. In 2014, GATE (Global Action for Trans* Equality) in partnership with ILGA convened in Geneva the first international meeting on intersex issues in the ICD reform process. After the meeting, a formal submission was sent to the WHO, highlighting the intrinsic connections among pathologizing categories, medically unnecessary treatment and human rights violations.⁶² In 2015, a second international intersex meeting reviewed the proposed new ICD terminology, and a new submission to the WHO is underway.



Natasha Jiménez of Mulabi Costa Rica. Photo credit: Arcus Foundation

CHALLENGES TO INTERSEX-LED ORGANIZING

Intersex-led organizations cite a range of obstacles in their work. There are the ever-present challenges of stigma, discrimination and invisibility of intersex issues in spite of their continued efforts. There are the problems of isolation, language barriers and limited opportunities for activists to come together. There is the common experience of co-optation or misrepresentation of intersex issues by others. **But far and away, the primary concern and challenge intersex groups emphasize is their limited access to funding.**

Some of the challenges in accessing funding are common to all grassroots organizations: many groups operate informally and some are not legally registered; they face language barriers in accessing calls for proposals; organizations working in high income countries are overlooked; and in places where civil society organizing is limited or threatened by the government, intersex rights activists, like other human rights activists, face restrictions in receiving direct funding.

But intersex organizations also face funding barriers that are particular to their situation. Only a handful of institutional donors have recognized the importance of funding work to promote the human rights of intersex people. This has much to do with the dominance of the medical discourse, which has prevented intersex issues from being widely recognized as human rights issues. Like the general public, many funders lack an understanding of the issues and believe that intersex variations are rare. For some donors, this translates to a perception that the population is “too small” to merit funding and attention. Often there is an assumption that LGBTQ groups are “covering” intersex issues or that

intersex concerns are automatically addressed when there is progress on issues related to sexual orientation or gender identity. Access to government funding is limited as well, since intersex rarely appears among government priorities.

All of this means that intersex-led organizations have extremely small budgets and face serious challenges to their sustainability. **A 2013 survey found that intersex-led groups have a median annual budget less than USD \$5,000 and that 90 percent of those groups have no cash reserves or savings to rely upon.**⁶³

One implication of this lack of access to funding is that organizations are predominantly volunteer run, with activists contributing their time and often personal resources as well. Those organizations that are able to access relatively significant amounts of funding primarily receive project-based grants. Organizations lack the flexible funding and operational support that enable investments in organizational sustainability (salaries, benefits, capacity development, etc.) or allow them to respond nimbly to new opportunities or challenges.

Another limitation intersex groups often face in building organizations has to do with the difficulties they face more generally in reaching and empowering intersex people. Simply finding other intersex people in the same place can be hard because individuals may not self-identify as intersex or feel a commonality with people who have different intersex traits. Further, few intersex individuals are willing to identify themselves publicly for fear of stigma, harassment or worse. This means that the number of intersex activists who are out remains relatively small; some of these activists are the only openly intersex person in their country, or



one of the few in their region. In Latin America, Asia and Africa, especially, where geographies are vast and the base of intersex leadership is small, this isolation can be especially pronounced. In some ways, it has contributed to the remarkable connectivity of intersex activists globally. With limited sources of support available locally, they have had to be notably proactive in building relationships and alliances across borders and regions. However, for many, challenges to local organizational development remain. Even when they are able to build a team of supportive individuals, which may include other intersex people, an organization's existence may still rely upon the leadership of one pioneering and committed intersex activist.

All of these pressures, alongside a host of issues related to safety and well-being, increase the risk of burnout for intersex activists. Intersex individuals face the emotional toll of public exposure and discrimination, as well as the effects of vicarious trauma experienced through providing peer support or relating stories of violations over and over. In addition, in some places, dehumanizing stereotypes and ignorance make it potentially dangerous for intersex leaders to do their work publically. As Fund advisor Nthabiseng Mokoena described it, "I knew the secrecy we were all raised under but I did not expect that speaking out would involve isolation and literal threat to my life at times."⁶⁴ It is remarkable that intersex activists have developed strong political capacities and made significant gains, despite these challenges.

Given all of this, the importance of intersex-only spaces for intersex leaders cannot be overemphasized—not only for strategizing and mobilizing, but also for affirming the realities of shared experiences and providing respite. Intersex advocates know very well the value of spaces for peer support for their communities, but too rarely find such spaces for themselves. The costs of international in-person

meetings can be prohibitive. With little access to funding and while trying to make good on numerous competing priorities, few organizations are in a position to advocate for such convenings. **OII Francophonie** offers an example of best practice. In conjunction with its participation in the annual Douarnenez film festival to highlight intersex issues, the group organized a week-long intersex-only residence for intersex artists and activists from around the world. This was specifically not a political meeting, but an opportunity for intersex individuals to engage with one another in a safe, positive and nurturing environment.

Alliance building with others also poses its own challenges. As part of a relatively nascent movement, intersex organizations are striving to find a balance between creating the space to foster intersex leadership and seizing opportunities to collaborate and leverage partnerships with other human rights groups. Relationships with other human rights organizations can be even more important where intersex visibility and organizing are just emerging or are limited by a conservative or repressive context. Many intersex activists understandably approach these relationships with caution, fearing misrepresentation or misappropriation of their agenda. While intersex issues are becoming more visible, understanding is still limited, providing ample opportunity for intersex to be used for other ends, inadvertently or not. One concern is that if nominally allied organizations receive funding on behalf of intersex people, without genuinely recognizing and supporting intersex-led activism, they will simply replicate the same structural injustices intersex people face elsewhere. For example, activists have witnessed LGBTQ groups without meaningful leadership or input from intersex people fundraising for intersex issues or incorrectly representing intersex as a sexual orientation or a gender identity instead of a set of bodily variations.

RECOMMENDATIONS TO FUNDERS

“Realise that the movement will achieve great things if you invest in intersex leadership, intersex organisations and intersex work. If you deliberately take the effort to increase the capacity of intersex organisations to lead, if you deliberately increase institutional funding instead of project funding, if you truly understand what self-care means for persons that have and continue to be the victims of medical and societal violence, then the movement...will survive with or without some of us.” — Nthabiseng Mokoena ⁶⁵

In the Malta Declaration, activists call upon funders to engage with intersex organizations and support them in the struggle for visibility, to help increase their capacity, build knowledge and affirm the human rights of intersex people. It is now up to funders to take the initiative to learn more about intersex issues and the work of intersex-led organizations.⁶⁶ Given the clear need for investment in the intersex movement and the flourishing opportunities for new partnerships, funders are encouraged to:

- 1. Fund organizations and projects led by and for intersex people.** Don't assume that the population is “too small” or that LGBTQ groups have got it covered. There is a vibrant and growing movement that needs our support now. In cases where intersex issues are being addressed by broader human rights organizations, make sure there is meaningful participation and leadership from as well as accountability to intersex people. Pay attention to ensure that you're supporting groups from diverse geographic and other backgrounds and reaching organizations with limited access to traditional sources of funding. If you look, you'll find them. Intersex-led groups and activists are working in almost all regions of the world to defend intersex people's rights to self-determination, bodily autonomy and physical integrity, and to be free from discrimination and violence.
- 2. Provide groups with flexible funds, including and especially core support.** Intersex-led organizations cite a range of obstacles in their work, but more than anything, groups struggle with limited access to funding. Only a handful of institutional donors have recognized the importance of supporting this work. We urgently need to expand that pool. Most intersex-led groups are volunteer run and have annual budgets of less than USD \$5,000. Despite funding challenges, intersex-led groups are growing their reach and impact every year. Flexible and general operating support is critical for their growth and sustainability, and to enable them to respond nimbly to new challenges or opportunities. With more partners and funding, they will be able to increase their impact and accelerate the potential for change.
- 3. Support intersex-led groups to pursue a range of strategies, including direct service provision, research, and advocacy.** More specifically, funders should support organizations to:
 - *Provide information, safe spaces and assistance to intersex people and parents of intersex children.* The stigma and shame projected onto intersex bodies has silenced and isolated too many people. Intersex-led groups are breaking through this barrier, using innovative methods to reach and empower intersex people around the globe. They are creating human rights-based resources, connecting intersex people with one another for the first time, and building a community that celebrates bodily diversity.
 - *Gather quantitative and qualitative information about the situation of intersex people in various parts of the world.* Violations of intersex people's human rights have been hidden from public view and there is an enormous lack of research into the prevalence and impacts of discrimination that intersex people face. Intersex-led organizations are leading the way with research that responds to the priorities and concerns of intersex people and that engages the intersex community meaningfully in the process.
 - *Raise awareness and educate the public and key stakeholders regarding the existence of intersex people and their concerns.* Far too few of us know about the specific human rights violations that intersex people experience, in large part because the medicalization

of intersex bodies has propagated shame and silence. Intersex activists are using everything from film and performance to conferences and protests to spread information about intersex issues and share the real life experiences of intersex people, and call for the respect of intersex people's human rights. Through education and training programs, they are sharing their expertise with teachers, religious leaders, medical professionals and policy makers.

- *Advocate for actions to respect, protect and fulfill the human rights of intersex people at the local, national, regional and international levels.* Few countries have explicit legal protections for intersex people. This means that human rights abuses are widespread and access to justice is almost non-existent. Intersex activists are campaigning for bans on non-consensual, medically unnecessary surgeries and treatment and lobbying for the explicit inclusion of intersex (or sex characteristics) in countries' anti-discrimination policies. They are working to promote the right of gender identity, seeking greater provisions for intersex—and all people—to change their legal gender. They are engaging in strategic litigation and calling for reparations for survivors of medical abuse. Within international human rights spaces, intersex-led groups are creating a new level of visibility and urgency regarding intersex people's human rights, and bringing pressure to bear on national governments.

4. **Fund and connect organizations to opportunities for capacity strengthening.** This includes organizational development, financial management and resource mobilization, as well as other areas that groups identify. Intersex-led groups know their own needs best. Funders should partner with organizations to link them to opportunities for development and growth. Too many intersex-led groups are operating with limited financial and human resources. They need the support to build the skills and knowledge that will boost their sustainability and open doors to new funding.
5. **Support movement building.** Provide funds and support intersex groups to hold convenings to strategize, deepen relationships, develop leadership and strengthen their ability to engage in collective action. The number of intersex activists in the world is relatively small, and most groups are the only intersex-led organization in their country—or even their region. Opportunities for in-person networking, skills sharing and planning are

vital. They enable groups to fortify their work at the local level and enable coordinated advocacy at the regional and international levels. Support activists to work together and multiply the remarkable gains they have made so far.

6. **Help groups promote the recognition of intersecting oppressions and develop partnerships and alliances with other human rights NGOs.** Many of the abuses intersex people experience are shared with other marginalized communities and are rooted in the same discriminatory beliefs and attitudes. Intersex-led groups have already made strides in building relationships with children's rights, LGBTQ rights and feminist organizations, and many are seeking to strengthen ties to disability rights organizations. Following the lead of intersex activists, funders can help to identify and leverage opportunities to increase connections across movements—based on key issues of self-determination, bodily integrity and physical autonomy.
7. **Promote organizational and movement sustainability through strategies to address the safety, security and well-being of activists.** Intersex activists face a high risk of burnout. They are often pursuing this work voluntarily and with a small team of supporters. In some places, an intersex activist may be the only openly intersex person in their entire country. In their public work, they contend with ridicule, discrimination and threats of violence. In providing counseling to other intersex people, they risk the effects of vicarious trauma. And this may be on top of dealing with their own health concerns related to unwanted medical treatments. Because of this, funders should support the creation of spaces for intersex leaders—not only for strategizing and mobilizing, but for experience sharing, rest and respite. In addition, funders should support activists to analyze and address safety and protection concerns.
8. **In collaboration with intersex activists, help raise awareness and build capacity among other funders and stakeholders to foster greater understanding and advance the human rights of intersex people.** Learn more about intersex people's human rights concerns and the incredible work of intersex-led organizations. Share what you learn with others. We all have a role to play in ensuring that intersex issues are recognized universally as human rights issues—and in illuminating their connections to the struggles of other marginalized communities.

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- 67 Information about the Intersex Human Rights Fund’s grantees can be found at <http://astraeaintersexfund.tumblr.com/>. A list of resources, many of which are referenced in this report, is available on the Astraea Foundation’s website at <http://www.astraeafoundation.org/uploads/IntersexResources.pdf> and on grantee partners’ websites.

STATEMENT BY THE THIRD INTERNATIONAL

PREAMBLE:

We affirm that intersex people are real, and we exist in all regions and all countries around the world. Thus, intersex people must be supported to be the drivers of social, political and legislative changes that concern them.

We reaffirm the principles of the First and Second International Intersex Fora and extend the demands aiming to end discrimination against intersex people and to ensure the right of bodily integrity, physical autonomy and self-determination.

IN VIEW OF THE ABOVE THE FORUM CALLS ON:

- 1 International, regional and national human rights institutions to take on board, and provide visibility to intersex issues in their work.
- 2 National governments to address the concerns raised by the Intersex Forum and draw adequate solutions in direct collaboration with intersex representatives and organisations.
- 3 Media agencies and sources to ensure intersex people's right to privacy, dignity, accurate and ethical representation.
- 4 Funders to engage with intersex organisations and support them in the struggle for visibility, increase their capacity, the building of knowledge and the affirmation of their human rights.
- 5 Human rights organisations to contribute to build bridges with intersex organisations and build a basis for mutual support. This should be done in a spirit of collaboration and no-one should instrumentalise intersex issues as a means for other ends.

INTERSEX FORUM {MALTA DECLARATION}

DEMANDS

- To put an end to mutilating and ‘normalising’ practices such as genital surgeries, psychological and other medical treatments through legislative and other means. Intersex people must be empowered to make their own decisions affecting own bodily integrity, physical autonomy and self-determination.
- To put an end to preimplantation genetic diagnosis, pre-natal screening and treatment, and selective abortion of intersex foetuses.
- To put an end to infanticide and killings of intersex people.
- To put an end to non-consensual sterilisation of intersex people.
- To depathologise variations in sex characteristics in medical guidelines, protocols and classifications, such as the *World Health Organization’s International Classification of Diseases*.
- To register intersex children as females or males, with the awareness that, like all people, they may grow up to identify with a different sex or gender.
- To ensure that sex or gender classifications are amendable through a simple administrative procedure at the request of the individuals concerned. All adults and capable minors should be able to choose between female (F), male (M), non-binary or multiple options. In the future, as with race or religion, sex or gender should not be a category on birth certificates or identification documents for anybody.
- To raise awareness around intersex issues and the rights of intersex people in society at large.
- To create and facilitate supportive, safe and celebratory environments for intersex people, their families and surroundings.
- To ensure that intersex people have the right to full information and access to their own medical records and history.
- To ensure that all professionals and health-care providers that have a specific role to play in intersex people’s wellbeing are adequately trained to provide quality services.
- To provide adequate acknowledgement of the suffering and injustice caused to intersex people in the past, and provide adequate redress, reparation, access to justice and the right to truth.
- To build intersex anti-discrimination legislation in addition to other grounds, and to ensure protection against intersectional discrimination.
- To ensure the provision of all human rights and citizenship rights to intersex people, including the right to marry and form a family.
- To ensure that intersex people are able to participate in competitive sport, at all levels, in accordance with their legal sex. Intersex athletes who have been humiliated or stripped of their titles should receive reparation and reinstatement.
- Recognition that medicalization and stigmatisation of intersex people result in significant trauma and mental health concerns.
- 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.



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