

**STANDING UP**

---

**FOR THE HUMAN**

---

**RIGHTS OF**

---

**INTERSEX**

---

**PEOPLE –**

---

**HOW CAN**

---

**YOU HELP?**

---

ILGA  
EUROPE 

**oii**  
EUROPE

Dan Christian Ghattas  
December 2015

**Standing up for the  
human rights of intersex people –  
how can you help?**

**Dan Christian Ghattas**



Rue du Trône/Troonstraat 60

1050 Brussels

Belgium

Telephone: + 32 2 609 54 10, Fax: + 32 2 609 54 19

[www.ilga-europe.org](http://www.ilga-europe.org)



[www.oiiurope.org](http://www.oiiurope.org)

Design & layout: Silja Pogule, [www.siljapo.com](http://www.siljapo.com)

Printer: Corelio Printing, [www.corelio.be](http://www.corelio.be)



Funded by the European Union



---

**ILGA-Europe** – the European Region of the International Lesbian, Gay, Bisexual, Trans and Intersex Association (ILGA) – is an international non-governmental umbrella organisation bringing together over 400 organisations from 45 European countries. ILGA itself was created in 1978. ILGA-Europe was established as a separate region of ILGA and an independent legal entity in 1996.

Our vision is of a world where dignity, freedoms and full enjoyment of human rights are protected and ensured to everyone regardless of their actual or perceived sexual orientation, gender identity, gender expression and intersex status.

**The two main pillars of ILGA-Europe’s work are:**

1. **advocating for human rights and equality** for LGBTI people at European level, before organisations such as the European Union, the Council of Europe and the Organization for Security and Co-operation in Europe (OSCE) in particular in relation to asylum, hate crime and hate speech, education, employment, family, freedom of assembly, association and expression, health, legal gender recognition and bodily integrity.

2. **strengthening the European LGBTI movement** by providing training and support to its member organisations and other LGBTI groups on advocacy, fundraising, organisational development and strategic communications and much more.

---

---

**OII Europe** (Organisation Intersex International Europe) is the umbrella organisation of European human rights-based intersex organisations. It was founded on Human Rights Day (10 December) during the Second Intersex Forum in Stockholm in 2012.

OII Europe is working for the protection and full implementation of intersex people's human rights in Europe and worldwide. OII Europe offers expertise on intersex human rights violations to EU and UN institutions. It also provides trainings and information for policy-makers, NGOs and the general public about the living situation of intersex people and the human rights violations they face. OII Europe is building a strong European movement by reaching out to intersex individuals, activists and organisations all over Europe; and helping them to advocate for intersex rights.

OII Europe is an autonomous affiliate of Organisation Intersex International (OII), a decentralised global network of intersex organisations. OII was founded in 2003 and since then has operated through its national groups in every region of the world.

---

## Table of contents

---

**8**

**Being intersex in Europe**

**18**

**Frequently asked questions**

**24**

**What can you do to help?**

**28**

**Annexes**

**32**

**Resources**

“

**Dear readers,**

Since the mid-1990s, a steadily growing number of intersex people in Europe and all over the world have found the courage needed to raise their voices and denounce the human rights violations suffered by intersex people. In order to do this, they had to overcome secrecy, shame, pathologisation or self-pathologisation and society's vast knowledge gap about the concerns (or even the sheer existence) of intersex people. Such challenges were – and still are – hard to overcome.

But the world is changing. The year 2015 has been a turning point in Europe, with Malta becoming the first country in the world to protect intersex people's physical autonomy and bodily integrity on the ground of 'sex characteristics' on 1 April. Malta and Greece (since 24 December) became the first countries in Europe to explicitly protect intersex people against discrimination.

2015 was also the year of two landmark documents: the Council of Europe (CoE) Commissioner for Human Rights' issue paper "Human Rights and Intersex people", and the EU Agency for Fundamental Rights (FRA) focus paper "The fundamental rights situation of intersex people". Both documents confirm that sex 'normalising' treatments are still taking place without consent all over Europe.

The cornerstone of successful advocacy is knowledge. If you want to know how you can work for change, this toolkit will help. It will explain the major challenges intersex people face in different areas of life, set out intersex people's demands, provide information about current political developments, as well as give advice on how to become a great intersex ally.

We thank ILGA Europe for making this toolkit possible and for their ongoing and dedicated support in advocating for intersex human rights. We thank the European Commission for providing the funds needed to undertake this task.

**Dan Christian Ghattas,  
Miriam van der Have**

Co-Chairs OII Europe

”

“

**Dear readers,**

Thanks to the brave and dedicated work of intersex activists across Europe, the silence and low general awareness that previously surrounded intersex issues have been replaced by increased interest from NGO allies and policy-makers, more media coverage and strong political statements.

Once people find out about the human rights violations and life experiences of intersex people, their first reaction is to ask: How can I become an intersex ally? What can I do?

Since we added the 'I' to our mission in 2008 and co-organised the first European Intersex Forum in 2011, we, at ILGA-Europe, have been asking ourselves the same questions. We have gone through a great process of learning and relationship building in partnership with OII-Europe. This learning process has been reinforced by the annual Intersex Forum, ongoing contacts with intersex activists and trainings for ILGA-Europe staff and member organisations. And we are still learning every day.

Throughout the year, we have seen a growing interest in intersex issues from a number of human rights institutions, equality bodies, policy makers, health professionals, teachers, NGOs, and of course LGBT activists. We are encouraged by their willingness to join us in this attempt to learn about intersex issues, thus becoming strong allies in the fight for intersex human rights.

We hope that this tool-kit will help to inform all our allies and be a starting point for many conversations.

Intersex has become an integral part of our human rights work. Now we would like to encourage you to include intersex in your human rights efforts too.

”

**Evelyne Paradis**

Executive Director of ILGA-Europe

**BEING**

**INTERSEX**

**IN**

**EUROPE**

# Who are intersex people?

Intersex individuals are born with sex characteristics (such as chromosomes, genitals, and/or hormonal structure) that do not belong strictly to male or female categories, or that belong to both at the same time. Doctors often advise parents to perform surgical and other medical interventions on intersex new-borns and children, to make their body (seemingly) conform to male or female characteristics. In most cases, such interventions are not medically necessary and can have extremely negative consequences on intersex children as they grow older.

'Intersex' stands for the spectrum of variations of sex characteristics that naturally occur within the human species. It also stands for the acceptance of the physical fact that sex is a spectrum and that people with variations of sex characteristics other than male or female do exist.

Historically, the term 'intersex' was used as if it was as a disorder that needed medical intervention to 'fix it'. In the past two decades, the term has been reframed and established by intersex human rights defenders and their organisations as the human rights-based umbrella term.

Our sex characteristics are set out from birth, whether we are intersex or not. However, the fact that someone has an intersex body can become apparent at different times in their life: at birth, during childhood, in puberty or even in adulthood. Depending on the specific life circumstances and the degree of taboo in their environment, a person might learn that they have an intersex body at a very early age or later in life. Some intersex people never find out at all.

## What is the main problem faced by intersex people in Europe today?

In a world where the overwhelming majority of people and governments only know and accept two sexes ('male' and 'female') the existence of intersex people and their bodies is not recognised. Instead, healthy intersex bodies are considered to be a 'medical problem' and a "psycho-social emergency"<sup>1</sup> that needs to be fixed by surgical, hormonal, other medical and sometimes psychological means.

According to a ground-breaking 2015 FRA focus paper on the fundamental rights situation of intersex people in the European Union, 'normalising' surgery is carried out on intersex children in at least 21 Member States.<sup>2</sup> This situation is mirrored all over the world.<sup>3</sup>

<sup>1</sup> Ladee-Levy JV.: Ambiguous genitalia as a psychosocial emergency In: Z Kinderchir. 1984 Jun;39(3):178-81.

<sup>2</sup> In 8 Member States, a legal representative can even consent to sex 'normalising' medical interventions if the minor is old enough to decide. European Union Agency for Fundamental Rights: FRA Focus Paper. The Fundamental Rights Situation of Intersex People. Vienna 2015, p. 1.

<sup>3</sup> Dan Christian Ghattas: Human Rights between the sexes. A preliminary study on the life situations of inter\* individuals. Ed. by Heinrich Böll Foundation. Berlin 2013.

# WHAT IS IT LIKE TO BE INTERSEX IN EUROPE TODAY?

## Human rights violations faced by intersex people during their lifetime – examples:

All over Europe, intersex people face pathologisation and extreme violations of their human rights. Because being intersex is seen, in itself, as a disorder, when pre-implantation diagnosis or pre-natal screening show a risk of variation of sex characteristics in embryos and foetuses, the latter may be prevented from further developing. In other cases, prenatal treatment with high-risk off-label use medication (dexamethasone) is prescribed.

After birth, as children, adolescents and adults, intersex people face violations of their physical integrity, including medical interventions without personal, prior, persistent and fully informed consent. This can cause psychological trauma as well as severe physical impairments, ranging from painful scar-tissue or lack of sensation to osteoporosis and urethral issues. Intersex children face the risk of a disturbed family life due to taboo and medicalisation. They are also at risk of dropping out of school, due to the effects of medical treatments and bullying.

Intersex adults may have difficulty finding a job due to lack of education, physical impairments or a lack of self-esteem caused by social stigma. There is a reported higher risk of poverty due to lack of education as a result of pathologisation and related trauma. At every age, intersex people can face stigma, structural and verbal discrimination, harassment, lack of adequate medical care, lack of access to needed medication, lack of legal recognition, and the invisibility of their bodies in our society.

When growing older, just like anyone else, intersex people need to rely on the health sector much more. However, because they had to undergo traumatising treatments in the past, becoming dependent on health services is very challenging for them. In addition, there is very little information on how their health may be affected by the treatments they took for most of their lives.

---

<sup>4</sup> “Off-label-use” means the use of medication outside of the originally tested and licensed indication.

## Access to healthcare and violence in medical settings

Access to general healthcare is often impaired by prejudices of healthcare professionals and the refund policies of health insurance companies. This is particularly true where accessibility to particular services (e.g. availability of preventive check-ups for certain conditions or general health services) is related to the sex/gender of the individual seeking the service or where the medical history of a person matters (e.g. life insurance, private health insurance, own-occupation disability insurance).

Disbelief, prejudices and disgust expressed by health care personnel can lead intersex people to avoid seeking healthcare. They can also lead health professionals to deny intersex people access to health services. Such incidents have been reported to OII Europe and its member organisations from all over Europe. Contrary to what medical advice often suggests, having sex-altering surgery does not help intersex people to avoid these barriers to health services in later life: incidents have been reported both by intersex individuals who have had surgery and by those who have not.

Intersex individuals have repeatedly reported physical and psychological abuse by medical staff (e.g. unconsented examination, rough use of examination tools or blaming intersex people for deliberately not cooperating when their bodies did not allow the traditional examination to take place).

Other common issues faced by intersex people in Europe are a lack of access to hormone substitution (after the surgical removal of a hormone producing tissue) or a hormone substitution which does not fit the real needs of the person's body (and instead aims to enforce the assigned sex of female or male).

<sup>5</sup> With the exception of the Maltese 'Trans, gender-variant and intersex students in schools policy' and the Icelandic queer education program that is brought to schools with the long-term goal of implementing it in the regular curriculum.

## Education

Problems can exist for intersex people in educational settings from the very outset. To start with, intersex people are not constructively included in any educational curriculum.<sup>5</sup> Most often, they do not appear at all. If they are mentioned, they find themselves treated as an imaginative product of mythology (hermaphrodite), as an example of abnormality or viewed in a pathological way (in biology texts, medical handbooks or encyclopaedias).

In addition, sex education does not refer to their existence or their bodily experience. Instead, it tends to perpetuate the notion that only two sexes exist. These experiences increase the feeling of shame, secrecy, not existing at all or being a fraud at a vulnerable age.

Moreover, intersex students may face direct discrimination at school and in further education if their gender expression, stature or other parts of their appearance do not conform with the female or male norm. Intersex individuals have reported bullying at school on those grounds (e.g. use of derogatory language, psychological and physical violence). Places where the body becomes visible to others, such as toilets and changing rooms, are common areas of anxiety and reported harassment, regardless of whether the intersex person has had a so-called 'normalising' surgery performed on them or not.

On an even more alarming level, intersex individuals also face educational impairments directly linked to the violation of their bodily integrity. Most surgeries, which are performed at an early age, lead to several follow-up operations over the years. These are often performed during the school holidays, at the expense of the child's need to relax and have fun. Some children drop out of school as a result of this long-term recovery process. Unwanted hormonal treatment, in childhood or puberty, with the aim of altering the body towards the assigned sex has also been reported to coincide with a decrease in school grades.

This physical and psychological strain often prevents intersex people from developing their full potential and leads to under-achievement at school. As a result, these children and young adults face significant difficulties in obtaining a higher education degree and are at risk of poverty when growing older. Intersex people who manage to achieve higher education still struggle with the combined impact of the human rights violations they experienced and the discrimination they still face in adulthood.

# Intersex people drop out of school

A recent Australian study gathering data on 272 intersex individuals, aged 16-85+, showed that only a quarter of participants rated their overall experience at school positively. The overwhelming majority of participants (92%) did not attend a school with inclusive puberty/sex education. Overall, 18% of people with variations of sex characteristics had primary school education only (compared to 2% of the general Australian population). Many participants (66%) had experienced discrimination ranging from indirect to direct verbal, physical or other discriminatory abuse. Well-being risks were reportedly high.<sup>6</sup>

## Employment

Challenges faced by intersex people in school often continue into their working life, perpetuating taboo, secrecy and shame. They can be victims of direct or indirect discrimination and harassment because of their physical appearance or gender expression.<sup>7</sup>

When applying for a job, intersex people might need to explain gaps in their education or employment history, resulting from times where they were hospitalised or when they were not able to work due to depression or trauma. Past and ongoing treatments have an impact on the physical and psychological well-being of the person and directly reduce their ability to work.

Employee medical checks can be extremely difficult for intersex people; especially when the medical practitioner in charge is not educated about the existence of intersex individuals at all or considers intersex people to have a disorder of sex development. When applying to join some professions (e.g. police force, fire fighters), intersex people have reportedly been rejected on the grounds of their DSD diagnosis and/or the surgeries they had been subjected to without their consent.

Once they secure employment, intersex people have reported intrusive curiosity about their body from co-workers.<sup>8</sup> Some intersex people who dared to open up about their intersex body have reported disbelief and rejection by colleagues and superiors.<sup>9</sup> Just as in education, the strain of discrimination and

stigmatisation leads to higher absence rates, increasing the risk of intersex people losing their job.

Some intersex people have obtained a disability status due to the physical impairments they have as a result of unconsented surgery. Depending on the country, this status can offer some protection, but it can also come at the cost of additional discrimination and stigma as a disabled person.<sup>10</sup>

<sup>6</sup> UNESCO TH/DOC/HP2/15/042, p. 38, <http://unesdoc.unesco.org/images/0023/002354/235414e.pdf>

<sup>7</sup> Unpublished interviews conducted by the project "Antidiskriminierungsarbeit und Empowerment für Inter\*" with intersex people living in Germany. A summary of the results can be found at [https://interprojekt.files.wordpress.com/2015/09/interprojekt\\_konzept.pdf](https://interprojekt.files.wordpress.com/2015/09/interprojekt_konzept.pdf)

<sup>8</sup> OII Australia, *Pride in Diversity (2014): Employers' Guide to Intersex Inclusion*, p. 17. <https://oii.org.au/wp-content/uploads/key/Employer-Guide-Intersex-Inclusion.pdf>

<sup>9</sup> The Netherlands Institute for Sociological Research: *Living with intersex/ DSD An exploratory study of the social situation of persons with intersex/ DSD*. Written by Jantine van Lisdonk. 2014, p.56.

<sup>10</sup> OII Europe (2015): *Statement of OII Europe on Intersex, Disability and the UN Convention on the Rights of People with Disabilities*. [http://oiieurope.org/wp-content/uploads/2015/05/CRPD\\_2015\\_Statement\\_OII\\_Europe.pdf](http://oiieurope.org/wp-content/uploads/2015/05/CRPD_2015_Statement_OII_Europe.pdf)

## Discrimination in other areas

Intersex people are at risk of discrimination when their gender appearance does not fit within social norms of so-called male and female bodies. As a result, they may face harassment or discriminatory practices in all areas of life, including when accessing goods (e.g. medicine, clothes, cosmetics) and services (e.g. fitness club, hotels rooms, flight tickets).

## The human rights of intersex people at stake

Right to life, Prohibition of torture, inhuman and degrading treatment, Right to self-determination and bodily integrity, Right to private and family life, Non-discrimination, Right to an effective remedy, Right to information, Freedom of expression...

## Legal recognition

While growing up, intersex individuals may find that the sex they were assigned at birth through official registration (and often after medical treatments) does not fit their own gender identity. The process that individuals have to go through to access gender recognition varies greatly between European countries. If legal gender recognition is available at all, the procedure often requires intersex people to declare themselves as trans in order to change their gender marker. In some countries, the requirements for legal gender recognition may prevent people with an intersex-related medical diagnosis from using those legal procedures, most often leaving them in legal limbo.

## What do intersex people want?

The unanimous demands of the international intersex human rights movement were laid out in the *Declaration of Malta* at the 3rd International Intersex Forum in 2013.<sup>11</sup> The Declaration demands that an **end is put to mutilating and 'normalising' practices** such as genital surgeries, psychological and other medical treatments. Instead, intersex people must be empowered to make their own decisions about issues that affect their bodily integrity, physical autonomy and self-determination.

Practices like infanticide and killings of intersex people are happening in some parts of the world, but not in Europe. However, the fact that, in Europe, the pathologisation of intersex increasingly leads to pre-implantation genetic diagnosis, pre-natal screening and treatment, and selective abortion of intersex foetuses is concerning. These abuses result directly from the notion that intersex bodies are disordered. The Declaration therefore calls for **depathologising variations in sex characteristics** in medical guidelines, protocols and classifications, such as the World Health Organization's International Classification of Diseases.<sup>12</sup>

The Malta Declaration also emphasises that **creating and facilitating supportive, safe and celebratory environments** for intersex people, their families and surroundings is key. This

<sup>11</sup> <http://oiieurope.org/public-statement-by-the-third-international-intersex-forum/>

<sup>12</sup> See also the report 'Intersex Issues in the ICD' (2014). The submission addresses specific concerns related to intersex issues in the ICD reform process. <http://wp.me/a1djE5-aw>

includes enacting anti-discrimination legislation protecting the ground of sex characteristics and ensuring that intersex people are protected against intersectional discrimination. It also means ensuring the provision of all human rights and citizenship rights to intersex people, including the right to marry and form a family and the right to have documents that reflect the person's gender identity.

In relation to the injustice and suffering caused to intersex people in the past, the Declaration calls for **providing**

**adequate redress**, reparation, access to justice and the right to truth. This means that intersex people must have the right to full information and access to their own medical records and history.

Medicalisation and stigmatisation of intersex people results in significant trauma and mental health concerns. It is important to ensure that **non-pathologising psycho-social and peer support** should be available to intersex people as required throughout their life, as well as to parents and/or care providers. should be available to intersex people as required throughout their life, as well as to parents and/or care providers.

---

## The legal situation in Europe

---

Unfortunately, Europe is not a safe place to be for intersex people. Despite the growing attention that intersex issues receive in some countries, intersex people have remained mostly invisible all over Europe. Furthermore, there is a huge lack of non-pathologising information on intersex. Intersex people are at risk of being considered as disordered in all areas of life.

Apart from Malta and its *Gender Identity, Gender Expression and Sex Characteristics Act 2015*, no other European country has enacted provisions to ensure the physical integrity, bodily autonomy and self-determination of intersex individuals in protected.

The Maltese Act, adopted in April 2015, is currently the leading example of best practice worldwide on how to ensure the protection of intersex individuals. The Act provides protection on the ground of sex characteristics in equal treatment legislation and in anti-hate crime and hate speech provisions in the Criminal Code.

Importantly, the bill outlaws any “medical intervention which is driven by social factors, without the consent of the individual concerned”. In addition, the law establishes the right to access psychosocial support as well as peer support and allows for every person to have their gender identity legally recognised or changed by a simple administrative procedure.

---

<sup>13</sup> Malta (2015), Act for the recognition and registration of the gender of a person and to regulate the effects of such a change, as well as the recognition and protection of the sex characteristics of a person, Art.

<sup>14</sup> States of Jersey (2015), Discrimination (Sex and Related Characteristics) (Jersey) Regulations 201, Par. 7.3.

<sup>15</sup> Basque Country Act 14/2012; Scottish Offences (Aggravation by Prejudice) Act. The latter will be reviewed in 2016.

<sup>16</sup> Austria, Denmark, Netherlands (gender); Romania, Slovenia (gender identity); Sweden (gender and gender identity); see: European Union Agency for Fundamental Rights: FRA Focus Paper. The Fundamental Rights Situation of Intersex People. Vienna 2015, p. 4.

<sup>17</sup> Bulgaria, Estonia, Hungary, Italy, Luxembourg, Poland, Portugal, Romania, Spain and Slovakia; see: European Union Agency for Fundamental Rights: FRA Focus Paper. The Fundamental Rights Situation of Intersex People. Vienna 2015, p. 4.

**Iceland** is working towards legislation similar to the Maltese law. It proposes including protection of a person's bodily integrity and self-determination on the ground of sex characteristics. It also plans to offer protection from hate crime and hate speech as well as protection in the area of employment, goods and services and other spheres of life on the basis of gender identity, gender expression and sex characteristics.



**Finland** revised its Gender Equality Act in 2015, which now also covers "gender features of the body" which is meant to protect intersex people against discrimination.

**The island of Jersey** adopted discrimination regulations in 2015, introducing 'intersex status' as being covered by the new protection ground of 'sex' in their Discrimination (Jersey) Law of 2013.<sup>14</sup>

The **Basque Country in Spain** and **Scotland in the United Kingdom** have taken the first steps at regional level towards explicitly protecting intersex people against discrimination by referring to intersex under the ground of gender identity.<sup>15</sup> Some countries in Europe implicitly cover intersex under the ground of gender and/or gender identity.<sup>16</sup> Other European countries have an open list of grounds of discrimination, offering the ground of 'other', which could be used to protect intersex people.<sup>17</sup> However, in the absence of any case law, this ground remains untested. Considering the lack of social and legal visibility of intersex people, using the ground of 'other' in this way needs to be preceded by educating society and stakeholders on intersex issues.

**Malta** and, since 24 December 2015, **Greece** are the only countries in Europe to explicitly provide protection against discrimination on the ground of 'sex characteristics'. The Maltese Act requires public services to eliminate unlawful discrimination and harassment and to promote equality of opportunity for all, irrespective of these characteristics.<sup>13</sup>

## Data Collection

Intersex people have only started to speak up in the last 20 years about who they are and the often terrifying experiences they have gone through. Just like society as a whole, administrations and research institutes are largely unaware of the existence of intersex people. During the launch of the EU Agency for Fundamental Rights' focus paper in 2015, the unprecedented hardship in collecting data and the general lack of statistical data were highlighted as two of the most important findings of the study.<sup>18</sup>

There is a great need for general data collection as well as surveys on the psychological and physical living situation of intersex individuals. All research needs to be conducted from a sociological and depathologising human rights perspective. Data collection therefore should preferably be co-conducted by intersex scholars and/or in collaboration with intersex organisations; it should also acknowledge and remunerate their expertise.

Most of the few psycho-social surveys that do exist were conducted by medical practitioners and/or psychologists. When reviewing their findings, it is important to acknowledge that respondents may have

been traumatised by earlier medical treatments and find a medical setting an overwhelming place to be interviewed in. Respondents may also have felt uncomfortable with the interviewers themselves. It is also very likely that those most negatively affected by medical treatments will not even have been willing to take part in the interviews in the first place, depriving the surveys of highly relevant responses. However, even in this limited number of surveys (and taking these potential information gaps into account) the percentage of participants who reported severe problems related to medical intervention is substantial.

## Intersex people's mental and physical health

**A German study conducted by a medical team between 2005 and 2007 covered the experiences of 439 intersex individuals of all ages, from Germany, Austria and Switzerland. 81% had been subjected to one or multiple surgeries due to their DSD diagnosis. Almost 50% of the participating adults reported psychological problems and a variety of problems related to their physical well-being and their sex life. Two-thirds made a connection between those problems and the medical and surgical treatment they had been subjected to. Participating children reported significant disturbances, especially within their family life and in relation with their physical well-being.<sup>19</sup>**

**These findings are worrying. A study performed with a focus on children's rights and human rights may have led to even more disturbing outcomes.**

<sup>18</sup> Rights: FRA Focus Paper. The Fundamental Rights Situation of Intersex People. Vienna 2015, p. 4.

European Union Agency for Fundamental Rights: FRA Focus Paper. The Fundamental Rights Situation of Intersex People. Vienna 2015, p. 5.

<sup>19</sup> Netzwerk Intersexualität (Ed.): Erste Ergebnisse der Klinischen Evaluationsstudie im Netzwerk Störungen der Geschlechtsentwicklung/ Intersexualität in Deutschland, Österreich und Schweiz Januar 2005 bis Dezember 2007. [http://www.netzwerk-dsd.uk-sh.de/fileadmin/documents/netzwerk/evalstudie/Bericht\\_Klinische\\_Evaluationsstudie.pdf](http://www.netzwerk-dsd.uk-sh.de/fileadmin/documents/netzwerk/evalstudie/Bericht_Klinische_Evaluationsstudie.pdf)

---

# Funding

---

The rising number of visible intersex activists and the establishment of intersex organisations have helped to raise awareness of the issues faced by intersex people. Through this awareness raising, intersex activists have created momentum for change. Policy-makers, governments and international institutions are now becoming interested in exploring how to ensure the protection of the human rights of intersex people. As welcome as this development is, it means a heavy workload on intersex activists and intersex organisations that work with minimal (or non-existent) budgets.

According to a 2013 study conducted on 'The State of Trans\* and Intersex Organizing'<sup>20</sup>, intersex organisations are underfunded worldwide, including in Europe. Intersex human rights organisations and groups were found to have a median annual budget of \$0 - \$ 5,000; a budget which by no means matched their extensive work portfolio. Although the situation has improved slightly, with the establishment of the Astraea Intersex Human Rights Fund<sup>21</sup> in 2015, all intersex organisations in Europe are struggling with a lack of resources. In order for intersex organisations to be able to support policy makers, there is a need to support their capacity.

Intersex organisations are key to providing the experience and expertise regarding the lived experience of intersex people. When working for the protection of the fundamental rights of intersex people, European institutions, governments and equality bodies must work with intersex organisations.

---

<sup>20</sup> The State of Trans\* and Intersex Organizing. A case for increased support for growing but under-funded movements for human rights. Published by Global Action for Trans Equality together with American Jewish World Service and Strength in Numbers. [http://ajws.org/wp-content/uploads/2015/05/ajws\\_trans-intersex-funding-report.pdf](http://ajws.org/wp-content/uploads/2015/05/ajws_trans-intersex-funding-report.pdf)

<sup>21</sup> The first of its kind, the Astraea – Lesbian Foundation for Justice – Intersex Human Rights Fund supports organisations, projects and campaigns led by intersex activists working to ensure the human rights, bodily autonomy, physical integrity and self-determination of intersex people worldwide.

**FREQUENTLY**

---

**ASKED**

---

**QUESTIONS**

---

## How many people are intersex?

---

Previous estimates referred to 1 in 2000, 1 in 4000, 1 in 5000 or less, depending on the variation they focus on. However, a recent Dutch study compared existing medical sources and found a much higher prevalence.

The total prevalence lies with 0.5078 %. This means that 1 person in 200 has a variation of sex characteristics which, according to the medical norm, falls in the category of “Disorder of Sex Development” and “needs” medical attention as a psychosocial emergency.<sup>22</sup>

---

## Do intersex people define themselves as men or women or as intersex/ a third sex?

---

According to existing statistics, most intersex individuals have a male or female gender identity and this suggests that they do identify as men or women. However, as intersex individuals are usually forced by medical intervention and by social pressure to perform as ‘male’ or ‘female’, developing a gender identity other than male or female can be a particular challenge.

---

## Is intersex a gender identity?

---

People with an intersex body can have as many gender identities (and sexual orientations for that matter) as people with a non-intersex body. Some intersex people have an intersex gender identity.

Intersex people are still very much invisible in our society. People who do not have an intersex body and want to use ‘intersex’ to describe their gender identity, should be aware of the fact that, unfortunately, they are actually making intersex human rights violations less visible.

---

## Does being intersex mean that the sex of the person is unspecified/ unclear/ unknown?

---

No. It is only the current practice of only recognising two sexes, male and female, that leads to categorising intersex as “unspecific”. Equating intersex with an unclear or unknown sex is disrespectful and deprives intersex people of the rightfulness of their body. This false judgement also leads to the fact that their right to bodily integrity is often violated by unconsented medical treatments.

---

---

<sup>22</sup> The Netherlands Institute for Sociological Research: Living with intersex/DSDAn exploratory study of the social situation of persons with intersex/DSD. Written by Jantine van Lisdonk. 2014 (see: Appendix B Prevalence table for intersex/dsd).

# What does DSD mean?

DSD means Disorder of Sex Development. It is a medical umbrella term, which was introduced in 2006 by a Clinician Consensus Statement. Together with new categories of syndromes, it replaced the older medical terms. The term refers to intersex sex characteristics as characteristics that are 'deviant' from the norm of male and female bodies and thus need to be 'disambiguated' or 'fixed'.

The idea of "disorder of sex development" pathologises intersex people and their bodies. DSD language is used to justify 'normalising' medical treatments to make intersex bodies conform to medical and social norms. In an effort to avoid the pathologising connotations of 'disorder', some clinicians use DSD to stand for "differences of" or "diverse" sex development.

## What are the important differences and commonalities between intersex and trans people?

### The most important differences are:

Intersex is about the body: being intersex means to be born with sex characteristics that do not conform to the medical and societal norms of so-called male and female bodies. Trans is about gender identity: being trans means to have a gender identity that is other than the gender/sex assigned at birth. Most people who are trans were born with a body that matches with the medical and societal norms of so-called male and female bodies.

Intersex people are subjected to invasive, irreversibly treatment without their consent.

Trans people often seek medical interventions to adjust their body to their gender identity but face problems getting the medical care they need.

**Please note:** Intersex individuals may have a gender identity that does not match the sex that was enforced on them at birth. As a result, they may decide to use the legal mechanisms available in their country to adjust their name, gender marker and/or body to their personal comfort zone. Very often the only mechanisms available are those available to trans people. In practice though, some intersex people can be prevented from accessing those mechanisms, depending on legal or other requirements for each of those steps in their country.

### The most common similarities are:

Both lack recognition of their fundamental right to self-determination. Intersex people because they are subjected to invasive medical treatment without their consent; trans people because they often face massive hurdles in obtaining the medical care they need as well as the recognition of their gender.

Both are considered to have a "disorder" according to medical guidelines, protocols and classifications (although trans people have to deal with a "psychological disorder" whereas intersex persons are attested to have a "physical disorder")

Both suffer from discrimination and human rights violations in a society where the dichotomy of male and female prevails, e.g. in school, at the workplace or when practicing sport.

# If doctors say that the ‘true’ sex of a child is male or female, would that child benefit from treatments that align their intersex body with that sex?

**There is no such thing as identifying a ‘true’ sex at birth.**

The two categories of seemingly ‘true’ sex (i.e. male and female) do not reflect the entire spectrum of sex characteristics. Treatments that aim to alter the sex characteristics of a child artificially towards female or male are a clear violation of the child’s right to physical autonomy and bodily integrity. The UN Committee on the Rights of the Child, among others, has denounced “medically unnecessary surgical and other procedures on intersex children, without their informed consent, which often entail irreversible consequences and can cause severe physical and psychological suffering” as a harmful practice<sup>23</sup> and a clear violation of the human rights of the child.

It is also impossible to foresee the future gender identity of any child, including intersex children<sup>24</sup>. Intersex people might at later stage in their lives decide to undergo treatment to align their bodies with their gender identity. But only intersex people themselves should make these informed decisions.

# Isn’t it true that medical practitioners are abstaining more and more from performing unnecessary surgery?

There is a growing awareness among practitioners that surgeries on intersex children should be postponed until the child can decide for themselves. However, this thinking does not apply to all intersex children. There is a tendency within the medical establishment to reserve this cautiousness only for some intersex variations and DSD diagnoses (e.g. intersex individuals diagnosed with CAIS<sup>25</sup>). Other intersex individuals (e.g. intersex children with XX-chromosomes and a CAH<sup>26</sup> diagnose) are still considered to ‘benefit’ from early invasive cosmetic treatment.

In practice, some medical professionals now claim that they don’t operate on intersex children anymore, defining ‘intersex’ as those children whose sex they do not consider determinable. In fact they are still performing surgeries on intersex children; they are operating on those whose sex they consider determinable via medical measures. It is crucial to understand that the unconsented treatments performed on this latter group are deeply invasive treatments, which lead to scar tissue, loss of sensation, multiple follow up surgeries, problems with hormonal balance, trauma and other physical and psychological impairments.

<sup>23</sup> CRC/C/CHE/CO/2-4, para. 42.

<sup>24</sup> Of the participants of a medical research study on intersex individuals of 12 years and older with different DSD related diagnoses, a substantial percentage rejected the gender they were assigned to at birth. Instead of acknowledging that the assignment had obviously been proven to be wrong, the researchers interpreted the findings as gender dysphoria. See: **de Vries A, Doreleijers T, Cohen-Kettenis P.** Disorders of sex development and gender identity outcome in adolescence and adulthood: understanding gender identity development and its clinical implications. *Pediatric Endocrinology Reviews.* 2007;4(4):343-351.

<sup>25</sup> CAIS stands for Complete Androgen Insensitivity Syndrome.

<sup>26</sup> CAH stands for Congenital Adrenal Hyperplasia.

## Why do parents consent to such interventions?

---

Research has demonstrated that parents are often ill-informed and under pressure at the time when consent is sought. They do not always have adequate time or information to provide genuinely informed consent.<sup>27</sup> Medical professionals may be quick to propose 'corrective' surgeries and treatments aiming to 'normalise' the sex of the child, even when such surgeries are unnecessary and merely cosmetic.<sup>28</sup> Those parents that are provided with medicalised information are almost three times more likely to consent to surgery than those that receive non-medicalised information.<sup>29</sup>

---

## Do intersex people want an X in their passport to reflect their variation of sex characteristics?

---

That depends on the individual. The majority of intersex people do not have an issue with having a male or female gender marker in their official documents, even if it does not reflect their gender identity. However, options other than 'male' and 'female' should be available for all individuals regardless whether they are intersex or not, and official documents should be amendable by a simple administrative procedure at the request of the individual concerned.

## Do you recommend assigning intersex children to a third sex or leaving the gender marker entry open?

---

No, not when this option is compulsory for intersex children and unavailable to all other children. Assigning a third sex by law to an intersex child will out the child as intersex in any situation where their birth certificate has to be provided. If it is only available to intersex children, it is just another label that segregates them from the rest of society. As a result, the pressure on parents to choose medical measures in order to make the child eligible for one of the two categories (male and female) might even increase.<sup>30</sup>

Instead, providing the options for all parents to leave the sex/gender entry open for their child would promote the equality of all sexes and genders. This improves the situation for intersex children and non-intersex children alike. As long as this possibility is unavailable, OII Europe recommends registering 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.

---

<sup>27</sup> State of Victoria, Department of Health (2013), *Decision-making principles for the care of infants, children and adolescents with intersex conditions*, pp. 2 [http://docs.health.vic.gov.au/docs/doc/0D331CCCA75EE85ACA257B1800707957/\\$FILE/Final%20Intersex%20Conditions%20Resource.doc](http://docs.health.vic.gov.au/docs/doc/0D331CCCA75EE85ACA257B1800707957/$FILE/Final%20Intersex%20Conditions%20Resource.doc)

<sup>28</sup> Charlotte Greenfield (8/7/2014), *Should We 'Fix' Intersex Children?*, The Atlantic <http://www.theatlantic.com/health/archive/2014/07/should-we-fix-intersex-children/373536/>

<sup>29</sup> Jürg C. Streuli, Effy Vayena, Yvonne Cavicchia-Balmer & Johannes Huber (2013), *Shaping parents: impact of contrasting professional counseling on parents' decision making for children with disorders of sex development*, *Journal of Sexual Medicine*, Vol. 8 No. 3, pp. 1953–1960 <http://www.ncbi.nlm.nih.gov/pubmed/23742202>

<sup>30</sup> For details see also OII Germany: Sham package for Intersex: Leaving sex entry open is not an option <http://oiieurope.org/bluff-package-for-inter-leaving-sex-entry-open-is-not-an-option/>

# How can intersex be included in anti-discrimination legislation?

---

OII Europe and its national member organisations recommend the adoption of anti-discrimination legislation on the ground of 'sex characteristics' – regardless of the specific appearance or configuration of these characteristics. The Maltese *Gender Identity, Gender Expression and Sex Characteristics Act*, which specifies 'sex characteristics' as a protected ground, is currently the best example worldwide on how to ensure the protection of intersex individuals.

If the ground of 'sex characteristics' is not available, the rights of people with variations of sex characteristics should be protected by *explicitly* including them under the ground of 'sex'.

---

## Isn't intersex covered by sexual orientation and gender identity (SOGI)?

---

No. There is no link between specific sex characteristics, gender identity and/or sexual orientation.

Just like women or trans people, intersex people are primarily discriminated against or stigmatised as a result of gender stereotypes, which continue to prevail in our societies. The most pressing intersex concerns are unwanted, unconsented and enforced medical interventions on intersex bodies. Existing European and domestic legislation that protects the rights of lesbian, gay, bisexual and trans people on the grounds of sexual orientation or gender identity does not address this issue.

However, there are issues of structural as well as individual discrimination, harassment and violence on the ground of physical appearance and gender expression that intersex people share with trans people. Therefore, some member states have explicitly included intersex (e.g. hate crime legislation) under the umbrella of SOGI.<sup>31</sup>

In such cases, OII Europe recommends extending the acronym SOGI to SOGIESC in order to explicitly cover sex characteristics (SC) under that umbrella, together with sexual orientation (SO), gender identity (GI) and gender expression (E).

---

<sup>31</sup> See Section 1 of this toolkit: **The legal situation in Europe**

**WHAT**

---

**CAN YOU**

---

**DO TO**

---

**HELP?**

---

# THERE ARE SOME EASY THINGS THAT YOU CAN DO THAT REALLY HELP:

## Talk about it!

---

Lack of knowledge is one of the key reasons for the human rights violations and the discrimination intersex people face. By spreading the word about the existence of intersex people and the human rights violations and discrimination they face, you work towards making society a safer and more welcoming space for intersex people. This includes making intersex people's existence visible by mainstreaming intersex issues in all areas of life and politics.

---

## Create a safe space for intersex people!

---

It is very likely that you already have intersex people in your organisation, at your work place or even amongst your friends and family; therefore creating a safe space for them to come out is crucial. Those individuals might not feel safe enough to come out yet. Sometimes the intersex person themselves does not know that they are intersex.

A good way to be inviting is to add the "I", but only if you are willing to work for intersex people's rights. Do not just add another letter to the acronym for the sake of it. In doing so, be aware of intersex diversity! Not all intersex people are queer. Make sure that you provide spaces where intersex people feel comfortable with their identities, including the fact of not being LGBT.

---

## Integrate the 'I' into your work!

---

Inform your colleagues and the members of your networks on intersex human rights issues. As a first step, you might consider asking intersex activists if they can provide training or advice for you. This will help you better understand intersex issues, the challenges intersex organisations face and how you can effectively work for the improvement of intersex people's situation in your country.

Reading this toolkit is a good first step. But there is far more to know than can possibly be covered in these pages. Check out the references in the back of the toolkit for further information. Read OII Europe and ILGA-Europe's websites for regular updates on current developments. The demands formulated in the 'Declaration of Malta' (2013) are the key demands of the European as well as international intersex human rights community. The 'Statement of Riga' (2014) covers the objectives of the European intersex human rights movement. Following the lead of those two documents is the right thing to do.

---

## Integrate the ‘I’ into your work!

Inform your colleagues and the members of your networks on intersex human rights issues. As a first step, you might consider asking intersex activists if they can provide training or advice for you. This will help you better understand intersex issues, the challenges intersex organisations face and how you can effectively work for the improvement of intersex people’s situation in your country.

Reading this toolkit is a good first step. But there is far more to know than can possibly be covered in these pages. Check out the references in the back of the toolkit for further information. Read OII Europe and ILGA-Europe’s websites for regular updates on current developments. The demands formulated in the ‘Declaration of Malta’ (2013) are the key demands of the European as well as international intersex human rights community. The ‘Statement of Riga’ (2014) covers the objectives of the European intersex human rights movement. Following the lead of those two documents is the right thing to do.

## Support intersex activists and NGOs!

Being visibly intersex is still a very difficult task all over Europe. Despite this fact, the number of intersex activists and organisations in Europe is growing but they all work with almost none or very limited funding. Becoming an intersex activist most often means having to forfeit the chance of having a regular income. Due to the lack of funding, you are expected to provide professional and highly specialised expertise for free. Helping intersex activists and NGOs financially to perform their task is key to ensuring they can share the unique expertise they have.

The advocacy work of the last few years is producing its first successes. Now is the time when resources are really needed to make the work sustainable and effective. If you have the financial means to support intersex human rights organisations, this is a great way to help. This can be very small ad-hoc support for certain tasks or travel, as well as more on-going support of the movement.

## “Nothing about us without us”!

Work with intersex NGOs and help them to create new alliances. Intersex human rights organisations are the best contact point for getting up-to-date information on the human rights violations faced by intersex people. They have long-term experience in advocating for intersex human rights.

Contact your national intersex human rights NGO or OII Europe and offer your help. Ask them which strategies they pursue and how you can assist them in reaching their goals. This can include simple tasks like sending material to your mailing lists on a regular basis, sharing information on Facebook or putting them in touch with policy makers, political parties, equality bodies, opinion leaders, practitioners, mainstream human rights organisations, and other stakeholders.

When you think of engaging in specific actions in the field of legislative, parliamentary or judicial procedures, we strongly recommend that you get in touch with either your national intersex human rights NGO or, if not available, with OII Europe. Those organisations are more likely to be informed in detail on the current national and international developments. If you don’t have this expertise within your NGO, then working together is the way to go for the betterment of intersex people’s situation in your country.

# Make use of human rights standards and tools!

Promote the statements of international human rights bodies on intersex. Encouraging all relevant stakeholders to implement the recommendations of the Council of Europe's Human Rights Commissioner is very beneficial.

Monitor the human rights situation of intersex people in your country. Help intersex people to report human rights violations and the discriminatory practices they face to your national intersex human rights organisation and your national equality body. At the international level, there are many tools that can be used.

For example, if you live in an EU Member State you can help intersex activists to collect data for EU Agency for Fundamental Rights reports. At the Council of Europe level, you can assist OII Europe and ILGA-Europe in sending information to the European Commission against Racism and Intolerance (ECRI) for their periodic country reports.

Since 2008, UN treaty bodies have proven to be of utmost importance in raising awareness of intersex human rights violations, internationally and in Europe. If you are writing a shadow report for your country's periodic review, offer intersex organisations the opportunity to write a section about intersex human rights concerns. Where particularly serious and well-documented violations are concerned, cases under the European Convention on Human Rights, the European Social Charter, and before the UN Human Rights Committee can be considered. Seek advice from OII Europe and ILGA-Europe. In all cases, whether non-binding recommendations or binding judgments, monitoring the implementation process is vital.

## Tips for LGBT activists

**Please don't apply for extensive funding just to start working on intersex, especially if you have no intersex leadership in your organisation.**

**Please bear in mind that the needs of intersex people differ from LGB and T needs. Do not take action without being sure that you understand the issues at stake and the wider consequences of your action.**

**Remember that the very simple rule "Nothing about us without us!" also applies for intersex people and their allies.**

# **ANNEXES**

# Recognising the human rights violations – International human rights bodies’ references to intersex

**In the past 10 years, more than 15 international human rights bodies have issued very clear recommendations that call on governments to end non-consensual medical interventions on intersex individuals.**

In 2011, the **UN High Commissioner for Human Rights** Navi Pillay, in a submission to the Human Rights Council, highlighted that intersex children are subject to discrimination and medically unnecessary surgery performed without their consent or that of their parents.

In that same year, the **UN Committee on the Elimination of Discrimination against Women** expressed concern about intersex women as “victims of abuses and mistreatment by health service providers”<sup>32</sup> in Costa Rica.

Also in 2011, the **UN Committee against Torture** called, in its **review on Germany**, to ensure the application of “best practices of granting informed consent to medical and surgical treatment of intersex people, including full information, orally and in writing, on the suggested treatment, its justification and alternatives” and to properly inform intersex individuals and their parents about consequences of unnecessary surgical and other medical treatment. The Committee further asked to investigate incidents that lacked informed consent and to provide redress and adequate compensation. Finally, the Committee urged Germany to provide adequate training for medical and psychological professionals on the range of sexual and related biological and physical diversity.<sup>33</sup>

The **UN Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment** Juan Mendez reaffirmed (in 2013) the Committee’s against Torture recommendations by calling upon all states to repeal laws permitting intrusive and irreversible treatments, “including forced genital-normalizing surgery [and] involuntary sterilization [...] when enforced or administered without the free and informed consent of the person concerned” and to provide special protection to individuals who are part of marginalized groups.<sup>34</sup>

In 2014, the **UN High Commissioner for Human Rights** Navi Pillay again stressed that “irreversible surgeries and sterilisations continue to be performed on intersex children without their informed consent, causing lifelong harm.”<sup>35</sup>

The **UN Committee on the Rights of Child** in its 2014 **review of Switzerland** urged the country to protect intersex children’s rights to bodily integrity, autonomy and self-determination, to prevent unnecessary medical or surgical treatment, and provide families of intersex children with adequate counselling and support.<sup>36</sup>

In 2014, the Commissioner for Human Rights of the Council of Europe, Nils Muižnieks, published his human rights comment ***A boy or a girl or a person – intersex people lack recognition in Europe***. In this document the Commissioner affirmed that “early ‘normalising’ treatments do not respect intersex persons’ rights to self-determination and physical integrity” and that “proxy consent given by parents may not be free and fully informed and can hardly take into account the best interests of the child in the long-run”.<sup>37</sup>

That same year, **seven UN bodies**, some of which had not previously spoken out on intersex issues, released an **interagency statement** describing non-consensual, cosmetic and other non-medically necessary surgery on intersex infants as human rights violations.<sup>38</sup>

<sup>32</sup> CEDAW/C/CRI/CO/5-6, para. 40

<sup>33</sup> CAT/C/DEU/CO/5, para. 20

<sup>34</sup> A/HRC/19/41, para. 56

<sup>35</sup> <http://www.ohchr.org/en/NewsEvents/Pages/DisplayNews.aspx?NewsID=14654&LangID=E>

<sup>36</sup> [http://tbinternet.ohchr.org/\\_layouts/treatybodyexternal/Download.aspx?symbolno=CRC%2fCO%2fCH%2fCO%2f2-4&Lang=en](http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRC%2fCO%2fCH%2fCO%2f2-4&Lang=en)

<sup>37</sup> <http://www.coe.int/hu/web/>

commissioner/-/a-boy-or-a-girl-or-a-person-intersex-people-lack-recognition-in-euro-1

<sup>38</sup> [http://www.who.int/reproductivehealth/publications/gender\\_rights/eliminating-forced-sterilization/en/](http://www.who.int/reproductivehealth/publications/gender_rights/eliminating-forced-sterilization/en/)

In 2015 alone, three **UN bodies called on seven State Parties**, four of which in Europe, to protect the physical integrity, bodily autonomy and right to self-determination of intersex individuals. The recommendation included a call to take the “necessary legislative, administrative and other measures to guarantee the respect for the physical integrity and autonomy of intersex persons and to ensure that no one is subjected during infancy or childhood to non-urgent medical or surgical procedures intended to decide the sex of the child”.<sup>39</sup>

Also in 2015, the **UN High Commissioner for Human Rights**, Zeid Ra’ad Al Hussein, addressed the human rights violations faced by intersex people in his **opening speech for the 30th Human Rights Council**, emphasising that intersex children and adults are “frequently subjected to forced sterilization and other unnecessary and irreversible surgery, and suffer discrimination in schools, workplaces and other settings” because their bodies don’t comply with typical definitions of male or female.<sup>40</sup>

Earlier that year, **the Office of the High Commissioner for Human Rights** had already published a **Fact Sheet on Intersex** as part of the UN Free & Equal Campaign, which included an extensive list of action points, addressing states, the media and the general public.<sup>41</sup>

In 2015 **the Commissioner for Human Rights of the Council of Europe**, Nils Muižnieks, published his **issue paper Human Rights and Intersex People**, which calls on member states to “end medically unnecessary “normalising” treatment of intersex persons when it is enforced or administered without the free and fully informed consent of the person concerned” and provides ways forward in terms of protection against discrimination of intersex people, adequate recognition of their sex on official documents and access to justice.<sup>42</sup>

**The European Union Agency for Fundamental Rights** joined the Commissioner’s recommendations by publishing its own focus paper, **The Fundamental Rights Situation of Intersex People**. The findings of the FRA confirmed the concerns expressed by intersex human rights NGOs, stating that in “at least 21 Member States sex ‘normalising’ surgery is carried out on intersex children” and that in “eight Member States a legal representative can consent to sex ‘normalizing’ medical interventions independently of the child’s ability to decide”. The FRA concluded that legal and medical professionals lacked knowledge about the fundamental rights of intersex people, particularly children and emphasised that “Member States should avoid non-consensual ‘sex-normalising’ medical treatments on intersex people”. The paper also pointed out that intersex concerns sex characteristics and therefore was better to be covered under the ground of “sex” rather than on the basis of sexual orientation and/or gender identity. In regards to sex/gender markers in official documents, the FRA recommended to review the current laws and practices to better protect intersex people.<sup>43</sup>

<sup>39</sup> Committee on the Rights of the Child Concluding Observations on Switzerland (CRC/C/CHE/CO/2-4), Committee on the Rights of People with Disabilities Concluding Observations on Germany (CRPD/C/DEU/CO/1), Committee Against Torture Concluding Observations on Austria (CAT/C/AUT/CO/6), Denmark (CAT/C/DNK/CO/6-7) and Switzerland (CAT/C/CHE/CO/7).

<sup>40</sup> <http://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=16414&LangID=E#sthash.q0fjniwo.dpuf>

<sup>41</sup> [https://unfe.org/system/unfe-65-Intersex\\_Factsheet\\_ENGLISH.pdf](https://unfe.org/system/unfe-65-Intersex_Factsheet_ENGLISH.pdf)

<sup>42</sup> <https://wcd.coe.int/com.instranet.InstraServlet?command=com.instranet.CmdBlobGet&InstranetImage=2768767&SecMode=1&DocId=2282716&Usage=2>

<sup>43</sup> European Union Agency for Fundamental Rights: FRA Focus Paper. The Fundamental Rights Situation of Intersex People. Vienna 2015.

# The recommendations of the Commissioner for Human Rights of the Council of Europe

- » Stop unnecessary medical treatment and surgery of intersex people without their consent
- » Respect intersex persons' right not to undergo sex assignment treatment
- » Review medical classifications which pathologise intersex people
- » Improve law and policy to facilitate the legal recognition of intersex individuals on official documents, respecting their right to self-determination
- » Ensure that national equal treatment and hate crime legislation protects intersex people
- » Give intersex people full access to their medical records
- » More in-depth research needed to adequately address discrimination and other violations of intersex people's human rights
- » Raise public awareness and improve professional training about the problems encountered by intersex people
- » Involve intersex people in the development of measures to address these problems
- » Improve counselling of intersex children and their parents
- » Facilitate intersex people's access to justice and investigate and acknowledge past human rights violations

**LINKS,**

**RESOURCES**

**AND**

**CONTACTS**

---

## Intersex Demands and Objectives

- Declaration of Malta (Public Statement by the 3rd International Intersex Forum, Valetta, Malta, 2013)

<http://oiieurope.org/public-statement-by-the-third-international-intersex-forum/>

- Statement of Riga (Statement of the European Intersex Meeting Riga, 2014)

<http://oiieurope.org/statement-of-the-european-intersex-meeting-in-riga-2014/>

---

## WHO/ICD Revision

- Intersex Issues in the International Classification of Diseases: a revision.

<http://transactivists.org/2015/10/26/intersex-issues-in-the-international-classification-of-diseases-icd/>

---

## Intersex and Disability

- OII Europe (2015): Statement of OII Europe on Intersex, Disability and the UN Convention on the Rights of People with Disabilities.

[http://oiieurope.org/wp-content/uploads/2015/05/CRPD\\_2015\\_Statement\\_OII\\_Europe.pdf](http://oiieurope.org/wp-content/uploads/2015/05/CRPD_2015_Statement_OII_Europe.pdf)

---

## Employment

- OII Australia, Pride in Diversity (2014): Employers' Guide to Intersex Inclusion

<https://oii.org.au/wp-content/uploads/key/Employer-Guide-Intersex-Inclusion.pdf>

---

## Legislation and policies

- Maltese bill on gender identity, gender expression and sex characteristics (2015)

<http://justiceservices.gov.mt/DownloadDocument.aspx?app=lom&itemid=12312&l=1>

- Maltese educational policy on how to accommodate the needs of trans, intersex and gender-variant students (2015)

<http://education.gov.mt/en/resources/News/Pages/News%20items/Imniedi-d-dokument-%E2%80%98Trans,-Gender-Variant-and-Intersex-Students-in-Schools%E2%80%99.aspx>

---

## Reports on the human rights of intersex people

- Human rights and intersex people. Issue Paper published by the Council of Europe Commissioner for Human Rights (2015)

<https://wcd.coe.int/ViewDoc.jsp?Ref=CommDH/IssuePaper%282015%291&Language=lanEnglish&Ver=original>

- EU Fundamental Rights Agency (2015): The fundamental rights situation of intersex people

<http://fra.europa.eu/sites/default/files/fra-2015-focus-04-intersex.pdf>

- United Nations (2015): Human Rights of Intersex Persons (Side event at the 30th Session of the Human Rights Council in September 2015)  
<https://www.youtube.com/watch?v=uPGOnBSYbOc#t=20>
  - 24. GMFK Konferenz (2014): Top 8.1: Rechte intersexueller Menschen wahren und Diskriminierung beenden – insbesondere Schutz der körperlichen Unversehrtheit  
[http://www.gleichstellungsministerkonferenz.de/documents/2014\\_10\\_13\\_Beschluesse\\_GESAMT\\_Extern.pdf](http://www.gleichstellungsministerkonferenz.de/documents/2014_10_13_Beschluesse_GESAMT_Extern.pdf)
  - Council of Europe Commissioner for Human Rights (2014): Human Rights Comment: A boy or a girl or a person – intersex people lack recognition in Europe  
<http://www.coe.int/hu/web/commissioner/-/a-boy-or-a-girl-or-a-person-intersex-people-lack-recognition-in-euro-1>
  - United Nations (2014): Intersex People and Human Rights: Violations, Voices and Visions. (Side event at the UN prior to the 25th Session of the Human Rights Council in March 2014) <http://youtu.be/hhTYYqCv7gE>
  - Parliamentary Assembly of the Council of Europe (2013): Children’s right to physical integrity  
<http://assembly.coe.int/ASP/Doc/XrefViewPDF.asp?FileID=20174&Language=en>
  - United Nations General Assembly (2013): Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, Juan E. Méndez  
[http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53\\_English.pdf](http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53_English.pdf)
  - Dan Christian Ghattas (2013): Human Rights between the Sexes. A preliminary study on the life situations of inter\* individuals. Ed. by the Heinrich-Böll-Foundation. Berlin <http://www.boell.de/en/2013/10/21/human-rights-between-sexes>
  - Swiss National Advisory Commission on Biomedical Ethics: On the management of differences of sex development Opinion No. 20/2012. Ethical issues relating to “intersexuality”  
[http://www.nek-cne.ch/fileadmin/nek-cne-dateien/Themen/Stellungnahmen/en/NEK\\_Intersexualitaet\\_En.pdf](http://www.nek-cne.ch/fileadmin/nek-cne-dateien/Themen/Stellungnahmen/en/NEK_Intersexualitaet_En.pdf)
  - San Francisco Human Rights Commission (2005): A human rights investigation into the medical “normalization” of intersex people (2005)  
[http://www.isna.org/files/SFHRC\\_Intersex\\_Report.pdf](http://www.isna.org/files/SFHRC_Intersex_Report.pdf)
- This is only a selection. You can find a more comprehensive and regularly updated list of resolutions, reports and recommendations, including UN recommendations, on [www.oiiurope.org](http://www.oiiurope.org)**

## Movies, Articles and Books

- Mauro Cabral (2015): The marks on our bodies (Article published for Intersex Awareness Day, 26th of October)  
<http://intersexday.org/en/mauro-cabral-marks-bodies/>
- Inter – Erfahrungen intergeschlechtlicher Menschen in der Welt der zwei Geschlechter (2013, ed. by Barth, Ghattas, Böttger, Schneider), a collection of essays and conversations on the experience of intersex individuals from five continents.
- Intersexion (Documentary featuring various intersex people’s life histories, New Zealand, 2012)
- Orchids, My Intersex Adventure (Autobiographical documentary about an intersex filmmaker, Australia, 2010)
- Interdicciones – Escrituras de la Intersexualidad en Castellano (2009, ed. by M. Cabral), a collection of essays and conversations on the experience of intersex people in Latin America and Spain.
- XXY (Drama film about an intersex adolescent, Argentina, Spain, France, 2007)
- Octopusalarm (OT: Tintenfischalarm, first European documentary about an intersex person, Austria, 2006)
- Hermaphrodites Speak! (Documentary from the first Intersex Retreat 1995, United States 1996,  
[https://www.youtube.com/watch?v=VMER3\\_nxIN0](https://www.youtube.com/watch?v=VMER3_nxIN0))

---

## Websites

[oiieurope.org](http://oiieurope.org)

[intervisibility.eu](http://intervisibility.eu)

[intersexday.org](http://intersexday.org)

[www.interfaceproject.org](http://www.interfaceproject.org)

[www.ilga-europe.org/what-we-do/our-advocacy-work/trans-and-intersex/intersex](http://www.ilga-europe.org/what-we-do/our-advocacy-work/trans-and-intersex/intersex)

---

