Position paper

Equality and full enjoyment of human rights for intersex people

ILGA-Europe aim to achieve equality for intersex people and ensure they are protected against human rights violations, discrimination and violence based on sex characteristics.

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<th>Intersex individuals are born with physical sex characteristics that don’t fit medical or social norms for female or male bodies. These variations in sex characteristics may manifest themselves in primary characteristics (such as the inner and outer genitalia, the chromosomal and hormonal structure) and/or secondary characteristics (such as muscle mass, hair distribution and stature).</th>
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Intersex people’s basic human rights are routinely violated due to their non-adherence to sex norms. For example, this can impact their right to life, to physical integrity, to self-determination, to non-discrimination, to private and family life and access to an effective remedy.

Even today, intersex people are often subjected to non-consensual medical treatments right after birth and/or during early childhood. This can include unnecessary surgeries and hormonal treatments solely to force intersex people to fit the notion of male and female that persists in our societies as the norm. Treatments often result in emotional and physical trauma, complications after surgery and a lifelong need for treatment.

Moreover, a large majority of intersex people face discriminatory practices, harassment and stigmatisation, at school, in employment, and in access to services (in particular when accessing healthcare services).

After decades of invisibility, intersex activists are speaking out and are organising to advocate for the protection of their human rights, in Europe and worldwide. ILGA-Europe actively support these intersex activists and the community – not only to increase their resources and capacity to advocate successfully for their human rights, but also to grow as a supportive and inclusive movement.

ILGA-Europe aim to include the needs of intersex people in all our work. One of ILGA-Europe’s key role is to contribute to raising awareness about the ongoing discrimination faced by intersex people in our societies, and to enable LGBT organisations to be supportive and inclusive of intersex human rights concerns and intersex people.

Specifically, we want to contribute to ensuring the full **respect of the right to bodily integrity** of intersex people.
We also call for quick, transparent and accessible legal gender recognition procedures, available to intersex persons, and based on self-determination. Information about those procedures needs to be easily available and understandable.

We advocate for non-discrimination legislation and policies that protect intersex people, as well as specific measures tackling hate crime and incitement based on sex characteristics.

The rest of this position paper outlines how we will put these advocacy goals into practice.

I. **Full respect of the right to life, to bodily integrity and to health**

In a world where the overwhelming majority of people and authorities only know and accept two sexes, ‘male’ and ‘female’, the existence of intersex people and their bodies is not recognised. As a result, intersex people are often made to feel like they are invisible. According to the 2015 FRA focus paper, ‘normalising’ surgery is carried out on intersex children in at least 21 EU member states. The sole purpose of these surgeries is to make them fit the prevailing notions of ‘male’ and ‘female’. In addition, intersex people do not always have access to information regarding the treatments they went through during their childhood.

- ILGA-Europe call for legislative measures and policies to end all mutilating and sex aligning or sex normalising practices such as genital surgeries, psychological and other medical treatments. In the absence of an express wish, (with free, full and informed consent of the intersex individual) all surgeries, hormone treatments and other invasive medical procedures that are not strictly medically necessary must be banned.

- Intersex people must be empowered to make their own decisions affecting their bodily integrity, physical autonomy and self-determination. In order to do so, intersex people, as well as their families, should be provided with transparent and objective information on bodily diversity and the health issues they may face. The right of intersex people to full information and access to their own medical records and history needs to be ensured.

- Treatments that are deemed necessary by intersex people themselves should be accessible, affordable and covered by health care coverage as much as possible.

- To ensure the bodily integrity and well-being of intersex people, autonomous, non-pathologising psycho-social and peer support should be available throughout their life (as self-required), as well as to parents and/or care providers.

- Standards of care and guidelines in all areas (urology, gynecology, surgery, psychology, psychiatry, etc.) should be updated on the basis of the principles
mentioned above. They should be widely promoted and implemented, including through specific trainings to healthcare practitioners.

- Variations in sex characteristics need to be depathologised in medical guidelines, protocols and classifications, such as the World Health Organization’s International Classification of Diseases.

- All too often, intersex is still seen as a disorder. Where pre-natal screening shows a risk of variation of sex characteristics in embryos and fetuses, parents can sometimes be advised to terminate a pregnancy. In other cases, fetuses may be prevented from developing further. In some other cases, doctors might prescribe prenatal treatment aimed at reducing the rate of so-called ‘ambiguous sex characteristics’. To that end, they might use an approved medicine outside the context for which it was initially approved. This is often referred to as ‘off-label use’. As this medication is not tested in these circumstances, it can have a detrimental effect on the health of the child. These practices must stop. They must be replaced by access to objective and comprehensive information about intersex-related issues from both a medical and a human rights perspective, that allow for everyone to exercise their right to decide the outcomes of their pregnancy in a fully informed manner, in all circumstances.

II. Legal gender recognition

In order to reflect the full spectrum of sex characteristics variations, parents should ideally be able to register their child using multiple options (female (F), male (M), non-binary, etc) on the basis of a declaratory-model. Where this is not available, in order to get away from the medical pressure to “correct” their bodies to make them fit into one sex category or another, intersex children should be registered as females or males, with the awareness that, like all people, they may grow up to identify with a different sex or gender.

Legislation on quick, transparent and accessible legal gender recognition based on self-determination, is therefore a key precondition to ensure the full recognition of the gender identity of intersex people.

III. Ensuring non-discrimination and equality for intersex people in all areas of life

Intersex people face discrimination in all areas of life. They have a higher risk of dropping out of school due to the effects of medical treatments or bullying. Intersex adults may have difficulty finding a job due to lack of education, physical impairments, stigma and discrimination. At every age, intersex people can face stigma, structural and verbal discrimination, harassment, lack of legal recognition and the invisibility of their bodies in our society. To ensure full equality of intersex people in all areas of life, ILGA-Europe call for:

- The adoption of non-discrimination legislation and policies that include the ground of sex characteristics in all areas, including employment, health, education and access to goods and services.
• The respect and protection of the rights of all intersex people to freely express their own identity and to fully enjoy their rights to freedom of association and participation in political and cultural life.

• Legislative and non-legislative measures to tackle hate crime and incitement on the ground of sex characteristics.

• Measures to ensure that the right of all intersex people to marry, and to found a family, are fully respected.

• Training on bodily diversity, harassment and discrimination on the grounds of sex characteristic for school staff, health practitioners, social services, police officers, prosecutors, judges, lawyers and all relevant professionals, so that they provide inclusive quality services and address discrimination where it occurs.

• Regulations ensuring that intersex people are able to participate in competitive sport, at all levels, in accordance with their legal sex, and without being forced to undergo medical treatment to retain the right to compete.

IV. Awareness-raising, visibility and community building

Lack of knowledge is one of the key reasons for the human rights violations and discrimination that intersex people face. Therefore, ILGA-Europe want to work closely with the intersex movement to raise the awareness of the existence of intersex people and the human rights violations and discrimination they face.

• ILGA-Europe commit to cooperating closely with the intersex movement, to raising awareness around intersex issues and the rights of intersex people in society at large. We want to create and facilitate supportive, safe and celebratory environments for intersex people and their families.

• We call for fact-finding research on human rights violations experienced by intersex people in the past, involving intersex victims and activists from the start of research projects as much as possible.

• In order to build a base for equality for intersex people in the future, it is of the utmost importance to acknowledge and offer redress for the suffering and injustice caused to intersex people, mainly through non-consensual medical treatments, in the past.

• Barriers to intersex activism, i.e. limited financial resources and lack of data should be addressed. Intersex people should be encouraged to voice their needs and to organise themselves.
• Civil society organisations should reach out to intersex activists, support them, and create a safe space for them. In this context, ILGA-Europe continue in our active support for the intersex movement and will further engage in providing information and advice to enable our member organisations to become true intersex allies and intersex-inclusive organisations.

• Media agencies, sources and outlets should ensure intersex people’s right to privacy, and dignity, by covering intersex issues in an accurate, sensitive and ethical way.

• We call on 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.