

The fundamental rights situation of intersex people

FRA Focus

Most European societies recognise people as either male or female. However, this does not account for all variations in sex characteristics. As a result, intersex people experience fundamental rights violations ranging from discrimination to medical interventions without their consent.

This paper examines the legal situation of intersex people from a fundamental rights perspective. It draws on evidence from the Agency's updated legal analysis on homophobia, transphobia, and discrimination on grounds of sexual orientation and gender identity, which now includes a section on intersex issues.

Key facts

- Many Member States legally require births to be certified and registered as either male or female.
- In at least 21 Member States, sex 'normalising' surgery is carried out on intersex children.
- In 8 Member States, a legal representative can consent to sex 'normalising' medical interventions independently of the child's ability to decide.
- 18 Member States require patient consent provided the child has the ability to decide.
- Intersex discrimination is better covered by sex discrimination rather than discrimination on the basis of sexual orientation and/or gender identity as it concerns physical (sex) characteristics.

Key conclusions

- Legal and medical professionals should be better informed of the fundamental rights of intersex people, particularly children.
- Gender markers in identity documents and birth registries should be reviewed to better protect intersex people.
- Member States should avoid non-consensual 'sex-normalising' medical treatments on intersex people.

Introduction

'Intersex' is used in this paper as an umbrella term to denote a number of different variations in a person's bodily characteristics that do not match strict medical definitions of male or female. These characteristics may be chromosomal, hormonal and/or anatomical and may be present to differing degrees. Many variants of sex characteristics are immediately detected at birth, or even before. Sometimes these variants become evident only at later stages in life, often during puberty. While most intersex people are healthy, a very small percentage may have medical conditions which might be life-threatening, if not treated promptly.

Intersex is a collective term for many natural variations in sex characteristics. It is not a medical condition.

Medically, some of these variants are grouped under 'disorders of sexual development'. However, this is rejected by many, including activists and intersex people themselves, who perceive it to be stigmatising and pathologising.¹ It should also be noted that some intersex people may not wish to identify as such.

Background

In the European Union intersex issues have progressively emerged as relevant to fundamental rights protection. However, they are still largely treated as medical issues falling outside the scope of public scrutiny. A number of developments at EU level in recent years have contributed to a better understanding of the problems intersex people face. For example, in 2013, the 'working definitions' laid down by the Council of the European Union stated that traditional notions of maleness and femaleness are culturally established.² The 'Lunacek Report' of the European Parliament, also adopted in 2013, recommended that the European Commission, EU Member States and relevant agencies address the current lack of knowledge, research and relevant legislation on the human rights of intersex people.³

Member States have also raised the issue of intersex. For instance, in 2010, the Italian Committee on Bioethics published a report reinforcing the exclusively medical approach to intersex issues, reinstating sex binary as an "indispensable element of personal identity".⁴ However, the Committee also stressed the importance of acting in the best interest of the child, following a case-by-case approach, and

Practices, such as issuing birth certificates and medical treatments, can have an impact on the fundamental rights of intersex people. For example, Article 1 of the Charter of Fundamental Rights of the European Union, protects human dignity. Other Charter rights include: the right to integrity of the person (Article 3); respect for private and family life (Article 7); the right to found a family (Article 9); and rights of the child, including the right of children to express their views freely and to have their views taken into consideration on matters which concern them in accordance with their age and maturity (Article 24). Intersex people also benefit from the prohibition of discrimination under the Charter (Article 21).

When basic aspects of a person's legal status (e.g. birth or death registration), social status (e.g. access to services) or health conditions are frequently defined by the so-called 'sex binary' classification of being either 'male' or 'female' intersex people are often discriminated against. This is because their sex characteristics cause them to fall outside of this classification. It can also lead to grave violations of their rights to physical and psychological integrity as well as other fundamental rights.

avoiding surgical and medical intervention until the child is able to give informed consent. In 2012, the German Ethics Council (*Ethikrat*) published a comprehensive Opinion on intersex issues, providing a range of recommendations to safeguard the rights of intersex people.⁵ The Opinion argues that legal systems presume a strict sex binary that does not always occur in nature. Thus, intersex issues should concern legal professionals and policy makers, and not only health and healthcare professionals. However, most organisations concerned with protecting the rights of intersex people in the EU support the recommendations developed by the Swiss National Advisory Commission on Biomedical Ethics instead of those adopted in EU Member States. The Swiss recommendations emphasise that, as a rule, sex assignment treatment should only be performed when the person concerned agrees. They also emphasise that intersex children and their parents should be given psychological counselling and support. The recommendations consider protecting the child's integrity as being essential.⁶

A study of intersex people published by the Netherlands Institute for Social research in 2014 found



that virtually all the intersex people interviewed encountered problems in their social situation. They talked about being 'different', feeling lonely and experiencing shame and embarrassment.⁷ The study called for further research into their experiences.

Intersex issues are increasingly emerging also among the activities of civil society, including lesbian, gay, bisexual and transgender organisations. For example, ILGA-Europe started working on intersex issues in 2008.⁸ The Organisation Intersex International Europe (OIIE) has been established as a cooperation

platform for intersex organisations in several European countries.⁹ In Austria for instance, the Homosexual Initiative Salzburg (*Homosexuelle Initiative Salzburg*, HOSI) assigned a representative for intersex issues (*Intersex-Beauftragte*). Specific intersex NGOs have also been established, such as the Association of Intersex People Austria (*Verein Intersexueller Menschen Österreich*), and the Intersex Platform Austria (*Plattform Intersex Österreich*) – an independent network of NGOs, scientists and activists that aims to foster public discussion, and offer advice and information.¹⁰

Grounds for protection from discrimination

The Council of the European Union,¹¹ and the European Parliament¹², as well as the Council of Europe,¹³ the UN High Commissioner for Human Rights,¹⁴ and the UN Special Rapporteur on Torture¹⁵, have all pointed out that intersex people can suffer from discrimination that may result in ill treatment, especially during childhood. An overview of the key human rights at stake in the protection of intersex people can also be found in the Commissioner for Human Rights of the Council of Europe's *Issue Paper on human rights and intersex people*.¹⁶

The provision of protection from discrimination under Article 21 of the EU's Fundamental Rights Charter is of special relevance for EU law and policy. This is an area where the EU has exercised its competence in several specific domains which touch on the protection of intersex people, such as employment, access to goods and services, and free movement.

Unequal treatment of intersex people has been frequently addressed in EU policies and advocacy as part of discrimination on the ground of sexual orientation and/or gender identity. However, such treatment can better be addressed as discrimination on the ground of sex, as it is linked to the sex assigned to a person at birth and its direct consequences. For example, an intersex person incorrectly assigned a female sex at birth, may be prevented from marrying a woman in those countries where civil marriage is not possible for same-sex couples.

It is also important to bear in mind that intersex refers to the bodily characteristics of a person. There is no evidence linking specific sex characteristics with either gender identity or sexual orientation. Thus, intersex people might be as likely as non-intersex people to self-identify as heterosexual, bisexual, homosexual, trans, etc. However, regardless of the sexual orientation or gender identity of intersex people, they should benefit from protection

from discrimination on the ground of sex under Article 21 of the EU's Fundamental Rights Charter. Regarding secondary EU law, it should be noted that the Lunacek Report has called on the European Commission, together with relevant agencies to "issue guidelines specifying that transgender and intersex persons are covered under 'sex' in Directive 2006/54/EC [Gender Equality Directive (recast)]" (para. C. ii).¹⁷

So far, however, it appears that the directive has not been implemented in this way. FRA's research did not find sufficient legislation or case law to find out whether or not intersex people are actually protected from discrimination on the grounds of sex in the Member States. In this regard, the German Ethics Council clarified that discrimination against intersex people is generally intended to be covered under the category of sex. However, the explanatory note of the German General Law on Equal Treatment subsumed intersex issues under the ground of 'sexual identity'.¹⁸

Intersex civil society organisations are advocating that a specific ground, 'sex characteristics', best identifies their needs when it comes to protection from discrimination.¹⁹ Malta recently became the first (and only) EU Member State to explicitly provide protection against discrimination on the ground of 'sex characteristics'. The recently-adopted 'Gender Identity, Gender Expression and Sex Characteristics Act'²⁰ requires public services to eliminate unlawful discrimination and harassment on the ground of sex characteristics. It also requires public services to promote equality of opportunity for all, irrespective of these characteristics.²¹

Two other positive examples were identified in Spain and the United Kingdom, both at the regional level. In Spain, the Basque Country Act 14/2012 on non-discrimination based on gender identity includes references to "intersex persons".²² In the

United Kingdom, the Scottish Offences (Aggravation by Prejudice) Act 2009 includes intersex issues in its very wide definition of gender identity i.e. “not standard male or female”²³ - thus also equating intersex with a form of gender identity.

In at least 10 EU Member States (Bulgaria, Estonia, Hungary, Italy, Luxembourg, Poland, Portugal, Romania, Spain and Slovakia) the law has an open list of grounds of discrimination. Here, intersex may be included under the protected characteristics or social groups category of ‘other’. This could help protect intersex people from discrimination. However, given the social and legal invisibility of intersex issues in society and in the legal system, considering such an approach can perpetuate this invisibility. It could also result in acts of discrimination against

intersex people remaining unchallenged. Using this ground of protection remains largely untested and unclear in practice, given the scarcity of case law.

In seven EU Member States, policy makers or courts embrace broader concepts. These may implicitly cover intersex, for instance: gender (in Austria,²⁴ Denmark,²⁵ Finland²⁶ and the Netherlands²⁷); gender identity (in Romania²⁸ and Slovenia²⁹); or both gender and gender identity (in Sweden³⁰).

Intersex covers a large and diverse variation of sex characteristics. Therefore, it is likely that in the absence of specific protective legislation, intersex cases will be legally approached in different ways, even within the same legal system.

Registration of sex at birth

Apart from a few recent pieces of legislation described below, birth registration legislation in EU Member States tends to consider all individuals as either male or female. Consequently, in most Member States it is required, but not always possible, to assign a sex to intersex new-borns. The moment when birth certificates and registration takes place is frequently the first instance in which intersex people are confronted with a legal issue. This is very problematic for intersex children as it forces those involved in certifying and registering birth (particularly parents or other family members responsible for the child, health professionals, and birth registry officials) to legally choose between the ‘male or female’ options. In addition, parents frequently lack psychological support services. Such support would allow them to adequately face parenthood of intersex children, and better respond to the challenges posed by the social expectations, and legal and medical requirements which they, and their children, face.

In this way, legal requirements for birth certification and registration reinforce social expectations that a child fits into existing sex categories. This influences the perceived ‘medical need’ for treatment and intervention. The interplay of legal, social, and medical expectations creates a context in which the child’s rights to physical and mental integrity, and to express views freely can be easily overridden. Such views should be taken into consideration on matters which concern the child in accordance with the child’s age and maturity.

Concerning birth certificates, 18 EU Member States allow a certain delay in the registration of a new birth: within a week in Austria, Belgium, Bulgaria,

France, Luxembourg and Slovakia; longer in Cyprus, Denmark, Greece, Hungary, Ireland, Italy, Malta, Portugal, Romania, Slovenia, Spain and the United Kingdom. Sometimes certification follows a preliminary communication that has been immediately filed by the medical staff. For some intersex children, this delay may be sufficient to allow for the medical identification of a ‘preponderant’ sex, however this may be defined. This leads to the legal imposition of a ‘male’ or ‘female’ sex. However, medical treatments, including surgery, on very young intersex children is common.³¹

At least four EU Member States allow a sex-neutral identification to be registered in birth certificates, such as ‘unknown sex’ in the United Kingdom. In Latvia, sex is not included on the birth certificate, but ‘unclear sex’ is allowed in medical certificates issued by medical staff.³² In the Netherlands, if the sex of a child is unclear, the birth certificate can state that the sex could not be determined. Within three months of the date of birth, a new birth certificate should be drawn up and the first one destroyed. In the new birth certificate, the sex of the child should be mentioned based on a medical statement. If no medical statement is submitted or if the sex cannot yet be determined, the new birth certificate should indicate that it is not possible to determine the sex of the child. It is assumed that once an intersex person has decided on their sex identity, they can change the registration according to Article 1:24 of the Civil Code, but no time limit is set. In Portuguese intersex cases, a person reporting the birth at the civil registry office is advised to choose a first name that is easily adapted to either sex. It is expected that the birth certificate will be



amended accordingly, once a sex can be attributed with some precision.³³

The German Ethics Council has recommended allowing the 'other' sex category in certifications.³⁴ In Germany, it is possible to issue birth certificates without a sex identifier or marker; since 1 November 2013, there is no deadline to include such a marker.³⁵

In Malta, the entry of a sex marker on the birth certification can be postponed until the gender identity of the child is determined. This follows the adoption of the 'Gender Identity, Gender Expression and Sex Characteristics Act' in April 2015.³⁶ Malta has also committed to recognising gender markers other than male or female, as well as the absence of such markers, from a competent foreign court or responsible authority acting in accordance with the law of that country.

To a limited extent it is also possible to issue birth certificates without a sex identifier or marker in France and Finland. In France, ministerial guidelines advise parents to check with their doctor what the sex of the new-born is 'most likely' to be. This should be based on the expected results of medical treatments, where appropriate.³⁷ In this case, it is

possible not to specify a child's sex, with the public prosecutor's consent as long as sex determination can be reasonably expected after a maximum of three years of medical treatment.³⁸

In Finland, the lack of sex certification implies that an intersex child gets an incomplete personal identity code. This has potentially negative consequences. For example, a personal code is needed for contact with authorities, for the payment of wages and salaries, or to open a bank account.

In cases of errors in birth certificates, it is possible for intersex people to change the sex identifier later in life in EU Member States, such as Denmark, France and the Netherlands, without meeting the requirements demanded for trans people. In France these requirements include: the diagnosis of gender dysphoria; hormonal treatment or physical adaptation; a court order; a medical opinion; and genital surgery leading to sterilisation.

In general, intersex people and those who are responsible for caring for intersex children, largely need to rely on external, medical assessments when it comes to the certification of an intersex person's sex.

Medical treatment of intersex children

In May 2014, various UN bodies released an inter-agency statement noting that "Intersex persons, in particular, have been subjected to cosmetic and other non-medically necessary surgery in infancy, leading to sterility, without informed consent of either the person in question or their parents or guardians. Such practices have also been recognized as human rights violations by international human rights bodies and national Courts." These bodies included the World Health Organisation (WHO), the Office of the High Commissioner for Human Rights (OHCHR), UN Women, the Joint United Nations Programme on HIV/AIDS (UNAIDS), the UN Development Programme (UNDP), the UN Population Fund (UNFPA) and the UN's Children's Fund (UNICEF).

In Europe, there are no comprehensive statistical data on medical treatments or surgeries performed on intersex children. The Commissioner for Human Rights of the Council of Europe has repeatedly pointed out that intersex children are often subjected to surgery and hormonal or other medical treatments aimed at imposing a sex on them.³⁹ Such surgery, performed on intersex babies and toddlers, which can be cosmetic rather than medically essential, may result in irreversible sex assignment and even sterilisation.⁴⁰

The Parliamentary Assembly of the Council of Europe in its Resolution 1952 (2013) on a child's right to physical integrity called on its Member States to "ensure that no-one is subjected to unnecessary medical or surgical treatment that is cosmetic rather than vital for health during infancy or childhood, [and to] guarantee bodily integrity [...] to persons concerned".⁴¹

The UN Special Rapporteur on torture has similarly called upon States

"to repeal any law allowing intrusive and irreversible treatments, including forced genital-normalizing surgery, involuntary sterilization, unethical experimentation, medical display, 'reparative therapies' or 'conversion therapies', when enforced or administered without the free and informed consent of the person concerned."

The UN Special Rapporteur on torture has also called on States to outlaw forced or coerced sterilisation in all circumstances and to provide special protection to individuals belonging to marginalised groups.⁴²

When not dictated by medical emergency, surgery and medical treatments without the consent of the patient or legal representatives are recognised by international human rights law as a form of cruel, inhuman and degrading treatment. Genital surgery performed on intersex people was equated to female genital mutilation (FGM) by the Conference of State (Länder) Ministers for Equality of Germany.⁴³ FGM is internationally recognised as a violation of the human rights of women and a form of child abuse, and has been strongly condemned by the EU Commission⁴⁴ and Council.⁴⁵ In Malta, the 'Gender Identity, Gender Expression and Sex Characteristics Act'⁴⁶ forbids sex assignment treatments and/or surgical intervention on the sex characteristics of a child which can be deferred until the person to be treated can provide informed consent, unless in exceptional circumstances. Agreement between an interdisciplinary team, appointed by the equality minister, and those with parental authority, or the child's tutor, is also required.⁴⁷

There is little information on the existence of medical protocols concerning the treatment of intersex people across the EU. In Austria, Estonia, Spain, Finland, France, Hungary, Ireland, Italy, Luxembourg and the United Kingdom no official, general medical protocol is applied. In Sweden, the National Board of Health and Welfare (*Socialstyrelsen*) has produced guidelines regarding the treatment of intersex children. The procedure specifies that examinations and genital surgical procedures should not be performed between the ages of 2 and 12. However, in most cases genital surgery is reportedly performed before the age of six months.⁴⁸ In Austria the recommendations of the previously mentioned German report⁴⁹ and the Lawson Wilkins Pediatric Endocrine Society (USA) and the European Society for Paediatric Endocrinology are referenced. These two institutions have published the so-called '*Consensus Statement on the management of intersex disorders*' (also known as 'the Chicago Consensus') which proposed changes in terminology.⁵⁰ However, this document has been criticised by intersex organisations as it introduced the term 'disorders of sex development' to describe intersex characteristics. Intersex organisations consider that the use of this term pathologises the sex characteristics of intersex people, and can justify 'sex normalising' medical treatment.⁵¹

In the Netherlands, it is also common practice to follow 'the Chicago Consensus', but this may not apply to all hospitals.⁵² In any case, the issue is not how 'good' the treatment becomes, but whether it meets human rights standards if administered without consent when the 'condition' is not life threatening or will not lead to significant harm.

In the United Kingdom, there are specific medical protocols for specific types of intersex characteristics. In addition, there is a general information page on the National Health Service website.⁵³ In Spain, protocols for specific forms of intersex characteristics are followed, such as the protocol developed by the Spanish Association of Paediatrics (*Asociación Española de Pediatría*)⁵⁴ or the protocol of the European Association of Urology.⁵⁵ In France, the protocol on the management of a specific form of intersex (congenital adrenal hyperplasia due to 21-hydroxylase deficiency) refers to surgical treatment in the first months after birth. Although there is no reference to consent, the protocol notes that "patients and parents should be accompanied psychologically in the surgical project".⁵⁶

There is also little case law on medical treatments of intersex people. In one important case in Germany, the Cologne District Court recognised the pain and suffering of an intersex person who had been subjected to medical surgery 30 years earlier without adequate information.⁵⁷ The claimant brought a suit for damages - on the grounds of erroneous assignment of a sex and physical mutilation - against the surgeon who, when the claimant was 18 years old, had removed her uterus and fallopian tubes. In its decision, the court ruled that the operation had been conducted without the necessary consent and that the claimant had not been comprehensively informed by the defendant surgeon. The court later awarded damages of €100,000 plus interest.⁵⁸

Sex (re)assignment or sex-related surgery seems to be performed on intersex children, and young people, in at least 21 EU Member States (Austria, Belgium, Bulgaria, the Czech Republic, Denmark, Estonia, Finland, France, Germany, Hungary, Ireland, Italy, Latvia, Lithuania, Malta, the Netherlands, Poland, Slovakia, Spain, Sweden and the United Kingdom). However, it is not known how frequently such operations are conducted. In all these countries, informed consent for surgery is required from the patient and/or legal representatives, except in cases of medical emergency.

In eight Member States (Austria, Belgium, Bulgaria, the Czech Republic, Estonia, Hungary, Poland and Sweden), the legislation or medical practice requires consent by the legal representative, independently of the child's ability to decide. In Spain, this is the case if medical interventions entail 'a serious risk' for the child.

Patient consent seems to be legally required in at least 18 Member States (Austria, Belgium, Bulgaria, Denmark, Finland, France, Germany, Ireland, Italy, Latvia, Lithuania, Malta, the Netherlands, Poland, Slovakia, Spain, Sweden and the United Kingdom). This is provided that the child is considered to possess



adequate cognitive faculties and the ability to decide. In 14 Member States (Austria, Belgium, Bulgaria, Denmark, Germany, Ireland, Lithuania, Latvia, the Netherlands, Poland, Slovenia, Spain, Sweden and the United Kingdom), the child is presumed to have such abilities after a certain age.

However, there is often flexibility in assessing these abilities, both in Member States where a certain reference age exists (for example, 12 years in Belgium; 14 in Austria, Bulgaria, and Germany; 15 in Slovenia; and 16 in Lithuania and the United Kingdom) and in Member States where there are individual assessments (for example, Finland, France and Italy). Such flexibility, while necessary in view of the variation in cognitive development, runs the risk that medical procedures may be imposed on children against their will.

This is a broader issue concerning the involvement of children in decision-making on matters that concern them. While adequate child participation mechanisms are particularly important, in this context the key determinants appear to be:

- (i) the minimum age from which a child is involved in the decision-making process: this is complicated by variations in sex development that arise or are found before or at puberty. From this perspective, ages of consent around or higher than 15 years old, as, for example, in Denmark, Ireland,

Lithuania, Poland, Slovenia, Spain and the UK might be too high.

- (ii) whether intervention is postponed or consent is sought from parents, when the child is considered to be unable to decide: in at least six EU Member States, Austria, Germany, Hungary, Malta, the Netherlands and Sweden, current practices or government guidelines show a tendency to postpone medical treatments that are not strictly necessary to safeguard health, until a child is considered capable of deciding. However, 'sex normalising' and/or cosmetic surgeries may still be performed on children without their informed consent.
- (iii) what happens in cases of disagreement between the child, and parents or legal representatives when a child can decide, but parental or a legal representative's consent is also necessary: the situation varies between Member States. In Italy and Poland, for example, the decision is made by a guardianship court; in Lithuania and Latvia the decision is made by the medical staff involved. In a German Federal Court of Justice case – not directly related to intersex issues – the parents' right to decide on medical treatment was limited by the child's opposition to it given that the postponement of the intervention did not endanger the child's health.⁵⁹

Concluding remarks

Intersex people face several challenges which relate to the law and medical intervention. Legal and medical professionals should be better aware of these challenges to ensure that the fundamental rights of intersex people are fully respected – particularly when they are children.

Intersex people will remain vulnerable to discrimination as long as birth, and other, registries do not record sex identities appropriately, and as long as they are medically diagnosed as men or women with a health disorder.

Alternatives to gender markers in identity documents should be considered to protect intersex people. The possibility of including a gender-neutral marker could also be considered. This is particularly important for birth registration/certificates in situations where the new-born child's sex is unclear.

EU Member States should avoid 'sex-normalising' medical treatments on intersex people without their free and informed consent. This would help prevent violations of the fundamental rights of intersex people, especially through practices with irreversible consequences.

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