



Learning Resource Guide on Intersex People's Rights Bring-In Project

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ΠΑΝΤΕΙΟ ΠΑΝΕΠΙΣΤΗΜΙΟ
ΚΟΙΝΩΝΙΚΩΝ ΚΑΙ ΠΟΛΙΤΙΚΩΝ ΕΠΙΣΤΗΜΩΝ

symplexis

bilitis



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Foreword

This Learning Resource Guide was produced by Bilitis Foundation with the support of the Rights, Equality and Citizenship Program (2014-2020) of the European Union, which provided funding for the project “BRING-IN – Building professional capacity to combat discrimination against and better meet the needs of Intersex Persons”.

The Learning Resource Guide aims to provide resources to four target groups: health professionals, social workers, policy-makers, and parents of intersex children with the aim to raise their awareness on the human rights of intersex people and improve the access to health and social services, and the general access to rights of the latter.

The learning resources included here cater to the capacity-building needs of the health and social care professionals that have been identified in the national research conducted in Greece, Bulgaria, Hungary and the UK within the BRING-IN project.

Bilitis Foundation extends its gratitude to all partners in the consortium of the BRING-IN project as well as to IntersexGreece and OII Europe for the help provided with the development of the guide. Last but not least, we would like to thank all external experts from the Working Group for learning resource exchange created within BRING-IN project for helping gather relevant resources.

1 Introduction



https://youtu.be/iN3sY_MWVHY

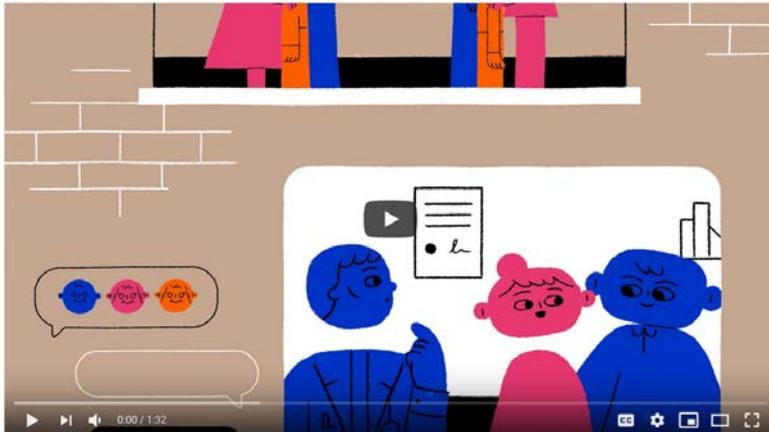
My name is Pol Naidenov. When I was born, I was registered as a girl. I was born in the main town of North-West Bulgaria in 1970. Since my early childhood years, I knew that I was different from the other girls, but I did not know why or how. In my early teenage years, my body began to change and I was diagnosed with Morris syndrome. At that time, I felt more like a boy than a girl, but I knew that I couldn't be either one of these. I remember being hospitalized without explanation and spending too many days in the genetic department of one of the leading hospitals in Sofia, the capital of Bulgaria. The doctors would not tell me what treatment they were giving. My parents had given their consent to the treatment without being informed of all potential negative effects on my psychological and physical development. The doctors may not have known of these potential effects either. At some point, I was told that I needed to undergo a surgery in order, "to feel more comfortable as a young woman". I remember begging the doctors to make me a boy, and telling them through tears that I do not want to grow up as a woman. The surgery was nevertheless performed and a dark period of my life began, which I do not want to remember. Taking female hormones led to severe depression and suicidal thoughts. I felt that something, which was completely wrong, had been done to me. After many years of living with a strong discontent with my legal gender, and with my "normalized" body, I finally found the inner strength to start a case for legal gender recognition as a man. I began self-identifying as an intersex person around 2010. The Bulgarian law does not allow for recognizing a neutral gender, that is why, I requested a change of my legal gender marker from female to male, since I felt closer to being a man than to being a woman.

Today, one of my main goals in life is to protect other intersex children from living in the hell that I've been through. I would like to help families and institutions raising intersex children understand that they should not start gender affirmation therapies until the moment when the intersex child is able to self-identify. I wish to make health practitioners understand that some of the conventional therapies for treating intersex children may do more harm than good. I wish to make lawmakers understand that some people cannot fit into the binary gender model and a neutral gender marker is needed. Last, but not least, I wish to make society understand that biological sex is a spectrum and intersex bodies are not abnormal – they are just different.

Pol Naidenov
Intersex activist
Bilitis Resource Center Foundation

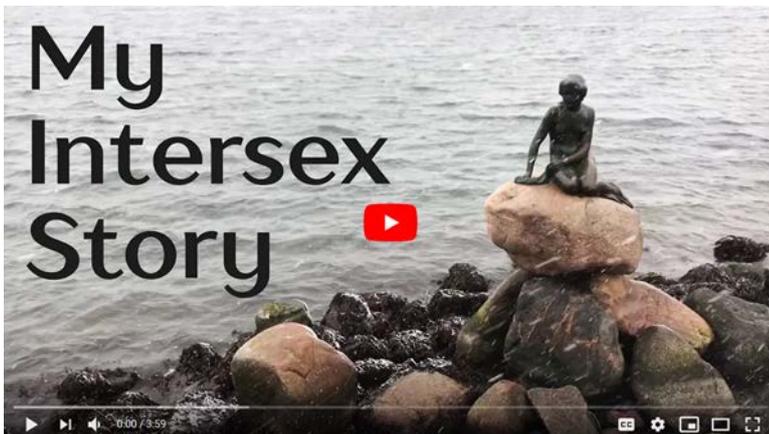
1.1 Before you start

1.1.1 Protect intersex children!



<https://youtu.be/vFkRVMAVa-k>

1.1.2 My intersex story



<https://www.youtube.com/watch?v=XXELQ5GNSwY>

2 General Information about Intersex

2.1 What is intersex?

Intersex is an umbrella term that describes bodies that fall outside the strict male/female binary. There are lots of ways someone can be intersex.

Intersex is a general term used for a variety of situations in which a person is born with reproductive or sexual anatomy that doesn't fit the boxes of "female" or "male." Sometimes doctors do surgeries on intersex babies and children to make their bodies fit binary ideas of "male" or "female". Doctors always assign intersex babies a legal sex (male or female, in most states), but, just like with non-intersex people, that doesn't mean that's the gender identity they'll grow up to have. This brings up questions about whether or not it's acceptable to do medical procedures on children's bodies when it's not needed for their health.

Miriam van der Haave gives us another perspective: "Intersex refers to the lived experience of the socio-cultural consequences of being born with a body that does not fit within the normative definitions of "man" and "woman." In short, it is about our experiences and not a medical diagnosis."

2.2 The term DSD and its implications

The fact that a person has an intersex body can become apparent at birth, in early childhood, in puberty, or even in adulthood. A study Living with intersex/DSD: An exploratory study of the social situation of persons with intersex/DSD¹ published in the Netherlands in 2014 reveals that at least 1 in 200 intersex people are at risk of being subjected to invasive surgeries and other medical interventions, e.g. hormonal treatment, based on being diagnosed by medical professionals as having a "Disorder of Sex Development" (DSD) or an unspecified diagnosis, such as "unspecified malformation of the male/female genitalia"

"Disorder of Sex Development" (DSD) is a medical umbrella term, which was introduced in 2006 by a Clinician Consensus Statement². It replaced the older terms used for intersex people, the oldest one of which was "hermaphrodite". Some clinicians use DSD to stand for "differences of" or "diverse" sex development. In any of its forms, the term DSD pathologizes healthy variations of sex characteristics and refers to intersex sex characteristics as characteristics that are "deviant" from the norm of male and female bodies, and thus need to be "fixed". By implying the necessity of "normalizing" therapies for intersex individuals, the term DSD breaches human rights standards.

<https://www.nhs.uk/conditions/differences-in-sex-development/>

1

https://www.researchgate.net/publication/290446986_Living_with_intersexDSD_An_exploratory_study_of_the_social_situation_of_persons_with_intersexDSD

2 <https://dsdguidelines.org/files/clinical.pdf>



<https://youtu.be/n6BLZHFbeL0>

2.2.1 How many people are intersex?

United Nations Office of the High Commissioner for Human Rights (2015): Fact Sheet. Intersex³

Intersex people are often thought to be a rare find, however, according to the United Nations up to 1.7% of the population, or, globally speaking, as of 2020 over 131 million people have been born with intersex traits rsex?

Intersex people are often thought to be a rare find, however, according to the United Nations up to 1.7% of the population, or, globally speaking, as of 2020 over 131 million people have been born with intersex traits

³ https://unfe.org/system/unfe-65-Intersex_Factsheet_ENGLISH.pdf

3 Personal Stories



<https://www.youtube.com/watch?v=zHalPNqM55o>

Op-ed: What's in a Name: Intersex and Identity (by Hida Viloria)⁴

In 1987, I was outed to my parents by my older brother in a scene straight out of the hysterical queer comedy *But I'm a Cheerleader*:

Dad yells, "Why can't you be more like your sister!" Gay son replies, "Guess what? She's a lesbian!"

⁴ <https://www.advocate.com/commentary/2014/05/14/op-ed-whats-name-intersex-and-identity>

4 Resources for Health and Social Care Professionals, Policy Makers, and Parents

4.1 Resources for Health Professionals

The Bring-In National Situation Analysis reports, produced by the partners in the BRING-IN project demonstrated that health care and social work professionals need to be better informed about the fundamental rights of intersex people because they commonly act as mediators between the system and the intersex individuals ensuring access to education, employment, goods and services, etc. They should be equipped with the necessary skills, knowledge and tools that would allow more appropriate support and care for intersex people.

The BRING-IN national research teams collected information about the level of awareness, perceptions, thoughts and behavior toward intersex people and their rights of the social and healthcare staff in each of the targeted countries. The training needs assessment was based on the results of an online survey for social and health professionals, which collected 203 valid answers in all partner countries, and focus groups, one with social professionals and another one with healthcare (medical/paramedical) staff in each country, in order to validate the findings on the online survey and provide additional qualitative information. Seventeen social-service professionals and sixteen health-care professionals in total took part in focus groups in the four countries.

There were no major differences in the training of health and social-care professionals on intersex issues in all four countries. Most professionals have not had at least one class on intersex issues in particular during their studies and / or LGBTI issues in general (a higher percentage of social service professionals answered negatively, compared to the health professionals). Regarding their training in the relevant subject during their professional career, we observed that in all countries they have not attended relevant training except for some Bulgarian health professionals who had received some in-service training on intersex issues.

InterACT: What We Wish Our Doctors Knew⁵

- “Be honest. I have a right to know about my own body. Secrets make me feel like I should be ashamed.”
- “I’ll end up doing my own research online, and would so much rather hear it from you.”
- “I wish that I had known about everything at age thirteen, when my parents knew.”
- “Please don’t lie to my parents, or advise them not to tell me about my own body.”

⁵ <https://live-interact-advocates.pantheonsite.io/wp-content/uploads/2015/12/BROCHURE-interACT-Doctors-final-web.pdf>

- “ I’m not as fragile as you may think I am. I can handle the truth!”

“What do intersex people need from doctors?”⁶

“simple concerns with transparency, accountability and respect. Current medical practices give rise to serious concerns and they need to change to bring them into line with human rights norms”

Sex characteristics are determined by a combination of chromosomes, hormones and anatomy⁷:

- Chromosomes: A binary model assumes two sex-specific chromosomal patterns: 46XX for females and 46XY for males. People with intersex variations may have atypical chromosomal patterns and combinations including a fewer or greater number of chromosomes (such as 47XXY, 47XYY, 45XO, 47XXX, 48XXXX and 49XXXXX) or chromosomal mosaics – cellular combinations of two different chromosomal patterns (such as 46XY/45XO or 46XY/47XXY). Some intersex people may have been assigned to one sex but have the chromosomal pattern of the opposite sex (male presentation and 46XX chromosomes or female presentation and 46XY chromosomes), while others may combine characteristics of both sexes. These natural variations mean that sex chromosomes alone are an unreliable determinant of sex and gender.
- Hormones: A binary model assumes hormone levels and ratios in which females have greater levels and sensitivities to oestrogen than males, and males have greater levels and sensitivities to testosterone than females. And yet, some people with intersex variations produce hormones in greater or lesser amounts than is common to the sex they have been assigned or exhibit more or less sensitivity to hormones than is common for their assigned sex (such as androgen insensitivity syndrome). Some people with intersex variations may have hormone levels and ratios that lead to a delay or absence of puberty or to developmental impacts that are atypical for their assigned sex.
- Anatomy: A binary model assumes development of clearly differentiated primary sex characteristics (ovaries, a clitoris and vagina for XX females, and testes and a penis for XY males), as well as secondary sex characteristics such as height, vocal cord length and/or tenor, facial and bodily hair distributions and thickness, breast development, jawline prominence, muscle mass and other features. People with intersex variations may experience atypical primary sex characteristics relating to differences in the development, size, appearance and/or absence of internal and external genitalia. The development of secondary sex characteristics may also differ as a result of an intersex variation.

6 <https://ihra.org.au/16568/carpenter-ranzcog-ogmag/>

7 <https://www2.health.vic.gov.au/Api/downloadmedia/%7BB6F44633-5E80-40EB-89DD-F4B348054E8A%7D>

Shaping parents, shaping penises: How medical teams frame parents' decisions in response to hypospadias⁸

Psychological research provides insights into how parents approach medical decisions on behalf of children. The medical decision of concern here is the surgical alteration of a hypospadiac penis, whose urethral opening does not appear at the tip. Hypospadias surgery is routinely carried out in infancy, despite criticism by international organizations concerned about children's rights. The focus of this study is on the framing of hypospadias surgery.

Reducing obstacles and promoting access to health services for intersex people: recommendations to health professionals⁹

Reducing Health inequalities experienced by LGBTI people: What is your role as a health professional?

The Trainers manual from the project Health4Lgbti includes intersex specific questions and topics

'Intersexion' debate at Melbourne medical student conference, 2020¹⁰

2020 On 23 June, the annual Melbourne Medical Student Conference held a session on the medical treatment of people with intersex variations. Participants were Professors John Hutson, Sonia Grover and Clare Delany of the University of Melbourne and Royal Children's Hospital Melbourne, and Morgan Carpenter from IHRA. This video includes a debate, and also some discussion immediately prior. The entire video has been recorded and shared with conference participants as it is here.

4.1.1 Main Issues Faced by Intersex People in Healthcare

- Lack of knowledge around intersex lives
- Difficulty in finding intersex-specific health services
- Lack of information for both parents of intersex children and intersex persons
- Widespread assumptions that intersex status is an illness which requires "fixing"

Issues faced by Intersex People in the EU in Healthcare¹¹

Only 14% of all respondents have received specific diagnosis and relevant information about their variation of sex characteristics from the health service

⁸ <https://pubmed.ncbi.nlm.nih.gov/30054962/>

⁹ https://ec.europa.eu/health/sites/health/files/social_determinants/docs/2018_lgbti_trainersmanual_en.pdf

¹⁰ <https://ihra.org.au/36471/intersexion-mdscx-2020/>

¹¹ FRA LGBTI Survey 2020: Intersex Specific Questions <https://fra.europa.eu/en/data-and-maps/2020/lgbti-survey-data-explorer>

Over half of the respondents have received determination of variation of sex characteristics by a health professional in an age when they were not capable of independent decision regarding their self-determination (before birth – 3%; in childhood – 14%, in adolescence – 34%)

22% of all respondents have received medical treatment to modify their sex characteristics

21% have received the above medical treatment at the age of 5 or less

2020 On Clinical Guidelines: Important things to understand¹²

The linked policy briefing considers whether or not guidelines are enough to ensure medical interventions on infants, children and adolescents with intersex variations conform to human rights norms, and eliminate harmful so-called “normalising” interventions.

4.1.2 Access to General Healthcare

- Access to general healthcare is often impaired by prejudices of healthcare professionals and the refund policies of health insurance companies.
- 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.
- Intersex individuals have repeatedly reported physical and psychological abuse by medical staff.
- Other common issues faced by intersex people in Europe are lack of access to hormone substitution or hormone substitution which does not fit the real needs of the person’s body

9 Doctors Changing the Face of Healthcare for Intersex People¹³

Too many members of intersex communities are survivors of medical harm. Many endure the effects of infant genital surgeries that changed their lives before they were old enough to speak. Some intersex adults grow up to fear and distrust all healthcare interactions because of these experiences. This pain is real, and a central focus of interACT’s work. We also know that there are doctors dedicated to working beside us for change.

4.1.3 Wellbeing and Mental Health

- There is a need for large-scale research into the psychological and emotional wellbeing of intersex people, as well as the long-term impact of “normalising” treatments for older intersex people.
- Younger intersex people report experiencing isolation due to stigma, bullying, discrimination or rejection from family or peers.¹⁴

12 <https://ihra.org.au/guidelines/>

13 <https://interactadvocates.org/doctors-changing-intersex-healthcare/>

14 <https://interactadvocates.org/wp-content/uploads/2016/01/Intersex-Stories-Statistics-Australia.pdf>

- Specialist long-term follow up services for intersex people should include psychological support to address psychosexual, emotional and social wellbeing.

Divergence or Disorder?: the politics of naming intersex¹⁵

ABSTRACT The conditions once known under the umbrella terms *intersex* and *hermaphroditism* are now generally being called *disorders of sex development* in medical settings. The terms might seem synonymous, but in fact there are significant differences with controversial consequences. *Hermaphroditism*, an older term that can still be found in many medical writings, is vague, demeaning, and sensationalistic, conjuring mythic images of monsters and freaks. In the 1990s, activists advocated *intersex* to describe discordance between the multiple components of sex anatomy, but that word alienated many parents of affected children, as it suggests a self-conscious alternative gender identity and sexuality. *Disorders of sex development* also refers to intersex, but it deemphasizes the identity politics and sexual connotations associated with *intersex*, avoids the degradation associated with *hermaphrodite*, and instead highlights the underlying genetic or endocrine factors that cause prenatal sex development to take an unusual path. I argue that using *disorder* is problematic, because it implies medical conditions in need of repair, when some intersex anatomies, though atypical, do not necessarily need surgical or hormonal correction. I advocate a less pathologizing new term, *divergence of sex development*, that might reduce some of the conflict over nomenclature and satisfy intersex people, their parents, and their doctors.

4.1.4 Outcomes of Surgery

- Satisfaction with “treatment” outcomes vary markedly ranging from satisfied with treatment outcomes after surgical intervention to significant dissatisfaction (prolonged sexual anxiety, dyspareunia, and dissatisfaction with genital function).
- Any treatment of intersex people should occur in the context of open dialogue between practitioners, the intersex person and their family with full informed consent prior to any surgical intervention and increased access to psychological support services.

“I Want to Be Like Nature Made Me”: Medically Unnecessary Surgeries on Intersex Children in the US¹⁶

(Reader Advisory: This report contains graphic descriptions of traumatic experiences, often affecting children.)

¹⁵ <https://muse.jhu.edu/article/222245>

¹⁶ <https://www.hrw.org/report/2017/07/25/i-want-be-nature-made-me/medically-unnecessary-surgeries-intersex-children-us>

Intersex-Affirming Hospital Policy Guide: Providing Ethical and Compassionate Health Care to Intersex Patients¹⁷

...“80 percent of intersex people have changed healthcare providers due to their providers’ use of insensitive or offensive language. 20 percent of us have had to knowingly use harmful, pathologizing language to refer to and describe our bodies in order to access care.”

4.2 Resources for Social Care Professionals

This section will provide useful resources for social workers. The vast majority of social care professionals who took part in the BRING-IN project’s focus groups had never provided support services to an intersex person and/or a close family member of an intersex person (for issues related to the intersex status of their family member) during their career. In the case of Greece, Hungary and the UK, none of the persons interviewed had such an experience. However, interviewees in the UK pointed out that they might have provided support services to intersex people, but intersex people might not have wanted to disclose their intersex status or were not aware that they were intersex. None of the social workers who participated in the qualitative research had ever had training on intersex issues. On the positive side, they were interested to increase their knowledge on the topic.

We recommend that social workers familiarize themselves with the resources aimed at the parents of intersex children. The videos below are extremely useful for intersex people and their parents, as well as for getting acquainted with the problems that intersex people face. Intersex people who have undergone surgery often develop post-traumatic stress as well as a lack of sense of bodily autonomy. Intersex children and adolescents, as a result of the experience, are easy prey for abusers. They are often trained not to talk about their experiences and traumas, and as a result, they do not share cases of sexual violence. Life-related decisions: Never bring together parents who have already operated on their children and those who have decided not to. Often meeting such a meeting becomes a traumatic experience both for yourself and for the parents of intersex children.

“Intersex” refers to people who are born with any of a range of characteristics that may not fit *traditional conceptions* about male or female bodies.¹⁸

17 FRA LGBTI Survey 2020: Intersex Specific Questions <https://fra.europa.eu/en/data-and-maps/2020/lgbti-survey-data-explorer>

18 <https://live-interact-advocates.pantheonsite.io/wp-content/uploads/2017/03/INTERSEX101.pdf>



Rinio Simeonidou: “We knew – like most people already are taught at school – we knew that babies are coming to the world in just two “versions”. Babies are born boys and girls. Boys with XY chromosomal features, or girls with XX chromosomes.”¹⁹

The “normalisation” of intersex bodies and “othering” of intersex identities²⁰

In 2015, a UN factsheet named Australia and Malta as countries that have made demonstrable progress in recognising the human rights of intersex people. Australia had held the first Parliamentary inquiry on involuntary or coerced medical interventions, and also added an attribute of ‘intersex status’ to federal anti-discrimination law. Australia also implemented a federal third-sex classification, and laid claim in 2017 to ‘some of the most advanced laws in the world, including on intersex status’. Yet the report of the Parliamentary inquiry has not been implemented and so-called medical ‘normalisation’ of intersex bodies continues with the imprimatur of the Family Court of Australia. In contrast, Malta had enacted legal protections for the bodily autonomy of infants and children.

4.3 Resources for Policy Makers

Intersex persons in Europe face numerous practical obstacles when seeking legal gender recognition. The lack of a neutral gender marker in the laws of most European countries leads to the effect that decisions on the legal registration of intersex children as either male or female are made under the pressure of the binary legal model. This model breaches the right to self-determination of intersex individuals. The possibility to register a child as either “male” or “female” creates an environment in which variations are not welcome. This notion implies the justification of “normalizing” therapies which will overcome physical ambiguity and reinforce the legal unambiguity. Research has proved that people whose gender marker in their legal documents matches with their self-identification with a particular gender are less likely to experience mental health issues. This is practically not possible for those intersex people who do not self-identify as either men or women. The gender binary system amplifies the trauma and challenges, which intersex people face in their daily lives. Their very existence is compromised. (Based on Written comments submitted jointly by OII Europe, ILGA-Europe, and C.I.A. on Y against France (Application no. 76888/17) in the ECHR)

¹⁹ Intersex Human Rights Rinio Simeonidou @TEDxLesvos <https://youtu.be/t-VBkZrU818>

²⁰ <https://morgancarpenter.com/normalisation-bodies-othering-identities/>

Divergence or Disorder?: the politics of naming intersex²¹

ABSTRACT The conditions once known under the umbrella terms *intersex* and *hermaphroditism* are now generally being called *disorders of sex development* in medical settings. The terms might seem synonymous, but in fact there are significant differences with controversial consequences. *Hermaphroditism*, an older term that can still be found in many medical writings, is vague, demeaning, and sensationalistic, conjuring mythic images of monsters and freaks. In the 1990s, activists advocated *intersex* to describe discordance between the multiple components of sex anatomy, but that word alienated many parents of affected children, as it suggests a self-conscious alternative gender identity and sexuality. *Disorders of sex development* also refers to intersex, but it deemphasizes the identity politics and sexual connotations associated with *intersex*, avoids the degradation associated with *hermaphrodite*, and instead highlights the underlying genetic or endocrine factors that cause prenatal sex development to take an unusual path. I argue that using *disorder* is problematic, because it implies medical conditions in need of repair, when some intersex anatomies, though atypical, do not necessarily need surgical or hormonal correction. I advocate a less pathologizing new term, *divergence of sex development*, that might reduce some of the conflict over nomenclature and satisfy intersex people, their parents, and their doctors.

Protecting Intersex people in Europe: A toolkit for law and policymakers²²

"Bodily autonomy – making one's own informed decisions about one's body and what happens to it – is a fundamental human right, repeatedly enshrined throughout myriad human rights instruments globally. Each of us holds this right individually. However, it is not equally protected nor enforced for everyone.

Across Europe, as well as much of the world, the right to bodily autonomy is regularly and grievously violated on the basis of sex characteristics. These violations are increasingly documented, and today, people with variations of sex characteristics are internationally recognised as victims of harmful medical practice and other human rights violations."

4.3.1 Human rights violations faced by intersex people

"Normalizing treatment" of intersex individuals

Surgeries and medical interventions on intersex infants and children are still common. According to a 2015 survey published by the EU Fundamental Rights Agency, so-called sex-"normalizing" surgeries on intersex infants and children are carried out in at least 21 of the EU Member States. As of the end of 2020, only Malta and, with certain nuances, Portugal explicitly prohibit these harmful medical interventions. In 2017, the Parliamentary Assembly of the Council of Europe confirmed in its resolution "Promoting the human rights of

²¹ <https://muse.jhu.edu/article/222245>

²² https://oieurope.org/wp-content/uploads/2019/05/Protecting_intersex_in_Europe_toolkit.pdf

and eliminating discrimination against intersex people that these surgeries are serious breaches of physical integrity” and highlighted that they are performed “despite the fact that there is no evidence to support the long-term success of such treatments, no immediate danger to health and no genuine therapeutic purpose for the treatment”.²³

In 2019, the European Parliament emphasized in its resolution The rights of intersex people that it “strongly condemns sex-normalizing treatments and surgeries” and that it encourages Member States to adopt legislation prohibiting such surgeries as soon as possible²⁴

Normalizing therapies are performed on the ground that intersex conditions are seen as a “disorder” and intersex people are strongly pathologized.

Why are “Normalizing therapies a problem?”

- They are performed on healthy bodies.
- They are irreversible, deferrable, and non-emergency medical interventions performed without the consent of the individual (usually a child).
- If a fetus is diagnosed as intersex, this may entail abortion in some countries.

A parent of an intersex child says: It is common, for expectant parents to be pressured or strongly guided by experts with intense pathologizing views (mostly obstetricians) to terminate - otherwise healthy and desirable- intersex babies.

- The psychological distress caused by the negative outcomes of “corrective” surgery can result in self-harming and suicidal behaviour.
- To this day, medical and surgical treatment of intersex infants and minors rests on the belief that such treatment is necessary and desirable. Thus, although parents of intersex children are asked to provide their proxy consent to the treatment, they are often ill-informed and impressionable, and are not given adequate time or options necessary to provide fully informed consent.
- “Normalizing” therapies usually aim to reinforce the sex assigned at birth. A substantial number of intersex people reject the sex they were registered with at birth. A 2012 clinical review paper found that between 8.5% and 20% of intersex people, regardless of whether their body was subjected to medical interventions, developed a gender identity that did not match the sex or gender that was assigned to them at birth.²⁵
- Variations in sex characteristics of intersex people are currently codified in medical classifications as pathologies or disorders, usually referred to as ‘disorders of sex development’. This raises serious questions with regard to the medical profession’s ability to help intersex people attain the highest possible level of health that they have a right to.

²³ Parliamentary Assembly of the Council of Europe (PACE), Resolution 2191 (2017), Promoting the human rights of and eliminating discrimination against intersex people, §2.

²⁴ European Parliament (EP), Resolution of 14 February 2019 on the rights of intersex people (2018/2878(RSP)), §2.

²⁵ P.S. Furtado *et al.* (2012): Gender dysphoria associated with disorders of sex development, in: *Nat. Rev. Urol.* 9 (11): 620-627.

To this day, medical and surgical treatment of intersex infants and minors rests on the belief that such treatment is necessary and desirable. Thus, although parents of intersex children are asked to provide their proxy consent to the treatment, they are often ill-informed and impressionable, and are not given adequate time or options necessary to provide fully informed consent.

“Normalizing” therapies usually aim to reinforce the sex assigned at birth. A substantial number of intersex people reject the sex they were registered with at birth. A 2012 clinical review paper found that between 8.5% and 20% of intersex people, regardless of whether their body was subjected to medical interventions, developed a gender identity that did not match the sex or gender that was assigned to them at birth.

Variations in sex characteristics of intersex people are currently codified in medical classifications as pathologies or disorders, usually referred to as ‘disorders of sex development’. This raises serious questions²⁶ with regard to the medical profession’s ability to help intersex people attain the highest possible level of health that they have a right to.

Legislating intersex equality: building the resilience of intersex people through law²⁷

The last 20 years has seen a global increase in the legal recognition of intersex.¹ Whilst a number of qualitative studies have examined the experiences of intersex persons in relation to medicine, this paper offers findings from the first study to examine the practical impact that law has had on the lives and experiences of intersex embodied people.

Human rights and Intersex

“Binary classifications of sex and gender are omnipresent in our society and inform the way we understand and organise the world around us. The classification of humankind into two categories – “F” (female) and “M” (male) – and the entrenchment of those categories in identification documents, expose people who do not fit neatly into those two categories to human rights breaches. Among them, intersex persons are especially vulnerable.”

“Stereotypes hinging on the supposed dichotomy of gender as well as the medical norms of so-called female and male bodies have allowed for the establishment of routine medical and surgical interventions on intersex people, even when such interventions are cosmetic rather than medically necessary, or when those concerned have not been adequately consulted or informed prior to these procedures. Secrecy and shame around intersex bodies have permitted the perpetuation of these practices for decades, while the human rights issues at stake have remained for the most part unaddressed.”²⁸

²⁶

<https://www.google.com/url?q=https://www.jstor.org/stable/25165367?seq%3D1&sa=D&source=editors&ust=1614418795083000&sg=AOvVaw24RltPZv9qHJCBv9utLc8J>

²⁷ <https://www.cambridge.org/core/journals/legal-studies/article/legislating-intersex-equality-building-the-resilience-of-intersex-people-through-law/>

²⁸ <https://wcd.coe.int/ViewDoc.jsp?Ref=CommDH/IssuePaper%282015%291&Language=lanEnglish&Ver=original>

Background Note on Human Rights Violations against Intersex People²⁹

“Intersex is an umbrella term used to describe a wide range of innate bodily variations in sex characteristics. Intersex people are born with sex characteristics that do not fit typical definitions for male or female bodies, including sexual anatomy, reproductive organs, hormonal patterns, and/or chromosome patterns.

In recent years, awareness of intersex people, and recognition of the specific human rights abuses that they face, has grown, thanks to the work of intersex human rights defenders. These include risks of forced and coercive medical interventions, harmful practices and other forms of stigmatisation due to their physical traits. To date, only a handful of countries have implemented measures to prevent and address such abuses, and the effectiveness of existing measures remains to be fully documented.”

First, Do No Harm: ensuring the rights of children born intersex³⁰

‘Is it a boy or a girl?’ It is often the first question people ask parents about their baby. It’s a question based on the assumption that the world is divided into two groups of people, male and female, and that everyone’s biological and genetic characteristics fit neatly into one of two categories.

Joint statement by 33+ countries at the UN Human Rights Council³¹

2020 Austria made a statement on behalf of countries from every region of the world, calling on the Human Rights Council to investigate and address human rights violations and abuses against intersex persons.

Survey shows: intersex people are highly vulnerable during the Covid-19 pandemic³²

4.4 Resources for Parents of Intersex Children

Supporting your intersex child – A parents’ toolkit³³

Is it a boy or a girl? This is the question that is asked the world over when someone gives birth. Many parents will answer that question without much thought. But for a significant number the answer will be more complex. The toolkit describes the most common medical and social situations

29 <https://www.ohchr.org/Documents/Issues/Discrimination/LGBT/BackgroundNoteHumanRightsViolationsagainstIntersexPeople.pdf>

30 <https://www.amnesty.org/en/latest/campaigns/2017/05/intersex-rights/>

31 <https://ihra.org.au/36635/hrc45/>

³² <https://oieurope.org/covid-19-survey-report/>

³³ <https://oieurope.org/supporting-your-intersex-child-a-parents-toolkit/>

parents of intersex children/ children with a variation of sex characteristics might find themselves in and provides recommendations.

Your Beautiful Child: Information for Parents³⁴

This information addresses common questions and concerns regarding variations in sex development, also known as intersex variations, to help you welcome your baby and make decisions that promote the health and well-being of your child and the entire family.

2006 Handbook for Parents: Consortium on the Management of Disorders of Sex Development³⁵

This document addresses all ages of an intersex child and may be well digestible for parents and other people who are still very much caught in a medicalising and pathologising perspective. On one hand, it introduces human rights based concepts and practices, but on the other, it includes statements that maintain the medicalization of the intersex identities.

Read it critically!

³⁴ http://www.intersexequality.com/wp-content/uploads/2014/07/One-sheet_Your-Beautiful-Child.pdf

³⁵ <https://dsdguidelines.org/files/parents.pdf>

5 Additional Resources

5.1.1 English language resources:

OII Europe channel: <https://www.youtube.com/channel/UC8QIKeKG4TKDMuUmydBN0KQ>

Intervisibility Project: <https://intervisibility.eu/category/artivism/>

<https://www.cambridge.org/core/journals/legal-studies/article/legislating-intersex-equality-building-the-resilience-of-intersex-people-through-law/>

Intersexuality in the Family: An Unacknowledged Trauma, pages 27-56*

https://www.tandfonline.com/doi/abs/10.1300/J236v10n02_03

People born with intersex conditions experience trauma and stigma that have not been fully recognized by the medical and therapeutic professions. Current treatment protocols require rapid diagnosis followed by surgical alteration of infants born with ambiguous genitalia which has led to a lack of thorough attention to the psychosocial issues faced by these children and their families. Histories of surgery and silence have left children and families unable to address many of the traumas associated with intersexuality, including stigma, shame, surgical complications, and potential questions about sexual and gender identity.

What's in a Name? The Controversy over "Disorders of Sex Development", by Ellen K. Feder and Katrina Karkazis*

<https://www.jstor.org/stable/25165367?seq=1>

In 2006, when the U.S. and European endocrinological societies published a consensus statement announcing a significant change in nomenclature for those born with atypical sex anatomy, whereby variations on the term "hermaphrodite" and "intersex" would be replaced by the term "Disorders of Sex Development"

The needs of students with intersex variations^{36*}

To date, people with intersex variations have been mainly studied via small-scale clinical research, with only a small amount of reflective commentary contributed by sociocultural scholars. This paper reports on findings from a 2015 online Australian survey of 272 people with intersex variations, which aimed to redress the gap in research on this groups' experiences and perspectives concerning education. Participants ranged in age from 16 to 87 years, and represented all Australian states and territories. Most had experienced two medical treatment interventions related to their intersex variation: commonly reported interventions included hormonal treatment and genital surgery delivered to participants when they were aged under 18 years of age. Participants reported various

(*) These resources can be accessed only by registered users

³⁶ https://www.researchgate.net/publication/297891165_The_needs_of_students_with_intersex_variations

physical and psychological impacts from these treatments. Well-being risks were high; most of the group had engaged in suicidal ideation, particularly when individuals first found out about their variation. This impacted on their schooling – almost one-fifth of survey respondents had received no high school certification due to their early dropout and the overwhelming majority did not attend schools with inclusive puberty/sex education provision or counselling. Most survey participants had not disclosed their intersex variation to staff, although more than half had done so to their classmates. Many had experienced bullying. Only one-quarter of participants rated their overall education experiences positively. Participants suggested improvements to schools' information provision and support features.

5.1.2 Resources in other languages

Intersex Russia channel: <https://www.youtube.com/channel/UC3Ye2qi8eDWtnPzTJxbR9mQ>

XYSpectrum channel: <https://www.youtube.com/channel/UChZwErtvGLaG6mTtS7pGeFg>

Multilingual: <https://brujulaintersexual.org>

Russia: <https://www.intersexrussia.org/resources>

Ukraine: <https://intersexukraine.org/nashi-vidannya/>

Serbia: <http://xyspectrum.org/materijali/>

Netherlands: <https://www.seksediversiteit.nl/publicaties/>

Austria: <https://vimoe.at/ueber-inter/#toggle-id-2>

Multilingual: <https://oiieurope.org/library-en/publications/>

Hungary: <https://hatter.hu/kiadvanyaink/interszex-utmutato-szuloknek> (Translation of <https://oiieurope.org/supporting-your-intersex-child-a-parents-toolkit/>)

Hungary: <http://lmbtszovetseg.hu/eroforrasok/az-interszex-emberek-jogainak-vedelme-hogyan-segithetsz-te> (Translation of <https://oiieurope.org/tag/allies-toolkit/>)