



Human rights and intersex people



Issue paper



COMMISSIONER
FOR HUMAN RIGHTS

COMMISSAIRE AUX
DROITS DE L'HOMME

COUNCIL OF EUROPE



CONSEIL DE L'EUROPE

Human rights and intersex people

Issue paper published
by the Council of Europe
Commissioner for Human Rights

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Cover and other photos: © Del LaGrace Vol-
cano from the series "Visibly Intersex"
Cover: Documents and Publications Produc-
tion Department (SPDP)
Layout: Jouve

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First edition: April 2015
Second edition: September 2015
Printed at the Council of Europe

Acknowledgements:

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List of abbreviations and initialisms

AIC	Advocates for Informed Choice
AIS	Androgen insensitivity syndrome
APA	American Psychological Association
CAH	Congenital adrenal hyperplasia
CEDAW	Convention on the Elimination of All Forms of Discrimination against Women
CESCR	UN Committee on Economic, Social and Cultural Rights
CJEU	Court of Justice of the European Union
CRC	Convention on the Rights of the Child
DSD	Disorders of sex development
DSM	Diagnostic and Statistical Manual of Mental Disorders
ECHR	European Convention on Human Rights
EQUINET	European Network of Equality Bodies
EU	European Union
F	Female
FIFA	International Federation of Association Football
FRA	European Union Agency for Fundamental Rights
FRANET	European Union Agency for Fundamental Rights multidisciplinary research network
GATE	Global Action for Trans Equality
GID	Gender identity disorder
IAAF	International Association of Athletics Federations
IACHR	Inter-American Commission on Human Rights
ICAO	International Civil Aviation Organisation

ICCPR	International Covenant on Civil and Political Rights
ICD	International Classification of Diseases
ICESCR	International Covenant on Economic, Social and Cultural Rights
ICJ	International Commission of Jurists
IGM	Intersex genital mutilation
ILGA	International Lesbian, Gay, Bisexual, Trans and Intersex Association
IOC	International Olympic Committee
LGBTI	Lesbian, gay, bisexual, trans and intersex
M	Male
NEK-CNE	Swiss National Advisory Commission on Biomedical Ethics
NGO	Non-governmental organisation
NHRS	National human rights structure
OAS	Organization of American States
OHCHR	UN Office of the High Commissioner for Human Rights
OII	Organisation Intersex International
PACE	Parliamentary Assembly of the Council of Europe
UDHR	Universal Declaration of Human Rights
UN	United Nations
UNHCR	UN High Commissioner for Refugees
UNHRC	UN Human Rights Council
WHO	World Health Organization
WPATH	World Professional Association for Transgender Health
X	Intermediate/intersex/unspecified

Summary

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.

To this day, European society remains largely unaware of the reality of intersex people. However, through the pioneering work of a growing number of intersex groups and individual activists, the human rights community and international organisations are becoming increasingly conscious of this situation and are working to draw on human rights standards to address such concerns.

In May 2014, the Commissioner for Human Rights published a Human Rights Comment entitled “A boy or a girl or a person – intersex people lack recognition in Europe” which highlighted the human rights challenges faced by intersex people. This issue paper gives more detailed guidance and presents the Commissioner’s recommendations to address the question. It informs governments and practitioners about current ethical and human rights developments, including global best practices in this area. Consultations with intersex rights activists and legal and medical experts preceded the drafting of the document.

Several positive steps have already been taken towards understanding and responding to the situation of intersex people. The recent adoption of a United Nations (UN) interagency statement on sterilisation that refers to breaches of bodily integrity of intersex people constitutes a milestone in combining medical and human rights approaches. The publication of reports on intersex issues by national councils on medical ethics has improved awareness of the problems encountered. There have also been useful initiatives for protecting intersex people against discrimination through reforms of equal treatment legislation. However, the positive developments remain isolated. There is an urgent need to make further progress to improve the enjoyment of human rights by intersex people.

This issue paper aims to stimulate the development of a framework of action by suggesting a two-pronged approach. On the one hand, it 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. On the other, it provides possible ways forward in terms of protection against discrimination of intersex people, adequate recognition of their sex on official documents and access to justice.

The Commissioner's recommendations

1. Member states should end medically unnecessary “normalising” treatment of intersex persons, including irreversible genital surgery and sterilisation, when it is enforced or administered without the free and fully informed consent of the person concerned. Sex assignment treatment should be available to intersex individuals at an age when they can express their free and fully informed consent. Intersex persons’ right not to undergo sex assignment treatment must be respected.
2. Intersex persons and their families should be offered interdisciplinary counselling and support, including peer support. Intersex persons’ access to medical records should be ensured.
3. National and international medical classifications which pathologise variations in sex characteristics should be reviewed with a view to eliminating obstacles to the effective enjoyment, by intersex persons, of human rights, including the right to the highest attainable standard of health.
4. Member states should facilitate the recognition of intersex individuals before the law through the expeditious provision of birth certificates, civil registration documents, identity papers, passports and other official personal documentation while respecting intersex persons’ right to self-determination. Flexible procedures should be observed in assigning and reassigning sex/gender in official documents while also providing for the possibility of not choosing a specified male or female gender marker. Member states should consider the proportionality of requiring gender markers in official documents.
5. National equal treatment and hate crime legislation should be reviewed to ensure that it protects intersex people. Sex characteristics should be included as a specific ground in equal treatment and hate crime legislation or, at least, the ground of sex/gender should be authoritatively interpreted to include sex characteristics as prohibited grounds of discrimination.
6. National human rights structures such as ombudspersons, equality bodies, human rights commissions and children’s ombudspersons should be active in their outreach towards intersex people, including children. They should be clearly mandated to work on issues related to intersex people and to provide victim-support services to them. There is a need to facilitate intersex persons’ access to justice.

7. Member states should carry out research into the situation and human rights protection needs of intersex people in different settings. There is an urgent need to improve public awareness and professional training about the problems encountered by intersex persons. Intersex people and organisations representing them should be enabled to participate actively in research concerning them and in the development of measures improving their enjoyment of human rights.
8. The human rights violations intersex people have suffered in the past should be investigated, publicly acknowledged and remedied. Ethical and professional standards, legal safeguards and judicial control should be reinforced to ensure future human rights compliance.



Chapter 1

Introduction

1.1. Understanding intersex people

When a newborn is welcomed into this world, the same question is repeatedly posed: “Is it a boy or a girl?” While at face value that question is innocent, it indicates just how fundamental sex and gender classifications are to our society, as well as the binary manner in which the human sexes are categorised. It also demonstrates our limited understanding of sex, given that the rigid line with which we separate the sexes into two mutually exclusive categories does not have a parallel in nature.¹

The sex assigned at birth will subsequently become a legal and a social fact for the newborn and will accompany them throughout the rest of their life. As they grow, go through adolescence, and become an adult, certain mannerisms, behaviours and interests will be expected to develop as “normal” manifestations of the person’s assigned sex. Additionally, that sex will be clearly designated on identification documents as an “F” or an “M”, and in some countries with an even or odd digit in personal social security numbers. Gendered symbols will also indicate which sex-segregated facilities are available to that person, and which are not. Likewise, various forms and documents throughout people’s lives will oblige them to tick F or M as part of the personal data set required before the provision of the service or entitlement in question.

While the importance conferred to sex as a classifier does not pose difficulties for most people, it does create serious problems for those who do not neatly fit within the “female”/“male” dichotomy. This is because society does not usually recognise a person without reference to their sex, and as a result, the ability of intersex and trans people to enjoy their human rights is especially impacted by the current normative confines of sex and gender.²

It is important to note the distinction between intersex and trans people:³

Intersex individuals are persons who cannot be classified according to the medical norms of so-called male and female bodies with regard to their chromosomal, gonadal or anatomical sex. The latter becomes evident, for example, in secondary sex characteristics such as muscle mass, hair distribution and stature, or primary sex characteristics such as the inner and outer genitalia and/or the chromosomal and hormonal structure.⁴

Differences can include the number of sex chromosomes and patterns (e.g. XXY or XO), different tissue responses to sex hormones (e.g. having one ovary and one testis, or gonads that contain both ovarian and testicular tissue) or a different hormone balance. The genitalia of some intersex persons may not be clearly identifiable as male or female, and are hence easily identifiable as intersex at birth; however, for others the detection only occurs later in life during puberty or sometimes even later (e.g. due to the absence of menstruation or physical development that is not in line with the assigned sex). Although they do not usually face actual health problems due to their status, intersex people are routinely subjected to medical and surgical treatments – often while very young – to align their physical appearance with either of the binary sexes without their prior and fully informed consent.

Conversely, trans people externalise an innate gender identity which does not correspond with society's gender expectations in relation to their assigned sex, and often encounter various forms of discrimination, especially following their decision to undertake a process of transition to align their body, appearance and mannerisms with their gender identity.⁵

In essence, as a result of surgeries or other sex-altering medical interventions, intersex people are denied their right to physical integrity as well as their ability to develop their own gender identity, as an *a priori* choice is made for them. Additionally, these interventions often disrupt their physical and psychological well-being, producing negative impacts with lifelong consequences, which include sterilisation, severe scarring, infections in the urinary tract, reduced or complete loss of sexual sensation, removal of natural hormones, dependency on medication, and a deep feeling of violation of their person.

The invisibility of intersex people in society is another serious problem. Their life experience is often shrouded in secrecy and shame, also as a result of their frequently being unaware of the surgeries or treatments that were performed on them early on in their life. Access to medical records is often rendered very difficult, as is access to personal history, including childhood pictures and other memories. Intersex individuals who are discovered later on in life may experience the same invasive treatment – without their free and informed consent – as intersex individuals who are identified during childhood.⁶

A strong fear of stigmatisation and social exclusion forces most intersex people to stay “in the closet”, even when they become aware of their sex. Moreover, society remains largely ignorant about the existence of intersex people since hardly any information is made available to the public about the matter. Consequently, for many years, the human rights problems affecting intersex people's well-being were either unknown or ignored. Awareness about their suffering has only recently risen to the fore in a number of human rights fora, and is yet to be recognised by the wider human rights community as a pressing concern.

This new awareness can be attributed in part to pioneering work led by intersex human rights activists, self-help and patients' support organisations, some of which originated in the 1990s, and the growing interest by the lesbian, gay, bisexual and trans (LGBT) movement in intersex issues. For example, the mandate of the International Lesbian, Gay, Bisexual, Trans and Intersex Association (ILGA) was extended to cover intersex

issues during its general assembly in 2009. Following that, an annual International Intersex Forum was organised jointly with ILGA-Europe and intersex organisations and has, since 2011, provided a safe space for intersex activists from around the world to discuss their issues and build the movement's goals and demands. A number of national or local intersex (or intersex inclusive) organisations do exist, and such groups have grown in number and membership over recent years.⁷

1.2. Diversity of intersex people

It is important not to lump all intersex people into one new collective category, such as a "third sex", perhaps running in parallel to female and male. Such a classification would be incorrect due to the great diversity among intersex people and the fact that many intersex individuals do identify as women or men, while others identify as both or neither. In effect, intersex is an umbrella term including people with "variations in sex characteristics", rather than a type *per se*. This diversity is not unique to intersex people, as – unsurprisingly – a range of variations in sexual anatomy is also found in women and men that meet the medical norms of their respective categories.

The term "hermaphrodite" was widely used by medical practitioners during the 18th and 19th centuries before "intersex" was coined as a scientific and medical term in the early 20th century. Before the current medical classification of the disorder of sex development (DSD) was developed, variations in intersex sex characteristics were classified under different categories, the most common being: congenital adrenal hyperplasia (CAH), androgen insensitivity syndrome (AIS), gonadal dysgenesis, hypospadias, and unusual chromosome compositions such as XXY (Klinefelter Syndrome) or XO (Turner Syndrome). The so-called "true hermaphrodites" referred to those who had a combination of ovaries and testes.⁸

Importantly, variations in sex characteristics are different than sexual orientation and gender identity, even though the three layers interact in the formation of a person's personality. The Office of the United Nations High Commissioner for Human Rights' (OHCHR) *Free & Equal* campaign points out that: "Intersex people experience the same range of sexual orientations and gender identities as non-intersex people." In this vein, reference to intersex people as "intersexuals" is wrong since intersex sex characteristics are unrelated to sexual orientation. Similarly, reference to "intersex identity" is also incorrect as intersex is not necessarily a matter of identity or self-perception but mostly refers to physical aspects of the body.⁹

What links intersex people's experience to that of LGBT people is the homophobic and/or transphobic motives behind most discrimination to which they are subjected. For example: "Parental choice against intersex may ... conceal biases against same-sex attractiveness and gender nonconformity." One can say that human rights breaches against the wider LGBTI community often find their source in the sex and gender dichotomies which underpin society, particularly when they are accompanied with prejudicial assumptions that accord a superior and normative status to heterosexuality (heteronormativity) and conformity with the sex assigned at birth (cisnormativity). This is perceptible in the way such dichotomies are upheld through a stereotypical

separation between the appearances and roles that women and men are allowed to have, and the enforced legal and/or social distance separating the two.¹⁰

In view of the overlap in the experience of discrimination, LGBTI is often used as an umbrella acronym for this population group despite its inherent diversity. The use of the acronym has been adopted by European and international organisations such as the United Nations (UN), the Council of Europe and the European Union (EU).¹¹

Intersex people also share some human rights concerns with other minorities, including persons with disabilities and those who have been subjected to genital mutilation or cutting. As the legal framework protecting people with disabilities is well established at the international level and far-reaching in several countries, it may be useful for intersex people in the protection of their rights or as a reference for the development of intersex-specific legislation.¹²

Moreover, while numbers of a particular group should not have a bearing on their access to human rights, it needs to be noted that the prevalence of intersex people may not be as rare as is sometimes believed. While an expert at a health centre is likely to quote a figure between 1 in 1 500 and 1 in 2 000, based on an estimate on the number of newborns diagnosed as intersex, many people are born with subtler forms of sex variations that are not immediately detectable. This latter group, however, still does not meet medical standards of female and male and may be subjected to medical interventions at a later stage. In her research through medical literature for frequency estimates, Anne Fausto-Sterling concluded that around 1.7% of human births are intersex.¹³

1.3. Current knowledge base

Several gaps remain with regard to the human rights knowledge base on intersex issues. To date there is little information about the legal and social situation of intersex people in many European countries and around the world. It is thus not surprising that the first resolution inclusive of intersex issues, adopted within the Council of Europe setting, called on member states to: “undertake further research to increase knowledge about the specific situation of intersex people”.¹⁴

To address this knowledge gap, the EU Agency for Fundamental Rights (FRA) has carried out initial research about some aspects of the situation of intersex people in EU member states in light of the update of their 2010 legal comparative report on LGBT people. The results of that research, to be published in 2015, are expected to provide European and national policymakers with the first comparative dataset on the matter. The two topics addressed are the coverage of intersex people in non-discrimination legislation and the national frameworks regulating surgical and medical interventions performed on intersex people. Some of the data provided by the FRA is already referred to in this paper.¹⁵

It is to be noted that when it comes to the human rights of intersex people, research from the pioneering work of the New Zealand and San Francisco human rights commissions is especially useful in indicating the recurrent human rights concerns, as well as providing access to testimonies of intersex people about their life experiences.

Likewise, the opinions published by the German and Swiss ethics councils as well as the Australian Senate's inquiry on the topic are essential sources for the identification of ethical problems and possible responses.¹⁶

More in-depth research is urgently needed and should be encouraged to ensure that discrimination and other human rights breaches experienced by intersex people are adequately addressed through legislative and policy frameworks.

In the preparation of this issue paper, the Commissioner for Human Rights consulted intersex people, hoping to ensure that the community is involved in both the data collection process and in human rights protection efforts at the outset. Additionally, the Commissioner consulted with established experts from different fields – including law, social science and paediatric medicine – who favour a human rights-based approach.



Chapter 2

Medicalisation of intersex people

2.1. Reassigning sex

In the 19th century, when scientists believed that homosexuality was the result of “sexual inversion”, hermaphrodites were considered as potential homosexuals or “inverts”. In light of the deeply entrenched negative attitudes towards homosexuality in western society at the time, the desire to “correct” intersex people’s “atypical” sex was driven by a crude desire to eradicate ambiguity and prevent homosexuality, rather than a genuine concern for the well-being and best interest of intersex people.

Current approaches to reassigning or “fixing the sex” of intersex people find their root in the science of the 1950s, when particular attention was given to issues of sexual difference, gender and sexual orientation. John Money and his colleagues Joan and John Hampson from Johns Hopkins University focused their studies on sexual identity and the biology of gender. Their research into intersex people stemmed from their interest in identifying the “normal” development patterns of the two sexes. They concluded that gonads, hormones and chromosomes did not automatically determine a child’s “gender role”, and that therefore, “mixed-sex children” could be assigned to the “proper gender” early in their childhood and be nurtured within that gender role provided the appropriate behavioural interventions ensued. Money believed that the best results from such assignments were achieved when the babies were not older than around two years of age.¹⁷

Money gained increased notoriety following his intervention in the case of David Reimer (originally named Bruce), a boy who, after his penis was accidentally burnt off during a botched circumcision, was transitioned into and raised as a girl (Brenda), beginning at the age of 22 months. Money initially reported the case as a success, and he continued to follow the case annually for a decade. During that time, his view of the malleability of gender became the dominant viewpoint among physicians and doctors, and led to the growing popularity of sex reassignment surgeries. However, during his teen years Reimer transitioned back to his male state, indicating that, in spite of the dresses that he was made to wear and the oestrogen that he was administered, he never felt female. Plagued by the deep psychological trauma of this experience, he committed suicide in 2004 at the age of 38.

In spite of the negative outcome of David's case – which was only first revealed in 1997 – Money's theory had a disproportionate impact on medical procedure regarding intersex treatment, and continues to inform the medical practices that affect intersex newborns today. The prevailing medical opinion is that ambiguous sex can and should be "fixed", and in fact, genital surgeries on intersex babies have become routine in spite of the fact that they are rarely medically necessary. Emphasis is placed on the newborn's ability to pass for one sex or the other, thus meeting social expectations, rather than on the child's best interests and welfare. For example, male newborns with penises smaller than 2 cm considered "too small" are "assigned the female gender and reconstructed to look female", while clitorises larger than 0.9 cm are considered "too big" and are reduced in size. Additionally, a greater number of intersex children are transitioned to a female sex since "a functional vagina can be constructed in virtually everyone [while] a functional penis is a much more difficult goal." Individuals with CAH and XX chromosomes are often not considered intersex and as a result are routinely assigned a female sex (or "gender disambiguated") through a number of treatments to preserve their possible fertility regardless of their bodily integrity or future male or non-binary gender identity.¹⁸

Intersex foetuses are also within the reach of medical intervention. In an effort to prevent the "development of ambiguous genitalia, the urogenital sinus, tomboyism, and lesbianism" mothers who are predisposed to give birth to XX-CAH babies are often administered dexamethasone. This occurs despite clear indications that exposure to the drug "in preterm infants is associated with increased aortic arch stiffness and altered glucose metabolism in early adulthood" – in other words, increased risk of heart disease and diabetes. Other intersex foetuses are selectively aborted for no other reason than their sex characteristics; in some variations (e.g. 47, XXY), the termination rate may reach 88% on the basis that these variations supposedly represent "major genetic defects".¹⁹

Notwithstanding the significant change in attitudes since the 1950s regarding sexuality and gender diversity, it seems that the medical field often rejects the voices of intersex people harmed by surgery. In 1969, Christopher Dewhurst and Ronald Gordon argued: "One can only attempt to imagine the anguish of the parents. That a newborn should have a deformity ... [affecting] so fundamental an issue as the very sex of the child ... is a tragic event which immediately conjures up visions of a hopeless psychological misfit doomed to live always as a sexual freak in loneliness and frustration." They then added that, "fortunately, with correct management the outlook is infinitely better than the poor parents – emotionally stunned by the event – or indeed anyone without special knowledge could ever imagine". The same line of thought continues today. In 2003, in an introduction to their journal article on babies with ambiguous genitalia, authors Low and Hutson wrote: "Next to perinatal death, genital ambiguity is likely the most devastating condition to face any parent of a newborn."²⁰

In a report presented to the Parliamentary Assembly of the Council of Europe (PACE), Rapporteur Marlene Rupprecht confirmed the occurrence of routine surgeries and medical interventions, but contradicted the claimed benefits, stating:

Different empirical studies in Germany have shown that until now 96% of all intersex persons across different categories had received hormonal therapy. 64% of persons

concerned had received a gonadectomy, 38% a reduction of their clitoris, 33% vaginal operations and 13% corrections of their urina[ry] tract. Many had been submitted to a series of operations and were confronted with post-operative complications. Relevant treatment was traumatising for them and often involved humiliating procedures such as being exposed to large groups of medical professionals and students studying this curious phenomenon. For many, the interventions linked to their syndrome had long-term effects on their mental health and well-being.²¹

This view is further supported by testimonies found amongst others in reports of the New Zealand and San Francisco human rights commissions and the documentary *Intersexion*, which document the traumatic experiences of intersex people's suffering following medical interventions without their consent.²²

Amongst these testimonies of trauma and pain is the experience of Christiane Völling, who was born in 1960 in Germany with "indeterminate external genitalia" and was raised as a boy. In her autobiography, Völling stated:

The castration [removal of internal testes] that I suffered and the paradoxical administration of high-dose testosterone considered as necessary resulted in physical and psychological damage such as hot flashes, depression, sleeping disorders, early osteoporosis, the disappearance of my sexuality and my reproductive capacity, trauma linked to the castration, lesion of the thyroid glands, change in my brain's metabolism and my bone structure as well as many other secondary effects and lesions. The taking of testosterone has caused the development of a typical male hair pattern, a masculine beard, the loss of all my hair linked to the impact of the androgens, a masculinisation of my previously feminine voice, the masculinisation of my facial features and the production of a male anatomy despite female predispositions. The male genitalia surgically constructed have caused irreversible damage such as chronic urinary infections, disorders of urination, strictures and scarring. These interventions have made me lose all my innate feeling of belonging to a sex and all sexual behaviour.²³

Ms Völling only discovered what had happened to her following an unrelated incident during which a questionnaire on intersex issues was passed on to her in 2006, almost 30 years after the intervention.²⁴

Similarly, Tiger Howard Devore complains about the "masculinising" treatment that he received regarding hypospadias, stating that his childhood was filled with pain, surgery, skin grafts, and isolation, adding: "And I still have to sit to pee." For him, "[i]t would have been just fine to have a penis that peed out of the bottom instead of the top, and didn't have the feeling damaged".²⁵

The feminising procedure of vaginoplasty, i.e. creating a vaginal opening, can be both painful and psychologically scarring. When it is performed in early childhood, the neo-vagina must be kept open using a dilator, which is usually inserted regularly by the child's mother. This procedure is repeated throughout childhood and intersex people have stressed that it has been extremely painful and akin to a form of rape. Some parents have had the impression of committing rape on their child. The procedure may have to be continued later on in life as described by intersex people:

In adolescence, if the "girl" wishes to continue to have a cavity, new operations have to be carried out and it now becomes her turn to dilate herself for the rest of her life with

a replica of the member which was taken away from her in early childhood without it ever being revealed to her that she was castrated. Even if, by chance, the medical team has matched the person's body with her gender identity, she will go through living hell with this badly made body and will often abandon the regular dilations, have no sexual relations and experience many urinary problems including, in the worst cases, incontinence.²⁶

The psychological distress caused by the negative outcomes of surgery can result in self-harming and suicidal behaviour. A study published in 2007 found that “[t]he prevalence rates of self-harming behaviour and suicidal tendencies in the sample of persons with DSD were twice as high as in a community based comparison group of non-traumatized women, with rates comparable to traumatized women with a history of physical or sexual abuse”. Moreover, “[w]ithin the total sample, the subgroup of persons with gonadectomy was significantly more distressed, with depression being particularly increased”.²⁷

Some intersex people, such as Hida Viloria, the Director of OII-USA, have managed to escape medical intervention and have had no negative impacts as a result of the lack of surgery. On the contrary, Viloria says she is “very lucky to have escaped the ‘corrective’ surgeries and/or hormone treatments ..., because [her] father went to medical school before these practices began (in the mid-late ‘50s), and knew that you shouldn’t operate on a baby unless it’s absolutely necessary”. She adds that she has become “an activist after hearing that doctors believed that intersex people would be unhappy if they did not receive ‘normalising’ treatments” and she wanted to voice that she was very happy she did not receive such unwanted procedures.²⁸

2.2. Intersex in medical classifications

As was the case with homosexuality and as is still the case with trans identities, 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” (DSD). The 2006 “Consensus statement on the management of intersex disorders” proposed a new medical classification system based on removing labelling and defining the situation of intersex people more clearly for patients, family members and medical practitioners alike. It was intended to introduce the best standards of care for people affected by DSD. However, in spite of its stated goal, the result was that additional decision-making powers over the bodies of intersex infants were provided to medical practitioners and parents. In addition to many intersex people finding the term “disorder” stigmatising, Morgan Holmes has noted that the terminology shift “reinstitutionalise[d] clinical power to delineate and silence those marked by the diagnosis”.²⁹

Currently, both the World Health Organization’s (WHO) International Classification of Diseases (ICD) and the American Psychologists Association’s (APA) Diagnostic and Statistical Manual of Mental Disorders (DSM) classify intersex conditions as pathologies in their nomenclatures. The fifth edition of APA’s DSM published in 2013 has replaced the term “gender identity disorder (GID)” with “gender dysphoria”. The term now includes intersex people who were assigned a sex at birth which did not

correspond with their gender. In her reaction to this development, Anne Tamar-Mattis, Executive Director of Advocates for Informed Choice (AIC) asked: "If the child later decides that the guess [of the doctor] was wrong, is that a sign that something is wrong with the child?"³⁰

The WHO's ICD is also undergoing a process of revision. In fact, a new draft version of the ICD, the ICD-11 (currently in its Beta draft), is presently being consolidated and its formal adoption is expected in 2017. The two sections of particular concern for intersex people within the current Beta draft version, mainly due to their inclusion of DSD classifications, are sections 5 (Endocrine, nutritional and metabolic diseases, especially subsection: "Endocrine diseases") and 20 (Developmental anomalies, especially subsections: (i) "Multiple developmental anomalies and syndromes"; (ii) "Chromosomal anomalies, excluding gene mutations"; and (iii) "Balanced rearrangements and structural markers").³¹

In 2011, the World Professional Association for Transgender Health (WPATH) included DSD for the first time in its 7th version of the Standards of Care. This was lambasted as "an act of breathtaking hypocrisy" by OII Australia, as WPATH included pathologising language and treatments for intersex people despite having previously stated that it considered the pathologising language surrounding trans people unhelpful.³²

It is worrying that the gap between the expectations of human rights organisations of intersex people and the development of medical classifications has possibly widened over the past decade. 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.³³

2.3. Acquisition of parental consent

To this day, medical and surgical treatment of intersex infants and minors rests on the belief that such treatment is necessary and desirable both for society and the people involved. Parents of intersex children are thus asked to provide their proxy consent to the treatment. However, recent research has demonstrated that parents are often ill-informed and impressionable, and are not given adequate time or options necessary to provide fully informed consent. Research has demonstrated that parents who are provided with medicalised information are almost three times more likely to consent to surgery than those who receive more broadly-based, including psychological, information. 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. This raises serious questions as to how the consent of parents is sought and under what premise. One mother of twins recounted that she can see how parents can be swayed, as doctors led her to question herself "because of how adamant they were".³⁴

Additionally, as highlighted in Chapter 1, one's gender does not necessarily develop in conformity with one's assigned sex. In the case of intersex people, estimates of assigning the wrong sex to them vary between 8.5% and 40%. These children end up rejecting the sex they were assigned at birth demonstrating the major infringements of their psychological integrity.³⁵

Eric Schneider refers to the following testimony that he received from an intersex man whose mother was specifically asked by medical practitioners to raise him as a girl:

I was assigned female at birth but very quickly, it was clear that my behaviour tended to be that of a male. Alongside the surgery, my parents were strongly advised to bring me up in a manner which was geared more to femininity. This began with the toys and the clothes they chose for me and continued with moving me from a mixed school to a school for girls, carefully monitoring my recreational activities with the boys in the neighbourhood (no football or so-called boy's games) and registering me for so-called girl's extra-curricular activities (such as knitting and sewing). Despite all this, my male identity remained. During this period, my Mum was accused by medical professionals of not being strict enough. When I was ten or eleven, my Mum saw that I was unhappy and above all lonely because I did not have any friends, and slackened the reins a little, which allowed me to make new contacts. Except for school, she gradually respected my choices more and more but it was a long road. I've forgiven her now as I know she was only following the practices of the time and it was impossible to find any other information (through the Internet, books or the media). Our relationship was sorely tested when I learnt the truth about my intersexuality. The fact that I was intersex did not shock me as much as finding out that I had been lied to all my life, and although I have forgiven my mother our relationship was knocked back by this.³⁶

In 2006, Sarah Graham, an intersex woman, wrote the following testimony about her experience:

When I was eight, a gynaecologist told my parents this devastating news: that I had a very rare genetic condition and that if my ovaries weren't removed I would develop cancer when I reached puberty and die. Nearly 20 years later I discovered that my doctors had lied to my parents and me. And this wasn't a one-off – it was standard policy (until the mid-1990s) to hide the truth about all conditions like mine. I was 25 when I found out the extent of the cover-up, and the shock of suddenly being told the true nature of my diagnosis – with no support and after being systematically lied to for so many years – nearly killed me. I went into an emotional meltdown.³⁷

Her testimony indicates that irreversible sex assignment surgery and sterilisation are often performed without the fully informed consent of the parents, let alone the consent of intersex persons themselves.

However, the Swiss National Advisory Commission on Biomedical Ethics (NEK-CNE) warns that one cannot assume that parents will always endeavour to promote their child's welfare in such a situation, even when they are not put under undue pressure by medical practitioners. It is thus important that the emotionally challenging situation is dealt with professionally to ensure that "a normal emotional attachment [is] established between [the parents and the child]". They also propose that parents should be relieved of any time or social pressures so that in the event that any decisions need to be made, they will arrive at them after "careful considered decision making".³⁸

Parents can build a very close bond with an intersex child, and strive to protect the child's integrity. In a case that reached the courts in the United States in 2013, Mark and Pam Crawford, the parents of M.C. (an adopted child), sued North Carolina over a surgical procedure that was consented to, alleging that "the state of South

Carolina violated M.C.'s constitutional rights when doctors surgically removed his phallus while he was in foster care, potentially sterilizing him and greatly reducing, if not eliminating, his sexual function". Pam Crawford noted that she "was really sad that that decision had been made for him," and that "it's become more and more difficult just as his identity has become more clearly male. The idea that mutilation was done to him has become more and more real. There was no medical reason that this decision had to be made at that time."³⁹

2.4. Changing perspectives

An emerging shift in the medical perspective towards intersex people is perceptible among a number of practitioners. In its 2011 Opinion, NEK-CNE clearly indicated that "[a]n irreversible sex assignment intervention involving harmful physical and psychological consequences cannot be justified on the grounds that the family, school or social environment has difficulty in accepting the child's natural physical characteristics". It thus recommended that any irreversible sex assignment treatment should be deferred until "the person to be treated can decide for him/herself", as long as no urgent intervention was necessary to prevent severe damage to the person's body or health. In its view, a child "attains capacity between the ages of 10 and 14 years" and even before this age children should be able to participate in decision making in an age-appropriate manner. NEK-CNE also stressed the need to protect the child's integrity, indicating that "[p]rofessional psychosocial counselling and support should be offered free of charge to all affected children and parents".⁴⁰

Unlike many others in his profession, the paediatric surgeon Mika Venhola has denounced surgical interventions of intersex people during childhood. In an interview, he stated: "When I was training to become a paediatric surgeon I was taught how to do these, 'corrective' cosmetic surgeries ... but when I was doing my first intersex surgery due to cosmetic reasons I felt it was such a huge human rights violation, and especially a violation of children's rights, that I swore I would never do this when I became independent and could decide for myself. And I have never done it, since then." He notes that a sizable group of intersex people who have been operated upon are unhappy with the outcomes, and believes that their voices should be adequately heard by other surgeons. Venhola believes that "the gender of the [intersex] child is an educated guess and entails a great risk of error. The atypical genitals of babies with intersex conditions are not a health risk, but early genital surgery is performed for aesthetic or social purposes. To stress his point, he rhetorically asks: "Why operate on the child's body if the problem is in the minds of the adults?"⁴¹

In a recent ground-breaking UN interagency statement issued by the WHO in 2014, several UN institutions addressed the fact that "in some countries, people belonging to certain population groups, including ... intersex persons, continue to be sterilized without their full, free and informed consent". It noted that such sterilisation practices violate fundamental human rights, including the right to health, the right to information, the right to privacy, the right to decide on the number and spacing of children, the right to found a family and the right to be free from discrimination; as well as the right to be free from torture and other cruel, inhuman and degrading treatment or punishment.⁴²

The document adds that

Intersex persons may be involuntarily subjected to so-called sex-normalizing or other procedures as infants or during childhood, which, in some cases, may result in the termination of all or some of their reproductive capacity. Children who are born with atypical sex characteristics are often subjected to cosmetic and other non-medically indicated surgeries performed on their reproductive organs, without their informed consent or that of their parents, and without taking into consideration the views of the children involved. As a result, such children are being subjected to irreversible interventions that have lifelong consequence for their physical and mental health.⁴³

The statement recommends that in the absence of medical necessity, where the physical well-being of the intersex person is in danger, treatments that result in sterilisation should be postponed until the “person is sufficiently mature to participate in informed decision making and consent”. This statement points towards an emerging consensus on intersex recognition within the UN system. It is timely in view of the current ICD revision and should facilitate a human rights approach in the process.⁴⁴



Chapter 3

Enjoyment of human rights

3.1. Universality of human rights

Human rights are universal and indivisible, and hence apply to everybody, including intersex people. The Universal Declaration of Human Rights (UDHR) affirms that all human beings are born free and equal in dignity and rights and that everyone is entitled to all the rights and freedoms set forth in the instrument, without distinction of any kind, such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth, or other status. The European Convention on Human Rights (ECHR) (ETS No. 5) also protects everybody and contains an open-ended list of prohibited grounds of discrimination.

In spite of the fact that no specific provision currently refers to intersex people, the rights contained in international human rights treaties apply to all people, and thus to intersex people through the conventions' open-ended non-discrimination clauses. This interpretation was confirmed by the UN Committee on Economic, Social and Cultural Rights (CESCR), with regard to the International Covenant on Economic, Social and Cultural Rights (ICESCR). The committee stated that "other status" as recognised in Article 2(2) includes "gender identity ... as among the prohibited grounds of discrimination", adding that "persons who are transgender, transsexual or intersex often face serious human rights violations, such as harassment in schools or in the workplace".⁴⁵

Inclusion of the ground of sex or gender is important and useful if it is not simply framed in terms of the binary female/male dichotomy which would restrict its coverage of intersex people. In its 1996 decision in the case of *P v. S and Cornwall County Council* as well as two other subsequent judgments, the Court of Justice of the European Union (CJEU) held: "that the scope of the principle of equal treatment for men and women cannot be confined to the prohibition of discrimination based on the fact that a person is of one or other sex. In view of its purpose and the nature of the rights which it seeks to safeguard, it also applies to discrimination arising from the gender reassignment of a person." That principle is now established and included in EU sex equality legislation. Building on the court's reasoning, Schiek, Waddington and Bell argue that there is "a close relation between intersexualism and gender or sex, for which reason it would not be illogical to classify distinctions based on intersexualism or hermaphroditism as being gender based".⁴⁶

3.2. Key human rights at stake

3.2.1. Right to life

The right to life is established under Article 3 of the UDHR, Article 6 of the International Covenant on Civil and Political Rights (ICCPR), and Article 2 of the ECHR. Article 6 of the Convention on the Rights of the Child (CRC) further establishes the duty of States Parties to ensure to the maximum extent possible the survival and development of the child.

Intersex people's right to life can be violated in discriminatory "sex selection" and "preimplantation genetic diagnosis, other forms of testing, and selection for particular characteristics". Such de-selection or selective abortions are incompatible with ethics and human rights standards due to the discrimination perpetrated against intersex people on the basis of their sex characteristics.⁴⁷

The Council of Europe Convention on Human Rights and Biomedicine (ETS No. 164) prohibits discrimination on the grounds of a person's "genetic heritage" as well as the use of techniques of medically assisted procreation "for the purpose of choosing a future child's sex, except where serious hereditary sex-related disease is to be avoided". The explanatory report of the convention leaves the definition of "hereditary sex-related disease" open to the "internal law" of member states. Nonetheless, the report raises concern with regard to genetic testing as it "may become a means of selection and discrimination".⁴⁸

While the convention has not yet been tested with regard to its applicability to intersex, many Council of Europe institutions have already raised concerns about the use of sex selection techniques. In its 2011 resolution on pre-natal sex selection, PACE stressed that "the social and family pressure placed on women not to pursue their pregnancy because of the sex of the embryo/foetus is to be considered as a form of psychological violence" and that the practice of forced abortions should be criminalised. Similarly, in a recent Human Rights Comment, the Commissioner for Human Rights called for the "deeply discriminatory practice" of sex selection to be "vigorously countered and banned in law". The Committee of Ministers' 2002 recommendation clearly called on member states to "prohibit enforced sterilisation or abortion, contraception imposed by coercion or force, and pre-natal selection by sex, and take all necessary measures to this end".⁴⁹

3.2.2. Prohibition of torture and inhuman or degrading treatment

Torture and other cruel, inhuman or degrading treatment or punishment are prohibited under Article 5 of the UDHR, Article 7 of the ICCPR and Article 3 of the ECHR. They are also prohibited under a specific 1984 UN Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment and the 1987 European Convention for the Prevention of Torture and Inhuman and Degrading Treatment or Punishment.

The key advocacy goal of intersex rights organisations is to end "normalising" surgeries and other cosmetic medical treatment, which some organisations call

“intersex genital mutilation” (IGM). In his report to the UN Human Rights Council (UNHRC) in 2013, Juan E. Mendés, the UN Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, issued a strongly worded statement condemning non-consensual surgical intervention on intersex people as a form of torture. His report states that “[t]here is an abundance of accounts and testimonies of persons being ... subjected to ... a variety of forced procedures such as sterilization, State-sponsored forcible ... hormone therapy and genital-normalizing surgeries under the guise of so-called ‘reparative therapies’. These procedures are rarely medically necessary, can cause scarring, loss of sexual sensation, pain, incontinence and lifelong depression and have also been criticized as being unscientific, potentially harmful and contributing to stigma”. The UN Committee on the Elimination of Discrimination against Women (CEDAW) has also expressed concern about intersex women as “victims of abuses and mistreatment by health service providers”.⁵⁰

The UN Special Rapporteur on torture pointed out that intersex children are often subject to irreversible sex assignment, involuntary sterilisation and/or genital-normalising surgery, performed without their informed consent or that of their parents “in an attempt to fix their sex” as they fail to conform to socially constructed gender expectations. This leaves intersex children with permanent, irreversible infertility and causes severe mental suffering. He added that discrimination on the grounds of sexual orientation or gender identity may often contribute to the process of the dehumanisation of the victim, which is often a necessary condition for torture and ill-treatment to take place.⁵¹

3.2.3. Right to respect for private life

The right to respect for private life is enshrined in Article 12 of the UDHR, Article 17 of the ICCPR, Article 16 of the CRC and Article 8 of the ECHR. The right to physical and psychological integrity is included in the protection of the right to private life. The right to self-determination and personal autonomy is also relevant.

The right to physical and psychological integrity is particularly important in the context of involuntary medical treatment. The European Court of Human Rights has held that even a minor interference with the physical integrity of an individual can be regarded as an interference with the right to respect for private life under Article 8 if it is carried out against the individual’s will. Therefore Article 8 is applicable in many cases where the severity of interference required by Article 3 is not attained. Furthermore, Article 8 entails a positive obligation on the part of the state to protect the physical integrity of people within their jurisdiction.⁵²

In her report to PACE, Marlene Rupprecht points out that “[s]ex-determining operations undertaken without the consent of the person concerned are indeed increasingly perceived as a violation of personal rights given that the latter include the right to live one’s life according to the subjectively perceived sexual identity.” The principle of medical ethics “first, do no harm” should also guide all physicians whereby, whatever the intervention or procedure, the patient’s well-being should always be the primary consideration.⁵³

In 2006, the *Yogyakarta Principles*, a set of principles relating to sexual orientation and gender identity, were developed by eminent human rights experts based on established human rights. Principle 18 states: “No person may be forced to undergo any form of medical or psychological treatment, procedure, testing, or be confined to a medical facility, based on sexual orientation or gender identity. Notwithstanding any classifications to the contrary, a person’s sexual orientation and gender identity are not, in and of themselves, medical conditions and are not to be treated, cured or suppressed.”⁵⁴

Although Article 8 of the ECHR does not contain a right to self-determination as such, the notion of personal autonomy is an important principle underlying the interpretation of its guarantees. Therefore, the European Court of Human Rights has stressed that elements such as gender identification, name, sexual orientation and sexual life fall within the personal sphere protected by Article 8. In 2013, PACE called on Council of Europe 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, guarantee bodily integrity, autonomy and self-determination to persons concerned, and provide families with intersex children with adequate counselling and support.”⁵⁵

3.2.4. Right to health

The right to health is enshrined in Article 25 of the UDHR, Article 12 of the ICESCR, Articles 17, 23 and 24 of the CRC, and Article 25 of the UN Convention on the Rights of Persons with Disabilities. Within the European framework, the right is guaranteed under Articles 11 and 13 of the revised European Social Charter.

Everyone has the right to the highest attainable standard of physical and mental health, without discrimination. Sexual and reproductive health is a fundamental aspect of this right, as are considerations of the person’s future development. For intersex people, the right to health is two pronged: (i) avoiding involuntary and unconsented treatment and interventions that have negative lifelong consequences to their physical and mental health; and (ii) having access to general health services that are appropriate, adequate and respectful of their bodily diversity.

In its report on involuntary and coerced sterilisation, the Australian Senate stated that:

There is frequent reference to “psychosocial” reasons to conduct normalising surgery. To the extent that this refers to facilitating parental acceptance and bonding, the child’s avoidance of harassment or teasing, and the child’s body self-image, there is great danger of this being a circular argument that avoids the central issues. [...] Irreversible medical treatment, particularly surgery, should only be performed on people who are unable to give consent if there is a health-related need to undertake that surgery, and that need cannot be as effectively met later, when that person can consent to surgery.⁵⁶

In view of this, the Australian Senate recommended that “all medical treatment of intersex people take place under guidelines that ensure treatment is managed by multidisciplinary teams within a human rights framework. The guidelines should favour deferral of normalising treatment until the person can give fully informed

consent, and seek to minimise surgical intervention on infants undertaken for primarily psychosocial reasons”.⁵⁷

In order to meet this goal, the UN interagency statement calls for medical protocols to ensure that any operations that are not immediately necessary on medical grounds only take place at an age when intersex people can give their consent and participate actively in decisions about any treatment and sex assignment. Additionally, such protocols need to ensure that intersex people have the right to full information about treatments, and have access to their own medical records and history.⁵⁸

3.2.5. Rights of the child

In view of the fact that the most acute human rights violations against intersex people happen during their infancy, childhood or adolescence, the rights of the child as established in the CRC are especially relevant in upholding the human rights of intersex people.

The set of rights, in addition to those already referred to under previous sections, most relevant to intersex children are:

- ▶ Article 3 establishing that the best interests of the child is a primary consideration with regard to all issues affecting children;
- ▶ Article 7 establishing the right to be registered immediately after birth and have the right from birth to a name;
- ▶ Article 8 establishing the right of the child to preserve their identity, including name;
- ▶ Article 12 establishing the child’s right to form and express their views freely in all matters affecting them;
- ▶ Article 13 establishing the right to freedom of expression, which right includes the freedom to seek, receive and impart information and ideas of all kinds.

In relation to intersex children, these rights can be construed to mean that all non-medically necessary normalisation or gender-related treatment leading to permanent modifications to the body and possible loss of sexual function and fertility must be expressly consented to by the child in line with their best interests, and their ability to form and express their views regarding their body and identity. Likewise, the registration of an immutable (or legally difficult to change) sex marker on the intersex child’s birth certificate without regard to their gender identity may be arbitrary and in breach of the child’s right to personal identity. Furthermore, secrecy around their sex and the interventions that may have been performed on their body at a young age, as well as coercion to conform to a gender that is not congruent with their gender identity, interfere with their right to receive and impart information and the right to express their personality.

In February 2015, the UN Committee on the Rights of the Child expressed concern about “[c]ases of medically unnecessary surgical and other procedures on intersex children, which often entail irreversible consequences and can cause severe physical and psychological suffering, without their informed consent, and the lack of redress and compensation in such cases”. The committee urged the state party concerned to “ensure that no-one is subjected to unnecessary medical or surgical treatment during

infancy or childhood, guarantee bodily integrity, autonomy and self-determination to children concerned, and provide families with intersex children with adequate counselling and support”.⁵⁹

In the light of such concerns, the Yogyakarta Principles calls on states to: (i) “ensure full protection against harmful medical practices ..., including on the basis of stereotypes, whether derived from culture or otherwise, regarding conduct, physical appearance or perceived gender norms;” (ii) “ensure that no child’s body is irreversibly altered by medical procedures in an attempt to impose a gender identity without the full, free and informed consent of the child in accordance with the age and maturity of the child and guided by the principle that in all actions concerning children, the best interests of the child shall be a primary consideration;” and (iii) “establish child protection mechanisms whereby no child is at risk of, or subjected to, medical abuse”.⁶⁰

3.3. Emerging position of international organisations

Several international organisations have started addressing the human rights concerns raised by intersex people. In 2012, the EU Commission published a report tackling discrimination against trans and intersex people followed by training and awareness-raising activities. The EU has also adopted a set of external action guidelines on the promotion and protection of human rights of LGBTI persons, including specific attention to intersex issues.⁶¹

In 2013, PACE adopted a resolution that acknowledged the human rights breaches suffered by intersex people and called on member states to change current practices. Subsequently, in a 2014 Human Rights Comment, the Commissioner for Human Rights urged governments in Europe to “review their current legislation and medical practices to identify gaps in the protection of intersex people and take measures to address the problems”. In December 2014, the Council of Europe Sexual Orientation and Gender Identity Unit published a major report on the situation of trans and intersex children in Europe.⁶²

In 2013, the Inter-American Commission on Human Rights (IACHR) created a rapporteurship on the Rights of Lesbian, Gay, Bisexual, Trans and Intersex Persons to address issues of sexual orientation, gender identity, gender expression, and body diversity. The clear inclusion of “body diversity” in the mandate of the Rapporteurship indicates the need to pay specific attention to intersex issues, although such reference was not included in the related resolution that the Organization of American States (OAS) adopted earlier in the year.⁶³

In 2014, Navi Pillay, the UN High Commissioner for Human Rights, acknowledged that “medically unnecessary and irreversible surgeries and sterilizations continue to be performed on intersex children without their informed consent, causing lifelong harm”. She proposed that the UNHRC, governments, members of parliament, national human rights institutions, judicial actors and civil society organisations direct their focus towards human rights breaches against LGBTI people.⁶⁴

These developments, along with the 2013 condemnation of non-consensual surgical intervention on intersex people by Juan E. Mendés, the UN Special Rapporteur on

torture, the 2014 UN interagency statement on forced, coercive and involuntary sterilisation, as well as 2011 guidance provided by the UN High Commissioner for Refugees (UNHCR) on treatment of LGBTI in forced displacement, clearly demonstrate an emerging position among international and regional human rights bodies about the urgent need to find adequate responses to the severe problems experienced by intersex people.⁶⁵



Chapter 4

Legal recognition of sex and gender

Across Europe, an indication of sex is required for the official registration of births, which limits the recognised sexes to the “F” and “M” dichotomy. This requirement is based on the belief that sex is “one of the essential features of a person’s identity” and that all people can be clearly designated as belonging to either of the provided categories.⁶⁶

In turn, this requirement puts pressure on parents to render their child not only “legally ‘unambiguous’, but physically unambiguous too”. In most countries, once the sex is recorded, it becomes difficult to amend such a record (if it is legally possible at all), thus entailing “significant disadvantages for the person concerned”.⁶⁷

4.1. Registration of sex on birth certificates

The intertwining between legal requirements and medical pressure following the birth of an intersex baby traps both the parents and their children between a rock and a hard place. For example, a German mother recounts that, “the pressure exerted by the registry office to [...] slot one’s child into one of the two genders [builds] up an unreasonable pressure that is only surpassed when the attending physicians demand to consent to allegedly pressing operations at the same time. [...] The option to leave the sex/gender entry vacant for years would have let me know from the legal side that it is absolutely appropriate to wait in this situation”.⁶⁸

Currently, some countries allow for the registration of the sex of the child to be delayed in the event that the sex of a newborn cannot be immediately determined at birth. Nonetheless, this measure is usually temporary, even in the case of an intersex child. For example, in Belgium the sex is usually registered during the first week and a maximum period of three months from the birth of an intersex child; while in France a maximum period of three years is allowed in exceptional cases for intersex births, even though, in practice, it is reported that parents tend to “have their child assigned to one or the other sex/gender as quickly as possible”. Finland and Portugal seem to be the only two countries that do not impose a time limit on the registration of sex when it cannot be clearly defined.⁶⁹

In Germany, following the 2009 Civil Status Regulation, the sex/gender of an intersex newborn could be left open until it was resolved, although a birth certificate could not be issued during this period. This limitation is reported to have led to problems regarding health insurance, parental benefits, inheritance and other issues. Following the adoption of the 2013 *Civil Status Act*, intersex children now receive a birth certificate. However, the sex/gender marker field in the birth register is left blank once a child has been diagnosed as being “affected by DSD”. This means that the assignment decision is passed to the doctors and subsequently enforced by law. Human rights practitioners fear that the lack of freedom of choice regarding the entry in the gender marker field may now lead to an increase in stigmatisation and to “forced outings” of those children whose sex remains undetermined. This has raised the concern that the law may also lead to an increase in pressure on parents of intersex children to decide in favour of one sex.⁷⁰

4.2. Flexibility in assigning and reassigning legal sex/gender

A case challenging the binary sex model was taken to the Regional Court of Munich by an intersex person in 2002. In its decision in 2003, the court recognised that “hermaphrodites” do occur in nature, but held that the complainant was not a “hermaphrodite”. Furthermore, it argued that “[t]he entry of ‘intersexual’ or ‘intrasexual’ as a gender identification in the Register of Births, Deaths and Marriages cannot be considered as an option” since according to its reasoning “the terms do not indicate any specific gender” and “[b]iology and medicine make the assumption that human beings belong to one of two sexes, and consider the various forms of doubtful gender as exceptions to the rule”. Finally it dismissed research presented by the complainant, as a “minority opinion” and argued that a call for the inclusion of a third sex classification could not be claimed under fundamental human rights or the German Constitution, and that its inclusion “would lead to considerable difficulties in the defining of terms and to uncertainties in the law”.⁷¹

A similar case was brought in the Almelo District Court in the Netherlands around the same time by an intersex person who did not identify as either female or male. It was also denied twice, including by the Supreme Court which found “no general international tendency to protect persons who are intersexual in this respect [i.e. to be registered as belonging to neither gender]”.⁷²

In its 2012 Opinion, NEK-CNE was more sympathetic to the complainants’ demand and people who cannot fit into the sex/gender binary. Indeed, NEK-CNE believes that parents should not be subjected to pressure in the assignment of their child’s sex, and recommended a review of current binary assignments of sex of those who are not clearly identifiable as female or male, proposing three options:

- ▶ the broadening of current categories, either through a third option such as “other” or the introduction of two further categories based on the binary classification, yet indicating uncertainty e.g. “female *” or “male *”;
- ▶ the revision of the ordinance regulating civil status to remove the indication of sex altogether; or

- ▶ the retention of the current binary categories, while introducing flexibility and simplification of the procedure to amend the sex recorded on the civil status register.⁷³

Of the three options, NEK-CNE favours the third as, on the one hand the “present binary classification system ... is deeply embedded socioculturally”, while simplified amendments “would offer the advantage of sparing (already overstrained) parents, or the person of ambiguous sex, the need for court proceedings” relying on the individual’s self-identified gender.⁷⁴

This opinion matches the demands of the Intersex Forum’s Public Statement of 2013 which call for:

- ▶ “intersex children [to 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”; and
- ▶ “sex or gender classifications [to be] amendable through a simple administrative procedure at the request of the individuals concerned. All adults and capable minors should be able to choose between female (F), male (M), non-binary or multiple options” with the prospect that in the future such entries on birth certificates or identification documents will become superfluous.⁷⁵

The 2012 Argentinean Law Establishing a Right to Gender Identity of the Person represented a fundamental shift in international best practice regarding gender recognition based on human rights principles. While it does not go beyond the female/male dichotomy, which may be a pitfall regarding cases of non-binary genders, it is still very useful as a legal model for the recognition of intersex people who identify as “F” or “M” irrespective of the sex they were assigned at birth. The law provides all people with the right to recognition of their gender identity, including the ability to “request that the recorded sex be amended, along with changes in first name and image, whenever they do not agree with the self-perceived gender identity”. Furthermore the law clearly states that “[i]n no case will it be needed to prove that a surgical procedure for total or partial genital reassignment, hormonal therapies or any other psychological or medical treatment has taken place” for a change in the legal sex/gender to be effected; at the same time, it empowers “[a]ll persons ... with the aim of ensuring the holistic enjoyment of their health” and allows “access [to] total and partial surgical interventions and/or comprehensive hormonal treatments to adjust their bodies, including their genitalia, to their self-perceived gender identity, without requiring any judicial or administrative authorisation.”⁷⁶

In 2014, Denmark became the first European country to adopt a gender identity law based on the same self-determination principle whereby an individual above the age of 18 may obtain a change in legal sex on the basis of her/his gender declaration, without the need for verification by a third party.⁷⁷

Interesting legal proposals have been tabled in Luxembourg and adopted in Malta to enable parents to omit reference to the sex of the child on birth certificates. In Luxembourg, Draft Bill No. 6568 on Reform of Filiation will allow for the leaving out of the sex/gender marker of a child on childbirth certificates: “The bill includes changes on granting legal recognition for intersex or transsexual individuals and that could guarantee equality of all individuals, regardless of biological sex, gender identity and

gender expression.” Similarly, the Maltese bill entitled the Gender Identity, Gender Expression and Sex Characteristics Act which entered into force in April 2015 allows parents or guardians to postpone the inclusion of a sex marker on the birth certificate until the child’s gender identity is determined. The bill also allows for changes to the sex/gender marker to align it with one’s gender identity at any point in one’s life following a simple administrative procedure.⁷⁸

4.3. Non-binary sex/gender marker on identification documents

Currently, the sex/gender on identification documents in Europe is required and limited to “F” or “M” only. The sole exception is Germany, as it omits any reference to sex/gender on its identity cards. When it comes to passports, the International Civil Aviation Organisation (ICAO) has allowed for sex to be registered as “F”, “M” or “X” (i.e. “unspecified”) since 1945. However, following EU harmonised rules regarding the passports’ information page, the sex entry included on the passports of all EU-28 member states has remained limited to “F” or “M” alone.⁷⁹

This contrasts with countries such as Australia, Malaysia, Nepal, New Zealand and South Africa that already allow for “X” as another sex entry on passports, while the Indian passport application form allows for three gender categories: “Female”, “Male” and “Others”. Of note, the Australian Passports Office’s Sex and gender diverse passports applicants: Revised policy, provides flexibility as it makes it clear that “[b]irth or citizenship certificates do not need to be amended for sex and gender diverse applicants to be issued a passport in their preferred gender. A letter from a medical practitioner certifying that ... they are intersex and do not identify with the sex assigned to them at birth, is acceptable.” Furthermore, the Australian Government’s Guidelines on the recognition of sex and gender standardise the evidence required for a person to establish or change their sex/gender in personal records held by Australian Government departments and agencies. When sex is recorded, the guidelines require that “individuals [are] given the option to select M (male), F (female) or X (Indeterminate/Intersex/Unspecified).”⁸⁰

In 2007, a Nepali Supreme Court ruling proclaimed that “third gender” people have the right to enjoy the fundamental human rights guaranteed to all citizens, thus striking down a policy that denied citizens the ability to register in a sex other than female or male. In accordance with the ruling, the Nepalese Government issues citizenship certificates recognising a third gender, even though until 2011 only two such certificates had been issued. The delay in the issuance of more such certificates is claimed to be due to legal and technical difficulties.⁸¹

However, further reflection on non-binary legal identification is necessary. Mauro Cabral, Global Action for Trans Equality (GATE) Co-Director, indicated that any recognition outside the “F”/“M” dichotomy needs to be adequately planned and executed with a human rights point of view, noting that: “People tend to identify a third sex with freedom from the gender binary, but that is not necessarily the case. If only trans and/or intersex people can access that third category, or if they are compulsively assigned a third sex, then the gender binary gets stronger, not weaker.”⁸²



Chapter 5

Non-discrimination and equal treatment

5.1. Experience of discrimination

Intersex people are vulnerable to discrimination and abuse in all spheres of life. Their invisibility and the general lack of knowledge about intersex issues in society can result in the perpetration of discrimination with impunity especially in the absence of specific non-discrimination guarantees. Dan Christian Ghattas states that “[i]n all of the countries examined [in his study], intersex is treated as a taboo, and intersex individuals encounter prejudices. ... The[ir] experiences range from structural and verbal discrimination to physical violence and life-threatening situations”. Perpetrators usually discriminate on the basis of what they perceive as gender non-conformity on the part of intersex people, in behaviour, appearance or in both. Homophobia may also be at play as awareness of intersex people remains low. Visible physical differences such as androgyny or sex characteristics usually attributed to the sex considered opposite to the one assigned at birth (e.g. breast development on males) may serve as a pretext for bullying and exclusion in schools, as well as underemployment or dismissal later in life. Additionally, intersex individuals may be vulnerable to hate speech and/or physical violence “in instances in which they either disclose their intersex status or if their behaviour and/or outer appearance do not match stereotypical notions of male and female norms”⁸³

The discriminatory medical practices extensively covered throughout this document have a secondary impact later in life, as intersex people may refuse to consult a doctor even in the case of serious problems due to lack of trust in medical practitioners in general. Their fears may be justified as intersex people are subject to direct and indirect discrimination in access to health care services. AIC reported that intersex people are sometimes denied care once their atypical anatomy is known. They highlighted one extreme case when an adult intersex man died of vaginal cancer in the United States after he was refused treatment at several health centres due to his sex characteristics, specifically due to his having a vagina. Intersex people may also be exposed to indirect discrimination following gendered policies which deem that certain medical treatment may only be available to one or the other sex (e.g. ovarian cancer treatment), disregarding intersex people who may be registered under another sex, but still need it. Similar problems may be experienced with regard to health insurance coverage, especially private insurance, where exclusion criteria are permissible when medically certified conditions exist. AIS Group Australia Inc. reports that people “with genetic conditions have been denied personal insurance or been quoted premiums that are prohibitively high because of pre-conceived ideas about their condition”⁸⁴

Sport is the field *par excellence* in which discrimination against intersex people has been made most visible. The reader may remember the case of Caster Semenya, who in August 2009 had won a gold medal in the 800 m women's race of the Berlin 12th IAAF World Championships in Athletics. Following her success, however, she was globally outed as intersex and all eyes were turned on her, while her world was turned upside down, to the point that she was placed on suicide watch. Following "gender testing" by the International Association of Athletics Federations (IAAF), she was withdrawn from international competition until July 2010 when the Association cleared her return to competition. Other athletes before and after Semenya have faced a similar fate.

International sports bodies, such as the International Olympic Committee (IOC) and the International Federation of Association Football (FIFA) also have guidelines for sex verification. These gender guidelines are problematic, as Hida Viloria and Maria Jose Martínez-Patino have pointed out: the IAAF and the IOC "propose that their new policies for women with high levels of testosterone ... are implemented to ensure fairness 'for all female athletes', yet fairness to the women they will directly impact is not considered". Additionally, Rebeca Jordan-Young *et al* question the ethical nature of these policies, which induced "four young athletes (aged 18-21) from developing countries [... to undergo a] gonadectomy and 'partial clitoridectomy'" in order to be compliant with the guidelines and to be able to compete.⁸⁵

5.2. Current legislative responses to discrimination and violence

Over the past decade, some inroads have been made in terms of recognising the need to specifically protect intersex people in equal treatment legislation. For the most part, the countries that made a leap in this direction interpreted the grounds of "sex" to implicitly or explicitly cover intersex people along with women and men. This approach had the advantage that national legal frameworks already included the ground of sex, and thus its extension to cover intersex was relatively easier than the introduction of a new ground.

Recently, however, that approach was put into question. Much in the same way that the development of terms such as "sexual orientation" and "gender identity" have provided the LGBT community with powerful tools to increase visibility and foster equality, intersex people would probably benefit from a similar specificity of the prohibited ground of discrimination. However, at this stage there is no international agreement on what the new term would be, even though both "sex characteristics" and "intersex status" are both in use.

The first country in the world to include an express reference to intersex in its equality legislation was South Africa. Through the *Judicial Matters Amendment Act 2005* amendments were made to the *Promotion of Equality and Prevention of Unfair Discrimination Act 2000*, stating that: "[I]ntersex' means a congenital sexual differentiation which is atypical, to whatever degree"; and that "sex' includes intersex". This law was truly ground-breaking, as apart from it being the first of such laws, it was formulated in a way as to cover all intersex people within its definition without exception.

Germany followed suit a year later. Upon the adoption of the General Equal Treatment Act – which was primarily aimed at transposing EU equality legislation into national legislation – “transsexual” and “intersexual” people were implicitly included within the definition of “sex”, in line with Germany’s interpretation of CJEU jurisprudence. The ground of “sexual identity” mentioned in the German legislation may be useful too. Austria’s Ombudperson for Equal Treatment argues that the same applies for Austria, where the term “gender” in the Equal Treatment Act would also cover intersex.⁸⁶

Another legal approach has been to associate intersex status with gender identity or gender expression. Recent modifications to the Finnish Gender Equality Act, which came into force in January 2015, expressly state that the Act’s new provisions on gender identity and gender expression also apply to discrimination related to a person’s physical sex characteristics which are not unequivocally male or female. The Finnish Ombudsman for Gender Equality had previously called for implementing the earlier provisions of the Gender Equality Act to cover trans and intersex people while also advocating express modifications to the law. The Scottish Offences (Aggravation by Prejudice) (Scotland) Act of 2009 included protection against hate crime on the basis of actual or presumed “intersexuality” within the meaning of “transgender identity”.⁸⁷

In 2012, the Autonomous Basque Community in Spain adopted a law on non-discrimination on the grounds of gender identity and for the recognition of trans people, including coverage of intersex people. While the law primarily addresses the needs of trans people, Article 6(4) establishes that intersex individuals are entitled to access the following services: “a) Information, guidance and advice, including legal assessment, to intersex individuals and their families in order to provide for needs specifically related to their status”. The law also aims to “promote the defence of [intersex] rights and fight all sorts of discrimination suffered within the social, cultural, labour or educational scope. Furthermore [...] participation in public services of associations of intersex people, and organisations working in the field of gender identity, will be promoted”.⁸⁸

The Australian federal law entitled Sex Discrimination Amendment (Sexual Orientation, Gender Identity and Intersex Status) Act 2013 broke away from the extension of the definitions of “sex” or “gender identity” by introducing an intersex-specific ground (i.e. “intersex status”) for the first time. It defines intersex status as “the status of having physical, hormonal or genetic features that are: (a) neither wholly female nor wholly male; or (b) a combination of female and male; or (c) neither female nor male”. The act considers that a person (the perpetrator) discriminates against another person (the aggrieved person) on the grounds of intersex status if the discriminator treats the aggrieved person less favourably than a person who is not of intersex status, by reason of “(a) the aggrieved person’s intersex status; or (b) a characteristic that appertains generally to persons of intersex status; or (c) a characteristic that is generally imputed to persons of intersex status”.⁸⁹

The Maltese Gender Identity, Gender Expression and Sex Characteristics Act of 2015 defines “sex characteristics” as “the chromosomal, gonadal and anatomical features of a person, which include primary characteristics such as reproductive organs and genitalia and/or in chromosomal structures and hormones; and secondary characteristics such as muscle mass, hair distribution, breasts and/or structure”. It provides

protection on this ground in equal treatment legislation and in anti-hate crime and “hate speech” provisions in the Criminal Code. Importantly, the bill makes “medical intervention which is driven by social factors without the consent of the minor” a violation of the law.⁹⁰

All these different national and regional approaches to tackling discrimination and violence against intersex people have their value, and some may fit specific legal traditions better than others. Whatever the approach, however, legal certainty needs to be guaranteed. In this respect, a specific provision for intersex, such as “sex characteristics” or “intersex status”, has the advantage of playing an educational role for society at large as well as providing visibility to this marginalised group. In the absence of a specific term, an authoritative legal interpretation of the applicability of the category of sex/gender would appear necessary.

In the same vein, it is also important that the material scope of the legislation tackling discrimination covers all spheres of life, and that the framework tackling hate crimes and “hate speech” also expressly covers violence against intersex people.

5.3. Awareness raising, social inclusion and support services

So far, virtually all awareness-raising initiatives on intersex issues have been carried out by intersex organisations at the grassroots level. Among these initiatives is the designation of 26 October (since 1996) as Intersex Awareness Day, as well as various activities which are carried out annually to end shame, secrecy and unwanted genital cosmetic surgeries on intersex children during the week leading up to 8 November, which has been declared the Intersex Day of Remembrance. Intersex people have also produced an array of materials in different media to draw attention to their plight.

Collaborations between public institutions and intersex organisations are very rare, but do exist. For example, the portal www.meingeschlecht.de was launched through funding received from the German Federal Anti-Discrimination Agency and others, in collaboration with trans, genderqueer and intersex organisations. Its aim is to strengthen the self-confidence of intersex people by making their real life situations more visible. It targets young people with the goal of providing information and promoting the idea that physical and sexual diversity is normal. The portal provides texts, images and videos of young people who talk about their experiences as trans, genderqueer and/or intersex and their perception of themselves, and provides points of contact throughout Germany. During 2014, three German constituent states funded intersex-specific activities carried out by NGOs.

Interesting initiatives have also been developed in Austria. The Austrian Advertising Council has stated in its document on gender discrimination “that advertisements are discriminatory because of gender, if they are likely to depreciate persons not living up to common understandings about belonging to one of the sexes (like intersexual persons or transgender persons)”. Additionally, a “brochure on sexual education of children aged 6 to 12 also contains information on intersexuality as well as an introduction on how to conduct an exercise with children on intersexuality.”⁹¹

Further afield, policy developments coming from Australia can serve as inspiration for similar policies within Europe. For example, the Victoria Department of Education and Early Childhood Development has adopted a policy “[t]o ensure schools support students with transgender or intersex status”. The policy: (i) details privacy and confidentiality approaches; (ii) demands that principals provide well-being support services; (iii) demands that toilets, showers and changing rooms “are appropriate to the student’s preferred or chosen gender”; (iv) indicates how to ensure community adjustment in case of change of gender identity while enrolled at the same school; and (v) how school documentation should change accordingly to reflect the student’s preferred name and sex. The Maltese Ministry for Education and Employment recently followed suit and drafted a policy entitled Trans, Gender Variant and Intersex Students Policy developed in conjunction with LGBTI civil society.⁹²

Through funding from the Australian Government Department for Social Services, OII Australia has published brochures for allies, parents and service providers, laying down clear information about intersex, obligations of service providers, the 2013 anti-discrimination law, how to include intersex in sex and gender information, the use of inclusive language and so on.⁹³

On the cultural front, the Douarnenez film festival in Brittany, France, has openly and prominently embraced the intersex and trans community in its programme since 2012. The festival, which welcomes more than 10 000 visitors annually, has also become a place for intersex individuals and European intersex activists to meet, share their experiences and plan further advocacy strategies, as well as find new allies.⁹⁴

While these initiatives are most welcome and can serve as good practices, it is obvious that much more needs to be done to reach out to the general public. Hence it is important to include intersex-specific messages in general equality campaigns and at the national and local levels. Professional training on mainstreaming intersex issues among service providers needs to be provided systematically to all those who need it and included in the curricula.

In view of the lifelong impact of past traumas and pain due to surgery, medicalisation and other forms of discrimination affecting their well-being, many intersex people would benefit from access to interdisciplinary counselling and support as well as peer support, framed outside of a medical or pathological framework. Similar support should also be provided to parents, friends and colleagues in order to foster understanding and social inclusion.



Chapter 6

Access to justice and accountability

6.1. Emerging national jurisprudence

To date, few cases have been taken to court to challenge the human rights breaches suffered by intersex people. This is possibly due to the fact that in many cases, lawsuits would need to be taken against the parents (or the legal guardians) who consented to surgical interventions rather than the institutions or the individuals who carried out the treatment. However, a small but important body of jurisprudence does exist.

In 1999, the Constitutional Court of Colombia issued two intersex-specific decisions – a global first – which significantly restricted the ability of doctors and parents to resort to surgery when children are born with “atypical genitals”, as surgery could impinge on the rights of the child and his or her best interests. The International Commission for Jurists (ICJ) summed up the court’s reasoning, stating that “the need to protect the right of free development of personality was greater in the case of an eight-year old child, who had already become aware of his or her genitalia and was better able to define his or her gender identity; as a child grew older, his or her autonomy increased and deserved increased protection”. Furthermore, in these decisions, the court recognised intersex people as a minority entitled to protection by the state against discrimination motivated by intolerance. It also noted that it is the responsibility of public authorities, the medical community and ordinary citizens “to open a space to these people, who until now have been silenced”.⁹⁵

In 2008, the Constitutional Court of Colombia was presented with yet another case where the complainant was a father who wished to opt for surgery for his five-year-old intersex child; however, in view of the standards set by the 1999 court rulings, his decision was not supported by the social services and the General Northern Clinic. Holding on to its previous assessment, the court discussed “the clash between the constitutional right to autonomy and the rights of the beneficiary, specifically in cases involving children ... [and] found that, in intersex cases involving surgery, the decision of the child was paramount, while the right of the parent to make decisions in a protective capacity was secondary”.⁹⁶

In one case, an intersex individual took a case against her surgeon. In 2007, Christiane Völling sued the surgeon who removed her uterus, tube and ovaries without her consent 30 years previously. One year later, the Cologne District Court found that the doctor had “culpably violated her health and self-determination”, and ordered the surgeon to pay her €100 000 in damages. Importantly, this case established two key principles: i) the continued effect of surgeries suffered in the past and ii) compensation beyond a mere token gesture or apology.⁹⁷

Other cases have reached the courts and had positive results in the Philippines and in Kenya. In the first case, the Supreme Court of the Philippines relied on the fact that the complainant’s wish to change the sex marker on the birth certificate was the result of a “natural” biological medical condition, and that it was thus reasonable to allow an intersex person to determine her or his own sex as his or her body matured. In the second case, the complainant was Richard Muasya, who had suffered a number of discriminatory experiences as a result of never being provided with a birth certificate due to his “ambiguous genitalia”. As an adult, he was charged with the capital offence of robbery with violence and was later convicted and placed in a male-only prison. The High Court of Kenya found that his treatment in prison amounted to inhuman and degrading treatment, as he was humiliated and exposed to derision, and that invasive body searches on his person were “motivated by an element of sadism and mischievous curiosity, to expose the petitioner’s unusual condition”. The court concluded that this was contrary to the Kenyan Constitution and Article 5 of the UDHR, and awarded him damages of 500 000 Kenyan shillings (equivalent to around €4 000). In 2014, the same Kenyan Court ordered the government to issue a birth certificate to an intersex child, which represents one more step towards the recognition of intersex people in the country.⁹⁸

6.2. National human rights structures

National human rights structures (NHRs) such as ombudspersons, equality bodies and human rights commissions have proved especially useful in promoting equality for minority groups and reaching out to them, addressing their complaints, and advocating for greater recognition in society. As low-threshold complaints mechanisms they are easier and less costly to access than courts. The initiatives of Finland’s Ombudsman for Gender Equality advocating for the inclusion of intersex in the law, and the German Federal Anti-Discrimination Agency regarding gender designation of intersex people, indicate how much can be done by such institutions when they are mandated to cover intersex issues.⁹⁹

The European Network of Equality Bodies (EQUINET) has taken the initiative of issuing its own perspective which, amongst others, looks at action that could be taken by equality bodies to develop their work on LGBTI issues and possible EU-level action to support it. This document clearly shows that intersex people rarely feature in the reports and work of equality bodies and that no complaints from intersex people were received by any of its members. It therefore called for greater engagement with intersex people and their organisations, highlighting a good practice from Austria where the Ombud for Equal Treatment organised a conference that allowed for the building of bridges with intersex organisations and the development of a thematic brochure.¹⁰⁰

EQUINET also called on its members to advocate for equality legislation which fully protects LGBTI people from discrimination under the law and to name intersex people specifically in equal treatment legislation. It urged its members to “[e]xpress concern at early surgical interventions for intersex children without the child’s participation”.¹⁰¹

Children’s ombudspersons, child protection authorities and patients’ ombudspersons also have a role to play in protecting the best interests of intersex children and advocating their human rights. For example, in Advice towards the Irish General Scheme of the Gender Recognition Bill 2013, the Irish Ombudsman for Children stated that, in view of the “extraordinary adversity and barriers to living with dignity”, gender recognition legislation should aim to mitigate the challenges faced by transgender and intersex children; and that “[t]he legislation must be informed by a thorough assessment of what the impact of maintaining the status quo will be on transgender and intersex young people”.¹⁰²

6.3. Accountability for suffering caused in the past

Both the German and the Swiss ethics councils take the position that intersex people’s suffering due to past interventions should be acknowledged by society. NEK-CNE notes that “[t]he medical practice of the time was guided by sociocultural values which, from today’s ethical viewpoint, are not compatible with fundamental human rights, specifically respect for physical and psychological integrity and the right to self-determination”.¹⁰³

In this respect, the German council also suggests that there should be “at least symbolic compensation especially to those who, on account of what would now be seen as incorrect medical treatment, are afflicted with physical or psychological suffering and often also incur expense that would not have arisen without this treatment”. The council went on to state that “the creation of appropriate social conditions for those concerned and sensitive treatment of their families” was highly important. Additionally, financial compensation should be considered, and should be channelled through a state-financed fund or a foundation, thus recognising that the “the medical measures now deemed to be wrong were tolerated, or not prevented, by the state”.¹⁰⁴

The International Intersex Forum’s Public Statement has called for the provision of “adequate redress, reparation, access to justice and the right to truth”. Another common call by intersex individuals regards access to their own medical records. The frequent unavailability of medical records also hinders intersex people’s access to judicial remedies.¹⁰⁵

6.4. Guaranteeing future human rights compliance

To conclude, member states have a duty to end the secrecy around intersex issues, and the current impunity in cases of discrimination. Truth, and accountability for past malpractice and human rights violations, should be the cornerstones of any process towards reparation. Furthermore, in order to ensure compliance with human rights in the future, more needs to be done at all levels and by all relevant institutions to gather information about current practices regarding intersex people and assess

them through the lens of the highest ethical and human rights standards. Intersex people and their organisations need to be key partners in such a process.¹⁰⁶

There is a need to address current stereotypes which lead to the marginalisation of intersex people, and to address the issue of early interventions and surgeries. Legislation needs to be introduced to establish the applicability of domestic human rights protections to intersex people, as well as to facilitate access to courts, NHRs and other means of access to justice. Clear ethical standards need to guide case professionals, including medical doctors and psychosocial care providers. Educational campaigns to promote bodily diversity can also play an important role and should be encouraged.

Finally, intersex children, their parents and families need adequate counselling and support. Civil society advocates of intersex people should be able to participate in the provision of information and services to intersex families in addition to medical and social professionals. Training about intersex issues and their human rights implications needs to be improved among health and social services.

Notes

1. J. A. Greenberg (1998), "Defining Male and Female: Intersexuality and the Collision between Law and Biology", *Arizona Law Review*, Vol. 41 No. 2, pp. 265-328.
2. The terms "sex" and "gender" are used inconsistently in different contexts and do not have the same meaning across Europe, especially since some languages do not distinguish between the two. For the purpose of this document, distinction is drawn between someone's assigned sex at birth and the gender affirmed or preferred later on in life.
3. This issue paper focuses on the specific issues related to intersex people's enjoyment of human rights. It builds on the Human Rights Comment, published by the Commissioner for Human Rights, entitled "A boy or a girl or a person – intersex people lack recognition in Europe" (9 May 2014), available in English, French and Russian at: www.coe.int/web/commissioner/blog.
4. D. C. Ghattas (2013), *Human Rights between the Sexes: A preliminary study in the life of inter* individuals*, Heinrich Böll Stiftung: Publication Series on Democracy, Vol. 34, p. 10.
5. In 2009, the Commissioner for Human Rights published an issue paper entitled "Human rights and gender identity" dealing with the specific human rights issues of trans people, available in English, French, Russian, Spanish and Turkish at: wcd.coe.int/ViewDoc.jsp?id=1476365.
6. Swiss National Advisory Commission on Biomedical Ethics (NEK-CNE) (2012), "On the management of differences of sex development: ethical issues relating to 'intersexuality'" Opinion No. 20/2012; Intersexuelle Menschen e. V. / XY-Frauen (2008), Shadow Report to the 6th National Report of the Federal Republic of Germany on the United Nations Convention on the Elimination of All Forms of Discrimination against Women (CEDAW).
7. Transgender Equality Network Ireland (2013), "Human rights violations in Ireland on the basis of gender identity and intersex identity", submission to the Country Report Task Forces, 109th Session of the Human Rights Committee, Geneva, October-November 2013; J. Eisfeld, S. Gunther and D. Shlasko (2013), "The state of trans* and intersex organizing: A case for increased support for growing but under-funded movements for human rights"; see two relevant statements from the International Intersex Fora: (i) Public statement by the Third International Intersex Forum (2013) at: www.ilga-europe.org/home/news/latest/intersex_forum_2013; and (ii) Statement of the European Intersex Meeting in Riga (2014) at: <http://oiieurope.org/statement-of-the-european-intersex-meeting-in-riga-2014/>.
8. A. Fausto-Sterling (2000), *Sexing the body: gender politics and the construction of sexuality*, New York: Basic Books, p. 51; Intersex was coined as a scientific term by German scientist Richard Goldschmidt in the first edition of the 1901 professional journal entitled *Endocrinology* and became the leading medical term towards the mid-20th century; see section 2.2 for a detailed overview of medical nomenclature.
9. OHCHR (2013), Fact sheet: "LGBT rights: frequently asked questions".
10. J. Behrmann and V. Ravitsky (2013), "Queer liberation, not elimination: Why selecting against intersex is not 'straight' forward", *The American Journal of Bioethics*, Vol. 13 No. 10, pp. 39-41.
11. LGBTIQ (an acronym intended to cover queer people along with LGBTI) is starting to be used at institutional level on some occasions.

12. FRANET thematic legal study on Austria serving as background information for the FRA "Report on homophobia, transphobia, and discrimination on grounds of sexual orientation, gender identity and intersexuality – 2015 Update – comparative legal analysis" reported that an intersex woman successfully brought forward a case of discrimination under disability protection provisions found in the Bundes-Behindertengleichstellungsgesetz (Federal Disability Equal Treatment Act), see Oberste Gerichtshof (Austrian Supreme Court), 1Ob189/09i, 15.12.2009; Y. Menon (2011), "The intersex community and the Americans with Disabilities Act", *Connecticut Law Review*, Vol. 43 No. 4, pp. 1221-1251.
13. A. Fausto-Sterling (2000), op. cit., p. 51.
14. Parliamentary Assembly of the Council of Europe (2013), Resolution 1952 (2013) children's right to physical integrity, paragraph 7.5.3.
15. FRA's multidisciplinary research network's (FRANET) national contributions for the FRA Report on Homophobia, Transphobia, and Discrimination on Grounds of Sexual Orientation, Gender Identity and Intersexuality – 2015 Update – Comparative Legal Analysis are referred to in this issue paper.
16. New Zealand Human Rights Commission (2010), "To be who I am" – intersex material from report of the inquiry into discrimination experienced by transgender people; San Francisco Human Rights Commission (2005), "A human rights investigation into the medical 'normalization' of intersex people"; German Ethics Council (2012), "Intersexuality opinion"; NEK-CNE (2012), op. cit., p. 8; Commonwealth of Australia (2013), "Second report: Involuntary or coerced sterilisation of intersex people in Australia".
17. A. Fausto-Sterling (2000), op. cit., p. 46; J. D. Hester (2004), *Intersex(es) and informed consent: How physicians' rhetoric constrains choice*, *Theoretical Medicine and Bioethics* Vol. 25, No. 1, pp. 21-49.
18. J. Colapinto (11/12/1997), "The True Story of John/Joan", *Rolling Stone*, pp. 54-97; J. Woweries (2010), *Intersexualität: Eine Kinderrechtliche Perspektive* (Intersexuality: A Child Rights Perspective), frühe Kindheit, Issue 0310, pp. 18-22; A. Dreger (1998), *Hermaphrodites and the medical invention of sex*, Cambridge: Harvard University Press, pp. 182-183; N. Ben-Asher (2006), "The necessity of sex change: A struggle for intersex and transsex liberties", *Harvard Journal of Law and Gender*, Vol. 29, No. 1, pp. 51-98; American Academy of Pediatrics (2000), "Evaluation of the newborn with developmental anomalies of the external genitalia", *Pediatrics* Vol. 116 No. 1, pp. 138-142.
19. A. Dreger, E. K. Feder and A. Tamar-Mattis (2012), "Prenatal dexamethasone for congenital adrenal hyperplasia", *Journal of Bioethical Inquiry*, Vol. 9 No. 3, pp. 277-294; B. A. Kelly, A. J. Lewandowski, S. A. Worton, E. F. Davis, M. Lazdam, J. Francis, S. Neubauer, A. Lucas, A. Singhal and P. Leeson (2012), "Antenatal glucocorticoid exposure and long-term alterations in aortic function and glucose metabolism", *Pediatrics*, Vol. 129, No. 5, pp. 1282-1290; A. Briffa (2003), *Discrimination Against People Affected by Intersex Conditions*, p. 9; M. Carpenter (2014), "Submission on the review of Part B of the Ethical guidelines for the use of assisted reproductive technology in clinical practice and research", 2007, p. 6; C. M. Girardin and G. Van Vliet (2011), "Counselling of a couple faced with a prenatal diagnosis of klinefelter syndrome", *Acta Paediatrica*, Vol. 100, No. 6, pp. 917-922.
20. C. J. Dewhurst and R. R. Gordon (1969), *The Intersexual Disorders*, London: Baillière, Tindall and Cassell, p. 52; Y. Low, J. Hutson and Murdoch Children's Research Institute Sex Study Group (2003), "Rules for clinical diagnosis in babies with ambiguous genitalia", *Journal of Paediatrics and Child Health*, Vol. 39 No. 6, pp. 406-413.
21. M. Rupprecht (2013), "Children's right to physical integrity", report, Committee on Social Affairs, Health and Sustainable Development, PACE (Doc. 13297).
22. New Zealand Human Rights Commission (2010), op. cit., and San Francisco Human Rights Commission (2005), op. cit.; Ponsonby Productions Ltd. (2012), "Intersexion" op. cit.
23. C. Völling (2010), *Ich war Mann und Frau: Mein Leben als Intersexuelle* (I was a man and a woman: my intersex life), Fackelträger, p. 94.

24. Court proceedings and decision covered in Chapter 6.
25. M. Bauer and Zwischengeschlecht.org (2013), "Stop intersex genital mutilations!"
26. E. Schneider (2013), "An insight into respect for the rights of trans and intersex children in Europe", Council of Europe, pp. 29-30.
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To this day, European societies remain largely unaware of the reality of intersex people. The classification of humankind into two categories, female and male, is omnipresent and informs the way we understand and organise the world around us. People who do not fit neatly into these two categories are exposed to human rights violations. Among them, intersex people are especially vulnerable.

The supposed dichotomy of gender – and the corresponding medical norms – have resulted in routine medical and surgical interventions on intersex people even when they have not been adequately consulted or informed prior to such procedures. Secrecy and shame surrounding the bodies of intersex people have permitted the perpetuation of these practices while the human rights issues at stake have remained for the most part unaddressed.

This issue paper traces the steps which have already been taken towards understanding and responding to the situation of intersex people from an ethical and human rights perspective. It urges governments to end medically unnecessary “normalising” treatment of intersex people when it takes place without their free and fully informed consent. It also suggests ways forward in terms of protection against discrimination, adequate recognition of sex on official documents and access to justice.



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