



# FIRST, DO NO HARM

ENSURING THE RIGHTS OF CHILDREN WITH VARIATIONS OF SEX CHARACTERISTICS IN DENMARK AND GERMANY

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**Cover illustration:** INTER\*SHADES by Alex Jürgen\*. Alex is an intersex artist living and working in Austria. Alex spells their name with a \* to signify that intersex is not a recognized sex, and is currently involved in a court case to change their name and passport.

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# CONTENTS

|  |           |
|--|-----------|
| <b>1. EXECUTIVE SUMMARY</b>  | <b>7</b>  |
| 1.1 METHODOLOGY  | 7         |
| 1.2 MEDICAL PRACTICES  | 7         |
| 1.3 THE IMPACT ON INDIVIDUALS  | 9         |
| 1.4 HUMAN RIGHTS AND GENDER STEREOTYPING                             | 10        |
| 1.5 FURTHER HUMAN RIGHTS VIOLATIONS                                  | 10        |
| 1.6 PRINCIPAL RECOMMENDATIONS  | 11        |
| <b>2. SCOPE AND METHODOLOGY</b>                                      | <b>13</b> |
| 2.1 SCOPE  | 13        |
| 2.2 TERMINOLOGY  | 14        |
| 2.3 METHODOLOGY  | 14        |
| 2.4 ACKNOWLEDGEMENTS   | 15        |
| <b>3. CONTEXT</b>  | <b>16</b> |
| 3.1 HOW MANY PEOPLE ARE BORN WITH VARIATIONS OF SEX CHARACTERISTICS? | 16        |
| 3.1.1 DENMARK  | 16        |
| 3.1.2 GERMANY  | 16        |
| 3.2 A BRIEF HISTORY OF MEDICAL INTERVENTIONS                         | 17        |
| 3.3 OVERCOMING STIGMA AND INVISIBILITY                               | 19        |
| <b>4. MEDICAL POLICIES AND PRACTICES</b>                             | <b>21</b> |
| 4.1 CONSENSUS STATEMENT TERMINOLOGY                                  | 22        |
| 4.2 MEDICAL INTERVENTIONS  | 23        |
| 4.2.1 IDENTIFICATION IN INFANCY                                      | 23        |
| 4.2.2 IDENTIFICATION LATER IN LIFE                                   | 25        |
| 4.2.3 SEX ASSIGNMENT   | 25        |
| 4.2.4 TO ACT OR NOT  | 26        |
| 4.2.5 DECISION-MAKING  | 28        |
| 4.2.6 INFORMED CONSENT   | 31        |

|  |           |
|--|-----------|
| 4.2.7 OPERATIONS   | 31        |
| 4.2.8 HORMONE TREATMENT  | 36        |
| 4.2.9 PSYCHOSOCIAL SUPPORT   | 37        |
| 4.3 A LACK OF RESEARCH   | 40        |
| 4.3.1 THE IMPACT OF INTERVENTIONS  | 40        |
| 4.3.2 THE IMPACT OF NOT ACTING   | 41        |
| <b>5. HUMAN RIGHTS AT STAKE</b>  | <b>42</b> |
| 5.1 THE RIGHTS OF THE CHILD  | 42        |
| 5.1.1 BEST INTERESTS OF THE CHILD  | 43        |
| 5.1.2 RIGHTS TO PRIVATE LIFE, TO PHYSICAL AND BODILY INTEGRITY AND SELF-DETERMINATION  | 44        |
| 5.1.3 EVOLVING CAPACITIES AND THE RIGHT OF THE CHILD TO EXPRESS ITS VIEWS              | 45        |
| 5.1.4 RIGHT TO THE HIGHEST ATTAINABLE STANDARD OF HEALTH                               | 45        |
| 5.2 DISCRIMINATION AND GENDER STEREOTYPES  | 46        |
| 5.3 FREEDOM FROM TORTURE AND OTHER CRUEL, INHUMAN OR DEGRADING TREATMENT OR PUNISHMENT | 48        |
| <b>6. LEGAL ANALYSIS</b>   | <b>49</b> |
| 6.1 DENMARK  | 49        |
| 6.1.1 THE DANISH HEALTH ACT  | 49        |
| 6.1.2 RECORDS, COMPLAINTS MECHANISM AND STATUTE OF LIMITATIONS                         | 50        |
| 6.1.3 MEDICAL GUIDELINES   | 50        |
| 6.1.4 BIRTH REGISTRATION   | 51        |
| 6.1.5 LEGAL GENDER RECOGNITION AND ACCESS TO GENDER-AFFIRMING TREATMENT                | 51        |
| 6.2 GERMANY  | 51        |
| 6.2.1 CRIMINAL AND PRIVATE LAW   | 51        |
| 6.2.2 BIRTH REGISTRATION   | 52        |
| 6.2.3 PERSONAL STATUS LAW  | 52        |
| 6.2.4 GOVERNMENT INITIATIVES   | 52        |
| 6.2.5 HEALTHCARE FUNDING   | 53        |
| 6.2.6 2016 GUIDELINES  | 53        |
| 6.2.7 REPARATIONS AND STATE ACCOUNTABILITY   | 54        |
| <b>7. RECOMMENDATIONS</b>  | <b>55</b> |
| 7.1 GENERAL RECOMMENDATIONS  | 55        |
| 7.2 DENMARK  | 55        |
| 7.3 GERMANY  | 56        |
| <b>8. APPENDIX: MALTA DECLARATION</b>  | <b>58</b> |

# GLOSSARY

| WORD                                     | DESCRIPTION   |
|--|---|
| <b>DISORDER OF SEX DEVELOPMENT (DSD)</b> | A term widely used by medical professionals, defined as “congenital conditions in which development of chromosomal, gonadal or anatomic sex is atypical.” Considered stigmatising by many individuals with variations of sex characteristics.   |
| <b>GENDER</b>                            | Socially constructed characteristics of people commonly predicated on their biological sex. This varies from society to society and can change or be changed. When individuals or groups do not “fit” established gender norms, they often face stigma, discriminatory practices or social exclusion.   |
| <b>GENDER IDENTITY</b>                   | Each person’s deeply felt internal and individual experience of gender, which may or may not correspond with the sex assigned at birth.   |
| <b>INTERSEX</b>                          | An umbrella term used to describe a person whose genital, gonadal, chromosomal or hormonal characteristics do not correspond to the given standard for male or female categories of sexual or reproductive anatomy.<br><br>Intersex variations may take different forms and covers a wide range of traits. Intersex bodied, intersexed or intersexuality can also be ways of naming diversity of sex characteristics. |
| <b>“NORMALIZING” GENITAL SURGERY</b>     | Operations intended to construct or reconstruct the genitalia of a person to comply with the normative medical standards of male or female appearance. For a list of “normalizing” genital surgeries, see Appendix II.  |
| <b>PRIMARY SEX CHARACTERISTICS</b>       | These include: sex chromosomes (e.g. XX, XY, X, XXY), external genitalia (e.g. glans penis, scrotum, foreskin, perineum, clitoris, labia, vulva, perineal urethra), gonads (e.g. ovaries, testes), hormones (e.g. oestrogen, progesterone, testosterone) and internal reproductive organs (e.g. uterus, ovaries, fallopian tubes, prostate).  |
| <b>SECONDARY SEX CHARACTERISTICS</b>     | Characteristics that develop later in life, usually during puberty and relate to hormone development and the growth of the individual. They include: facial and body hair, the menstrual cycle, breast development, height, muscle distribution and body fat.   |
| <b>SEX</b>                               | The set of biological and reproductive attributes and characteristics of a person.  |
| <b>SEX ASSIGNMENT</b>                    | The process or act by which an infant or neonate is assigned a legal sex or gender. This can take place at birth or later, depending on national legal requirements for birth registration.   |
| <b>SEX CHARACTERISTICS</b>               | Physical traits or organs that can be indicative of an individual’s biological sex and are distinguished into primary and secondary sex characteristics.  |

| WORD                                     | DESCRIPTION  |
|--|--|
| <b>SEXUAL ORIENTATION</b>                | Each person's capacity for profound emotional, affectionate and sexual attraction to, and intimate and sexual relations with, individuals of a different gender or the same gender or more than one gender.                                      |
| <b>VARIATIONS OF SEX CHARACTERISTICS</b> | Characteristics that, either at birth or in developmental stages, do not fit the medical or societal standards of binary biological sex and gender (male and female) with regards to their internal or external sexual and reproductive anatomy. |

# 1. EXECUTIVE SUMMARY

Every year, children are born with sex characteristics – genitals, gonads, hormones, chromosomes or reproductive organs – which vary from the established norms for ‘male’ and ‘female’. These variations of sex characteristics differ in nature and frequency. Some have a recognised medical diagnosis, others do not. Some are apparent from birth, others become apparent at puberty or even later. Still others are never detected or diagnosed.

Some people – but not everyone - with a variation of sex characteristics uses the term ‘intersex’. The Office of the UN High Commissioner for Human Rights has stated that “intersex people are born with sex characteristics (including genitals, gonads and chromosome patterns) that do not fit typical binary notions of male or female bodies.”

In this report, Amnesty International documents the specific human rights violations faced by children and adults with variations of sex characteristics. We focus specifically on the human rights violations – in particular the violation of their rights to a private life, to the highest attainable standard of health, to bodily integrity, self-determination and recognition before the law - experienced in the course of non-emergency, invasive and irreversible ‘normalising’ surgeries and other medical practices, and the failure of the state to protect individuals against these violations.

The UN Committee on Economic, Social and Cultural Rights (CESCR) has made clear in General Comment 14 that States, as the parties to the the International Covenant on Economic, Social and Cultural Rights (ICESCR), have a responsibility to ensure that all members of society, “including health professionals” fulfil their responsibilities regarding the realisation of the right to health.

## 1.1 METHODOLOGY

In researching this report, Amnesty International carried out field and desk-based research between October 2015 and March 2017. In Denmark and Germany, we interviewed 16 individuals with variations of sex characteristics themselves, and eight parents of children with these variations, about their experiences. In order to contextualise our findings, we also spoke with 15 intersex activists based in other European countries with research and advocacy experience and personal experiences of human rights violations.

We reviewed quantitative and qualitative medical research on variations of sex characteristics, statistical reviews of diagnoses and medical interventions, reports by civil society, and international treaty bodies as well as academic research on sex and gender. We interviewed 31 medical and health professionals involved in the treatment of children and adults with variations in sex characteristics in Denmark and Germany, and sought medical expertise and verification from other medical and health professionals practicing in other European countries. We also carried out an analysis of Danish and German legislation.

## 1.2 MEDICAL PRACTICES

Some variations in sex characteristics require urgent intervention. However, in Denmark and Germany, Amnesty International found evidence that infants who are born with visible variations in their sex characteristics, particularly in their external genitalia and gonads, undergo non-emergency, invasive and irreversible surgery and hormonal treatment that can cause short and long term harm..

**“I have been operated on, it’s too late for me, but if I stay silent it’s like I support surgeries and I can only change things if I speak up”**

D\*, Germany, who underwent five genital operations beginning before the age of one.

Surgical operations which hide an enlarged clitoris - known as clitoral recessions – are often performed on children with congenital adrenal hyperplasia (CAH). These operations carry risks of possible nerve damage, scarring and pain. Children with CAH have XX chromosomes (associated with the female sex) and genitalia that appears ‘masculine’ resulting from a higher production of masculinising hormones. Infants with CAH may also have an absence of a vaginal opening (vaginal agenesis) or a small vaginal opening (vaginal atresia). In these cases, vaginal surgery (vaginoplasty) – sometimes involving multiple surgeries over time - is also performed on children. Feminising surgeries including clitoral and vaginal surgeries are primarily carried out for cosmetic rather than anatomical reasons.

Gonadectomies – removal of the gonads – are performed on children under the age of ten. These surgeries are irreversible and result in the need for lifelong hormone treatment. They are often performed on children with variations such as partial or complete androgen insensitivity syndrome (PAIS, CAIS) who are born with XY chromosomes (associated with the male sex) and unformed or undescended gonads resulting from a resistance to certain sex hormones.

A variety of different surgeries known as hypospadias repair operations are used to reposition the urethra to the tip of the penis. In cases of hypospadias, the urethral opening is further down the penis, on the glans, shaft, or close to the scrotum. While in some cases the operations are necessary to cover the urethra and prevent infections, many surgeries are not emergencies and are performed in order that the child conforms to gender stereotypes: in the words of staff at one Danish hospital, “so that the boy can pee standing up.”

**“[The endocrinologist I saw] spoke a lot about getting treatment with oestrogens, progesterone and testosterone suppressing medications. But the only thing he wanted to treat me with was testosterone treatment ‘to make a man out of me’ and to have my breasts cut off because ‘that is what we normally do’”**

Stine, intersex woman, Denmark

Individuals with variations of sex characteristics may also undergo hormone treatment. In some cases, such as in cases of CAH where cortisol (a type of hormone) deficiencies are life-threatening, this treatment is lifesaving. In other cases, however, sex hormone treatment is administered to compensate for surgical removal of gonads, or in order that an individual go through puberty according to expectations for their assigned gender. Several individuals that Amnesty International spoke to reported that the hormones they were able to access did not always reflect their gender identity.

In Denmark, the Health Authority (an agency of the Ministry of Health) has not produced specific guidelines for the treatment of individuals with variations of sex characteristics. Hospitals therefore base their protocols on sections of different guidelines (including for example endocrinology or urology) and on their own guidelines. Amnesty International has documented that these guidelines are not fully consistent with the human rights legal framework, and are insufficient to prevent human rights violations; the Danish authorities, in particular the Ministry of Health, have an obligation to rectify this.

In Germany, several professional physician’s associations, in collaboration with support groups, have drawn up a set of guidelines for medical treatment of individuals with variations of sex characteristics. These



guidelines, however, are not agreed at a level that is binding and physicians may choose not to follow them. Amnesty International has documented that this framework is insufficient to prevent human rights violations; the German authorities, in particular the Ministry of Health, which has legal oversight for the Federal Joint Committee, have an obligation to rectify this.

## 1.3 THE IMPACT ON INDIVIDUALS

The majority of individuals, in both Germany and Denmark, that Amnesty International spoke to who underwent medical interventions have experienced long-term negative physical or mental difficulties as consequences of the surgery, often compounded by a lack of information about what was done to them, as many have not been able to access their medical records.

**“The doctors thought they were doing something good so we would fit better with society – they didn’t realize that it’s worse with damaged bodies.”**

Anjo, activist, Germany

There is a significant lack of research on the impact of medical interventions and on the long-term outcomes for individuals. Many of the individuals who spoke to Amnesty International about their own and their children’s experiences reported negative outcomes from surgeries, both at the time and in their lives subsequently.

**“From the day [an individual with variations of sex characteristics] is born [they] are told, ‘you are wrong and we need to fix you.’ That can have catastrophic psychological consequences.”**

Karina Lins, psychologist, Denmark

Parents of children with variations of sex characteristics that Amnesty International interviewed report that they were provided with insufficient information to enable them to make an informed decision about medical interventions proposed for their children. Individuals with variations of sex characteristics continue to report a lack of psychosocial support to help them adjust to the social implications of their variation. Likewise, parents of children with variations of sex characteristics report a lack of psychosocial support for them, to help them support their child, and for the children themselves.

**“Johannes\* is very fearful as a result of the operations he has had. He has problems sleeping. We have not been offered any psychological support for him”**

Parents of Johannes\*, Germany, who was born in 2013 and underwent hypospadias surgery in 2014 and 2015.

## 1.4 HUMAN RIGHTS AND GENDER STEREOTYPING

Children, adolescents and adults with variations of sex characteristics may undergo non-emergency, invasive and irreversible medical interventions to ‘normalise’ their bodies; these interventions are frequently justified on the grounds that they assign the child one of two binary options for sex and gender, that they enable penis-in-vagina sexual intercourse from adolescence; and that they prevent psychological damage and bullying of the child when it starts socialising with other children. These justifications are based on deeply ingrained gender stereotypes: that gender is binary, that children will grow up to be heterosexual, and that children whose bodies are gender non-conforming will suffer psychological damage as a result. These assumptions are not backed up by evidence, and in some cases they result in interventions being carried out that are not in the best interests of the child.

**“The medical profession only thinks in this gender binary system. Instead of saying your child is normal, and will grow up healthily, they say something is wrong and it can be fixed with surgery.”**

Sandrao, Germany, who underwent a gonadectomy at the age of five.

Article 5 of the Convention on the Elimination of All Forms of Discrimination against Women calls on States to eliminate practices based on stereotyped roles for men and women. These practices also violate Article 2 of the UN Convention on the Rights of the Child (CRC) which prohibits discrimination of any kind against children, and Article 2 of the ICESCR which similarly prohibits discrimination of any kind on any ground including sex, which the Committee on Economic, Social and Cultural Rights has interpreted to “cover not only physiological characteristics but also the social construction of gender stereotypes, prejudices and expected roles.” Neither Denmark nor Germany explicitly includes sex characteristics as protected grounds in anti-discrimination provisions.

## 1.5 FURTHER HUMAN RIGHTS VIOLATIONS

The human rights of children, adolescents and adults with variations of sex characteristics are recognised and protected under international law. International human rights treaties protect everyone against discrimination and against violation of their rights to a private life, to the highest attainable standard of health, to bodily integrity, and to recognition before the law.

Denmark and Germany have both ratified the Convention on the Rights of the Child (CRC), which strengthens the position of children as rights-holders and gives due consideration to how children can enjoy the full range of human rights guaranteed for all people in international standards. Performing non-emergency, invasive and irreversible surgeries with harmful effects on children violates Article 3.1 of the CRC which states that the best interest of the child must be the primary consideration in all actions concerning the child. The Committee on the Rights of the Child has specifically noted that “an adult’s judgement of a child’s best interests cannot override the obligation to respect all the child’s rights under the Convention;”

**“When I think about what happened, I get upset, because it wasn’t something for anyone else to decide – it could have waited. I get sad when I think about the fact that it is**

## **considered necessary to operate on these children, only because other people [think] it should be done”**

H\*, Denmark, who was operated on at the age of five for hypospadias.

Non-emergency, invasive and irreversible medical treatment with harmful effects violates the right of the child to the highest attainable standard of health as guaranteed by Article 24.1 of the CRC and also by Article 12.1 of the International Covenant on Economic, Social and Cultural Rights (ICESCR). The Committee on Economic, Social and Cultural Rights (CESCR) has specifically noted in General Comment 14 that this right confers obligations on States to respect the right to health, including by: “abstaining from enforcing discriminatory practices” as well as obligations to protect the right to health, including by: “tak[ing] measures to protect all vulnerable or marginalised groups of society.” The CESCR has, in the same General Comment, noted that states also have obligations to fulfil the right to health, including by “ensuring...that health-care staff are trained to recognise and respond to the specific needs of vulnerable or marginalised groups...[and] supporting people in making informed choices about their health.”

The UN Special Rapporteur on the Right to Health has explicitly stated that “Health-care providers should strive to postpone non-emergency invasive and irreversible interventions until the child is sufficiently mature to provide informed consent”, noting that “This is particularly problematic in the case of intersex genital surgery, which is a painful and high-risk procedure with no proven medical benefits”.

The medical standards and decision-making processes which lead to these non-emergency medical interventions being carried out on young children– which in many cases could wait until the child is able to express their views – may constitute a violation of the child’s right to express their views and to participate in decisions which affect them, as guaranteed by Article 12 of the CRC, and to the right to a private life - guaranteed by Article 16 of the CRC, Article 17 of the International Covenant on Civil and Political Rights (ICCPR) and Article 8 of the European Convention of Human Rights (ECHR). The European Court of Human Rights has interpreted the concept of the right to a private life to encompass the right to physical and psychological integrity.

The right to respect for physical and mental integrity is also protected by Article 3.1 of the Charter of Fundamental Rights of the European Union; Article 3.2 stipulates the respect for free and informed consent in medicine. When failing to ensure that the healthcare system and its staff provide information to enable parents and guardians to make an informed decision about medical interventions, states are in violation of this right as well as Article 18.2 of the CRC, which requires states, in order to guarantee and protect children’s rights, to render appropriate assistance to parents and legal guardians in the performance of their responsibilities.

In both Denmark and Germany, there are legal limits on the amount of time that can elapse before complaints or private claims can no longer be filed. This, combined with difficulties in accessing medical records, makes it difficult for individuals whose rights were violated by surgical or other interventions performed as children to obtain reparations for the harm they have suffered. In Germany, there have been only two successful court cases; in Denmark, there have been none. The authorities in both countries have an obligation to provide appropriate redress for physical and psychological suffering.

## **1.6 PRINCIPAL RECOMMENDATIONS**

Amnesty International recommends that Germany and Denmark:

- Develop and implement a rights-based healthcare protocol for individuals with variations of sex characteristics to guarantee their bodily integrity, autonomy and self-determination and to ensure that no child is subjected to non-emergency, invasive and irreversible surgery or treatment with harmful effects
- Postpone non-emergency, invasive and irreversible genital surgery or hormone treatment on infants and children with variations in sex characteristics until they are able to meaningfully participate in decision making and give their informed consent, in line with the principle of evolving capacities of children and adolescents

- Increase availability of psychosocial support for children and adults with variations of sex characteristics, and for the parents of children with variations of sex characteristics
- Ensure medical and healthcare professionals receive training on gender and bodily diversity, focusing on variations in sex characteristics, which does not perpetrate gender stereotypes
- Explicitly include sex characteristics as protected grounds in anti-discrimination provisions
- Make available compensation or other reparations for individuals who underwent unnecessary, irreversible, non-consensual medical treatments as children

# 2. SCOPE AND METHODOLOGY

## 2.1 SCOPE

This report examines the human rights violations experienced by people born with variations of sex characteristics in Denmark and Germany. It focuses in particular on non-emergency, invasive and irreversible medical interventions, both surgical and hormonal, on infants and children with variations in sex characteristics that can have harmful consequences. While Amnesty International's research focuses in detail on these two countries, we aim to illustrate a broader problem which also exists in many other countries.

These interventions are defined in this report as treatments, either surgical or hormonal, that are not aimed at saving the life or health of the infant, child or adolescent, but which seek to "normalize" their sex characteristics to fit the gender binary categories of male or female.

There are more than 40 medical diagnoses of types of variation in sex characteristics,<sup>1</sup> not all of which are referenced in this report. Amnesty International acknowledges that for certain types of variations, surgical and hormonal interventions are urgent and necessary. For example, in cases of life threatening loss of sodium in infants<sup>2</sup> or in cases where there is a serious threat of infection and urinary problems due to the exposure of the urethra. This report focuses on situations where medical interventions performed may be non-emergency interventions. Variations where this may be the case include:

- Some forms of congenital adrenal hyperplasia (CAH), a genetic variation associated with a decrease in the blood level of the hormone cortisol and an increase in the level of androgens.<sup>3</sup> In some countries including Germany and Denmark, it is also called androgenital syndrome (AGS);
- (Complete) androgen insensitivity syndrome (CAIS or AIS) is a variation in which the body cannot fully (or at all) respond to androgens, affecting the development of genitalia in the foetus;
- Hypospadias refers to a situation in which the hole through which urine passes is not at the tip of the penis;
- Klinefelter syndrome is a variation in which individuals have one Y chromosome and two or more X chromosomes.<sup>4</sup> It has physical characteristics that may include lower levels of testosterone and slow, partial or no development in puberty;
- Turner Syndrome is a variation in which individuals have a single X chromosome. This can lead to physical characteristics that may include short stature and ovaries that are partially developed.

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1 Even this set of diagnoses is not comprehensive; many individuals with variations of sex characteristics who seek a diagnosis do not meet the characteristics for any of these conditions

2 Salt-losing congenital adrenal hyperplasia (ICD-10 E25.0) is a type of CAH. For more information about ICD-10 classifications, see Section 4.1

3 Hormones, including testosterone, that stimulate or control the development or activity of male-associated sex characteristics

4 XX chromosomes are associated with the female sex, and XY chromosomes are associated with the male sex.

Children, adolescents and adults who were born with variations in sex characteristics face discrimination and other human rights violations, some of which are documented in this report. Individuals with variations of sex characteristics who wish to change their name and gender in their identification documents may face specific human rights violations in relation to this process of legal gender recognition. However, these violations are not the focus of this particular report and are referred to only insofar as earlier medical interventions exacerbate the obstacles faced.<sup>5</sup>

## 2.2 TERMINOLOGY

The terms used to refer to variations in sex characteristics are diverse and in some cases contentious. This report frequently makes reference to the term ‘intersex’, which is widely used and with which many individuals with variations of sex characteristics globally self-identify. Depending on the context, some activists prefer to use terms more common in their language which are closer in meaning or traditional usage to the term ‘hermaphrodite,’ for example ‘Zwitter’ in German.

However, it is important to note that not all individuals with variations in sex characteristics identify as intersex. Some do not accept the term because they find that it conflicts with how they represent or identify, or because it is viewed as an indicator of gender identity often conflated with transgender. Some people prefer to identify with their particular type of variation: for example, as a person with Turner Syndrome.

Some individuals with variations of sex characteristics view certain terms as stigmatizing and this report seeks to avoid those except where quoting individuals, institutions or medical frameworks. For example, the term Disorders of Sex Development (DSD) is widely used by the medical establishment to denote a group of congenital variations. While the word “disorder”, according to statements from patients, activists and even medical professionals, can add to existing stigma and pathologization, the term is used in particular frameworks around variations of sex characteristics and is therefore used at points in this report. The alternative term ‘Differences of Sex Development’<sup>6</sup> tends to be used by medical professionals when discussing with patients and parents.

Other terms that may be considered pathologizing or medicalizing of intersex bodies (such as ‘sex of rearing,’ ‘virilizing’ or ‘masculinizing,’ ‘feminizing,’ ‘malformation’ or ‘ambiguity’ of sex characteristics or genitals) are used in this report where necessary to reflect the opinions or testimonies of individuals cited.

Amnesty International is sensitive to the fact that there are differing views about the terminology that should be used regarding variations of sex characteristics among medical professionals, activists, patient support groups and others. When referring to specific cases, Amnesty International always uses the term with which the individual chooses to identify; in translating this report and other associated materials, we work with individuals to identify the closest appropriate term.

## 2.3 METHODOLOGY

Individuals with variations of sex characteristics face violations of their human rights all around the world. Our report focuses on two European countries, Denmark and Germany. We selected these two countries in response, in part, to the long-term work of activists, the availability of information on these human rights violations and the scope for research. Our findings are specific to these countries, but we believe that similar situations – and thus similar human rights violations – occur in other countries around the world. Since we have not researched the situation in other countries to the same level of detail, we do not have evidence to assess whether the situation in Denmark and Germany is better or worse than in other countries.

The information contained in this report was collected through research undertaken from October 2015 to March 2017, which included a review of quantitative and qualitative medical research on the issue of variations of sex characteristics, reports by civil society, and international treaty bodies as well as academic research on sex and gender. Amnesty International also carried out an analysis of Danish and German legislation.

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<sup>5</sup> Transgender people face similar violations regarding legal gender recognition. For an analysis of the human rights violations faced by individuals who seek legal recognition of their gender in Europe, see Amnesty International, *The state decides who I am: Lack of legal gender recognition for transgender people in Europe* (Index: EUR 01/001/2014), available at <https://www.amnesty.org/en/documents/EUR01/001/2014/en/>

<sup>6</sup> Also sometimes abbreviated as ‘DSD’. In this report, DSD refers only to the term ‘Disorders of Sex Development’.

Information was also collected from field research undertaken by the International Secretariat of Amnesty International jointly with Amnesty International Denmark and Amnesty International Germany. These included seven research visits: four to Denmark in April, June and September 2016 and January 2017; and three to Germany in September and November 2016 and January 2017. Information was also collected through phone and in-person interviews with individuals in other countries, as well as in the context of Amnesty International's participation in international, regional and national forums and conferences, in order to further our understanding of this complex topic and contextualise our findings from Germany and Denmark.

Amnesty International interviewed 16 people with variations in sex characteristics (eight in Denmark, 14 in Germany) and eight parents of children with variations in sex characteristics (three in Denmark, five in Germany) about their experiences. Amnesty International did not interview children directly for this report. In addition, researchers spoke to 15 intersex activists with extensive research and advocacy knowledge and personal experience of human rights violations in European countries, in order to contextualise our findings in Germany and Denmark. Our interviewees included intersex rights activists, members of support groups including patient support groups for individuals with CAH and Turner Syndrome, and individuals not affiliated with groups. Some names have been changed at the individuals' request: these are marked with an asterisk.

In Denmark, Amnesty International interviewed 22 medical and health professionals involved in the treatment of children and adults with variations in sex characteristics: nine from Arhus University Hospital, seven from Odense University Hospital, five from Rigshospitalet (also known as Copenhagen University Hospital) and two members of the Midwives Association (Jordmoderforeningen). These included specialists in paediatrics, endocrinology (paediatric and adult), paediatric and adult surgery, urology (paediatric and adult), genetics, gynaecology, clinical growth and reproduction, psychology, midwifery and nursing.

In Germany, Amnesty International interviewed nine medical professionals from three hospitals, including specialists in paediatric surgery, psychology, endocrinology, and genetics.

Amnesty International also sought medical expertise and verification from medical and health professionals who are specialists in the field of sex differentiation and gender variation practicing in other European countries.

## 2.4 ACKNOWLEDGEMENTS

Amnesty International would like to thank all of the people who agreed to be interviewed for this report and who spoke with us about their sometimes deeply troubling experiences.

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# 3. CONTEXT

## 3.1 HOW MANY PEOPLE ARE BORN WITH VARIATIONS OF SEX CHARACTERISTICS?

In 2000, biologist Anne Fausto-Sterling produced one of the first estimates of the number of people with variations in sex characteristics. According to her research, 1.7% of people globally are born with a variation of sex characteristics.<sup>7</sup> The difficulty of determining a precise number of people born with variations in sex characteristics is widely acknowledged among the medical community. In part this is the result of the large number of undiagnosed cases. Variations in data collection and classification further complicate arriving at an overarching agreed estimate.

### 3.1.1 DENMARK

In November 2016, the Danish Ministry of Health and the Aged (Sundheds- og Ældreministeriet) published data on DSD cases<sup>8</sup> and operations recorded in the Danish National Patient Registry (Landspatientregisteret) between 2011 and 2015.<sup>9</sup>

The data included 86 categories of ‘congenital malformations’ in female and male genitals. The register included 1,314 cases of “malformations” in female genitals, 388 involving minors under 15 years of age; and 4,581 cases of “malformations” in male genitals, 2,949 of which involved minors under 15.

Certain types of variations in sex characteristics accounted for a relatively large number of hospital visits for minors. For example, 128 cases of mild glanular hypospadias<sup>10</sup> were recorded in children aged under five. However, these cases accounted for 1,640 hospital visits.

Separate clinical studies in Denmark have attempted to measure specific variations in sex characteristics. A study between 1977 and 2005, indicated that over 2.5% of children were born with hypospadias and that the rate was increasing.<sup>11</sup> Between 2011 and 2015, 1,498 cases of individuals with hypospadias were registered in hospitals in Denmark.

### 3.1.2 GERMANY

A 2016 study by Ulrike Klöppel found that in 2014, there were 4,498 diagnoses of conditions related to variations in sex characteristics in children aged under 10, broken down as follows:<sup>12</sup>

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7 Anne Fausto-Sterling, *Sexing the Body*, 2000, (hereinafter: Fausto-Sterling, 2000), p. 53

8 In response to a parliamentary question from August 2016. Full response available at:

<http://www.ft.dk/samling/20151/almindel/suu/spm/857/svar/1355435/index.htm>

9 Diagnosis data from National Patient Registry, available at: [http://www.esundhed.dk/sundhedsregistre/LPR/Sider/LPR01\\_Tabel.aspx](http://www.esundhed.dk/sundhedsregistre/LPR/Sider/LPR01_Tabel.aspx)

10 Individuals with urethral openings on the glans, not the tip, of the penis

11 Lund et.al., ‘Prevalence of hypospadias in Danish boys: a longitudinal study, 1977-2005’, 2009, *European Urology*, Volume 55, Issue 5, May 2009, p. 1022–1026

12 Ulrike Klöppel, ‘On the current state of cosmetic surgery of ‘ambivalent’ genitalia in childhood’ (‘Zur Aktualität kosmetischer Operationen „uneindeutiger“ Genitalien im Kindesalter’), 2016, pg.81-83 (hereinafter: Klöppel, 2016), available at [www.gender.hu-berlin.de/de/publikationen/gender-bulletins/texte-42/kloepfel-2016\\_zur-aktualitaet-kosmetischer-genitaloperationen](http://www.gender.hu-berlin.de/de/publikationen/gender-bulletins/texte-42/kloepfel-2016_zur-aktualitaet-kosmetischer-genitaloperationen). The numbers include



| DIAGNOSIS  | ASSIGNED SEX <sup>13</sup> | NUMBER |
|--|----------------------------|--------|
| ADRENOGENITAL DISORDERS INCLUDING CAH <sup>14</sup>  | Female                     | 82     |
|  | Male                       | 44     |
| OTHER CONGENITAL <sup>15</sup> MALFORMATION OF FEMALE GENITALIA <sup>16</sup>  | Female                     | 142    |
| UNDESCENDED TESTICLE, <sup>17</sup> HYPOSPADIAS, <sup>18</sup> AND OTHER CONGENITAL MALFORMATIONS OF MALE GENITAL ORGANS <sup>19</sup> | Male                       | 4,188  |
| OTHER INTERSEX DIAGNOSES <sup>20</sup>   | Female                     | 18     |
|  | Male                       | 26     |

The same study found that for the period 2005-2014, the relative frequency<sup>21</sup> of adrenogenital disorders and of 'other intersex' diagnoses decreased, while the number of diagnoses falling into the category of 'congenital malformations' increased.<sup>22</sup>

The German Inter-ministerial Working Group (IMAG)<sup>23</sup> on the Situation of Intersex and Trans Persons estimates that – depending on the definition used – there are between 8,000 and 120,000 intersex people in Germany.<sup>24</sup>

## 3.2 A BRIEF HISTORY OF MEDICAL INTERVENTIONS

Surgical and hormonal interventions on people with variations in sex characteristics were not common practice before the middle of the 20<sup>th</sup> century.<sup>25</sup> The 'management'<sup>26</sup> of infants and children with variations in sex characteristics through surgical and other medical interventions became more common in the 1950s as a result of what was at the time considered the ground-breaking work of John Money and theories of

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here and thereafter all cases of hospital admission with residency in Germany (a patient might be treated several times in the same year and every new admission (or to be more exact: treatment cycle) is counted as a case).

13 The German DRG statistics from which the data was obtained do not list any surgeries for children under 10 who were not assigned male or female. Therefore, these cases were not included in the analysis.

14 ICD-10 E25 diagnoses: E25.0 Congenital adrenogenital disorders associated with enzyme deficiency (including congenital adrenal hyperplasia, 21-Hydroxylase deficiency, Salt-losing congenital adrenal hyperplasia); E25.8 Other adrenogenital disorders; E25.9 Adrenogenital disorder, unspecified

15 Present from birth

16 ICD-10 Q52 diagnoses including: Q52.0 Congenital absence of vagina; Q52.4 Other congenital malformations of vagina; Q52.5 Fusion of labia; Q52.6 Congenital malformation of clitoris; Q52.7 Other congenital malformations of vulva; Q52.8 Other specified congenital malformations of female genitalia; Q52.9 Congenital malformation of female genitalia, unspecified

17 ICD-10 Q53 diagnosis

18 ICD-10 Q54 diagnosis. Included here are only the more severe forms of hypospadias: Q54.1 Hypospadias, penile; Q54.2 Hypospadias, penoscrotal; Q54.3 Hypospadias, perineal

19 ICD-10 Q55 diagnosis. Included here are the following subcategories: Q55.0; Q55.1; Q55.2; Q55.6; Q55.8; Q55.9

20 The definition of 'Intersex' used in these data is narrower than that used by intersex activists. This subcategory includes: E29.1 Testicular hypofunction (including 5-Alpha-reductase deficiency (with male pseudohermaphroditism)); E34.5 Androgen resistance syndrome; Q56 Indeterminate sex and pseudohermaphroditism; Q97 Other sex chromosome abnormalities, female phenotype, not elsewhere classified; Q99 Other chromosome abnormalities, not elsewhere classified (included are only the subcategories Q99.0 Chimera 46,XX/46,XY; Q99.1 46,XX true hermaphrodite (including 46,XX with streak gonads; 46,XY with streak gonads; Pure gonadal dysgenesis))

21 The total number of specific diagnoses analysed in relation to the number of inpatient hospital admissions

22 Klöppel, 2016

23 For more information on the IMAG, see section 6.2.4 of this report.

24 IMAG, "The situation of transgender and intersex persons in focus" ('Situation von trans- und intersexuellen Menschen im Fokus'), German Family Ministry, (hereinafter: IMAG, "The situation of transgender and intersex persons in focus", 2016)

available from <https://www.bmfsfj.de/blob/112092/46d6be33eb8f2b5d2ee81488da03029c/situation-von-tans--und-intersexuellen-menschen-im-fokus-data.pdf>, p.8

25 Georgiann Davis, *Contesting Intersex, the Dubious Diagnosis*, 2015, (hereinafter: Davis, 2015), p. 58

26 'Management' of variations of sex characteristics is placed under quotation to denote the use of medical terminology as prescribed by the medical profession through the Consensus Statement and in practice. Some individuals consider the term 'management' to be stigmatising as it implies that healthy persons with variations of sex characteristics are diseased and their 'condition' needs to be managed.

gender binary behaviour.<sup>27</sup> The concept that sex, once assigned, can be conditioned and adapted in a child through gender norms and social upbringing influenced medical approaches towards the ‘management’ of variations in sex characteristics.<sup>28</sup>

Under this model, children with atypical external or internal sex characteristics could be assigned a ‘sex or gender of rearing’ in early childhood through surgical means, ideally before the age of two or three, and raised to eventually adapt into identifying or complying as that gender.<sup>29</sup>

John Money’s clinical and surgical management of variations of sex characteristics in children, as well as his influence among the medical establishment regarding perceptions of sex, sexuality and gender, remained largely uncontested for decades.<sup>30</sup> Anne Fausto-Sterling describes how John Money and his colleagues’ approach was founded on the belief that an intersex person’s physical make-up was a product of abnormal processes and that “they ought to have become either a male or a female” and were, therefore, in need of medical treatment.<sup>31</sup>

**“Intersex persons were labelled as for example ‘female pseudo-hermaphrodite’ if they only had ovarian tissue, ‘male pseudo-hermaphrodite’ if they only had testicular tissue, ‘true hermaphrodite’ if they had both ovary-like tissue and testicular-like tissue, and ‘gonadal dysgenesis’<sup>32</sup> if they had no such tissue. This was some kind of magical thinking – only ‘true hermaphrodites’ are real and the rest were ‘failed males’ or ‘failed females’. This language was very damaging for individuals and for parents. If a person didn’t look like they ‘should’, physicians and surgeons had to intervene.”**

M\*, physician working in Germany, reflecting on historical practices and terminology<sup>33</sup>

While John Money’s theories are no longer widely accepted,<sup>34</sup> echoes can still be found within the medical establishment today.<sup>35</sup> For example, in Denmark, there are no official national medical guidelines covering variations in sex characteristics. However, the Aarhus University Hospital guidelines state that: “Concerning gender, it is not advised to name the child by any gender before it is established which endocrinological and reconstructive opportunities would yield the best results.”<sup>36</sup>

In 2005, international and regional medical societies<sup>37</sup> comprising experts in different specialties (endocrinology, paediatrics, urology and surgery) and activists came together to develop what eventually became the Consensus Statement on Management of Intersex Disorders (Consensus Statement) of 2006.<sup>38</sup>

This document established the term Disorders of Sex Development (DSD) and was welcomed by some doctors as an advance in the medical management of people with variation in sexual characteristics.<sup>39</sup> However, it has also been heavily criticized by activists for perpetuating the medicalization of variations of sex characteristics and compounding the stigma intersex people face by characterizing their bodily traits as disorders.

The Consensus Statement had a major impact on the formulation of today’s policies on the treatment of children and adults with variations in sex characteristics. It promotes peer support and calls for parents to be given full information as well as, most importantly, endorsing a cautious approach to genital cosmetic surgery. It also recognizes both the lack of clinical research and the health problems that may result from genital surgery. Nevertheless, it still prescribes detailed evaluation and diagnostic measures to assess variations and recommends genital surgery for infants in cases of ‘severe virilisation’ (where the child will be raised female but the genitalia appears very masculine) as well as gonadectomies for some children, citing the risk of cancer in later life. It also introduced the terminology ‘Disorders of Sex Development’ (DSD) which many find stigmatising.

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27 Davis 2015, p. 60

28 Davis 2015, Chapt. 3

29 Fausto-Sterling, 2000

30 Katrina Karkazis, *Fixing Sex*, 2008, Chapter 8

31 Fausto-Sterling, 2000

32 Abnormal development of the gonad(s) during embryonic growth and development

33 Interview, Berlin, September 2016

34 Davis 2015, p.61-63

35 Interviews with medical professionals in Denmark, (Germany) and the UK

36 Aarhus University Hospital guidelines on Disorders of Sex Development, currently under review

37 Specifically the European Society for Paediatric Endocrinology and the Lawson-Wilkins Endocrine Society

38 Lee et al, ‘Consensus Statement on Management of Intersex Disorders’, 2006, *Pediatrics* Aug 2006, 118 (2) e488-e500; (hereinafter: Consensus Statement, 2006)

39 Davis 2015, p. 46

An update to the Consensus Statement, published in 2016,<sup>40</sup> placed a greater focus on individual approaches to each case and on “open and on-going communications with patients and parents,” and noted that “timing, choice of the individual and irreversibility of surgical procedures are sources of concerns. There is no evidence regarding the impact of surgically treated or non-treated DSDs during childhood for the individual, the parents, society or the risk of stigmatization.”

### 3.3 OVERCOMING STIGMA AND INVISIBILITY

**“ There were just seven or eight of us. We were so glad to find each other – we spoke and laughed and cried. There was so much need for exchange. There had been so much suffering and sadness and hardship.”**

Elisabeth, a participant in the first meeting in Germany of individuals with variations of sex characteristics, held in Hamburg in 1997<sup>41</sup>

In the 1990s, an increasing number of people with variations of sex characteristics who had undergone extensive surgical and other medical interventions beginning in childhood began to speak out about their experiences. Many of these people highlighted their opposition to the ‘normalizing’ medical treatment they had undergone and promoted the use of the term ‘intersex’ as part of their campaign for recognition.

Since then, organizations, activist groups, individual human rights defenders and patient and parent support groups have worked hard to bring visibility to the fact that people with variations of sex characteristics exist, and to the non-emergency, invasive and irreversible medical procedures to which they are often subjected. They have begun to claim their place in decision-making and in shaping policies around the treatment of individuals with variations of sex characteristics. Some have focused on developing communication with the medical establishment; others campaign at the level of international and regional human rights institutions.

In 2013, intersex human rights defenders from 30 countries around the world attended the third International Intersex Forum in Malta. The Forum resulted in the Malta Declaration.<sup>42</sup> This reiterated the principles set out in two previous Intersex Forums and highlighted the demands and recommendations of the international intersex movement. These include an end to “mutilating’ and ‘normalizing’ practices such as genital surgeries, psychological and other medical treatments through legislative and other means;” the depathologization of “variations in sex characteristics in medical guidelines, protocols and classifications, such as the World Health Organization’s International Classification of Diseases;” and the “recognition that medicalization and stigmatization of intersex people result in significant trauma and mental health concerns.”

The advocacy and awareness-raising work by intersex-led organizations has led to intersex rights issues being incorporated in a declaration by 12 UN agencies calling on states to end violence and discrimination against lesbian, gay, bisexual, transgender and intersex people and highlighting the practice of “unnecessary surgery and treatment on intersex children without their consent.”<sup>43</sup>

Parent and patient support groups continue to provide peer support and information and in many cases self-organize according to specific types of variation of sex characteristics. In many European countries these constitute an important source of peer support for people with variations in sex characteristics of all ages and their parents. They have also established relationships with multidisciplinary teams in hospitals.

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40 Global Disorders of Sex Development, Update since 2016: Perceptions, Approach and Care, Hormone Research in Paediatrics 2016;85: 158-180 (hereinafter: Consensus Statement Update, 2016)

41 Interview, Hamburg, September 2016

42 See Appendix for full text of Malta Declaration.

43 ‘United Nations entities call on States to act urgently to end violence and discrimination against lesbian, gay, bisexual, transgender and intersex (LGBTI)1 adults, adolescents and children,’ September 2015, available from: [http://www.ohchr.org/Documents/Issues/Discrimination/Joint\\_LGBTI\\_Statement\\_ENG.PDF](http://www.ohchr.org/Documents/Issues/Discrimination/Joint_LGBTI_Statement_ENG.PDF)

**“The problem with intersexuality is that it is still considered taboo and when you have this taboo it’s difficult to go out and join a self-help group. I have a huge mailing list – about 120 families – but there are people who have never come to a meeting, others who took eight years to come to a first meeting.”**

Gerda Janssen-Schmidchen, coordinator of XY-Frauen and Intersexuelle Menschen parents’ groups<sup>44</sup>,

Parent and patient support groups and intersex-led rights organizations and groups work tirelessly to increase the standard of care for people with variations in sex characteristics. These groups hold a range of opinions about the merits of non-emergency, invasive and irreversible surgery on infants and children. For example, the Androgenital Syndrome (AGS) Association in Denmark strongly believes that surgeries on children with AGS should take place as early as possible, primarily to avoid future psychological damage to children and bullying in school.<sup>45</sup> Other organizations, including human rights-focused organisations, have campaigned against non-emergency, invasive and irreversible interventions on individuals with variations of sex characteristics. For example Intersex Danmark, an intersex-led group in Denmark, have been campaigning for an end to medically unnecessary **treatment on intersex people** and a general improvement in the healthcare treatment of intersex people. They argue that intersex people are still largely unrepresented in public life, in the media and on the agenda of health authorities.<sup>46</sup>

Despite the efforts of such groups, there is little public awareness of the rights of people with variations of sex characteristics. According to Danish psychologist Karina Lins, this lack of visibility is due to stigma and an unwillingness amongst intersex people to speak publicly about their experiences: “because from day one, from day zero, from the day they are born they are told ‘you are wrong and we need to fix you’. That can have catastrophic psychological consequences.”<sup>47</sup>

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44 Interview, Emden, November 2016

45 Interview with Pernille Nygaard-Nissen, Chairperson of AGS Association, and private written communication with members.

46 Interview with Stephanie Stine Toft and Inge Toft, September 2016

47 Interview, September 2016

# 4. MEDICAL POLICIES AND PRACTICES



## CAMILLA, MIDWIFE IN DENMARK

Camilla Tved is a midwife and a Health Adviser to the Enhedslisten political party (The Red-Green Alliance) in Denmark. She recalled a case she worked on in 2008 as a student midwife.<sup>48</sup>

“The child had what was called an enlarged clitoris, comparable to a small penis, and since I had never come across a case like this and the midwife attending the birth with me never had a case like this before either, we had to look for instructions on what to do.”

One of the instructions Camilla came across was a scale to measure the child’s genitals.

“It was about the clitoris being I think more than 0.9cm, and then [it would be considered] a micro penis. I heard during a seminar recently that this scale still exists, it’s still used, and a penis on a small baby boy can be no smaller than 2.5 cm.<sup>49</sup> I found that so disturbing that you could just put a ruler and say ‘this child has a disorder’ so that kind of aroused my curiosity.

“The parents were informed that the child was not a boy and not a girl and that they were ‘something in between’ – those was the words chosen – and that they recommended further examinations, but they were told immediately when the paediatrician was speaking with them a few hours after the birth... that they recommended a surgery within the first month.

“The parents were extremely shocked, and disturbed, and worried first that there was something else wrong with the child, the possibility of the child having a syndrome or something else. As they put it they said ‘or something else that would have to be examined’ and that they recommended [should be] fixed.

“I asked the paediatrician a few weeks after when I got the chance and was told that the baby was scheduled for surgery two months later. And for a reduction of the clitoris.

“I think in general in the health system really emphasized a lot that you would want a child in any way possible to look like the other children, somehow.”

The 2006 Consensus Statement and the 2016 Consensus Statement Update<sup>50</sup> have played an important role in shaping current medical policies and practices on the treatment of children, adolescents and adults with variations in sex characteristics. They have been accepted by the majority of the medical community in Europe as the standard for the definition, assessment and management of types of variations of sex characteristics.

The Consensus Statement, aimed to provide a standard and an alternative to previous policies and treatment practices, which had been severely criticized particularly with regard to the lack of focus on patient

48 Interview, June 2016

49 Penile length of <2.5cm in a newborn is considered a micropenis. See Hatipoğlu, and Kurtoğlu. ‘Micropenis: Etiology, Diagnosis and Treatment Approaches.’ *Journal of Clinical Research in Pediatric Endocrinology* 5.4 (2013): 217–223, Table 1.

50 Consensus Statement Update, 2016

care. It set out recommendations for detailed clinical evaluations by an experienced multidisciplinary team in charge of long-term treatment and placed an emphasis on open communication with and providing full information to parents. The Consensus Statement has served as a guide for many national health authorities, which have modelled their national guidelines on it.<sup>51</sup> However, this has not been the case in Denmark or Germany.

In Denmark, the Danish Health Authority, the government body responsible for the development of medical and health guidelines, has not drafted national guidelines on the care of intersex people. Instead, specific variations in sex characteristics are incorporated in different national guidelines and each hospital in Denmark is responsible for developing its own guidelines.<sup>52</sup>

In Germany, there are no binding guidelines for the treatment of intersex children, nor any automatic immediate referral to specialists of children born with variations in sex characteristics.<sup>53</sup> The German Ethics Committee<sup>54</sup> recommended in 2012 that diagnoses and treatment take place in specialist centres and some individual hospitals have formed multidisciplinary teams in line with the Consensus Statement recommendations.<sup>55</sup>

In late 2016, the European Commission approved the creation of the European Reference Network for Rare Endocrine Conditions (ENDO-ERN), which includes some conditions resulting in variations of sex development. ENDO-ERN's stated aim is to "provide the best possible care for every patient with a rare endocrine condition" through 71 specialist healthcare providers in 19 European countries (including two in Denmark and 11 in Germany). ENDO-ERN's workplan includes education and training for healthcare professionals and its activities will begin in 2017.<sup>56</sup>

## 4.1 CONSENSUS STATEMENT TERMINOLOGY

The Consensus Statement rejected the term intersex, a term embraced by some people with variances in sex characteristics, as well as some activists and civil society, in favour of Disorders of Sex Development (DSD), a term many view as stigmatising. In so doing, the Consensus Statement defined variations of sex characteristics as disorders, malformations and anomalies in need of diagnosis and treatment. The variations classified as 'DSDs' are classified under three primary groups referred to as 'sex chromosomal' '46,XX' and '46,XY.'

XX sex chromosomes are attributed to females, while XY sex chromosomes are attributed to males. The groups of '46,XX' and '46,XY DSDs'<sup>57</sup> include variations linked to either the development of gonadal tissue or the levels and action of hormones, particularly androgen. In 46,XX cases, individuals have XX sex chromosomes and a variation in ovarian development or increased androgen, and in 46,XY DSDs the variation is linked to the response to androgen or testicular development, while the individuals have XY sex chromosomes. Individuals with 'sex chromosomal DSDs' have sex chromosomes other than XX and XY.<sup>58</sup>

There is disagreement among medical professionals, civil society and academics as to whether other variations of sex characteristics not covered by the categories listed above (i.e. without chromosomal, hormonal or gonadal variations), such as some case of hypospadias, are in fact incorporated within this DSD classification. The 2006 Consensus Statement does not recognize hypospadias as part of the DSD classification, nor do many physicians and members of multidisciplinary teams. Nevertheless, identification of hypospadias in newborns can serve as an indication of the presence of a DSD, prompting physicians to investigate further.<sup>59</sup> Estimates suggest that infants born with hypospadias form a large group of individuals with variations in sex characteristics.<sup>60</sup>

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51 For example, the 'UK Society for Endocrinology guidance on the initial evaluation of an infant or an adolescent with a suspected disorder of sex development (Revised 2015)', reflects policies and guidelines from the Consensus Statement.

52 See section 6.1.3 of this report

53 Interview with an endocrinologist and a psychologist in a German multidisciplinary team, November 2016

54 An independent council of experts tasked with analysing and communicating questions of ethics, society, science, medicine and law, in particular in relation to the life sciences.

55 See section 6.2.4 of this report

56 'Building the European Reference Network for Rare Endocrine Conditions (Endo-ERN)', December 2016, [http://www.firendo.fr/fileadmin/user\\_upload/JAF2016/FIRENDO\\_Journee\\_Annuelle\\_2016\\_Alberto\\_Pereira\\_Building\\_EndoERN.pdf](http://www.firendo.fr/fileadmin/user_upload/JAF2016/FIRENDO_Journee_Annuelle_2016_Alberto_Pereira_Building_EndoERN.pdf)

57 The majority of people have 46 chromosomes including two sex chromosomes

58 Examples include X or XXY. Individuals with these conditions do not have 46 chromosomes.

59 Wittenhagen, 'The Hypospadias Guidelines by the Odense University Hospital'

60 According to the Consensus Statement Update 2016, 1 in 300 to 500 infants are born with either mild or severe hypospadias. The Aarhus University Hospital Multidisciplinary Team in Denmark told Amnesty that they have approximately 150 cases of children with hypospadias each year in their hospital alone and around 20 to 30 children with proximal hypospadias.

Classification of variations in sex characteristics varies from country to country. In addition to the classification standard for some conditions proposed by the Consensus Statement, the World Health Organization's International Classification of Diseases (ICD-10)<sup>61</sup> uses different terminology. For example, some variations in sex characteristics are grouped under the classification of 'Congenital malformations, deformations and chromosomal abnormalities',<sup>62</sup> a categorization which risks further pathologizing intersex bodies.

## 4.2 MEDICAL INTERVENTIONS

### 4.2.1 IDENTIFICATION IN INFANCY

In Denmark, when a child is born, the nurse or midwife notifies a paediatrician of any perceived "ambiguity" in the genitals. This triggers a process of consultation with the DSD multidisciplinary team. In Germany, in contrast, there is no automatic referral to a specialist team.<sup>63</sup>

In 2012, the German Ethics Committee issued the following recommendation: "Medical and psychological counselling for those affected with DSD and their parents, as well as the diagnosis and treatment of people with DSD, should be provided only at specialized interdisciplinary centres of competence and given by medical practitioners and experts in all the relevant fields."<sup>64</sup> This recommendation was echoed in a statement by the German Medical Association,<sup>65</sup> but there is as yet no official requirement to implement it.<sup>66</sup> Nonetheless, some hospitals in Germany have established multi-disciplinary teams for the treatment of individuals with variations in sex characteristics.



**ANNA,\* MOTHER OF NINA\*<sup>67</sup>**  
**GERMANY**

Nina\* is 11 and has complete androgen insensitivity syndrome (CAIS).<sup>68</sup> Her mother Anna\* explained how a supportive medical environment helped her: "Before my daughter was born I had an examination due to my age. I was told a boy would be born. But then there wasn't a boy. At first I thought: Science got it wrong. In hindsight I think: the medical staff had an idea straight away of what was behind this. They treated us very sensitively. I felt well looked after. For the first two days I had a defensive attitude towards my daughter. But the medical staff supported me, our situation was treated confidentially. I was given a recommendation and a contact in the university hospital, appointments were arranged for us. We did not need to take care of that.

In the university hospital we felt well looked after and advised. We were told what needed to be done: a [process of] diagnosis, to see how this was caused. [The doctor] explained the medical background to us. I would not have been able to take in much more than that in the first few months. We started doing our own research. We had a medical student in the family who quickly found some studies. The risk of malignancies was always mentioned [in the studies], but those giving us advice held back on this issue. This is different from what I heard from other parents."

She compared her treatment by other medical professionals. "My gynaecologist treated this [situation] as a threat. Meanwhile I knew: this isn't quite how it is. This had a lasting negative impact on my trust in her. That was not a relationship on equal terms."

61 Available online at: <http://apps.who.int/classifications/icd10/browse/2016/en/>

62 Denoted as Q category in ICD-10

63 Interviews with a German multidisciplinary team, November 2016

64 Deutscher Ethikrat, 'Intersexuality', 2013, p.163

65 Opinion of the German Medical Association: 'Care of children, adolescents and adults with variations/disorders of sex development' (Stellungnahme der Bundesärztekammer „Versorgung von Kindern, Jugendlichen und Erwachsenen mit Varianten/Störungen der Geschlechtsentwicklung (Disorders of Sex Development, DSD)“), 2015, pg. 10

66 Interviews with a German multidisciplinary team, November 2016

67 Interview, January 2017

68 See Section 2.1

The 2016 Consensus Statement Update highlights that the criteria for requiring that a newborn or infant be investigated for a DSD is “when the external genitals are sufficiently ambiguous to hamper sex assignment or inconsistent with the result of prenatal tests”.<sup>69</sup> It states that the length and diameter of the phallus constitute assessment criteria upon which infants and children are evaluated.<sup>70</sup> Medical professionals from Arhus University Hospital explained to Amnesty International that a common measurement used to assess DSD is the Prader scale.<sup>71</sup> This is a seven-point scale where zero represents what is considered “normal” female genitalia (vaginal opening, labia, clitoris) and six represents “normal” male genitalia (penis, scrotum, testicles). The points in between indicate variations of external sex characteristics.

Additional tests to establish a diagnosis for DSD are explicitly set out in the Consensus Statement and involve chromosomal testing, ultrasound to examine internal organs and other blood tests.<sup>72</sup> More invasive ways to examine the internal organs of the infant with a suspected DSD may in some situations include MR scanning in general anaesthesia or laparoscopy, a procedure whereby the surgeon examines the internal organs of a patient through small incisions, as well as gonadal biopsy to rule out cancer or precursors of cancer.<sup>73</sup>

Medical professionals that Amnesty International spoke to in Rigshospitalet confirmed the series of tests that take place, including ultrasound, blood tests and chromosomal testing, “to determine the sex, and the underlying reason for DSD. We cannot start guessing what the sex of the child without looking at the physical appearance of the external genitals, sex chromosomes, genes, hormone receptors, and the internal organs.”<sup>74</sup> Arhus University Hospital guidelines state: “After 10-12 days the gender of the child *should* be determined...[But] it can take up to three months in order to determine the phenotypic gender, which is why it is not advisable to give the parents a time scale for the final decision of gender.”<sup>75</sup>



#### **PARENTS OF JOHANNES\*<sup>76</sup>** **BERLIN, GERMANY**

Johannes\* was born 90 days premature in 2013. His father told Amnesty International: “During a diagnostic test at 23 weeks of gestation he was introduced to us as a girl. He was born 90 days early. He had multiple genital malformations which were diagnosed at birth. He had split testes. His penis was extra bent. His urethra was short. His urine flowed away through the testes. At birth [it was difficult] to recognise his genitals as a penis.

“He spent 90 days in an incubator, underwent diverse operations. He is healthy now. During his first year, the focus was on his breathing. He had four operations. Early on he suffered a hernia which required him to be operated on. After the follow-up operation we were told his genitals were not OK, that an operation was needed. This was about the functionality and about the appearance.

“After Johannes’s birth, at the beginning we did not talk to the doctors or other people about the genital malformations as we did not know if he would survive. Finally a chromosomal test was done during the twenty-first week [after birth]. We were told this was “to exclude the possibility that he had female chromosomes.” He also had an ultrasound examination of his internal organs. Were we able to take this in at that point? No, not at all. We also did not receive any support, no information. We were told we should not name him until after the chromosome test. We were coping with so many impressions at once. One would have needed someone to explain everything. It was clear visually that something was not right, even though he only weighed 840g.”

Even with the array of tests and examinations recommended by the Consensus Statement, specific diagnoses are often not possible or inconclusive. A molecular geneticist in Germany told Amnesty International: “It is often not possible to diagnose a DSD. Maybe you know it’s an [46,XY DSD<sup>77</sup>], but without the [specific] diagnosis you don’t know if the virilisation [masculinisation] will happen in puberty. Then the

69 Consensus Statement Update, 2016

70 Consensus Statement Update, 2016

71 Otherwise known as Prader Staging, named after Dr Andrea Prader.

72 Consensus Statement Update, 2016

73 Interview with Rigshospitalet medical professionals, September 2016, and email, April 2017

74 Interview, April 2016, and email, April 2017

75 Arhus University Hospital guidelines on Disorders of Sex Development

76 Interview, January 2017

77 See Section 4.1



problem is what the child wants. This decision has to be made just before puberty – sometimes the doctors have to decide to delay puberty using drugs. Prediction is very difficult. We had one boy, whose testes had descended, who had hypospadias.<sup>78</sup> He got hypospadias repair and grew up as a boy. Later his older sister came in with [absence of menstruation] at 12. She was found to [hav XY chromosomes]. They had the same mutation – but two completely different phenotypes.<sup>79</sup>”

## 4.2.2 IDENTIFICATION LATER IN LIFE

Due to the wide spectrum of variations in sex characteristics, they can remain undiagnosed or be diagnosed at a late stage in someone's life.

**“I was diagnosed when I was 21 so that’s really late... I think it’s very good to be diagnosed [with Turner syndrome] early so you can check [for potential problems].”**

Sofie\* from the Turner Association in Denmark<sup>80</sup>

**“One might think it’s better to detect [variations of sex characteristics] as early as possible, even if just for the statistics, but there are good reasons not to, because of what the medical profession has done [to individuals].”**

M\*, a physician in Germany<sup>81</sup>

Diagnosis is above all a complex process, at whatever age it is undertaken. Stefanie from German support group XY-Frauen (XY-Women), told Amnesty International that some 30-35 people a year approach the organization to ask how they can get a diagnosis: “They ask, could I be intersex? I advise them to go to a specialist doctor (endocrinologist, andrologist/gynaecologist) and convince them to give a hormone test, then a chromosome test, and then if necessary a molecular genetic analysis. This takes a long time and does not always lead to a conclusion, additionally it is very expensive. I had an analysis 11 years ago and I still don’t have a diagnosis.”<sup>82</sup>

## 4.2.3 SEX ASSIGNMENT

**“If we talk about sex, then we have to define the terminology. We have so many different sexes in Germany: external anatomical sex, internal anatomical sex, gonadal sex, chromosomal sex, hormonal sex, legal sex, the sex assigned by the midwife, and self-perception.”**

Lucie Veith, head of Intersexuelle Menschen, Germany<sup>83</sup>

Both the Consensus Statement and the 2016 Update<sup>84</sup> provide recommendations on sex assignment for infants born with variations in sex characteristics. The principle of establishing the sex or gender of rearing is part of evaluating an infant or child with variation in sex characteristics, particularly when the child is born with external genital features to which physicians and midwives are not able to assign a gender. However, the reliance on chromosomes, internal and external sex characteristics and assumptions of future gender identity can be problematic.

**“It’s vital that we start to realize that gender identity doesn’t necessarily fit the surgeon’s incisions.”**

Karina Lins, psychologist, Denmark<sup>85</sup>

For example, the 2016 Consensus Statement Update recommends that infants or children with one specific variation, 5-alpha-reductase-deficiency,<sup>86</sup> should be assigned male “since 60% later identify themselves as

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78 See Section 2.1

79 Physical characteristics of an individual, resulting in part from genetic identity

80 Interview, June 2016. Turner syndrome is associated with heart and kidney complications which require monitoring.

81 Interview, Berlin, September 2016

82 Interview, Berlin, September 2016

83 Interview, Hamburg, September 2016

84 Consensus Statement Update 2016

85 Interview, September 2016

86 Classified in ICD-10 as E29.1. Individuals with this variation have XY chromosomes and a shortage of a hormone that virilises the genitalia in utero; infants may be born with genitalia that appear female or ambiguous while secondary male sex characteristics may develop at puberty

male.”<sup>87</sup> in other words, it recommends a sex assignment in this case that is only successful three times out of five.

Karina Lins, a psychologist working with non-binary children in Denmark, told Amnesty International, “Research since the 1970’s has consistently shown that gender isn’t purely a sociological phenomenon, it also has psychological, biological and cultural influences. It’s very complex; we don’t know how gender identity comes about. We don’t know what for example makes somebody a cis or trans person so there are a lot of unanswered questions. The medical establishment really tries to make people fit in as well as they can because they hope that these people will go on to live ‘normal’ lives. It’s a misunderstood kind of care. Instead of trying to make intersex people fit into the two boxes of either male or female, we need to change our terminology, which requires a paradigm shift, because there needs to be room for variation, rather than just this binary view of people.”<sup>88</sup>

This binary approach to assigning sex results in assumptions about gender identity and physical characteristics, which are not always correct. For example, one doctor in the UK told Amnesty International that children born with hypospadias are routinely assigned male by doctors: “They are boys, no doubt about that.”<sup>89</sup> However, members of a multidisciplinary team in Denmark described a case in which a child with severe hypospadias was undergoing surgery for functional reasons and during the operation it “transpired that there was something that wasn’t as it should be...we [confirmed] that the boy had an ovary on one side.”<sup>90</sup>

Claus Gravholt, an endocrinologist<sup>91</sup> at Arhus University Hospital, highlighted the lack of follow-up and knowledge about the outcome of assignment on individuals: “The problem is that we always [are the] end caretakers of the patient. So how is it going, how are these children developing into adults and do they feel they fit with the sex that they were assigned to? ... They might be reared as a female and when they grow up they feel like a male or vice versa. And we lack this kind of data internationally, although such data is slowly being accumulated thanks to international collaboration.”<sup>92</sup>

Delays in assigning a sex can also be difficult for the parents of the child. A psychologist in a multidisciplinary team in a German hospital told Amnesty International, “Although only [a few] children don’t fit pink or blue, for those families, there is a lot of anxiety. Being in limbo for a week or so is terrifying for the parents.”<sup>93</sup>

## 4.2.4 TO ACT OR NOT

Following diagnosis and sex assignment, physicians will present options for the parents of children with variations of sex characteristics. In some cases – for example, if the child has a urogenital sinus<sup>94</sup> - there is a clear medical necessity for surgery. Yet many other forms of medical intervention do not have the same level of urgency.

Physicians working with individuals with variations in sex characteristics acknowledge that there should not be a blanket one-size-fits-all policy for the management of DSD. Katharina Main, clinical professor in paediatrics at Rigshospitalet in Copenhagen, has stated that a case-by-case approach to treatment is necessary to provide the best medical options for patients. “A current proposal in the EU is that operations on small children’s genitals should be forbidden. This point of view is not the way forward in my opinion. I do not like the bold pronouncements like you are not allowed to do this or that and that one solution fits all. I simply don’t believe in that – and this is not seen anywhere else in the medical world, where one increasingly strives towards individualized treatment.”<sup>95</sup>

**“We discussed with other parents, and we decided to do it [genital surgery]. We thought it was more important to look normal when she started at school; that it is important for her to have an identity as a girl. My girl is quite normal”.**

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87 Consensus Statement Update, 2016

88 Interview, September 2016

89 Interview, August 2016

90 Interview with Arhus DSD multidisciplinary team, September 2016

91 Endocrinologists specialize in conditions related to hormones

92 Interview with Claus Gravholt, June 2016

93 Interview, November 2016

94 A condition where urine from the urethra leaks into the vagina, with a high risk of infection

95 Interview published in ‘Interior’, (‘IndenRigs’), the staff magazine for employees of Rigshospitalet in Denmark, in January 2016

Parent member of AGS Association, Denmark<sup>96</sup>

Surgery – despite the fact of irreversibility and the lack of direct consent from the child – is sometimes undertaken in part with the assumption beneficial effect on their socialization and acceptance by other children and society. Dr Dorte Hansen, a paediatric endocrinologist at Odense University Hospital in Denmark, told Amnesty International that parents worry: “how it would be to go to school with a very large clitoris, to have to go to the baths with the other school kids looking? That might affect how these children develop, and their identity.”<sup>97</sup> Medical professionals in Rigshospitalet in Denmark referenced the assumptions underlying decisions to operate in cases of mild hypospadias so that the boy can conform to expectations and “pee standing up.”<sup>98</sup>

In Denmark, the Department for Growth and Reproduction at the University Hospital of Copenhagen (Rigshospitalet) is one of the leading centres for the treatment and long-term follow-up of patients with variations in sex characteristics.<sup>99</sup> The hospital carried out a long-term impact study on patients diagnosed with CAH between 1953 and 2003, and a follow-up study, of 33 women with CAH on genital satisfaction, compared to a control group of women without variation in sex characteristics.<sup>100</sup> Twenty-seven of the 33 women had undergone operations in childhood or adolescence. This study found that with women with CAH who had undergone genital surgery at a young age exhibited limited genital satisfaction with regards to both appearance and function, compared to the control group. It leaves unanswered the question of the relative benefits of early surgery compared to the experience of women with CAH who had not undergone surgery.

While physicians may justify surgery on the grounds of avoiding psychological damage, some research on the quality of life of people with variations in sex characteristics that have undergone such surgery shows dissatisfaction with both appearance and function.<sup>101</sup> Anjo, a German activist, told Amnesty International: “The doctors thought they were doing something good so we would fit better with society – they didn’t realize that it’s worse with damaged bodies.”<sup>102</sup>



### **PARENTS OF JOHANNES\*<sup>103</sup>** **BERLIN, GERMANY**

Johannes\* was born in 2013 and operated on for hypospadias in 2014 and 2015. His father told Amnesty International: “We started to do research, my wife read clinical PhD theses. Hypospadias – this was not a term we knew. [We went not to the first hospital we spoke to but to a specialist who] explained what he would do and it sounded plausible. He was the first to explain to us that Johannes also has pendulous testes. He proposed a course of four operations.”

Johannes’s mother told Amnesty International, “I am glad we had the time to do some research. One physician said he would do one six-hour operation. We thought this could not be right. One physician wanted to treat the micropenis hormonally. Many patients had complaints after the operations, like fistula.<sup>104</sup> At [the first hospital] there were no visual materials regarding the operation methods, no information about which physician was going to be the one doing the operation. After the operation potentially another physician would do the after-care. We wanted comprehensive care. [At the specialist’s clinic] we met parents for the first time who spoke about intersex – this was not an issue before that. After the operations Johannes healed without complications, he is not experiencing pain now.

According to Amnesty International interviews with medical professionals, there are varied views on the optimal outcome of non-emergency, invasive and irreversible genital surgeries on children, although there

96 Interview, Denmark, August 2016

97 Interview, 2016

98 Interviews with Rigshospitalet medical professionals, September 2016

99 It is classified as a centre of research and expertise in Denmark, along with Odense and Arhus University Hospitals.

100 Johannsen et al, ‘Long-term gynaecological outcomes in women with Congenital Adrenal Hyperplasia due to 21- Hydroxylase deficiency,’ August 2010, *International Journal of Pediatric Endocrinology*, Vol.2010, 784297

101 Research in both Germany and Denmark.

102 Interview, Hamburg, September 2016

103 Interview, January 2017

104 An abnormal tunnel or connection between two hollow parts of the body, caused by injury, surgery or infection

appears to be a consensus that definitions of the ‘optimal outcome’ from these surgeries have changed over time

**“Thirty years ago, [the] optimal outcome was for someone to be in a steady heterosexual relationship and to have a child – now this isn’t so important”.**

Paediatric endocrinologist, one of the participants in the Consensus Statement meeting<sup>105</sup>

### **CANCER RISK**

One factor that physicians and experts refer to in assessing treatment options with parents include the potential cancer risks should surgery not take place. However, medical opinion varies as to the necessity of surgery at a young age to prevent cancer. The Consensus Statement Update states that although some DSD patients have a higher risk of developing some types of cancer, this risk varies widely. A 2010 study found that the tumour risk varied widely – from 0.8% to 60% - depending on diagnosis.<sup>106</sup>

Mika Venhola, Assistant Chief of Paediatric Surgery at Oulu University Hospital in Finland, is an expert on children with variations in sex characteristics and an opponent of genital “normalizing” surgeries without the child’s direct consent. He explained to Amnesty International that substantive research is lacking with regards to the risk of cancer posed by the gonads of intersex people.

**“It [used to be] customary to perform gonadectomies...and this resulted in unneeded operations and caused potential harm and problems to patients. Nowadays we should offer counselling to all and gonadectomies to only risk groups when they reach adulthood.”**

Mika Venhola, paediatric surgeon, Finland<sup>107</sup>

The multidisciplinary team at one German hospital told Amnesty International that, “The cancer risk even for the high risk groups is not so high. We can monitor with ultrasound and for tumour markers.”<sup>108</sup>

Ditte Trolle, a gynaecologist at Aarhus University Hospital who has work with children with variations in sex characteristics opposes surgery on infants and children with atypical genitalia and firmly believes parents should wait until the child can give consent: “Alternatives to just removing intraabdominal testis on infants could be a MRI<sup>109</sup> scan. If this is done at an early stage, then one would be able to screen for potential changes/negative developments. In my opinion, that is a method that should be evaluated... There are clear advantages if the testes stays since they create hormones necessary for a normal puberty, normal sexual development and general health. If they are removed, no hormones will be produced which will increase the risk of cardiovascular disease, osteoporosis etc. So, there is a risk if you remove them.”<sup>110</sup>

## **4.2.5 DECISION-MAKING**

For a child too young to consent, the ultimate decision is left to the parents. The majority of the experts and medical professionals interviewed by Amnesty International explained the nature of the information they offer parents in order for them to make an informed decision, particularly with regard to genital surgery.

Intersex individuals and activists, however, have told Amnesty International that the information provided to them and to parents is often not sufficient for them to make an informed decision. Based on the interviews Amnesty conducted, parents often feel that information on the specific surgeries and whether this is emergency treatment is insufficient. According to the Federal Ministry of Family Affairs, Senior Citizens, Women and Youth, it is essential for the parents to receive the necessary information as to which interventions are really necessary, and which could wait.<sup>111</sup>

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105 Interview, August 2016

106 Pleskacova et al, ‘Tumor Risk in Disorders of Sex Development’, 2010, *Sexual Development*, available from: <http://www.aissg.org/PDFs/Pleskacova-et-al-Tumour-Risk-2010.pdf>

107 Interview, January 2017 and email, April 2017

108 Interview, January 2017

109 Magnetic resonance imaging, a type of scan that uses magnetic fields and radio waves to produce detailed images of the internal organs of the body.

110 Interview and subsequent follow up, April 2017

111 Interview, 2016, and email, April 2017

The shock of discovering that their child has a variation in sex characteristics, and the complexity of medical terminology used around these issues, add to difficulty in processing the information. Gerda Janssen-Schmidchen, who runs the XY-Frauen and Intersexuelle Menschen parents' groups, told Amnesty International: "More often than not there is lots of terminology. It's useful to have the information but it takes a while to process... In the past doctors used to advise surgery before 18 months. Now it depends on the doctor you see, where you live, whether you have money to travel. And the decision also depends on the educational background of the parents, and on to what extent parents want to commit themselves and learn about the problem and fight".<sup>112</sup>

**"There is a difference between hearing about something and actually learning about it and understanding."**

Gerda Janssen-Schmidchen, who runs the XY-Frauen and Intersexuelle Menschen parents' groups<sup>113</sup>

Intersexuelle Menschen runs a counselling service for the parents of intersex children. Lucie Veith, head of Intersexuelle Menschen, told Amnesty International: "Most of them come when the children are three or four years old and operations have already been done. If the parents come before the surgeries – when the children are six months old – they see [the counsellor] and she [often] gives them a new perspective – the parents are frightened but sometimes they find information on our website and they meet us, they read the stories, [and] decide they don't want the surgeries."<sup>114</sup>

A psychologist practising in Germany, told Amnesty International: "we also need to define what is medically necessary – and we need to define the necessity. I ask doctors to make clear why they recommend interventions. Everything that helps families have more time is important. The devil is in the detail – you have to ask very precise questions about what will happen, how often the child will have to take hormones for example."<sup>115</sup> Gerda Janssen-Schmidchen told Amnesty International: "Very often it is the perspective of the parents that changes over the years. What they learn is that every question you ask and answer you get leads to several more questions. It really takes time until you manage to integrate this into your life and live it your own way."<sup>116</sup>

**"Treatment starts with information management– not just once but as a process. But this is something that is not done in every clinic."**

Psychologist, Germany<sup>117</sup>



### THE FISCHER\* FAMILY<sup>118</sup> COLOGNE, GERMANY

Amnesty International spoke to the Fischer family, who have a child with a variation of sex development.

"We knew as the result of a prenatal test that our child had XY chromosomes. I gave birth [to my daughter] in a municipal hospital. We did not know what variations there were. This has to change: Medical professionals must know about variations.

"During the regular examination two days after the birth, our daughter had a blood sample taken and a chromosome test was done. We then got a phone call: "Yes, it's correct, the chromosomes are XY." We were not given any explanation. The physician who helped me give birth knew nothing. She was as shocked as we were. I expected that she would know and could reassure us but that is not how it was.

Then you're by yourself at home with this news. I searched for information on the internet: What variations exist? What does this mean for our daughter?

"The endocrinologist was the first to finally explain to us: "This has always existed, this isn't anything abnormal, it's not a 'punishment by God', it's nothing terrible." He explained to us that Swyer Syndrome is not a heritable condition but is a consequence of a spontaneous mutation – this was important for us to know as parents.

112 Interview, Emden, November 2016

113 Interview, Emden, November 2016

114 Interview, Hamburg, September 2016

115 Interview, November 2016

116 Interview, Emden, November 2016

117 Interview, November 2016

118 Interview, January 2017

“But on the other hand he conveyed too much detailed knowledge in that conversation about causes etc. As a mother or a father you have a different set of question. You want to know: What will happen now? What will this mean to our child not to know what sex it belongs to? Now these questions are no longer terrible for me because I have met children and adults who say: I am both – people who do not feel an unambiguous gender classification is the main issue in their lives. But back then my question was simply: What will my child’s life be like?”

“When our daughter was examined by a radiologist to determine what sex organs she had inside her body I was so angry. I simply wanted to come to terms with what I was being told. But the doctor had brought students to sit in on the consultation. It was me who had to tell him: I only want people here who need to be here as part of this conversation. Did he treat us as parents sensitively? No!”

“The question was: What do we need to do straight away? Our daughter has no genital anomalies, she has no problems in that regard. I am glad of this because I don’t know what we would have decided to do (if she had had anomalies.) We know people who had their son operated on. Now he has female sex organs but feels he is a boy! We will see how our daughter will develop. She is free to be whoever she wants to be. I feel sorry for the children who do not have unambiguous [i.e. have ambiguous] sex organs where the parents have to decide what to do and where those decisions may put obstacles in the children’s path. We will wait. For the moment, our daughter behaves as a girl even though she can be however she wants to be.

“But the most important thing, for a start, is to have information...[Another endocrinologist] told us: The gonads have to come out, at the latest by the time your daughter reaches the age of ten. Then I found out elsewhere that it is possible that she is able to produce hormones, this remains to be seen. So this advice should not be given to us! It’s the same as with people with CAIS who have their testes removed and have to take hormones. There isn’t a sufficient basis of medical research to give people this advice. This is a tainted viewpoint. We have no proof that our daughter cannot produce hormones. It is important to us that our daughter herself makes the decisions concerning her body. We will wait until we know if she can produce hormones and then we will see.”

However, members of multidisciplinary teams and individual physicians told Amnesty International that ultimately it is the parents’ decision what course of treatment or surgery, if any, should be undergone and that parents often insist on surgery and simply go elsewhere if physicians refuse to perform genital operations.

**“The core issue is that parents want their children to be operated on because they don’t want their children to [have a condition] on the ICD list.”**

Jörg Woweries, retired German paediatrician<sup>119</sup>

Based on Amnesty International’s investigations, decision-making about surgical or other medical interventions for intersex variations is influenced by the type of information and different options provided by physicians to patients and their parents.<sup>120</sup> A factor that may influence the decision-making of the parents is the existing stigma and pathologization of variations in sex characteristics. The importance of psychological support to parents, therefore, not only serves the purpose of their emotional relief, but also aims at the best decision-making for the treatment of their child in the longer term.

**“If a physician in a white coat says you can treat this and it will help your child – it is still difficult for parents to ask if there are other options. Parents are afraid. Physicians are used to showing self-confidence and knowledge – they learn this during their training”.**

M\*, physician, Germany<sup>121</sup>

Uschi Durant, member of the extended board of the AGS Initiative, a support group, in Germany, told Amnesty International, “People in the surgical field are very convinced of their own approach and it is very difficult for parents to see the advantages and disadvantages of [what is proposed]. We try to prevent people from taking very quick decisions about surgeries and from going to surgeons who are enthusiastic but not experienced. We always say, if you are in contact with a surgeon, ask him questions...we have a list of

119 Interview, Berlin, November 2016. See Section 4.1 for more information on the ICD.

120 See also Streuli, J. C., Vayena, E., Cavicchia-Balmer, Y. and Huber, J. (2013), Shaping Parents: Impact of Contrasting Professional Counseling on Parents’ Decision Making for Children with Disorders of Sex Development. *J Sex Med*, 10: 1953–1960.

121 Interview, Berlin, September 2016

questions to ask. We advise, don't take a decision before speaking to at least two doctors who really have a lot of experience with [the operation they are proposing]."<sup>122</sup>

Gerda Janssen-Schmidchen from Intersexuelle Menschen described the experiences many parents have of visiting the doctor, "for example, if I have a child and I go to the doctor with my child and they see that the genitals are different and the doctor asks me if I feel uneasy in a way that suggests I should actually feel uneasy. Even the way they talk – it's about the wording that you use, it has an impact. Maybe the parent thought everything was OK and now they are worried."<sup>123</sup> Vanja, a German activist, told Amnesty International, "Parents feel very lost when they find out that they have a child with one of these conditions."<sup>124</sup>

## 4.2.6 INFORMED CONSENT

In both Germany and Denmark, parents or legal guardians have the responsibility to make medical decisions on behalf of children too young to give consent on their own. According to Lucie Veith of Intersexuelle Menschen, "Decisions are taken that lead to the fact that later on they realize the parents made a mistake, that leads to distance between parents and children"<sup>125</sup>

This is a concern also for people who are diagnosed during puberty. Vanja, a German intersex activist, told Amnesty International: "Finding out about my condition was not a very good experience, and it wasn't like I was given options. I think if I was given time and information, I could have said even at that age that I would rather have male puberty or take testosterone, but I [wasn't given that option]. The biggest problem with medical treatment is that doctors think they know the one way to treat this but there is {often} not only one way."<sup>126</sup>

The lack of information can also have an impact later in life. Historically, children who were operated on were not given a lot of information about what had happened.



**CLAUDIA**<sup>127</sup>  
**GERMANY**

"My mother told me a lot of lies and it was not right. I can understand that my parents were not the source of the problem, it was the doctor.

"My baby clothes were pink and then 18 months later they changed to blue. My mother told me that my children's clothes were pink because the county where my mother came from had different traditions, boy's clothes were pink. Why would I question my parents?

"I don't know fully what was done. But I found my first birth certificate, in which I was assigned female. After 42 years, there was no more information. Eighteen months after I was born, I had a small operation. I was told this was to remove my appendix. But it wasn't. I had my appendix out at seven.

"Now I'm 58. I had a chromosomal analysis done – it found male and female cells. Two thirds female, one third male.

"It's my decision to have the choice of what I want, not my parents, not my doctor – I must have all the information about myself, what are my own realities."

## 4.2.7 OPERATIONS

Some medical professionals assert that early genital surgeries are preferable to surgery in adolescence. The multidisciplinary team in Arhus University Hospital told Amnesty that based on the evidence available to

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122 Interview, February 2017

123 Interview, Emden, November 2016

124 Interview, Berlin, September 2016

125 Interview, Hamburg, September 2016

126 Interview, Berlin, September 2016

127 Interview, Trier, November 2016

them, “genital surgery, when indicated, is best performed and with least adverse outcome on the child’s emotional, sexual and cognitive wellbeing at the age of one to two years.”<sup>128</sup>

Paediatric surgeon Mika Venhola disagrees that the advantages of early surgery outweigh the risks. Speaking about surgeries on infants with variations of sex characteristics, he said: “There are persons who benefit from surgery psychologically, but there are also persons who think they have been treated wrongly. We don’t know which baby belongs to which group. We should have studies that say that these people benefit and these don’t... The logical outcome is that we wait for the surgeries – we are more likely to benefit the patients and avoid the harm.”<sup>129</sup>

Even though operations on intersex children have been taking place for decades and new methods of surgery were being developed, activists as well as medical professionals insist that these surgeries still carry risks. M,\* a physician, told Amnesty International: “Any surgery causes scar tissue. Children grow and some aspects of the body change – the scar tissue can’t grow the way that other tissue can grow. Even if something looks ‘regular’ or ‘normal’ when the child is an infant, this will change when the child reaches puberty. Everyone’s genitalia changes over this time”.<sup>130</sup>

A 2016 study found that in the period 2005-2014, the relative frequency of genital operations performed in Germany on children under the age of 10 diagnosed with variations in physical sex characteristics remained constant, despite the 2012 recommendations of the Ethics Committee which advised against these operations in some cases and the 2013 legislation which aimed to reduce pressure to surgically assign a sex.<sup>131</sup>

The Danish Ministry of Health also published data on operations performed between 2011 and 2015 on children diagnosed with DSD, although this only covers surgeries for hypospadias and hysterectomies.<sup>132</sup> No hysterectomies were performed on minors during that period. However, 1,005 hypospadias repair operations took place nationally, with the vast majority (895 operations) performed on children under the age of 10. No other data on surgeries was provided by the Ministry of Health, even though individuals interviewed by Amnesty International, including medical professionals and the AGS Association, confirmed operations to enlarge or reduce the clitoris (nerve-sparing clitoral operations or clitoral recessions) and to construct the vagina (vaginoplasties) were performed on children with variations in sexual characteristics during this period.

## CLITORAL SURGERY

Historically, infants and children with CAH and XX chromosomes,<sup>133</sup> have been treated with genital operations and hormones. The surgical techniques have varied over time and today clitoral reduction<sup>134</sup> or recession<sup>135</sup> are the most commonly practised forms of surgery for these conditions.

Based on information provided by parents to Amnesty International, clitoral recession is often presented as a reversible surgical option to parents of CAH infants with a hypertrophic (enlarged) clitoris as it consists of covering the clitoris by creating a hood from the labia minora. However, such surgeries present risks including possible nerve damage, loss of clitoral tissue, loss or reduction of clitoral sensation, scarring and pain.<sup>136</sup> In the period 2012-14, an average of 12 clitoral operations were carried out each year on female-assigned children aged under 10 in Germany.<sup>137</sup>

**“There is no medical reason to operate on the clitoris. But these operations are still being done.”**

Jörg Woweries, retired paediatrician, Germany<sup>138</sup>

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128 Interview, September 2016 and subsequent email, April 2017

129 Interview, January 2017

130 Interview, Berlin, April 2016

131 Klöppel, 2016

132 Data available at: <http://www.ft.dk/samling/20151/almdel/suu/spm/857/svar/1355435/1683320/index.htm>

133 See Section 2.1

134 Some types of clitoral reduction are also known as clitoroplasty. For example, nerve-sparing clitoroplasty is a form of clitoral reduction which aims to preserve the nerves.

135 Reifsnnyder et al, ‘Nerve Sparing Clitoroplasty is an Option for Adolescent and Adult Female Patients with Congenital Adrenal Hyperplasia and Clitoral Pain following Prior Clitoral Recession or Incomplete Reduction,’ *Journal of Urology*, 2016 Apr;195(4 Pt 2):1270-3. (hereinafter: Reifsnnyder et. al, 2016)

136 Reifsnnyder et. al, 2016

137 Klöppel, 2016, pg.44

138 Interview, Berlin, November 2016



A surgeon in a multidisciplinary team in a German hospital told Amnesty International, “we only operate on the clitoris in Prader<sup>139</sup> 5 cases: where the child is typically male looking but 95% of the individuals identify as female and they can get pregnant. In these cases we prefer to operate in the first six months of life, but there is no clear solution.”<sup>140</sup>

Medical practice evolves and new surgical techniques are being developed, used and recommended by physicians for CAH.<sup>141</sup> According to Jörg Woweries: “For many years intersex children who were supposed to be brought up as girls had a neovagina [vagina created through surgery] constructed, which only served to allow copulation/penetration. Since 2003 a new operative method to construct a neovagina has come into fashion, through which the child has to be operated on during the first 6, maybe 12 months of their life. The children to whom this was done are now at the most 13 years old; no surgeon could really assess how successful these operations were.”<sup>142</sup> An endocrinologist in a German multidisciplinary team told Amnesty International: “No one has really assessed if early or late [surgeries in CAH cases] is better.”<sup>143</sup>

## **PATIENT SUPPORT GROUPS AND SURGERIES**

While several intersex activists and patients’ organizations strongly campaign under a human rights framework against non-emergency, invasive and irreversible surgical interventions, other patient and parent support groups strongly support some specific early surgical interventions on children with variations in sex characteristics, even if they are non-emergency interventions.

The AGS<sup>144</sup> Association in Denmark is one of the groups that believe that early clitoral surgery is preferable. The Chair of the AGS Association stated that: “The members of the Association do not want operations of these AGS girls to be banned. Everyone who has given feedback [parents and women with AGS] is convinced that the operation at an early age is the best. The psychological side of not undergoing surgery is quite significant. The women and older girls who are operated between the age of eight and 16 years think it has been very difficult to go through surgery that late [for psychological and social reasons]...Now they are operating on all the [AGS] girls. I only know one person who was not operated, where the virilisation was so minor that the surgery was deemed unnecessary.”<sup>145</sup>

A parent member of the AGS Association described to Amnesty International how surgical specialists in Denmark receive training in new techniques of clitoral reduction “without damaging the nerves”. She explained that both her daughters had had surgery: “the skin that was removed from the side of the clitoris was then being used to make [the] labia minora. In addition, the entrance of the vagina was also made larger... I think that the new way to operate on these girls will in the future mean that both children and adults will get a better quality of life. It is not fair to let girls grow up with something that looks like a little penis when you can avoid it.”<sup>146</sup>

In Germany, Uschi Durant, member of the extended board of the AGS Initiative told Amnesty International, “We are able to link parents up to parents of girls who have and have not been operated. People who have experienced AGS in the last 20 years have a very different experience from people before that. Some girls say that they were happy that they were operated on as babies because they didn't have to deal with it later. The operational methods have changed a lot. [Before] there was no microsurgery, for example: the clitoris was simply reduced and the girls and women felt quite mutilated. It is understandable that these concerned persons demand that no girl should be operated before the age of 18.”<sup>147</sup>

## **VAGINOPLASTY AND DILATIONS**

Research indicates that in the period 2012-2014, an average of eight operations to construct a vagina were carried out per year on children under 10 in Germany.<sup>148</sup> M\*, a physician, told Amnesty International: “You don't need a vagina when you are a child, it's useful for intercourse, for periods – but children younger than ten years don't need one.”<sup>149</sup>

Lucie Veith, head of Intersexuelle Menschen, told Amnesty International about these surgeries, “For children with CAH – either the vagina is closed or the opening is too little or the urethra doesn't end where it should –

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139 See Section 4.2.1 for an explanation of the Prader scale

140 Interview, January 2017

141 Reifsnnyder et. al, 2016

142 Interview, Berlin, November 2016

143 Interview, November 2016

144 Another term for CAH; see Section 2.1

145 Interview, August 2016

146 Written statement by anonymous parent of the AGS Association in Denmark via the Chair of the AGS Association, November 2016

147 Interview, February 2017

148 Klöppel, 2016

149 Interview, Berlin, September 2016

doctors create an artificial vagina – if [there is] no vagina – or if it's very small, they dilate it. Very often, parents have to perform vaginal stretching. This means every night inserting rods into the vagina, and the children must then sleep with a bandage. This is not condemned in Germany and to me that's a complete scandal. The scar tissue for the urethra takes up the space where the vagina should be. It's widened so that the child can have penetration later... I've been in this field 12 years but it still puts tears in my eyes because I know these children.”<sup>150</sup>

Feminising surgeries including clitoral and vaginal surgeries “[are] primarily done during childhood for cosmetic rather than anatomical reasons.”<sup>151</sup> Vaginal dilations can be very controversial, particularly when used on children. Most medical professionals that Amnesty International spoke to said that they did not perform dilations on pre-pubescent children.

## GONADECTOMIES

Gonadectomy, the surgical removal of the gonads,<sup>152</sup> is irreversible and results in sterilization. Individuals who have undergone gonadectomies require lifelong hormone treatment. The 2006 Consensus Statement recommended removal of the testes for individuals diagnosed with CAIS and those with PAIS raised female, citing the option of early removal with oestrogen replacement but allowing for the possibility of defer<sup>153</sup> until puberty. The common reason given for removal is the risk that the gonadal tissue may become cancerous.<sup>154</sup>

The 2006 Consensus Statement recommended gonadectomy at the time of diagnosis for five specific variations in sex characteristics.<sup>155</sup> Similarly, for example, the DSD guidelines at Aarhus University Hospital, advise gonadectomies for infants with ovotestis<sup>156</sup> within a month.<sup>157</sup> The 2016 Consensus Statement Update differentiated the management strategy according to the assigned gender. Medical literature also differentiates recommendations according to the sex assigned – recommending orchiopexies (surgery to move undescended testicles into the scrotum), biopsies and monitoring for children assigned male and gonadectomies for children assigned female.<sup>158</sup> There is therefore a clear link between assigned gender and surgical interventions.



**SANDRAO<sup>159</sup>**  
**GERMANY**

“My biggest problem is that I have completely forgotten my first 11 years and I am trying to figure out what happened to me. I only found out [anything about] what happened to me two years ago. Before that, I was miserable for 34 years.

“When I was five I had surgery to remove testicles. I had other operations, other genital surgery. I don't know if I had a vagina at birth or if it was a reconstruction. My urethra is a different position. I saw a gynaecologist in 2014 and there is a lot of scarring.

“I knew I was different, I thought I was some kind of monster. I was unable to develop a gender identity. I was pressed into the female role, I had to wear skirts, I had to have long hair. It was painful to have sex with men and I thought this was normal.

“I took part in a study and they found a ‘genetic disorder’. But I don't like this word. I have a variation.

“Physicians don't give enough information to parents. I think the reason is that the medical profession only thinks in this gender binary system. Instead of saying your child is normal, and will grow up healthily, they say something is wrong and it can be fixed with surgery.

150 Interview, Hamburg, September 2016

151 Crouch, N. S. and Creighton, S. M. (2007), Long-term functional outcomes of female genital reconstruction in childhood. *BJU International*, 100: 403–407

152 In individuals without sex characteristic variations, these are ovaries (producing egg cells) or testes (producing sperm cells).

153 See Section 2.1 for information about these diagnoses

154 See section 4.2.4 for more discussion of cancer risk

155 Consensus Statement 2006, Table 4

156 Gonads containing both ovarian and testicular aspects

157 Aarhus University Hospital guidelines on Disorders of Sexual Development

158 See for example Consensus Statement Update 2016

159 Interview with Sandrao, Hamburg, 8 September 2016

“I see an endocrinologist. When I first came to see him, he said I needed to make up my mind whether to be male or female. They are unable to think outside the box. But now his opinion has changed. This is what gives me the power and the energy to fight.”

The multidisciplinary team at one German hospital told Amnesty International that, “It is no longer standard to remove the gonads. The cancer risk even for the high risk groups is not so high. We can monitor with ultrasound and for tumour markers. We don’t do anything during the early years.”<sup>160</sup>

Data from Germany shows that in the entire country in the period 2005-2014, 37 gonadectomies were performed on children under 10 diagnosed with variations in sex characteristics: 19 were registered female and 18 were registered male.<sup>161</sup> The data does not show whether these were carried out because of cancer risk. The Fischer family in Germany told Amnesty International that they were advised that their child should have her gonads removed under the age of ten.<sup>162</sup>



**ANNA,\* MOTHER OF NINA\*<sup>163</sup>**  
**GERMANY**

Nina\* is 11 and has complete androgen insensitivity syndrome. Her mother Anna explains: “The risk of [malignancy] was raised by the medical professional. I was glad that I had an alternative source [of medical] knowledge [so] that I could be assertive. The medical professionals are not aware of this: It’s not that they misinform. But they give little thought to the idea that there are other perspectives, that it makes sense to consider these together“

## **HYOSPADIAS REPAIR**

‘Hypospadias repair’ is the term for the variety of different surgeries used to restore the urethra to the usual position on an infant or child’s penis. Medical professionals Amnesty International interviewed outlined that hypospadias repair surgery, when indicated, take place when the child is one or two years old.<sup>164</sup>

In Denmark, the vast majority of operations for hypospadias, even in its mildest form which is not life threatening or likely to cause infection, are carried out on infants and children. From 2011 until 2015, a total of 851 out of 1,006 of all types of hypospadias repair operations took place on children under the age of seven, the majority of whom were under the age of two.<sup>165</sup> Most operations are for glanular or distal hypospadias. This is the mildest form of the condition and surgery in these cases is not emergency surgery. One surgeon at Rigshospitalet stated that the optimal outcome after surgery would be that “the boy pees standing up, in a normal way.”<sup>166</sup>



**H\*<sup>167</sup>**  
**DENMARK**

H\* discovered in 2016 that he was born with hypospadias and was operated on at a young age. His discovery was made by accident when he accessed his old medical journal from when he was a child. He recalled:

“I knew I had a surgery in 1984 as a five-year-old. But I never knew what that was about. My mother told me I didn’t pee straight so that was the explanation I was told and that’s what I believed.”

After surgery, H remembered:

160 Interview, January 2017

161 Klöppel, 2016, pg.48-49

162 Interview, January 2017

163 Interview, January 2017

164 Interview with Arhus University Hospital, September 2016

165 Data available at: <http://www.ft.dk/samling/20151/almindel/suu/spm/857/svar/1355435/1683320/index.htm>

166 Interview at Rigshospitalet, September 2016

167 Interview, September 2016

“I had to pee and it just hurt really [badly], so I held back my urine because it hurt so much. I was screaming in the toilet, running around, I had no clothes on. In the end, I peed all over – I screamed, I was afraid, I didn’t understand what was happening. I was a bit embarrassed for peeing all over the place. That was the only thing I remember after the 1984 incident... I still often sit down when I pee because I can’t always control the urine.

“When I think about what happened, I get upset, because it wasn’t something for anyone else to decide – it could have waited. I get sad when I think about the fact that it is considered necessary to operate on these children, only because other people think it should be done.”

An endocrinologist in a German multidisciplinary team stated some of the justifications for surgeries: “It’s not a life-threatening condition but there are medical grounds for giving security to a child. For hypospadias repair, you need to reconstruct every centimetre. The side effects go up with age. There is a much higher complication rate in older children. We have seen older children ask for hypospadias repair. We need to do this in a [specialist] centre, not because we are the best at surgery but because we need the long-term follow-up to see if the prognosis was correct.”<sup>168</sup>

A psychologist in the same team told Amnesty International: “parents want their boy to be able pee standing up, to pee in a urinal. We need to talk to them about this, it is not paramount. The desire is about not having their children stand out, but children know that their genitalia look different. We should tell parents that just because it looks the same doesn’t mean it is the same.”<sup>169</sup>

In Germany, an average of 1,617 masculinising surgeries per year took place in the period 2012-2014. Most of these procedures were hypospadias repair to relocate the urethral opening to the tip of the penis. In 10-16% of the cases diagnosed with hypospadias, plastic reconstruction of the penis was carried out.<sup>170</sup> Hypospadias can occur in its own or as part of other variations in sex characteristics. The multidisciplinary team at one hospital in Germany told Amnesty International that they carry out hypospadias repair only if “there is no underlying endocrine diagnosis or intersex condition.”<sup>171</sup>



D\*172

GERMANY

“I was born with hypospadias and penile-scrotal transposition on one side i.e. one scrotum is too high.

“I personally was operated on in the 1980s in the doctor’s office in an outpatient setting. I don’t know if such doctors’ offices still exist. The one where I was operated on no longer exists and therefore I have no documentation.

“My surgeries started before I turned one. I had at least five operations before I turned 18. I was under anaesthetic but I wasn’t given a catheter and if I wanted to pee it burned like hell.

“Then between 2004 and 2006 I was operated on four times. I was told that the surgeries I had as a small kid were in vain.

“When I was a child no-one asked me if I wanted the surgeries or not... it was a third party who made the decision for me and I didn’t have a say in it. I have been operated on, it’s too late for me, but if I stay silent it’s like I support surgeries and I can only change things if I speak up.”

## 4.2.8 HORMONE TREATMENT

Hormone treatment is the other major form of treatment undergone by children with variations in sex characteristics, often in combination with surgery.

168 Interviews, November 2016

169 Interviews, November 2016

170 Klöppel, 2016, pg. 51-53

171 Interview, January 2017

172 Interview, Hamburg, September 2016

Generally hormone treatment includes Hormone Replacement Therapy (HRT), induction of puberty when hypogonadism (diminished gonad activity) is present and in certain cases, suppression of puberty.<sup>173</sup> Often such treatment is urgent and life-saving. For example, in cases of salt-wasting types of CAH<sup>174</sup> which result in a drastic loss of sodium, the administration of cortisol from the moment of diagnosis and throughout a person's life is vital. Such hormonal treatment can also affect physical appearance. For example, the administration of cortisol to combat the lethal loss of sodium, may reduce the size of the phallus.

In cases of individuals with certain sex characteristics such as Turner and Klinefelter syndromes, hormone replacement is needed to enter puberty: however, many individuals Amnesty International spoke to reported receiving hormones that are prescribed by physicians to patients based on binary gender assignment and assumption about gender identity. This means, for example, that Turner patients are assigned the female gender and administered oestrogen, and Klinefelter patients are assigned the male gender and administered testosterone. This policy and pattern may cause difficulties for individuals who don't identify as the gender they have been assigned at birth.

Stine, one of the founders of Intersex Danmark, has XXY chromosomes and identifies as an intersex woman.. She told Amnesty International that her experiences with the medical profession have not been positive. She said the endocrinologist she had been referred to, about getting treatment with oestrogens, progesterone and testosterone suppressing treatment, had only offered treatment with testosterone treatment 'to make a man out of me' and to have my breasts cut off because 'that is what we normally do', in his words."<sup>175</sup>



**FRANCES**  
**INTERSEX ACTIVIST, GERMANY<sup>176</sup>**

"I have Swyer Syndrome with deletion of the SRY [gene]. I was castrated and put on estrogen to make me look more female. Over the years my health got worse and worse. I knew about my XY Chromosomes. Because of that I start asking my gynaecologists and endocrinologists if my health problems had anything to do with my XY-Chromosomes. They always said "no". In the year 2005 I changed to testosterone under medical control. Since than I feel better."

A psychologist practicing in Germany told Amnesty International: "There is a tendency to see the sex hormones as just for sex but it's much broader than this. Medicine sees hormones as only affecting certain things – bone density, sex, growth... for women with completed androgen insensitivity syndrome – they had gonadectomies and then oestrogen, but the gonads had produced testosterone... we don't know what other effects it had and many people report health effects e.g. depression. The integrity of the body isn't just genitals – it's also hormones. There are no studies on the lifelong effect of sex hormone treatment. As a psychotherapist, I see patients who have difficulty getting combination hormone treatments of testosterone and oestrogen. Doctors think in binaries and in science we have difficulty dealing with different forms of knowledge."<sup>177</sup>

For individuals with Turner syndrome, the transition from pediatric treatment to adult treatment can be difficult. Kerstin Subtil, responsible for public relations for the German Turner Initiative, told Amnesty International that children with Turner syndrome are seen by paediatricians but there are no specialists for adults, who have to see a range of doctors for complications including gynaecologists, heart specialists and kidney specialists: "one specialist who can handle everything would be better."<sup>178</sup>

## 4.2.9 PSYCHOSOCIAL SUPPORT

According to the 2006 Consensus Statement, psychological support should be part of the process for managing DSD. It advises that psychologists should be members of DSD multidisciplinary teams and provide individual advice and consultation to patients and parents of children diagnosed with variations in sex characteristics, including discussing different treatment options. The 2016 Consensus Statement Update

173 Consensus statement, pp.172

174 See Section 2.1

175 Interview with Stephanie Stine Toft, September 2016

176 Email correspondence, April 2016

177 Interview, November 2016

178 Interview, February 2017

stated that “Education and psychological support regarding the impact are needed for each individual to make sense of the condition, relate to their community and establish relationships.”



**PAULA\***  
**GERMANY<sup>179</sup>**

In 1997, at the age of 17, Paula was diagnosed with MRKH.<sup>180</sup> She underwent treatment to create a vagina. “At the clinical level, I did not lack anything. I was referred immediately because my doctors lacked the necessary knowledge and thought I would be better off with a specialist physician. I was well taken care of. When one is having a vagina entrance created operatively, one is offered psychological support. But after one is discharged from hospital, one needs to figure this out oneself. I started psychotherapy [independently]. No one was in charge of making sure I had psychological support.”

Significant adult psychological support is provided by various patients and parents groups and associations in both Denmark and Germany. However, the public provision of psychological support is limited. Lack of funding is often cited as the reason for limited psychological support services. A psychologist in a multidisciplinary team in a German hospital reported that the waiting list for access to specialist psychologists was between six and nine months at the time of writing.<sup>181</sup>

Psychologist Katinka Schweizer carried out a study of treatment experiences and quality of life for intersex adults who had been treated as children.<sup>182</sup> “It was difficult to find differences between treated and untreated people because almost everyone had been treated. Finally we had 69 people in the study... 61% of the people in the study recorded clinically relevant psychological distress – this is very high compared to the general population. The rates of suicidal thoughts were significantly higher than the [general] population”<sup>183</sup>

Karina Lins, an experienced psychologist working with gender non-binary children, expressed her concern about the impact early surgery can have on the attachment between parents and children: “If you look at psychological development, these [early years of a child’s life] are the most important years of bonding. The attachment you have to the mother, to the father or whichever caregiver. And then suddenly you have to be gone and you are under the age of two, you don’t really know what’s going on and you have to stay in the hospital away from your caregivers; you have to undergo extremely painful surgery that can even cut through nerves, making the genitals become insensitive or causing other damage. These children will have experienced early traumatic events. Even if they don’t remember it, it stays in their bodies if we don’t help.”<sup>184</sup>

In addition, the support intersex people receive is not always appropriate for their specific situation. In 2002 Frances, an intersex activist, was referred to a psychologist. Frances told Amnesty International: “I told the psychologist that I am xy-chromosomal and have been put on for almost 30 years. I said her that I feel more and more uncomfortable in the female role and unhealthy. I went four times to see her and after eight hours she told me: “You have many healthy parts, You are a complete woman” These appointments had been absolutely useless. They had brought me no further forward.”<sup>185</sup>

Additional psychological support often comes from other parents and intersex people. Stefanie from XY-Frauen told Amnesty International: “Parents ask themselves whether to carry out surgeries or not, they ask what are the consequences if it is done or not done, what are the benefits to the child? They ask about the child’s identity, and how to talk to children about being intersex.”<sup>186</sup>

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179 Interview, February 2017

180 Mayer-Rokitansky-Küster-Hauser (MRKH) syndrome causes the vagina and uterus to be underdeveloped or absent.

181 Interview, November 2016

182 Schweizer et al, ‘Coping With Diverse Sex Development: Treatment Experiences and Psychosocial Support During Childhood and Adolescence and Adult Well-Being’, *Journal of Paediatric Psychology*, July 2016

183 Interview, Hamburg, November 2016

184 Interview, September 2016

185 Interview, Trier, November 2016, and email, April 2017

186 Interview, Berlin, September 2016



**THE FISCHER\* FAMILY<sup>187</sup>**  
**COLOGNE, GERMANY**

“The Guidelines [see section 6.2.6] are important. But it would also be important for self-help groups to be involved early on so that affected people can have an exchange with people with whom they need not feel ashamed. Now we have dealt with the issue and it’s nothing terrible anymore. If someone had told me your daughter is lesbian, I would have said “that’s not a problem.” I wish it had been like that with intersex. My husband and I both studied at university but we nevertheless felt so stupid because we simply had no clue.

“I have now spoken with adults who have had problems because they did not know the truth. But there are also adults who are living their lives regardless. These are often the younger people, more open-minded people. We have become acquainted with a woman with Swyer Syndrome. For her this isn’t the main issue in her life. It is a shame that she does not have eggs and cannot have children. For us as parents it would have been important if someone had helped us to deal with these limitations. The normal expectation just is: My children will have children. Does this mean I will never be a grandmother? Women with Swyer Syndrome can actually have children.<sup>188</sup> It would have really helped me to know that. But no one gave me answers to these kinds of questions.”

Mika Venhola, a paediatric surgeon in Finland, told Amnesty International: “the tradition has been to do the operations, and to tell the parents that now this will be OK, but it doesn’t really work like this... The surgeries will create tensions within the family - the family cannot cope with these alone.”<sup>189</sup>



**PARENTS OF JOHANNES\*<sup>190</sup>**  
**BERLIN, GERMANY**

Johannes\* was born in 2013 and operated on for hypospadias in 2014 and 2015. His mother told Amnesty International: “We had no psychological support and there was no aftercare. Johannes is very fearful as a result of the operations he has had. He has problems sleeping. We have not been offered any psychological support for him. We took the initiative to seek alternative healing methods for him. After almost four years we are now doing a family trauma therapy.

“I would have wished for a doctor who is knowledgeable and could advise us. Before the operations we were really afraid. We would have liked to have a physician able to support us. The paediatrician did not refer us [to a psychologist but] I would have liked psychological support.”

The multidisciplinary team at one German hospital told Amnesty International, “it is very important to have a psychologist in the team. Parents want doctors to solve the problem. But when we explain step-by-step – we can see a change and parents adapt to the condition. They understand that this is not the only feature of the child and we can help them bond with the child”<sup>191</sup>



**ANNA,\* MOTHER OF NINA\*<sup>192</sup>**  
**GERMANY**

Nina\* is 11 and has complete androgen insensitivity syndrome. Her mother Anna explains: “in the past few years my daughter regularly visited the university hospital for check-ups, at the moment twice yearly. I wish my daughter and I had psychological support, interlocutors with some level of understanding. I raised this with the endocrinologist at the university hospital. She recommended someone in Berlin which is 150km away – that is not suitable for me. There was a discussion within the Ethics Commission– this

187 Interview, January 2017

188 Women with Swyer Syndrome do not have ovaries; they can become pregnant through implantation of donated eggs

189 Interview, January 2017

190 Interview, January 2017

191 Interview, January 2017

192 Interview, January 2017

should filter through to the relevant areas of clinical expertise, should lead to a certain level of commitment for people to get trained. This need not mean that everyone needs to undergo specialist training. But it should be possible for medical staff [who work with people with variations of sex characteristics] to take a ‘crash course.’ I don’t want to be left feeling I have to explain everything. I would like to have physicians who are sensitive to the issues.

“I feel like the health professionals are really not sensitive to the psychosocial situation of affected people. For example: During the consultation the medical notes will be lying – openly visible – on the table so one can see the photos. Those photos were taken with my permission [some time ago when Nina was little]. One’s gaze falls on those photos – the medical professionals do not notice that. I don’t agree with this, I find it lacks sensitivity. Equally, when the conversation is about my daughter there are issues about the use of language: in addressing my daughter, a doctor talks about “testes.” I then say “let’s agree to use the term “germinal glands.” I raise this kind of thing, draw people’s attention to it, because I know the medical professionals are not conscious of this. I speak on my own behalf as a representative in the presence of my daughter because I want her to learn that it’s absolutely fine to raise such matters.”

## 4.3 A LACK OF RESEARCH

It is broadly recognized that there is a significant lack of evidence about the effects of variation in sex characteristics or about the impact of medical treatment and long-term outcomes.

International and regional projects have developed attempting to record data on patients with variation in sex characteristics for the purpose of improving care. In 2008, a global i-DSD Registry<sup>193</sup> was created to record cases and gather data on infants, children and adults with variations in sex characteristics. It has collected over 2,500 cases from around the world; physicians enter information and data about the patient, which the patient can also access.

Another example of such projects is the DSD-Life project, an ongoing €3 million project funded by the European Union. It aims to retrieve long-term data on patients including through quality of life studies.<sup>194</sup>

### 4.3.1 THE IMPACT OF INTERVENTIONS

While there have been various clinical studies and research on types of variations in sex characteristics, including on clinical assessment of new genital surgery techniques versus older ones, evaluation of genital appearance and satisfaction by patients, and quality of life assessments, usually focusing on individual types of variation, there are significant gaps in evidence on the benefit of genital surgeries and hormonal treatment for children versus non-interference. The multidisciplinary team from Odense University Hospital told Amnesty International: “There is no evidence. What is the evidence that it’s good to wait [before you conduct surgery] or what is the evidence that it’s good to have an assigned gender? Nobody knows.”<sup>195</sup>

Uschi Durant, member of the extended board of the AGS Initiative in Germany, told Amnesty International, “The experts that we work with have been documenting the outcomes for the cases that they have treated. There is a need for follow-up operations for people who had prior operations as babies performed by someone who was not competent. There is a need to document outcomes for people operated over the age of one.”<sup>196</sup>

One German psychologist set out some of the key concerns with existing studies: “There are four problems with research. First, the dichotomous view of sex – that it is ‘either/or’. Second, the pathologization of intersex people. If they feel neither male nor female, then they are seen to have gender dysphoria, even if this is not necessarily a problem for them. Third, decisions on social gender allocation have been mixed up with medical decisions on sex assignment – these are two separate decisions but they have been enmeshed and it’s really hard to separate them. And finally – and this is maybe the most important problem – ... We deny that we don’t know. We don’t have proof about how most intersex individuals develop as adults in terms of gender identity. This is the human rights ground for why we must not make irreversible interventions.”<sup>197</sup>

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193 For more information, see <http://www.gla.ac.uk/schools/medicine/research/childhealth/researchinterests/i-dsdproject/>

194 More information can be found at <https://www.dsd-life.eu/#>; project results not yet published at time of writing.

195 Interview, September 2016

196 Interview, February 2017

197 Interview, November 2016



## 4.3.2 THE IMPACT OF NOT ACTING

Existing research and ongoing studies on DSD treatment are primarily focused on sample groups of people with variations in sex characteristics that have undergone genital surgery as children or adolescents or hormonal treatment. Claus Gravholt, a specialist endocrinologist in Denmark, acknowledged that: “We don’t have any experience with postponing the operation until the kid is an adult... we do not have the data to discuss that.”<sup>198</sup>

Even in established clinical studies that examine wellbeing, quality of life and genital function, there are few studies where the control group is composed of people with variations in sex characteristics who have not undergone surgical or other treatment as minors, rather than people without variations in sex characteristics. This research therefore does not address the question of the relative merits of intervention and non-intervention at an early age.

M,\* a German physician, told Amnesty International that she has treated older patients with intersex variations who had not had surgeries: “No-one has said that they were angry that they did not receive surgery. Some persons who did not have surgery noted that peeing was different from other boys... but it was not a big problem”.<sup>199</sup> Activists also told Amnesty International about the benefits they had seen in children whose parents delayed the decision on whether or not to operate. Gerda Janssen-Schmidchen of the XY-Frauen and Intersexuelle Menschen parents’ groups told Amnesty International: “I don’t know anyone who waited to have surgery and then could not have it. There are cases of children whose parents waited for treatment and later they chose it for themselves – they chose hormone treatments or vagina construction. But I don’t know any of them who said they would have wanted it younger.”<sup>200</sup>

Long-term research is lacking that would establish whether difficulties that intersex adults face are due to their individual anatomy, to the surgery they were subjected to as infants, to poor or non-existent psychosocial support<sup>201</sup> or to a combination of these. Addressing the lack of long-term data to assess the quality of life and health of individuals who have not undergone surgical or hormone treatment should be a key factor in assessing the value of surgery and offering support and alternatives to early surgery, and developing appropriate frameworks for informed consent, to better meet the needs of people with variations of sex characteristics and realize their right to health.

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198 Interview, June 2016

199 Interview, Berlin, April 2016

200 Interview, Emden, November 2016

201 Liao et al, ‘Parental choice on normalising cosmetic genital surgery,’ 2015, *British Medical Journal*

# 5. HUMAN RIGHTS AT STAKE

In October 2016, to mark Intersex Awareness Day, a group of UN and regional human rights experts issued a statement calling for an end to human rights violations against intersex children and adults and specifically to prohibit harmful medical practices on intersex children, including unnecessary surgery, treatment without their informed consent and sterilization.<sup>202</sup>

Amnesty International has documented how the treatment of individuals with variations of sex characteristics in Germany and Denmark violates international human rights law, in particular the rights of the child. These practices violate the rights to the highest attainable standard of health, to a private life and to physical and bodily integrity, and the right to freedom from discrimination and the elimination of practices based on gender stereotypes.

The rights of people with variances in sex characteristics are protected by international human rights law including the Convention on the Rights of the Child (CRC), the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW), the International Covenant on Civil and Political Rights (ICCPR), the Convention against Torture (CAT), the European Convention on Human Rights (ECHR) – all of which have been ratified by both Germany and Denmark – and the Charter on Fundamental Rights of the European Union which is legally binding on EU countries. As such, Denmark and Germany are bound to comply with their international legal obligations under these treaties.

## 5.1 THE RIGHTS OF THE CHILD

The Convention on the Rights of the Child (CRC) strengthens the position of children as rights-holders and gives due consideration to how children, can enjoy the full range of human rights guaranteed for all people in international standards. According to the CRC, in all decisions affecting a child, the child's best interests must be a primary consideration. The Committee on the rights of the child has recognised that "Young children are holders of all rights enshrined in the Convention and that early childhood is a critical period for the realization of these rights".<sup>203</sup>

The Committee of the Rights of the Child and other treaty bodies, such as the Committee for the Elimination of Discrimination against Women, have repeatedly classified non-emergency, invasive and irreversible

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202 Full statement available from <http://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=20739&LangID=E>. The signatories were: UN Committee against Torture (CAT); UN Committee on the Rights of the Child (CRC); UN Committee on the Rights of People with Disabilities (CRPD); UN Subcommittee on Prevention of Torture and other Cruel, Inhuman or Degrading Treatment or Punishment (SPT); Mr. Juan Méndez, UN Special Rapporteur on torture and other cruel, inhuman, or degrading treatment or punishment; Mr. Dainius Pūras, UN Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health; Ms. Dubravka Šimonović, UN Special Rapporteur on violence against women, its causes and consequences; Special Representative of the UN Secretary-General on Violence against Children Ms. Marta Santos Pais; Commissioner Lawrence Murugu Mute, Chairperson of the Committee for the Prevention of Torture in Africa, Council of Europe; Mr. Nils Muižnieks, Council of Europe Commissioner for Human Rights; Inter-American Commission on Human Rights.

203 Committee on the Rights of the Child, General Comment No. 7 (2005), CRC/C/GC/7/Rev.1, 20 September 2006, (hereinafter: CRC General Comment 7, 2005) para 1

surgical and hormonal interventions in intersex children without consent as harmful and in violation of the rights of the child.<sup>204</sup>

## 5.1.1 BEST INTERESTS OF THE CHILD

Central to the respect and fulfilment of the rights of intersex children is the standard set out in the CRC, Article 3.1 of which states: “In all actions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies, the best interests of the child shall be a primary consideration.”<sup>205</sup>



### **ANNA,\* MOTHER OF NINA\*<sup>206</sup>** **GERMANY**

Nina\* is 11 and has been diagnosed with CAIS. Her mother Anna explains: “The ‘best interest of the child’ – that’s a concept I encounter in my work. It’s so important and I use this term intentionally, including in exchanges with physicians... The criterion has to be that all people involved are concerned to find the best solutions for the children.”

The Committee on the Rights of the Child’s General Comment No. 14 on the Best Interests of the Child<sup>207</sup> sets out the guiding human rights standards for the full and effective enjoyment of all the rights recognized in the CRC and the holistic development of the child.<sup>208</sup> Development is interpreted as a “holistic concept, embracing the child’s physical, mental, spiritual, moral, psychological and social development”.<sup>209</sup>

Amnesty International’s research indicates a divergence between the best interests of the child principle set out in the CRC and medical policy and practice in relation to children with variances in sex characteristics in German and Denmark. In its present form, medical practice neglects to consider the full rights of children with variations in sex characteristics. Specifically, the practice of performing non-emergency, invasive and irreversible surgeries, which may have harmful effects, on children during infancy or early childhood, without reasonable indication of long term impacts, constitute a violation of their right to a private life and bodily integrity, to the highest attainable standard of health.

One justification given for non-emergency surgeries and treatment is to protect the child psychologically so that they is not bullied and feels “normal” at school or in their socializing environment.<sup>210</sup> Bullying harms the physical and emotional well-being of children and adolescents, and has a significant impact on their education;<sup>211</sup> however, the risk of bullying cannot be used as a justification for harmful practices which themselves may be in conflict with the child’s best interests.

There is a lack of long-term research on the psychological effects on children of growing up with variations in sex characteristics to support this generally held belief. What little research does exist indicates a considerable degree of dissatisfaction with genital appearance and poor quality of life among adults who have undergone genital surgery as infants.<sup>212</sup>

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204 See for example CRC on Switzerland CRC/C/CHE/CO/2-4, Chile CRC/C/CHL/CO/4-5, Ireland CRC/C/IRL/CO/3-4, France CRC/C/FRA/CO/5, UK CRC/C/GBR/CO/5, Nepal CRC/C/NPL/CO/3-5, South Africa CRC/C/ZAF/CO/2, New Zealand CRC/C/NZL/CO/5; CEDAW on France CEDAW/C/FRA/CO/7-8, Ireland CEDAW/C/IRL/CO/6-7, Germany CEDAW/C/DEU/CO/7-8

205 The Committee’s explanatory General Comment 14 on the Best Interest of the Child, para 26, defines “public or welfare institutions” as to include institutions related to economic, social and cultural rights, such as health but also institutions dealing with civil rights and freedoms, such as birth registration- applicable in the cases of children born with variances in sex characteristics whose parents feel pressure by national legislation on birth registration to declare their child’s gender, therefore are forced to a rapid decision towards sex assignment.

206 Interview with Amnesty International, January 2017

207 General Comment No 14(2013) on the right of the child to have his or her best interests taken as a primary consideration (art.3, para.1)\*, CRC/C/GC/14, Committee of the Rights of the Child, 29 May 2013

208 GC 14 para. 4, as

209 General comment 5 (2003) CRC/GC/2003/5, para 12.

210 This conclusion is assessed through statements by all the medical professionals Amnesty International interviewed in Denmark and Germany, through medical guidelines and through the Consensus Statement of 2006 and 2016.

211 UNESCO, ‘School Violence and Bullying: Global Status Report’, 2017, available at: <http://unesdoc.unesco.org/images/0024/002469/246970e.pdf>

212 Creighton research/ Katharina Main research.

Dr Venhola also stated that infants do experience trauma, even if they do not remember the surgery. “We already know that even though that memory can fade, the body remembers. If a baby has been in intensive care and subjected to many kinds of pain and discomfort, these babies when they grow up, they can experience physiological reactions, for example during blood tests. This is the same for people who had surgeries. They may not have any cognitive memories of the pain and the hospitalization, but their bodies do remember, and later when attending a doctor’s office, hospitals and so on, they will have higher stress levels.”<sup>213</sup>

The Committee on the Rights of the Child also provides guidance to states to ensure appropriate assistance to parents before a child is able to give consent to what happens to their body. Such assistance “can best be achieved as part of comprehensive policies for early childhood, including provision for health, care and education during the early years. States parties should ensure that parents are given appropriate support to enable them to involve young children fully in such programmes, especially the most disadvantaged and vulnerable groups”.<sup>214</sup> In order to involve young children fully, such policies need to revolve around expert psychological support to parents in order to navigate options .

Furthermore, the 2006 Yogyakarta Principles,<sup>215</sup> state at Principle 18.8 that: “States shall take all necessary legislative, administrative and other measures to 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”.

## 5.1.2 RIGHTS TO PRIVATE LIFE, TO PHYSICAL AND BODILY INTEGRITY AND SELF-DETERMINATION

**“It’s a human rights issue to speak up against surgery on people who can’t give consent”**

M\*, a physician in Germany <sup>216</sup>

International human rights standards differ from the legal or even procedural standards in the medical establishment. Medical standards and decision-making processes still lead to on non-emergency, invasive and irreversible genital surgery and hormonal treatment of children with variations of sex characteristics. This may constitute a violation of the child’s right to express their views and to participate in decisions which affect them (Article 12 of the CRC) and of the right to a private life (Article 6 of the CRC, Article 17 of the International Covenant on Civil and Political Rights and Article 8 of the European Convention of Human Rights<sup>217</sup>), which encompasses the right to physical integrity and self-determination. It can also have a present and future impact on the child’s right to the highest attainable standard of health (Article 24 of the CRC and Article 12 of the International Covenant on Economic, Social and Cultural Rights).

In its concluding observations on France and Ireland in 2016 and Switzerland in 2015, the Committee on the Rights of the Child stated its concerns about the routine practice of medically unnecessary surgeries and other treatment on intersex children that can be irreversible, while recommending states develop and implement a rights-based healthcare protocol for intersex children to guarantee their bodily integrity, autonomy and self-determination<sup>218</sup> and to ensure that no child is subjected to unnecessary surgery or treatment.<sup>219</sup>

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213 Interview with Dr Mika Venhola, January 2017. See for example ‘The Long Life of Early Pain’, Harvard Medical School 2011, [https://hms.harvard.edu/sites/default/files/HMS\\_OTB\\_Winter11\\_Vol17\\_No1.pdf](https://hms.harvard.edu/sites/default/files/HMS_OTB_Winter11_Vol17_No1.pdf)

214 CRC General Comment 7, 2005 para 21

215 In 2006, in response to well-documented patterns of abuse, a distinguished group of international human rights experts met in Yogyakarta, Indonesia to outline a set of international principles relating to sexual orientation and gender identity. The result was the Yogyakarta Principles: a universal guide to human rights which affirm binding international legal standards with which all States must comply.

216 Interview with M\*, Berlin, September 2016

217 The European Court of Human Rights has interpreted the concept of the right to a private life to encompass: “the physical and psychological integrity of a person”

218 Concluding Observations Switzerland, CRC/C/CHE/CO/2-4, February 2015

219 CRC/C/FRA/CO/5 – Concluding Observations France (2016), Ireland 2016

The European Charter of Fundamental Rights also sets the regional standards with regards to the right to physical integrity. It states: “1. Everyone has the right to respect for his or her physical and mental integrity.” Children and adults with variations in sex characteristics have the right to physical integrity and private life through affirmation of their gender and recognition of their affirmed gender before the law, whether it is aligned with what they were assigned at birth or not.

### 5.1.3 EVOLVING CAPACITIES AND THE RIGHT OF THE CHILD TO EXPRESS ITS VIEWS

Under international human rights law, states must recognize that respecting young children’s evolving capacities - processes of maturation and learning whereby children progressively acquire knowledge, competencies and understanding, including acquiring understanding about their rights and about how they can best be realized - is crucial for the realization of their rights. Respecting evolving capacities is especially significant during early childhood, because of the rapid transformations in children’s physical, cognitive, social and emotional functioning, from earliest infancy to the beginnings of schooling.<sup>220</sup>

Psychological support aimed at empowering the child over time to make decisions based on the principle of evolving capacities, would enable children with variations in sex characteristics to exercise their agency in its fullest potential in order to enjoy their rights. While the justification often given for interventions is to protect the child from bullying, General Comment No. 7 of the Committee on the Rights of the Child states: “Evolving capacities should be seen as a positive and enabling process, not an excuse for authoritarian practices that restrict children’s autonomy and self-expression and which have traditionally been justified by pointing to children’s relative immaturity and their need for socialization. Parents should be encouraged to offer ‘direction and guidance’ in a child-centred way”.<sup>221</sup>

Most parents want what is best for their child, yet the parents interviewed by Amnesty International spoke at length about the lack of information they received about their child’s options. Article 18.2 of the CRC requires states in order to guarantee and protect children’s rights, to render appropriate assistance to parents and legal guardians in the performance of their responsibilities. The Committee on the Rights of the Child has stated that: “an adult’s judgement of a child’s best interests cannot override the obligation to respect all the child’s rights under the Convention”.<sup>222</sup> However, the tendency of doctors to give overarching weight to parental initial views and fears regarding the psychological wellbeing of their children, rather than to provide information and support to allow parents to make an informed decision about their child’s best interest, restricts the rights of bodily and decision-making autonomy of the child.

### 5.1.4 RIGHT TO THE HIGHEST ATTAINABLE STANDARD OF HEALTH

The right to the highest attainable standard of health is closely related to other human rights standards.<sup>223</sup> The link with, for example, the right to bodily integrity is apparent in the case of on non-emergency, invasive and irreversible surgery on a child where there is a lack of data on eventual outcomes. General Comment No. 14 of the Committee on the Rights of the Child states that: “Children’s right to health contains a set of freedoms and entitlements. The freedoms, which are of increasing importance in accordance with evolving capacity and maturity, include the right to control one’s health and body, including sexual and reproductive freedom to make responsible choices.”<sup>224</sup> Article 12.1 of the ICESCR states that everyone has the right to the highest attainable standard of health, and Article 12.2 further states that States must take steps necessary for the positive development of the child.

The 2006 Consensus Statement recognized that operations such as vaginoplasties and clitoroplasties on children can have negative health consequences in adulthood, while also highlighting the lack of research to substantiate long-term effects into adulthood of genital surgery on infants.<sup>225</sup>

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220 CRC General Comment 7, 2005, para 17.

221 CRC General Comment 7, 2005, para 17.

222 General Comment 14, CRC/C/GC/14, para 4 and General Comment 13 on the rights to protection from all forms of violence, para.61

<sup>223</sup> CESCR GC 14 para.3

224 General Comment 14/ child’s health- CRC article 24

225 Consensus statement 2006, pp 493

Existing research has indicated that many girls subjected to genital surgery in infancy have had to undergo further surgery in adolescence to facilitate menstruation and intercourse.<sup>226</sup> In addition, new surgical techniques of clitoroplasty have been used in adolescent girls to reverse the clitoral recessions undergone as infants in order to treat pain and infections.<sup>227</sup>

The UN Special Rapporteur on the right to health stated in 2009 that: “Health-care providers should strive to postpone non-emergency invasive and irreversible interventions until the child is sufficiently mature to provide informed consent”, noting that “This is particularly problematic in the case of intersex genital surgery, which is a painful and high-risk procedure with no proven medical benefits”.<sup>228</sup>

## 5.2 DISCRIMINATION AND GENDER STEREOTYPES

Under the International Covenant for Economic, Social and Cultural Rights: “State parties undertake to guarantee that the rights enunciated in the present Covenant will be exercised without discrimination of any kind as to race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status.”<sup>229</sup> The CRC in Article 2 similarly states that. “States Parties shall respect and ensure the rights set forth in the present Convention to each child within their jurisdiction without discrimination of any kind, irrespective of the child's or his or her parent's or legal guardian's race, colour, sex, language, religion, political or other opinion, national, ethnic or social origin, property, disability, birth or other status.”

International and regional human rights standards on gender and sex discrimination apply to individuals with variations in sex characteristics, not only to shield a child from non-emergency, invasive and irreversible genital surgery, but also to combat discrimination against intersex children and adults in areas such as healthcare and to enable them to enjoy their rights to physical and integrity and a private life.

Intersex people face discrimination on the grounds of their sex characteristics because of deeply embedded gender norms that paint a specific physiological picture of what the bodies of men and women bodies should be in order to be considered “normal”. This manifests itself in a lack of acceptance of anyone who does not conform to the binary stereotypes of what is male and female.

International treaties highlight sex as a prohibited ground for discrimination, which includes discriminatory treatment of intersex people because of their atypical sex characteristics. Specifically, the Committee on Economic, Social and Cultural Rights in General Comment No. 20 on Non-discrimination in economic, social and cultural rights, asserts that: “the notion of the prohibited ground ‘sex’ has evolved considerably to cover not only physiological characteristics but also the social construction of gender stereotypes, prejudices and expected roles, which have created obstacles to the equal fulfilment of economic, social and cultural rights.”

This applies to treatment that discriminates, excludes and stigmatizes people because of their physical characteristics and “ambiguity” of genitalia, chromosomes and hormones. It can be applied to protect individuals with diverse sex characteristics from discrimination within the medical establishment, family environment or overall surroundings.

In 2015, the UN Office of the High Commissioner for Human Rights’s Free and Equal Campaign recognized that people with variations in sex characteristics may face discrimination because of their atypical physiology and because they are not perceived to fit established gender norms.<sup>230</sup> The campaign acknowledges that gaps in national anti-discrimination legislation leaves people with variations in sex characteristics unprotected and therefore at risk of discrimination in many aspects of their lives including in education, workplace and healthcare.

The majority of European countries do not recognize in domestic law variations of sex characteristics as a specific ground of discrimination.<sup>231</sup> However, at the regional level, individuals with variations in sex characteristics are protected from discrimination on the grounds of both sex and genetic features, under the

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226 Creighton, 2001

227 Reifsnnyder et. al, 2016

228 A/64/272, 2009, ‘Right of everyone to the enjoyment of the highest attainable standard of physical and mental health’ Para.49, n.67

229 Article 2.2 of the ICESCR

230 UN OHCHR Fact Sheet: Intersex (Free and Equal Campaign) available from

[http://www.ohchr.org/Documents/Issues/Discrimination/LGBT/FactSheets/UNFE\\_FactSheet\\_Intersex\\_EN.pdf](http://www.ohchr.org/Documents/Issues/Discrimination/LGBT/FactSheets/UNFE_FactSheet_Intersex_EN.pdf)

231 Malta’s Gender Identity, Gender Expression and Sex Characteristics Act of 2015, establishes sex characteristics within its anti-discrimination provisions. (See <http://justiceservices.gov.mt/DownloadDocument.aspx?app=lom&itemid=12312&l=1>). In December 2015, Greece was the second country to legally recognize sex characteristics as a ground of discrimination through the new Civil Partnerships Act (Article 81A of Law 4356).

European Charter of Fundamental Rights.<sup>232</sup> In addition, the Council of Europe Convention on Human Rights and Biomedicine explicitly prohibits discrimination on the grounds of a person's "genetic heritage".<sup>233</sup>

The Council of Europe Commissioner for Human Rights in his 2015 paper on "Human Rights and Intersex People" highlighted continuing patterns of stigmatization and discrimination against people with variations of sex characteristics which derive from normative perceptions of sex and gender linked to specific appearance and behaviour.<sup>234</sup> Legal protection from discrimination is only a first step. States should recognize that discrimination against people with variations in sex characteristics derives from deeply engrained stereotypical notions of sex and gender.



**ANNA,\* MOTHER OF NINA\*<sup>235</sup>**  
**GERMANY**

"I am not aware that these issues are addressed in the public sphere. Even advice centres in the big city have only existed for the past two years. The "classical case" are gay, lesbian or trans people. The letter 'I' has been newly added – because that just is part of it. But this is not reflected in the work. It's got to be possible that biology teachers and ethics teachers receive trainings on this subject. To refer to diversity as part of the school curriculum – are schools ready to do that? There is much to be done in this regard. My background is in social work and I wonder: affected families, the best interest of the child, decisions regarding operations – how much of an obstacle is it that the "Jugendamt" [municipal agencies dealing with the welfare of children] and social workers mostly lack knowledge? There is no training on sexual diversity. There is a need for education everywhere. I need to stop myself: we live in a small city, I must keep in mind that I cannot draw attention to this issue all the time, that I must be careful."

Deep-seated gender stereotypes, lack of education and information on variations of sex characteristics and historical interphobia<sup>236</sup> lead to a conflation of variations of sex characteristics, sexual orientation, and gender identity. Widespread discrimination on the basis of sexual orientation and gender identity can also inform decisions that are made about irreversible surgery on young children, which are often predicated on assumptions about the child's identity.

Therefore, intersex adults can also face direct discrimination on the grounds of their sex characteristics in combination with their gender identity, a ground which has been interpreted by the Committee on Economic, Social and Cultural Rights to fit under the "other status" within the listed grounds of discrimination in General Comment No. 20.<sup>237</sup>

States have an obligation under international law to eliminate harmful gender stereotypes and as an instrument of the state, health institutions and professionals are obliged to work to eliminate and not perpetuate stereotypes. For example, Article 5(a) of the Convention on the Elimination of All Forms of Discrimination against Women requires states "to modify the social and cultural patterns of conduct of men and women, with a view to achieving the elimination of prejudices and customary and all other practices which are based on the idea of the inferiority or the superiority of either of the sexes or on stereotyped roles for men and women."

Furthermore, international organizations such as the World Health Organization,<sup>238</sup> regional human rights institutions<sup>239</sup> and national bodies<sup>240</sup> have all asserted that healthcare professionals should be educated and

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232 European Charter of Fundamental Rights - Article 21

233 Convention for the Protection of Human Rights and Dignity of the Human Being with Regard to the Application of Biology and Medicine: Convention on Human Rights and Bio medicine (ETS No. 164); and the explanatory report to the convention. Germany is one of the Council of Europe member States not to have ratified the Convention on Human Rights and Biomedicine, otherwise known as the Oviedo Convention, while Denmark ratified it in 1999 and was put in force the same year

234 CoE Commissioner for Human Rights, 2015, 'Human Rights and Intersex People' available from <https://rm.coe.int/CoERMPublicCommonSearchServices/DisplayDCTMContent?documentId=09000016806da5d4>

235 Interview with Amnesty International, January 2017

236 As per the terms homophobia and transphobia, interphobia is a term used to describe negative and discriminatory attitudes and perceptions against intersex people.

237 CESCR General comment 20 para 32.

238 WHO and others. 'Eliminating forced, coercive and otherwise involuntary sterilization: An interagency statement,' available from [http://www.who.int/reproductivehealth/publications/gender\\_rights/eliminating-forced-sterilization/en/](http://www.who.int/reproductivehealth/publications/gender_rights/eliminating-forced-sterilization/en/)

239 Council of Europe Commissioner of Human Rights, issue paper on "Human Rights and Intersex People"

240 On the management of differences of sex development: ethical issues relating to "intersexuality". Opinion 20/2012. Berne, Swiss National Advisory Commission on Biomedical Ethics, 2012, pp.18

trained about bodily diversity as well as sexual and related biological and physical diversity as a means to combat gender stereotypes.

In addition, the Convention on the Rights of the Child recognizes that young children are especially at risk of discrimination because they are relatively powerless and depend on others for the realization of their rights.<sup>241</sup> The Committee on the Rights of the Child has highlighted the need for education for children to be empowering and to “strengthen the child’s capacity to enjoy the full range of human rights and to promote a culture which is infused by appropriate human rights values.”<sup>242</sup>

## 5.3 FREEDOM FROM TORTURE AND OTHER CRUEL, INHUMAN OR DEGRADING TREATMENT OR PUNISHMENT

The UN Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment stated in 2008 that: “Whereas a fully justified treatment may lead to severe pain or suffering, medical treatments of an intrusive and irreversible nature, when they lack a therapeutic purpose, ... may constitute torture and ill-treatment if enforced or administered without the free and informed consent of the person concerned.”<sup>243</sup>

In 2011, the UN Committee against Torture in its review of Germany specifically addressed this issue in the context of surgeries on intersex people: “[T]he Committee remains concerned at cases where gonads have been removed and cosmetic surgeries on reproductive organs have been performed that entail lifelong hormonal medication, without effective, informed consent of the concerned individuals or their legal guardians, where neither investigation, nor measures of redress have been introduced. The Committee remains further concerned at the lack of legal provisions providing redress and compensation in such cases”.<sup>244</sup> The Committee made several recommendations regarding informed consent, redress and compensation for medical treatment performed without consent, training for medical professionals, and information provision.<sup>245</sup>

As this chapter has highlighted, the human rights of children, adolescents and adults with variations in sex characteristics are recognized and protected under international law. Human rights treaties provide protection for intersex individuals against discrimination and against violations of the rights of bodily integrity, to a private life, to the highest attainable standard of health, to self-determination and to recognition before the law. However, the research on which this report is based indicates that these protections are not, in practice, fully enforced in current models for dealing with infants and children with variations in sex characteristics in Denmark and Germany.

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241 CRC General Comment 7, on development, para 11 (a)

242 CRC General Comment No. 1: The Aims of Education (article 29) (2001)

243 Interim report of the Special Rapporteur on the question of torture and other cruel, inhuman or degrading treatment or punishment, UN Doc. A/63/175, of 28 July 2008, available from <http://www.ohchr.org/EN/Issues/Disability/Pages/UNStudiesAndReports.aspx> para. 47

244 CAT, ‘Concluding observations of the Committee against Torture: Germany’, CAT/C/DEU/CO/5, available from

[http://tbinternet.ohchr.org/\\_layouts/treatybodyexternal/Download.aspx?symbolno=CAT%2fC%2fDEU%2fCO%2f5&Lang=en](http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CAT%2fC%2fDEU%2fCO%2f5&Lang=en), para.20

245 Full recommendations reproduced in Section 7.3



# 6. LEGAL ANALYSIS

Legislation on access to healthcare, the prohibition of certain medical practices such as female genital mutilation, sterilization and castration as well as broader provisions on consent and medical malpractice, aim to protect children and adults with variations in sex characteristics. However, existing legislation and its implementation may not be sufficient to protect individuals.

Administrative laws, such as birth registration, legal gender recognition and complaints and compensation procedures, may impose restrictions on people with variations in sex characteristics or may act as a point of pressure for parents to make a decision about irreversible genital surgery on their children and gender assignment. The EU Fundamental Rights Agency's report in 2015 on intersex people highlights the problem of parents of intersex children being immediately put under pressure to register the sex of their child as male or female.<sup>246</sup> In 18 EU Member States, including Denmark, parents must register their child within a week.

## 6.1 DENMARK

### 6.1.1 THE DANISH HEALTH ACT

The 2010 Danish Health Act is the primary source of legal provisions applicable to adults and minors with variations in sex characteristics in Denmark.<sup>247</sup> It includes provisions on consent, access to medical records and complaints mechanisms, which aim to protect patients against medical malpractice.

Variations in sex characteristics are not specifically covered by the Health Act, nor are there provisions related to medically unnecessary surgery. Nonetheless, certain legal requirements can be applied to practices of non-emergency, invasive and irreversible surgeries on intersex children which may have harmful effects. Specifically provisions on sterilization and castration<sup>248</sup> are relevant to gonadectomies on minors with gonadal dysgenesis or androgen insensitivity syndrom.

#### CONSENT OF CHILDREN AND PARENTS

In Denmark, the age of consent for medical treatment is 15. Paragraph 17 of the Health Act sets the provisions of consent for minors and gives power of final decision-making, even with parents' objections, to minors aged 15 or over, who also have the right to access their personal medical records at that age.<sup>249</sup> The Health Act does not explicitly address situations of consent for children under the age of 15 regarding medically unnecessary surgery. The Regulation on Cosmetic Surgery prohibits cosmetic surgical procedures (defined as where the main purpose is to change or improve the appearance) on children under the age of 18.<sup>250</sup>

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246 FRA, 'The fundamental rights situation of intersex people,' April 2015

247 LBK nr 1188 af 24/09/2016 Gældende- Sundhedsloven, Offentliggørelsesdato: 29-09-2016, Sundheds- og Ældreministeriet, <https://www.retsinformation.dk/Forms/R0710.aspx?id=183932>

248 Section VIII, Chapter 30 (Sterilisation), Chapter 31 and Chapter 33 (Castration)

249 Section 17, including subsection 3

250 Denmark, Regulation no 834 of 27 June 2014, section 3

Paragraph 16 of the Health Act sets out the right for patients to obtain information about their treatment options: it stipulates that this information must be understandable and tailored to the individual, and that it must include the possible consequences of intervening, as well as of not undergoing medical treatment.

Consent, according to the Health Act, can be given in written or oral form or it can be “tacit” or “implied”.<sup>251</sup> General legal standards on patients who cannot give informed consent provide for the right of the patient, in this case a minor, to express their views as part of their right to be informed and involved in discussions about their treatment, to the extent that they understand the situation.<sup>252</sup> Infants would fall outside this provision, but with older children, physicians simply relaying information to the patient, sometimes after surgery or the administration of long-term hormonal treatment, without allowing them to express their views does not comply with Danish law.

### **CASTRATION AND STERILIZATION**

Section VIII of the Health Act<sup>253</sup> sets the legal provisions around castration and sterilization. Specifically castration is not permitted for people under 18 and <sup>254</sup> sterilization is not permitted for people under 21 years of age. Under the Health Act for a castration or sterilization to take place, the patient must make a request to a doctor or a regional council; the law does not include any provisions for sterilization or castration requests by guardians for minors under 18. Gonadectomies, in the absence of an immediate health risk, on children with undescended testes would qualify as castration and the sterilization provisions of the Health Act.<sup>255</sup>

## **6.1.2 RECORDS, COMPLAINTS MECHANISM AND STATUTE OF LIMITATIONS**

Danish legislation is limited with regards to seeking redress and compensation as a person with variations in sex characteristics who has undergone non-emergency, invasive and irreversible medical intervention with harmful effects as a child. Complaints by patients about health treatment they have received must be lodged within five years of the treatment taking place and no later than two years after they became aware of the treatment (Health Act in conjunction with the Act on Access to Complaints and Compensation).<sup>256</sup>

These provisions do not in effect allow patients with variations in sex characteristics who underwent surgery as children or adolescents to put forward legal complaints concerning their surgery or hormone treatment. This legal timeframe leaves people with variations in sex characteristics without options for redress and compensation. The UN Committee against Torture in its observations of the 6<sup>th</sup> and 7<sup>th</sup> periodic report on Denmark recommended that the state “provide adequate redress for the physical and psychological suffering caused by such practices to intersex persons”.<sup>257</sup>

### **6.1.3 MEDICAL GUIDELINES**

There are no specific official guidelines produced by the Danish Health Authority on variations of sex characteristics. Protocols for the management of DSDs at the national level can be found in the guidelines of different medical specialties. There are sections on variations in sex characteristics within the Guidelines for Endocrinology, Paediatrics, Urology and Plastic Surgery.

Hospitals treating patients, which are also centres of expertise, have developed their own guidelines either on DSDs as a group or on specific variations in sex characteristics. For example, Arhus University Hospital developed its own guidelines,<sup>258</sup> according to which a DSD at birth is classified as: “an acute condition often necessitating acute treatment of a variety of problems”. They state: “it’s important to establish the child’s gender<sup>259</sup> as early as possible”. Physicians from the MDT at Arhus University Hospital told Amnesty International that the guidelines are out-of-date as they are from 2008 and stated that they are currently under review, and in the meantime they follow the latest international guidelines.<sup>260</sup>

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251 Danish Health Act, Paragraph 15, section 4.

252 Danish Health Act, Paragraph 20

253 Specifically paragraphs 104-117 in Chapters 29-33 of the Health Act

254 Danish Health Act, Section 3 of paragraph 115

255 Danish Health Act, paragraphs 104-117

256 Act on Access to Complaints and Compensation within the health system, section 4.

257 CAT/C/DNK/CO/6-7

258 Arhus University Hospital guidelines on Disorders of Sexual Development 2008

259 In Danish, the word *kon* denotes both sex and gender and there is no differentiation.

260 Interview with Arhus University Hospital, September 2016, and subsequent email, April 2017

The Arhus guidelines contain recommendations, for example, that genital surgery be offered at 12-15 months for children with “true hermaphroditism and/or gonadal dysgenesis”. They also note the psychological effects and the need for follow-up: “In some places around the world the question of when operations should take place has been raised. It is believed it would be more correct to wait for any intervention and gender correction until such time as the patient in question is able to make the decision him/herself. In Denmark this is however unthinkable, as we do not consider it to be possible for a child to develop psychologically without defined outer genitalia. Our recommendations are therefore unchanged – operations should be conducted in accordance to chromosomal and phenotypic gender. The child should at appropriate time, and slowly, be informed about his/her treatment, and the consequences thereof.”<sup>261</sup>

## 6.1.4 BIRTH REGISTRATION

Personal data about Danish citizens and residents is stored in the Civil Registration System (CRS). The data includes information about the date of birth, the gender and the CPR (*det Centrale Personregister*), which is a unique 10-digit number. The CPR number includes a gender marker.<sup>262</sup> Medical professionals themselves stated that it is difficult to change the CPR number given to a person at birth,<sup>263</sup> a fact that further complicates the process of gender affirmation if the original sex assignment is found to be wrong.

## 6.1.5 LEGAL GENDER RECOGNITION AND ACCESS TO GENDER-AFFIRMING TREATMENT

All the doctors Amnesty International spoke to in Denmark confirmed that if an individual with a variation of sex characteristics was assigned the ‘wrong’ gender<sup>264</sup> via surgery or other treatment, they would have to go through the existing system of trans-specific healthcare to be able to affirm their gender. Amnesty International requested information from the Danish Sexology Clinic on how many intersex people were referred to them; at the time of publication, this information had not yet been received.

This has implications not only for legal gender recognition of gender but also for access to appropriate healthcare. Individuals who seek, for example, hormone treatment appropriate to their identified gender, not their assigned gender, must seek recognition through the process designed for trans people.

## 6.2 GERMANY

### 6.2.1 CRIMINAL AND PRIVATE LAW

German legislation does not ban non-emergency, invasive and irreversible surgeries on infants and children too young to consent. The German Inter-ministerial Working Group (IMAG, see below 6.2.4) has stated that under existing German criminal law, parents cannot generally consent to ‘feminizing,’ ‘masculinizing’ or ‘disambiguation’ surgeries, absent medically necessary and urgent cases.<sup>265</sup> The Civil Code in Germany also prohibits the sterilization of children.<sup>266</sup> Legal experts, however, disagree on the extent to which the existing provisions cover gonadectomies of intersex children, and its scope has not yet been decided by the courts.<sup>267</sup>

In 2017, the German National Human Rights Institution – commissioned by the Family Ministry – produced a proposal for an amendment to the Civil Code prohibiting surgeries on children’s genitals, inner

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261 Arhus University Hospital guidelines on Disorders of Sexual Development 2008

262 *The state decides who I am*, pp.31

263 Interview with Arhus University Hospital- September 2016

264 i.e. a gender with which they did not identify

265 IMAG, “The situation of transgender and intersex persons in focus”, 2016, p.19

266 Section 1631c of the Civil Code: Prohibition of sterilization: “The parents may not consent to a sterilization of the child. Nor can the child itself consent to the sterilization. [...]” Original available at: [https://www.gesetze-im-internet.de/englisch\\_bgb/englisch\\_bgb.html#p5752](https://www.gesetze-im-internet.de/englisch_bgb/englisch_bgb.html#p5752)

267 IMAG, “The situation of transgender and intersex persons in focus”, 2016, annex 6

reproductive organs or gonads without a court order obtained by the parents.<sup>268</sup> The Family Ministry is now considering whether to take forward this proposal.

## 6.2.2 BIRTH REGISTRATION

On 1 November 2013, a modification to the German Personal Status Law came into effect requiring that, if it is not possible to assign the child a sex, the sex marker in the birth registry be left blank.<sup>269</sup>

“Section 22(3) If the child can be assigned to neither the female nor the male sex, then the child is to be entered into the register of births without such a specification”.<sup>270</sup>

While the legislation did draw attention to the challenges faced by intersex people, it has been widely criticized by intersex activists. Lucie Veith, head of Intersexuelle Menschen, told Amnesty International: “this [requirement] is discrimination against that child. Everyone in school or kindergarten would know this is an intersex child – they are outed, there is no privacy.”<sup>271</sup>

It is not clear whether the infrastructure to allow blank registrations was widely in place at the time of writing. A psychologist in a multidisciplinary team told Amnesty International: “We had one family who wanted to leave the gender open for their child but the local office did not know how to do it. It took six months to get health insurance cards”.<sup>272</sup> In the two years after the new law came into effect, only 12 children were registered without a sex marker in the birth registry.<sup>273</sup>

## 6.2.3 PERSONAL STATUS LAW

In Germany, health insurance cards depend on your personal code and the gender on your birth certificate. Intersex people whose gender presentation does not match their documentation, face ongoing challenges and can be at increased risk of discrimination.<sup>274</sup> Frances, an activist from Germany, told Amnesty International: “I have female papers and every time I see a new doctor, I have to tell them to treat me as a male according to my XY chromosomes. You have to out yourself to every doctor, every receptionist.”<sup>275</sup>

Frances and Claudia are an intersex married couple whose papers say female and male respectively. Neither can access a change of documentation without risking their marriage rights. They told Amnesty International, “we do not want a marriage of secondary importance.”<sup>276</sup> While Germany has permitted registered life partnerships for same-sex couples since 2001<sup>277</sup> and a 2008 Constitutional Court decision ruled that a marriage in which one of the partners was transgender remained valid,<sup>278</sup> there is as yet no legal clarity on the retention of marriage rights for intersex people who seek a change or removal of their gender marker.

## 6.2.4 GOVERNMENT INITIATIVES

Following the 2009 CEDAW review of Germany where the Committee requested German “to enter into dialogue with non-governmental organizations of intersexual and transsexual people in order to better

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268 Report about the protection and recognition of the diversity of sexual identities in the context of German Law, with particular consideration of transgender and intersexual identities

Conducted by the German Institute for Human Rights

<https://www.bmfsfj.de/blob/114066/e06661c7334f58078eccfc8332db95cc/geschlechtervielfalt-im-recht---band-8-data.pdf>

269 The Bundestag on 31 January 2013 unanimously adopted recommendation 17/12192 (available from

<http://dip21.bundestag.de/dip21/btd/17/121/1712192.pdf>) of the Civil Liberties Committee (see

[http://www.bundestag.de/dokumente/textarchiv/2013/42726396\\_kw05\\_angenommen\\_abgelehnt/210774](http://www.bundestag.de/dokumente/textarchiv/2013/42726396_kw05_angenommen_abgelehnt/210774))

270 Translation of law provided by OII Europe <http://oiiieurope.org/bluff-package-for-inter-leaving-sex-entry-open-is-not-an-option/>

271 Interview with Lucie Veith, Hamburg, September 2016

272 Interview, November 2016

273 Registrations during the period November 2013 - November 2015. Data from: German Institute for Human Rights, ‘Geschlechtervielfalt im Recht Status quo und Entwicklung von Regelungsmodellen zur Anerkennung und zum Schutz von Geschlechtervielfalt’, available from

<https://www.bmfsfj.de/blob/114066/e06661c7334f58078eccfc8332db95cc/geschlechtervielfalt-im-recht---band-8-data.pdf>

274 For more information on the challenges faced by people whose gender presentation and expression does not match their documentation in Germany, see Amnesty International, 2013, *The state decides who I am*, pp. 83-89.

275 Interview with Frances, Trier, 9 November 2016

276 Interview with Frances, Trier, 9 November 2016

277 *Eingetragene Lebenspartnerschaft* provide most but not all of the rights of marriage.

278 See TGEU, <http://tgeu.org/germany-constitutional-court-rules-divorce-requirement-in-gender-recognition-is-incompatible-with-the-basic-law/>

understand their claims and to take effective action to protect their human rights,”<sup>279</sup> the German Ministries of Education and Research and of Health instructed the German Ethics Council to “continue the dialogue with intersex people and their support groups.”<sup>280</sup> In its report, published in 2012, the Council distinguished between “intersexuality...[which] relates to persons who cannot be unambiguously categorized as male or female”,<sup>281</sup> and “DSD...[used here] in accordance with the prevailing conception in the debate in Germany today, to mean *differences of sex development*” [emphasis in original].<sup>282</sup>

The report further distinguished between “sex ambiguity correction” and “sex assignment”, the former aiming “to bring anatomical particularities of the external sex organs into line with the existing sex where the person otherwise belongs unambiguously to a given sex”, and the latter “intended to put an end to the state of ambiguity where unequivocal categorization really is impossible.”<sup>283</sup>

The report also states: “Whereas ambiguity correction interventions, for example, correct a biochemical/hormonal dysfunction that is potentially harmful to health and bring the individual’s biochemical and anatomical sex into line with that individual’s genetic sex, in the case of sex assignment treatments parents and doctors are interfering much more profoundly with the child’s personality, because they are deciding, in the case of uncertainty, to which sex the child is to belong.”<sup>284</sup>

While the report recognized that irreversible sex assignment surgery constitutes an “interference with the rights to physical integrity, to the preservation of sexual and gender identity, to an open future and often also to procreative freedom”,<sup>285</sup> it does not say the same about sex ambiguity correction. This omission has drawn criticism from intersex activists<sup>286</sup> who argue that it does not criticise non-emergency, invasive and irreversible surgeries with harmful effects when the sex of rearing is not in question.

In 2014, the Federal Ministry for Family Affairs, Senior Citizens, Women and Youth set up a “Same-sex Lifestyles, Gender Identities” Division. One of its initiatives was the creation in September 2014 of the Inter-ministerial Working Group (IMAG) on the Situation of Intersex and Trans Persons.<sup>287</sup> This IMAG has released an interim report, ‘The situation of transgender and intersex persons in focus’<sup>288</sup> and held consultations on psycho-social support and counselling for intersex people.

## 6.2.5 HEALTHCARE FUNDING

The German national statutory health insurance system covers 85% of the German population.<sup>289</sup> Hospitals are reimbursed for the operations and procedures carried out.<sup>290</sup> This creates a financial incentive to provide treatment that can be reimbursed.

The process of diagnosis is underfunded in the German healthcare system. An endocrinologist in a multidisciplinary team told Amnesty International: “We are not reimbursed for our expertise. Consultations are reimbursed very little. As a surgeon, you can only get money if you operate. We can claim but it doesn’t cover the actual costs. The general consultation fee is €70 and four or five experts spend three or four hours making a decision. This is a general problem for rare conditions and it’s known that this is a problem.”<sup>291</sup>

## 6.2.6 2016 GUIDELINES

In July 2016, the German Society of Urology, the German Society for Paediatric Surgery and the German Society for Paediatric Endocrinology and Diabetes drew up a new set of guidelines for the medical treatment

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279 CEDAW/C/DEU/CO/6 para. 62

280 Ethics council paper, p.9

281 Ethics council paper, p.9-10

282 Ethics council paper, p.11-12

283 Ethics council paper, pg.26

284 Ethics council paper, pg.100

285 Ethics council paper, pg.163-4

286 See for example Ghattas, ‘Human Rights Between the Sexes’ p.34

287 The Ministries involved are the Family, Internal Affairs, Justice, Health Care and Defence

288 IMAG, ‘The situation of transgender and intersex persons in focus’, 2016

289 Obermann et al, ‘Understanding the German Healthcare System’, 2013, available from <https://www.goinginternational.eu/wp/de/understanding-the-german-health-care-system/>, p.163

290 Obermann et al, ‘Understanding the German Healthcare System’, 2013, available from <https://www.goinginternational.eu/wp/de/understanding-the-german-health-care-system/>, p.188. There are other factors affecting the reimbursement including ICD diagnosis, age, sex, and length of hospital stay.

291 Interview,, November 2016

of individuals with variations in sex characteristics.<sup>292</sup> These were compiled in collaboration with other organizations of medical specialists as well as three support groups: XY-Frauen, Intersexuelle Menschen and the AGS Parent and Patient Initiative.

The AGS Parent and Patient Initiative, however, has partially criticised the new guidelines, and a statement from the initiative is included in the appendix to the guidelines, in which the Initiative states that many of their members are happy with the results of their surgery and glad that it took place at a young age. The statement specifically references surgeries to separate the vagina and urethra, and further states that gender assignment is not relevant for AGS patients because they consider themselves as people with a metabolic disorder and “have clear female internal sex organs and clearly female genes.”<sup>293</sup> Uschi Durant, member of the extended board of the Initiative, told Amnesty International “People often say that parents of children with AGS make operations for cosmetic reasons but there are various medical reasons to prevent health problems. The grouping of people with AGS into the DSD group is incomprehensible for most affected parties. People with AGS do not care about a gender assignment but about the survival of a serious metabolic disorder”<sup>294</sup>

The guidelines are not binding and not all doctors follow them. Gerda Janssen-Schmidchen, who runs the XY-Frauen and Intersexuelle Menschen parents’ groups, told Amnesty International: “There are four levels of guidelines and these are second level.<sup>295</sup> If they were third or fourth level, doctors would have to provide reasons about why they are not following them. I’m pretty sure that some doctors have implemented them – but doctors can choose and decide in a different way.”<sup>296</sup>

## 6.2.7 REPARATIONS AND STATE ACCOUNTABILITY

Under international human rights law, Germany has an obligation to ensure that individuals who have suffered human rights violations can access appropriate remedies.

Two private cases have been successful in Germany. In 2009, the Regional Court of Cologne found that the surgeon who carried out an operation for the removal of a women’s reproductive organs in 1977 had not fully informed her of the true nature and extent of the surgical procedure, and thus had not obtained informed consent. The surgeon was ordered to pay €100,000 in compensation.<sup>297</sup> However, this was one of the very rare cases where a person operated on without their informed consent was able to obtain redress. In December 2015, one individual won a provisional court judgment against the Erlangen University hospital where she was treated in 1995 at the age of 19.<sup>298</sup>

People with variations in sex characteristics who have undergone genital surgery at a very young age or who have been diagnosed in circumstances of secrecy have historically had difficulties in accessing their medical records. In Germany, intersex adults told Amnesty International of the obstacles they faced by simply trying to retrieve their medical history and information and finding out what happened to their bodies.

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292 S2k-Leitlinie 174/001: Varianten der Geschlechtsentwicklung aktueller Stand: 07/2016 1, available from [http://www.awmf.org/uploads/tx\\_szleitlinien/174-001l\\_S2k\\_Geschlechtsentwicklung-Varianten\\_2016-08\\_01.pdf](http://www.awmf.org/uploads/tx_szleitlinien/174-001l_S2k_Geschlechtsentwicklung-Varianten_2016-08_01.pdf) (hereinafter: 2016 Guidelines)

293 2016 Guidelines page 24

294 Interview, February 2017

295 S2k according to the S-classification used by the Association of Scientific Medical Societies in Germany, which coordinates the development of medical guidelines. For more information see p.10, available from [http://www.awmf.org/fileadmin/user\\_upload/Leitlinien/AWMF-Regelwerk/AWMF-Guidance\\_2013.pdf](http://www.awmf.org/fileadmin/user_upload/Leitlinien/AWMF-Regelwerk/AWMF-Guidance_2013.pdf)

296 Interview with Gerda Janssen-Schmidchen, Emden, 10 November 2016

297 Case summary: <https://www.icj.org/sogicasebook/in-re-volling-regional-court-cologne-germany-6-february-2008/>. Compensation awarded 2009: <http://zwischenengeschlecht.org/pages/Hermaphrodite-wins-damage-claim>

298 <https://www.justiz.bayern.de/gericht/olg/n/presse/archiv/2015/05075/index.php>

# 7. RECOMMENDATIONS

## 7.1 GENERAL RECOMMENDATIONS

- States should develop and implement a rights-based healthcare protocol for individuals with variations of sex characteristics to guarantee their bodily integrity, autonomy and self-determination and to ensure that no child is subjected to non-emergency, invasive and irreversible surgery or treatment with harmful effects
- States should take steps to regulate healthcare providers with the intent of postponing non-emergency, invasive and irreversible genital surgery or hormone treatment on infants and children with variations in sex characteristics until they are able to meaningfully participate in decision making and give their informed consent, in line with the principle of evolving capacities of children and adolescents
- States should make legal gender recognition available through an accessible and smooth process to adults and to minors, taking under consideration their evolving capabilities.
- Long-term psychological support should be available to families and children with variations in sex characteristics
- Individuals who have undergone surgeries should be able to access long-term psychological support
- Sex characteristics should be explicitly recognized as a prohibited ground of discrimination in anti-discrimination legislation.
- Guidelines on the treatment of individuals with variations in sex characteristics should be developed with the active participation of intersex organizations, activists, parents and peer support groups, and ensure accountability mechanisms. The views of children with variations of sex characteristics should be taken into account when developing these policies.
- Medical professionals should receive education and training on variations in sex characteristics
- Disaggregated data should be collected on diagnoses of variations of sex characteristics, and operations linked to these diagnoses, that are taking place annually.
- States should take steps to uphold their obligations to eliminate harmful practices based on gender stereotypes

## 7.2 DENMARK

- To Parliament: Introduce sex characteristics as a ground of discrimination in the Danish Act on Non-discrimination, the Danish Act on Equal Treatment and relevant anti-discrimination provisions within legislation in the areas of health, housing, education and employment, as well as hate crime legislation.

- To the Minister for Health: instruct the Danish Health Authority to develop – in consultation with individuals with variations in sex characteristics and activists working on these issues - guidelines at the national level for responding to people with variations in sex characteristics that are human rights-focused and include an emphasis on postponing non-emergency, invasive and irreversible genital surgery or hormone treatment on infants and children with variations in sex characteristics until they are able to meaningfully participate in decision making and give their informed consent, in line with the principle of evolving capacities of children and adolescents
- To the Ministry of Health: in consultation with individuals with variations in sex characteristics and activists working on these issues, develop and provide mandatory training to medical and healthcare professionals on gender and bodily diversity, focusing on individuals with variations in sex characteristics.
- To the Ministry of Health: Ensure that resources are available to provide long-term psychological support to adults, adolescents and children with variations in sex characteristics and their parents
- To the Ministry of Health: Individuals should be able to access their medical records
- To Parliament: implement a mechanism through which the state will provide compensation or other reparations to adults who underwent harmful and unnecessary medical treatments
- To the Danish Government: ensure that individuals with variations in sex characteristics who seek gender reaffirming treatment in accordance with their gender identity can access it
- To the Danish Government: Ensure that individuals with variations of sex characteristics should be able to access legal recognition of their gender through a quick, transparent, and accessible process. Biological characteristics or medical diagnoses should not be used to justify additional barriers to accessing legal gender recognition.

## 7.3 GERMANY

- To the Ministry of Health: take steps to ensure that all medical professionals implement July 2016 guidelines on the treatment of individuals with variations of sex characteristics (S2k-Leitlinie 174/001 Varianten der Geschlechtsentwicklung), and to develop and implement a rights-based healthcare protocol for individuals with variations of sex characteristics to guarantee their bodily integrity, autonomy and self-determination and to ensure that no child is subjected to non-emergency, invasive and irreversible surgery or treatment with harmful effects
- To the Ministry of Health: Ensure that hospitals postpone non-emergency, invasive and irreversible genital surgery or hormone treatment on infants and children with variations in sex characteristics until they are able to meaningfully participate in decision making and give their informed consent, in line with the principle of evolving capacities of children and adolescents
- To the Ministry of Health: Ensure that health insurance funds consultation and diagnosis of variations of sex characteristics
- To the Ministry of Health: Ensure that health insurance funds psychological support for adults and children with variations of sex characteristics, as well as for parents of children with variations of sex characteristics
- To the Ministry of the Interior: Ensure that individuals who wish to change their assigned sex are able to do so through a quick, transparent and accessible procedure
- To the Federal Anti-Discrimination Agency: Protect and promote equal treatment of individuals with variations of sex characteristics in law and practice
- To Parliament: end discrimination in civil marriage laws on the grounds of sex, including for individuals with variations of sex characteristics
- To Parliament: implement a mechanism through which the state will provide compensation or other reparations to adults who underwent harmful and unnecessary medical treatments
- To all political parties: Ensure that a continuation of the Inter-ministerial Working Group's work on intersex issues is part of their election manifestoes for the 2017 federal elections



- To the German Government: Implement the recommendations made by the Committee Against Torture in its 2011 review of Germany:<sup>299</sup>
  - (a) Ensure the effective application of legal and medical standards following the best practices of granting informed consent to medical and surgical treatment of intersex people, including full information, orally and in writing, on the suggested treatment, its justification and alternatives;
  - (b) Undertake investigation of incidents of surgical and other medical treatment of intersex people without effective consent and adopt legal provisions in order to provide redress to the victims of such treatment, including adequate compensation;
  - (c) Educate and train medical and psychological professionals on the range of sexual, and related biological and physical, diversity; and
  - (d) Properly inform patients and their parents of the consequences of unnecessary surgical and other medical interventions for intersex people.

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299 CAT, 'Concluding observations of the Committee against Torture: Germany', CAT/C/DEU/CO/5, available from [http://tbinternet.ohchr.org/\\_layouts/treatybodyexternal/Download.aspx?symbolno=CAT%2fC%2fDEU%2fCO%2f5&Lang=en](http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CAT%2fC%2fDEU%2fCO%2f5&Lang=en), para.20

# 8. APPENDIX: MALTA DECLARATION

As drawn up at the Third International Intersex Forum, 2013.<sup>300</sup>

## PREAMBLE

We affirm that intersex people are real, and we exist in all regions and all countries around the world. Thus, intersex people must be supported to be the drivers of social, political and legislative changes that concern them.

We reaffirm the principles of the First and Second<sup>301</sup> International Intersex Fora and extend the demands aiming to end discrimination against intersex people and to ensure the right of bodily integrity, physical autonomy and self-determination.

## DEMANDS

- To put an end to mutilating and “normalising” practices such as genital surgeries, psychological and other medical treatments through legislative and other means. Intersex people must be empowered to make their own decisions affecting own bodily integrity, physical autonomy and self-determination.
- To put an end to preimplantation genetic diagnosis, pre-natal screening and treatment, and selective abortion of intersex fetuses.
- To put an end to infanticide and killings of intersex people.
- To put an end to non-consensual sterilisation of intersex people.
- To depathologise variations in sex characteristics in medical guidelines, protocols and classifications, such as the World Health Organization’s International Classification of Diseases.
- To register intersex children as females or males, with the awareness that, like all people, they may grow up to identify with a different sex or gender.
- To ensure that sex or gender classifications are 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. In the future, as with race or religion, sex or gender should not be a category on birth certificates or identification documents for anybody.
- To raise awareness around intersex issues and the rights of intersex people in society at large.
- To create and facilitate supportive, safe and celebratory environments for intersex people, their families and surroundings.

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<sup>300</sup> Text from the OII Europe website: <http://oiiurope.org/malta-declaration/>. Reproduced for reference. Amnesty International is not a signatory to this Declaration, which was created by intersex activists and intersex-led organisations.

<sup>301</sup> <http://oiiurope.org/the-second-international-intersex-forum-has-just-concluded-in-stockholm-with-an-affirmation-of-seven-key-demands-and-priorities-for-intersex-people/>

- To ensure that intersex people have the right to full information and access to their own medical records and history.
- To ensure that all professionals and healthcare providers that have a specific role to play in intersex people's wellbeing are adequately trained to provide quality services.
- To provide adequate acknowledgement of the suffering and injustice caused to intersex people in the past, and provide adequate redress, reparation, access to justice and the right to truth.
- To build intersex anti-discrimination legislation in addition to other grounds, and to ensure protection against intersectional discrimination.
- To ensure the provision of all human rights and citizenship rights to intersex people, including the right to marry and form a family.
- To ensure that intersex people are able to participate in competitive sport, at all levels, in accordance with their legal sex. Intersex athletes who have been humiliated or stripped of their titles should receive reparation and reinstatement.
- Recognition that medicalization and stigmatisation of intersex people result in significant trauma and mental health concerns.
- In view of ensuring the bodily integrity and well-being of intersex people, autonomous non-pathologising, psycho-social and peer support be available to intersex people throughout their life (as self-required), as well as to parents and/or care providers.

**IN VIEW OF THE ABOVE THE FORUM CALLS ON:**

1. International, regional and national human rights institutions to take on board, and provide visibility to intersex issues in their work.
2. National governments to address the concerns raised by the Intersex Forum and draw adequate solutions in direct collaboration with intersex representatives and organisations.
3. Media agencies and sources to ensure intersex people's right to privacy, dignity, accurate and ethical representation.
4. Funders to engage with intersex organisations and support them in the struggle for visibility, increase their capacity, the building of knowledge and the affirmation of their human rights.
5. Human rights organisations to contribute to build bridges with intersex organisations and build a basis for mutual support. This should be done in a spirit of collaboration and no-one should instrumentalize intersex issues as a means for other ends.

**AMNESTY INTERNATIONAL  
IS A GLOBAL MOVEMENT  
FOR HUMAN RIGHTS.  
WHEN INJUSTICE HAPPENS  
TO ONE PERSON, IT  
MATTERS TO US ALL.**

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# FIRST, DO NO HARM

## ENSURING THE RIGHTS OF CHILDREN WITH VARIATIONS OF SEX CHARACTERISTICS IN DENMARK AND GERMANY

Every year, children are born with sex characteristics – genitals, gonads, hormones, chromosomes or reproductive organs – which vary from the established norms for ‘male’ and ‘female’. In this report, Amnesty International documents the specific human rights violations faced by children with variations of sex characteristics in Denmark and Germany, and the lifelong effect of these violations.

The report focuses in particular on subjection to non-emergency invasive and irreversible surgeries and other medical treatments. These interventions may violate human rights, including the rights of the child, the right to physical and bodily integrity and the right to the highest attainable standard of health.