



NO SHAME IN DIVERSITY

THE RIGHT TO HEALTH FOR PEOPLE WITH VARIATIONS OF SEX CHARACTERISTICS IN ICELAND

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Cover photo: Pipette and DNA samples on DNA autoradiogram. Many variations of sex characteristics are associated with chromosomal variations.

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GLOSSARY

WORD	DESCRIPTION
ANDROGEN INSENSITIVITY SYNDROME (AIS)	A variation in which the body cannot respond to androgens, affecting the development of genitalia in the foetus; includes complete androgen insensitivity syndrome (CAIS), in which a person's body does not respond at all to androgens, and partial androgen insensitivity syndrome (PAIS) in which the body has some response.
BIOLOGICAL SEX	The set of biological and reproductive attributes and characteristics of a person.
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. In some countries it is also called androgenital syndrome (AGS).
DISORDER OF SEX DEVELOPMENT (DSD)	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.
GENDER	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.
GENDER BINARY	Interpretations of gender which assume only two gender identities, male and female, and which usually define these as distinct from each other with no overlap, and oppositional.
GENDER IDENTITY	Each person's deeply felt internal and individual experience of gender, which may or may not correspond with the sex assigned at birth.
HYPOSPADIAS	Refers to a situation in which the hole through which urine passes is not at the tip of the penis.
INTERSEX	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. 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.
KLINFELTER SYNDROME	A variation in sex characteristics in which a person is born with 47 chromosomes and XXY sex chromosomes.

WORD	DESCRIPTION
'NORMALISING' GENITAL SURGERY	Operations intended to construct or reconstruct the genitalia of a person to comply with the normative medical standards of male or female appearance.
PRIMARY SEX CHARACTERISTICS	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).
SECONDARY SEX CHARACTERISTICS	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.
SEX ASSIGNMENT	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.
SEX CHARACTERISTICS	Physical traits or organs that can be indicative of an individual's biological sex and are distinguished into primary and secondary sex characteristics.
SEXUAL ORIENTATION	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.
TURNER SYNDROME	A variation in sex characteristics in which a person is born with 45 chromosomes, and one X sex chromosome.
VARIATION OF SEX CHARACTERISTICS	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

“Good healthcare is so hard to get because we are seen as ‘disorders’ that need to be fixed.”

Kitty, founder and chair of Intersex Iceland

Every year, children are born with sex characteristics (genitals, gonads, hormones, chromosomes or reproductive organs) that 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. Some variations of sex characteristics are never detected or diagnosed.

An estimated 1.7% of people worldwide are born with variations of sex characteristics (some – but not all – people with a variation of sex characteristics use the term ‘intersex’ to describe themselves). In Iceland, this indicates around 6,000 individuals.

In this report, Amnesty International documents the specific human rights violations faced by children and adults with variations of sex characteristics in Iceland. Our research found that the lack of clear protocols and multidisciplinary care, combined with inadequate social support for individuals with variations of sex characteristics and their families as they navigate Iceland’s health care system, undermines their ability to access the highest attainable standard of physical and mental health. It also puts individuals with variations of sex characteristics at risk of other human rights violations.

Amnesty International also found that despite Iceland’s worldwide reputation for gender equality (Iceland has ranked top of the World Economic Forum Global Gender Gap Index every year since 2009) gender stereotypes and discrimination persist. As a result, individuals whose sex characteristics are perceived not to meet standards for ‘male’ and ‘female’ may be subjected to discrimination and attempts to ‘normalise’ their bodies through surgical and hormone treatment.

1.1 METHODOLOGY

Individuals with variations of sex characteristics face violations of their human rights all around the world. Our report focuses on Iceland; however, there is emerging evidence that similar situations – and thus similar human rights violations – may occur in other countries around the world and we expect that some findings and recommendations are more widely applicable.

The information contained in this report was collected through research undertaken from February 2018 to January 2019, which included desk and field-based research. We reviewed medical literature, including updates and developments since our previous report on this topic was published in May 2017. We also reviewed human rights research on the rights of individuals with variations of sex characteristics worldwide, and drew on information provided, and discussions that took place at, conferences and formal and informal meetings with intersex rights activists across Europe.

For this report, Amnesty International interviewed 21 individuals, including two adults with variations of sex characteristics, four family members of individuals with variations of sex characteristics, and two adults with hormone conditions. Some names have been changed at the individuals’ request; these are marked with an

asterisk. Several interviewees agreed to speak with us but asked that their testimonies be excluded from the final report.

Many of the people interviewed discussed the specific challenges faced in Iceland – a country with an extremely small population. They commented on how living in a small and close-knit community can exacerbate the stigma of feeling in some way variant from a ‘norm.’ This goes some way to explaining the small number of people willing to speak to Amnesty International as part of this research.

Amnesty International also interviewed 13 medical professionals, covering specialities including paediatric and adult endocrinology, neonatology, surgery, midwifery, child psychology and gynaecology. Almost all of these interviewees had direct experiences working with individuals with variations of sex characteristics. Not all of the medical professionals agreed to be named in this report: those who did not are identified by their specialism or, where that would identify them, as ‘medical professionals’.

1.2 MEDICAL PRACTICES

Some variations of sex characteristics require urgent intervention. However, Amnesty International found evidence that in Iceland, children who are born with visible variations of 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.

Children with salt-wasting congenital adrenal hyperplasia (a variation in which individuals cannot produce certain kinds of hormones, and over-produce others) receive hormone treatments as life-saving treatments from infancy. Children and adolescents with other variations of sex characteristics may naturally not produce hormones – or if they underwent gonadectomy, may not be able to produce hormones as a result – and so may receive hormone replacement treatments to ‘mimic normal puberty’.

Surgical treatments that are carried out in Iceland include gonadectomies, operations on the genitals, and vaginoplasties. Gonadectomies – removal of the gonads – are irreversible and result in the need for lifelong hormone treatment. They are performed on individuals whose gonads are deemed inconsistent with their other sex characteristics. Genital operations include operations on the clitoris or the penis. Clitoral operations are rare in Iceland but do take place. Operations on the penis to reposition the urethral opening (hypospadias repair) are more frequent and are carried out on children around the age of nine months to one year, while children with congenital adrenal hyperplasia undergo vaginoplasties between the ages of one and two.

Individuals who spoke to Amnesty International reported that surgeries and hormone treatment had detrimental impact on their quality of life for many years. This was compounded by a lack of access to medical records.

While attitudes are shifting and medical professionals now support giving children information about their biology, individuals who underwent treatment prior to this shift experienced shame and stigma, and may not have full information about what was done to their bodies.

Although an estimated 1.7% of individuals have variations of sex characteristics, the range of possible diagnoses means the prevalence of individual medical diagnoses is low and medical professionals may see very few cases throughout their careers. Nonetheless, groups of medical professionals across different countries have produced a series of ‘Consensus Statements’ since 2006, which make recommendations for the medical care of individuals with variations of sex characteristics.

“These kinds of cases are so rare, they should be treated in a specialist centre... In the past, mistakes have been made. But with a multidisciplinary team, we are less and less likely to make mistakes.”

Kolbeinn Guðmundsson, paediatric endocrinologist

One clear international recommendation is that care be provided by multidisciplinary teams of medical professionals working together in order to provide optimum care to individuals with variations of sex characteristics. These teams vary across different countries and centres of medical care, but often include specialists in disciplines including endocrinology, urology, gynaecology, andrology, psychology, nursing, social work, genetics and medical ethics: the aim of the multidisciplinary team is to provide holistic care to individuals.

There is no multidisciplinary team for individuals with variations of sex characteristics in Iceland. Consequently, Amnesty International's research found, individuals may be under the care of a single coordinating doctor and may or may not receive care and support from other specialists.

There is no overarching protocol in Iceland for providing medical care for individuals with variations of sex characteristics. Since Iceland has a small medical community, medical professionals frequently use protocols for specific diagnoses, developed overseas, and collaborate with medical professionals based in other countries. These protocols may not be rights-based and they have not been developed in collaboration with affected individuals.

“They don’t treat individuals on the basis of how you feel, they go by norms, and the norms are set by humans.”

Kristin, mother of an adult with variations of sex characteristics

The lack of rights-based healthcare protocols for conditions related to variations of sex characteristics in Iceland creates a climate in which human rights violations can occur. This includes violations of the right to the highest attainable standard of health, as well as of the right to freedom from discrimination and from harmful gender stereotypes.

The combined lack of a multidisciplinary team and formal, rights-based protocols, means that individuals with variations of sex characteristics – and their families – are left to navigate the healthcare system on their own and may not be able to access psychosocial support. There are no patient support groups for individuals with variations of sex characteristics, and medical professionals may advise people to look into international support groups.

“There is no overall guidance system: the state takes care of some things, the hospital takes care of other things, then there are the healthcare centres, the schools, the municipalities, and they don’t talk together.”

Snjólaug Sveinsdóttir, neonatologist

Medical professionals who spoke to Amnesty International recognised the importance of support for individuals and their families, but acknowledged that in Iceland there is not enough support, particularly for parents of children with variations of sex characteristics. Parents who spoke to Amnesty International emphasised that they did not feel they had enough information or support to be able to support their children.

1.3 GENDER STEREOTYPING AND SEX ASSIGNMENT

In discussions about individuals with variations of sex characteristics worldwide, there is frequently a conflation between *legal* sex assignment (the process of registering a child as male or female on a birth certificate and/or in a central registry) and *medical* sex assignment (the process of ‘normalising’ a person’s body so that they look closer to the ‘norms’ for male and female). While these two concepts are entirely distinct, in practice – historically and today – they are frequently conflated in discussions and decision-making involving individuals with variations of sex characteristics.

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; so that they prevent psychological damage and bullying of the child when they start socialising with other children.

“I would like to see doctors start listening to the patients. Our current doctor, she is always comparing Briet to a ‘normal’ woman who has had her ovaries removed, but she is not like that.”

Hrefna, mother of an adult with variations of sex characteristics

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, result in interventions being carried out that are not in the best interests of the child.

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 both

physiological characteristics and the social construction of gender stereotypes and prejudices. Iceland does not explicitly include sex characteristics as protected grounds in anti-discrimination provisions.

1.4 VIOLATIONS OF THE RIGHT TO HEALTH

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 from discrimination and from the violation of their rights to the highest attainable standard of health, to freedom from discrimination and harmful gender stereotyping, and to an effective remedy. These rights as they pertain specifically to sex characteristics are expressed in the Yogyakarta Principles (2006) and the Yogyakarta Principles+10 (2017). Iceland, alongside all states parties to the International Covenant on Economic, Social and Cultural Rights (ICESCR), has a responsibility to ensure that all members of society, including health professionals, fulfil their responsibilities regarding the realisation of the right to health.

Iceland has ratified the Convention on the Rights of the Child (CRC), which strengthens the position of children as rights-holders. This includes the right to health. The Committee on the Rights of the Child has recognised that children have the right to control their own health and body, in accordance with their evolving capacity and maturity, and has emphasised state obligations to ensure that health-related facilities, goods and services are respectful of children's needs.

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.”

“I would like to see more openness and communication between intersex people and doctors.”

Briet, who has variations of sex characteristics

The human rights of children, adolescents and adults with variations of 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 individuals with variations of sex characteristics in Iceland.

1.5 PRINCIPAL RECOMMENDATIONS

- Protect and promote the human rights of individuals with variations of sex characteristics in law and practice;
- Align laws, policies and practices to comply with s.7.1.1 of Resolution 2191 of the Parliamentary Assembly of the Council of Europe to ‘prohibit medically unnecessary sex-“normalising” surgery, sterilisation and other treatments practised on intersex children without their informed consent’, in a manner that does not entail criminal penalties;
- Create a specialised, multidisciplinary team for the medical treatment of children and adults with variations of sex characteristics;
- 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;
- Ensure that legal sex assignment or legal gender recognition for any individual at any age is not predicated on medical interventions.

2. SCOPE AND METHODOLOGY

2.1 SCOPE

This report focuses on whether persons with variations of sex characteristics can access the highest attainable standard of health, and the gaps in the Icelandic health system that impact this. These violations include those that result from discrimination against individuals on the grounds of their sex characteristics, and from gender stereotyping.

There are more than 40 medical diagnoses of types of variation in sex characteristics,¹ not all of which are referenced in this report. Some relatively common diagnoses are explained in the glossary above, or in the text. Amnesty International acknowledges that for certain types of variations of sex characteristics, surgical and hormonal interventions are urgent and necessary. For example, in cases of life-threatening loss of sodium in infants² or in cases where there is a serious threat of infection and urinary problems due to the exposure of the urethra.

This report covers some, but not all, human rights violations faced by children, adolescents and adults born with variations of sex characteristics in Iceland. For example, human rights violations related legal gender recognition (the process related to changing one's name and gender in identification documents) for individuals with variations of sex characteristics are not covered in this report.³

This report is the second produced by Amnesty International on the rights of individuals with variations of sex characteristics. The first, focusing on non-emergency, invasive and irreversible medical interventions on infants and children with variations of sex characteristics in Denmark and Germany, was released in 2017.⁴

2.2 TERMINOLOGY

The terms used to refer to variations of sex characteristics are diverse and, in some cases, contentious. This report frequently uses the term 'intersex', which is widely used and with which many individuals with variations of sex characteristics globally self-identify with. However, it is important to note that not all individuals with variations of sex characteristics identify as intersex. Some do not accept the term because they find that it conflicts with how they identify, or because it is viewed as an indicator of gender identity often conflated with being transgender. Some people prefer to identify with their particular type of variation: for example, as a person with Turner Syndrome.

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-wasting** congenital adrenal hyperplasia (ICD-10 E25.0) is a type of CAH.

3 See, for example: Amnesty International, 'Europe: The State Decides Who I Am: Lack of Legal Gender Recognition for Transgender People in Europe,' EUR 01/001/2014, <https://www.amnesty.org/en/documents/eur01/001/2014/en/>

4 'First, Do No Harm: Ensuring the Rights of Children with Variations of Sex Characteristics in Denmark and Germany', EUR 01/6086/2017, <https://www.amnesty.org/en/documents/eur01/6086/2017/en/>

Some individuals with variations of sex characteristics view certain terms as stigmatizing. This report seeks to avoid these terms, 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, but many individuals and families have negative views about this term.⁵ While the word “disorder”, according to statements from patients, activists and even medical professionals, can add to existing stigma and pathologization,⁶ it is used in particular frameworks around variations of sex characteristics and is therefore used at points in this report.

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.

2.3 METHODOLOGY

The information contained in this report was collected through desk and field-based research undertaken from February 2018 to January 2019. We reviewed medical literature, including updates and developments since our previous report on this topic, which was published in May 2017. As discussed in the report, medical literature on individuals with variations of sex characteristics is limited. We also reviewed human rights research on the rights of individuals with variations of sex characteristics worldwide, and drew on information provided, and discussions that took place, at conferences and formal and informal meetings with intersex rights activists across Europe.

For this report, Amnesty International interviewed two adults with variations of sex characteristics, four family members of individuals with variations of sex characteristics, and two adults with hormone conditions who responded to a public call for interviewees. Some names have been changed at individuals’ request – these are marked with an asterisk. Many of those interviewed discussed the specific challenges associated with living in Iceland as a country with an extremely small population. Interviewees with personal or family experience with variations of sex characteristics spoke about how a small and close-knit community can exacerbate feelings of stigma. This goes some way to explaining the small number of people willing to speak to Amnesty International as part of this research. Some individuals agreed to speak with us but asked that their testimonies be excluded from the report.

Amnesty International interviewed 13 medical professionals, covering specialities including paediatric and adult endocrinology, neonatology, paediatric surgery, midwifery, child psychology and gynaecology. Almost all of these interviewees had direct experiences working with individuals with variations of sex characteristics. Not all of the medical professionals agreed to be named in this report – those who did not are identified by their specialism or, where that would identify them, as ‘medical professionals’. Amnesty International also met with the Icelandic Ombud for Children.

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 experiences and those of their families. We would also like to thank activists from Intersex Iceland and Samtökin '78 (The National Queer Organisation of Iceland) for their support and advice, as well as intersex rights activists from across Europe who continue to provide guidance and input.

5 ‘Attitudes towards “disorders of sex development” nomenclature among affected individuals,’ 2017, <https://www.ncbi.nlm.nih.gov/pubmed/28545802>

6 See, for example: Morgan Carpenter, 2018, ‘What do intersex people need from doctors?’, https://www.ogmagazine.org.au/20/4-20/what-do-intersex-people-need-from-doctors/?fbclid=IwAR30GjuJ_tnYge-5e117P9d1F8ft3pU-Gqz9DL0VMaii4GDt3T2pZiCvRww

3. INTERNATIONAL HUMAN RIGHTS STANDARDS

Iceland has ratified many of the international human rights treaties, including the International Covenant on Economic, Social and Cultural Rights (ICESCR) and the International Covenant on Civil and Political Rights (ICCPR) in 1979; the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW) in 1985; the Convention on the Rights of the Child (CRC) in 1992; and the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (CAT) in 1996.

These treaties set out a series of rights that are relevant for the issues detailed in this report, including the right to the highest attainable standard of health and the rights of the child.

MULTIPLE AND INTERCONNECTED VIOLATIONS

People with variations of sex characteristics face multiple violations of their human rights. In his report to the Parliamentary Assembly of the Council of Europe (PACE), Piet de Bruyn, General Rapporteur on the rights of lesbian, gay, bisexual, transgender and intersex (LGBTI) people, stated that:

“it is crucial to take a holistic view of the issues faced by intersex people. We must look not only at the very important medical concerns at stake but also understand the full range of human rights issues affecting intersex persons – which unquestionably include the right to physical integrity and questions around informed consent, but also relate to legal gender recognition and civil registration, human dignity, and the right to be free of discrimination, for example.”⁷

In 2017, the PACE voted 33 to 3⁸ to adopt Resolution 2191 on ‘Promoting the human rights of and eliminating discrimination against intersex people’.⁹

The Yogyakarta Principles (adopted in 2006) and the Yogyakarta Principles+10 (YP+10, 2017) provide an authoritative, expert exposition of international human rights law as it currently applies to the grounds of sexual orientation, gender identity, gender expression and sex characteristics.¹⁰ While these documents are not a human rights treaty and therefore not open for signature or ratification by states, they represent the current state of international human rights obligations and help clarify these obligations, including on the grounds of sex characteristics.

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

7 PACE Doc. 14404, Sept 2017, available from: <http://assembly.coe.int/nw/xml/XRef/Xref-DocDetails-EN.asp?FileID=24027&lang=EN>, p.6.

8 <http://assembly.coe.int/nw/xml/Votes/DB-VotesResults-EN.asp?VoteID=36947&DocID=16396&MemberID=>

9 <http://assembly.coe.int/nw/xml/XRef/Xref-XML2HTML-en.asp?fileid=24232&lang=en>

10 <http://yogyakartaprinciples.org/principles-en/official-versions-pdf/>

against lesbian, gay, bisexual, transgender and intersex people and highlighting the practice of “unnecessary surgery and treatment on intersex children without their consent.”¹¹

3.1 RIGHT TO HEALTH

Article 12.1 of the ICESCR, ratified by Iceland in 1979, states that everyone has the right to the highest attainable standard of health. Article 12.2(a) further states that States must take steps necessary for the healthy development of the child. The Committee on Economic, Social and Cultural Rights, which monitors the implementation of the ICESCR, has noted that the right to the highest attainable standard of health is closely related to other human rights standards.¹²

The right to health requires health facilities, goods and services to be available, accessible, acceptable and of good quality. This includes an obligation to ensure that “health-care facilities, goods and services, as well as programmes ... [are] available in sufficient quantity”.¹³ It also requires that health facilities, goods and services are accessible to everyone without discrimination, and includes the right to seek, receive and impart information and ideas concerning health issues. Health facilities, goods and services must also be scientifically and medically appropriate and of good quality. In its General Comment on the right to health, the Committee on Economic, Social and Cultural Rights said that this includes “skilled medical personnel”,¹⁴ and that the obligation to fulfil the right to health requires states to “ensure the appropriate training of doctors and other medical personnel”.¹⁵

NON-EMERGENCY, INVASIVE AND IRREVERSIBLE MEDICAL INTERVENTIONS

In 2009, the UN Special Rapporteur (SR) on the right to health stated that “[h]ealth-care providers should strive to postpone non-emergency invasive and irreversible interventions until the child is sufficiently mature to provide informed consent”, noting that “[t]his is particularly problematic in the case of intersex genital surgery, which is a painful and high-risk procedure with no proven medical benefits”.¹⁶ The Human Rights Committee has called for an end to “irreversible medical treatment, especially surgery, of intersex infants and children, who are not yet able to provide fully informed and free consent, unless such procedures constitute an absolute medical necessity.”¹⁷

In this report, ‘non-emergency, invasive and irreversible medical interventions’ are defined as treatments, either surgical or hormonal, that are not aimed at saving the life or health of the individual, but which seek to “normalize” their sex characteristics to fit the gender binary categories of male or female.

Non-emergency, invasive and irreversible genital surgery and hormonal treatment of children with variations of sex characteristics may constitute a violation of the child’s right to express their views and to participate in decisions that 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),¹⁸ 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).

The right to the highest attainable standard of health is expressed in Yogyakarta Principle 17, and the right to bodily and mental integrity is expressed in Yogyakarta Principle 32.

11 ‘United Nations entities call on States to act urgently to end violence and discrimination against lesbian, gay, bisexual, transgender and intersex (LGBTI) adults, adolescents and children,’ September 2015, available from:

http://www.ohchr.org/Documents/Issues/Discrimination/Joint_LGBTI_Statement_ENG.PDF

12 CESCR GC 14 para 3.

13 Para 12, <https://www.refworld.org/pdfid/4538838d0.pdf>

14 Para 12, <https://www.refworld.org/pdfid/4538838d0.pdf>

15 Para 36, <https://www.refworld.org/pdfid/4538838d0.pdf>

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

17 CCPR/C/AUS/CO/6 para 26.

18 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”.

3.2 RIGHT TO FREEDOM FROM TORTURE

The CAT, ratified by Iceland in 1996, obliges states to take steps to prevent torture or other forms of cruel, inhuman or degrading treatment. The UN Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment has specifically commented on torture in medical settings, stating 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.”¹⁹

MEDICAL INTERVENTIONS ON INDIVIDUALS WITH VARIATIONS OF SEX CHARACTERISTICS

In 2011, the UN Committee against Torture in its review of Germany specifically addressed torture 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”.²⁰ The Committee made several recommendations regarding informed consent, redress and compensation for medical treatment performed without consent, training for medical professionals, and information provision.²¹

The 2017 YP+10 update to Principle 10, on the right to freedom from torture, spells out the state obligations to “recognise that forced, coercive and otherwise involuntary modification of a person’s sex characteristics may amount to torture, or other cruel, inhuman or degrading treatment” and to “prohibit any practice, and repeal any laws and policies, allowing intrusive and irreversible treatments on the basis of sexual orientation, gender identity, gender expression or sex characteristics, including forced genital-normalising surgery, involuntary sterilisation, unethical experimentation, medical display, “reparative” or “conversion” therapies, when enforced or administered without the free, prior, and informed consent of the person concerned.”²²

3.3 RIGHT TO FREEDOM FROM DISCRIMINATION AND FROM GENDER STEREOTYPES

Under the ICESCR, “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.”²³ 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.”

Under CEDAW, ratified by Iceland in 1985, 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. Article 5(a) of the CEDAW 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.”

19 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.

20 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, para 20.

21 Full recommendations reproduced in Section 7.3.

22 http://yogyakartaprinciples.org/wp-content/uploads/2017/11/A5_yogyakartaWEB-2.pdf

23 Article 2.2 of the ICESCR.

PROHIBITION OF SEX DISCRIMINATION

International treaties highlight sex as a prohibited ground for discrimination, which includes discriminatory treatment of individuals because of their 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.” Consequently, this prohibition on discrimination applies also to treatment that discriminates, excludes and stigmatizes people because of their physical characteristics and “ambiguity” of genitalia, chromosomes and hormones within the medical establishment, family environment or overall surroundings.

International organizations such as the World Health Organization,²⁴ regional human rights institutions²⁵ and national bodies²⁶ have all asserted that healthcare professionals should be educated and trained about bodily diversity as a means to combat gender stereotypes.

GENDER STEREOTYPES AND VARIATIONS OF SEX CHARACTERISTICS

Deep-seated gender stereotypes, lack of education and information on variations of sex characteristics and historical marginalisation of people with variations of sex characteristics lead to a conflation of variations of sex characteristics with 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, adults with variations of sex characteristics 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. 20.²⁷

The Yogyakarta Principles specify, in Principle 18 on Protection from Medical Abuses, that states should take measures to stop children undergoing irreversible medical procedures that “attempt to impose a gender identity.”²⁸

3.4 RIGHTS OF THE CHILD

In 1992, Iceland ratified the Convention on the Rights of the Child (CRC), which sets out state obligations to respect, protect and fulfil the human rights of children.

3.4.1 BEST INTERESTS OF THE CHILD

Central to the respect and fulfilment of the rights of children with variations of sex characteristics is the standard set out in Article 3.1 of the CRC, which states that, “[i]n 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.”²⁹ The Committee on the

24 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/

25 Council of Europe Commissioner of Human Rights, issue paper on “Human Rights and Intersex People”.

26 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.

27 CESCR General Comment 20 para 32.

28 http://yogyakartaprinciples.org/wp-content/uploads/2016/08/principles_en.pdf

29 The Committee’s explanatory General Comment 14 on the Best Interest of the Child, para 26, defines “public or welfare institutions” to include institutions related to economic, social and cultural rights, such as health institutions, as well as institutions dealing with civil rights and freedoms, such as birth registration. This is applicable in cases where parents of children born with variations of sex characteristics feel pressure by national legislation on birth registration to declare their child’s gender, thereby having no choice but to make a rapid decision towards sex assignment.

Rights of the Child's General Comment No. 14 on the Best Interests of the Child³⁰ 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.³¹ Development is interpreted as a "holistic concept, embracing the child's physical, mental, spiritual, moral, psychological and social development".³²

The 2006 Yogyakarta Principles³³ 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".

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 "[t]his is particularly problematic in the case of intersex genital surgery, which is a painful and high-risk procedure with no proven medical benefits".

3.4.2 CHILDREN'S RIGHT TO HEALTH

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."³⁴

The Committee on the Rights of the Child has also stated that states are obliged to "ensure that adolescents have access to the information that is essential for their health and development,"³⁵ and that, "[i]n accordance with their evolving capacities, children should have access to confidential counselling and advice without parental or legal guardian consent, where this is assessed by the professionals working with the child to be in the child's best interests."³⁶

The Committee has also noted state obligations to design and implement all health-related facilities, goods and services in a way that takes full account, and is respectful, of medical ethics as well as children's needs, expectations, cultures, views and languages, paying special attention to certain groups, where necessary, in order to provide acceptable health services for children.³⁷

3.4.3 INFORMATION FOR PARENTS

Under Article 18.2 of the CRC, states have an obligation to provide "appropriate assistance to parents and legal guardians in the performance of their child-rearing responsibilities". This is particularly crucial during early childhood given that it is "a critical period for realizing children's rights". The Committee on the Rights of the Child has instructed States parties to ensure that "parents are given appropriate support so that they can fully involve young children in [early childhood programmes], especially the most disadvantaged and vulnerable groups".³⁸ In order to do this, policies must include the provision of expert psychological support to parents in order to navigate their options in making decisions on behalf of their children. Parents of children with variances in sex characteristics should therefore be able to obtain appropriate assistance before a child is able to provide consent to what happens to their body.

30 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.

31 GC 14 para 4.

32 General Comment 5 (2003) CRC/GC/2003/5, para 12.

33 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.

34 General Comment 14, child's health, CRC article 24.

35 CRC GC 4 para 35(b) (CRC/GC/2003/4).

36 CRC GC 15 para 31 (CRC/C/GC/15).

37 CRC GC 15 para 115 (CRC/C/GC/15).

38 CRC General Comment 7, 2005 para 21.

3.4.4 PROTECTION FROM BULLYING

One justification given for non-emergency surgeries and treatment is to protect the child psychologically so that they are not bullied and feel “normal” at school or in their socializing environment.³⁹ Bullying harms the physical and emotional well-being of children and adolescents, and often has a significant impact on the rights of the child, including the right to education,⁴⁰ as well as the right to physical integrity, health, standard of living, privacy, non-discrimination, and in the worst cases, the right to life and to be free from torture and other ill-treatment. The risk of bullying, however, cannot be used as a justification for harmful practices which, in themselves, may be in conflict with the child’s best interests.

THE RIGHTS OF CHILDREN WITH VARIATIONS OF SEX CHARACTERISTICS

The Committee on the Rights of the Child has made specific recommendations in relation to children born with variations of sex characteristics, including that states:

- prohibit “unnecessary medical or surgical treatment from being performed on intersex children, when those procedures entail a risk of harm and can be safely deferred until the child can actively participate in decision-making”⁴¹
- develop and implement a “child rights-based health-care protocol for intersex children”⁴²
- investigate and provide redress for past violations⁴³
- provide education and training for medical professionals⁴⁴
- provide counselling and support for families with intersex children.⁴⁵

The CEDAW has also called for:

- a prohibition on “unnecessary surgical or other medical treatment on intersex children until they reach an age when they can give their free, prior and informed consent”⁴⁶
- a rights-based healthcare protocol for intersex children⁴⁷
- counselling and support for families⁴⁸
- redress for past violations.⁴⁹

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-determination⁵⁰ and to ensure that no child is subjected to unnecessary surgery or treatment.⁵¹

The state has a positive duty to take effective measures to protect children from violence and abuse, including bullying. The Committee on the Rights of the Child has outlined state obligations to “[i]ntensify efforts to tackle bullying and violence in schools including through teaching human rights, building capacities of students and staff members to respect diversity at school, improving students’ conflict

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

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

41 CRC/C/ESP/CO/5-6 para 24.

42 CRC/C/DNK/CO/5 para 24, CRC/C/ARG/CO/5-6 para 26.

43 CRC/C/DNK/CO/5 para 24.

44 CRC/C/DNK/CO/5 para 24.

45 CRC/C/ARG/CO/5-6 para 26.

46 CEDAW/C/MEX/CO/9 para 22, CEDAW/C/AUS/CO/8, para 26, CEDAW/C/NZL/CO/8 para 24.

47 CEDAW/C/IRL/CO/6-7 para 25, CEDAW/C/LUX/CO/R.6-7 para 28, CEDAW/C/LIE/CO/5 para 36.

48 CEDAW/C/AUS/CO/8 para 26, CEDAW/C/NZL/CO/8 para 24.

49 CEDAW/C/LUX/CO/R 6-7 para.28, CEDAW/C/CHL/CO/7 para 23, CEDAW/C/AUS/CO/8, para 26, CEDAW/C/NZL/CO/8 para 24.

50 CRC/C/CHE/CO/2-4.

51 CRC/C/FRA/CO/5.

resolution skills, conducting regular monitoring of incidences of bullying at school, and involving children in the initiatives and monitoring aimed at eliminating bullying.⁵²

3.5 RIGHT TO REMEDY

As this chapter has highlighted, the human rights of children, adolescents and adults with variations of sex characteristics are recognized and protected under international law. However, the research on which this report is based indicates that these protections are not, in practice, fully enforced in current models for engaging with individuals with variations of sex characteristics in Iceland. People whose human rights have been violated have the right to access remedy and reparations.

3.6 HUMAN RIGHTS DEFENDERS

Since the 1990s, an increasing number of people around the world have begun to speak out about their experiences after undergoing non-emergency, invasive and irreversible medical interventions as infants and children. Many of these people highlighted their opposition to such ‘normalizing’ medical treatment 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 existence of people with variations of sex characteristics, 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 the development of policies related to the treatment of individuals with variations of sex characteristics. Some of these individuals and groups have focused on building relationships and working with the medical establishment, while others have focused on campaigning at the level of international and regional human rights institutions.

“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.”⁵³

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.⁵⁴ 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 of 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.”

⁵² CRC/C/GBR/CO/5, para 48

⁵³ Preamble, Malta Declaration.

⁵⁴ <https://oieurope.org/malta-declaration/>

4. THE ICELANDIC HEALTH CARE SYSTEM

4.1 NUMBERS

“We don’t see babies [with variations of sex characteristics] every year.”⁵⁵

The difficulty of determining a precise number of people born with variations of sex characteristics is widely acknowledged by medical professionals worldwide. In part, this is because a large number of individuals with variations of sex characteristics have not received a medical diagnosis. It is also a result of differences in data collection and classification, including the fact that different terms are used by medical professionals and activists. For example, the category ‘DSD’ (see section 2.2) does not necessarily include some diagnoses, like hypospadias, that we and others classify as variations of sex characteristics. Amnesty International researchers were not able to locate studies on the number of diagnoses – either in adults or in children – in Iceland.

ESTIMATED NUMBERS IN ICELAND

In 2000, biologist Anne Fausto-Sterling produced one of the first estimates of the number of people with variations of sex characteristics globally. According to her research, 1.7% of people globally are born with a variation of sex characteristics.⁵⁶ Iceland has a population of 355,620⁵⁷ which would indicate that there are around 6,000 individuals with variations of sex characteristics living in Iceland. Iceland has just over 4,000 births a year,⁵⁸ so an estimated 68 infants are born with variations of sex characteristics each year.

In 2015, a Member of Parliament from Iceland’s Bright Future party submitted a formal question to the Minister of Health⁵⁹ asking how many children had been born intersex and subjected to surgical interventions. The response from the government was that there had been three cases. However, this assessment used an extremely narrow definition of the term ‘intersex’.⁶⁰ The medical professionals that spoke to Amnesty International in Iceland, mostly estimated the number of cases they had seen in the tens. Kolbeinn Guðmundsson, a paediatric endocrinologist, told Amnesty International that, “in 14 years of practicing in Iceland, I have seen perhaps two to three [ambiguous] cases.”⁶¹

55 Interview with medical professional, June 2018.

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

57 As of the end of Q3 2018. Data obtained from Statistics

Iceland https://px.hagstofa.is/pxen/pxweb/en/lbuar/lbuar_mannfjoldi_1_yfirlit_arsfjordingstolur/MAN10001.px

58 In 2017, there were 4,071 live births, <https://www.statice.is/publications/news-archive/population/births-2017/>

59 Text available from: <https://www.althingi.is/altxt/raeda/144/rad20150511T155856.html>

60 Presentation by Kitty Anderson, Brussels, October 2018.

61 Interview with Kolbeinn Guðmundsson, paediatric endocrinologist, June 2018.

4.2 DIAGNOSES

Worldwide, not everyone with variations of sex characteristics receives a medical diagnosis. However, Iceland has a universal healthcare system, and so individuals may receive a diagnosis, either at birth, in infancy, in adolescence, or later in life. Medical professionals told Amnesty International about the individuals they have seen and the process by which the individuals enter into the medical system.

“I have encountered 10-15 cases and I have been practicing for 15 years. CAH [congenital adrenal hyperplasia] cases are the most common – I have seen five CAH cases – and another five patients with Klinefelters, and perhaps the same with Turner.”⁶²

70% of births are at Landspítali, the National University Hospital of Iceland, in Reykjavik.⁶³ Landspítali has the only NICU (neonatal intensive care unit) in Iceland. If any problems are anticipated, the baby will be born at Landspítali.⁶⁴ Most births in Iceland are attended by midwives,⁶⁵ and all babies are screened at birth and then at five days old. The birth screening may be done by a junior doctor, while the five-day screening is done by a neonatologist, paediatrician or family doctor.⁶⁶ Neonatologist Snjólaug Sveinsdóttir told Amnesty International:

“When a child with ambiguous genitalia is born, the midwife talks to the junior doctor who talks to me. I am usually the one who tells the parents. I say, ‘don’t worry, this is a perfect baby, but we’re not sure if it’s a boy or a girl.’”⁶⁷

The infant may stay under the care of a neonatologist until a diagnosis is confirmed, especially if salt-wasting CAH (which is life-threatening) is suspected.⁶⁸ Infants may be referred to specialists for a more specific diagnosis. In some instances, the variations are not apparent until the individual is an adolescent or adult, in which case the identification and diagnosis process happens at a later stage.

“We become aware of cases differently, it really varies. For example, for CAH cases, they are referred to us by the neonatologist and diagnosed within seven days, while XY females are often diagnosed in puberty.”⁶⁹

Medical professionals told Amnesty International that they had treated individuals with diagnoses including primordial gonadal dysgenesis,⁷⁰ CAIS,⁷¹ and Klinefelters⁷² who had been diagnosed in adolescence or adulthood. While some variations are straightforward to diagnose, others are not and the process may be complicated. Arna Guðmundsdóttir, endocrinologist, told Amnesty International:

“I usually get referrals from GPs, before there is a diagnosis. The patient has something like amenorrhea, gynecomastia, or infertility. We do blood tests and check for hormones, and if it’s indicated, send for genetic testing. We can refer to a clinical geneticist for hereditary conditions. But other patients know about their condition from birth, they are referred from a paediatric endocrinologist, they already know their diagnosis.”⁷³

Some variations may not show up unless another condition is being investigated, for example a hernia.⁷⁴ Since some variations are so rare, they are not always easy to identify. Snjólaug Sveinsdóttir, neonatologist, told Amnesty International:

“Girls with Turner syndrome, it’s not always apparent at birth. It’s apparent for very experienced neonatologists, but not for junior doctors. It’s common to diagnose this through swelling of the feet, it’s quite a distinctive kind of swelling, and they may have thick necks. Then we do genetic testing.”⁷⁵

62 Interview with Arna Guðmundsdóttir, endocrinologist, June 2018.

63 Interview with medical professional, June 2018.

64 Interview with medical professional, June 2018.

65 Interview with medical professional, June 2018.

66 Interview with medical professional, June 2018.

67 Interview with Snjólaug Sveinsdóttir, neonatologist, June 2018.

68 Interview with Snjólaug Sveinsdóttir, neonatologist, June 2018.

69 Interview with medical professional, June 2018.

70 Interview with Soffía Jónasdóttir, paediatric endocrinologist, June 2018.

71 Interview with Soffía Jónasdóttir, paediatric endocrinologist, June 2018.

72 Interview with Arna Guðmundsdóttir, endocrinologist, June 2018.

73 Interview with Arna Guðmundsdóttir, endocrinologist, June 2018.

74 Interview with Soffía Jónasdóttir, paediatric endocrinologist, June 2018.

75 Interview with Snjólaug Sveinsdóttir, neonatologist, June 2018.

Diagnosis may involve a range of physical examinations as well as hormone and genetic testing. Some conditions are identified or confirmed through genetic testing. But this is not standard practice so some conditions – for example, androgen insensitivity syndrome (AIS) - may not be detected.⁷⁶

4.3 A LACK OF RIGHTS-BASED PROTOCOLS

Although an estimated 1.7% of individuals have variations of sex characteristics (see Section 4.1), the range of possible diagnoses means that the prevalence of individual medical diagnoses is low. For some diagnoses, individual national and international medical societies have produced their own guidelines. For example, the European Society of Endocrinology and the Pediatric Endocrine Society (USA) initiated the development of clinical practice guidelines for the care of girls and women with Turner syndrome (published in September 2017).⁷⁷ In September 2018, the Endocrine Society⁷⁸ also updated their guidelines for CAH.⁷⁹ Worldwide, while some protocols have been based on the human rights of the individual being treated, and others have been developed in collaboration with affected individuals, there is no system to ensure that this is the case.

“There are no overarching guidelines, not in Iceland. We use the Endocrine Society guidelines.”⁸⁰

Iceland is a small country with a small medical community. Consequently, many protocols used in Iceland are sourced from overseas. Doctors told Amnesty International that they used and adapted protocols from Sweden, the National Institutes of Health and American Academy of Pediatrics in the USA and The National Institute of Health and Care Excellence in the UK.⁸¹ There is a procedure to adapt and finalise protocols for use in Iceland. However, there is no formal obligation in Iceland for doctors to use any of these protocols.. Arna Guðmundsdóttir, endocrinologist, told Amnesty International:

“It’s quite common to have protocols but we don’t develop them here. We adapt them, we look at what other countries are doing, what is doable here and what is different. It’s usually a hospital committee who does this, and then presents the results to the [Medical Director of Health] who publishes it on the website of the Directorate of Health, if they feel the need for it and if the patient population is big enough.”⁸²

At an international level, some professional organisations are working together with patient groups, and groups working for the rights of individuals with variations of sex characteristics. For example, 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 of individuals with variations of sex characteristics.⁸³ 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. No such initiative has taken place in Iceland.

Medical professionals told Amnesty International that since many Icelandic doctors train overseas, they have a wide contact network.⁸⁴

“We use Swedish protocols, a lot of people have trained in Sweden. They are very evidence-based and quite good. There are also the NICE guidelines from the UK. The USA guidelines are quite useful sometimes, but there are quite a lot of things about preventing being sued. We only need to do things that benefit the baby. These guidelines [from other countries] are widely used, but there is no formal reason to use them. We have lots of internal discussions, there are only six neonatologists and not very many paediatricians, so we can talk.”⁸⁵

For the adequate treatment of individuals with variations of sex characteristics, these protocols should be accessible to medical professionals. Soffía Jónasdóttir, a paediatric endocrinologist, explained that protocols for some conditions exist:

76 Interview with Soffía Jónasdóttir, paediatric endocrinologist, June 2018.

77 <https://eje.bioscientifica.com/view/journals/eje/177/3/EJE-17-0430.xml>

78 An international organization for endocrinologists and endocrinology researchers: <https://www.endocrine.org/about-us>

79 <https://www.endocrine.org/guidelines-and-clinical-practice/clinical-practice-guidelines/congenital-adrenal-hyperplasia-guideline-resources>

80 Interview with Arna Guðmundsdóttir, endocrinologist, June 2018.

81 Interviews with Snjólaug Sveinsdóttir, neonatologist, and other medical professionals, June 2018.

82 Interview with Arna Guðmundsdóttir, endocrinologist, June 2018.

83 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 (hereinafter: 2016 Guidelines).

84 Interview with medical professionals, June 2018.

85 Interview with Snjólaug Sveinsdóttir, neonatologist, June 2018.

“We have a written protocol [for CAH] for treatment plans. And we give parents written guidelines to help them care for their children. This is in the health care computer system that is available to nurses and doctors working at the University Hospital of Iceland and the primary care service.”⁸⁶

However, Arnar Hauksson PhD, a gynaecologist, explained some of the general problems with the use of protocols in Iceland.

“It is essential to have protocols for the quality of treatment. The Ministry of Health and the social department give doctors and nurses a free hand: the guideline is that they want them to be at the forefront of health and education. Protocols are then approved by the heads of departments at the University Hospital, or by the working team. But then the protocols are not always being followed. Most of the doctors at the University Hospital are overworked so very often it is the nurses and midwives that decide that they need protocol, and form a working group and make the protocol.”⁸⁷

At an international level, organisations working for the human rights of individuals with variations of sex characteristics have also produced their own guidelines and standards for medical care. In the USA, InterACT and Lambda Legal produced a guide for hospitals on providing healthcare for intersex patients.⁸⁸ The guide “provides a set of model hospital policies aimed at promoting best practices to ensure appropriate, ethical, and quality care is being provided to intersex patients, and to address bias and insensitivity toward intersex patients and their families.”⁸⁹ In Europe, OII Europe, IGLYO and EPA have produced a toolkit for parents titled ‘Supporting your intersex child’ which includes information on medical decision-making.⁹⁰ This toolkit has been available in Icelandic since its launch in October 2018.

The lack of rights-based healthcare protocols for conditions related to variations of sex characteristics in Iceland creates a climate in which human rights violations can occur, including violations of the right to the highest attainable standard of health, as well as of the right to freedom from discrimination and from harmful gender stereotypes.

4.4 NO MULTIDISCIPLINARY TEAM

A consensus statement titled ‘Caring for individuals with a difference of sex development (DSD)’⁹¹ (published in *Nature Reviews Endocrinology* in May 2018) recommends multidisciplinary care for adults as well as children with variations of sex characteristics. The Consensus Statement notes that the specialists involved may include “endocrinology, urology, gynaecology, andrology, psychology, nursing, social work, genetics and medical ethics.”⁹²

There is no multidisciplinary team (MDT) in Iceland for the treatment of individuals with variations of sex characteristics. Snjólaug Sveinsdóttir, neonatologist, told Amnesty International:

“We are too small to have a specific team around rare and unusual problems.”⁹³

Instead of a specialist team, referrals are made between doctors directly. Kolbeinn Guðmundsson, paediatric endocrinologist, told Amnesty International: “We try to involve everyone: the parents, the surgeon, the endocrinologist. Not the psychiatrist, though – this is missing.”⁹⁴

Several of the medical professionals who spoke to Amnesty International emphasised that there is no formal referral process⁹⁵ and that referrals are made on a personal level.⁹⁶ With the absence of a specialist team, as well as a lack of protocols for some conditions (see section 4.3), referrals can be inconsistent. Therefore, persons with variations of sex characteristics may not receive the necessary treatment. According to medical professionals, the other specialists involved depend on what is indicated in the case:

86 Email communication with Soffía Jónasdóttir, paediatric endocrinologist, January 2019.

87 Email communication with Arnar Hauksson PhD, gynaecologist, December 2018.

88 https://www.lambdalegal.org/sites/default/files/publications/downloads/resource_20180731_hospital-policies-intersex.pdf

89 P 3.

90 <https://oiieurope.org/parents-toolkit/>

91 <https://www.nature.com/articles/s41574-018-0010-8#group-1>

92 <https://www.nature.com/articles/s41574-018-0010-8#group-1>

93 Interview with Snjólaug Sveinsdóttir, neonatologist, June 2018.

94 Interview with Kolbeinn Guðmundsson, paediatric endocrinologist, June 2018.

95 Interview with Snjólaug Sveinsdóttir, neonatologist, June 2018.

96 Interview with medical professional, June 2018.

“[For new-borns], it is the neonatologist who decides which other specialists to involve. Most of the malformations are relatively simple. We confer with paediatric surgeons. If the anomaly is a hypospadias or a single undescended testicle, we do not involve the endocrinologist, only the surgeons. If we are in doubt – for example, if both testicles are undescended – we may involve the endocrinologist.”⁹⁷

Alternatively, one doctor might coordinate the involvement of other specialists. This may depend on what is considered most serious:

“The coordination depends on what the main problem is. For example, for Turner syndrome, the main problem is the heart condition, so the cardiologist coordinates. It’s a small medical community, this is good and bad. We are all generalists as well. In Sweden there is an MDT [multidisciplinary team], but we are too small.”⁹⁸

There are cases where doctors do not involve other specialists. Snjólaug Sveinsdóttir, neonatologist, told Amnesty International about a 2017 case, which was discussed at a staff meeting:

“The endocrinologist [handling the case] did not think it was easy to decide the gender [of] the baby. No other specialists were involved when I was involved in the case but the endocrinologist had discussions later on with other endocrinologists.”⁹⁹

Some doctors support the idea of specialist teams and treatment centres. Kolbeinn Guðmundsson, paediatric endocrinologist, told Amnesty International: “These kinds of cases are so rare, they should be treated in a specialist centre.....In the past, mistakes have been made. But with a multidisciplinary team, we are less and less likely to make mistakes.”¹⁰⁰

Others point to the difficulties of maintaining a specialist team, particularly in a small country. For example, other countries include a paediatric urologist in their multidisciplinary teams; however, there is no doctor with this speciality in Iceland.¹⁰¹

“Most of these cases are so rare...you cannot have a multidisciplinary team when there are 1-2 cases a year. It’s not possible to keep up expertise. We have contacts in Norway, we also work with the trans team here, although they have a different type of approach.”¹⁰²

Medical professionals recommend multidisciplinary teams in order to provide optimum care to individuals with variations of sex characteristics and support their families.¹⁰³ However, there do not appear to be proposals to introduce such a model in Iceland.¹⁰⁴

4.4.1 MULTIDISCIPLINARY TEAMS IN ICELAND

Several of the medical professionals who spoke to Amnesty International noted that Iceland uses a multidisciplinary team model for other conditions. For example, children with diabetes are treated by a specialist team which includes a psychologist.¹⁰⁵

Iceland also has a specialised clinic for trans adults, which may see adults with variations of sex characteristics. Arna Guðmundsdóttir, endocrinologist, told Amnesty International:

“Four or five years ago, some doctors started a specialised clinic for trans adults and also adults with variations of sex characteristics. It was prompted by a sudden increase in the number of cases.”¹⁰⁶

Arnar Hauksson PhD, a gynaecologist, commented on the extra burden that being part of a specialist team can bring for medical professionals:

“There was a great need to set up a special entity for endometriosis patients, for example, but the doctors assigned to that special task had to do this on top of their other duties.”¹⁰⁷

97 Interview with medical professional, June 2018.

98 Interview with Snjólaug Sveinsdóttir, neonatologist, June 2018.

99 Email communication with Snjólaug Sveinsdóttir, neonatologist, January 2019.

100 Interview with Kolbeinn Guðmundsson, paediatric endocrinologist, June 2018.

101 Interview with Soffía Jónasdóttir, paediatric endocrinologist, June 2018.

102 Interview with medical professionals, June 2018.

103 <https://onlinelibrary.wiley.com/doi/full/10.1111/cen.12857>

104 Interview with medical professional, June 2018.

105 Interview with Kolbeinn Guðmundsson, paediatric endocrinologist, June 2018.

106 Interview with Arna Guðmundsdóttir, endocrinologist, June 2018.

107 Email communication with Arnar Hauksson PhD, gynaecologist, January 2019.

4.5 MEDICALISATION OF SEX ASSIGNMENT

4.5.1 SEX ASSIGNMENT

In Iceland, a child must be registered male or female. For the majority of infants born, this decision is taken based on the primary sex characteristics. There are no figures on how many individuals later identify with a different gender from the one they were assigned at birth.¹⁰⁸ For some infants, however, the primary sex characteristics are not ‘typically male’ or ‘typically female’ and so it is not clear to medical professionals whether the child should be legally assigned male or female.

In cases where the sex is ambiguous, the doctors may carry out tests in order to guess what gender the child will identify as. This takes into consideration factors like genes and hormones,¹⁰⁹ as well as future fertility.¹¹⁰ However, there is often little evidence upon which to make a decision about sex assignment. Neonatologist, Snjólaug Sveinsdóttir, explained:

“For cases of ambiguous genitalia, there might be a differential diagnosis. [As the neonatologist] I do the first tests, then pass the case to the endocrinologist. If there are some [testosterone] responders, then you define the child as a boy, but for CAIS it’s much more difficult.”¹¹¹

Another medical professional explained some of the considerations:

“There are only two options – at least in Iceland. For appearance only, it’s easier to make a female. The possibility of fertility is heavily weighted – in both directions. We take genotype into account but are not relying on this as much as we were previously. There are other things that seem to be more important now. We try to make the best judgement and present it to the parents. I’m very happy not to be the one making this decision.”¹¹²

Gender identity is not a medical question and cannot be determined through medical testing: it is solely determined by how an individual identifies. For infants, it is not possible to discern a gender identity, since they cannot communicate it until they are older. Decisions about medical interventions should be taken based on what is in the child’s best interests, not on whether the child’s body fits into physiological norms for male and female.

4.5.2 SEX ‘NORMALISATION’

“Regardless of how virilised, in my opinion [a child with CAH] is a girl. She has a uterus and potential fertility. Even if [the appearance] is of a penis, there are no testes. It is a clitoris that is much too big.”¹¹³

Where the sex of the child has been decided, or was not in question, the doctors interviewed by Amnesty International frequently noted the ways in which the child’s body differed from the norms expected for children of a given sex, and framed interventions in terms of ‘normalising’ the child’s body.

4.5.3 PSYCHOLOGICAL JUSTIFICATIONS

Adverse psychological impacts of *not* carrying out medical interventions on children are often cited as a justification for medical intervention. This implicitly conflates legal sex assignment and medical interventions.

“There is the risk of doing the wrong sex assignment in the early stages, versus exposing the child to being in no-man’s-land and causing psychological trauma to the child... Parents understand that it is going to be a very

108 It is possible for individuals whose gender identity does not accord with the sex they were assigned at birth to obtain legal recognition of their gender, but the current procedure does not meet human rights standards of being quick, accessible and transparent, so this process is not available in practice to everyone who might want to seek it.

109 Interview with medical professionals, June 2018.

110 Interview with Kolbeinn Guðmundsson, paediatric endocrinologist, June 2018.

111 Interview with Snjólaug Sveinsdóttir, neonatologist, June 2018.

112 Interview with medical professional, June 2018.

113 Interview with Kolbeinn Guðmundsson, paediatric endocrinologist, June 2018.

difficult life if you are not a boy or a girl. Most go along with the intervention. You need to assign a sex and then that has consequences.”¹¹⁴

This includes the psychological impact of not conforming to gender norms, including for boys who sit down to urinate,¹¹⁵ or girls with a large clitoris.¹¹⁶ Kolbeinn Guðmundsson, a paediatric endocrinologist, talked about why he considered genital surgery to be important for psychological health:

“Our rule of thumb is that before the kid goes into kindergarten, they would have as normal external genitalia as possible. It’s important to have everything in place, for the child’s psychological well-being, by the time they are 5 or 6 and going into primary school. For boys, we try to get them to stand to pee by age 6.”¹¹⁷

He emphasised that medical professionals make recommendations to parents, noting that “we would and could not enforce this in any way.”¹¹⁸

However, other doctors interviewed by Amnesty International also expressed concern about the psychological impact of assigning the wrong sex. According to one medical professional:

“There are some cases where you have to operate because the genital area is open. You try to reconstruct it, and then you have to decide how the genitalia will look. When do you decide between two options? Based on the chromosomes? In my view, if you don’t have to make a decision, don’t do it. The pressure from parents is very strong but what if the baby grows up thinking something different. Sometimes the parents don’t know what’s best. It’s a terrible thing to have done something and then everyone is unhappy 15 years later.”¹¹⁹

As discussed in Section 3.4.4, the risk of bullying cannot be used as a justification for harmful practices, which themselves may 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 of 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.¹²⁰

4.5.4 DELAYING INTERVENTIONS

Some interventions are framed as ‘medically necessary,’ but as one medical professional explained, this does not mean that they must be done soon:

“Generally speaking, “medically necessary” does not necessarily mean “acute”. This depends on the nature of the medical problem. Some “medically necessary” surgeries might be acute, other might not.”¹²¹

While, as noted above, early surgical intervention has historically been the default, opinions about this in Iceland have changed. One psychologist told Amnesty International:

“There is no simple answer to the question of whether these surgeries are psychologically justified... Surgeons and psychologists have very different views on plastic surgery. We would wait.”¹²²

Interventions may also be delayed if that is what the parents want.¹²³ One medical professional explained how medical practice has changed over time:

“Historically, doctors took more of a decision on their own. Now it’s a collaboration with the parents. Usually it’s good to take decisions with the parents but sometimes they want other things. In the end, we are advocates for the baby. If there are different opinions, usually they can work something out. But you can’t ask the baby, that’s the problem, and the baby is the one living with the decision.”¹²⁴

114 Interview with Kolbeinn Guðmundsson, paediatric endocrinologist, June 2018.

115 Interview with Kolbeinn Guðmundsson, paediatric endocrinologist, June 2018.

116 Interview with Kolbeinn Guðmundsson, paediatric endocrinologist, June 2018.

117 Interview with Kolbeinn Guðmundsson, paediatric endocrinologist, June 2018.

118 Email communication, January 2019.

119 Interview with medical professional, June 2018.

120 Creighton research/ Katharina Main research.

121 Email communication with medical professional, Reykjavik, January 2018.

122 Interview with medical professional, June 2018.

123 Interview with Kolbeinn Guðmundsson, paediatric endocrinologist, June 2018.

124 Interview with medical professional, June 2018.

5. MEDICAL INTERVENTIONS

People with variations of sex characteristics, particularly children, tend to experience extensive medical interventions (surgeries and hormone therapy) from early in their life. In some instances, these interventions are urgent and necessary. For example, in a small number of cases, an infant might be born with an open genital area, the urinary path might not be clear, or urine might be leaking from the bladder into the vagina. These situations require surgical intervention to prevent infection.

In other cases, interventions may be carried out to normalise the appearance or functionality of the body for a person with variations of sex characteristics. This includes clitoral operations, penis operations, and vaginal operations. Similarly, individuals with internal gonads may be advised to undergo surgery to remove them. The common reason given for removal is the risk that the gonadal tissue may become cancerous. For example, a study of data from 22 centres in 16 countries found that 67% of the centres recommended gonadectomy in early adulthood for girls with CAIS.¹²⁵

Several variations of sex characteristics are characterised by variations in hormone levels, meaning individuals with variations of sex characteristics are frequently treated with hormones. Moreover, hormone replacement treatment is required for individuals that have been treated with a gonadectomy.

As a result of these interventions, many people with sex variations need extensive follow up care, often for the rest of their lives. Hormone treatment must be carefully managed and can continue for life. It can also have serious consequences for the health of people with variations of sex characteristics. These interventions and their consequences are complicated, and often require psychological and mental health support. However, a lack of protocols and specialists in Iceland mean that it can be difficult for people to access necessary services.

Amnesty International's research indicates a divergence between the obligation of Iceland to give a primary consideration to the best interests of the child and medical policy and practice in relation to children with variations of sex characteristics in Iceland. In its present form, medical practice neglects to fully consider the rights of children with variations of sex characteristics.

5.1 SURGICAL INTERVENTIONS

Surgeries on individuals – including children – with variations of sex characteristics are carried out in Iceland. In general, major surgeries in Iceland take place in Reykjavik.¹²⁶

¹²⁵ 'Management of Gonads in Adults with Androgen Insensitivity: An International Survey', 2018. <https://www.karger.com/Article/Abstract/493645>

¹²⁶ Interview with medical professional, Reykjavik, June 2018.

5.1.1 EMERGENCY INTERVENTIONS

“[We have seen] one or two cases of cloacal extrophy, where the infant has an open bladder and no genitalia.”¹²⁷

In a small number of cases, an infant can be born with an open genital area, an unclear urinary path¹²⁸ or with urine leaking from the bladder into the vagina.¹²⁹ These situations require surgical intervention to prevent infection.

5.1.2 CLITORAL, VAGINAL AND PENIS OPERATIONS

There are three main types of intervention that may be carried out to normalise the appearance or functionality of the body for a person with variations of sex characteristics: clitoral operations, penis operations, and vaginal operations.

Globally, there are documented historical cases of clitoridectomies on individuals with variations of sex characteristics. Kolbeinn Guðmundsson, a paediatric endocrinologist, like many medical professionals, recognised the devastating impact of these surgeries, noting that “[i]n the past, some disasters have been done.”¹³⁰ However, he acknowledged that clitoroplasties – albeit fewer than one per year – take place in Iceland.¹³¹ Soffía Jónasdóttir, also a paediatric endocrinologist, told Amnesty International that “they used to do clitoral resection but with better anatomical understanding. If a surgery is done today in that region it aims at minimizing the clitoral hood but avoiding damaging the nerves and clitoris. Sometimes there is a complete closure of the labial folds and surgery is needed to open the labia as the vaginal opening is otherwise covered or closed over by the labia.”¹³²

For children with congenital adrenal hyperplasia, surgery is also routinely advised. Medical professionals working with these children told Amnesty International that:

“For children with CAH, we would advise corrective surgery. They are girls – they are fertile girls. We do the same procedure as for trans women: to turn the penis into the first third of the vagina. We do this between one and two years of age.”¹³³

While the operations that are done on children with CAH are done at a young age, this contrasts with the procedure for trans women, who do not undergo surgery until the age of 18. Hannes Sigurjónsson, an Icelandic plastic surgeon practicing in Sweden, explained the decision-making process in these cases:

“For trans women, you want to have as much tissue as possible to work with. The outcomes are better if you have more tissues. We wait until they are 18: we want to be as sure as we can be that the patient is mature enough to take these decisions, and that they have physically finished the end phase of genital maturation.”¹³⁴

‘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. Arna Guðmundsdóttir, endocrinologist, differentiated hypospadias from other variations of sex characteristics:

“Some of these things are really easy to fix and we should fix them. If it’s a really minor thing like hypospadias, we should fix it. We should not make any rules that prevent people from fixing this at a young age.”¹³⁵

Medical professionals told Amnesty International that most cases of hypospadias are unproblematic¹³⁶ or a minor problem.¹³⁷ Medical professionals who spoke to Amnesty International emphasised the psychological impact – and in particular the impact on interpersonal relationships and the risk of bullying – in explaining their recommendations to carry out surgical interventions.

127 Interview with medical professionals, June 2018.

128 Interview with Kolbeinn Guðmundsson, paediatric endocrinologist, June 2018.

129 Interview with medical professionals, June 2018.

130 Interview with Kolbeinn Guðmundsson, paediatric endocrinologist, June 2018.

131 Interview with Kolbeinn Guðmundsson, paediatric endocrinologist, June 2018.

132 Email communication with Soffía Jónasdóttir, paediatric endocrinologist, January 2019.

133 Interview with medical professionals, June 2018.

134 Interview with Hannes Sigurjónsson, plastic surgeon practicing in Sweden, June 2018.

135 Interview with Arna Guðmundsdóttir, endocrinologist, June 2018.

136 Interview with medical professional, June 2018.

137 Interview with Kolbeinn Guðmundsson, paediatric endocrinologist, June 2018.

“For hypospadias, it is nonsense to wait until the boys are old enough to decide. There could be a lot of psychological problems. Do you know many kids that want to be different? Especially when it comes to sex. Swimming is very important here and if they go, they will get laughed at because they are different. The penis might be bent, they cannot pee without spraying everywhere. Some of the comments that kids with delayed puberty get, kids are not nice if they find a weak spot. Adults are not nice either. If [the kid] looks strange, that is going to be noticed.”¹³⁸

A 2006 Consensus Statement written by medical professionals 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.¹³⁹ 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.¹⁴⁰ 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.¹⁴¹ In performing medical interventions, the child’s right to health – including in adolescence and adulthood – and their best interests must be paramount. This means non-emergency, invasive and irreversible interventions with harmful effects must not be carried out.

5.1.3 CANCER RISK

“Surgery is never an immediate need unless there is an emergency.”¹⁴²

Individuals with internal gonads may undergo surgery. Gonadectomy, the surgical removal of the gonads,¹⁴³ is irreversible and results in sterilization. The common reason given for removal is the risk that the gonadal tissue may become cancerous. A study of data from 22 centres in 16 countries found that 67% of the centres recommended gonadectomy in early adulthood for girls with CAIS.¹⁴⁴ Soffía Jónasdóttir, paediatric endocrinologist, told Amnesty International about a case she had seen where a teenager had a tumour:

“[One] girl who is 15...we did an MRI and she had no working gonads: the gonadotropin[-releasing] hormones in her brain were trying to talk to something that wasn’t there. There was some tissue on one side that looked like an ovary but it wasn’t working and would never have made hormones or germ cells.¹⁴⁵ We would always recommend removing that because of the risk of cancer and she did have a cancer, it was 2x2cm and we had to evaluate if it had spread...There is some discussion that you should not remove the gonads but now I have seen a cancer case I can’t say not to remove it.”¹⁴⁶

Some individuals with variations of sex characteristics have ‘streak’ gonads where there is gonadal tissue but no follicles.¹⁴⁷ Medical professionals working with these individuals explained the actions they recommend in cases of streak gonads:

“Children with AIS have genitalia but they don’t menstruate. [The action we take] depends on the gonads. We remove streak gonads as soon as we know – they are a time bomb for cancer...The gonads are not good for anything anyway. If they are testes, it is a more difficult question. These could be testes, streak gonads, or ovotestes. We usually take it out. The testes do not produce sperm because of the lack of androgen receptors. If they produce testosterone, it will not work. There is no research on the impact of leaving the gonads in place.”¹⁴⁸

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 deferral until puberty.¹⁴⁹ Individuals who have undergone gonadectomies require lifelong hormone treatment which carries its own health risks (see Section 5.2.2).

138 Interview with medical professionals, June 2018.

139 <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2082839/>

140 Creighton, 2001.

141 Reifsnyder et. al, 2016.

142 Interview with Kolbeinn Guðmundsson, paediatric endocrinologist, June 2018.

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

144 ‘Management of Gonads in Adults with Androgen Insensitivity: An International Survey’, 2018.

<https://www.karger.com/Article/Abstract/493645>

145 Eggs or sperm.

146 Interview with Soffía Jónasdóttir, paediatric endocrinologist, June 2018.

147 Interview with Soffía Jónasdóttir, paediatric endocrinologist, June 2018.

148 Interview with medical professionals, June 2018.

149 Consensus Statement 2006, Table 4.

5.1.4 DECIDING WHEN TO OPERATE

Medical professionals explained how they decide whether to operate:

“We make decision about genital surgery at a year or two old. It’s more risky to operate on infants under the age of nine months, because of the risks of anesthesia. We bring the family in for an appointment. We need to know about the inner genitalia – we can try an ultrasound or an MRI but sometimes you need to do a laparoscopy. With some girls, they are peeing into the vagina – there is a risk of future infections.”¹⁵⁰

While there are some surgeries that are urgent, not all the surgeries described above meet the medical definition of acute cases:

“It’s the surgeon’s call whether a surgery is medically necessary. Do you need the surgery to live a healthy life? There is a time factor – how severe is the problem and how rapidly do you need the surgery? For acute conditions, the surgery might need to take place within minutes or hours. For less acute procedures, maybe within days. In general, for elective procedures there is a longer time frame to work with and the procedure does not take place until the patient is ready – but they might still be medically necessary.”¹⁵¹

One medical professional explained how surgery takes place later than in previous years, but still at a young age.

“To justify surgery, you need to show that early surgery is substantially better than waiting. There has been a drift towards waiting – we used to not be aware of the impacts of surgery. You don’t do it unless the advantages substantially outweigh the risks. You need a strong justification to operate at the age of one year rather than two.”¹⁵²

Hannes Sigurjónsson, an Icelandic plastic surgeon practicing in Sweden, explained that the DSD team that he is part of at Karolinska University Hospital in Stockholm, Sweden now advises waiting for the individual themselves to be able to make a decision about surgery.

“If there’s no functional need to operate, we would want to wait. The most important thing is to let the patient mature on their own – most importantly psychological maturing. The DSD group at the Karolinska Institute [in Sweden] is of the opinion that we should wait for surgery until everything else has been explored and the patient has a chance to decide for themselves.”¹⁵³

Existing research and ongoing studies on DSD treatment are primarily focused on sample groups of people with variations of sex characteristics that have undergone genital surgery as children or adolescents, or hormonal treatment. Long-term research is lacking that would establish whether difficulties that adults with variations of sex characteristics face are due to their individual anatomy, to the surgery they were subjected to as infants, to poor or non-existent psychosocial support¹⁵⁴ or to a combination of these factors.

5.1.5 CONSEQUENCES OF NOT OPERATING

Some medical professionals who spoke to Amnesty International were concerned about efforts to stop surgeries altogether.

“We do what is best for our patients. Very often we are told we are not doing what is best for our patients. What is being asked for is a total ban for all surgeries and this is absolute rubbish, there is no research to support this. There are very few people who think that what has happened is bad.”¹⁵⁵

Medical professionals cite concerns about it being ‘too late’ to intervene in the future if operations are not done.

“There has been some talk about surgeons who had done operations but thought they probably should not have done it, about the importance of not defining gender too early and not doing anything irreversible. I have been to

¹⁵⁰ Interview with medical professionals, June 2018.

¹⁵¹ Email communication, January 2019.

¹⁵² Interview with medical professional, June 2018.

¹⁵³ Interview with Hannes Sigurjónsson, plastic surgeon practicing in Sweden, June 2018.

¹⁵⁴ Liao et al, ‘Parental choice on normalising cosmetic genital surgery,’ 2015, British Medical Journal.

¹⁵⁵ Interview with medical professionals, June 2018.

surgical conferences and the doctors say this is so extremely difficult. If you don't do the surgery then it might be too late, you might have been able to help the baby if you had done it.”¹⁵⁶

While there have been various clinical studies and research on types of variations of 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 versus non-interference.

5.2 HORMONE TREATMENT

Several variations of sex characteristics are characterised by variations in hormone levels, and so individuals with variations of sex characteristics are frequently treated with hormones.

5.2.1 EMERGENCY HORMONE TREATMENT

Some variations of sex characteristics require emergency treatment. One example of this is 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.¹⁵⁷ CAH affects 1:14,000 to 1:18,000 births,¹⁵⁸ and so it is expected that one infant with CAH would be born in Iceland every three to five years. If there is a family history of CAH, doctors may advise a prenatal screening.¹⁵⁹ One form of CAH, salt-wasting CAH, can be life-threatening and so early diagnosis and treatment – usually hormonal – is required to save the life of the infant.

“For salt-wasting CAH, girls are diagnosed at birth because they have ambiguous genitalia. Boys are picked up later, around 4-5 weeks old. I don't think we have lost any boys to this [in Iceland]: all mothers have a midwife that goes to their house.”¹⁶⁰

Not all forms of CAH are life-threatening but they are likely to be diagnosed by appearance at birth: if there is a diagnosis of CAH or one is suspected, the infant is referred to an endocrinologist.¹⁶¹ Children with CAH receive hormone treatments as life-saving treatment.

“For children with CAH, we have a treatment plan of corticoid steroids and mineral steroids. It is a replacement treatment – it normalises the metabolism. Without this treatment, the condition is life-threatening.”¹⁶²

Children with CAH also require hormones to manage physical stress responses.¹⁶³ These hormonal treatments also have the effect of ‘normalising’ their sex characteristics.

“For milder cases of CAH, they may have clitoromegaly and a narrowing of the vaginal opening. Usually we treat with hydrocortisone and the clitoromegaly will subside.”¹⁶⁴

In previous years, if CAH was diagnosed prenatally, the pregnant person may have even been treated with dexamethasone to control virilisation, but in Iceland medical professionals told Amnesty International that this had a negative impact on the parents' health, and did not affect virilisation, so this treatment has stopped.¹⁶⁵

Children are monitored to ensure that they receive the correct dose. This also has an impact on their height.

“We manage the treatment throughout childhood: the individual dose that is needed is quite varied. Now we have [technology that can measure] hormone samples and change the dose as needed. What is really needed is to

156 Interview with Snjólaug Sveinsdóttir, neonatologist, June 2018.

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

158 Speiser et al, 2018, 'Congenital Adrenal Hyperplasia Due to Steroid 21-Hydroxylase Deficiency: An Endocrine Society' Clinical Practice Guideline', <https://academic.oup.com/DocumentLibrary/ENDO/JCEM/ic.2018-01865.pdf>

159 Interview with Kolbeinn Guðmundsson, paediatric endocrinologist, June 2018.

160 Interview with Soffía Jónasdóttir, paediatric endocrinologist, June 2018.

161 Interview with Soffía Jónasdóttir, paediatric endocrinologist, June 2018.

162 Interview with medical professionals, June 2018.

163 Interview with Soffía Jónasdóttir, paediatric endocrinologist, June 2018.

164 Interview with medical professionals, June 2018.

165 Interview with Kolbeinn Guðmundsson, paediatric endocrinologist, June 2018.

keep the androgens down, otherwise they will be very short and hairy and get a male appearance. They don't grow if you give too much, or too little."¹⁶⁶

5.2.2 HORMONE REPLACEMENT

Some variations of sex characteristics mean that an individual may not go through puberty as a teenager. In these cases, medical professionals prescribe hormone replacement treatment with either oestrogen or testosterone.¹⁶⁷ Hormone treatment must be carefully managed through puberty. For example, Soffía Jónasdóttir, paediatric endocrinologist, told Amnesty International that oestrogen replacement therapy must be carefully prescribed to control breast growth.¹⁶⁸

Hormone replacement treatment may also be required following surgery to remove gonads.

Hormone treatment can carry its own health risks and have a severe impact on the health of an individual with variations of sex characteristics.



BRIET, EGILSSTAÐIR

"I JUST WANT TO FEEL HEALTHY."¹⁶⁹

Briet is a member of Intersex Iceland and the cousin of Kitty (see section 6.1)

"I was born 14 years after my cousin Kitty. My mum had had a screening that said I had XY chromosomes, so she knew when I was born. Kitty was having a lot of difficulties; my mum knew that they had a better chance to do this right – no shaming, no secrets. My mum told me when I was two or three. I don't remember not knowing that I had a variation. My mum evolved the information she was telling me as I grew up. I knew that I couldn't have kids, for example, so she reminded me that I could adopt.

"When I was eight and a half months old, I had a hernia. The doctors said they needed to fix that, and since they were already operating, they could take out my gonads. They said they were useless and the risk of cancer was too high.

"I saw a doctor in Reykjavik once a year when I was growing up. We made it a family trip, so it was quite enjoyable. Usually it was just height, blood pressure – basic things like that. I think my mum was trying to accustom me to the doctors.

"When I was around 10-12, [the doctors] said I had to go on hormones. They said that I didn't have any gonads anymore because they took them out, and because of that, I had to have hormones. I knew that they had been taken out – I had the scars.

"First, I was prescribed hormone patches, but I had sensitive skin, so I was allergic to them. I was supposed to wear them for three days, but I could only wear them for one because I got rashes. I had a lot of tiredness. Every time I had to change dosage, I had a period of extreme tiredness. My mum and I kept a detailed diary for a long time and eventually the doctor agreed to change the method.

"Then I started on the birth control pill. It didn't work better – it was horrible. The tiredness got worse. Originally, I took it for three weeks and then had a week without pills – this was not very logical. I kept keeping the diary which showed that the pill break wasn't working. I managed to get the dosage up to every other day. I had side effects: I gained weight, and I had what I am now reasonably sure was depression. I went through menopause a few times. At one point, I went abroad for a year, so I had a lot of supply and I experimented. Taking a pill for two days and then not taking one for a day worked better, but I still felt bad. When I came home, the paediatric endocrinologist wasn't very happy with my self-experimentation.

"Then, when I was 18 or 19, I got really sick. I had been on the pill for a few years at this point. I couldn't get out of bed. I had a lot of tiredness and fatigue, my brain was foggy, I had to think extra hard to do anything, I wasn't really functioning. I was so sick that I couldn't remember to take my medicine, I couldn't remember to do anything. I was falling asleep at 11pm and waking up at 4pm. One Christmas

¹⁶⁶ Interview with medical professionals, June 2018.

¹⁶⁷ Interview with medical professionals, June 2018.

¹⁶⁸ Interview with Soffía Jónasdóttir, paediatric endocrinologist, June 2018.

¹⁶⁹ Interview with Briet, June 2018.

when things were at their worst, I woke up at 10am to help prepare for a party. I fell asleep at 4 or 5pm and slept through until 2 or 3pm the following day. I skipped a lot of school, sometimes I showed up after lunch. I had a school counsellor who gave me a pass to come in when I could. I tried my best, but I still failed some courses and flunked out of school.

“I told the paediatric endocrinologist that I don’t like this treatment, and I suggested that I try taking testosterone. There is some research that this can help. The doctor disagreed with trying testosterone and said that he wouldn’t treat me anymore. I didn’t have a doctor for one and a half years. I tried to contact an adult endocrinologist, but I couldn’t get past the secretary. In the meantime, I kept taking the birth control pill because it’s better than osteoporosis.

“When I was 19 or 20, my mum and my aunt called the [Medical Director of Health]’s office every day for a month. They wanted to get me a doctor, and [for] my cousin [to be] referred overseas. Eventually, they offered us an appointment for the next day. So, we got in the car and drove 650km to Reykjavik. At the meeting at the office of the [Medical Director of Health], they said there was a team working on my treatment and that I would meet them, but I haven’t met any of the team.

“They did assign me an endocrinologist – the same one who was treating my cousin. I asked for injections, because I knew people who had injections and they didn’t have the same side effects [as the pill]. [The doctor] told me that, at the moment, this was not an option for me. But she tested me, and my hormones were really low. I think I wasn’t digesting the pills properly because I was lactose intolerant and I had a lot of diarrhoea. She decided I was deliberately not taking the pills and that I could not be trusted with my own hormones, so she decided to give me the injections.

“The first injection was administered by a nurse. She had to write a note to confirm this because my doctor thought I couldn’t be trusted. I was working at a farm and it was a sunny day and I realised the grass was really green and pretty. I was very aware that there was butter on my bread and I didn’t want it and I started crying. I went home and for a day or two I was really emotional. I read that it takes a day to absorb the hormones, which makes sense. After a day or two, I didn’t feel so different, but things weren’t a constant struggle any more. Things were getting easier. I could walk upstairs without being exhausted.

“Two years later, I am still noticing improvements. I still have side effects – I’m not at full health now. If I work too much or I run too long, I tend to sleep a lot. The doctor says she is concerned about my hormone levels, she says they are too high for me. But honestly, I don’t care about my levels. I just want to feel healthy. She is trying to decrease the amount I’m injecting with to see how I feel. The choice is between being sick but better in the long-term, or feeling better now but having concerns about the future. Too high hormone levels might lead to increased problems in the future, possibly cancer, according to my doctor.

“I want to try testosterone, but I’m worried about how this doctor will react. I have osteopenia and there is some research showing that testosterone helps with this, but this doctor has reacted badly to Kitty asking for this in the past.

“When I was little, I didn’t care, but now I’m pretty pissed about it. All of this could possibly have been prevented. I don’t know whether it’s a good thing that the scars aren’t that visible. I haven’t had any apologies from the doctors. They still think that they did the right thing.”

As with surgical interventions, the right to health for children and adults – and for children, the best interests of the child – must be paramount in making decisions on whether or not to intervene, and in developing treatment plans.

5.3 FOLLOW-UP

“I would like to see more openness and communication between intersex people and doctors.”¹⁷⁰

Individuals with variations of sex characteristics may require lifelong lifesaving treatment and may also require monitoring to ensure they do not experience health problems as a result of lack of treatment or

¹⁷⁰ Interview with Briet, June 2018.

ineffective treatment. Most of this follow-up is medical and handled by the endocrinologist, and if a child has undergone surgery, they will attend follow-up appointments with the paediatric surgeon every six months.¹⁷¹

In Iceland, children who require endocrinological treatment see a paediatric endocrinologist at least until they are 18. Following this, they should be transferred to an adult endocrinologist before the age of 20.¹⁷²

Arna Guðmundsdóttir, an adult endocrinologist, explained that for the past two decades, doctors have been working to ease this transition:

“The transition from paediatric endocrinology to adult endocrinology used to be difficult. We’re very aware that people might drop out... Fifteen to twenty years ago, we started working more closely with paediatrics. Frequently, people now stay in paediatric endocrinology until they finish menntaskoli [upper secondary education] in Iceland – around 18-20 years old.”¹⁷³

The follow-up appointments may also be a chance to address emotional and psychological issues. One medical professional working with adolescents with CAH told Amnesty International:

“The advice we give is to make this part of their lives from day one, not to have any secrets. Secrets are bad, you need to talk about things. If they are asking questions, I offer to talk to them alone, or with their parents.”¹⁷⁴

However, not all individuals with variations of sex characteristics who spoke with Amnesty International find follow-up appointments supportive or helpful.¹⁷⁵

5.3.1 CASE MANAGEMENT

Since there is no multidisciplinary team in Iceland, doctors told Amnesty International that the type of follow-up, and the way individuals’ medical treatment is managed, varies, even for individuals with the same diagnosis.

“The referral depends on the problem with the child. Turner girls usually have a very high rate of congenital heart conditions, so we refer to the cardiologist... If there are no heart problems, we might refer directly to the endocrinologist.”¹⁷⁶

The type of medical diagnosis that someone receives (regardless of their age) may determine the coordinating doctor. This individual oversees the involvement of other specialists.

“It depends on what the main problem is. If it’s a development problem, for example, the child neurologist is the main contact. It depends on who has the most work to do. The coordinating doctor model is quite widely used, but it’s hard to be a coordinating doctor if you don’t use your speciality.”¹⁷⁷

Families of children with variations of sex characteristics also told Amnesty International that they struggle to keep on top of all their child’s medical needs.

If an adult with variations of sex characteristics is being managed by an endocrinologist, they see an adult endocrinologist at least once a year. Arna Guðmundsdóttir, endocrinologist, told Amnesty International that “follow up is usually scheduled one to three times a year. If everything is going well and there are no complications from the treatment, then a yearly visit is usually enough. People need to be monitored both for their well-being but also for long-term complications of steroids, such as diabetes, hypertension and osteoporosis.”¹⁷⁸

Arnar Hauksson PhD, a gynaecologist, explained the problems with the case management system and how difficult it can be to refer to other doctors:

“There is a lack of doctors in Iceland and there is a need for easy and quick referral system for our patients. But then again, the ground cost [for establishing a new system] is always the same if you are a big or small country, and there is less money in our Icelandic health system for us to use to that end, because we are a small country.

171 Interview with medical professionals, June 2018.

172 Interview with Kolbeinn Guðmundsson, paediatric endocrinologist, June 2018.

173 Interview with Arna Guðmundsdóttir, endocrinologist, June 2018.

174 Interview with medical professionals, June 2018.

175 Interview with intersex individual, June 2018.

176 Interview with Snjólaug Sveinsdóttir, neonatologist, June 2018.

177 Interview with medical professionals, June 2018.

178 Email communication with Arna Guðmundsdóttir, endocrinologist, January 2019.

Therefore, our referral system is not smooth and often you have to have a personal friend in the field to avoid that your patients get stuck on long waiting lists.”¹⁷⁹

Soffía Jónasdóttir, paediatric endocrinologist, does not feel that the system in place causes problems. She told Amnesty International that “we haven’t had to handle disagreements with other professionals.”¹⁸⁰ However, feeling caught between several medical professionals, regardless of whether an individual has variations of sex characteristics, can be a difficult experience.



SIGRÍÐUR,* REYKJAVÍK¹⁸¹

“I DON’T LIKE TO BE IN THE MIDDLE OF THE DOCTORS.”

Sigríður* was diagnosed with an underactive thyroid in 2018 at the age of 21.

“I’m still a little bit shaken by the diagnosis, even though it’s not a serious disease. I was diagnosed after some blood tests as part of my work’s ‘healthcare week.’ My red blood cell count was very low, and I was told this was very risky and to go to my doctor. She did more tests and it turned out that my red blood cells were actually fine, but I had an underactive thyroid.

“My doctor told me I would need hormones and she wanted to start treatment immediately. She told me that it would be very hard for me to have children. I hadn’t mentioned children – I’m 21 – but she told me over and over again. She didn’t talk about any other aspects of my hormones. She told me that if I wanted to get pregnant, I would need to come in immediately to check up on my treatment. The doctor scared me a bit talking about pregnancy. I felt a bit of a rejection in myself. I told my friends and they were supportive. If I can’t get pregnant, there are other ways to have children.

“I decided that I didn’t want to take the medication and instead I wanted to try controlling it with diet. It wasn’t a big change, I just tried to eat a bit healthier, so I tried that for four weeks. I’m also seeing a psychiatrist and he sent me for another blood test, because he thought this might explain some things. He called me that night to say the thyroid was stable, and it could be part of my brain sending my thyroid mixed signals. My GP confirmed this – she said it could be a brain thing and, in the meantime, I could start hormones or I could keep trying the diet, but it was always going to be a problem so I would need to keep having check-ups.

“I don’t like to be in the middle of the doctors. They are good, but it’s confusing when they all give different answers. I don’t think they talked to each other, but they can see my files with all the blood test results. It’s kind of a minor problem, but if it was bigger, it would be even more confusing. The doctors don’t think it’s a very big problem but it kind of is. Maybe they don’t think, “it’s my patient, I should collect everything together for them.” They have different opinions, and no-one seems to resolve it. It would be good to have one doctor to see who could take care of everything.

“I have a little bit of mistrust now. I’m worried that if I see a third person, they will say nothing is wrong at all.

It matters where in the country you are. I would like to go to Akureyri, to ask for a blood test. I would like to have more information, more research, more check-ins. I would like to know more about if I’m getting worse or better.

“I don’t know if there are any support groups. I found one on Facebook. Many women have the same problem as me and they are asking questions.”

Individuals with variations of sex characteristics who spoke to Amnesty International felt that the lack of a multidisciplinary team and rights-based protocols leaves them, and their families, struggling to access appropriate healthcare. This risks undermining the right to access the highest attainable standard of health for individuals with variations of sex characteristics in Iceland.

179 Email communication with Arnar Hauksson PhD, gynaecologist, January 2019.

180 Interview with Soffía Jónasdóttir, paediatric endocrinologist, June 2018.

181 Interview with Sigríður,* June 2018.

6. LACK OF SOCIAL SUPPORT

“I kept seeing the same stories: people were afraid, ashamed. People were so secretive that it was having an impact on their life.”

Kitty, founder and chair of Intersex Iceland¹⁸²

Around the world, many individuals with variations of sex characteristics have spoken publicly about how their treatment, as well as a lack of support, has had a negative psychological impact. In Iceland, individuals who spoke to Amnesty International talked about the lack of both psychological support and social support in navigating the health and welfare systems.

6.1 SUPPORT FOR INDIVIDUALS

All of the medical professionals in Iceland that spoke to Amnesty International echoed the importance of mental health care and support for people with variations of sex characteristics. Many told Amnesty International that the approach to supporting individuals psychologically has changed.

“I don’t think there are support groups. Some patients do have some psychiatric issues and they need extra support. It’s often very complicated... But there has been a change – an increased awareness of intersex conditions and of how you talk to people. You don’t treat people like objects. And there is less shame in seeking mental health support. It used to be a big deal but now there is no stigma attached to seeing a psychologist.”¹⁸³

Medical professionals also emphasise the importance of communicating with patients and now encourage individuals to understand their conditions. Kolbeinn Guðmundsson, paediatric endocrinologist, told Amnesty International that “it is not difficult for the children [with CAH] to understand. There are many diagnoses that are much more difficult.”¹⁸⁴

Medical professionals also pointed to the need to take a holistic view of the impact on a person of finding out that they have a variation. However, adults with variations of sex characteristics told Amnesty International that they experienced silencing and stigma about their variation, which have had long-lasting effects.



KITTY, EGILSSTAÐIR

“I DON’T WANT PEOPLE TO HAVE TO HIDE OR TO BE ASHAMED.”¹⁸⁵

¹⁸² Interview with Kitty, June 2018.

¹⁸³ Interview with Arna Guðmundsdóttir, endocrinologist, June 2018.

¹⁸⁴ Interview with Kolbeinn Guðmundsson, paediatric endocrinologist, June 2018.

¹⁸⁵ Interview with Kitty, June 2018.

Kitty is the founder and chair of Intersex Iceland.

“I didn’t really know anything until the year I turned 13. Before that, I knew that occasionally I went to see a doctor, but I didn’t know why. When I was 13, my mother sat me down and told me that I was different. She told me that I would never be able to have children, and that to start puberty I would need to go and see this doctor. I was super pissed off. I didn’t trust her. I felt like I had been lied to my entire life.

“Shortly after that, we went to Reykjavik to see this doctor. I was given the choice to start hormones immediately or to wait until the autumn. I wanted to wait; they told me that the hormones would stop me growing and I wanted to be as tall as possible. It was all really surreal.

“The day that I started the hormones, I got really angry and irrational. But we went home, and I just kept taking the hormones. For the year after that, I was a little shit to all adults. I was super defiant, I didn’t want to listen, I would isolate myself and try to escape into my own world. My mother was having a difficult time managing me.

“The following spring, I went to see a psychiatrist, who diagnosed me with ADHD¹⁸⁶ and oppositional deficiency disorder. My endocrinologist pulled strings to get me into the state psychiatric ward for children and youth in the summer, so that I wouldn’t have to miss school. While I was waiting, I wasn’t supposed to tell my GP or healthcare providers. Before I went into the state ward, I had an appointment with the psychiatrist and he told me not to disclose my intersex condition. He said they would treat me differently and I would not get the treatment I needed.

“In the ward, I burned through all the psychiatrists: they were all men and all old men like my endocrinologist. I sat there and didn’t say a word in all my appointments. Eventually, they put me with a psychiatric nurse and she was really nice. We had a few sessions and I ended up telling her about my diagnosis and that’s when my therapy started. I was in the ward for seven or eight weeks and it was actually quite good in a way. Eventually the staff realised that I wasn’t there for the same reason as some of the others. I started on mild anti-depressants, and when I left the ward, I had a diagnosis of mild depression.

“After that, life got a bit easier. I started reconnecting with my mother. But I hated my endocrinologist completely. I felt that it was his fault I ended up in the psychiatry ward. I kept having to go and see him for hormone treatment and I loathed every single appointment. He made me strip down and would weigh me, take my height, check my breast growth. He checked under my underwear, saying he was checking my gonadectomy scars. I felt he was transgressing the boundaries and I didn’t feel like I could say no. I didn’t understand it then but as I grew older, I realised that I felt the way that young kids feel when they are sexually abused. I kept seeing him until I turned 18 but I only had one appointment after I turned 18.

“When I was 15 or so, I had my first appointment with a gynaecologist. I was given vaginal dilators, but I really didn’t like them, so I stopped using them. After I stopped seeing the endocrinologist, I just kept seeing the gynaecologist. She handled my hormones and switched me to hormonal implants when I was about 19 or 20. Before that, I had taken pills until I reached a full dose, and then I had used gels and patches, but they burned my skin. The implants were designed for post-menopausal women, they were supposed to last four to six months. For me, they would last for three, and then I would go into menopause. I complained, and they reduced the spacing to five months, then to four. I would be okay for three months and then I would crash. I was exhausted all the time. I would stop speaking properly. I gained 20kg the last year I was on the gels, but on the implants, I lost 12kg in a few months. I went through menopause about 30 times and I got sicker and sicker. I was diagnosed with fibromyalgia, which is quite common in my family when people go through menopause, but I was only 27.

“The gynaecologist was great, she really listened to me, but she wasn’t able to make changes [to my prescription]. I finally gave up and went looking for an adult endocrinologist. The first one I saw took my history but then he never called me. I tried to book an appointment, but I couldn’t get one. I saw a lot of other specialists as well – I looked online and convinced my GP to refer me.

“Eventually I saw another endocrinologist and she suggested I switched to injections. I tried it and we did a lot of bloodwork, and eventually we settled on injections every three weeks and a couple of days. She let me do my own injections, she listened to me and started the process of switching me on to testosterone. We were discussing me seeing a specialist in the UK and coming up with a treatment plan. But then she left the country to work abroad, in around 2011. My health was horrendous. I couldn’t work anymore, so I was put on full disability. I would have a relaxing weekend day and then the next day I would be wrecked.

¹⁸⁶ Attention deficit hyperactivity disorder.

I was tired all the time. Even eating would make me feel dizzy – if I ate too much, I would black out. I couldn't work at all for five years.

"I found a new doctor and she told me I didn't need testosterone, I didn't need to see a specialist. I saw her a number of times and she always said she would check on this and that, but she never did anything between appointments. In the end I stopped seeing her. This was a few years ago. I haven't seen an endocrinologist or really any other doctors since then. I just see a gynaecologist once a year, who prescribes my hormones.

"My health is still not great, I have chronic pain. I have to maintain a balance between doing enough physical exercise to not freeze up, and not physically overexerting myself. I can't lift heavy things or do very physically demanding things, or I wake up the next day and everything is painful. I have had a good physiotherapist for years who helps me find my balance. I have had lots of support from my family and the people around me. When I was feeling like giving up, they supported me and got me through it. If I hadn't had my family, I would have given up. There was no doctor to help me through this.

"In 2015, I filed a report with the Directorate of Health, saying that my medical treatment had not been adequate with long-term effects on my health, but they didn't want to take the case on and it was never examined properly. This is the only avenue for complaints in Iceland. I first contacted them in 2014 and it took me six months to get information about the complaints procedure. The only reason I got the appointment to speak with them was because we kept calling them and went there in person. But even after pushing for this, we never heard anything back.

"Around the same time, I tried to get all of my medical records. That was extremely difficult, it took a long time and I had to call every doctor's office that I'd ever been to. The director of public health reviewed them before sending them – I have no idea why. There was barely anything in them. I did find out that my paediatric endocrinologist had lied to me and my mother throughout my life. I had a gonadectomy when I was a few months old. I discovered that my 'non-functioning gonadal tissue' had actually been testes. The files said that they removed 'healthy testicular tissue'. This confirmed what I learned at an AIS support group in 2005, that [people with this variation] are born with testes.

"After I was in the psych ward, I was offered psychologist support – there was nothing before this. Where we were living, there was a psychologist who visited once a month, but I didn't like him. Instead, I saw my GP monthly and I told him because I trusted him and I needed a neutral party. He reacted fine, he said he had no knowledge about this, but he was completely fine with it. I talked issues through with him, and once every few months I called the psychiatric nurse from the ward and spoke to her about things I didn't feel comfortable talking to a man about. But I think she was doing that as a favour to me – none of that was approved by my endocrinologist.

"When I was a teenager, the endocrinologist was adamant that I should not tell anyone about my variation. When I was 16, I told him that I had started telling my friends and he told me that I should not do this – I should not talk to anyone, not even my GP. He kept saying that people wouldn't understand and I would be treated differently and it would have been bad for me. I don't think this would have been true. Every time I told someone, it was okay, and I became increasingly open every year.

"Then I left Iceland and went to Australia and I decided to be really open. I thought, this is a limited time, if it's really negative, it's an experiment. I didn't introduce myself with my variation, but I didn't hide anything. I made a lot of friends in Australia and at some point, I mentioned it to everyone. If it came up, like if someone asked me for a tampon, I would just tell them I don't have periods. There was nothing negative, no-one treated me differently. In fact, I had to tell a couple of people twice because they forgot! When I came home, I decided this was just part of who I am.

"Good healthcare is so hard to get because we are seen as 'disorders' that need to be fixed. And there is a lot of paternalism – a lot of doctors are telling us what we need without really listening to how we are, how we are doing in general. A lot of the health issues that arise are because of the treatment that we got as children. We wouldn't have all these cases of osteopenia or osteoporosis if we hadn't gone through gonadectomies as children and incompetent hormone therapy as teenagers. Most doctors don't know anything, but they are very invested in 'immediate normalisation'. A lot has to do with their own perceptions: 'I wouldn't like to be like this'. This is what they were taught. Medicine has a tendency to change very slowly and it's hard for doctors to admit that what they have been touting as 'good care' is violating human rights.

"Gender plays a part in it. Everywhere there is this concept that gender is binary. If your biology doesn't fit, that will have a negative impact on you fitting into that binary. This is idiotic. Your biology doesn't have to fit perfectly for you to view yourself as a man or a woman – and even if your biology does fit, that

doesn't mean you see yourself that way. The last endocrinologist I saw denied me testosterone because I was a woman and therefore I should get oestrogen. But if I hadn't been sterilised as a child, my body would have produced testosterone – that isn't an indicator of my gender identity.

"I've heard from nursing students that they learn nothing about intersex issues. Medical students learn very little as well. If intersex issues weren't included in S78's educational programmes, teachers wouldn't know either. There's a lack of education in all fields, a lack of funding to create educational programmes and deliver them. What little education there is is provided largely by volunteers.

"There need to be complaint mechanisms in place. There's a lack of independence – all the doctors know each other, it's a tiny country. If the director-general of public health doesn't take your complaint seriously, there isn't anywhere else that you can go. There needs to be an independent body that's not as closely connected, and a means for people to get their complete medical records easily. Doctors stop practicing and people who try to get records from them are told they don't know where they are.

"I would like to see protections in place to guarantee that every person would be allowed to make their own choice about what happens to their bodies. I would like to see qualified psychosocial support for parents and kids and teenagers. I know that my mother had a difficult time because she was not offered qualified social support. I would like qualified healthcare professionals who are able to provide healthcare in this area – not just based on 'you are a woman and so we do this.' I have to go to the cancer screening centre because I have a higher risk of breast cancer because I take oestrogen. I keep being told that I am too young for breast screening and I must be there for a pap smear. I have to explain to the receptionist in front of a room that I don't have a cervix. I know most people my age are here for pap smears, but I am not.

"I would like for these variations to be something as normal as anything else. I don't want people to have to hide, to be ashamed. I want to see an understanding and acceptance that diversity exists and it's good and fine. I would like to see an Iceland where it's just normal and okay and you can get healthcare. I would like to see people care more about how people are feeling than what they think someone needs."

Some individuals who spoke to Amnesty International found it hard to access their medical records. This makes it difficult to identify what interventions they received, particularly in regards to interventions carried out when they were children. Briet told Amnesty International:

"I tried to get my medical records, but I was unsuccessful. It's supposed to be my legal right. I got all the normal records like injuries, but nothing about my intersex-related conditions. It just said: 'see letter from [my doctor].' I was told I didn't have access to them. I want records from my surgery, which was before records were computerised. I may have to go to all the clinics to get them. Honestly, maybe it's paranoia, but I'm starting to suspect that there aren't any records."¹⁸⁷

6.2 SUPPORT FOR FAMILIES

"The system is not good enough. Parents are not guided through the system. The support system for parents is awful in Iceland and needs to be improved."¹⁸⁸

Since many individuals who have variations of sex characteristics are identified and diagnosed in infancy or childhood, it is important to provide psychological support for their parents, families and caregivers.

6.2.1 AROUND DIAGNOSIS

In Iceland, there are general support services for parents of new-borns (for example, if there is a long neonatal intensive care unit (NICU) stay). This support includes psychologists, social workers, as well as priests.¹⁸⁹ Many of the medical professionals who spoke to Amnesty International talked specifically about how difficult the situation is for parents of an infant or child who has variations of sex characteristics.

¹⁸⁷ Interview with Briet, June 2018.

¹⁸⁸ Interview with Snjólaug Sveinsdóttir, neonatologist, June 2018.

¹⁸⁹ Interview with medical professional, June 2018.

Kolbeinn Guðmundsson, paediatric endocrinologist, told Amnesty International that, “these cases are rarely medical emergencies. But for the family, they are emergencies: psychological emergencies.”¹⁹⁰

Medical professionals talked about the need to support parents. One neonatologist told Amnesty International:

“For any baby that has any kind of variation, I meet the parents immediately after birth. It is always a stressful situation for the parents, whenever there is a need for care. My immediate concern is to take care of the wellbeing of the baby and stabilise them. Then I tell the parents about the situation... It is extremely distressing for the parents. How you approach them is very important. It’s important not to line up five specialists to talk to them.”¹⁹¹

When the situation is unexpected, the parents are likely to have a lot of questions and the medical professionals they are already in contact with may not know how to answer them. One midwife told Amnesty International:

“I saw one couple; they had had a previous foetus which had been born before 20 weeks, so they were having more tests than usual. They had an ultrasound which prompted genetic testing, and I received the results: the child had trisomy-X. The parents had a lot of questions: what does this mean, what do we tell our family. I told them to write down their questions and ask the doctor. They went to see a geneticist, and another doctor. It was up to them to handle this.”¹⁹²

However, not all parents are upset or distressed by the news, even if the medical professionals expect them to be. Snjólaug Sveinsdóttir, neonatologist, told Amnesty International that “[m]ost of [the parents] are not very upset. I think it’s partly because they haven’t realised how difficult it will be. For example, when I’m telling parents that their baby has other problems (for example, heart problems), when the problem is much more common, they get more scared. They have this preconception that things won’t turn out okay.”¹⁹³

Parents may not need support for themselves, but they may need support to provide information to other people; for example, their extended family. Snjólaug Sveinsdóttir told Amnesty International:

“In my experience, usually the parents – especially the mother – are so happy with the baby that they don’t care – they are the most calm, but they have difficulties in what to tell the extended family. I try to help them say what they are supposed to say in these first encounters. This is very often what the parents find most difficult. The norms are ‘is it a boy or a girl’? I was taught that it was very important to emphasise the beauty of the baby, to focus on the baby as an individual. After that, I call the endocrinologist.”¹⁹⁴

Parents may also need support in handling the stress of looking after a child with a medical condition. Kolbeinn Guðmundsson, paediatric endocrinologist, told Amnesty International that “[it] is difficult for the parents [of children with CAH]. They have to make sure their children take medicines three times a day. They know that this is potentially life-threatening – this is a stress factor. I can refer them to a psychologist if necessary, although I find I don’t do this more than for other conditions.”¹⁹⁵

6.2.2 IN DECISION-MAKING

Medical professionals who spoke to Amnesty International explained the information that they provide to parents in order to support decision-making about their children.

“The family are usually the most determined. We explain: here is what we have, here is what we don’t have. We talk through the future scenarios: the risk of malignancy, the possibility of fertility. In some cases, with new technology, there is a lot you can do. We talk about whether the child will go through puberty or if they will need help. We present the family with all kinds of options: we talk about what is surgically possible, what is hormonally possible. There is always a lot of guesswork and we try to be open with the family: nothing is ever for sure.”¹⁹⁶

190 Interview with Kolbeinn Guðmundsson, paediatric endocrinologist, June 2018.

191 Interview with medical professional, June 2018.

192 Interview with midwife, June 2018.

193 Interview with Snjólaug Sveinsdóttir, neonatologist, June 2018.

194 Interview with Snjólaug Sveinsdóttir, neonatologist, June 2018.

195 Interview with Kolbeinn Guðmundsson, paediatric endocrinologist, June 2018.

196 Interview with Kolbeinn Guðmundsson, paediatric endocrinologist, June 2018.

Medical professionals explained the importance of parental involvement in decision-making. Arna Guðmundsdóttir, endocrinologist, stated that “parents should have something to say. They are the ones who are going to bring up this child and I don’t think we can cut the parents out – that is terribly wrong.”¹⁹⁷

They also emphasised the importance of providing information to parents.

“Surgeries for variations of sex characteristics are like any surgery – patients and parents should be fully informed about the surgery. They need to know why [doctors] want to do the surgery, why does it have to happen now, what research is out there on mental and physical health and if there is no data.”¹⁹⁸

There is psychological support available in Iceland, but medical professionals told Amnesty International that not all families choose to access it.¹⁹⁹



KRISTÍN, REYKJAVÍK²⁰⁰

“YOU DON’T GET ANY SUPPORT, BUT YOU HAVE TO BE THERE FOR YOUR CHILD”

Kristín is Kitty’s mother (see Section X.X).

“It’s very difficult when you have a child and there is no information, no access to anything. You feel like one of a kind, you never meet anyone in the same situation. It was very traumatic and you have to get on with it. It was very hard at the beginning.

“When Kitty was around two months old, the paediatrician told me that something was wrong, but he didn’t say what, just that it was chromosomal. I had worked with a lot of children with chromosomal disorders. They told me that they wanted to bring her in overnight for some tests. A doctor – a paediatric endocrinologist – who had just finished his specialism in the USA had just arrived [back to Iceland]. The paediatric endocrinologist sat me down and explained about the chromosomes. He explained to me that she would have a short vagina with a blind ending. He said she had gonads that were underdeveloped and useless, and he advised removing them before the age of two so that she would not remember and not ask questions. If they weren’t removed, there was a very high risk of cancer. After that, she would need hormone treatments. He stressed that I shouldn’t tell anyone, and not tell her until she was old enough to start hormones, because society wouldn’t understand. I was so relieved because she wasn’t going to have cognitive difficulties. She was going to be 100% woman, apart from not being able to have children. But later in the day, it hit me and I broke down.

“Kitty had a recurring hernia, and she was a few weeks old when she had her first hernia operation. A few weeks after the first one, she needed another hernia operation on the other side, and since they were operating anyway, they removed her gonads. All the operations were finished by the time she was three months old. The operation took many hours, but they never gave me very much information. The surgeon said everything was fine. As it turned out, I didn’t get any more information before she turned two.

“I was told to bring her in once a year to the paediatric endocrinologist for a check-up. He always said I could phone him if I had questions, but I just felt like I had been left. I was very lucky because I had my sisters and I told four of them – I could talk about it to them. But sometimes you don’t really talk about it. I was in Reykjavik but only one of my sisters lived in Reykjavik. They all knew what I knew. And I had one friend that I had worked with before, I talked to her a little bit. But it was very difficult – there were no support groups. It brings shame, not being able to talk about it. If it’s so horrible that society won’t accept it, it must have been horrible.

“At the check-ups, the doctors measured her, weighed her, checked her scars. Kitty thought everyone saw a doctor annually. Later on, they took hand X-rays to see how she was growing. They didn’t tell me why, although I knew it was for her height. I asked if they could predict how tall she was going to be. After she started hormones, they checked her breast development as well.

“She started hormone treatment a bit late, because there is never a good time to tell someone about this. It was a hard time – we had moved abroad [to the UK] and expected to live there, and we would have found a doctor there if we had stayed. But I divorced, and we came back when Kitty was ten. It was difficult – she went through bad bullying in school when we moved back. She had always been a very strong personality and hadn’t had any problems before, but when we came back [to Iceland], she was bullied very badly. It didn’t matter what it was – the way she looked, acted, spoke – she came from a

¹⁹⁷ Interview with Arna Guðmundsdóttir, endocrinologist, June 2018.

¹⁹⁸ Email communication with medical professional, January 2019.

¹⁹⁹ Interview with medical professionals, June 2018.

²⁰⁰ Interview with Kristín, June 2018.

British school into a completely different environment. They would pick on anything, even her pronunciation. She still avoids certain words. She did very well in school and that was another reason to pick on her. She had her things taken. There was no reaction from the school until the final year, when I had a team of experts on my side. Then, the ones who were a big problem were threatened with expulsion and she was ignored.

“But the paediatric endocrinologist started to push me about this – he said you need to tell her, so she has time to adjust and make a decision about when to start hormones. He pushed me into telling Kitty, but he didn’t push her into starting anything. He was the only doctor she ever met – he didn’t want us to tell any other doctors. In small communities, things will leak.

“I told her when she was 12. She didn’t want me to tell anyone. I think she didn’t want to give them any ammunition. It was hard because I was not allowed to tell her brother, who is four years younger. This affected their relationship. He knew she took medication and went to see doctors, but didn’t know why. She was about 13 when she started hormone treatment and it was hard. Her body started to change, and she was not very happy. She was very angry with me because I had kept the truth from her. She told me she felt like a freak – she used that word. There was no other support – if you can’t tell anyone, how can you find support? I didn’t even know where to look.

“Kitty started to see a gynaecologist when she was around 14. The endocrinologist organised it – he said she needed a pelvic exam, and he wanted Kitty to see a female doctor. The gynaecologist was very kind. She was the closest thing Kitty ever got to support. She never did anything – she said there’s no need to do anything now, you can wait and do something whenever you want. Kitty saw her until she was about 28. She never pretended she knew everything – she listened to what Kitty had to say, and she was kind, but she ended up specialising in births and moving positions.

“The summer she was 15, she was feeling suicidal. The endocrinologist got an appointment for her in BUGL and she was there for about 6 weeks. I think he wanted to make her stronger to deal with the bullying. She was very happy doing art therapy. She came out feeling that there was nothing wrong with her – they are bullies and they need to be stopped. A psychiatrist and a psychiatric nurse came to talk to the school and the bullying stopped, so in that sense it was successful. The ward nurse thought it was very unhealthy how fixated she was on her syndrome – she wanted to talk too much about it. Obviously, Kitty tried to discuss it and didn’t get any support.

“After the last year of school, she went to college. She came in very strong and decided that they would not pick on her. Some of the same kids were there but it was a different system. She continued to study a lot – at one point she was taking a double class load. For the first year, she didn’t participate in any social activities until Christmas. The year after that – the year she turned 18 – she went to Australia as an exchange student. She came back as an adult. I don’t think she ever talked to anyone until she went to Australia, but I think she tested it there. And by the time she came back, the family knew because her cousin Briet [who has the same variation] had been born when Kitty was 14.

“Briet was an adorable baby, and around the time she was born, Kitty told me again that she [Kitty] was a freak. And I told her that if she was a freak, then Briet was a freak, and Kitty got very angry about that. After that she started to look at it differently.

“Part of how hard it is, is that you don’t get any support and you don’t really know anything; but you have to be there all the time for your child and be strong. I worry about her health, about how they are still treating her. I am angry about the healthcare that she received after she became an adult, especially after she started to ask questions. I cannot even think about the doctors after 4pm, because then I don’t sleep at night because I am so angry. Even now I have power of attorney to talk on Kitty’s behalf with doctors, and I put off writing to them because I am so angry.

“For a long time, she was sent from one doctor to another. Every time, she asked if her health had something to do with her AIS and they always said no. At one point, the doctors talked together without her knowledge and changed her hormone treatment without discussing it with her. They decided her hormones were too high, cut the levels and just left her. And even the gynaecologist who had always been supportive of her feelings questioned her own methods. They were measuring her against a ‘normal’ woman but she became so ill. She just slept.

“She was like this for a year, and then in 2012 we decided as a family to go to a conference in the UK. There was a gynaecologist there from UCLH and she gave a lecture, then stayed to talk. I asked what was the right level of hormones, and she said the level that a person feels good at. So, when we went home, we wanted to change the treatment, and we found another endocrinologist, but she said Kitty was crazy. She told us in the beginning that she didn’t know much but she would find out. She said she would

consult with doctors in the UK and Sweden, but then she didn't and denied she had ever said that. She still insists that she knows the right treatment, and she accused Kitty of being mentally unstable. I go with her to every appointment.

"We filed a complaint to the [Office of the Medical Director of Health]. We went to the appointment as a family – Briet and her parents too – and the directorate of health ordered the doctor to assist Kitty in getting a referral to UCLH, and to start treating Briet as well. This was in August 2015, but there is still no referral. Since then, the law has changed, and you don't need approval from the Icelandic health system to go abroad for treatment. You can make an appointment yourself, but the UK NHS still requires a referral. I am still waiting for information that I need for the doctor in the UK as well. This system is EU-wide, so it's not clear what will happen if the UK leaves the EU.

"It's like fighting windmills – and there is no other doctor to go to. Within the medical profession, the doctors talk to each other and they believe Kitty to be mentally unstable and crazy. Only one doctor ever listened to her and prescribed testosterone, which makes her feel better, but that doctor left and moved to Sweden. The new doctor says it's only a placebo effect and refuses to prescribe it. Luckily, the GP will repeat her previous prescription, although sometimes there is a shortage of testosterone. But you are totally dependent on medical assistance that doesn't know what they are doing and refuses to listen to you. That's what makes me mad and it's so exhausting.

"The first doctor we saw, the paediatric endocrinologist: his treatment was based on wrong information, but he did fully believe he was doing the right thing. He did what he thought was right and he was compassionate – until Kitty started to criticise and ask questions. When Kitty started speaking publicly and founded Intersex Iceland, he refused to treat Briet anymore. He was treating her and had previously agreed to treat her until she was 20, but he discharged her without referral. We tried to refer Briet to Kitty's endocrinologist, but she never answered.

"When Kitty was born, they told me I would never meet anyone in the same situation. I have met lots! But none in Iceland. I was in a UK parents' group, but it disintegrated, and I don't have the energy to be in a support group. I met a parent in Denmark whose child was diagnosed when she was 12 and she is now about 26. We visited her in Denmark and we are still friends on Facebook. She sees everything I post about intersex but never responds because it's a secret for her.

"I would like to see the doctors become humans and listen to their patients. There are guidelines for the best care for cancer patients and one of the points is to always listen to the patient, because they will always be involved in the treatment and have something to say about it. Now, they are doing experiments with Briet – cutting her [hormone] levels because they are considered too high and it might have long-term effects. There are long-term studies – but they are based on women who do not have AIS. But you can't do anything about it because they can refuse to prescribe your medication. There is a feeling of being utterly helpless and they just continue to do it – they never listen to how you feel. They don't treat individuals on the basis of how you feel. They go by norms, and the norms are set by humans."

6.3 SUPPORT GROUPS

Iceland's population size and the fact that patient support groups are frequently organised around diagnoses mean that there are few support groups in Iceland. There are no patient support groups in Iceland for individuals with variations of sex characteristics, and medical professionals may advise people to look into international support groups.²⁰¹ Briet told Amnesty International that, "[w]e attended an AIS support group in the UK in 1999, when I was three. Later we went to the UK and attended a meeting. I think we met a doctor, but I was only nine."²⁰²

Medical professionals cited different reasons for the lack of support groups, including privacy²⁰³ and the fact that support groups may not meet the needs of individuals appropriately.²⁰⁴

201 Interviews with Soffia Jónasdóttir, paediatric endocrinologist, and other medical professionals, June 2018.

202 Interview with Briet, June 2018.

203 Interview with medical professionals, June 2018.

204 Interview with medical professionals, June 2018.

Even for diagnoses that are comparatively frequent – whether or not they are related to variations of sex characteristics – there are few support groups in Iceland.



MARGRÉT,* REYKJAVÍK²⁰⁵

“I WOULD HAVE LOVED TO BE ABLE TO TALK TO SOMEONE ELSE”

Margrét* has been diagnosed with Polycystic Ovary Syndrome (PCOS).

“PCOS has side effects that affected my self-esteem. It still affects how I look and I’m now 26. It has always affected how I think about my face and how I think about things. When I was 12 or 13, I had a lot of acne. I went to see a dermatologist and she prescribed me something, but it wasn’t enough. I was diagnosed with PCOS by a gynaecologist when I was 17. He told me that my hormone levels were affecting my periods – they were irregular – and causing acne, and hair growth. He said I needed to go on the pill. At that point, I didn’t have a boyfriend, I wasn’t having sex. He didn’t recommend any other methods of treatment, and ten years ago, I didn’t have any other sources of information. He also told me to watch my weight. So I went on the pill. I was in high school and there was lots of homework and exams and project work, I was very stressed. I had a lot of mood swings – I was very angry, very tearful, very insecure. I don’t know if the pill was affecting this, or if not taking it would have made a difference.

“Now I’ve done my own research on this so I know that diet and stress levels can affect PCOS. PCOS is very correlated with being overweight and so lots of the advice online is directed towards women who are overweight, but my BMI is 26. I might become overweight but I don’t have PCOS because I’m overweight, so the advice didn’t quite fit me. I have always been quite active, most of the time I’m doing sports. I could lose weight, but I’ve never been more than 2kg lighter or 5kg heavier than I am now.

“A couple of years ago, I decided that I didn’t want to take the pill anymore, because I had been on it for seven years and I didn’t like the mood swings, I wanted to see what my moods were like without the pill. This time the gynaecologist was helpful and gave me some other pills to regulate my periods. He is much more used to dealing with women who are trying to get pregnant. I wasn’t, but he treated me as if I was trying for a baby. Suddenly my treatment options changed and I could just take pills to regulate my periods: this also helped with the acne. Maybe he could have offered that from the start, but I didn’t feel I could discuss it with him, he was very old and I didn’t think that conversation would lead to anything. In his mind, a woman under 20 doesn’t want a baby so she goes on the pill, a woman in her mid-twenties with a partner wants a baby so no pill. He is an expert in PCOS but now I know what to expect from him and I tell him what I want. I have to map out my options, and if this doesn’t work I ask him for other options.

“I was never told that I could talk to anyone about my PCOS, there is no PCOS support group in Iceland. I would have loved to be able to talk to someone else about what they had tried, for example for hair removal options when I started to have more hair growth on my face and stomach. I found some groups on facebook but they were mostly for women who were trying to lose weight so they could get pregnant. No-one else from Iceland was in these groups. I have told my close friends that I have PCOS – I’m not ashamed of it – but I don’t talk much about it. Perhaps because [in Iceland] there are so few of us and it’s hard to keep something private, maybe, it’s hard to open up about things. It would be good to have a support group. I would have liked to have more options for treatment right from the beginning. I know now that there’s a lot more you can do than just go on the pill – you can work on your diet, on your stress levels – but I didn’t know that and the doctors didn’t tell me.

6.3.1 FOLLOW-UP

Medical professionals also spoke about the general challenges that face parents of children who need medical treatment.

“There is a profound lack of social workers to help guide people through the system. There needs to be more money in the system – BUGL²⁰⁶ is underfunded with a waiting list of years and years. There is no overall guidance system: the state takes care of some things, the hospital takes care of other things, then there are the

²⁰⁵ Interview, June 2018

²⁰⁶ BUGL is the psychiatric ward for children and adolescents in Iceland.

healthcare centres, the schools, the municipalities, and they don't talk together. Parents with children with severe difficulties have trouble navigating the system. High performance parents manage but others don't and their children are most in need of support.”²⁰⁷

Parents who spoke to Amnesty International talked about how hard it has been for their children and for them and how little support they have received.



HREFNA, EGILSSTAÐIR²⁰⁸

“I WOULD LIKE TO SEE DOCTORS LISTEN TO THEIR PATIENTS”

Hrefna is Briet's mother (see section 5.2.2)

“I knew when Briet was born that she had the same condition as my niece. I was 32 years old when I got pregnant, so I had to ask for an amniotic fluid test because it was generally not made until at the age of 35. I had to argue my case because of that, and they agreed when they heard of my niece's condition. So, I had had an amniotic fluid test while I was pregnant that had said my baby had XY chromosomes, so when she was born I knew straight away. But it took a few days to verify this. I had to push for it, the doctors said that there must have been some mistake. But I thought, compared to other children who have allergies and asthma, this isn't bad. My world didn't explode!

“Briet was born in Egilsstaðir, but when she was nine days old we went to Reykjavik for two days for lots of tests. They explained to me what they were doing but I can't remember much. I remember that they took a lot of blood. After this they verified that she had the same condition as my niece, and we went home.

“She was a very difficult child, she never slept for more than 20 minutes and she woke up and cried every night until she was four and a half years old. She had an abdominal hernia and it was two or three months before we found out, she cried so much. We went to Reykjavik for the surgery for that when she was eight and a half months old. The doctors said that they wanted to remove her gonads at the same time, because there was a high risk of cancer. They said they wanted to do this before she stopped wearing nappies so that she wouldn't remember anything.

“When Briet came out of the surgery, the first thing the doctor said to me was that she needed an operation to lengthen her vagina as hers was only 2cm. That was the first thing he said – not that she was doing well, instead he said she would need more surgery later on. It was hard to hear this – it was not what mattered to me. There were lots of doctors and medical students around. They thought this was very interesting. I was there on my own because my husband's employer hadn't let him take time off. But there was one nurse there that I knew, and it was good to have [a] familiar face there.

“We went home the next day and the only advice they gave me was to go to the local medical centre to change the dressing. They told me not to tell Briet too much about her condition and not to tell anyone outside the family. But I saw what happened with my niece and my sister and it was awful. I read a story told by a British parent in a British support group we joined in 1999, that the family felt better being more open, so I decided to do the same. I told Briet from the beginning, but of course started very simply. We told her she was special, and reminded her that she couldn't have children, she would need to adopt. When Briet was two years old, she went to nursery school. I had a meeting with the principal and staff there and I told them about my daughter's condition. I asked them to emphasise that all children are different, no two children are the same and you can't always tell by looking at them. They were very helpful, they were always discussing those things with the children.

“Every six months, we saw the paediatrician in Egilsstaðir, like all the other children. We went back to Reykjavik once a year initially. We made it into a family trip: we saw the doctor on Thursday and then stayed through the weekend. She had blood tests, they checked her height and weight. Every two years she had a bone scan on her hand. When she was seven, her bone age was four and a half – she was very slow growing and her bone maturity was much lower than her actual age. Her bone growth didn't finish until she was about 20.

“We always went to hospital appointments as a family, and I insisted her father came with me. It was very expensive for the family – Briet's airfare costs are covered but no other travel costs, and the same for one parent until she was 18 years old, but not for both parents. After Briet was 18 years old, we as parents did

207 Interview with Snjólaug Sveinsdóttir, neonatologist, June 2018.

208 Interview with Hrefna, June 2018.

not get our costs covered, [but] we felt that the doctors treated us differently if her father was with us. Perhaps they thought I was a hysterical woman.

“Briet went to primary school and I met a new teacher and asked him to do the same as the nursery school. She changed teachers every two or three years and every time she had a new teacher I explained the situation to them. I didn’t want to write it down – I wanted to tell everyone. We were always learning more and more and if I wrote it down it wouldn’t be up to date. When she was in fifth grade, she and I held a meeting with the whole class. We explained her situation and asked the class to look after her. The other kids were surprised, and they asked a lot of questions. This was important later when they reached age of puberty as they remembered some of what they had been told and protected her against bullying.

“Briet was always a very active child, a ball of energy. I found her first on the roof when she was two! And she fell off the roof when she was seven. But she started hormone treatment when she was about ten and a half, and everything changed. She had no energy, she couldn’t do what she was doing before. I didn’t let her go out after 7pm because she would be too tired the next day. Sometimes she had a fever. Before this, she was playing violin, playing piano, practicing gymnastics, joined the scouts, playing with her friends – but now she was too tired to do these things. She needed to stop gymnastics and playing with her friends after school as she had no energy left for that.

“I took Briet to the doctors and they did some tests, but they all said it couldn’t be because of the hormones, they had never heard about this. If they didn’t change her medication for a long time, she started to get better, but every time they changed it she got sick. Starting secondary school was very difficult because they changed her medicine. Until the age of 16, she had hormone patches, and her skin was allergic all the time. After that she started on tablets. She went on an 11-month exchange student programme to Costa Rica when she was 17, and she slept for most of the year she was there. She couldn’t do everything she wanted.

“I had a meeting with the secondary school. I wanted them to know what was wrong with her. I met every new teacher she had. When she was 18, she went to school 60% of the time. They allowed her to do her schoolwork at home when she was feeling too bad to go to school, and most of the time she had to study from her bed. One year she finished most of her courses because I helped, or her younger sister helped, because she was so foggy in her head. She still needs to finish two natural science courses. It was worst after she turned 18 or 19. She was taking the medicine (Microgine and Vagifem) and it didn’t work, the doctor said he couldn’t find any trace of it. We knew she was taking it, but the doctor said she wasn’t.

“Briet still hasn’t recovered. She started taking hormones by injection two years ago, and she now gets a hormone shot every two weeks. During this time of experiments, they kept increasing the dose and shortening the time between her injections to see what would work. Every time she finished a dose, it was awful, she just slept. If things are busy, sometimes it takes one to three days before she can get an injection and she just sleeps. She has been diagnosed with osteopenia as well. She can’t work full-time, so she is still living at home. She can’t afford to live on her own if she is always getting sick.

“The doctors don’t believe us. Last year, we gave an education lecture to medical students. We keep a diary of her symptoms, but the doctors don’t believe it. I told them that they should listen to their patients. In August 2015, we went to the [Medical Director of Health] to complain about her treatment. The endocrinologist we see is the only doctor who can do anything, according to the [Medical Director of Health]. We didn’t want to see that doctor because she was also my niece’s doctor and she had a very bad experience, but she was assigned to us. That doctor didn’t want to see us initially: it took her four months to respond to us and we first got an appointment with her in January 2016 with a [lot of] help from our GP.

“We tried to be optimistic, and I said I would give the doctor two years. We go to her twice a year, but this is our only contact with her. We wanted to seek treatment in the UK, but we can’t do this unless she writes a referral and she won’t do that. My daughter is still sleeping a lot. It shouldn’t be like that, she is now 22.

“As a parent, at least I always had my sister, and she had me to talk to. Maybe I overprotected Briet. I didn’t let her do things, she missed out on things. She did go to scout camps and things like that, but she always went to bed earlier than the others, she was too tired. I never stopped her younger sister from doing things, but she had much more energy. With Briet, I was always keeping an eye out for her.

“The doctors did always try to explain what they were doing – they gave us some information. But we were never told, for example, that she had testes – the doctor always just said ‘gonads.’ It was such a big impact when she went on the hormones, she lost all her energy. If she hadn’t had the surgery, perhaps

she would have had more energy. The doctors say now that her body would have produced testosterone and her body could use it and stay healthy.

“These years have been very tiring. I am always thinking about Briet’s health. I would like to see doctors start listening to the patients. Our current doctor, she is always comparing Briet to a ‘normal’ woman who has had her ovaries removed, but she is not like that. But the doctor doesn’t want to talk about it.”

Briet explained how she and her mother worked with her school: “My mum and I talked to the other kids in school. We emphasised that not everyone is the same, but you help each other. When I was 10, I held an educational meeting about my intersex condition. Things went well and nothing really changed.”²⁰⁹

6.4 ACTIVISM IN ICELAND

Intersex Iceland is the only group working publicly for the rights of individuals with variations of sex characteristics in Iceland. Kitty, the founder and chair, explained to Amnesty International why she started the organisation.



KITTY

“I COULDN’T NOT DO SOMETHING”²¹⁰

“I was connected to a support group in the UK and went to meetings there in 2005 and 2012. I was involved in an email list, which then became a secret Facebook group. It gave me a lot to have contact with people who were going through the same things. I kept seeing the same stories: people were afraid, ashamed. People were so secretive that it was having an impact on their life. And so many people with health issues, like osteopenia or osteoporosis. I heard horrendous stories about really shitty healthcare. It just felt so wrong: people shouldn’t have to experience this. I couldn’t not do something.

“I had been thinking about being an activist for a few years. In 2006, shortly after I moved to Reykjavik, I contacted S78 (at the time, the national gay and lesbian organisation), and asked to borrow their space once a month. I planned to advertise a support group, but I was told not to contact them again, that they did not have space for ‘freaks’. So, I stepped back until the end of 2013, when I was contacted by a friend involved in Reykjavik Pride, who wanted to interview an intersex person. I was very wary but she was super nice and understanding and it was a positive experience.

“I had been involved in various sorts of activism in Iceland before. I couldn’t just sit still and not do anything about it. It took a few years, but then we founded Intersex Iceland. I reached out to S78 again and had a meeting with a couple of board members. I realised that the attitude was completely different. Intersex Iceland applied for membership in 2015 and S78 changed their statutes so that their mandate covered intersex people.”

But even the presence of a visible group of human rights defenders has not necessarily made it easy for other individuals to talk about the fact that they have a variation in sex characteristics. Briet told Amnesty International:

“We are not out. At the moment, it’s just me and [my cousin] Kitty who are out. I think the shaming was very successful because it’s a small community. If you know everyone then it’s difficult. In a small town like mine, it’s okay to be different in some way as long as you’re not too different.”²¹¹

209 Interview with Briet, June 2018.

210 Interview with Kitty, June 2018.

211 Interview with Briet, June 2018.

7. LEGAL PROVISIONS IN ICELAND

7.1 MEDICAL LAWS

In Iceland, the Ministry of Welfare administers legal provisions and sets policy related to health services, including health records and data collection for the health sector; patients' rights; and licensing of healthcare professionals.²¹² The responsibilities of the Ministry of Welfare are divided between two cabinet ministers: the Minister of Social Affairs and Equality and the Minister of Health. The Minister of Health is responsible for issues relating to health services.²¹³

The Directorate of Health is an agency that operates under the authority of the Minister of Health and is headed by the Medical Director of Health. The responsibilities of the Medical Director of Health include monitoring health services and healthcare practitioners, working for quality development, and advocating for health care practitioners to be trained in line with prevailing standards for the provision of health services.²¹⁴

7.1.1 PATIENTS' RIGHTS ACT

The objective of the Patients' Rights Act²¹⁵ is to “to ensure specific rights for patients in accordance with general human rights and human dignity and thus strengthen their legal status vis-à-vis the health service, and to support the confidential relationship which must exist between patients and healthcare practitioners.”²¹⁶

Article 3 of the Patients' Rights Act states that:

- “The patient has the right to the best health service available at each time.
- “The patient has the right to service appropriate to his/her condition and prognosis at each time and the best knowledge available. The healthcare practitioner shall endeavour to establish a sound relationship with the patient.
- “The patient has the right to continuity of service and cooperation between all healthcare practitioners and institutions involved in the treatment.”

Articles 7-9 of the Patients' Rights Act govern patients' consent to treatment and right to refuse it, while Articles 25-27 make specific provisions for patients who are children, including:

212 Article 9, Items 4.I through 4.o, Presidential Decree No. 84/2017.

213 Article 9, Para 1, Presidential Decree No. 85/2017.

214 Articles 2 and 4, Medical Director of Health and Public Health Act No. 41/2007, as amended. See an English translation of the Act at <https://www.government.is/library/04-Legislation/Act%20on%20the%20Medical%20Director%20of%20Health%20and%20Public%20Health%20as%20amended%202018.pdf>

215 Patients' Rights Act No. 74/1997, as amended. A “patient” is defined in the Act as “a user of the health services”, cf. Article 2, Para 1 of the Act. An English translation of the Act can be found at <https://www.government.is/Publications/Legislation/Lex/?newsid=e2b13be0-42fc-11e8-942b-005056bc530c>

216 Article 1, Patients' Rights Act No. 74/1997, as amended.

- For children under 16, information should be provided to the parents and consent for necessary treatment shall be given by the parents. If the parent refuses, then the relevant healthcare professional shall seek assistance from the child protection authorities (Articles 25-26).
- Children shall be given information “appropriate to their age and maturity” (Article 25) and shall always be consulted if they are over 12 and in general should be consulted “as far as possible” (Article 26).
- “Everything possible must be done to enable a child who is a patient to develop and enjoy life, in spite of illness and medical treatment, as far as the child’s condition permits.” (Article 27).
- “Children shall be spared unnecessary tests and procedures.” (Article 27).

7.1.2 HEALTHCARE PRACTITIONERS ACT

The rights and responsibilities of healthcare professionals are set out in the Healthcare Practitioners Act.²¹⁷ In particular, Article 13 sets out professional standards and responsibilities for healthcare providers:

- “A healthcare practitioner shall display respect for the patient and perform his/her tasks vigilantly and conscientiously and in accord with the professional standards required at any time.
- “A healthcare practitioner must be aware of his/her duties and ethical rules, maintain his/her knowledge and professional skill, master innovations in his/her field of work, and familiarise himself/herself with legislation and regulations applying to healthcare practitioners and healthcare services at any time.
- “A healthcare practitioner is responsible, as applicable, for the diagnosis and treatment of patients who consult him/her. The duty of a healthcare practitioner to impart information to the patient is as provided in the Patients’ Rights Act.
- “A healthcare practitioner shall recognise his/her professional limitations, and seek assistance or refer the patient to another healthcare practitioner as necessary or possible, for instance if he/she judges that he/she cannot provide appropriate healthcare service.”

7.1.3 HEALTH RECORDS ACT

The entering of, storage of and access to health records is governed by the Health Records Act.²¹⁸ This stipulates that patients have access to their own health records (Article 14). One midwife explained the system by which medical records are kept in Iceland:

“We keep records of all check-ups and follow-up, we keep a copy and a copy goes to the healthcare office. It’s standard practice to send copies to other offices. But if everything is going well, we give a report by phone and the healthcare office notes it down. It’s like a closed loop: when one healthcare professional stops treating someone, they pass them on to another one.”²¹⁹

It is only in recent years, she told Amnesty, that records have been digitised.²²⁰ She also explained that some clinics in Iceland are not necessarily complying with the laws and policies on record-keeping:

“For private clinics, their record-keeping is not good. They are supposed to keep records of everything they do, but they don’t. They are supposed to report data to the [Office of the Medical Director of Health], but they seem to get away without doing this – it’s terrible. Their rationale is that they are protecting the privacy of their patients... The laws are clear but they are not complying with them, and there are no consequences.”²²¹

Despite the provisions of the Act, individuals who spoke to Amnesty International reported difficulties in accessing their medical records.

217 <https://www.government.is/Publications/Legislation/Lex?newsid=8ef83975-fbd6-11e7-9423-005056bc4d74>

218 <https://www.government.is/Publications/Legislation/Lex?newsid=8ef83905-fbd6-11e7-9423-005056bc4d74>

219 Interview with midwife, June 2018.

220 Interview with midwife, June 2018.

221 Interview with midwife, June 2018.

7.1.4 ACT ON HEALTH INSURANCE

The Act on Health Insurance²²² governs the Icelandic health insurance system.

Article 23 of the Act on Health Insurances determines the criteria for seeking medical treatment overseas if such treatment is not available in Iceland, and Article 23a determines the criteria for treatment overseas if it is available.

Article 44 requires that healthcare providers deliver evidence-based services: “Providers of health services shall generally base their operations on evidence-based knowledge in the field of health services, follow the professional instructions of the Medical Director of Health and utilise, as appropriate, the Director’s clinical guidelines, cf. the Medical Director of Health Act.”

7.2 REGISTRATION OF BIRTHS

If a baby is born in Iceland, the midwife or the healthcare institution is responsible for registering the birth.²²³ The registration includes the gender of the baby. Neonatologist, Snjólaug Sveinsdóttir, explained how the system is gendered:

“Right after birth we have to register the baby and it needs a social security number. We have to fill out a birth certificate and the information goes into the central registry. These have the weight of the baby etc., come in pink or blue, there is no other option, and they say ‘girl’ or ‘boy.’”²²⁴

7.2.1 NAMING

Iceland, unlike many European countries, uses a patronymic or matronymic naming convention. Icelandic second names are gendered. Men usually have a last name adding in the suffix -son (“son”) and women a last name ending in -dóttir (“daughter”). For example, Iceland’s Prime Minister, Katrín Jakobsdóttir, is the daughter of Jakob Ármannsson. The last name is usually (but not always) taken from the father’s first name.

Iceland also restricts the first names that are given to individuals. This has been the source of controversy in the community for a number of years. Names that are not on a prescribed list must be submitted to the Icelandic Naming Committee (*Mannanafnanefnd*) for approval and may be rejected.

Consequently, Icelandic full names are heavily gendered, putting parents of some children with variations of sex characteristics in a difficult situation if they cannot assign a sex to their child. In Iceland, a child must be named by the age of six months.²²⁵

²²² <https://www.government.is/Publications/Legislation/Lex?newsid=8ef838db-fbd6-11e7-9423-005056bc4d74>

²²³ <https://www.skra.is/english/individuals/me-and-my-family/registration-of-children/>

²²⁴ Interview with Snjólaug Sveinsdóttir, neonatologist, June 2018.

²²⁵ <https://www.skra.is/english/individuals/me-and-my-family/registration-of-children/>

8. ICELANDIC POLICIES AND IMPLEMENTATION

8.1 GOVERNMENT COMMITMENT

In November 2017, the current Icelandic government published its coalition agreement, which included a plan to introduce legislation on the rights of LGBTI people. The plan states:

“The government aims to put Iceland in the front rank regarding LGBTI people’s issues with ambitious legislation on self-determination based on gender awareness in accordance with the recently-published resolution on the human rights of intersex people. The legislation should lay down provisions under which individuals are able to determine their gender and gender identity; their gender awareness is to be respected, individuals are to enjoy the right to respect of their physical persons and equality before the law irrespective of their sexual orientation, gender awareness, gender characteristics and expression of their gender identity.”²²⁶

As of January 2019, this legislation has not yet been introduced.

8.2 OMBUD FOR CHILDREN

The office of the Ombud for Children²²⁷ released a statement in 2015²²⁸ on the situation of intersex children. It expressed the opinion that “unnecessary and irreversible interventions on the infant’s body” were not in accordance with the rights of the child. It also recommended that better information should be provided to parents, and intersex children should be empowered to make their own decisions regarding treatment options as they gain the necessary maturity to do so.

8.3 TRAINING

8.3.1 MEDICAL PROFESSIONALS

Medical professionals told Amnesty International that the provision of training related to working with individuals with variations of sex characteristics varies. One midwife told Amnesty International that she had not received training on babies with ambiguous genitalia:

“I have not seen a case of ambiguous genitalia, as far as I can remember. We never received any training on this. I would ask a neonatologist for advice... We can send families to Landspítali. It’s not an acute problem.”²²⁹

²²⁶ <https://www.stjornarradid.is/lisalib/getfile.aspx?itemid=c0c3c70a-051d-11e8-9423-005056bc4d74>

²²⁷ <https://barn.is/um-embattid/upplysingar-a-erlendum-tungumalum/enska/>

²²⁸ <https://barn.is/um-embattid/verkefni/adgerdir-a-intersex-boernum/>

²²⁹ Interview with midwife, June 2018.

Because of the country's small size, many Icelandic medical professionals do part of their medical training in other countries, where they may receive more extensive training.

"I was trained in Sweden in general paediatrics and this included endocrinology...[and] neonatologist training. The training included how to deal with parents, including specific trainings on ambiguous genitalia, downs syndrome, fatal conditions. For intersex babies, we were taught not to gender them...When the baby was born [with ambiguous genitalia in 2017] we trained [junior doctors] thoroughly on this."²³⁰

Medical professionals also receive training on psychological health:

"It's more acceptable now to talk about psychological health, mental health. In general, we receive training about the psychological health of the patient."²³¹

Arnar Hauksson PhD, gynaecologist, stressed the importance of working groups for progressing knowledge in all areas of medicine.²³² However, there is no working group on medical care for individuals with variations of sex characteristics in Iceland.

8.3.2 EDUCATION PROFESSIONALS

As discussed above, interventions on children are often justified in terms of the psychological impact of not intervening, and particularly the risk of bullying in schools. Anna-Lind Pétursdóttir, psychologist, told Amnesty International that the detrimental effects of bullying, including anxiety issues and school avoidance, are well-documented, and there is a growing awareness of the needs of students who are bullied. However, she also noted that many schools do not allocate enough time or resources to implement effective anti-bullying strategies.²³³ This includes a lack of training and resources for teachers to implement existing programmes in schools:

"Teachers are not very well prepared as part of their training to think about diversity and things like that. There are not many courses on this. I am not sure if there are any courses on gender. Seven years ago, we started teaching a course on children with special needs, trying to cover the most common needs like reading difficulties, behavioural difficulties. But in the five-year study period there is just one course specifically focused on this. However, studies have repeatedly shown that teachers feel they are lacking the resources and skills needed to teach a diverse group of students."²³³

230 Interview with Snjólaug Sveinsdóttir, neonatologist, June 2018.

231 Interview with Óláf Viktorsdóttir, anaesthesiologist, June 2018.

232 Interview with Arnar Hauksson PhD, gynaecologist, June 2018.

233 Interview with Anna-Lind Pétursdóttir, psychologist, August 2018.

9. ATTITUDES, STIGMA AND DISCRIMINATION

“When I was born, they said [my variations of sex characteristics] would have to be a secret because society wouldn’t understand what I was. My mum knew this had been bad for my cousin, so she thought why not try something different?”

Briet, activist²³⁴

Iceland has a worldwide reputation for gender equality and has topped the World Economic Forum Global Gender Gap Index every year since 2009.²³⁵ However, this does not guarantee equality and equal treatment; nor does it ensure freedom from gender stereotypes.

9.1 ICELANDIC ATTITUDES TO SEX AND GENDER

Iceland’s approach to people with variations of sex characteristics is rooted in societal attitudes, and, despite the levels of gender equality, gender stereotypes remain common.

“We are stereotyped into female and male. Even now, there is a new custom to have baby showers with pink or blue decorations, a sex reveal party. It’s a brand-new custom in Iceland. I was kind of disappointed when I saw this was a new thing – it’s a backwards step.”²³⁶

This is reflected in attitudes of pregnant people. One midwife explained how new parents think about their children in gendered terms:

“The majority of parents – more than 90 per cent – want to know the sex of the baby in advance, but I think it’s out of curiosity more than because it is important for them... Right after the 20-week ultrasound, when they get the sex, the parents start to refer to the baby as he or she. I think it’s important because it is rooted in our social values, it’s something we grew up with.”²³⁷

Icelandic is also a very gendered language, which makes it difficult to talk about people without linking them to their gender. Even talking about oneself is gendered: the equivalent of the English ‘myself’ is ‘ég sjálfur’ for men and ‘ég sjálf’ for women.

234 Interview with Briet, June 2018.

235 <https://www.weforum.org/agenda/2017/11/why-iceland-ranks-first-gender-equality/>

236 Interview with Arna Guðmundsdóttir, endocrinologist, June 2018.

237 Interview with midwife, June 2018.

9.2 MEDICAL ATTITUDES TO SEX AND GENDER

Medical science and practice is a product of society. As such, it is not immune to societal attitudes and gender stereotypes. This is reflected in systems and practices as well as in how medical professionals are trained to interact with patients and their families. Some medical professionals who spoke to Amnesty International spoke about their expectations that parents would react badly to a child who is in some way outside of gender norms.

“Parents are scared to go home with an ambiguous child – everyone wants a boy or a girl. Parents find it essential to decide on a name. Then, later on, we will see how the child will behave – they will show by their inner feelings who they are. We can decide the genetics of the child, but they may not necessarily agree with the genes. You [your]self can’t take that decision until the child is ready to decide for themselves. It used to be very difficult to discuss with the parents of trans kids. But our society has become more open and parents today almost always support their children in their decision on gender.”²³⁸

Medical professionals discussed the way in which they interact with parents differently. One medical professional told Amnesty International: “It’s an extra burden for [cases of variations of sex characteristics] because there are extra expectations about boys and girls. Sometimes you have to tell parents something is dangerous, but it’s more difficult to tell a parent that you don’t know if you have a boy or a girl.”²³⁹

Medical professionals are also influenced by their own reactions to a situation:

“If I was in this position, I would react like most parents or grandparents. I would be devastated. Parents have more distress than if you tell them something is wrong with the kidneys or the heart.”²⁴⁰

And they bring their own assumptions about gender norms into their discussions with parents. One medical professional told Amnesty International:

“30% [of girls with CAH] become homosexual. We make parents aware of this.”²⁴¹

Other medical professionals, however, have considered how to challenge the use of gender stereotypes in their work.

“In the neonatal unit we used to have pink and blue blankets, but in 2014 or 2015 we changed it all. Now the parents can choose from lots of colours: but they often still default to pink or blue. We changed the birth certificates to white as well.”²⁴²

Neonatologist Snjólaug Sveinsdóttir explained how medical professionals had to work around the birth registration system in order to register one baby in 2017:

“[In summer 2017] a baby was born with ambiguous genitalia. The midwife had already registered the child as a boy [when we realised]. When I was in training 15 years ago, there was no way for a baby that was ambiguous to get a social security number without a gender. But in this case, we were able to get a number [because the] system has been changed. The central registry has been changed but the certificates are still pink or blue. For this baby, we took a [new] birth certificate and put a sticker over the sex and photocopied it so that it was on white paper... the grandmother was a bit worried. [The mother and grandmother] asked if the baby will be okay. I said yes, and they were fine with that. But they had difficulties with what to tell their extended family.”²⁴³

238 Email communication with Arnar Hauksson PhD, gynaecologist, January 2019.

239 Interview with medical professional, June 2018.

240 Interview with medical professional, June 2018.

241 Interview with Kolbeinn Guðmundsson, paediatric endocrinologist, June 2018.

242 Interview with midwife, June 2018.

243 Interview with Snjólaug Sveinsdóttir, neonatologist, June 2018.

10. RECOMMENDATIONS

“We don’t want to declare a war on doctors and their methods. We want to show them a better way to do things. I sometimes say that the person who cut me up and took my organs, they didn’t think they were doing something wrong and hurting me. They thought that they were saving me, and I want to find a better way for them to save me.”

Briet, activist²⁴⁴

10.1 TO THE OFFICE OF THE PRIME MINISTER

- Protect and promote the human rights of individuals with variations of sex characteristics in law and practice;
- Align laws, policies, and practices to comply with s.7.1.1 of Resolution 2191 of the Parliamentary Assembly of the Council of Europe to ‘prohibit medically unnecessary sex-“normalising” surgery, sterilisation and other treatments practised on intersex children without their informed consent’, in a manner that does not entail criminal penalties;²⁴⁵
- Ensure that legal sex assignment or legal gender recognition for any individual at any age is not predicated on medical interventions.

10.2 TO LANDSPÍTALI – THE NATIONAL UNIVERSITY HOSPITAL OF ICELAND

- Create a specialised, multidisciplinary team for the treatment of children and of adults with variations of sex characteristics and ensure that the team:²⁴⁶
 - takes a holistic and patient-centred approach;
 - comprises not only medical professionals but also other relevant professionals such as psychologists, social workers and ethicists;
 - bases its practices on guidelines developed together with intersex organisations and the professionals concerned.

244 Interview with Briet, June 2018.

245 PACE Resolution 2191 s.7.1.1.

246 PACE Resolution 2191 s.7.1.3.

10.3 TO THE UNIVERSITY OF ICELAND

- In consultation with individuals with variations of sex characteristics and activists working on these issues, develop and provide mandatory training to medical professionals on gender and bodily diversity, focusing on individuals with variations of sex characteristics.²⁴⁷

10.4 TO THE MINISTER OF HEALTH

- Conduct an inquiry into the harm caused by past invasive and/or irreversible sex-“normalising” treatments practised on individuals without their consent;²⁴⁸
- Implement a mechanism through which the state will provide compensation or other reparations to adults who underwent harmful and unnecessary medical treatments.

10.5 TO THE MEDICAL DIRECTOR OF HEALTH

- Review the existing mechanism to address complaints with healthcare provision and ensure that it effectively meets the needs of all individuals, including those with rare conditions.
- Develop 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;
- Ensure that healthcare professionals comply with their obligations under Article 13 of the Healthcare Practitioners Act, including in providing effective medical care to individuals with variations of sex characteristics throughout their lives;²⁴⁹
- Ensure that healthcare professionals comply with their obligations under the Health Records Act in keeping records, including regarding the medical treatment of individuals with variations of sex characteristics, and ensure that individuals with variations of sex characteristics can access their medical records;²⁵⁰
- Ensure that individuals with variations of sex characteristics are able to enjoy the rights laid out in the Patients' Rights Act;
- 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.²⁵¹

10.6 TO THE MINISTER OF EDUCATION

- In consultation with individuals with variations of sex characteristics and activists working on these issues, develop and provide mandatory training to education professionals on gender and bodily diversity, focusing on individuals with variations of sex characteristics, including as part of efforts to combat bullying in schools;

247 PACE Resolution 2191 s.7.1.4.

248 PACE Resolution 2191 s.7.5.1.

249 PACE Resolution 2191 s.7.1.4.

250 PACE Resolution 2191 s.7.1.4.

251 PACE Resolution 2191 s.7.1.2.

10.7 TO THE MINISTER OF JUSTICE

- Carry out an analysis of the role and remit of the Naming Committee in perpetuating gender stereotypes, and consider amending the role and remit of the Naming Committee;
- Ensure that laws and practices governing the registration of births, particularly in regards to the recording of a new-born's sex, duly respect the right to private life by allowing sufficient flexibility to deal with the situation of intersex children without forcing parents or medical professionals to reveal a child's intersex status unnecessarily.²⁵²

10.8 TO THE GOVERNMENT OF ICELAND

- Take steps to implement PACE Resolution 2191²⁵³ in a manner that does not entail criminal penalties;
- Ensure all government entities comply with the Yogyakarta Principles and YP+10,²⁵⁴ particularly:
 - Principle 10: The Right to Freedom from Torture and Cruel, Inhuman or Degrading Treatment or Punishment;
 - Principle 17: The Right to the Highest Attainable Standard of Health;
 - Principle 18: Protection from Medical Abuses;
 - Principle 28: The Right to Effective Remedies and Redress;
 - Principle 30: The Right to State Protection;
 - Principle 32: The Right to Bodily and Mental Integrity;
 - Principle 37: The Right to Truth.

²⁵² PACE Resolution 2191 s.7.3.1.

²⁵³ Resolution 2191 on 'Promoting the human rights of and eliminating discrimination against intersex people'.

²⁵⁴ While the Yogyakarta Principles (2006) do not explicitly mention sex characteristics, the Preamble to YP+10 (2017) notes that "that 'sex characteristics' as an explicit ground for protection from violations of human rights has evolved in international jurisprudence, and...that the Yogyakarta Principles apply equally to the ground of sex characteristics as to the grounds of sexual orientation, gender identity and gender expression." For clarity, we have included the grounds of sex characteristics in the principles expressed here. Available at: <http://yogyakartaprinciples.org/principles-en/official-versions-pdf/>

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NO SHAME IN DIVERSITY

THE RIGHT TO HEALTH FOR PEOPLE WITH VARIATIONS OF SEX CHARACTERISTICS IN ICELAND

Every year, children are born with sex characteristics (genitals, gonads, hormones, chromosomes or reproductive organs) that 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 Iceland, and the lifelong effect of these violations.

In particular, the report documents challenges faced by individuals with variations of sex characteristics in accessing appropriate healthcare, and the consequent risks of violations of their right to the highest attainable standard of health.