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STUDY ON THE RIGHTS AND EXPERIENCES OF INTERSEX PEOPLE IN FINLAND

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Tiivistelmä

Valtioneuvoston ihmisoikeusselonteon (2014) mukaan seksuaali- ja sukupuolivähemmistöihin kuuluvien henkilöiden perus- ja ihmisoikeuksien toteutumista on seurattava ja tietoa toteutumisesta levitettävä. Tätä taustaa vasten sukupuolivähemmistöjen koskemattomuuden ja itsemääräämisoikeuden edistäminen sisällytettiin kansalliseen perus- ja ihmisoikeustoimintaohjelmaan 2017-2019. Osana toimintaohjelman toimeenpanoa oikeusministeriö ja ulkoministeriö teetättivät tämän ulkopuolisen selvityksen.

Selvityksessä tarkastellaan intersukupuolisten ihmisten ja intersukupuolisten lasten vanhempien kokemuksia suomalaisessa terveydenhuollossa ja yhteiskunnassa. Selvityksessä käsitellään sitä, miten intersukupuolisten lasten syntymän yhteydessä tehdyt ratkaisut sekä lapsuus- ja nuoruusajan hoidot ovat vaikuttaneet heidän elämäänsä. Lisäksi tarkastellaan sitä, minkälaista tietoa ja tukea intersukupuolisten lasten vanhemmille on annettu, ja minkälaista tietoa ja tukea he kokevat tarvitsevansa. Lisäksi käsitellään hyviä käytäntöjä intersukupuolisten lasten huomioimiseen päivähoidossa, koulussa, harrastuksissa ja terveydenhuollossa. Selvitys sisältää myös katsauksen lainsäädäntöön ja käytäntöihin Maltalla, Portugalissa, Saksassa ja Islannissa.

Eri ihmisoikeustoimijat ovat viime vuosina antaneet suosituksia intersukupuolisten ihmisten perus- ja ihmisoikeustilanteen parantamiseksi. Selvityksessä annettavat suositukset pohjaavat selvitysaineiston lisäksi myös näille ihmisoikeustoimijoiden jo aiemmin Suomelle antamille suosituksille.

Julkaisu on tehty oikeusministeriön ja ulkoministeriön rahoituksella. Julkaisussa esitetyt näkemykset eivät välttämättä edusta ministeriöiden virallista kantaa.

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Abstract

According to the Government of Finland Human Rights Report (2014), the realisation of the fundamental and human rights of persons belonging to sexual and gender minorities must be monitored and information about it disseminated. Against this background, promoting the right to bodily integrity and the right to self-determination of persons belonging to sexual and gender minorities was included in the National Action Plan on Fundamental and Human Rights 2017–2019. As part of the implementation of the Action Plan, the Ministry of Justice and Ministry for Foreign Affairs commissioned a third party to carry out this study.

The report maps the experiences of intersex persons and the parents of intersex children in the Finnish healthcare system and society. It examines how the decisions made when an intersex child is born and the treatments the child receives in childhood and adolescence have affected their lives. It also considers what kinds of information and support the parents of intersex children were offered and what kinds of information and support they feel is needed. The report addresses good practices for taking intersex children into account in daycare, schools, leisure activities and healthcare and contains an overview of legislation and practices in Malta, Portugal, Germany and Iceland.

In recent years, different human rights actors have issued recommendations on how to improve the fundamental and human rights of intersex people. The recommendations given in this report are based on the data studied along with the earlier recommendations Finland has received from human rights actors.

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Contents

Summary and recommendations

This report explores the experiences of intersex individuals and parents of intersex children in Finnish healthcare services and society from the perspective of fundamental and human rights.

The purpose of the report is to establish how the decisions made when intersex children were born and the intersex-related treatments that they received during childhood and adolescence have affected their lives. It also discusses the types of information and support that parents of intersex children were offered and the kinds of information and support that they feel that they need. Furthermore, the report examines good practices for taking intersex children into account in daycare, school, leisure and healthcare settings, as well as relevant legislation and practices in Malta, Portugal, Germany and Iceland.

Intersex refers to congenital variations in bodily sex characteristics that are not unambiguously female-typical or male-typical. Intersex people's sex characteristics and bodies are healthy and natural variations of the human sexes. Estimates of the number of intersex people vary between 1:4,500 and 1.7%.

The study data primarily consists of interviews with 12 intersex individuals and 6 parents and their responses to online surveys.

The data and participants of the study do not constitute a quantitatively representative sample of intersex people in Finland. Conversely, the respondents' views and experiences are profound and informed descriptions of the kinds of experiences and issues that intersex people and their parents are living with in Finnish society. The respondents' experiences of medical interventions and the impacts of these on their lives also provide valuable information for the purposes of modernising intersex-related healthcare and safeguarding intersex people's fundamental and human rights more effectively.

The study participants had experiences of various intersex-related medical interventions, such as examinations of sex characteristics, medications, and surgical and other interventions. Whether a respondent's experience was positive or negative was essentially dependent on two factors: firstly, whether the medical intervention had clearly been vital for their health and, secondly, whether the respondent was allowed to participate in making treatment decisions.

Respondents' negative experiences of intersex-related medical interventions were related to situations where they had been subjected to different types of inappropriate and prejudiced treatment. By way of example, rather than being involved in discussions on different treatment options, they had merely been informed of the interventions; there had been attempts to put pressure on them; or interventions had been performed on them without informing them in advance. These respondents' experiences were steeped in an atmosphere of no alternatives, secrecy, pressure and compulsion. Their fundamental experience was that they had not been given a chance to participate in the decision-making concerning their own or their child's treatment. Negative experiences were also intrinsically associated with the fact that there were no clear health grounds for the treatments and interventions.

Respondents had such experiences also in the current decade, and also related to non-vital surgery to modify children's sex characteristics. These experiences go to show that the grave concerns about whether intersex children's fundamental and human rights are respected in Finnish healthcare services are still relevant.

The negative impacts of intersex-related medical interventions reported by respondents included various types of physical pain; issues with psychological wellbeing (incl. self-destructive behaviour, depression, anxiety, panic disorders, post-traumatic symptoms, dissociative disorders); problems due to a wrong type of hormone therapy (incl. body dysphoria, considerable weight gain); stigmatisation; and feelings of secrecy, shame and embarrassment. The respondents who had undergone involuntary and non-vital surgeries to modify their sex characteristics in childhood described their experiences in terms of sexual violence and sexual abuse.

Respondents' positive experiences of healthcare services were related to situations where they had been dealt with appropriately and sensitively. In such cases, respondents had received up-to-date information on treatments and the treatments offered had clearly been necessary for their actual health. Positive experiences were also intrinsically associated with the fact that the respondent felt that they had personally made the decisions concerning their own or their intersex child's treatments. Even in these situations, however, respondents frequently brought up a lack of information.

The positive impacts of intersex-related healthcare interventions reported by respondents were related to maintaining their own or their child's health (such as hormone therapy started on health grounds or preventive monitoring of the child's health status). Positive impacts of interventions aiming to modify sex characteristics were reported by respondents when the treatment had been performed of their own free will.

Respondents reported that they would have hoped to receive comprehensive information on the different aspects of being intersex and on the diversity of human sexes as well as peer support and other types of psychosocial support.

Some respondents reported that they currently avoided or delayed seeking healthcare services. The reason given by respondents was that they do not feel that they can trust healthcare professionals, or that they find it hard to have to 'educate' healthcare professionals on variations of sex characteristics when using healthcare services.

Being intersex and intersex-related medical interventions had affected the respondents' lives in different ways.

Most respondents had only shared being intersex with a close circle of family and friends. Being open about being intersex had mostly been a positive experience. It had helped respondents get over the shame and secrecy associated with being intersex, increased their sense of freedom, and reinforced their sense of living as who they are.

Some respondents felt that childhood medical interventions and the secrecy involved had taken a toll on their relationships with their parents. Respondents had varying experiences of the impacts of being intersex on their other relationships. Some had faced negative impacts and experienced challenges relating to sexuality, intimacy and falling in love. For others, however, dating and intimate relationships had provided healing experiences.

Being intersex or intersex-related medical interventions had also affected some respondents' schooling and studies (e.g. absences, bullying, poor psychological wellbeing), as well as their working lives (career choices, gaps in educational history).

A key issue in experiences concerning daycare, school, studying, leisure interests and working life was openness about being intersex. Intersex individuals and parents of intersex children reported that they had been forced to make this decision again and again. Some respondents felt that it was easier to keep the issue secret because they found it hard to have to keep educating other people on the topic or feared negative reactions. For others, however, sharing had been a positive experience.

A key way of promoting the equality of intersex people identified by the respondents was increasing access to factual and comprehensive information on being intersex and the diversity of human sexes among all professionals working with children (daycare, education, leisure activities, healthcare), as well as at educational institutions, in workplaces and in society at large. Respondents also put forward several improvement ideas relating to provision of care for intersex children. Those emerging as key priorities included abolishing non-vital surgical and other interventions; consolidating the multidisciplinary care approach; ensuring access to peer support; providing comprehensive and factual information on the different aspects of being intersex and the diversity of human sexes; and generally taking children's best interests and rights into account more comprehensively.

In recent years, international human rights actors, such as the Council of Europe Human Rights Commissioner and Parliamentary Assembly and the European Union Agency for Fundamental Rights (FRA), have issued a number of recommendations on how to improve the fundamental and human rights situation of intersex people. The data collected through this study indicates that these recommendations are still topical in Finland.

The study was carried out as part of the National Action Plan on Fundamental and Human Rights 2017–2019. This publication was funded by the Ministry of Justice and Ministry for Foreign Affairs. The views expressed in the publication do not necessarily reflect the official position of the Ministries.

Recommendations

1. Intersex people's rights to bodily integrity and self-determination should be ensured. Any non-vital surgeries or other interventions performed to 'normalise' intersex children's sex characteristics without the child's informed consent should be prohibited. With the exception of situations where a child's health is at immediate risk, no interventions aiming to modify sex characteristics should be performed until the child is capable of making an independent decision on the matter.

2. Healthcare for intersex people should be provided by multidisciplinary teams. In addition to medical professionals, these should include professionals in psychological and psychosocial support; experts with competence in ethical and human rights issues; as well as representatives of intersex people. Healthcare for intersex children should be outlined in clinical practice guidelines taking full account of the child's best interests and rights to participate in making decisions concerning their treatment in accordance with their age and maturity, in keeping with the obligations of the

Convention on the Rights of the Child. Intersex people and parents of intersex children must be guaranteed access to appropriate information regarding variations of sex characteristics and the diversity of human sexes. The clinical practice guidelines should also cater for ethical and human rights considerations. The clinical practice guidelines should be developed in multidisciplinary cooperation between professionals from different fields and representatives of intersex people.

3. Intersex people and their parents should be guaranteed access to psychosocial support and peer support. Adequate resources should be secured for organisations providing psychosocial and peer support.

4. Intersex people should be guaranteed access to the healthcare services that they require and the right to check records on their own treatment.

5. Healthcare professionals should be provided with training on variations of sex characteristics and the diversity of human sexes. Their awareness of the potential effects of intersex-related medical interventions on children's health and wellbeing should be raised.

6. Discrimination against intersex people should be prevented purposefully and systematically, in keeping with the obligations of the Equality Act. Sufficient resources should be allocated to equality promotion efforts.

7. Efforts should be made to increase awareness and information measures concerning variations of sex characteristics and the diversity of human sexes among all professionals working with children (daycare, education, leisure activities, healthcare), as well as at educational institutions, in workplaces and in society at large. Research should be conducted into the topic and information on being intersex and the diversity of human sexes should be communicated appropriately.

8. Legislation governing legal recognition of gender (the 'Trans Act') should be reformed such that the legal gender recognition procedure will be a quick and transparent administrative process based on the right to self-determination.

9. Resources should be allocated, both in Finland and internationally, to the activities of intersex people's organisations aiming to dismantle the stigma and silence associated with being intersex.

10. Finland should continue to play the role of an active supporter of LGBTI rights in international human rights forums. Finland should make an effort to promote the rights of LGBTI people in keeping with the EU Guidelines to promote and protect the enjoyment of all human rights by lesbian, gay, bisexual, transgender and intersex (LGBTI) persons, while also bringing issues relating to intersex people's rights increasingly to the fore.

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Tikli Oikarinen

1. Introduction

In recent years, realisation of intersex people's rights has emerged on the agenda in international human rights forums. Special concerns about intersex children's rights to self-determination and bodily integrity have been expressed by several human rights actors, including the UN Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, the UN Committee on the Rights of the Child, and the Council of Europe Human Rights Commissioner and Parliamentary Assembly. Intersex children are often subjected to surgical and other interventions to modify their sex characteristics. Non-vital interventions have been considered to violate intersex children's rights to self-determination and bodily integrity.[1]

Human rights actors have urged states to prohibit any non-vital interventions and treatments. Furthermore, they have urged states to ensure that, with the exception of situations where a child's health is at immediate risk, no interventions aiming to modify sex characteristics are performed until the child is capable of participating in making decisions on and giving their informed consent to such interventions. Intersex children's situation has also been discussed on the Committee on Bioethics, which is a European intergovernmental body dealing with medicine and human rights[2]. A study published by the Committee raises the possibility of creating a legally binding European standard on the topic, if necessary[3].

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[1] United Nations General Assembly: Discriminatory laws and practices and acts of violence against individuals based on their sexual orientation and gender identity (A/HRC/19/41); United Nations General Assembly: Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment Juan E. Méndez (A/HRC/22/53); United Nations Committee on the Rights of the Child (CRC/C/ESP/CO/5-6); United Nations Committee on the Elimination of Discrimination against Women (CEDAW/C/LUX/CO/6-7); Council of Europe Commissioner for Human Rights (2015): Human rights and intersex people; Council of Europe Parliamentary Assembly (2017a): Promoting the human rights of and eliminating discrimination against intersex people/Recommendation 2116 (2017); Council of Europe Parliamentary Assembly (2017b): Explanatory memorandum 14404 (2017); European Union Agency for Fundamental Rights (2015): The fundamental rights situation of intersex people.

[2] The Committee on Bioethics (DH-BIO) is the successor of the Steering Committee on Bioethics (CDBI), which was established as part of the Convention on Human Rights and Biomedicine (Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine). Finland ratified the Convention in 2010.

[3] Kavot Zillén, Jameson Garland & Santa Slokenberga (2017): The Rights of Children in Biomedicine. Challenges posed by scientific advances and uncertainties; Ton Liefaard, Aart Hendriks & Daniella Zlotnik (2017): From law to practice: towards a roadmap to strengthen children's rights in the era of biomedicine.

The medical interventions on intersex children have also been raised in public debate in Finland.[4]

This study on intersex people's rights and experiences was carried out as part of the National Action Plan on Fundamental and Human Rights 2017–2019[5] with a view to establishing:

- how the decisions made when intersex children were born and the medical interventions that they experienced during childhood and adolescence have affected their lives;
- what types of information and support parents of intersex children were offered at the time of their children's birth and what kinds of information and support they feel that they need;
- what types of good practices daycare, school, leisure, healthcare and other such communities working with children have in place for taking intersex children into account; and
- what intersex people's situation is like (in terms of legislation, good practices, other support measures) in certain other countries (Malta, Portugal, Germany, Iceland).

The aim of the study was to provide concrete recommendations for public authorities on how to improve intersex people's status and rights in Finland and as part of Finland's international activities in the field of human rights policy.

The study was carried out between May and December 2018. The study data primarily consists of interviews with 12 intersex individuals and 6 parents of intersex children and their responses to online surveys. In addition, the study also draws on secondary data and background interviews with experts[6].

Report outline

The report opens with Chapter 2, providing a brief overview of the rights of the child, which constitute the underlying approach of the study. The chapter first deals with the principle of the child's best interests and then moves on to discuss the child's right to participate in making decisions concerning them in accordance with their age and maturity.

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[4] See Section 3.5.

[5] The Finnish government's Human Rights Report submitted to Parliament in 2014 included development policies concerning sexual and gender minorities. The report calls for monitoring of and disseminating information on the realisation of the fundamental and human rights of people belonging to sexual and gender minorities. Parliament gave its strong support for implementing the policies outlined in the report. Against this background, the theme of promoting the rights of sexual and gender minorities to integrity and self-determination was included in the National Action Plan on Fundamental and Human Rights 2017–2019. As part of implementing the Action Plan, the Ministry of Justice and the Ministry for Foreign Affairs commissioned this external study.

[6] For background interviews, please see Sources.

Chapter 3 explores the concept of intersex.. It starts with a discussion of the definition of 'intersex' and the estimates of the number of intersex people. This is followed by a brief overview of the history of clinical practices applied to intersex children and the ways in which the human rights approach has evolved. The remainder of the chapter deals with debates concerning intersex issues in Finland.

Chapter 4 presents the data used in the study and the methods of implementing and reporting the interviews and online surveys.

This is followed by an analysis of the experiences of intersex individuals and intersex children's parents. Chapter 5 deals with experiences in healthcare services. It starts by describing experiences relating to learning about being intersex and to assigning a newborn intersex baby's sex. It then moves on to experiences of intersex-related medical interventions: examinations of sex characteristics, medications, surgical and other interventions and their effects. This is followed by a discussion of the types of information that respondents had received on medical interventions and options in healthcare services. The chapter then explores the respondents' experiences of psychological support and current health status and attitudes towards healthcare services. It concludes with respondents' views on how to develop intersex-related healthcare.

Chapter 6 deals with experiences of the impacts of being intersex on other aspects of life. It starts with an overview of intersex people's experiences of gender identity. This is followed by a discussion of what it was like for respondents to share being intersex with other people and how they felt that being intersex had affected their relationships. The chapter then moves on to describing experiences of peer support. It concludes with respondents' experiences of daycare, school, studies and working life. In this context, the chapter also outlines their views on how to take intersex children better into account in daycare, school and leisure settings and how to promote intersex people's equality and non-discrimination.

Chapter 7 provides a review of legislation and good practices relating to intersex people in Malta, Portugal, Germany and Iceland.

Chapter 8 sets out the key conclusions of the study and recommendations for Finnish public authorities.

2. Rights of the child

All fundamental and human rights also belong equally to children. The principal agreement protecting children’s human rights is the United Nations Convention on the Rights of the Child, which was implemented by Finland in 1991 (Finnish Treaty Series 59/1991 and 60/1991). Furthermore, the rights enshrined in all the other human rights agreements also belong equally to children.

The content of the Convention on the Rights of the Child can be summed up into the following three themes. Firstly, children are entitled to special care and protection against discrimination and exploitation, etc. (‘protection’). Secondly, children are entitled to special benefits and services for children, such as education and healthcare (‘provision’). Thirdly, children have the right to express their opinions and participate in making decisions concerning them (‘participation’). All these perspectives must be taken into account when organising healthcare for intersex children.[7]

Discussions about intersex children’s situation often focus on children’s right to participate in making decisions concerning them. Many interventions aiming to modify sex characteristics are usually performed during the first few years of a child’s life when the child is not yet capable of giving consent to these interventions.

However, the human rights guaranteed for children under the Convention on the Rights of the Child, such as the right to privacy and physical integrity, are not deferred until the child is capable of expressing their own consent or will. The UN Committee on the Rights of the Child has expressly emphasised that young children are also holders of all rights enshrined in the Convention on the Rights of the Child. The Committee has stressed that early childhood is a critical period for realising these rights, especially because children’s earliest years create the foundation for their physical and mental health, emotional security and personal identity.[8]

2.1 The principle of the child’s best interests

Under Article 3.1 of the Convention on the Rights of the Child, the best interests of the child must be a primary consideration in all actions and decisions concerning children. In other words, instead of being just one of the considerations to be taken into account when making decisions, the child’s best interests constitute a principle that takes a higher precedence over the interests of parents or the ‘general public’, for example, when

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[7] Sauli Hyvärinen, Senior Advisor, Central Union for Child Welfare. Lecture on 11 June 2018: Lastensuojelun keinot tukea intersukupuolisia lapsia [*Means available to child welfare services for supporting intersex children*].

[8] UN Committee on the Rights of the Child: General Comment No. 7 (2005): Implementing child rights in early childhood, paragraphs 1 and 6 (e).

deliberating on a decision. The obligation applies to public authorities, legislators, courts of law and all other parties dealing with children, including their parents and other guardians.[9]

Implementing the child's best interests amounts to interpreting these and taking action so as to realise the child's human rights in the best possible way. The UN Committee on the Rights of the Child defines the principle of the child's best interests from three perspectives. The child's best interests constitute:

I) a substantive right, which refers to the primacy of the child's best interests both as a premise for consideration and as an objective of making decisions;

II) an interpretative principle, which imposes an obligation to choose from a range of options the interpretation that most effectively serves the child's best interests; and

III) a rule of procedure, which means that the analysis relating to consideration of the child's best interests should be explicitly indicated in the decision-making process.

Consequently, the concept of the child's best interests is especially pronounced in terms of a 'principle of weighing'. Any decision affecting a specific child or a group of children requires an explanation of how and on what criteria the child's interests have been assessed and how the principle has been weighed against other principles. This makes it possible for decisions to establish the elements included in the assessment of the child's best interests, and to present arguments about and evaluate their validity.[10]

In healthcare services, the child's best interests can be regarded as consisting of different aspects: respect for the child's privacy and integrity; establishing the child's views and taking these into account; implementing child-friendly practices; opportunities for rest and play; respect for the child's right to family life; support for the primary carers responsible for the child's wellbeing; information provided for the child concerning their rights as a patient; and ensuring the child's legal safeguards.[11]

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[9] The European Court of Human Rights interprets the rights of the child in keeping with the purpose and object of the UN Convention on the Rights of the Child (Sahin v. Germany, App. No. 30943/96). The primacy of the best interests of the child is also laid down in the Charter of Fundamental Rights of the European Union (Article 24).

[10] UN Committee on the Rights of the Child: General Comment No. 14 (2013) on the right of the child to have his or her best interests taken as a primary consideration.

[11] Suvianna Hakalehto, LLD, LLM trained on the bench, Associate Professor, University of Eastern Finland. Lecture on 26 March 2016: Intersukupuoliset lapset [*Intersex children*]. Lasten oikeuksien näkökulma [*The perspective of children's rights*].

2.2 The child's rights to self-determination and participation in making decisions concerning them in accordance with their age and maturity

The right to self-determination is a multidimensional concept linked with several fundamental rights enshrined in the Constitution of Finland (731/1999), such as the right to personal liberty and integrity (section 7) and the right to privacy (section 10), which cover an individual's rights to decide for oneself and about one's own body. The right to self-determination also applies to children. According to the Convention on the Rights of the Child (Article 12) and the Finnish Constitution (section 6), they must be allowed to have a say in matters concerning them in accordance with their age and maturity.[12]

A child's right to self-determination and its realisation is intrinsically linked to other rights determined in the Convention on the Rights of the Child, such as:

- the primacy of the child's best interests (Article 3.1);
- the child's right to such protection and care as is necessary for their wellbeing, taking into account the rights and duties of their parents or other legal guardians (Article 3.2);
- the child's right to privacy (Article 16), including their right to know about the existence of any information stored about them, why such information is stored and who manages it;
- the child's right to physical and psychological integrity and protection from all forms of violence, injury or negligent treatment (Article 19); and
- the child's right to enjoy the highest attainable standard of health and health services (Article 24), which covers certain rights and freedoms, such as the child's right to make decisions about their own health and body in a manner consistent with the evolving capacities of the child.[13]

The child's right to self-determination also involves the primary responsibility of parents or other legal guardians for the child's growth and development and for direction and guidance in the exercise by the child of their rights. According to the Convention on the Rights of the Child (Article 5 and Article 18) and the Finnish Child Welfare Act (417/2007, section 2), the public authorities have an obligation to support parents in fulfilment of this responsibility.

In order to exercise their right to self-determination, an individual must be competent, i.e. capable of making independent decisions based on available information and of understanding the consequences of their decisions. In other words, the right to self-determination is about informed consent or refusal.[14]

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[12] National Action Plan on Fundamental and Human Rights 2017–2019 (p. 64–65; *p. 70–71 of the English version*).

[13] Merike Helander, Lawyer, Office of the Ombudsman for Children. Lecture on 25 November 2014: Lapsen itsemääräämisoikeuden käyttäminen [*The child's exercise of the right to self-determination*]; Sauli Hyvärinen. Lecture on 11 June 2018.

[14] Helander 2014.

Therefore, the key aspect in terms of the child's right to self-determination is to consider the child's evolving capacities and right to participate in making decisions concerning them in accordance with their age and maturity.

Considering the child's evolving capacities is also placed front and centre in the Act on the Status and Rights of Patients (785/1992; the 'Patients Act'). The Patients Act lays down provisions on patients' right to self-determination (section 6) and the status of minor patients (section 7) in healthcare. The Act provides that the opinion of a minor patient on a medical intervention must be assessed if it is possible with regard to their age or maturity. If a minor patient can decide on the treatment given to them on the basis of their age and maturity, they must be cared in mutual understanding with them. If a minor patient cannot decide on the treatment given to them, they must be cared in mutual understanding with their parent or other legal guardian. However, the parent or guardian does not have the right to forbid any care that may be required to avert a threat to the patient's life or health (section 9).

Another key instrument relevant when assessing the medical interventions intersex children experience is the Council of Europe Convention on Human Rights and Biomedicine (Finnish Treaty Series 24/2010), which entered into force in Finland in 2010. The Biomedicine Convention includes provisions on the protection of individuals who are not able to consent to a medical intervention for reasons such as age (Article 6). The Convention states that, in such cases, an intervention may only be carried out if it is for the direct benefit of the individual concerned.

3. Intersex

3.1 Definition of intersex

The UN Free & Equal Campaign defines intersex as follows:

"Intersex people are born with sex characteristics (including genitals, gonads[15] *and chromosome patterns) that do not fit typical binary notions of male or female bodies. Intersex is an umbrella term used to describe a wide range of natural bodily variations. In some cases, intersex traits are visible at birth while in others, they are not apparent until puberty. Some chromosomal intersex variations may not be physically apparent at all."*[16]

The definitions of 'intersex' used by Finnish parties are largely in line with this UN definition. By way of example, the first Finnish-language website to provide information on variations of sex characteristics at intersukupuolisuus.fi explains that intersex refers to *"a congenital condition where an individual's physical sex characteristics do not fit the classification of male and female categories or are inconsistent"*. Indeed, all definitions used in Finland share the fact that intersex refers to *a congenital, bodily 'condition'* in which sex characteristics do not correspond to the current definitions of what a female or male body ought to be like.[17]

Intersex is not the same thing as transgender. Intersex refers to the body and its sex characteristics. Transgender refers to an individual's experience of their own gender, i.e. gender identity. Most transgender or trans people were born in a body that conforms to medical definitions of what a female or male body ought to be like[18]. Intersex people, in turn, were born in a body that does not conform to such definitions.

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15 Gonads: the glands that produce sex hormones.

16 United Nations Free & Equal Campaign. Factsheet: Intersex.

17 ETENE (2016b): "'Intersex' refers to a condition where the physical markers or characteristics that determine an individual's sex are not unambiguously or exclusively female or male." According to ETENE, 'intersex' is "defined in quite narrow terms on the basis of physical sex characteristics" among Finnish medical professionals. Sosiaali- ja terveysministeriö [*Ministry of Social Affairs and Health*] (2015a): "'Intersex' generally refers to a condition where the physical markers or characteristics that determine an individual's sex are not unambiguously or exclusively female or male." Seta's Rainbow Glossary (*in Finnish*): "'Intersex' refers to a wide variety of congenital conditions where an individual's bodily, anatomical or other sex characteristics are not unambiguously female-typical or male-typical. Being intersex does not define the kind of gender identity that an individual will develop. Just like other children, a growing intersex child develops their own gender identity."

18 However, a trans person's gender identity or gender expression does not conform to the sex assigned to them at birth, nor to the expectations associated with it.

Most people have 46 chromosomes, two of which are sex chromosomes. Karyotype (chromosome complement) 46,XX is attributed to females, while karyotype 46,XY is attributed to males. However, sex development is a much more diverse process than is commonly thought. There is a wide variety of other combinations of sex chromosomes, such as 45,X and 47,XXY. Different combinations of sex chromosomes do not necessarily 'show' in any way. By way of example, not even close to all individuals with the XXY karyotype are necessarily aware of the fact that they have, as it were, an extra X chromosome. Karyotypes may also be mosaic. This means that an individual may have some cells with 46,XX chromosomes and others with 46,XY chromosomes, for example.[19]

Consequently, there are numerous variations in sex characteristics, which highlights the fact that sex is more of a continuum than a clear-cut dichotomy. By way of example, some people have a 'female-typical' body even though their sex chromosomes are of the XY pattern. Others, in turn, have a 'male-typical' body even though their chromosome pattern is XX. However, not all intersex individuals have sex chromosomes that differ from the ordinary 46,XX or 46,XY pattern.[20]

Some intersex people have genitalia that do not conform to the criteria set for a female or male body. A baby assigned as a girl, for example, may have a clitoris that is 'too big' according to medical criteria, while a baby assigned as a boy may have a urethra ending at the root of the penis instead of its tip. When some individuals assigned as girls at birth reach puberty, it may turn out that they do not have a vagina or a uterus, or that they have undescended testicles or testicular tissue under the abdominal wall in lieu of ovaries.[21] Comparing intersex people to hermaphrodites with a full set of both female and male genitalia is outdated language, which is seen as derogatory. Such sex development is not possible in human beings.[22]

In other words, being intersex is a form of body diversity, not a disease. However, the medical world refers to intersex bodies as 'disorders of sex development' (DSD) and has developed various diagnoses of types of variations in sex characteristics[23].

Some intersex people may have an elevated risk of heart or articular disease, while some intersex people may require hormone therapy at some point. However, situations where an

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[19] Tiffany Jones, Bonnie Hart, Morgan Carpenter, Gavi Ansara, William Leonard & Jayne Lucke (2016, 40): Intersex. Stories and Statistics from Australia.

[20] Amnesty International (2017): First, do no harm: Ensuring the rights of children with variations of sex characteristics in Denmark and Germany; Jones et al. (2016).

[21] Amnesty International (2017).

[22] IGLYO, OII Europe & European Parents Association (2018): Supporting your intersex child.

[23] In the medical world, the variations classified as 'DSDs' are classified under the following three groups: 'sex chromosomal DSD'; '46,XX DSD'; and '46,XY DSD'. The groups of '46,XX' and '46,XY DSDs' include variations linked to the development of gonadal tissue or the levels and action of hormones, particularly androgen. Variations included in 'sex chromosomal DSDs' are related to the fact that an individual has sex chromosomes other than XX or XY. (Amnesty International 2017, p. 22–23).

intersex child requires urgent care are very rare. Nevertheless, since atypical appearance of external genitalia may sometimes be a sign of an urgent need for medical attention, ensuring that a baby does not have any health-threatening condition is always the first priority when an intersex baby is born.[24]

All parties agree that, in cases where a child's health is endangered for some reason, the child must be provided with all the necessary treatment. The criticism of medical practices expressed by human rights actors concerns the kinds of surgical and other interventions that are non-vital. [25].

3.2 Number of intersex people

Estimates of the number of intersex people vary between 1:4,500 and 1.7%, depending on the definition of intersex.

The lowest estimate is presented by some medical professionals, who suggest that about one out of 4,500 newborn babies is intersex[26]. This prevalence estimate can be used to derive the frequently cited assessment that no more than a dozen intersex babies are born annually in Finland. However, this narrow definition only applies to situations where an infant's sex cannot be directly assigned as female or male at birth on the basis of external genitalia. In other words, this definition does not cover situations in which the individual's intersex body does not become visible until puberty, for example. At present, many medical professionals also view this definition as too narrow and prefer to define intersex in broader terms[27].

The broadest estimate of the number of intersex people, in turn, was suggested by biologist Melanie Blackless with her colleagues in 2000. They estimated that intersex people account for about 1.7% of the population. They used a definition that includes all

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24 One of the conditions requiring urgent care is the salt-losing type of hyperplasia of the adrenal cortex known as 'congenital adrenal hyperplasia' (CAH). A baby with CAH requires urgent salt-retaining hormone (aldosterone) therapy. Some children with CAH have atypical external genitalia, while others do not. All newborns are currently screened for CAH to ensure that medication can be started if required. According to ETENE's background report, other situations that require urgent surgical treatment include certain structural changes in urinary tracts and the intestines, congenital malformation of the abdominal wall (gastroschisis), or cloaca anomaly. (ETENE 2016b.)

25 Amnesty International (2017); Council of Europe Commissioner for Human Rights (2015); Council of Europe Parliamentary Assembly (2017a).

26 This estimate is used in documents such as the 2006 Consensus Statement (see Section 3.3).

27 See e.g. the EU-funded dsd-LIFE study, covering six European countries and 14 medical centres: Röhle et al. dsd-LIFE research group (2017): Participation of adults with disorders/differences of sex development (DSD) in the clinical study dsd-LIFE: design, methodology, recruitment, data quality and study population.

cases of sex development that do not progress in a typical manner in terms of chromosomes, gonads, hormones or genitalia.[28]

Yet another study, published by the Netherlands Institute for Social Research in 2014, pegged the prevalence of intersex people at 1:200, i.e. about 0.5% of the population. This figure was derived by adding up the estimates of prevalence of intersex-related medical diagnoses. The estimate includes the diagnoses that form the basis for the estimated prevalence at 1:4,500 plus eight other intersex-related medical diagnoses[29]. The study emphasises, however, that estimating the number of intersex people is both challenging and contextual and that a definitive estimate of the number is impossible to produce.[30]

Depending on the chosen definition, the estimate for the number of Finnish intersex people may vary from about 1,200 to 93,000 individuals[31]. Based on the 0.5% prevalence estimate, it is possible to put the number of intersex people in Finland somewhere between 20,000 and 30,000 individuals. Some of them have been subject to intersex-related medical interventions, while others have not. Nevertheless, the estimate that only about a dozen intersex babies are born annually in Finland clearly appears too low.

3.3 Evolution of clinical practices

Clinical practices applied to intersex children started to evolve in the early 20th century. Understanding the key features of this evolution will help to comprehend why having a variation of sex characteristics is still defined as a disorder in medical terms. Furthermore, it will clarify why the classification as a disease and the resulting invasive interventions on children's sex characteristics are problematic from the perspective of human rights. Outlining the key historical features of clinical practices will also highlight how much the awareness of sex and gender, gender roles, gender identity and the rights of the child has increased over the last few decades.

Both in Europe and the United States, the roots of surgical interventions on intersex children derived from debate over what sex characteristics should be used to determine

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[28] Melanie Blackless, Anthony Charuvastra, Amanda Derryck, Anne Fausto-Sterling, Karl Lauzanne & Ellen Lee (2000): How Sexually Dimorphic Are We? Review and Synthesis.

[29] Jantine van Lisdonk (2014): Living with intersex/DSD. An exploratory study of the social situation of persons with intersex/DSD. The diagnoses included in the prevalence estimate in the study are presented in *"Appendix B: Prevalence table for intersex/DSD: intersex/DSD with ambiguous genitals including CAH, PAIS, partial gonadal dysgenesis and partial forms of testosterone biosynthesis defects (e.g. 5-alpha-RD2 and 17-beta-HSD3); CAIS; XY-gonadal dysgenesis (Swyer syndrome); MRKH; hypospadias, with the exception of hypospadias in the region of the glans, as too mild; 47,XXY (Klinefelter syndrome); 45,X (Turner syndrome); 47,XYY; 47,XXX."*

[30] van Lisdonk (2014).

[31] Finland's preliminary population figure at the end of 2017 stood at 5,516,224 people. Väestörekisterikeskus [*Population Register Centre*] 2018.

a newborn's sex as a girl or a boy when it was not apparent based on external genitalia. The early 20th-century medical profession believed that children with atypical sex development would suffer stigma, social discrimination, sexual frustration, and rejection by their parents. At the time, people also thought that children living in the 'wrong' gender would become homosexual. In the early 20th century, homosexuality was still a crime in Europe and the United States.[32]

Around the same time, the practices of genital surgery had evolved through treatment of transgender adults who had voluntarily sought surgery. By the 1940s, clinicians were also increasingly performing these surgeries on intersex children at the request of the children's parents. At the same time, researchers were performing psychological studies of intersex individuals who had not been operated on in childhood, to determine whether their psychological wellbeing was impaired by this 'non-treatment'. Based on these studies, the individuals were psychologically healthy but suffered stigma and social rejection.[33]

The researchers also noted that children who were surgically operated over the age of three showed severe signs of psychological trauma. This was particularly true in cases where the sex assigned for a child by clinicians and parents was contrary to the gender identity that the child had already begun to develop. For such reasons, the prevailing thinking at the time was that surgery to modify sex characteristics should be done in infancy. The assumption was that parents could steer the child's gender development in the desired direction through upbringing. The resulting recommendations for treatment were not based on any clinical research; nor were any long-term follow-up studies conducted to verify the benefits to child patients. However, these clinical practices had three theoretical ambitions: to support care and upbringing in keeping with the preferred sex assignment; to enable penile-vaginal penetration; and to reduce anxiety among children that was thought to be due to their atypical sex development.[34]

Subsequently, there has been a significant increase in the understanding of the rights of the child and of the importance of early childhood for children's health, emotional security and personal identity. The early years of a child's life are critical for bonding between the child and their parents or other caregiver. A situation where a child is separated from their caregivers during this period to undergo surgery – which can in itself involve pain and complications – may result in a psychological trauma, which may manifest in physical symptoms, for example, regardless of whether the child can actively remember

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[32] Zillén et al. (2017, 41–42).

[33] Zillén et al. (2017, 41–42).

[34] Zillén et al. (2017, 41–42).

it.[35] Nowadays, gender identity is also understood to refer to each individual's deeply felt internal experience, which cannot be defined from the outside[36].

Up until the end of the 1990s, surgeries based on these practices were nevertheless performed without any long-term studies or follow-up to confirm their benefit to patients. Since then, the subject has been studied more extensively. There is plenty of documented evidence of the harmful effects of these interventions, such as pain, loss of sensation, scarring, challenges with sexual function, and traumatisation possibly due to secrecy, stigmatisation and operations. Regardless, rather than being completely reformed, clinical practices have only been modified.[37]

As a result of technological advancements, more detailed analysis has been used to attempt to predict the child's gender identity more accurately, in order to reduce the risk of genital surgeries and interventions 'going wrong'. At the same time, attempts have been made to develop new surgical techniques to reduce harms due to surgeries.[38]

However, it is never possible to give any definitive conclusion on a child's future gender identity at the time of birth. The likelihood that a child who has a variation of sex characteristics will develop a gender identity opposite to the sex assigned to them at birth varies from one per cent to as high as 50%. In light of current knowledge, the factors that play a role in the decision include i.e. the specific variation of sex characteristics concerned.[39]

One of the international recommendations that has had a major impact on European clinical practices is the *Consensus Statement on Management of Intersex Disorders*[40], developed as a result of a conference organised in Chicago and originally published in 2006. An updated version of the document was published in 2016[41]. The updated version notes that:

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[35] Amnesty International (2017, 38–42).

[36] See e.g. Yogyakarta Principles (2006). Principles on the application of international human rights law in relation to sexual orientation and gender identity; Yogyakarta Principles (2017). Additional Principles and State Obligations on the Application of International Human Rights Law in relation to Sexual Orientation, Gender Identity, Gender Expression and Sex Characteristics to complement the Yogyakarta Principles.

[37] Zillén et al. (2017, 41-43).

[38] Zillén et al. (2017, 41-43).

[39] Kreukels et al. dsd-LIFE research group (2018, 778): Gender Dysphoria and Gender Change in Disorders of Sex Development/Intersex Conditions: Results From the dsd-LIFE Study.

[40] It was developed by medical professionals in cooperation with representatives of certain patient organisations. In this context, the medical profession also adopted the abbreviation 'DSD', which comes from 'disorders of sex development'. Many feel that the term stigmatises and pathologises natural bodily variations in sex characteristics. Lee et al. (2006): Consensus Statement on Management of Intersex Disorders. Cited in: Amnesty International (2017).

[41] Lee et al. (2016): Global Disorders of Sex Development, Update since 2016: Perceptions, Approach and Care. Cited in: Amnesty International (2017, 19).

"timing, choice of the individual and irreversibility of surgical procedures are sources of concerns. There is no evidence regarding the impact of surgically treated or non-treated DSDs during childhood for the individual, the parents, society or the risk of stigmatization."[42]

Nevertheless, the Consensus Statement does not call for delaying non-vital surgeries.

Critics of medical interventions performed on intersex children, in turn, have argued that, in the absence of clear research evidence, the principle of 'first, do no harm' (*primum non nocere*) takes precedence[43]. They have also stressed the fact that any sex assignment made at birth is always just a guess. According to human rights actors, no irreversible and non-vital operations should be performed on the basis of guesswork.[44]

3.4 Evolution of the human rights approach

Since the 1990s, intersex people have pointed out the harms caused by medical interventions, demanding respect for their fundamental and human rights. The international human rights movement of intersex activists defined its demands in the Third International Intersex Forum held in Malta in 2013.

The Malta Declaration takes a stand on issues such as 'normalising' medical interventions; intersex people's psychological wellbeing and needs for psychosocial support; intersex people's access to their own medical records and history concerning their health and treatments; and raising awareness around intersex issues and the rights of intersex people in society at large.[45]

Since around 2005, various human rights actors have also started to pay attention to intersex people's situation.

Among these actors, one of the strongest interventions into violations against intersex people's human rights was made by Juan E. Méndez, UN Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment. Stating that involuntary genital-'normalising' surgery, performed without the informed consent of the person concerned, is a form of torture, Méndez has called on the UN Member States to prohibit such involuntary, irreversible and experimental interventions.[46]

Following the Méndez Report, the UN Committee against Torture (CAT), monitoring adherence to the UN Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, has repeatedly issued similar recommendations to various

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[42] Lee et al. (2016). Cited in: Amnesty International (2017, 19).

[43] Amnesty International (2017); ETENE (2016b).

[44] Amnesty International (2017, 26).

[45] Third International Intersex Forum (2013): Malta Declaration.

[46] (A/HRC/22/53).

Member States on respect for intersex people's integrity and rights to self-determination[47]. Furthermore, both the UN Committee on the Rights of the Child (CRC) and the UN Committee on the Elimination of Discrimination against Women, monitoring adherence to the UN Convention on the Elimination of All Forms of Discrimination against Women (CEDAW), have repeatedly expressed their concern of the non-consensual and irreversible surgeries performed on intersex children[48].

The recommendations issued by the CRC and CEDAW Committees to Member States are premised on their joint general comment No. 18 on harmful practices. According to the general comment, the causes behind harmful practices generally include stereotyped sex- and gender-based roles.[49]

The human rights organisation Amnesty International and the Council of Europe Human Rights Commissioner also point out in their respective research reports that discrimination against intersex people derives from deeply engrained gender stereotypes determining what female and male bodies should be like to fit in with the definition of 'normal'. People who do not fit into this dichotomy are at risk of 'normalising' surgical and other medical interventions and to discrimination and violence in more general terms.[50]

Furthermore, the clauses of the UN Biomedicine Convention are relevant to examining the situation of intersex people. The Biomedicine Convention prohibits both "any form of discrimination against a person on grounds of his or her genetic heritage" (Article 11) and "the use of techniques of medically assisted procreation [...] for the purpose of choosing a future child's sex, except where serious hereditary sex-related disease is to be avoided" (Article 14).[51]

There is not as yet any case law from the European Court of Human Rights concerning intersex issues under the Biomedicine Convention. However, human rights actors and researchers have expressed their concerns about the fact that new techniques such as embryonic and foetal diagnostics may be used to identify variations in sex characteristics. Intersex foetuses may also be medicated using experimental methods to eliminate variations in sex characteristics.[52]

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[47] See e.g. United Nations Committee against Torture (CAT/C/FRA/CO/7) and United Nations Committee against Torture (CAT/C/CHE/CO/7).

[48] See e.g. United Nations Committee on the Elimination of Discrimination against Women (CEDAW/C/LUX/CO/6-7) and United Nations Committee on the Rights of the Child (CRC/C/ESP/CO/5-6).

[49] UN Committee on the Rights of the Child: General comment No. 18 (2014) on harmful practices, paragraph 17.

[50] Amnesty International (2017); Council of Europe Commissioner for Human Rights (2015).

[51] The Act on Assisted Fertility Treatments (1237/2006) also provides that the determination of a child's sex may only be influenced by fertility treatments in the event that the child "would be at substantial risk of serious disease if the child were to be of the other sex" (section 5).

[52] Council of Europe Commissioner for Human Rights (2015, 20; 30); Council of Europe Parliamentary Assembly (2017b); Zillén et al. (2017, 28).

Drawing on the experiences of intersex individuals, various organisations representing them have also taken a stand on the issue. They have demanded putting “an end to preimplantation genetic diagnosis, pre-natal screening and treatment, and selective abortion of intersex foetuses”. They further demand changing the medical classifications behind these practices that define having a variation of sex characteristics as ‘disorders of sex development’ and depathologising variations in sex characteristics.[53]

While the World Health Organisation (WHO) has already criticised interventions aiming to ‘normalise’ intersex children’s sex characteristics, it still continues to define variations in sex characteristics as disorders in its updated International Classification of Diseases (ICD-11).[54]

For a long time, intersex issues were exclusively addressed within the medical profession and, consequently, its effects are still echoed in the ways in which being intersex is defined and discussed. Discussions on intersex focus on biology and intersex bodies, which are somehow “different from a female or male body”. A critical analysis of these types of language reveals that they place the problem in an intersex individual. As a result, attention is not drawn to society that is unable to understand the diversity of human sexes and bodies.[55]

On the one hand, it is important to speak about the bodily aspect, because intersex people are still subjected to irreversible, experimental or non-vital medical interventions. On the other, discussion focusing on biology and body parts – even if it took a critical approach towards clinical practices – also contributes to perpetuating the pathologisation of natural bodily variations in sex characteristics. One of the effects of pathologising variations of sex characteristics and the stigma, secrecy and suppression involved may indeed be the fact that it may be difficult to talk about intersex without using language that emphasises ‘abnormality’ or ‘difference’. After all, such language will always somehow otherise and end up excluding intersex people.

Miriam van der Have, Co-Chairperson of Organisation Intersex International (OII) Europe, a European umbrella organisation of intersex people, commented on the issue at the first Finnish seminar on intersex and human rights, organised in June 2018. Van der Have stated that you do not learn anything about intersex by “reading up on diagnoses”. Consequently, van der Have encouraged people to discuss being intersex in broader terms than just by focusing on body parts.[56]

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[53] Third International Intersex Forum (2013).

[54] OII Europe Statement 06/2018: WHO publishes ICD-11 – and no end in sight for pathologisation of intersex people; OHCHR, UN Women, UNAIDS, UNDP, UNFPA, UNICEF and WHO (2014): “Eliminating forced, coercive and otherwise involuntary sterilization: An interagency statement”; World Health Organisation (2015): “Sexual health, human rights and the law”.

[55] Miriam van der Have, Co-Chairperson, OII Europe. Lecture on 11 June 2018.

[56] van der Have (2018).

Van der Have defined intersex by saying that the concept refers to the *experiences* of the individuals who were born in a body that does not meet the norms set for a female or male body. Van der Have stressed that individual doctors and medicine are not the problem. What is problematic is that society has assigned doctors the task of moulding intersex children to fit into the category of a girl or a boy.[57]

3.5 Medical practices and debates concerning intersex in Finland

Finnish awareness and debates concerning variations in sex characteristics has taken significant steps in the current decade.

The medical interventions and practices intersex children are exposed to were especially raised in public debate in 2016 when the National Advisory Board on Social Welfare and Health Care Ethics (ETENE) published a report and a position statement on the topic. ETENE recommended that operations modifying children's external sex characteristics should not be performed until they are capable of both defining their own gender and taking a stand on their own sexuality. ETENE considered it problematic that a child's sex characteristics are altered and gender defined by somebody else, such as an authority, since gender is part of an individual's inner personality.[58]

Furthermore, the Ombudsmen for Children and Equality have repeatedly expressed their concerns about intersex children's situation while aiming to promote dialogue between different parties involved. The Ombudsman for Children has also recommended that clinical practice guidelines be prepared to strengthen intersex children's rights to self-determination.[59]

Various NGOs have also taken a stand on the realisation of intersex children's rights. Intersex issues were raised in public debate as early as around 2005 by Finnish LGBTI rights organisations Trasek and Seta – LGBTI Rights in Finland[60]. In 2005, Seta awarded its 'Apple of Good Information' recognition to Terhi Viikki, the then Chair of Trasek, and Mika Venhola, a paediatric surgeon, for their work to promote intersex people's wellbeing and human rights. Trasek, Seta and Amnesty have also reported on intersex children's situation to the UN Committee against Torture and the Finnish Midwifery Association has

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[57] van der Have (2018).

[58] ETENE (2016a): Position statement on care and treatment of intersex children; ETENE (2016b): Intersukupuolisuus [*Intersex*]. Taustaraportti ETENEn kannanottoon [*Background report to ETENE's position statement*].

[59] Tasa-arvovaltuutettu ja Lapsiasiavaltuutettu [*Ombudsman for Equality and Ombudsman for Children*] (2017); Lapsiasiavaltuutettu [*Ombudsman for Children*] (2016a & 2016b); Tasa-arvovaltuutetun toimisto [*Office of the Ombudsman for Equality*] (2012).

[60] See also Lepola & Villa (2007): Syrjintä Suomessa 2006 [*Discrimination in Finland 2006*].

also issued a statement on the topic[61]. Trasek also provides support for a peer support group for intersex people, organised monthly in Helsinki, which originated from intersex people's own active initiative.

Intersex people's own active efforts also led to the creation of the first Finnish-language website to provide information on variations in sex characteristics at intersukupuolisuus.fi, which was launched in 2015. The website offers information on intersex people's peer support, intersex people's stories, content intended for professionals, and studies, articles and documents concerning the different aspects of being intersex.

In 2018, Seta's Gender Diversity & Intersex Centre of Expertise initiated a project entitled 'Information for Intersex People, Means for Professionals' (TIKA) with a view to promoting intersex people's visibility and human rights in Finland. The project produces guides and information materials for intersex children and their parents and training materials for professionals. It also organises training and information events and publishes stories about intersex people and their parents.[62]

The reform of the Act on Equality between Women and Men (609/1986; the 'Equality Act') that entered into force in 2015 was an important step for preventing discrimination against intersex people. The revised Equality Act extended protection against discrimination to also apply to intersex people[63]. Following the reform of the Equality Act, information on the diversity of human sexes and genders has also been included in materials on gender equality produced for various public authorities, educational institutions and providers of compulsory basic education, staff employed in health clinics, etc.[64].

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[61] Trasek & Seta (2016): The cruel, inhuman and degrading treatment of trans and intersex people in Finland. Submission to the UN Committee against Torture; Kätilöliitto [*Finnish Federation of Midwives*] (2016): Kannanotto [*Position statement*]: Intersukupuolisen lapsen tulee saada itse määritellä oma sukupuolensa [*Intersex children should be allowed to determine their own gender*].

[62] Seta: TIKA-hanke [*The TIKA project*].

[63] The Equality Act also prohibits direct and indirect discrimination based on gender identity, gender expression or the fact that an individual's sex characteristics are not unambiguously female or male. Furthermore, the Act obliges authorities, education providers and employers to prevent discrimination purposefully and systematically. (Act on Equality between Women and Men, sections 3, 6c, 7, 5a, and 6a.)

[64] Sosiaali- ja terveysministeriö [*Ministry of Social Affairs and Health*] (2015a): Tasa-arvolaki, viranomaiset ja sukupuolen moninaisuus [*The Equality Act, authorities and gender diversity*]; Sosiaali- ja terveysministeriö [*Ministry of Social Affairs and Health*] (2015b): Tasa-arvolaki, oppilaitokset ja sukupuolen moninaisuus [*The Equality Act, educational institutions and gender diversity*]; Opetushallitus [*Finnish National Agency for Education*] (2015): Tasa-arvotyö on taitolaji [*Gender equality work is a game of skill*]. Opas sukupuolten tasa-arvon edistämiseen perusopetuksessa [*Guide to promoting gender equality in basic education*]; Sosiaali- ja terveysministeriö [*Ministry of Social Affairs and Health*] (2016): Sukupuolten tasa-arvo neuvolan asiakastyössä [*Gender equality when working with clients in maternity and child welfare clinics*]. Miten tukea vanhempia ja lapsia sukupuolten tasa-arvon näkökulmasta [*How to support parents and children from a gender equality perspective*]?

Nowadays, information on variations in sex characteristics is also available on the website of the National Institute for Health and Welfare (THL)[65].

Research into intersex people's experiences has been published to some extent in Finland. Riitta Fagerholm's working group has studied intersex women's experiences of surgeries performed on them, as well as the development of their gender identity and their psychological wellbeing[66]. Jukka Lehtonen[67] has analysed how intersex people are taken into account in school and working life studies, while Roosa Toriseva[68] has looked at gender perceptions among doctors treating intersex individuals. Marjo Rantala has studied intersex people's situation from the perspective of fundamental and human rights[69]. In addition, there are theses relating to intersex people's identity development, rights to self-determination, and experiences as clients of sexual health services and in school and daycare settings. As debate on the diversity of human sexes has increased over the last few years, more articles on the different aspects of being intersex have also been published for the general public.[70] However, having a variation of sex characteristics still constitutes a largely unknown phenomenon in Finnish society, involving plenty of misunderstandings. Due to the stigma associated with being intersex, many intersex individuals and parents of intersex children only dare to share the information with a close circle of family and friends, if at all.

Medical practices and support available for intersex people

According to ETENE's report, medical practices applied to intersex children are in line with those generally in place in the Nordic countries. While the five university hospitals treating intersex children have not agreed on any specific approaches, they aim to follow European guidelines in their clinical practices. However, there are also significant differences in practices between university hospitals, which are clearest in the area of non-vital surgical treatments. Furthermore, there are differences in operating procedures relating to children's parents, including the types of decisions in which parents are involved and the

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65 Terveyden ja hyvinvoinnin laitos [*National Institute for Health and Welfare*].

66 Fagerholm R. et al. (2011): Sexual function and attitudes toward surgery after feminizing genitoplasty; Fagerholm R. et al. (2012): Mental health and quality of life after feminizing genitoplasty; Mattila A. K., Fagerholm R. et al. (2012): Gender Identity and Gender Role Orientation in Female Assigned Patients with Disorders of Sex Development.

67 Lehtonen, Jukka 2017: Hankala kysymys [*A difficult question*]. Intersukupuolisuus suomalaisissa koulu- ja työelämätutkimuksissa [*Intersex in Finnish school and working life studies*].

68 Toriseva, Roosa (2017): Intersukupuolisuus suomalaisten lääkäreiden käytännöissä ja puheessa [*Intersex in the practices and speech of Finnish doctors*].

69 Rantala, Marjo (2016): Sukupuoleen sopeutetut: Intersukupuolisten ja transsukupuolisten henkilöiden oikeusasema Suomessa [*Adjusted to sex – legal status of intersex and transgender persons in Finland*].

70 Theses and articles: see intersukupuolisuus.fi (in Finnish).

extent of their involvement. Access to peer support and services of psychologists and paediatric psychiatrists also varies.[71]

ETENE's report suggests that potential surgical procedures of intersex children are mainly concentrated at Helsinki University Hospital's Children and Adolescents Department, but the university hospital in charge of treatment will also give its opinion on the need for surgical treatment. Tampere University Hospital has performed some surgical procedures, but a urologist from Helsinki University Hospital's Children and Adolescents Department will always be consulted prior to such procedures. Oulu University Hospital does not perform cosmetic genital surgery and only provides vital surgical procedures.[72]

The healthcare professionals who responded to ETENE's survey stress that all decisions concerning the treatment of intersex children will always be made in agreement with their parents. They also emphasise that any decisions are made on the basis of findings and prior research. Nevertheless, ETENE justifies the critical stand that it expresses on medical practices with the fact that, on the one hand, there is no unambiguous evidence of the benefits of reconstructive surgical procedures on external genitalia and, on the other, plenty of harmful effects from such surgeries have been documented.[73]

Furthermore, healthcare professionals responding to ETENE's survey state that "in connection with various surgical operations that are necessary for a child's health, it is possible to examine the status of the child's gonads, among other things, but, as a general rule, the aim is to preserve the child's fertility"[74]. In some former clinical practices applied to certain intersex people, it used to be customary to remove the gonads due to the potential risk of cancer involved. More recent research has shown that the risk varies significantly, depending on the variation of sex characteristics concerned[75]. As a result, it has been recommended that gonadal development be monitored by means such as ultrasound, unless there is some other vital reason to remove the gonads[76]. ETENE's report does not indicate the extent to which gonadectomies[77] are currently being performed in Finland, nor the types of situations involved. Those participating in this study had varying experiences of the issue, which will be discussed in Chapter 5 below.

At all university hospitals, an intersex child's care team always involves specialists in several medical specialities, including endocrinologists, neonatologists, paediatric surgeons, paediatric urologists, geneticists, radiologists, and laboratory physicians. Needs for psychological or psychiatric support are assessed at different ages and the aim is to always arrange conversational support for parents and, later on, for intersex individuals

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[71] ETENE (2016b, 3).

[72] ETENE (2016b, 6–8).

[73] ETENE (2016b, 6–8).

[74] ETENE (2016b, 7).

[75] See e.g. Pleskacova J, Hersmus R, Oosterhuis JW, Setyawati BA, Faradz SM, Cools M, Wolffenbuttel KP, Lebl J, Drop SL, Looijenga LH (2010). Tumor Risk in Disorders of Sex Development.

[76] Amnesty International (2017, 28).

[77] Gonadectomy: the surgical removal of the gonads, i.e. the glands that produce sex hormones .

themselves. However, ETENE's report estimates that there are insufficient numbers of specialists in different fields who are familiar with the different aspects of being intersex.[78]

The healthcare professionals who responded to ETENE's survey state that they try to inform the families of all possible support services available, but there are considerable regional variations in access to various support options. Adaptation training courses and peer support are available in some areas, such as a peer support group for intersex people, organised with professional guidance in Helsinki once a month. There are also individual patient organisations, such as the Finnish Turner Association, while peer activities have been organised for groups such as people living with CAH at the Norio Centre, which provides services relating to rare and genetic disorders. Intersex people and their parents can also receive support and counselling services from Seta's Gender Diversity & Intersex Centre of Expertise[79]. The Norio Centre also provides conversational support and advisory services[80].

Respondents to ETENE's survey agree that demand for peer support and NGO support would be considerably higher than what is currently available. However, ETENE's report notes that responses provided by healthcare professionals do not indicate whether intersex children's families are encouraged to search for information from sources such as the intersex information website at intersukupuolisuus.fi or NGO websites.[81]

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[78] ETENE (2016b, 8).

[79] Transtukipiste [*Trans Support Center*]: Palvelut [*Services*].

[80] Norio-keskus [*Norio Centre*]: Palvelut [*Services*].

[81] ETENE (2016b, 8).

4. Study data

4.1. Implementation of the study

The participants sought for the study were at least 15-year-old intersex individuals. The invitation to participate in the study specified that intersex refers to individuals born with bodily sex characteristics that are not unambiguously female-typical or male-typical. It also noted that respondents could have been diagnosed with one of the medical diagnoses of types of variation in sex characteristics[82]. The purpose of specifically mentioning medical diagnoses in the invitation was to also attract respondents with one of the diagnoses who were not familiar with intersex as a term or who did not self-identify as intersex. Another group of participants sought for the study included parents of intersex children.

Participants were sought through several different channels. Copies of the invitation were spread on the websites and social media channels of NGOs, associations, research projects and public bodies. In total, about 30 parties were involved in disseminating the invitation.

The key partners in planning the study included a team managing the intersex information website at intersukupuolisuus.fi, consisting of intersex individuals and their supporters, experts from Seta’s TIKA intersex project, and Jukka Lehtonen, senior researcher with the WeAll project from the University of Helsinki.[83] They also commented on the first version of the report on the study.

The preparatory stage of the study also involved exploring the possibilities to cooperate with university hospitals treating intersex people, with a view to seeking participants based on hospital records in addition to the public invitation. This procedure would probably have made it possible to recruit more participants, resulting in more diverse data. Unfortunately, however, cooperation was not possible due to the schedule of the study.

The study’s fundamental and human rights approach was indicated in the invitation to participate in the study. The invitation explained that the study was to be conducted as part of the National Action Plan on Fundamental and Human Rights, and that the data collected would form a basis for presenting public authorities with recommendations to improve intersex people’s situation. The partners assisting in the preparatory and implementation stages were mentioned in the invitation as part of explaining that further information on

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[82] The invitation mentioned congenital adrenal hyperplasia (CAH), androgen insensitivity syndrome (AIS, CAIS, PAIS), gonadal dysgenesis, 5α-reductase deficiency, hypospadias, 47,XXY (Klinefelter syndrome), or 45,X (Turner syndrome).

[83] Comments on questionnaire and interview templates were also provided by experts from the Ministry of Justice, the Ministry for Foreign Affairs, and the Office of the Ombudsman for Children.

intersex issues and intersex people's peer support activities was available on the intersex information website at intersukupuolisuus.fi and through Seta's TIKA intersex project.

As being intersex is a highly personal topic, the study was carried out with special attention to research ethics. In keeping with the research ethics guidelines specified by the Finnish National Board on Research Integrity (TENK), every effort was made to pay special attention to showing respect for the rights of the research subjects to self-determination; avoiding any harm; and ensuring data protection and privacy.[84]

Data was collected from intersex individuals and parents of intersex children by means of online surveys and interviews. The online surveys were implemented in Finnish and Swedish and published on the Equality.fi website managed by the Ministry of Justice at yhdenvertaisuus.fi. Responses to the online surveys were provided both in Finnish and Swedish. The interviews were conducted in Finnish. They were carried out in different parts of Finland, in a quiet place, such as the interviewee's home, a library or some other suitable location. One interview was conducted over the phone. The interviews were recorded on a recording device and transcribed.

The online survey and interviews for intersex individuals covered the following three themes: experiences of medical practices; experiences of impacts of being intersex on life; and good practices for promoting intersex people's equality and non-discrimination. Intersex children's parents were asked about their experiences relating to their child's healthcare and to the ways in which their child being intersex had affected their lives. The study also collected parents' views on good practices for promoting intersex people's equality and non-discrimination.[85] While the interviews advanced in line with the key

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[84] Finnish National Board on Research Integrity (TENK) (2012): Responsible conduct of research and procedures for handling allegations of misconduct in Finland. The participants were informed of data protection as follows: "Participation in the study is completely voluntary and you will not receive any compensation for participation. You do not have to answer all questions included in the online survey and the interview and you are free to revoke your consent to participation at any point whatsoever without giving any reason. The information collected through the survey and interview will be used to draw up a report on the experiences of intersex individuals with funding from the Ministry of Justice and the Ministry for Foreign Affairs. The study will be carried out anonymously. It does not intend to collect any information that would allow individual respondents to be identified. The study will be reported in such a manner that individual respondents or their responses cannot be identified. The data will be processed using secured network drives and secured storage media. The Ministry of Justice functions as the controller responsible for processing the data collected as part of the study. The purpose of processing the data and drawing up the report is to promote intersex people's rights to self-determination (Constitution of Finland, section 7, subsection 1, and section 22), in keeping with the National Action Plan on Fundamental and Human Rights. For information on data protection in the activities of the Ministry of Justice, please visit https://oikeusministerio.fi/tietosuoja."

[85] Intersex respondents spent an average of about 40 minutes filling in the online survey and the interviews took about 1.5–2.5 hours each. The parents spent an average of about 30 minutes filling in the online survey and the interviews took about 1–2.5 hours each.

themes, the interviewees were also given a chance to bring up issues outside the scope of the themes, if they felt that these were relevant to the study.

At the beginning of each interview, the author of the study provided information about the study and its implementation, introduced themself and checked whether the interviewee had any further questions about the study.

At this point, a number of interviewees wanted to ask how intersex was defined in the study. They explained that they asked this because they wanted to make sure whether they were able to participate in the interview. They verbalised this experience by saying that they were not certain whether they were "sufficiently" intersex or whether they were "even really" intersex, for example.[86]

The interviewer repeated the definition of intersex used in the study for them, explaining that the interviewee does not need to have any of the medical diagnoses of types of variations in sex characteristics, for example, in order to participate in the study. There are a number of reasons for this approach. The purpose of the study is to explore people's experiences from the perspective of fundamental and human rights. In this context, the type of diagnosis that an individual has, or whether they have any at all, is of secondary concern. Due to shame and secrecy, intersex people are not necessarily even aware of their diagnosis, even if they had undergone several operations to modify sex characteristics, as indicated by the study data.

All those who asked this question at the beginning of an interview eventually decided to participate in the study. In the course of these interviews, it emerged that all those who had initially posed this question also had an intersex-related diagnosis or experiences of medical interventions. However, their hesitation about whether they were "sufficiently intersex" aptly reveals how suppressed and stigmatised an issue being intersex still is in some respects.[87]

The actual interviews mainly commenced in one of two ways: either the author of the study started to ask questions relating to the first theme, or the interviewee began to freely tell their own story. As a result, the interviewer's role took different forms in different interviews. In all interviews, the interviewer asked probing follow-up questions based on what each interviewee had told. The interviewees were also given a chance to check their quotes before the study report was published.

4.2 Data and participants

The questionnaire surveys were filled in by 8 intersex individuals and 3 parents. Interviews were conducted with 7 intersex individuals and 3 parents. Three of the interview and survey

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[86] Respondents' experiences relating to this aspect will be discussed in Section 6.1 below.

[87] See also Janik Bastien-Charlebois (2015): My coming out: The lingering intersex taboo.

participants were the same individuals.[88] In other words, a total of 18 people participated in the study.

The intersex individuals who participated in the study were born between 1950 and 2003. Four of the respondents were born between 1990 and 2003, another four in the 1980s, two in the 1960s, one in the 1970s, and one in the 1950s.

The six parents participating in the study had a total of seven intersex children. Four of the children were born between 2010 and 2019, one was born between 2000 and 2009, one in the 1990s, and another one in the 1970s.

Most respondents had received one of the intersex-related diagnoses. Four intersex respondents reported that they had never received any specific diagnosis. Based on the medical interventions that they had undergone, however, they had made their own assessments about what their potential diagnosis might be. Two respondents did not indicate what intersex-related diagnosis they had received. One of these respondents reported that they had experiences of medical practices related to them being intersex.

The most common diagnosis received by respondents was androgen insensitivity syndrome (AIS) and its different forms. Five intersex respondents and four of the children whose parents participated in the study had been diagnosed with AIS. Other respondents had been diagnosed with congenital adrenal hyperplasia (CAH), various forms of gonadal dysgenesis, various forms of sex chromosome mosaicism, Mayer-Rokitansky-Küster-Hauser syndrome (MRKH), 47,XXY (Klinefelter syndrome), 45,X (Turner syndrome), and hypospadias[89]. The number of respondents who or whose child(ren) had received one of these diagnoses was 1–2. Some had more than one of the above-mentioned diagnoses, such as both sex chromosome mosaicism and hypospadias, Klinefelter syndrome, or Turner syndrome.

4.3 Reporting the data

The following two chapters describe the experiences of the intersex individuals and parents of intersex children who participated in the study. The chapters include plenty of direct quotes from the respondents so as to make their own voices and stories heard in the study. Quoting the respondents' own expressions and word choices may also make it

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[88] In addition, the survey was filled in by one respondent who was excluded from the data analysis. This respondent, born in the 1960s, had only filled in the mandatory question about the decade of birth and left some positive feedback on the fact that the study was being carried out. The respondent had copied the questions for their own use with the intention of exploring their own experiences.

[89] Hypospadias is a medical classification that refers to a condition of varying degrees where the urethral opening is on the underside of the penis rather than the tip. This particular case was so-called proximal hypospadias, which is a variation of sex characteristics commonly classified as intersex.

easier to understand intersex people's experiences, which may otherwise remain distant for someone who does not have any personal point of contact with the subject.

In order to improve readability, however, the quotes have been slightly edited by removing some characteristics of spoken language, filler words and repetitions. This is justified because the study focuses on the respondents' experiences, not on linguistics.

Quotes have also been edited to lessen the chance of identifiability. The responses have been scrubbed of identifiable details, such as names of places. Changes have also been made to some details relating to the variation of sex characteristics the individual respondents or their children have. The respondents' names have also been changed, with the exception of the three individuals who chose to be featured under their own names[90]. Some of the quotes are, however, cited without a pseudonym to reduce the chance of identifiability. The ages of respondents or their children are reported within the range of +/-4 years or by decade of birth. All Swedish quotes were translated into Finnish.

The data and participants of the study do not constitute a quantitatively representative sample of intersex people in Finland. The information obtained from the respondents cannot be generalised; nor does the report provide a comprehensive picture of intersex people's experiences in Finnish healthcare services and society. Instead, the views and experiences presented in the report are profound and informed descriptions of the kinds of experiences and issues that intersex people and their parents are living with in Finnish society. As such, they are unique, valuable and important. In the absence of comprehensive research[91], the respondents' experiences of medical practices and the impacts of these on their lives also provide valuable information for the purposes of modernising intersex-related healthcare and safeguarding intersex people's fundamental and human rights more effectively.

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[90] In this report, the interviewees with female names are referred to using female names; those with male names are referred to using male names; and those with gender-neutral names are referred to with gender-neutral names. Online survey respondents (whose names are unknown) are referred to using female, male or gender-neutral names. All interviewees are referred to with the gender-neutral pronoun 'they', as the interviews were conducted in Finnish and the respondents were not asked for their preferred English pronoun. Finnish language has only one pronoun 'hän', which is gender-neutral.

[91] One of the common challenges for research concerning intersex people is the difficulty of reaching intersex individuals and low participation rates in studies. By way of example, the recent EU-funded dsd-LIFE study, covering six European countries and 14 medical centres, only achieved a 30% response rate, which is why the study points out that the responses can mostly be seen to give some indication of the experiences of the individuals who were being treated at the medical centres concerned when the study was carried out. See Thyen et al. dsd-LIFE research group (2018): Quality of health care in adolescents and adults with disorders/differences of sex development (DSD) in six European countries.

5 Experiences within healthcare services

5.1 Learning about being intersex

INTERSEX PEOPLE'S EXPERIENCES

The respondents had mainly found out about being intersex (in this context: about their medical diagnosis) in one of three ways: they had either heard about it during a doctor's appointment or from their parents, or they had read about it in their patient records. About half of the respondents had learned about their intersex-related diagnosis when they were teenagers and another half in their adulthood. One respondent had found out about it before the age of ten.

The respondents' experiences were very different. A factor common to all of the responses was, however, that none of the respondents reported ever hearing the word intersex being mentioned by anyone. Nor had they been told about the diversity of human sexes and the natural bodily variations in sex characteristics. All of the respondents had typically received information that only concerned their medical diagnosis. In most cases, respondents had felt that this information was somehow tinged with negative overtones.

Most respondents had learned about being intersex - or, rather, about their diagnosis - during a doctor's appointment in connection with hearing about the results of a test or examination[92]. This had generally taken place when the respondents were aged between 12 and 17. They had gone to see a doctor with their parents to find out the reason for symptoms such as stomach-aches, delayed puberty or stunted growth.

In such cases, discussions with the doctor had typically concentrated on the ways in which the physical characteristics of their bodies were "abnormal". By way of example, some respondents had been told that they had "a boy's chromosomes", or that their hormonal activity or genitalia were somehow "abnormal" or "deficient". A number of respondents had also been told that they would not be able to have biological children, if this was associated with the variation of sex characteristics they had. Some respondents had been told about their diagnosis at the same time, while others had not. In this context, respondents had also typically been informed of the types of interventions that would be performed next.

Respondents described these experiences in different ways. Some described them as confusing and scary; others said that they had not properly understood what was going on. Some explained that they had initially been in mild shock but had then became mainly curious about being intersex and sought to read up all the information available on the subject.

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[92] Examples include chromosomal blood tests and ultrasound examinations.

Terhi[93], 39, for example, was at lower secondary school when they[94] learned about being intersex from their doctor, where their mother had taken them to find out the reason for Terhi's constant stomach-aches.

"I was told, 'You'll have some tests and operations and everything will be sorted out. You'll be a completely normal girl.' That was the message I picked up. Afterwards, I read in my records that 'the patient intellectualises everything and she will have problems internalising what is now happening to her womanhood'."

Pauliina, 32, was an adolescent when a doctor told them that they did not have a uterus. They had seen a doctor at their mother's insistence because they had not yet started menstruating.

"I was reluctant to see a doctor, but my mum made me go. We went to see a gynaecologist and it was gross and distressing. I had a scope and then I had a doctor's appointment. The doctor told me that I didn't have a uterus. I don't really remember the details, but the feeling I remember was that it didn't actually have much of an impact on me. It feels like it was a bigger deal for my parents and the doctor. I probably didn't come across very shocked by this, because the doctor said to me, 'Perhaps you will give this more thought in the future.'"

Sofia, 25, learned about being intersex around 2005 when they were twelve. They were told that they had androgen insensitivity syndrome and "a man's chromosomes". They reported that they would also have wanted the doctors to have told them that they were intersex. The same wish was expressed by the majority of the respondents.

"My endocrinologist was a lovely person, a woman of about forty. I remember that I always felt really comfortable at her appointments. Everyone was really nice. But no-one mentioned the word 'intersex' to me; all they were saying was that I had 'a man's chromosomes'. It was really confusing. I was totally like, was I a girl or a boy now, or what was this thing all about. There was just an awful lot of all those medical terms that they were using. The main thing that I got out of it was the knowledge that I couldn't have biological children. I would have hoped that they would have told me about being intersex. It would have made it clearer to me what this was all about and it would have helped me create and deal with my own identity."

Another aspect of learning about being intersex that emerged from the data was that some respondents had never really been told anything about the subject as such by anyone; instead, they had found out about it themselves in adulthood when they had felt the urge

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[93] Terhi, Mariaana and Sara are featured under their real names in this report. The names of the other respondents have been changed. Data anonymisation is discussed in more detail in Section 4.3 above.

[94] All respondents are referred to with the neutral pronoun 'they'. The interviews were conducted in Finnish and the respondents were not asked for their preferred English pronoun. Finnish language has only one pronoun 'hän', which is gender-neutral.

to explore it on their own. The way in which these respondents had found out about being intersex clearly goes to show the secrecy and suppression around being intersex, especially in earlier decades.

At the same time, these respondents' experiences also highlight how traumatising childhood interventions aiming to modify sex characteristics can be. These respondents were aware of their childhood doctors' appointments, or they might even still have regular medication and contact with a doctor. However, they did not know what the doctor appointments or their medications pertained to.

Kape, 47, for example, reports that they had been on hormone therapy well into their 30s without really knowing why. They describe taking "hormone pills" as a "confusing part of life that didn't really even exist".

Here is how Kape recounts their experience:

"I've always known something. But the suppression and secrecy around this has been so deep that it took me until my thirties to be able to start putting these things together. Those childhood doctors' appointments and the fact that I'm taking hormone pills. After all, I've been putting them in my mouth all by myself. But it had somehow become such a normal thing, like brushing your teeth, that I didn't even think about why I was taking them every day.

"When I finally set out to find out about it, I searched for information online and put things together in my mind. Then I went to see a doctor and asked for some tests. I said to the doctor that 'I'd like to have an explanation now for why I'm using these hormone pills' and told them about the doctors' appointments when I was little and the scars that I have on my body. I was tested for hormone activity and chromosomes and the doctor made an assessment of what had been cut off from my body when I was a child."

Elina, 36, also did not learn about being intersex until they set out to find out about the matter as an adult.

"I was never told that I was intersex, not by a doctor or by anyone else. All that I was ever told was the notion that I was born defective and I needed to have surgeries and operations to become whole."

"When I went to [name of hospital] for treatment for the last time in the mid-2000s, I got to read my patient file. The nurses didn't want to give it to me. I only got it after I really put my foot down and insisted that it was my right. I wanted to see the whole file because I had no idea why I was there and what had been done to me."

"In the papers, I read the term 'androgen resistance'. That's when I started searching for information online. I googled 'androgen resistance' and found further information. However, it took another two to three years until I finally ordered all of my patient records from the hospital. That's when it really dawned on me what had actually been done to me."

Besides Elina, another two respondents' stories also pointed to the phenomenon found in international research where intersex people's patient records tend to 'disappear' or their access to their patient records is restricted[95].

Kape describes the issue as follows:

"I don't have any diagnosis whatsoever; it's not possible to give one based on the available information. I have tried to obtain my medical charts, but I was told that some of the records couldn't be found while others, in turn, were secret. I got angry about this and was told in response that this was to protect the patients. This made me a bit angrier, like, could I perhaps have been protected some time earlier. Anyway, the thing is I haven't received those papers. This is not a unique story. I have heard quite a few people say that many people's records have 'burnt' or vanished or disappeared."

The patient records of another study participant, Mikko, 33, have also disappeared from the period before their seventh birthday.

Previously it has been presumed that learning about being intersex is invariably a negative experience for an individual. However, the respondents' experiences corroborate the observation made in previous studies[96] that the type of information provided and the way in which it is presented have a bearing on how people experience learning about being intersex.

The respondents who had received information focusing on what was "abnormal" or "deficient" or required "fixing" in their bodies reported that they had felt they were exactly like that: abnormal, deficient and in need of fixing. Similar experiences were also reported by the respondents who had not been given any reason for doctors' appointments or examinations.

Eeli, born in the 1980s, and Mikko, 33, verbalised the experience as follows:

"I was never told anything. All I knew was that there was something wrong with me."
– Eeli

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[95] By way of example, in a recent Australian study (Jones et al. 2016) with 272 intersex participants, making it one of the broadest studies on intersex people's experiences, only one fifth of the respondents reported that they had been able to access all of the patient records concerning their treatment history. Earlier clinical practice guidelines used to discourage doctors from telling people about the details of their variation of sex characteristics. It was thought that this would not be helpful for their wellbeing. The secrecy has been prone to heighten people's perception that what they had was something "so awful" that it could not even be talked about. This type of secrecy is no longer being promoted in current international clinical practice guidelines. Full closure of all information is the guideline for healthcare professionals who are treating intersex individuals and children are informed in keeping with their age and maturity. (van Lisdonk 2014, 41.)

[96] See e.g. Jones et al. (2016, 93–95).

"I must have already heard when I was quite little that there was something 'amiss' in my body. I remember when my genitals were looked at when I was a child and mum didn't look at me when the doctor was examining me. She was ashamed. And that's how I also learned to be ashamed of myself." – Mikko

However, these respondents typically described the relief they felt at the moment when they heard the word 'intersex' and found information on intersex as part of natural bodily variations in sex characteristics. As a general rule, they had found this information on their own on the internet. Once they had googled their diagnosis, they had landed on the websites of various support and non-governmental organisations. This was how they had begun to receive appropriate and comprehensive information and found peer support.

In addition to support, it was also crucial for respondents to receive information on intersex as part of natural bodily variations in sex characteristics and the diversity of human sexes in general. This had enabled them to question the disorder-oriented medical approach. It had also helped them deal with their own experiences and with the secrecy and shame they had associated with being intersex.

Kape, 47, describes this as follows:

"The actual diagnosis is not all that important to me. But what matters is that I found out that I was intersex. It was a big explanation for a lot of things. It helped that this thing had a name and there was an explanation for all of this. So it wasn't just that there was something wrong in my head because I felt weird and had weird thoughts and memories. Of course, it was also a shock in a certain sense. But on the whole, it was a relief."

Discovering the term 'intersex' had also helped respondents deal with their own identity.

Sofia, 25, describes this as follows:

"It has now been much easier for me to tell people who I am and what I'm really like. I always used to be embarrassed to tell people that I had 'a man's chromosomes'. In a way, I guess I was afraid that people would find me weird. So it's been like I've had some sort of secret. That's probably what has embarrassed me, like, what if someone found out. And that's where the feeling of shame has come from."

Learning about being intersex also came as a relief to Mariaana, 59. They only found out about being intersex in their 50s.

"I had been looking for a reason why I was sterile for a long time. My mother's very lame explanation that I had had mumps when I was little didn't sit well with me. Mother did confess later on that, in fact, she always knew but just couldn't bring herself to say so. A couple of years ago, my sister tipped me off about the possibility of having my chromosomes tested and that's how I found out that 77% of my chromosomes were female chromosomes. It really made me feel so much better to learn about this because it explained my bodily signs and why I am not, so to speak, a 'normal man'. It was certainly an awfully good thing for me to find out."

Mariaana says that they knew they were a girl even before the age of six, but have only been able to start a gender reassignment process a few years ago.

The youngest participant in this study, Karoliina, in their late teens, also had a positive experience. They say that they heard about being intersex from their parents at the age of about 6 to 10.

"I don't remember if my parents used the word 'intersex', but they told me about the bodily variation that I have. And it was in no way unusual. I have never been pigeonholed by gender, so I've just always been myself. So perhaps the knowledge just made me stronger."

Respondents' experiences of learning about being intersex varied considerably. Since the vast majority of people only know very little about the diversity of human sexes and the bodily variations in sex characteristics, it may be confusing to find out about being intersex.

The information provided by healthcare professionals to respondents only concentrated on the medical approach. In many cases, this information also tended to be somehow tinged with negative overtones, or the situations where they found out about their status were unpleasant. None of the respondents had heard the word 'intersex' mentioned within healthcare services.

Based on the respondents' experiences, what was crucial in terms of dealing with their own experiences was to receive comprehensive information regarding variations of sex characteristics and the different aspects of being intersex. Another key aspect was learning about the diversity of human sexes and that being intersex is part of natural bodily variations in sex characteristics. The majority of the respondents had to search for this information on their own on the internet. Respondents described the discovery of this information and the word 'intersex' as a relief. It was also important for them to read peer stories and receive peer support.

PARENTS' EXPERIENCES

There were also considerable differences between parents' experiences of learning about their children being intersex. Parents had found out about their child having a variation of sex characteristics in very different circumstances. Some had been informed of the chances of their child being intersex during pregnancy, while others found out at the time of birth or when the child was under the age of two or approaching puberty.

The experience of learning about their child being intersex was most confusing for those parents who had no prior knowledge of the natural variations of sex characteristics. They described their experiences as a "shock" or a "bombshell". These parents had often found out about their child being intersex immediately after birth or following several examinations to determine the reason for symptoms such as absence of puberty. In many cases, the confusion and shock was also associated with the fact that they felt as if the news had simply been "blurted out" to them.

Kaarina, for example, learned about their child being intersex in the 1990s when the child was 11 years old.

"Due to my child's symptoms, we were sent to [place name] for examinations. The paediatrician there said, without so much as an advance warning, that my child had no uterus or ovaries. My child asked what it meant. I said, 'You won't get periods and you won't be able to have a child.' My child very sad about this and I tried to make it better by saying that it would be possible to adopt a child instead."

In many cases, those respondents who had found out about their child having a variation of sex characteristics at birth had also been told by doctors and nurses that the child's sex was "ambiguous"[97]. These professionals had also used expressions such as "there is some kind of problem" or "not everything is looking normal here". This sort of language had heightened the parents' anxiety about the situation.

At the time of birth, medical staff had also always hurried to determine whether there was any medical condition that might require urgent treatment. Indeed, some of those who learned about their child being intersex at birth said that the "issue of sex" made no difference to them at the time of birth. All they wanted to know was that their child was healthy.

Maria found out that their child was intersex at the time of delivery in 2014. They describe the first few days as follows:

"They took a lot of blood tests, performed ultrasounds and monitored salt levels. We spent a total of two weeks in hospital. Among others, we saw an endocrinologist, who told me that my child was intersex. The endocrinologist also described the issue of chromosomes in great detail, drawing them on a piece of paper and explaining the subject. The endocrinologist was very good and nice. But the whole situation was pretty awful. I didn't know a thing about the subject and I had just given birth a few days ago. I just kept crying and crying. The first question that I and my spouse had in that situation was to make sure that we didn't have to be the ones to make the decision on the child's sex. The doctors replied that we didn't; it would be determined medically."

The parents who had some prior knowledge of the natural variation of sex characteristics did not consider finding out about their child being intersex to be a particularly startling experience. In many cases, these parents had either read about the diversity of human sexes and variations of sex characteristics issues online while looking for some health-related information, or they knew about the subject through their relatives. Some of these parents actually reported that they had already had an inkling that their child might be intersex. This was due to reasons such as the child's delayed puberty and the existence of other intersex people in their extended family.

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[97] Of course, an intersex child's sex is not in any way ambiguous at the time of birth. However, the choice of words aptly reflects the problem- and disorder-oriented approach towards the natural variations of sex characteristics in the medical world and, more broadly, in society at large.

By way of example, Kristiina, mother of two intersex children born in the last and the current decade, describes that learning about their children being intersex was not really all that strange.

"When my elder child was having a hernia repair surgery at just under age two, a doctor came in to inform me of the finding. I was told that it was an abnormal finding that resembled a testicle and that it had been biopsied. Learning about my child being intersex was in no way startling. Before the surgery, I had read about girls' groin hernia online and come across some websites with information about intersex in this context. The same conclusion was also made with my younger child as a result of a hernia that occurred at the age of one month."

In other words, parents had very different experiences of learning about their being child intersex. The aspect that all of the answers had in common was that the information that healthcare professionals had provided for parents had mainly been medicalised and focused on the types of "anomalies" that were found in their child's body.[98]

However, the respondents' experiences did point to one significant change that has taken place over the last few decades. At least some of the parents who had had an intersex child after the turn of the millennium had also heard the word 'intersex' mentioned in addition to going through the details of the intersex-related medical diagnoses. These respondents had neither been given any further information on the subject, nor pointed towards any sources of information or peer support. Nevertheless, when compared with the experiences of intersex individuals, the key difference was that the word 'intersex' had been mentioned to them. This had made it easier for parents to seek information on their own, which in turn had helped them deal with the issue.

5.2 Assigning the sex of the child

While biological sex is not defined by any law, the Act on the Population Information System and the Certification Services of the Population Register Centre (661/2009; the 'Population Information Act') requires that each person be assigned a sex. Under the Act, each individual must be provided with a personal identity code, which includes an individual number indicating their sex. The Population Information Act does not specify that sex must be male or female; nor does it include any provisions on how to determine sex.[99]

In practical terms, an individual's sex is determined at birth on the basis of external genitalia and often reported to the population information system as early as during the stay at the hospital of delivery. Intersex children's sex remains undetermined after birth

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[98] The information provided to parents concerning their child's diagnosis, related interventions and medications will be discussed in Section 5.5, which deals with access to information and making decisions.

[99] Rantala (2016, 10).

until a decision on their sex is made. Once this is done, the sex will be reported to the population information system and the child will receive a personal identity code.[100]

ETENE's report indicates that, at Finnish university hospitals, the sex of an intersex child is, as a general rule, decided by doctors. However, some university hospitals allow the parents to participate in this decision-making process to a varying degree. Sex determination often involves various examinations, such as analysing the child's chromosomes, while ultrasound examinations are also commonly performed on the lower abdomen and genital area in order to determine internal genital structures. Following these examinations, a decision will be made on whether to determine the child's sex as female or male.[101]

Two of the parents participating in the study had experiences of how the sex of their children had been determined at birth.

Johanna, whose child was born in the current decade, found out about the chance that their baby might be intersex during pregnancy. At the time, however, it was stressed to them that there were very few cases where a child's sex would be "ambiguous" at birth.

Johanna reports, however, that the situation turned completely around after their baby was born: all of a sudden, it was quite clear that the child was "ambiguous in terms of sex" and that it was necessary to start determining it at once. Subsequently, they were also told by hospital staff that if a chromosome result was already available for a foetus, this information was also added to the records in advance for delivery. Johanna would also have liked to have been informed about this to be able to prepare better for the situation.

This is how Johanna describes the process:

"After birth, they started to determine my child's sex through various tests. They tested the chromosomes and these were the same as what was tested during gestation. My child was found to have testicles and nothing else. The child's willy was measured and photographed and we were told that it was 'just barely' within the normal range; the limit was 2.5 cm or so, I think. So, my child just about cleared it to land on the boys' side. I don't know if this sort of thing has any place in today's world."

International clinical practice guidelines provide some general guidelines for the criteria on which an intersex child's sex should be assigned as a girl or boy. However, these guidelines have been updated and revised over the last few years. The likelihood that an intersex child will want to reassign their gender from the one chosen for them at birth is also known to vary a great deal, depending on factors such as the variation of sex characteristics concerned.[102]

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[100] Rantala (2016, 10).

[101] ETENE (2016b, 7).

[102] Kreukels et al. (2018).

At the same time, however, recent medical research has also started to pay attention to the fact that, rather than being just a male/female dichotomy, an individual's biological sex(as well as gender)forms more of a continuum[103]. An extensive EU-funded study recommends that this should also be taken into account when providing care for intersex individuals[104].

Johanna's experience of their child's sex determination process was, nevertheless, that there was virtually no room for acknowledging the diversity of human sexes. At no point did the healthcare professionals inform them of the chance of their child being intersex.

Johanna recounts the situation as follows:

"About a week later, we were brusquely informed that 'it's definitely a boy'. With that, the case was closed. No-one has ever raised the possibility that our child might be intersex. This information is something that we found afterwards."

Johanna also felt that once the decision on the child's sex was made, the healthcare professionals moved on very quickly to discuss what operations were to be performed next.

"After the sex was decided, we were told about what they were going to do next to make the boy 'normal'. They didn't actually say so in so many words, but this was how their attitude came across to me. It was like, 'You have a son, but he's not normal or complete. That's why we are now going to perform these surgeries to make him normal.'"

The other of the two participating parents with experience of their child's sex determination at birth was Maria, whose child was born in 2014.

Maria felt that the importance of quickly determining the child's sex was discussed a great deal during the first few days. The healthcare professionals had told them that it was important to determine sex in order to obtain a personal identity code for the child. Following a few weeks of examinations, the doctors made their decision. Maria felt that, in that instant, it was as if the fact that their child is intersex ceased to exist for the healthcare professionals. However, Maria does not think that this is the case at all.

Maria explains the matter as follows:

"Once sex was assigned, the fact that my child is intersex was no longer mentioned at all during doctors' appointments. But it's not like my child's body has stopped being intersex now.. For instance, my child will have to be put on hormone therapy at puberty because the gonads have been removed. I don't know whether it will be possible to take my child's

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[103] Kreukels et al. (2018). On the increase in medical information concerning gender diversity, see also Teemu Kärnä, Nina Uusi-Mäkelä & Aino Mattila (2018): Sukupuolen moninaisuus – lähestymistapa sukupuoleen muuttumassa [*The diversity of gender identities – Is the concept of gender changing*]?

[104] Kreukels et al. (2018).

own view into account at that point. My child has now been assigned as a girl and has a girl's personal identity code. But how will they proceed if my child would rather prefer testosterone therapy instead? I don't know whether it would be possible, or whether they'll automatically prescribe oestrogen therapy."

Two of the parents participating in the study had experiences of the process of determining their children's sex. The respondents had divergent experiences: their child being intersex had been mentioned to one of them, whereas the other had not been informed of the chance of the child being intersex. However, their experiences shared a certain sense of urgency and the fact that the child's sex came across as if it were a problem that needed to be solved. Once the healthcare professionals had 'solved' the issue of sex and a personal identity code was obtained for the child in keeping with the assigned sex, it was as if the issue ceased to exist. Following the decision, staff also moved on very quickly to discuss the medical interventions to be performed on the child.

5.3 Examinations, medications, surgeries and other interventions

Ten of the 12 intersex individuals who participated in the study had experiences of intersex-related healthcare interventions.

Seven respondents shared their experiences relating to medical interventions or medication. Six of them had experiences of hormone therapy, while experiences of genital surgeries[105] and vaginal dilations[106] were reported by four and three respondents, respectively. Four of these seven respondents had experiences of two or three of the above-mentioned interventions. All of the respondents had experiences of doctors' appointments and of examinations and monitoring of sex characteristics.

All of the respondents were underage when the examinations, procedures and medications were started. Surgeries had been performed on the respondents at ages ranging from infancy to adolescence, while one of them had undergone surgery as a young adult. Dilations had been carried out in adolescence. Hormone therapy was also typically started in adolescence.

All six of the parents participating in the study had experiences of their children's intersex-related healthcare interventions. All six had experiences of the examinations of their children's sex characteristics, while experiences of children's hormone therapy and genital surgeries were reported by five and four parents, respectively. Four of the parents had children whose treatments had started in early childhood, while another two reported that treatments had begun at the onset of puberty.

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[105] External genital or vaginal surgeries and gonadectomies.

[106] Vaginal dilation therapy refers to enlarging the vagina, which patients perform on themselves at home, using dilators, or dilation rods, designed for the procedure.

The intersex respondents who were born in the 1980s or earlier, in particular, stressed that their experiences should be mirrored against the zeitgeist of the past decades. They wanted to emphasise that it should not be automatically assumed that similar interventions, suppression and secrecy would still be going on.

On the other hand, the experiences shared by the parents whose children were born between 2010 and 2019 go to show that interventions such as non-vital genital surgery are still being performed. Parents' experiences also indicate that they question the need for such surgeries and the rationale provided for these. They also raise similar challenges with communication relating to children's interventions[107] as those reported by intersex respondents born in earlier decades. Children's surgical treatments are also mentioned in ETENE's report exploring clinical practices[108].

Respondents participating in this study had varying experiences of practices relating to removal of gonads (also) from recent years. The parents of children under primary school age reported that their children's gonadal development had been monitored via ultrasound instead of removing their gonads. This was the procedure in all but one case, where surgery was eventually performed because monitoring the gonadal tissue would have required regular biopsies due to its quality. On the other hand, two intersex respondents reported that their doctors had recommended gonadectomy in their adolescence, citing cancer risk. One of them had undergone a gonadectomy during the current decade while they were of full legal age.

5.4 Impacts of medical interventions

In various studies, intersex people have reported both negative and positive impacts of intersex-related healthcare interventions.[109]

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[107] One of the participants in the study's background interviews also raised the lack of effective communication between parents and healthcare professionals as one of the key themes. Furthermore, they reported having met parents during the current decade whose children had undergone genital surgeries under the age of five and who had subsequently been instructed to perform dilations on their children. These parents had identified inadequate pain relief for the child and lack of psychosocial support for parents as challenges relating to these situations. (Background interview with Ulla Parisaari, genetic counsellor, sexual health counsellor, clinical supervisor, Norio Centre, on 14 August 2018.)

[108] ETENE (2016b).

[109] See e.g. Jones et al. (2016); van Lisdonk (2014); Amnesty International (2017); Council of Europe Commissioner for Human Rights (2015); Callens, Nina, Yvonne G. van der Zwan, Stenvert L.S. Drop, Martine Cools, Catharina M. Beerendonk, Katja P. Wolffenbuttel & Arianne B. Dessens (2012): Do Surgical Interventions Influence Psychosexual and Cosmetic Outcomes in Women with Disorders of Sex Development; Nordenström et al. dsd-LIFE research group (2018): Hormone therapy and patient satisfaction with treatment, in a large cohort of diverse disorders of sex development; Thyen et al. (2018).

Ten of the intersex study participants had experiences of intersex-related healthcare interventions. Eight of the respondents described their experiences in mostly negative terms, while two were mostly positive.

Those who mostly described their experiences in negative terms had undergone hormone therapy, various surgeries, vaginal dilation therapy and/or examinations and monitoring of sex characteristics. Their treatments and procedures had started during infancy, childhood or adolescence.

The two who mostly described their experiences of intersex-related healthcare interventions in positive terms had undergone hormone therapy and/or gonadectomy. Their treatments had started during adolescence.

Surgery

The negative impacts of surgeries reported by intersex people in studies are often related to pain, loss of sensation, scarring, sterilisation, infections, and challenges with sexual function and pleasure.[110]

One of the rationales frequently provided for performing surgical procedures to modify sex characteristics at an early age is that children will retain no active memories of pain when operations are performed during early childhood. However, this assumption has been criticised by arguing, among other things, that even though any trace of the operations may fade from memory, they may still result in psychological trauma, which may manifest in physical symptoms, for example.

Two of the respondents participating in the study had experiences of surgeries performed during early childhood.

Elina, 36, described the experience as follows:

"I've gone through very extensive 'reconstructive operations' at age one to six. From that time I remember the pain and some short flashes from the hospital: some rooms and that we were playing some game. Of course, you can't explain to someone of that age what you are doing and why. My medical records say that I was always terribly plucky. At times, of course, I had some bouts of homesickness. But reading those papers, you don't get the feeling that I would have found it somehow difficult to be there, although I stayed there for several weeks. However, I do think that what was done to me back when I was just a baby was totally irresponsible and unethical. I'd say that it was nothing short of rape. I've been scarred for all eternity by that. They never should have operated on anything at all until I was old enough myself to be capable of making my own informed decision on the matter."

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[110] Jones et al.(2016, 109–113); van Lisdonk (2014, 34–37); Amnesty International (2017); Council of Europe Commissioner for Human Rights (2015); Callens et al.(2012).

Besides Elina, other respondents participating in this study also verbalised their experiences of surgeries by comparing them to sexual violence and sexual abuse.

Kape, 47, also raised the fact that surgeries can certainly leave traces, even if you are unable to remember them:

"Before I finally found out about all this, I'd felt all my life that I had feelings that were not related to my life. It felt crazy and like there was something wrong with me. It felt like I was unfit, defective, like I should be someone else and always change somehow. Like I was in the wrong place, born on the wrong planet. Of course, I can't remember things from the very first years of my life. But I assume that these feelings were quite literally about how people related to me, what was done to me and what was said to me when I was very little. I think it's totally unbearable that surgeries are still being justified by the idea that when 'something is done at a young enough age, it will leave no traces'. I'd definitely say that I am a very clear example of the fact that the traces remained."

Awareness and understanding of the potentially traumatising nature of surgical and other interventions have become increasingly clear over the last few decades.

In various studies, intersex people have reported experiences such as shame, secrecy and defectiveness in relation to surgical and other interventions. Moreover, they have described anxiety, depression, panic disorders and various post-traumatic symptoms.[111] Research has also documented that the risk of suicide among intersex people is several times higher when compared with the broader population[112].

Six of the intersex individuals participating in this study reported having suffered from various mental health problems, such as depression, anxiety, self-destructive ideation and various post-traumatic symptoms. Five respondents perceived that these resulted from the surgical and other interventions performed on them, or from the shame and secrecy associated with being intersex. One of the respondents said that their mental health issues were not necessarily related to them being intersex.

By way of example, Terhi, 39, who had undergone several genital surgeries during the 1990s, localised the reason for their mental health problems in the surgeries performed on them, leaving them traumatised.

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[111] Jones et al. (2016, 109–113); van Lisdonk (2014, 34–37); Amnesty International (2017); Council of Europe Commissioner for Human Rights (2015); Callens et al. (2012); Thyen et al. (2018); Falhammar et al. dsd-LIFE research group (2018): Health status in 1040 adults with disorders of sex development (DSD): a European multicenter study.

[112] In an extensive Australian study (Jones et al. 2016, 88–127), for example, over half of the respondents reported that they had thought about suicide at some point in their lives, while as many as almost one in five (19%) had attempted suicide because of being intersex. The study compares this with the fact that, based on general population studies, about 3% of the broader Australian population considered or had attempted suicide. Nevertheless, the majority of the intersex respondents considered their mental health to be good at the time of the survey.

"Once these operations were finally over, I just pushed the issue out of my mind. I thought that 'now you'll just move on, there's no need to talk or think about any of it any more'. Well, it didn't go quite like that in the end. The operations were over, but nothing felt like anything. I wondered why life just felt all gloomy."

Four years after the surgeries, Terhi started to get panic attacks. They had anxiety and depression and were treated at a psychiatric ward and in an outpatient unit.

"The good thing there was that I was able to have discussions and to grieve over my childlessness and my patchy school attendance. They also assessed my health status from a different perspective. In this context, they contacted [name of hospital], which then sent me an invitation for an examination. The examination was performed under general anaesthetic. When I woke up, I found out that I had undergone a vagina enlargement surgery – without anyone having told me anything about this."

After this, Terhi's state started to decline seriously. They were cutting themself and showing other self-destructive tendencies.

"After some time, I was invited to another examination. I immediately started cutting myself. It felt like I had to get everything to do with doctors and hospital out of my system. In the examination, I was given a glass dildo and instructions on how to perform dilation to keep my vagina open and in the right shape. They said that when you do it enough, you can 'have sex normally'. So, after that, I went ahead and started having sex. It felt bad and brought all the memories of surgeries and hospitals back to the surface. It became another way to harm yourself."

After some time, Terhi decided to "leave their body alone".

"I was contemplating whether I wanted to self-destruct or to live. I decided that I wanted to live. It meant that I dissociated[113]*my body away. I had already shown symptoms of dissociation as a child, but these operations have badly traumatised me and I developed a post-traumatic dissociative disorder as a result. I have only been treated for this in adulthood, from 2011 onwards. It has helped me understand why I can feel good one minute and then really bad the next."*

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[113] At a word level, 'dissociation' refers to isolation, dissolution, or separation of the constituent parts of a whole. In psychology, 'dissociation' refers to situations where the normal association between an individual's consciousness, memories, identity and perceptions is disturbed. For instance, if a child is repeatedly faced with events that they cannot bear, they may develop signs of post-traumatic dissociation. Dissociation gives the individual a chance of trying to survive unbearable situations which they cannot physically escape. Through dissociation, they may 'exit' the scene by breaking the connection with their emotions or physical experience, moving away to observe the situation as if outside of their own body. Traumatic experiences during childhood and adolescence, for example, may lead to dissociative disorders of varying degrees. (Traumaterapiakeskus [*Centre for Trauma Therapy and Trauma Education*]; Matti Huttunen 2018: Dissosiaatiohäiriö [*Dissociative disorder*].)

Sara, born in the 1990s, underwent a gonadectomy during the current decade when they were a young adult. Sara reported that they had decided on the surgery themself, but that they now felt that the procedure was unnecessary. They suffered from fatigue and lack of motivation for a long time after the surgery and had to drop out of university as a result. Sara explains that it has not been examined whether these symptoms were caused by the surgery they had undergone. Sara says that, had they been better informed of its potential effects, they would not have gone through with it.

"In my opinion, the gonadectomy was only performed because it's part of the 'old' way of treating AIS. In fact, it's highly unlikely that the gonads will develop anything malignant. And why should something be cut off in the first place just because it might possibly cause a disease at some point in the future? After all, you don't cut women's breasts off just because they might possibly develop breast cancer."

Nevertheless, Sara says that they are mainly satisfied with the treatment that they have received.

Vaginal dilation therapy

In various studies, intersex people have also reported a variety of experiences relating to vaginal dilation therapy. Negative impacts have been especially reported in situations where it has been prescribed to children and adolescents who have not as yet become sexually active.[114]

Three of the study respondents shared their experiences relating to vaginal dilation therapy. Their experiences varied depending on whether they had been able to decide on the therapy for themselves. Another significant factor was whether the respondents found it necessary and meaningful for themselves. All of these respondents had been prescribed vaginal dilation therapy during puberty. In other words, the possibility of asking for their own opinion existed, but this had rarely been done.

Two of the respondents reported hating the therapy prescribed to them.

One of them was Pauliina, 32. When they were young, they had found out that they did not have a uterus and that their vagina was small. This is how Pauliina describes their experience:

"Dilation was started back during my puberty, when examinations showed that the size of my vagina was small. It was repulsive and painful. The whole thing was to me somehow embarrassing and shameful. So it's been one of those topics and experiences that I've just wanted to forget. I can't remember that I would ever have wanted to discuss it with anyone. I don't remember exactly, but I think that if I was asked anything about it at all, it was no more than whether I've kept doing it. At any rate, no-one asked me if I wanted to be doing it."

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[114] Jones et al. (2016, 109–113).

Elina, 36, had positive experiences of vaginal dilation therapy, which they started during puberty. Elina had made the decision to start the therapy themself and felt that it was suitable and effective for them.

However, Elina explains that they were not advised of vaginal dilation therapy until they had “managed to delay” a planned vaginal surgery for years. This theme will be discussed in more detail in Section 5.5 about informed consent.

Hormone therapy

The hormones secreted by the gonads play an important role in terms of the wellbeing of bones, among other things. Should an individual’s gonads be removed, they will need to start hormone therapy. Lifelong dependency on hormone therapy is, indeed, one of the key harmful effects of treatments reported by intersex people in various studies.[115]

However, hormone therapy is not always linked to removed gonads; in some cases, hormone therapy may also be necessary for other reasons. Hormone therapy is nevertheless always necessary following a gonadectomy. For a variety of reasons, such as a poor relationship with healthcare services, some intersex people do not necessarily take the hormones prescribed to them, or the therapy involves other problems. As a result, diseases associated with bone health, such as osteoporosis, may become an issue.

Other challenges involved in hormone therapy, as reported by intersex people, include difficulties of getting the hormones in balance, causing obesity, depression, mood swings, aggressiveness and issues relating to sexuality.[116]

Individuals themselves may also want to seek hormone therapy to accentuate the feminine or masculine features of their own body. The wrong type of hormone therapy, in turn, may make people feel uncomfortable in their own body and heighten gender-related body dysphoria. Examples of such cases include situations where an individual would personally like to receive testosterone therapy but is prescribed oestrogen based on the gender chosen for them at birth.

The positive experiences reported by intersex people include, in turn, the right kind of hormone therapy that promotes their health[117].

Six of the intersex individuals participating in the study had experiences of hormone therapy. For some of the respondents, hormone therapy was vital due to how their body was congenitally. Others had been started on hormone therapy following a gonadectomy.

Four respondents brought up difficulties of varying degrees involved in the therapy. Their negative experiences involved finding a suitable therapy and dosage and starting the

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[115] Jones et al. (2016).

[116] Jones et al. (2016); Nordenström et al. (2018).

[117] Jones et al. (2016); Nordenström et al. (2018).

wrong type of hormone therapy. Other negative experiences included the fact that the respondents had not been provided with any rationale for the need for hormone therapy or that they had not been given any say in starting it.

By way of example, Mikko, 33, who had sought a gender reassignment process as an adult, shared their experiences relating to the wrong type of hormone therapy.

"I have received therapy, but I've also received the wrong kind of therapy. Due to my wrongly assumed gender, I was put on the wrong kind of hormones. I was monitored as a child because people were wondering whether I'd remain short-statured, or whether my periods would start too soon, or whether I might show signs of salt loss. If I had been asked about my gender as a child, they would have concluded that I would not grow tall enough. So I would have received growth hormones. But I wasn't too short for the gender chosen for me by doctors, so I didn't receive any growth hormones and now I'm fairly short. Subsequently, I was just given more and more oestrogen, which caused me to develop a pulmonary embolism."

Mikko's sex characteristics had been monitored and examined ever since their early childhood, but they had never specifically received any intersex-related medical diagnosis. Neither were Mikko's parents informed of any diagnosis. Mikko says that their parents had later told them that, after any examinations, they had just always been informed that "everything is okay".

Nevertheless, when reading their patient records as an adult, Mikko found out that the doctor they had seen at the age of 17 had suspected that Mikko had congenital adrenal hyperplasia, i.e. CAH. At the time, the doctor had also prescribed them hormone therapy to normalise their blood values. Mikko gained 30 kilos in weight within a year.

Mikko describes the situation as follows:

"Of course, the hormone imbalance was a situation that required medical intervention. Once I was put on medication, everything did look normal on paper. I just didn't feel good in any way. Gaining so much weight in such a short time affected every single aspect of my life. As a result, I also developed an eating disorder. At times, it's difficult to distinguish which of the things that happened in my life are down to intersex-related issues and which are due to some other experiences. But the eating disorder, at the least, was a totally direct consequence of the fact that I was given the wrong treatment and gained so much weight. And none of my health issues was being sorted out. So I just calmly and coolly stopped going to any of my doctors' appointments, because they distressed me so much."

In recent years, Mikko has received help from peer support, therapy and their close family and friends. Following their decision to start the gender reassignment process, they are now on the right hormone therapy.

The respondents participating in the study also raised positive experiences of hormone therapies. These experiences were linked to the fact that the medication had been essential to their bone wellbeing as well as to their overall health. Positive experiences were also reported by the respondents who had specifically sought hormone therapy for themselves, because it had helped them make their bodies more 'masculine' or 'feminine'.

The respondents had very different experiences of the impacts of intersex-related healthcare interventions. All of the respondents had both positive and negative experiences of the impacts of treatments. However, their experiences clearly tended either towards the more positive or the more negative end of the spectrum.

The negative impacts described by respondents were related to situations where they felt that the treatments had not been based on promoting their health. The positive impacts of interventions reported by respondents, in turn, were primarily related to situations where medical interventions had clearly been vital for their health. Respondents perceived the impacts of interventions aiming to modify their sex characteristics in a positive light where the treatment had been performed at their own request and with their informed consent.

The respondents' very different experiences point to two key aspects in terms of experience: on the one hand, the fact that the intervention performed promoted the individual's health played a significant role; on the other, the chance to participate in making decisions about the treatment was also essential. The next section deals with the respondents' experiences of receiving information and making decisions about interventions.

5.5 Access to information and making decisions about medical interventions

PARENTS' EXPERIENCES

According to ETENE's report, physicians treating intersex children discuss various options of non-urgent care with parents, but the extent to which parents are involved in making treatment decisions varies by university hospital. At some university hospitals, healthcare professionals also make the decisions on interventions such as non-urgent surgery, whereas others leave the ultimate decision about non-urgent surgical interventions to the parents. If surgical treatment in early childhood is not absolutely necessary, all of the healthcare professionals who responded to ETENE's survey agree unanimously that the child's own opinion decides when and what types of interventions are to be performed.[118] However, it is not unequivocal what the healthcare professionals who responded to ETENE's survey are referring to by 'absolutely necessary' situations. ETENE's report suggests that the practices in place at different university hospitals vary in terms of decisions such as whether to perform cosmetic genital surgery on children.[119]

Half of the parents responding to the study reported that they had always made the decisions about their own child's treatments. The remaining half had varying experiences of their chances to participate in making decisions about their children's care.

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[118] ETENE (2016b, 8).

[119] ETENE (2016b, 8).

Four of the parents[120] reported situations where they felt as if they had merely been informed of the interventions included as part of their children's care without providing any specific rationale for these. One respondent reported that they had been pressured. Three of these four parents had such experiences in relation to non-urgent genital surgery to be performed on their children. These respondents' experiences were from the 1990s and from the current decade.

Johanna, whose child was born in the current decade and is now at daycare age, described their experiences as follows:

"We were just informed of the interventions. They neither said that 'this is being considered', nor asked like, 'what do you think about this'. I don't feel like I would have had any chance to question this doctor's pronouncement."

Johanna compared the 'declaratory nature' of the genital surgery performed on their child with another medical intervention received by their child around the same time period. This intervention was not related to the child being intersex and it was significantly less extensive than the genital surgery.

"The doctor walked me through the risks and benefits [of the other intervention] really patiently. They told me that the risk/benefit ratio was such that there was no question as to whether the intervention was worth performing. Conversely, with the hypospadias surgery, I was offered no clarification whatsoever. Nor did I know to ask when I didn't even understand what the surgery was like. And I didn't realise that I should be afraid of the hypospadias surgery, even though I really should have. Had I realised it, I would have fought tooth and nail if necessary to have that discussion."

After the hypospadias surgery, Johanna took their child to follow-up appointments, during which the child was put under anaesthesia to undergo brief procedures in order to keep the newly constructed urethra open.

"Then came the appointment that was supposed to be the last. Throughout this whole follow-up period, the surgeon had told us that the recovery was progressing really well. The previous visits to the hospital had been really quick, but at the last time, it started to take longer for them again. Then the child emerged from there, and was tied to the bed again, like after the hypospadias surgery. I was like, what the hell. They told us, 'The thing is that it doesn't look like the urethra is really healing, so what we did now was we opened up the original urethra and what you'll need to do now at home every day for a year is to thrust a catheter in and out of the constructed urethra, so that it will remain open. In one year's time, there will be another surgery to close up the original urethral opening.'"

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[120] Three of these parents also reported situations where they felt that they had been involved in making decisions about their children's care. They typically described these situations by recounting that they had started to question the information provided to them by the doctors at some point and had subsequently found different information from other sources.

Johanna explained that they tried to follow the instructions for about a couple of weeks. They say that they don't believe that this – unlike the surgery itself – was necessarily painful for the child, but it was very uncomfortable at the very least.

"My child hated it. All the nappy changes were getting difficult, because the child was clearly afraid. And then what also happened was that the catheter was going in a shorter and shorter distance every time, meaning that the constructed urethra was beginning to close up."

Johanna explained that they had called the doctor, who said that they could stop catheterising. The doctor told them that a new surgery would be performed in a year's time. The child had been in a lot of pain after the first surgery, which had also made the situation very difficult for Johanna. They said that this was the point where they first began to question the medical interventions.

"That was the point at which I began to think for the first time that 'this can't be how this should go'. I started looking for information and found out that this was not at all necessary. That I wouldn't be doing any further damage to my child if I were to refuse these surgeries now. That all these operations could also be done later, if my child should want it at some point."

Kaarina, whose child's intersex body became visible at the onset of puberty, also felt that they did not really have any role whatsoever in making decisions about their child's care. Kaarina's child went through several surgeries aiming to modify sex characteristics during the 1990s.

Kaarina recounted the situation as follows:

"Once we received the examination results, we were first referred to an endocrinologist. Next, they started planning reconstructive surgeries. We were not told anything more about them. We were simply informed that 'these are going to be done now'. The only thing there was that they kept asking my child, 'do you feel like you're a girl'. What's a child supposed to answer to something like that?"

Kaarina said that they were not provided with any information about the surgeries. They have found out afterwards that the surgeries were not vital for their child's health.

"There was no role for me in the decision-making, since I didn't understand anything about the matter. No information was available and no-one said anything at all. Now I think that none of those kinds of unnecessary surgeries should have been done to someone so young. The child should have been allowed to make their own decisions on these things as an adult."

Some parents reported that they had a chance to participate in making decisions about their children's care. In many cases, however, they pointed out that they did not feel like they had received enough information about different therapeutic options or the advantages and disadvantages involved. Some of the parents had also been given rationales for surgical and other interventions that they had found questionable.

Maria, whose child was born in 2014, recounted that they had discussed genital surgery with a doctor when their child was just a few days old. The rationale given by the doctor for the surgery was not related to promoting the child's health.

"The first time that cosmetic surgery was suggested to us was right at the beginning, when they were first performing ultrasounds on the child's lower abdomen. So, the child was just a couple of days old. The doctor told us that it would be quite possible to perform this procedure and that our child can be made into 'quite a normal representative of her sex'. The doctor also said that 'it's advisable to perform this surgery because the sauna culture is so important in Finland'. They went on to say that this would also make it possible to prevent the child from being bullied at school."

Maria explained that the doctor had raised the possibility of surgery repeatedly during their conversations. The last time that this occurred was when their child was a couple of months old and was having the gonads removed. The gonads had to be removed because they were of such quality that it would not have been possible to monitor them merely by means of imaging. Maria described the conversation that they had with the doctor in this context as follows:

"I was waiting on the ward while the procedure was being performed. Finally, the doctor came back from the procedure and told me that my child was still in recovery and was receiving pain relief, but would certainly be coming back to the ward soon. Even at that stage, the doctor still brought up cosmetic surgery and said that it would be a good idea to perform the surgery before the age of one, so that the child would not be left with any pain memories."

By that time, however, Maria had absolutely decided that their child would not be having the surgery. They also said it out loud to the doctor again.

"The funniest thing in the situation was the expression of the intern who was with the surgeon. The intern looked very confused. I don't know whether it was because the doctor was 'pressing on' so hard, or because I confronted the doctor. And I'm not saying that it wasn't difficult. I myself also grew up in the belief that a doctor was more or less a demigod. But I had already read up on the subject and I knew that the surgery might result in loss of sensation and pains, or that the scar tissue might react later on. I was also wondering that, although my child is assigned as a girl now, what if they turn out to be a boy, after all. In that case, it would be very difficult, if not impossible, to start reversing this irreversible surgery."

Other parents also reported situations where they felt that the rationales given for treatments were not precisely based on promoting their children's health. One of the respondents described a situation where the rationale given for starting a child under primary school age on growth hormone therapy was that "society is used to men being taller than women"[121].

Johanna, whose daycare-aged child underwent genital surgery in the current decade, had this comment on the subject:

"You can't prevent someone from being bullied with surgeries. There's no surgery that would allow me to prevent my child from ever being bullied. There are a lot of other things that I can do to try and make sure that it will never happen, but surgeries are not the solution."

Indeed, several of the younger children's parents, in particular, had felt that healthcare staff's knowledge and attitudes were not up to date. Parents reported situations where they should have known to demand that their children receive up-to-date treatment and go to the doctor's appointment "armed with sheaves of print-outs", for example, because they had felt that the treatment offered by doctors was outdated and that the attitudes towards them and their children had been stereotypical.

By way of example, Heini, whose child was born with XXY chromosomes during the current decade, explains that they have been surprised by how little healthcare staff know about Klinefelter syndrome (47,XXY). Heini described their views as follows:

"I'd encourage healthcare staff to update their competence to the 21st century. One big reason why we don't tell people about our child's diagnosis is that the information available on the web is old, even scary. It's from a time when the desired result of research was to show that people with atypical sex chromosomes were mentally ill or morally deviant. In people's minds, the syndrome is automatically associated with sexuality, which in turn may cause unwarranted shame in XXY men. For fear of misunderstandings, it's easier not to tell anyone when attitudes are still negative, even in healthcare."

Kristiina, mother of two intersex children born in the last and the current decade, in turn, said that they had been forced to turn down doctors' prejudiced suggestions on their children's follow-up appointments.

"Last time we had a good doctor. After my second AIS child was born, the previous one offered me advice in case we were still planning a third pregnancy. The doctor said that there were ways to ensure that we wouldn't have a third intersex child."

Kristiina explained that, once the doctor was replaced, the examinations performed to monitor their children's sex characteristics had developed in a more appropriate direction.

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[121] In certain cases, growth hormone therapy may also be necessary for the child's actual health, but this particular case was a situation where the desire to start the therapy was purely based on cosmetic/social reasons.

The parents were most satisfied with the care given to their children and the decision-making about treatments in cases where the examinations, medications and interventions were clearly vital for their child's health.

Kristiina, for example, described their positive experiences of the treatments provided to their two intersex children as follows:

"At regular intervals, the children receive a referral to ultrasound to check the size of their gonads. The way I see it is that my children have received the treatment that they require if there actually is a real risk that the gonads may become enlarged. Regular checks are quite okay. And I assume that it's advisable to check the hormone levels before puberty."

Another essential aspect of a positive experience was that the parents had been clearly informed of issues relating to their children's health and that they had been allowed to participate in making decisions about treatments.

A couple who had learned about their child being intersex in the last decade when the child was a teenager described their experience as follows:

"Our hometown healthcare staff did not have enough information on the subject. But we received good information at the university hospital genetics outpatient clinic. They explained the medical background in depth and provided the information both verbally and in writing. We have made the decision on treatment for ourselves. However, we would have liked to have more thorough information on the potential effects of the therapeutic options (such as surgeries)."

There was considerable variation in the respondents' experiences relating to making decisions about their children's treatments. Some of the parents felt that they had not been given any options and had simply been informed of the interventions. One of the parents felt that they had been pressured. Parents also had similar experiences of non-vital surgery to modify sex characteristics, including from the current decade. Furthermore, parents had also been given rationales for medical interventions that were not precisely related to promoting the child's health.

The parents who reported that they had been allowed to participate in making decisions about their children's treatments also indicated that they had felt that the information concerning different therapeutic options and the advantages and disadvantages involved had been inadequate.

When discussing parental participation in medical decision-making, it is also necessary to pay attention to what parents are told about the different aspects of being intersex. All of the parents participating in this study who had received some information on variations of sex characteristics from healthcare services reported that this information had mostly been medicalised.

The way in which having a variation of sex characteristics is presented to parents and the kind of information with which they are provided on therapeutic options have a bearing on the types of decisions that they will make on treatments.

A psychological study published in 2013[122], for example, explored the reasons that had an impact on parents' decision to postpone genital surgery on their child. The study was conducted such that 89 medical students assumed the role of a parent of an intersex child[123]. Thirty-eight 'parents' ended up choosing genital surgery during early childhood. Of these, 27 (66%) had watched a video with highly medicalised information on their 'child's' DSD, while 11 (23%) had watched a video containing demedicalised information on their 'child's' status. This study does not allow very far-reaching conclusions to be drawn. However, it does help to understand that the information provided to parents about their child's status may play a significant role in shaping their decisions about their child's treatments.

INTERSEX PEOPLE'S EXPERIENCES

Intersex individuals also had varying experiences of their chances to participate in making decisions about their own treatments.

Some of the respondents felt that they had not been given any chance to participate in making such decisions. These were typically those who had undergone surgeries to modify sex characteristics during their early childhood or adolescence, or whose sex characteristics, such as the size of their breasts and genitalia, had been otherwise examined repeatedly against their will when they were children. One of the respondents had even undergone a vagina enlargement surgery without being informed of the procedure in advance, as was mentioned in the section concerning the impacts of interventions.

These respondents reported feeling that they had been treated as if they and their emotions did not make any difference. They recounted memories where doctors and/or parents were examining their body or speaking about it as if they were not present. They also described the confusion and fear that overtook them when they did not know what was happening and why. They further reported the sense of helplessness that they experienced when their body was touched and examined even though they did not want that.

Like several other respondents, Eeli, born in the 1980s, described their experiences on intersex-related healthcare interventions as "scary and repulsive".

"It was really horrible when the doctor examined my private parts with bare fingers and measured my breasts with a ruler. This happened on several occasions. I was also taken to a psychologist and I had no idea why. As for making decisions about treatments, I was never asked anything at all. Medical staff never told me anything about anything. [Name of hospital] became very familiar over the years. I didn't participate in making decisions about my treatments. I was never asked anything."

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[122] Streuli, J. C., Vayena, E., Cavicchia-Balmer, Y. & Huber, J. (2013): Shaping Parents: Impact of Contrasting Professional Counseling on Parents' Decision Making for Children with Disorders of Sex Development.

[123] In this context, a child diagnosed with a DSD.

Mikko, 33, said that they were never told what the examinations were about; nor was their opinion on the treatments asked at any point. They described their experiences as follows:

"Everything was one constant blur of vague examinations and being subjected to examinations, without me ever understanding anything. 'They'll check something out, be brave.' I was brave on command and got a strong sense that 'you're not even allowed to feel bad about this'. My mother took care of the health-related matters that the condition involved. These hold bad memories for me. Forced examinations of breasts and genitals. It was never explained to me what it was about and I always found the situations really distressing. It was just done on doctor's orders. It was okay to touch my body because the doctor said so, even though I myself was like, 'no-no-no-no'. It felt really bad. My parents and doctors made all the decisions about my treatments; I was never asked about them. And I was given no information. They just assumed that of course I was happy because I was relatively healthy and represented the gender chosen for me quite well enough, which I actually wasn't really in the end."

Several respondents explained that they had dealt with these difficult situations by withdrawing into their imagination or by dissociating themselves from the situation. A number of respondents also localised in these moments a sense of shame and being aware that they were somehow "defective". Respondents had these types of memories from pre-primary age all the way to adulthood. Some of those who had experienced this kind of treatment during childhood reported that, even in their adulthood, they still panicked at a doctor's appointment, feeling like "a small helpless child" all over again.

Kape, 47, recounts that they learned at a very young age that "it's best to feel nothing" at a doctor's appointment.

"Doctors' appointments didn't feel like anything at all. I learned at a very young age that it's best to feel nothing. From when I was under school age, what I mostly remember from doctors' appointments was that no-one was interested in whether I was there or not. People were interested in what was between my legs, but it was all the same to them whether I was there or not. From later childhood, I remember those bewildering doctors' appointments where all that remains is a glazed look. You just wait for it to be over and feel bewildered about what the hell is going on in here. But when you are so little, you can't question or do anything at all. So it's better just to disappear into your own imagination and wait for the situation to be over."

The decisions on these respondents' treatments were made by their parents and doctors. The respondents who reported that they had not discussed the issue with their parents until adulthood frequently pointed out that their parents had not been given enough information or options.

Elina, 36, sums up the issue as follows:

"The worst of it all was how the surgeons and doctors instructed my parents. My medical charts and interviews with my parents reveal that my parents were never given the option not to have these operations. My mother once said exhaustively that, with the current knowledge, she could have chosen differently. But back then, she was given no options."

Since the onset of puberty, the respondents reported remembering some discussions with doctors where they had been told what interventions would be performed next, typically after various examinations (blood tests, ultrasound, etc.). At these points, the respondents had also been involved in making decisions, or they had, at the very least, been told what these were about. These respondents also described their involvement as very nominal because they felt that they had not been given any options. Similar to what some of the parents reported, intersex individuals also described that it was as if they were simply informed of the interventions.

When recounting these discussions conducted during their puberty, some respondents also brought up some rationales given to them for interventions, which they had started questioning in adulthood.

Three respondents had either been told directly or felt that they had been given to understand that they should be operated or that their vagina should be stretched because “a girl must have a vagina in order for her to have sex”. Such experiences were reported both by respondents who had already been subjected to intersex-related healthcare interventions during early childhood and by those who had been subjected to interventions in puberty. One of the respondents had been “soothed” by saying, “not to worry, you are still a completely normal girl”.

Terhi, 39, for example, recounts that once the examinations had been conducted, they were informed that the next step would be to perform surgery to remove their gonads and to perform an enterostomy, so that the intestine could later be used to construct a vagina. Terhi was 14 years old at the time.

Terhi says that, before the first surgeries, they and their parents were further informed of what would be done to them and what it would mean. They went on to add, however, that they were not really prepared for the operations in any way.

Terhi had been very sore after the first surgery, and the doctors had wondered how they could be so sensitive to pain. At the point when they started vomiting black liquid, however, the doctors began to believe that something was wrong. The catheter inserted into the stoma had been placed backwards. Terhi described the situation as follows:

“The doctor came into the room, but didn’t even look in my direction at all, and put on a pair of gloves and then placed the catheter so it was right way round. I did not even receive an apology for this at any point. My bellyaches ended after this operation. I was able to go back to school. Still, the doctor said to me later, ‘It’s not the undescended testicles that caused your stomach-aches, as the pain was down to you stressing yourself out. The gonads were removed because a girl cannot have testicular tissue.’”

After some time, Terhi underwent another two surgeries: the first was to construct a vagina and the second to close up the stoma. They recovered well from these. Some time later, when they went to a doctor’s appointment for an examination, they received another surgery to enlarge their vagina without their knowledge. This led to a radical deterioration of their wellbeing.

Terhi commented on the operations performed on them as follows:

“In my opinion, these operations that were performed on me have quite clear elements of abuse. Something like that should not be present in any medical operations.”

As an adult, Terhi arranged to meet with the doctor who had operated on them.

“I asked why it was necessary to give me a vagina. The doctor said, ‘So that a penis will fit in.’ I asked why the surgery had to be performed when I was only fourteen. The doctor said, ‘That’s just the age when the surgeries are performed.’ I asked, ‘Well, what if I’m not even straight.’ To this they replied, ‘Well, that’s your own choice then.’”

At the onset of the 21st century, Terhi filed a complaint about their treatment with the Finnish Patient Insurance Centre. They recount that the response that they received was that there was no malpractice because the procedure was in keeping with clinical practice guidelines. The physicians consulted by the Patient Insurance Centre had also expressed the opinion that there was no need to review the clinical practice guidelines.

Pauliina, 32, likewise reported that they had been prescribed interventions aiming to modify sex characteristics during puberty, without asking their opinion on these.

“I was told that ‘what you need now is this dilation’. It wasn’t up for discussion, like, whether it was needed or not, but a proper doctor’s order.”

They also explained that they found the assumption underlying the treatment to be problematic.

“The assumption that was associated with that was that ‘your vagina needs to be made larger because you’ll probably want to be able to have penetrative sex in the future’. It was not expressed out loud, but it was the underlying assumption. And it’s problematic to be sure.”

Pauliina described hating the vaginal dilation therapy. In their opinion, this type of treatment and its necessity should have been discussed with the person to whom it was offered.

“They ought to explain why this is being suggested and ask what you think about this and whether you feel that this is relevant to you. After all, that’s how you gain the rationale and motivation to perform the treatment, if that’s the kind of treatment that you want. Now I’m thinking that if they’d discussed the matter with me and asked for my opinion, then all that stigma that this whole business involved, then it probably wouldn’t exist.”

The youngest study respondent, Karoliina, who is in their late teens, reports that they have not had any surgeries or medications. Nevertheless, they wish that someone had explained to them why they needed to keep going for examinations. They have also been told about the necessity of removing their gonads without giving the odds for the gonads to develop something malignant.

Karoliina described their experiences as follows:

“When I was younger, I didn’t know why I was always in hospital once every year. The uncertainty was annoying, since I didn’t know why. What’s good is that they’ve had a good attitude towards me, while the bad thing is that they haven’t explained the terms to me; instead, I’ve googled them afterwards myself. Seeing a doctor has been a bit scary sometimes, but I’ve had no surgeries or medications. The doctors have just said that my testicles may develop cancer and that it’s a good idea to remove them. However, I’ve not been given any figures or probabilities for that.”

The few respondents reporting that they had made the decisions about their treatments for themselves explained that they had been treated well and appropriately. However, they also brought up a lack of information. While the respondents’ experiences varied in degree, the lack of information pertained most typically to therapeutic options and effects.

By way of example, Sara, who underwent a gonadectomy in 2010 as a young adult, explains that, should they have been better informed of its potential effects, they would have given it a pass. On the whole, however, their experiences are positive.

Sara described their experiences as follows:

“On the whole, my experiences of healthcare are positive. I’ve received enough information and support. The doctors have always acted appropriately and, even though not everyone has always been all that familiar with my condition, I’ve always been able to explain it to them and they’ve behaved appropriately. With the exception of the gonadectomy, which I think with hindsight was unnecessary, I feel that I’ve received enough information about AIS. But that may also be related to the fact that there simply isn’t all that much medical knowledge and practice that doctors could trust. I’d say that about 40% of the information I’ve received has come from the doctors and the rest I’ve sought myself online from different support groups. However, I’m glad that plenty of advances have taken place over the last ten years, both in terms of the information available on AIS and with regard to what doctors know about variations of sex characteristics overall. What I would have hoped for was that there would have been support groups and access to peer support.”

To some respondents, however, a lack of information also meant that they had not received the kind of treatment that they wanted and required because no-one had been able to provide advice.

Maarit, born in the 1960s, described their experiences as follows:

“I went for tests when I was 16 due to absence of periods. I was not diagnosed as such, but they did find that I lacked ovaries and had developmental anomalies in all of my internal genitals. I was the only one informed of the matter and I was allowed to decide for myself what to tell my parents or others. My hospital stay remained a secret. Back in the day, I didn’t really receive any information, not even enough guidance on how a vagina could be created without surgery. People have definitely been sympathetic, but they haven’t been able to help me move forward with the matter.”

A number of respondents who described being excluded from making decisions about their treatments reported that they had eventually been able to decide on their own body at some point – usually only on reaching adulthood. The respondents often described this development as highly significant for themselves.

For Elina, 36, this process started in puberty, when they were about to undergo a vaginal surgery. Elina reported that they were given no alternatives to surgery:

“The message I received went like, ‘You are missing a vagina and that’s why it’s necessary to give you a vagina now. Full stop.’”

Elina said that, just before the surgery was about to be decided, their “alarm bells went off”.

“I just somehow got this subconscious feeling like, ‘why, what’s the need to perform this sort of surgery’. And so I somehow managed to postpone the surgery. The surgery was due to be performed when I was in lower secondary school. Every time I went to see a doctor, I always said ‘let’s wait one more year’. And then ‘let’s wait yet another year’. And then ‘let’s do it during the summer before upper secondary school’. But when that summer came, my feeling just kept getting stronger. And, eventually, I just didn’t show up for the doctor’s appointment at all.”

After Elina had already started their studies, the hospital contacted them yet again.

“They kept insisting that ‘now, you really need to come in’. So I went in for that last time. And I said, ‘I’m not going to have this sort of surgery.’”

Once they had announced this decision, Elina was finally advised on how to perform vaginal dilation therapy. They say that they have been happy with this treatment. Nevertheless, Elina’s experience aptly illustrates the atmosphere brought up by virtually all of the respondents, characterised by no alternatives and occasional pressure and compulsion, which enveloped their experiences within the healthcare services.

Kape, 47, had an experience of participating in making decisions about their own treatment as an adult when they planned to go off the hormones that they had been taking since childhood. This happened after they had found out at a doctor’s appointment that they were intersex when they were in their 30s.

At first, Kape’s physician reduced the dose of their hormone medication completely unprompted. Kape described the matter as follows:

“I don’t know whether the doctor said so voluntarily or whether I milked it out of them, but they did admit that I had been prescribed terribly huge amounts of oestrogen. The reason behind this must have been precisely because they wanted to make my breasts grow and make me look like a woman. In other words, they wanted to make it look like the surgeries made sense. It is really totally absurd, when you think about it: prescribing hormones to make your breasts grow and creating a high risk of breast cancer in the process.”

Kape recounted asking the physician about the age at which they would be able to stop hormone therapy. They said that they had been very clear about wanting to quit.

“The doctor was of the opinion that stopping the medication didn’t carry any particularly high risk. Some women also go through menopause at 40 and it doesn’t necessarily mean an awfully high risk of osteoporosis. So me and the doctor planned to reduce the medication gradually. The first six months were pure hell. I was having absolutely horrible withdrawal and menopause symptoms. I slept so little that I thought I would die. But it eased off gradually.”

Kape explained that they were still not quite certain whether or not stopping the therapy was a good decision for their health. They have not measured their bone density or monitored the situation in any other way for a long time. However, making the decision has been very significant for them.

“What was important was that it was my decision. It was the first decision relating to this theme that I was able to make for myself. And after that, it has also started to feel like I can actually make some decisions on other things in my life too.”

They said that stopping hormone therapy felt like a step towards what they used to be like.

“In some strange way, stopping hormone meds felt like those surgeries were finally over. They were over the moment that I quit hormones. Making the decision on this matter was the thing here. That it was me who said how it was going to be.”

There was very considerable variation in the experiences reported by the intersex individuals participating in the study of their chances to participate in making decisions about their own treatments. Some felt that they were completely excluded from making decisions about their treatments. These were often the respondents whose treatments had started in early childhood or no later than at the onset of puberty. Others reported being allowed to participate to some extent, but mainly in nominal terms, such that they had at the very least been told during puberty what the interventions were about. However, their opinions on these treatments had more seldom been probed.

Similar to the parents who responded to the study, intersex respondents also reported situations where the rationales given to them for interventions were not precisely related to promoting their health. According to the respondents, the rationales and the unquestioned assumptions underlying the interventions were rather more focused on the notion that their body should be modified because it was somehow defective and did not meet the idea of what the body of someone of the gender that they ‘represented’ should be like.

A few of the respondents said that they had made the decisions about their treatments for themselves. These respondents also reported wishing that they had received more comprehensive information about different therapeutic options and effects.

5.6 Psychological support

According to ETENE’s report, all university hospitals provide intersex children’s parents with the opportunity to discuss with a psychologist or a psychiatrist as well as with the doctors participating in their children's care. Other types of support are also available, such as an opportunity to talk to a social worker or a hospital theologian.[124]

ETENE's report indicates that children's needs for psychological or psychiatric support are monitored at different ages. Healthcare professionals tell the children about their situation in accordance with their age and maturity, while young people are offered an opportunity to go through their situation in further detail. However, it is noted that there are insufficient numbers of specialists in different fields who are familiar with the different aspects of being intersex, while all parties agree that there would be demand for peer support and support organised by NGOs.[125]

Some of the parents participating in the study reported having been offered an opportunity to talk to a psychologist. These were all parents whose children's intersex body had become visible at birth or during infancy.

The parents who had accepted the offered support had not found it relevant. The psychologist that they had seen had not known about the diversity of human sexes or understood the issues that they would have liked to discuss in relation to their child having a variation of sex characteristics. The parents whose children's intersex body only became visible during puberty reported that they had not been offered any psychological support.

Most of the intersex respondents had been offered an opportunity to talk to a psychologist or a psychiatrist. None of those who had accepted the support, however, had found it very useful. The reason for them as well was precisely the fact that the professional that they had seen had not really known anything about being intersex. The respondents felt that, as a result, the professional was also not able to support them in dealing with the issue. Some respondents referred to this offered support by saying that they "were taken to a psychologist" without them really knowing why.

The youngest study participant, Karoliina, in their late teens, summed up the issue as follows:

"The psychologist is nice but doesn't know much about the subject. The first appointment was rather odd because I didn't know why I was there."

Most of the intersex respondents who had been offered an opportunity to talk to a psychologist or a psychiatrist had not, however, seized it. The reasons cited by the respondents included the fact that, on the one hand, they had not seen any reason for it and, on the other, seeing a therapist had felt somehow embarrassing during puberty.

Sofia, 25, said that they had wished afterwards that they had accepted the support offered to them. Sofia described the issue as follows:

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[124] ETENE (2016b, 8).

[125] ETENE (2016b, 8).

“When it was offered to me, it got me all baffled, like what would I even talk about there with the therapist. But I’m definitely thinking now that I wish that I’d had that chat. Perhaps then I would have known how to always be open about this issue and it would have not at any point become the embarrassing thing that it now has been. And I might have got some kind of support or message like, ‘you are totally okay’.”

Some respondents reported that their rejection of psychological support had been affected by the fact that all the intersex-related treatments and doctors’ appointments felt so shameful. The idea that they would also have to talk about these to someone had seemed incomprehensible.

Pauliina, 32, verbalised the issue as follows:

“I’ve been given the opportunity to ask about all subjects and I’ve also had the chance to discuss with the doctor privately without my parents. But I found the whole dilation therapy somehow so embarrassing and shameful that I can’t remember that I would have wanted to discuss anything at all about it with anyone. I’ve just wanted to put it behind me.”

A number of respondents who had refused psychological support or found it pointless reported that they had subsequently received significant help through peer support. This will be discussed in Section 6.4.

The older respondents who had not been sufficiently informed of being intersex were also in a challenging position in terms of psychological support. They had either been kept completely in the dark about being intersex or they had not been told enough about it.

Mariaana, 59, describes the issue as follows:

“I didn’t receive any support in time because I didn’t know I was intersex. I only found out at 57, when my whole life was almost over. My parents certainly knew but didn’t tell me. I hope that children nowadays are told in due time: many things would probably be easier to sort out and deal with in time.”

Maarit, born in the 1960s, also reports that they have not received any support, although they have tried to seek it for themself.

“I would have needed and I would still need support for the mental aspect. I would have needed support for dealing with my identity crisis, problems with falling in love and self-destructive thoughts. I haven’t even found any support in the private sector; all I’ve met are unsympathetic gynaecologists, psychologists and therapists. I haven’t received any support that would have really helped because I still haven’t found a place where you could get the right kind of support.”

Most of the respondents – both the parents and the intersex individuals – found the psychological support that they had been offered pointless or irrelevant. In many cases, the problem boiled down to the fact that the professional that they had seen had not known about the different aspects of being intersex and/or how to support them in dealing with the issue. Intersex respondents also raised the point that, as all the other intersex-related healthcare treatments were so shameful and secret, the idea of also having to talk about the treatments to someone felt incomprehensible.

Almost all of the respondents participating in the study – both the parents and the intersex individuals themselves – wished that they had received more psychological and psychosocial support. In particular, the respondents hoped to have the opportunity to discuss with their peers.

5.7 Health status and current attitudes towards healthcare services

The majority of intersex people who have participated in various studies generally rate their current health status as good or relatively good.[126]

The health problems reported by intersex people in studies have been attributed to reasons such as the consequences of intersex-related medical interventions or medications, possible health considerations that may be related to their specific variation of sex characteristics, or the stigma associated with being intersex.[127]

Some of the intersex study participants rated their current health status as good or relatively good, others put it slightly below average, whereas some considered it to vary.

Half of the respondents reported positive changes that had taken place over the last few years. They explained, for example, that they had been unable to manage their health before but had now “shaped up”. Some of these respondents said that they thought that their previous indifference to their own health was related to their experiences of intersex-related medical interventions.

Some respondents especially described positive changes in their psychological wellbeing by recounting previous challenges and how their general wellbeing had developed positively in recent years. In many cases, this development was prompted by the peer support or therapy that they had received. International research has also documented the positive impact of peer support and other psychosocial support on intersex people’s wellbeing[128].

About one third of the respondents reported other health-related challenges, such as various chronic diseases, which required regular contacts with healthcare. They did not usually associate these health challenges with being intersex.

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[126] Falhammar et al. (2018); Jones et al. (2016, 99–127); van Lisdonk (2014, 44–45).

[127] For example, some variations of sex characteristics may involve a heightened risk for heart, joint or kidney problems. Jones et al. (2016, 99–127); van Lisdonk (2014, 44–45). See also Nordenström et al. (2018).

[128] van Lisdonk (2014, 44–45).

Attitudes towards healthcare services

All of the respondents disclosed their current attitudes towards healthcare services.

The respondents shared their experiences of contacts with primary and occupational healthcare and appointments with specialists, such as gynaecologists, etc. Some of the experiences were related to them being intersex in some way. These situations included refilling a hormone prescription or seeing a doctor to find out about a health issue relating to their variation of sex characteristics.

Some respondents described their attitudes towards healthcare services in general terms, such as how easy or difficult they found going to a doctor's appointment.

The respondents had quite varying experiences of healthcare contacts. Almost all of them, however, brought up the fact that, in many cases, the healthcare professionals that they had seen did not know about the natural variations of sex characteristics. As a result, they often ended up 'educating' the professionals about the diversity of human sexes. Some found this difficult while others did not. This was affected by both their own prior experiences and the attitudes shown towards them by the healthcare professionals that they were currently seeing.

The respondents who found it difficult to educate healthcare professionals about intersex issues also described their general attitudes towards healthcare services as difficult. By way of example, they mentioned difficulties going to a doctor's appointment.

These respondents typically had negative childhood experiences of intersex-related medical interventions. The aspect that they generally found most difficult was seeing a gynaecologist, which they described in terms such as "dreadful" and "distressing". Another common characteristic of their experiences was that they typically tried to delay and avoid seeing a doctor as long as possible.

By way of example, Pauliina, 32, described their experiences as follows:

"I definitely don't feel like seeing a doctor unless I really have to. I guess it's probably related to the fact that no-one ever knows the first thing about this situation of mine. When I've received an invitation to a smear test, for example, I've always called them to try and find out whether the test can even be performed on me and whether it's needed. No-one has ever known and so I've usually just cancelled those appointments. Last time I went in and I was nervous as hell and afraid, like, whether it was going to hurt. So, I had about a minute there to try and explain to the nurse why I was nervous and why I doubted that it would even be possible to take this sample from me. It was an awful situation, as I got the feeling that the nurse didn't even properly understand what I was saying."

Some respondents reported that they would see a doctor if they had an obvious complaint but that they avoided and delayed going in with symptoms if they were not quite clear about the reasons for these. Some of these respondents also mentioned that they had very little trust in doctors. Some of the respondents with negative attitudes had chronic diseases requiring them to be able to see a doctor on a regular basis. One of the respondents stated that, as a general rule, they tried to be their own doctor because they had "zero" trust in healthcare services.

Pauliina, 32, was among the respondents reporting that they had recently “shaped up” in terms of looking after their health. Pauliina said that they had made an appointment with a gynaecologist some time ago to have a specific issue relating to the variation of sex characteristic they have. However, the doctor they had seen had behaved in a very regrettable manner.

Pauliina described the situation as follows:

“I mentioned the idea of an atypical body to the doctor. They commented that ‘it’s not all that strange’. Once they had finished the examination, they said, ‘You can definitely see a uterus here, yes, it’s that over there, measuring a centimetre or half.’ As if saying, ‘look, you are definitely a woman after all’. What’s more, they reiterated that they were a specialist in gynaecology. It felt like this was their way of repeatedly signalling that ‘therefore, you are a woman too, not some sort of intersex’. Perhaps they had a bit of an old-school idea that intersex is something that’s not a woman or a man. When I was leaving, they shouted out in the end, ‘Hope you weren’t too upset.’”

Pauliina explained that they had been confused after the situation was over and had started to question their own experience.

“I did think afterwards myself like, ‘am I somehow totally wrong here’. It made me feel like you somehow start to question yourself, too, when someone like that professional with 25 years of experience suggests that there’s no such thing as intersex to begin with.”

About half of the respondents described their current attitudes towards healthcare as easy or normal, or otherwise reported mainly positive experiences. Some of those reporting positive experiences also mentioned that they had been forced to ‘educate’ doctors about variations of sex characteristics but had not found this difficult. As a general rule, they had also seen doctors who did not question their experience, at least not very visibly.

By way of example, Karoliina, in her their teens, who had known about being intersex from a very young age, explained the matter as follows:

“I’ve been asked what intersex means. But I’ve not found it at all difficult to explain, nor the situation in any other respect.”

The responses reporting positive healthcare experiences also highlighted the fact that the respondents had been dealt with in an appropriate, friendly and sensitive manner.

Mariaana, 59, for example, describe their current attitudes towards healthcare services in very positive terms:

“The doctors and nurses are wonderful: it feels like they understand that not everyone can be cut from the same mould.”

The intersex study participants rated their current health status as good, relatively good, slightly below average, or varying. Half of the respondents reported positive changes over the last few years to the effect that they were currently able to take better care of their health.

Some respondents reported that they avoided or delayed seeking healthcare services. The reason given by a number of them was that they did not feel able to trust healthcare professionals. Almost all of the respondents had experiences of having to ‘educate’ healthcare professionals about the natural variations of sex characteristics when currently using healthcare services.

5.8. Views on how to develop healthcare services

The intersex individuals and parents of intersex children participating in this study introduced several ways to develop intersex children’s care and the information and support provided for the children and their parents.

The first point raised by a number of respondents was that any non-vital surgeries on intersex children’s sex characteristics should unequivocally be stopped. None of such operations should be performed until children themselves are capable of participating in making decisions on the matter.

Respondents also stressed how important it is that, when an intersex baby is born, the parents are provided with comprehensive information regarding variations of sex characteristics, but also time and space to get used to a new situation. Having an intersex child can be a confusing situation and it is very concerning if the parents are forced to make urgent decisions about their child’s treatment while being overwhelmed by such confusion.

This is what Kape had to say about the subject:

“Let’s calm down. There’s nothing to worry about. And because there’s nothing to worry about, you don’t have to act like there’s some kind of emergency. If there’s a treatment or operation vital for the child’s health, then all that should be done. But anything that is not vital for health can wait.”

When speaking about surgeries and children’s sex assignment through these, respondents also raised the issue of hormone therapy and the fact that it should also be personalised and take the child’s situation into account. Instead of making an assumption about gender when arranging for hormone therapy, the child should be asked about this and involved in the discussion.

Mikko summed up the issue as follows:

“Hormone therapy should always be done on the patient’s own terms, discussing the options and taking special care to listen to the patient. Doctors must not be allowed to decide the gender, nor pressure the parents to decide their child’s gender on the child’s behalf.”

Another theme raised by the respondents was information concerning treatments. Respondents stressed the fact that any potential advantages and disadvantages of different therapeutic options should be comprehensively explained to intersex children’s parents, and also to the children themselves once they are old enough. They also emphasised in general terms that communication between healthcare professionals and parents and intersex children should be more open and respectful.

Kristiina, mother of two intersex children, had this to say about the subject:

“Healthcare needs more communication and more questions should be asked from the parents and the child personally, if the child is of a suitable age.”

Respondents emphasised the fact that both the parents and the child are entitled to receive information about the child’s health and all the different therapeutic options and their potential effects, and that they should be told about these honestly.

Some of the respondents also raised the point that obtaining comprehensive information requires more than just the information provided by doctors. They emphasised that, because the information received by parents has a crucial impact on the types of treatment decisions that they will make, it is vital to guarantee their access to a wide variety of comprehensive information. The means of doing so suggested by respondents included arranging for peer support and other psychosocial support.

Elina, for example, stressed the fact that new parents should also receive information from other sources besides just medical professionals.

“The parents must receive comprehensive information about the effects of interventions and different options. They must also get practical tools for how to talk about the subject with their child. I don’t believe that a surgeon whose ‘fingers are itching’ to perform such a rare surgery can give this sort of information. In my opinion, an absolute requirement for consenting to surgery should therefore be for parents to participate in a support group’s activities. They ought to be able to meet intersex people. Hearing personal stories would certainly be the best source of information. At the point when the child is capable of grasping the matter, they should be told about it openly. At the onset of puberty, at the latest, they must be provided with all information about the background and all different options.”

Respondents also stressed that no medical interventions– especially surgeries – that are non-vital can simply be presented as ‘absolutely necessary’, but that they must always be discussed with the parents.

Johanna summed up the issue as follows:

“Doctors can’t just present these kinds of surgeries that are not vital for the child’s health as fact, like, ‘this is just how it’s going to be’.”

With regard to provision of care, respondents also brought up paying attention to the child and respecting the child’s own views. They stressed that it is the responsibility of the adults to create the space where the child can process and verbalise and go through experiences relating to being intersex. They emphasised that the child should never be put in a situation where they have to hear that their genitalia are somehow wrong or should be somehow different.

Mikko underlined that the child must be told about treatments and the child’s opinions must be heard.

“You ought to explain the reason and purpose of medical interventions. And you should listen to the child’s opinion on matters where it’s possible to do so. If you need to touch the child’s breasts or genitals, you must always have permission to do so and it should never be done ‘because you just have to’. Even a child is allowed to say no, and even a child is entitled to receive information about their own health. You should listen to the child’s experience, also when it’s about their gender identity.”

Respondents also stressed that care should be provided by multidisciplinary teams that should include medical expertise as well as understanding of traumatisation, psychological wellbeing, and ethical and human rights issues involved in care.

Terhi commented on the multidisciplinary approach and regulation of intersex children’s care as follows:

“Care teams must also have understanding of the fact that being different is not a disability but part of human diversity. In addition, it must be understood that intersex children’s situation cannot rely on decisions made by individual doctors. The system should guarantee people the right to bodily integrity.”

A third theme raised by respondents was the peer support and other psychosocial support offered to intersex children’s parents and intersex individuals. They stressed that discussion and support groups are needed for both children and parents and that they should be referred to these groups directly from healthcare services. Respondents believed that providing such support would promote the wellbeing of intersex individuals and their families while also contributing to lessening the stigma and shame associated with having a variation of sex characteristics.

Karoliina verbalised the issue as follows:

“More opportunities to meet intersex people should be provided even for children to prevent them from developing a sense of being somehow the wrong sort.”

A fourth theme raised by respondents was disseminating information concerning the bodily variations of sex characteristics and the diversity of human sexes in society in general and within healthcare services in particular.

Several respondents thought that the best sources for intersex individuals and intersex children’s parents to obtain information about the diversity of human sexes would be outside the healthcare sector. This was often related to their experiences of healthcare professionals approaching the diversity of human sexes as a “matter of belief” or in an otherwise belittling manner. This is why respondents considered it so crucial to guarantee access to peer support and information available through this channel.

This is what Johanna had to say about the subject:

“Information about the diversity of human sexes should be disseminated. Everyone ought to understand that it’s a biological fact that there is also something else besides just women and men. I’d hope that this fact would be treated as a simple fact and not as some kind of matter of belief.”

However, a number of respondents also highlighted the importance of educating all healthcare professionals about the diversity of human sexes and the natural variations of sex characteristics so as to ensure that they are able to provide intersex people and their parents with comprehensive information and relate to them in a respectful manner. After all, in many cases, the healthcare sector is the first point of contact for intersex individuals and their parents and it is important that initial information they receive is appropriate.

Maria hoped that information on the different aspects of being intersex would already be available immediately at the hospital.

"People should be told much more about the different aspects of being intersex right at the hospital. And people should realise that the fact that the child has a variation of sex characteristics will not vanish anywhere from the child's body after their sex has been determined."

Respondents also considered it especially important that healthcare professionals use the appropriate language. They further raised the need to increase healthcare professionals' awareness of the harmful effects that examinations, surgeries and other intersex-related medical interventions may cause for a child.

Respondents also noted that it would be necessary to increase information concerning variations of sex characteristics and the diversity of human sexes in society at large. This theme will be discussed in more detail in Sections 6.5 and 6.6.

6. Experiences of the impacts of being intersex on life

6.1 Gender identity

Especially in the past, people used to refer to intersex people as a kind of 'third gender' or confuse them with a 'third gender identity' placed somewhere between the female and male categories.

However, intersex people are not a single coherent group. Consequently, there are numerous variations in sex characteristics, which highlights the fact that sex is more of a continuum than a clear-cut dichotomy.

Nor does being born in an intersex body define an individual's gender identity, i.e. their experience of their own gender. As with all people, intersex people develop a gender identity individually. According to studies most, but not all, intersex people will eventually identify themselves as either woman or man[129].[130]

When conducting this study, only the intersex interview respondents were asked about gender identity. Some of the online survey respondents also raised the subject, although the survey did not include a specific question about gender identity.

The respondents defined their gender identity in different ways. The answers given by respondents included "woman", "genderfluid", "masculine", "intersex", "non-binary", "transgender", "a woman in a man's body", etc. Some interviewees answered by saying, "I'm not a man, I'm not a woman."

The intersex children of the parents responding to the study had been registered as both girls (5) and boys (2).

A few intersex respondents reported that gender identity had always been "a clear thing" to them and that they had not reflected on it any further. In many cases, they also added that it had only made sense for them to contemplate how to deal with the interventions done to them or other issues relating to their own body.

One of the respondents reported being indifferent towards discussions about gender identity and gender roles. They explained their experience as follows:

"These things are not at all important in my inner world of experience. What happened to me physically is significant to me. Then again, I guess that these are somehow related

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[129] Jones et al. (2016, 73–77; 210).

[130] Neither does being intersex define an individual's sexual orientation; in other words, an intersex individual may be straight, gay, lesbian, bisexual, asexual, or something else in terms of sexual orientation.

to each other in some respects. The doctors who were involved in making the decisions probably had quite a strict idea that there can only be men and women in this world. And that's why they had to perform these surgeries. But what I'm thinking is that if my hand was cut off when I was a child, well, how would that be related to my gender. It would just be violence, and wrong."

Some respondents commented on the question about gender/gender identity by starting their answer with, "If it has to be defined somewhere, what I'll say is…". In many cases, they also went on to add that they did not even find the question very relevant.

This is what one of the respondents had to say:

"If I have to define my gender for someone, then I use the word 'intersex'. It's a bit peculiar word, but there's no better one to describe it. However, I don't speak about the subject very openly. Mostly I just criticise this thing. Why do people ask about your gender everywhere in the first place? In many situations, I think it's totally unnecessary."

Almost all of the respondents raised the issue that, in their opinion, questions about gender were asked "much too often, everywhere you go, and often with no reason whatsoever". Many also reported that, because of being intersex, they were more aware than average about gender-related norms and assumptions. Some of these respondents said, however, that they were mainly bored with "the gender debate" and that they had mainly passed over the question of gender in their personal lives as "uninteresting".

One respondent had this to say about defining gender:

"Someone asked me once, 'What kind of woman or what kind of intersex person are you then really?' I can't really define what, say, a woman is like. It's not any one single thing. Each and every one of us is an individual and can define themselves just as they want."

Some of the parents whose children were born in the last and the current decade also reported being "more aware than average" about gender-related norms and assumptions. They estimated that they dealt with their intersex children "in perhaps a slightly more gender-sensitive way than usual".

Parents recounted, for example, trying to take care not to unnecessarily genderise their children. On the other hand, they often noted that they did not exactly think about the issue "terribly much". They said that they mostly called their children a girl or a boy according to the child's current legal gender. At the same time, these respondents often stressed that they would try to do their best to be there for their child "whatever gender identity the child may develop as they grow older". They also said that the child's future gender identity would in no way negatively affect their attitudes towards their child.

Some intersex respondents reported having reflected more on their gender identity. A few explained, for example, that their own gender identity was made up of different parts. These respondents could say something like, "I am a woman and I am intersex."

A number of respondents also raised the point that, once they had finally found out about being intersex, it had become a significant way for them to verbalise their own experience. One of the respondents describes the subject as follows:

“The fact that I know I’m intersex makes it easier for me to define myself. I’ve always identified myself as a woman or a girl. But once I discovered the word ‘intersex’ and it started to take shape, it’s like now I feel that I am intersex and I am also a woman.”

Many respondents described how being intersex had become built in as part of their gender identity little by little. As explained above in the section dealing with the implementation of interviews, a number of respondents reported that they had pondered for a long time whether they were “even really” intersex or whether they were “sufficiently” intersex.

By way of example, one respondent recounted that, once they had found out about being intersex, they had been very sceptical about whether they were “really intersex” for a number of years.

“I felt like I wasn’t ‘intersex enough’. I don’t have any surgical scars all over my body and no-one has turned up to assault me with a forced hormone shot. Actually, I’ve only just started to realise over the last year and a half that, for goodness’ sake, I’m ‘quite intersex enough’ and that there have been quite a lot of things that haven’t gone as they should have. Nowadays, being intersex is a clear building block of my gender identity.”

A number of respondents highlighted the difference between how they perceived themselves in their heart of hearts, on the one hand, and how they assumed other people saw them, on the other.

“I am intersex. In my own way, I lead a double life because externally I’m a woman to quite a few people. I don’t feel like a man, but I also don’t fully feel like a woman either. I was just raised for that woman’s role and, in my own opinion, I can play that role well. It’s perhaps like this lifelong masquerade. In my heart of hearts, all I think is that I am me.”

This experience was often related to contemplating how open to be about being intersex and with whom to share this information. This theme will be discussed in more detail in Section 6.2.

When speaking about gender identity, one of the respondents also mentioned the impact of the medical interventions that they had undergone, on the one hand, and the lack of role models, on the other.

“I guess the most accurate definition of my sex/gender would actually be that I’m an intersex person who was cut and ‘fixed’ against their will. I have no idea what it would have been like to grow up without having been ‘fixed’ to be something else against my will. Or with a role model. A grown-up intersex person whose existence I would have been aware of.”

An intersex individual may also want to seek gender reassignment treatment and/or legal gender recognition i.e. change the gender marker on their identity documents.

Two of the study respondents reported that they were currently going through gender reassignment treatments, i.e. the transition process, with a view to also having their legal gender recognised as other than the one assigned at birth.

On the whole, there was very considerable variation in the experiences of gender identity among the intersex individuals participating in the study. Some of the respondents reported having reflected on the subject a lot and from different perspectives. Others had always been “clear” about their identity and had not felt any need to reflect on it. Some found the entire question uninteresting. Almost all of the respondents raised the point that they would like to see a society where they would only be asked about gender in the first place when it “actually has some relevance”.

While speaking about being intersex, however, the majority of the respondents emphasised that being intersex was not at all a problem for them but, rather, a reason for joy and pride. These respondents reported thinking that being intersex was one of the many things that made them special and unique.

One of the respondents summed up the subject as follows:

“There’s something truly unique in my body and it’s a part of me and I can be proud of it. Of course, being intersex involves those sad and unfortunate experiences beyond my control, but now they have already as if faded into the background. And of course I think about how far ‘out of the closet’ I want to be. But I’m very much square with myself.”

6.2 Openness about being intersex

A question that is frequently present in the lives of intersex individuals and intersex children’s parents is whether to be open about being intersex to other people.

Openness is often considered as part of dealing with being intersex and any potentially difficult experiences that may be associated with it and of developing a positive self-image. Openness also increases the chances of receiving peer support and psychosocial support. However, there is variation in what, where and with whom people share about being intersex.[131]

Intersex people are often very aware of the stigma associated with being intersex. Moreover, topics such as bodily norms, intimate parts of the body or childlessness are often considered taboos, which are difficult to talk about. Fear of other people’s reactions may therefore be a reason for not telling them about being intersex. Not sharing, withdrawing and isolating from others may be a strategy to avoid potential experiences of abandonment. On the other hand, intersex people have recounted that openness has, at the end of the day, been a positive experience even when it resulted in negative reactions.[132]

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131 MacKenzie, D., A. Huntington & J.A. Gilmour (2009). The experience of people with an intersex condition: a journey from silence to voice; van Lisdonk (2014); Jones et al. (2016).

132 MacKenzie, D., A. Huntington and J.A. Gilmour (2009); van Lisdonk (2014); Jones et al. (2016).

At the same time, however, not sharing may also be a means of protecting privacy and, as such, an effective approach. Not sharing, especially when it is somehow perceived to be secretive, may nevertheless lead to other issues, such as a sense of shame. It may also make it more difficult to build connections with other people.[133]

INTERSEX PEOPLE'S EXPERIENCES

A number of the intersex individuals participating in the study had been told in childhood that "this is not a topic that you want to talk about, you know".

Many respondents actually shared the feelings of shame and inferiority that the secrecy entailed. In many cases, secrecy had also delayed and complicated dealing with being intersex and with the experiences associated with it.

Elina, 36, recounted that one of the effects of secrecy was that the way things look to the outside world regardless of what they are really like was still really important for them.

"Even with the silliest things, everything in my life must always be in tip-top condition and just so. There is no such situation where I could just let it be like it is."

They say that they envy people who are capable of being more open about being intersex.

"It has definitely been such a big lie. For instance, just five years ago, I wouldn't have been capable of participating in this kind of interview. Even now, I notice that my voice drops when talking about this topic, even though I don't feel like this would be somehow particularly hard. I envy those totally ordinary people who want to make their own stories public to give strength to others. I don't think that I myself could bear it, at least not at the moment."

A few other respondents also mentioned that they would like to be more open about being intersex, both with their close circle of family and friends and in public, but they lacked the courage. Mikko, 33, had this to say about the subject:

"I'd like to be more open about being intersex and about my trans background. But the climate of hate speech prevalent in society, combined with my own history of trauma, is not compatible with openness."

Having shared being intersex with only a few people, Maarit, born in the 1960s, described the topic as follows:

"I think it's great that people are coming out of the closet. I personally haven't had much courage to share my own story. The secret isolates you from others."

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[133] MacKenzie, D., A. Huntington and J.A. Gilmour (2009); van Lisdonk (2014); Jones et al. (2016). On openness about being intersex, see also Lehtonen (2017).

However, all of the intersex study participants had told about being intersex to at least one person. There was nevertheless considerable variation in terms of how wide a circle of people they had told about it.

As a general rule, the respondents said that they had shared being intersex with their spouses, common-law partners, friends, peers, parents, siblings, close relatives, and some of their fellow workers or activists. Most noted that they had only told their nearest and dearest. Some, however, also said that they had shared the information on social media, such as with all of their Facebook friends.

All of the respondents described contemplating what to share with others about being intersex. They also explained that they had drawn some boundaries about how, with whom and at what level of detail to share the information.

A number of respondents reported that they had found it easier to share certain parts of their stories, such as the fact that they had “an atypical body and that I don’t have periods and can’t have children”. Conversely, sharing the fact that they had atypical chromosomes, for example, had been more difficult for some respondents. Moreover, using the word ‘intersex’ had also been difficult for some, even though they felt that the word described their own experience.

At the same time, however, it was precisely the discovery of the word ‘intersex’ that had been a transformative moment for most of the respondents who had long been only aware of their intersex-related medical diagnoses. It had helped them process their own experience. Many also felt that it was precisely by using the word ‘intersex’ that they were able to better explain to other people what their bodily experience was like.

There was a wide variety of situations where the respondents had shared being intersex with their close family and friends. A number of respondents reported taking up the topic with their friends, other close people or workmates when they had seen a story dealing with or touching on intersex issues on television or in a newspaper or magazine. By way of example, some respondents referred to the interviews of dancer Laura Allonen, who had recently publicly disclosed being intersex. A number of respondents also mentioned the public debate about testosterone limits set for female athletes[134], which had been challenged by runners Caster Semenya and Dutee Chand, receiving a lot of publicity.

One of the respondents also recounted a situation where one of their friends had run up to tell them, "foaming at the mouth", that their place of study had arranged a guest lecture on the diversity of human sexes and genders. The trans person who had given the lecture had also mentioned intersex children's situation. The respondent reported wondering whether their friend might possibly have known about their being intersex.

"I was wondering a bit whether my friend maybe had some idea of the matter. When I then went on to share it in that instant, it didn't at least seem to come as much of a surprise."

Several respondents also reported contemplating what the people around them "ought to know" about them being intersex, and at what level of detail. As a result of these contemplations, they had sometimes told people about being intersex from different perspectives.

One of the respondents described these contemplations as follows:

"With some people, I've used more of an emotional approach to sharing. Like what kinds of marks these medical interventions have left me with and what those previous events have meant for me. To others, I've told more from the perspective that I don't want to be categorised as male or female and on things relating to that. Like how it feels for me if people are saying something like, 'here's a bunch of us girls'. Or like if a group that I'm hanging out with is divided into men and women for some reason, then I'd like for someone to stay with me, because I don't want to join either group. This has been good, because it has also forced me to make it clear to myself in what situations this thing makes a difference."

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[134] The International Association of Athletics Federations (IAAF) was planning to introduce new regulations in November 2018, requiring women whose testosterone levels exceeded a certain limit to either take medication to lower their testosterone levels or compete in men's series. The regulations were intended to apply to certain running distances and, in practical terms, they are targeted at the Olympic winner Caster Semenya. However, their entry into force was postponed, as Semenya appealed to the Court of Arbitration for Sport (CAS). It has been estimated that the IAAF will lose the CAS case "6–0" for reasons such as the fact that, among over 200 genetic variations that confer an athletic advantage, the IAAF has zeroed in on a single hormone, i.e. testosterone. In the races where Semenya's hormone levels were analysed, her advantage was estimated to amount to 0.6–2.8%, while it has been argued that this edge could be due to a lot of factors. The IAAF's attempt at reforming its regulations has been characterised as a witch-hunt against Semenya. It has also been criticised as being mostly about a battle over what a female athlete is allowed to look like, rather than actually trying to promote equal opportunities for athletes to compete.

In many cases, drawing boundaries on what and whom to tell had, in one way or another, been related to the fear of how others would react to what the respondents were about to tell.

Respondents had both negative and positive experiences of other people's reactions. However, there were clearly more positive than negative experiences.

While recounting negative reactions, respondents often mentioned situations where the people whom they had told had not "got" what it was about. Those whom they had told had, for example, wondered why they were sharing it in the first place. While respondents said that they understood that it may be difficult to understand what being intersex means, they nevertheless described these experiences as unpleasant.

Some respondents mentioned that some of the people with whom they had shared the information had also dealt with it "over-cautiously". By way of example, these people would never "dare" to raise the topic again, or alternatively, would ask about it in a very roundabout and "overly sensitive" way.

One of the respondents reported that telling about being intersex in a conversation between a group of friends, for example, was sometimes a "risky contribution". They said that raising the topic could easily end up stifling the conversation. Even if this happened with people who appreciated them and even if the silence following the contribution was "quite respectful", they recounted that they would still start to wonder whether they may have been somehow "socially awkward". Consequently, they explain that they tend to scan social situations, deciding whether they can tell or not based on their reading.

Another respondent, in turn, mentioned that the most irritating reaction was how some people acted as if they had forgotten that they had told them about being intersex.

"I tell them, but then these same people just forget about it and behave as if I'd never even told them about this."

They interpreted this forgetfulness to mean that it might be almost impossible for some people to understand what it means to be intersex.

The majority of the respondents nevertheless reported that other people mostly responded positively to them and to sharing about being intersex. The people whom they had told about it had shown interest in the subject and had wanted to ask and talk about it. Several people had also taken it as a show of trust for the respondents to have decided to tell them about being intersex.

The positive impacts of sharing about being intersex identified by respondents included a sense of relief and liberation. Respondents also noted that sharing had helped them overcome their feelings of shame and embarrassment. A number of respondents said that sharing had made it possible for them to be seen as who they were. Completely in a league of its own as a positive and highly valuable experience was sharing the information with and the support given by their peers. This will be discussed in Section 6.4.

Websites, online forums and various online peer support groups, such as closed Facebook groups, had been among the most important channels for a number of respondents for obtaining a wide variety of information about intersex issues. Social media was also an important channel for many respondents for sharing about being intersex.

Respondents reported, for example, that they shared articles, video clips and statements concerning intersex issues on social media. Some did this while sharing that they were also intersex. Others, in turn, did not mention being intersex themselves while sharing such articles, but they did explain that they felt as if they were practising *"indirect communication"* about the topic. A number of respondents mentioned that this type of communication and information sharing was important for them. Many reported feeling that, by doing so, they were doing their own part to spread awareness about intersex issues.

A few respondents also recounted that they had initially shared the information about being intersex with their own networks specifically on social media. This is how they described the situations:

"I put that information straight away in a Facebook status update and shared it with all my friends. None of them has left after receiving that information. All I got was a ton of likes!"

"I contemplated the matter for several months and it was really totally liberating when I finally pressed that button. Like, alright, now I'm here as who I am. It was a really liberating feeling. And I was taken aback by how many people commented nicely and thanked me for sharing. It made me feel really good."

The respondents had very different experiences of telling other people about being intersex. All of the respondents had, however, shared the information with at least one person. Some had only shared being intersex with their nearest and dearest, whereas others had disclosed the matter very widely to their social networks. Being open about being intersex had mostly been a positive experience for the respondents. It had helped them get over the shame and secrecy they had previously associated being intersex with , increased their sense of freedom, and reinforced their experience of living as who they are.

PARENTS' EXPERIENCES

The parents of intersex children who participated in the study reported very similar contemplations on openness as intersex respondents.

Parents reported that they had made the decision about disclosing theirchild being intersex on a case-by-case basis. As a general rule, they had only shared the information with their closest family members and friends. Parents with younger children had also mentioned it at the daycare centre.

Parents' positive experiences of sharing were related to situations where the people whom they had told had in no way changed their behaviour towards them or their children. By way of example, Maria, mother of an intersex child, recounted that the staff at their child's daycare centre had accepted the information "without making a big deal out of it".

More negative experiences of sharing involved a lack of information. The people with whom they had shared the information had either voiced inappropriate questions and comments or “commiserated” about it. Parents reported understanding that people’s level of knowledge about the topic was low, but they nevertheless found the situations hard. They recounted that these were seldom the kinds of situations where they would actually feel like being able to start any conversation with the person in question. Some parents described how hard it was to always have to be prepared to educate people about the subject whenever they were sharing it.

Kristiina, mother of two intersex children born in the last and the current decade, recounted an experience relating to the children’s leisure activities. Kristiina had not told the instructors about their child being intersex.

“In the leisure activity, the children were divided to play a game of football with the girls against the boys. My daughter had said, ‘I feel like a boy today.’. The instructors told me afterwards that they eventually had to coax my child to play on the girls’ team. In my opinion, they should have formed mixed teams in that situation. I myself didn’t know how to express this to the instructors and I also haven’t told them about my child being intersex.”

It would by no means have required disclosing their child being intersex to ‘sort out’ this situation; all it would have taken was for the adult instructors to have some feel for the situation. Nevertheless, it is a good example of how unchallenged the unnecessary gendered divisions shaping children’s everyday lives can be and how important it can feel for adults that children adhere to these divisions. Such situations are often undesirable for children.

Some parents also reported balancing between respecting the child’s privacy, on the one hand, and avoiding an unnecessary sense of shame, on the other.

Reflecting on sharing their child being intersex, Johanna put it as follows:

“There’s nothing to be ashamed of in my child or in being intersex. So, I could share it for that matter. But in my opinion, sharing this information is something that my child needs to be allowed to decide independently.”

Intersex people’s organisations prefer the same approach. They urge parents to respect the child’s privacy and to talk with them from a young age about how they feel about telling others about being intersex. They also encourage parents to ask children what they think about it and talk with them about how other people may react to the subject.[135]

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[135] IGLYO, OII Europe & European Parents’ Association (2018).

The organisations also urge parents to be proud of their intersex children and, as far as possible, to be patient with other people's questions. The more people know about the subject, the more likely they are to become accepting and supportive about it.[136]

Talking about the subject with family members and relatives had been difficult in one way or another for some of the intersex respondents and parents of intersex children.

A number of respondents in fact noted that they had only shared a certain part of the story with their relatives, such as the fact that they or their child would not be able to have children. Some of the individuals whose extended families included other intersex people explained that the subject had been a taboo in their families. On the other hand, others specifically reported being capable of talking about it with their relatives who were also intersex and having received a lot of support from them.

Some of the respondents who had found it difficult to talk about the topic with their parents recounted that they had always been able to speak freely about everything with their siblings. Conversely, other respondents who had received significant support from their parents said that it had clearly taken longer for them to tell their siblings, for example. In fact, the only feature in common to the responses was that all of the respondents who had disclosed the information once again reported contemplating how open they wanted to be and what and how to share about the subject.

6.3 Relationships

RELATIONSHIPS BETWEEN CHILDREN AND PARENTS AND SUPPORT GIVEN TO CHILDREN

It has been suggested that the surgical and other medical interventions performed on intersex children in early childhood may have a negative impact on bonding between children and their parents. Parties critical of such interventions consider this to be one of the reasons why non-vital medical interventions should be avoided in early childhood in the first place.[137] In various studies, some intersex people have indeed reported that surgical and other interventions had caused a rift between them and their parents[138].

The intersex individuals who participated in the study reported very different experiences in their relationships with their parents.

Almost all of the respondents with experiences of childhood medical interventions reported trying to talk with their parents about the subject after reaching adulthood. This had also been done by those whose parents had not told them about them being intersex.

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136 IGLYO, OII Europe & European Parents' Association (2018).
137 Amnesty International (2017, 38–42).
138 Jones et al. (2016, 109–113).

In many cases, however, these respondents reported that they did not have proper lines of communication with their parents.

By way of example, Eeli, born in the 1980s, had this to say about the subject:

"It's no use talking about the subject with my parents, because the subject is taboo for my mum."

Another respondent reported talking with their parents about the subject, "but only about the facts". They went on to specify that talking about what things had felt like and how these things had affected them seemed like an impossible idea to them.

Nevertheless, these respondents typically pointed out that they understood the situation their parents were in. They said that their parents had not been given adequate information or options at the time. They explained that they understood that their parents had not had any chance to "decide otherwise".

Elina, 36, explained as follows:

"I can totally put myself in my parents' position and I don't blame them. They were not given any tools whatsoever to deal with this issue. It's been so strong, this norm, and it still is. Parents are given no options whatsoever as all that's being done is to try and 'fix' this thing in either direction. Even my mother has only now, over the last few years, started to understand what actually happened. This has been such a suppressed secret."

None of the intersex respondents specifically reported being angry with their parents. Some did mention that they were sad about or regretted how things had gone. They also recounted that they were sad about not having been able to talk properly with their parents about the subject even as adults. Nevertheless, virtually all of these respondents primarily stressed that they understood that their parents had been in a very difficult position.

Based on what was reported by intersex respondents, the subject is still – often several decades after the events – so painful for many parents of intersex children that they cannot bring themselves to talk about it with their children. There may of course be several reasons for this. One of the reasons may be the fact that the interventions performed on children and the shame and secrecy involved could also have been traumatising experiences for the parents.

Johanna, whose child underwent a non-vital genital surgery in the current decade, recounted that the procedure performed on their child was a very difficult subject for them.

Johanna described the issue as follows:

"The fact that I let the surgery happen is a really difficult thing for me. Although I do understand that I couldn't do anything about it."

Johanna said that they had tried to prepare themselves for the conversation that they would probably have with their child about the surgeries at some point. Johanna had not yet told their child about the matter because the child was still so young.

"I'm trying to prepare myself, so that when the time comes to have a conversation about this issue, I myself won't freeze and will be able to speak so that my child won't have to experience this pain of mine about this thing. It is my pain and my child won't have to go through it. But if the child wants to talk about having been mutilated at some point while growing older, then that's what we'll do. But I'm not going to put it like that. I'll let the child form a personal opinion on this thing."

Johanna reported having sought conversational help to process the issue. The psychological support offered to them from the hospital had not felt useful to them.

Nevertheless, being intersex and the intersex-related medical procedures had not invariably impacted negatively on the relationships between intersex respondents and their parents in all cases. Some of the intersex respondents reported that it was precisely their parents who had been a major support for them as they were dealing with being intersex and related issues. Such experiences were especially recounted by the respondents whose parents had been open with their children about them being intersex. Similar experiences were also reported by the respondents who had not had intersex-related surgeries or medications, or who had been personally involved in making decisions about treatments.

Sofia, 25, for example, described the subject as follows:

"I've talked with my mum and she's been a really big support for me. Every now and then, we've also argued [about a certain intersex-related issue]. We have such a good relationship that we are also able to quarrel."

The parents who participated in the study reported trying to support their children in different ways, such as by talking with them and offering them appropriate information about variations of sex characteristics. This had been done both by parents whose children were already adults and by those with younger children.

By way of example, Kristiina, mother of two intersex children, recounted that they had talked about the topic with their elder child. The topic came up when the child had read about the origins of biological sex at the age of eight and asked why they had got XX chromosomes.

"I explained truthfully that they have XY genes and what it meant in terms of having children, among other things. The child has simply experienced the matter as exciting. I nevertheless advised them that their classmates wouldn't necessarily understand and that whole subject of genes could go way over their heads instead. So, my child has only told a few people. My younger child doesn't quite understand the subject yet, although their big sister has enlightened them about it."

Parents also reported having supported their children by accompanying them at doctors' appointments and providing them with psychological support, for example.

Kaarina, mother of an intersex child, recounted as follows:

"I've been told that my child's friends have said that my child has a weird mum because she understands these things. I hear that many have parents who tell them not to talk about this."

The respondents had varying experiences of the impact of them or their child being intersex and of the intersex-related medical interventions on the relationships between them. Intersex respondents reported that their relationships with their parents had often been negatively impacted especially by the surgical and other interventions performed in childhood and the secrecy around these. Some of the intersex respondents, in turn, felt that their parents had been a significant support for them as they were dealing with being intersex. Parents had tried to support their children by offering them comprehensive information about the different aspects of being intersex and by talking with them about the subject, for example.

DATING, INTIMATE AND SEXUAL RELATIONSHIPS

Being intersex and the intersex-related medical interventions may also affect dating, intimate and sexual relationships.

It may be difficult to forge intimate – especially romantic – relationships for reasons such as the fact that it will probably become necessary to share about being intersex at some point during these relationships. Another theme that may be a challenge to share is the potential childlessness that may be associated with some specific variations of sex characteristics. . Moreover, research has suggested that what is understood as ‘normal’ or ‘desirable’ sexuality and what a ‘good partner’ is considered to be like may also have an impact on how confidently intersex people can embark on relationships.[139] Of course, there is no such thing as a single, generally accepted idea of ‘normal’ or ‘desirable’ partner or sexuality.

Repeated childhood experiences of examinations and assessments of sex characteristics may also lead to considerable difficulty in trusting other people and being vulnerable in front of them. There is also research available on the effects of intersex-related medical interventions on sexual function and pleasure; for example, the effects of surgeries on decreasing sexual function and pleasure have been documented. There is no unequivocal evidence in favour of surgical benefits.[140]

Some intersex study participants reported that being intersex and related medical interventions had negatively impacted on their relationships in one way or another. These respondents recounted challenges relating to aspects such as intimacy and having sex. They said, for example, that they found it difficult to let people get close to them, or that they had experienced difficulty being sexually open or sex had otherwise felt difficult or impossible.

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[139] van Lisdonk (2014, 49–51).

[140] By way of example, almost two thirds of the respondents to an Australian study (Jones et al. 2016, 172) said that them being intersex or intersex-related medical interventions had impacted on their sex lives in some way. Almost two thirds also reported being involved with one or more partners or dates.

Eeli, born in the 1980s, had this to say about the subject:

“My intimate relationships have been ruined because having sex feels like a chore.”

Maarit, born in the 1960s, in turn, explains that love has always meant self-destructive thoughts to them.

“That’s why I got married without love at 26. I wanted to be normal and married. I haven’t had enough courage. I’ve never been able to have physical intercourse in a situation where I’ve been in love.”

At the same time, however, some of the intersex respondents reported that being intersex had not impacted on their relationships, “at least not in any negative way”. They recounted that their dates and partners had always accepted them for who they were. They also explained that their dates and partners had given them invaluable healing experiences, allowing them to feel lovable and valuable. Some of the respondents reported that they wanted to share being intersex “right away” in a new intimate relationship. Others, in turn, said that they usually shared the information at a point when a relationship was becoming important for them.

A number of respondents also raised the point that they felt being more aware than average about norms and assumptions, not only relating to human sexes and genders, but also to sexuality and intimate relationships. Many also said that they believed that this was at least partially related to the fact that, due to being intersex, they had “inevitably had to think a bit more about the issue”, as noted by one of the respondents.

They verbalised these contemplations as follows:

“I’ve probably become more aware of all the aspects relating to human sexes and genders as well as sexuality and of the norms associated with them. I’ve thought about things like this stuff relating to the normative life cycle, such as intimate relationships and starting a family. If I weren’t intersex, I wonder if these things would have just happened without major soul-searching? Then again, I’ve never wanted them, I’ve never wanted to give birth to anyone. But I’ve definitely also become more aware of these norms because of being intersex.”

They reported having to “work a bit harder to find my place” because they could not automatically satisfy the norms associated with a human life cycle.

“You’ll just have to invent a life cycle of your own then. I’ve thought about things like what is a childless, self-sufficient woman or feminine character like? There are not that many characters like that in our culture. It’s really fun if you sometimes spot one somewhere, and even so that this person is somehow portrayed as a totally valid, real character. That makes me feel like this is something that I can relate to.”

Intersex study respondents had varying experiences of how being intersex had impacted on their dating, intimate and sexual relationships. Some had faced negative impacts and experienced challenges relating to sexuality, intimacy and falling in love. For others, however, dating and intimate relationships had provided healing experiences. A number of respondents reported that they were “more aware than average” about norms associated with human sexes and genders, but also sexuality and intimate relationships.

6.4 Peer support

The intersex individuals and parents of intersex children participating in this study typically reported that they had not particularly benefited from the psychological support offered within healthcare services.

At the same time, however, all of the respondents raised the point that it would be extremely important to have an opportunity to talk to peers when making treatment decisions. Psychological support received by parents should not only be seen as supporting their own wellbeing, but also as a prerequisite for them to be able to make decisions on treatments in accordance with the children’s best interests[141]. The positive impact of peer support and other psychosocial support on intersex people’s wellbeing, in turn, has been documented in several international studies[142].

Nevertheless, the experience shared by several parents and intersex individuals was that they had long been left completely alone with the issue. They reported that they had received the kind of support that they needed “only when it was too late”.

The parents who participated in the study reported having received support from their friends, online peer groups, foreign physicians, or NGOs (Trasek, Trans Support Center). Parents also recounted that NGOs had sometimes put them in contact with an intersex individual who had offered them information and support. A number of respondents also mentioned that they had received valuable information from Mika Venhola, Assistant Chief of Paediatric Surgery at Oulu University Hospital. Venhola has long voiced public criticism of cosmetic surgery on intersex children. One of the parents noted in this context, *“It’s simply not acceptable for this system to work this way that I decide that I want to have a chat with this surgeon, and it’s only then that I receive proper information about the subject.”*

Intersex respondents reported having received support from their friends, spouses and partners, parents, siblings, therapists and peers. The respondents who had received support from their parents were grateful for it, however, while also saying that they had longed for an opportunity to talk with other people as well, especially their peers.

Intersex individuals reported that they had mostly found peer support via the internet. A number of respondents said that they had received support from foreign peer websites and gatherings. Some of these respondents had subsequently found access to peer support in Finland as well. Some of those who had sought support from abroad explained that the shame and secrecy associated with the subject had run so deep that one of the reasons for

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[141] Amnesty International (2017, 30).

[142] van Lisdonk (2014, 44–45).

setting out to find support from abroad was because “there wouldn’t be any risk of meeting anyone you know”.

Some of the respondents reported that they would have liked to receive peer support but had been left without. Some, for example, had not known where to seek support. Others had participated in peer support for groups with a certain diagnosis, for example, but had not found the issues dealt with important to them, or had otherwise felt like outsiders. In many cases, this had increased their sense of being left completely alone with the issue.

None of the respondents reported ever being informed by healthcare services of a chance to access peer support. If anything, the message that they had received was how rare being intersex was.

Sofia, 25, described this as follows:

“No-one, for sure, ever talked to me about any peer support. I remember that my doctor told me that there was this Hollywood actor who had this same thing that I have. It was the only point of contact with, like, someone who might have this same thing. So, it definitely felt like you were quite alone with it.”

In many cases, the respondents who had received peer support mentioned it as the most important type of support for dealing with being intersex. Access to peer support had helped them process their experiences and strengthen their self-image while also releasing the shame and secrecy they had associated with being intersex. Peer support had also created an invaluable experience of no longer being left alone with the issue.

Such an experience was recounted by Elina, 36, for example:

“The most comforting thing was to discover that, although this is rare, it still follows a similar type of pattern with everyone.”

Terhi, 39, in turn, says that access to peer support played a decisive role in changing their chances of processing what had happened to them.

“Up until that point, nothing had really felt like anything. But then, all of a sudden, everything felt like everything. Before, I didn’t use to have the space or words for what I had gone through and what feelings it had stirred up in me. Through peer support, it was safe to start experiencing things for the first time. For the first time, life started to feel like something.”

Access to peer support had also empowered intersex people to stand up for their own rights. Activities originating in peer support have also resulted in the creation of the first Finnish-language website on intersex issues at intersukupuolisuus.fi.

Kaarina, whose intersex child has found access to peer support in adulthood, says that the support received by their child has also been a tremendous relief for them.

Kaarina describes as follows:

“I think it’s absolutely wonderful that my child has found peer support from other intersex people. It has been a terrific relief for my child, and for me too, to find out that

there are other similar people. No-one ever mentioned to us anywhere that there even could be anyone else in the same situation."

6.5 Views and experiences of daycare, school and studies

The respondents whose intersex body had become visible in childhood revealed the impact of being intersex or intersex-related medical interventions on their schooling or further studies.

Eeli, born in the 1980s, recounted that being intersex and the related interventions had negatively impacted on their schooling.

"I started to dissociate from a very young age. I made a complete hash of my comprehensive schooling because I didn't know who I was."

One of the respondents reported missing long periods of school due to surgeries and other intersex-related medical interventions. They had also needed to repeat a full year of schooling.

Elina, 36, in turn, noted that the surgeries performed on them in childhood had been deliberately scheduled for summer or other holidays, *"so as not to risk anyone finding out even by accident"*.

Sara, born in the 1990s, in turn, had to drop out of university because they suffered from fatigue and lack of motivation for a long time after undergoing a gonadectomy as a young adult.

These respondents' experiences were consistent with previous research, which suggests that bullying and medical interventions may often negatively impact on intersex people's schooling.

In the 2016 Australian study, for example, just over a third of the respondents rated their school experiences negatively for reasons such as bullying. Difficulties had led to a significantly higher proportion of intersex people (18%) than the general population (2%) leaving school early around the eighth–ninth grade. Dropping out of school had coincided with puberty, which is often the period associated with expectations of bodily changes and starting hormone therapy, for example.[143]

Respondents who had dropped out of school reported feeling that it would have helped them if education had normalised the diversity of human sexes and taught about biological sex development appropriately. The bullying reported by intersex people ranged from occasional rude questions through to regular psychological or physical violence.[144]

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[143] Jones et al. (2016, 129–142).

[144] Jones et al. (2016, 129–142).

Finnish research also suggests that the information about the diversity of human sexes, genders and sexualities provided for children at school may have a narrow scope. A distorted and imbalanced impression of the diversity of human sexes, genders and sexualities may also affect the position of LGBTI children and young people to such an extent that their safety at school cannot be guaranteed.[145]

Nevertheless, compulsory basic education plays an important role in promoting equality and increasing factual information on the diversity of human sexes and genders. The obligation to promote equality also applies to all forms of education and training provision. Dismantling, or at least alleviating, gendered norms should be a key aspiration of equality promotion efforts in basic education. An essential part of this is also increasing awareness about the diversity of human sexes and genders.[146]

A few intersex people responding to the study reported experiences of bullying. One of them was Mikko, 33, whose physical development was ahead of their classmates due to them beingintersex. Mikko recounted that they would have hoped for support for understanding the changes taking place in their body.

"At school, the impact of being intersex was that I felt like an outsider in ways that I didn't know how to verbalise in any way at the time. In terms of my physical development, I was clearly ahead of the others. I had to dissociate away from my body, because I didn't have any idea of how to explain those changes. Of course, that development of dissociation could also have been influenced by other stuff from childhood, but at least these experiences that I had of my body and of examining it didn't do anything to lessen the development of dissociation."

Intersex individuals will often need to carefully consider the situations in which they want to share being intersex in school settings as well.[147]

Kape, 47, recounted that hiding being intersex had also protected them from discrimination and bullying, although it was not a good solution in other respects.

"On the other hand, in all its negativity, suppressing this stuff had the positive side that it also protected me from discrimination. I would have faced different kinds of discrimination if my parents had been open and everyone had known about me being intersex. That's the truth. It's not that suppression was a good solution, but bad things can also have good effects. But I do think that openness would be a good idea."

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[145] See e.g. Jukka Lehtonen (2016): Sukupuolen ja seksuaalisuuden moninaisuus osana laaja-alaista seksuaalikasvatusta ja heteronormatiivisuuden purkamista [*Gender and sexual diversity as part of broad-based sex education and dismantling of heteronormativity*].

[146] Opetushallitus [*Finnish National Agency for Education*] (2015).

[147] See e.g. Lehtonen (2017).

At the same time, however, some of the respondents also reported that they had liked school and studying and that they had done well in these. Being intersex had also not necessarily caused any negative experiences at school.

Karoliina, in their late teens, for example, noted that being intersex has not had any negative impact on their schooling. Questions about menstruation have been omitted for them at health check-ups, but it has been the only effect from being intersex.

A number of the respondents reporting negative childhood experiences at school had also been able to subsequently move on to further studies and find pleasure in studying – and even "excel", as Eeli noted about their further studies.

Following the entry into force of the revised Equality Act in 2015, education providers are obliged to draw up a gender equality plan for each educational institution. Gender equality plans must be drawn up so as to take into account any discrimination based on gender identity, gender expression or sex characteristics, while special attention must be given to prevention and elimination of gender-based harassment, among other things. The Finnish National Agency for Education has also published a comprehensive guide to promoting gender equality in basic education[148].

The study respondents had several ideas on how to provide intersex individuals with better support for their daycare, school and study paths. For their part, these views also speak of the experiences of intersex people and their parents, because they have often been left without these experiences, which they thought would have been very important.

Johanna, for example, recounted contemplating disclosing their child being intersex at the daycare centre but had eventually decided not to say anything.

"When my child started in daycare, I was contemplating whether I should say something about this. But I haven't said anything. I wouldn't even know where to begin. On the one hand, it feels that I'd like to and, on the other, that I don't have the energy. It feels like you should always be ready to educate people about the subject and that you ought to have a comprehensive set of educational materials ready in your head. It feels like it's not possible to disclose the subject without going very deep into the details. And for all I know, they might actually have who knows how in-depth knowledge about it at the daycare centre. But because the level of ignorance about this subject is so chilling, it means that I can't possibly rely on that. Even though they are working there as professionals, it would still just be down to luck if someone there happened to know about intersex issues."

Kape had a practical tip for how to easily increase the visibility of the diversity of human sexes at daycare centres, while also signalling that all children are welcome for who they are:

"Daycare centres often have like these slips of paper on their walls, saying that there are people who come from different cultures. They could easily include some that would say

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[148] Opetushallitus [*Finnish National Agency for Education*] (2015).

that there are girls, boys and intersex people. And these could also cover other groups that are often left invisible. They could also include some sort of commitment to values. Something like, ‘at this daycare centre, we treat everyone equally and challenge the prevailing gender roles’.”

A number of respondents stressed that anyone working with children should receive information on variations of sex characteristics and the diversity of human sexes and genders.

They said that, rather than giving intersex people any special attention, they should just be seen as the ordinary people that they are – conversely, however, the misconception that biologically there are only girls and boys should be broken.

This is how Pauliina verbalised their view on this subject:

“Something ought to be actively done about this nonsense that people are still banging on about, that sex is just about the male/female dichotomy. Now that there’s information available, after all, that this doesn’t hold true at all. It would also help many other people besides just intersex people. Doing away with this binary dichotomy would benefit each and everyone. But of course it would also help us intersex people because all this business with interfering with people’s bodies and ‘fixing them up’ rests on this binary thinking and these ideals about the male and female body.”

Respondents encouraged professionals to relate to intersex children “as just as who they are” and give them space to grow. They further pointed out that intersex people are also different from each other and should not be lumped together in a single box.

With regard to schools, respondents raised the point that it would be important to increase information on and awareness of the natural variations of sex characteristics and of the diversity of human sexes. They called for special attention to be given to biology education, so as to broadly cover biological sex development, rather than simplifying it into ‘46,XX = girl and 46,XY = boy’. In reality, there are also plenty of other chromosomal variations alone.

Respondents highlighted the fact that it is possible to choose whether education reinforces the conception of intersex as ‘anomalies’ and ‘disorders’ or presents them as part of natural variations in sex characteristics. In addition to broadly describing sex development, schools can also address different ways of being sexual and having sex and cover different reproductive options and choices, including not having children. As part of providing comprehensive information about biological sex development, teachers also have an opportunity to create circumstances where people are able to be open about being intersex[149]. This can be helpful in releasing shame, secrecy and invisibility.[150]

6.6 Views and experiences of working life and promotion of equality

Being intersex may also have an impact on people’s working lives.

Intersex people’s educational histories may be patchier, which may make it more difficult for them to find employment. At the same time, intersex-related medical interventions may also result in functional problems, which in turn may reduce employment opportunities. The 2016 Australian study suggested that intersex respondents’ lower income levels when compared with the general population could be partially explained precisely by these reasons.[151]

Intersex individuals will also need to make decisions on whether they want to disclose being intersex at work. Indeed, some have reported difficulties finding and keeping a job in situations where they have shared being intersex at work.

Intersex individuals have also reported positive impacts. These have involved becoming interested in a certain field due to their own experiences or seeking a certain type of working environment, for example.[152]

About one in three respondents to this study reported being currently employed. Other respondents who shared this information were studying, retired or in rehabilitation. As a general rule, the respondents who were currently employed reported that being intersex had not had any impact on their working lives as such.

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[149] The most recent School Health Promotion Study (2017) was the first one to pay attention to gender and sexual diversity. The survey indicates that as many as over 5% of young people in grades 8 and 9 of compulsory basic education (aged 14–15) identify themselves as neither male nor female. It is possible that there are also intersex people among these respondents. (Terveyden ja hyvinvoinnin laitos [*Institute for Health and Welfare*] 2018: Kouluterveyskysely [*School Health Promotion Study*] 2017.)

[150] See also Lehtonen (2016).

[151] Jones et al. (2016: 145–150).

[152] van Lisdonk (2014); Jones et al. (2016); Lehtonen (2017).

They gave two different reasons for this: either they had not disclosed being intersex at work, or they did not feel that being intersex would have played any role in the abilities required in their work.

Sofia, 25, for example, had this to say about the subject:

"I don't think that being intersex has had any impact on my working life whatsoever. I haven't felt like it would have brought any advantage or any disadvantage."

A few respondents noted that the impact on their working lives could have emerged through their fragmented educational histories in consequence of their treatments.

Being intersex had also contributed to respondents' career choices.

Sara, born in the 1990s, reported that they were currently studying to become a medical doctor. Sara added that they hoped to be able to do research on variations of sex characteristics in the future. Another respondent noted that their childhood experiences relating to being intersex had contributed to their adulthood ambition to work for the wellbeing of families with children. Mariaana, 59, in turn, reported currently working as an experience-based educator for healthcare and social welfare professionals on topics such as the diversity of sexes and genders. Marjaana draws on theirown experiences in this work.

Three of the respondents reported telling their colleagues about being intersex. They mainly estimated that the attitudes of their colleagues towards them had not particularly changed.

One of the respondents had this to say about the subject:

"I'm not quite sure, but I guess it hasn't exactly impacted on their attitudes at all. I rather believe that their attitudes have somehow changed more in response to the fact that I'm currently dating someone whom my workmates take to be my girlfriend. But I'm not stressed about this at all really."

On the other hand, the respondents who had disclosed being intersex at work had, as a general rule, only shared the information with their close workmates or otherwise with people whom they knew to be open-minded about human diversity.[153]

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[153] Nevertheless, not all of the responses clearly indicate whether some of the negative experiences that the respondents raised in the context of sharing their intersex status in general terms had also involved some of these closest workmates. Such negative experiences included people dealing with the subject "over-cautiously" or "forgetting" about it and behaving as if they had never even heard of it.

Respondents reported that they had considered sharing about being intersex from different perspectives. They had considered aspects such as whether being intersex was relevant in the context of work, what other people's reactions would be like, or whether sharing would lead to any difficulties.[154]

One of the respondents who had not disclosed being intersex at work had this to say about the subject:

"The working environment where I'm currently working is just as narrow-minded as can be about whatever the issue. Most of those comments are obviously jokes, but all banter contains a kernel of truth. So, I've just decided to keep my working life completely separate from this. I've lost all faith in finding any understanding there. But, then again, I don't really feel like it's necessary for me to be shouting out about it. Maybe it's down to my weakness."

The revised Equality Act (2015) lays down obligations for non-discrimination of intersex people and measures to prevent discrimination, which also apply to employers. Employers with at least 30 regular employees must also prepare a gender equality plan, according to which their gender equality measures are to be implemented. These plans must also take into account any discrimination based on gender identity, gender expression or sex characteristics.

Respondents also had plenty of views on how to promote intersex people's equality in the world of work. Several of the views expressed by respondents can also be extended beyond workplaces to society at large.

As with schools and other educational institutions, respondents also considered it important for the world of work to increase information on the diversity of sexes and genders. They also found it important to make it somehow concretely visible that discrimination is not allowed and that everyone is welcome.[155]

A number of respondents noted that one way of making social situations easier for some intersex people is to avoid unnecessary gendering or, at least, to take note of the fact that there are also other people besides just men and women. In this context, respondents also raised the issue of using gendered language. By way of example, they wished that people would ask which pronoun each individual would prefer people to use to refer to them when speaking in a language other than Finnish, which only has one gender-neutral third person singular pronoun. Respondents also raised the point that people should not only speak

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[154] A recent Gender Equality Barometer explored people's views on how likely they considered that a trans or intersex individual would face discrimination in their own workplace. Just over a third of the respondents considered this very or fairly likely, while about two thirds rated it unlikely or very unlikely. (Sosiaali- ja terveysministeriö [*Ministry of Social Affairs and Health*] 8/2018: Tasa-arvobarometri [*Gender Equality Barometer*] 2017.)

[155] An example is the Discrimination-free Zone campaign, which allows employers and other parties to signal their commitment to people's equal and non-discriminatory treatment.

about women and men all the time at workplace events, for example, but should instead be mindful of the fact that there are other genders as well.

One of the respondents summed up the subject as follows:

"I'd hope that the word 'intersex' would be used more frequently. Simply just hearing or seeing it creates space and a sense that, hey, I exist too."

On the whole, several respondents believed that it would ease intersex people's situation if the attitudinal climate were to change. They hoped that people would try to relate to other people primarily as human beings, rather than as just representatives of a certain gender. Some also expressed the wish that their supervisors would intervene in the workplace "culture of banter" where people talk about LGBTI people in a derogatory tone.

Some of the respondents also pointed out that people should not be asked about their gender when it is not actually relevant.

Some respondents also raised the problems relating to legal recognition of gender (the 'Transgender Act'). They said that changing your gender marker and name on identity documents should be an easy procedure based on self-declaration, as is already the case in an increasing number of other European countries. Some wished that there were more gender options to choose from than just 'female' or 'male'.

Likewise, intersex people's organisations have also considered it a good option to provide more than just two legal gender options. However, the organisations have stressed that the key in this respect as well is for each individual to be able to choose the gender category suitable for them in accordance with their own gender identity. If a legal category for a third gender were to be created, for example, it should be open to both intersex and non-intersex people.

The point stressed by far the most frequently by respondents was that the diversity of human sexes and the existence of intersex people ought to be made a visible and everyday phenomenon in society in the first place. The means they identified for doing so included media visibility, campaigns, events, and providing information about the subject in general.

Respondents believed that spreading factual information on the subject would also contribute to creating the kind of social climate that would allow people to be openly intersex. Respondents also believed that disseminating factual public information would also make it possible to support parents who are having an intersex baby.

7. Legislation and practices in other countries

A study published by the European Union Agency for Fundamental Rights (FRA) in 2015 indicates that 'sex-normalising' surgery is still being carried out on intersex children in at least 21 Member States, including Finland. All of these Member States require informed consent of either the patients or their parents or other guardians as a condition for non-urgent treatment (surgery). In eight Member States, a child's parent or other guardian can consent to 'sex-normalising' medical interventions independently of the child's ability to decide.[156]

According to the FRA paper, there is little documented information on the existence of clinical practices in different countries. Similar to Finland, no official clinical practice guidelines concerning the treatment of intersex children are in place in several other EU countries.[157]

The Fundamental Rights Agency recommends that EU Member States should avoid 'sex-normalising' medical interventions on intersex people without their free and informed consent. It further urges Member States to increase awareness of intersex people's fundamental rights and review their sex registration procedures and anti-discrimination laws.[158]

Clinical practices applied to intersex children have also drawn attention from healthcare ethics advisory bodies and other parties in various countries[159].

The so-called 'sex-normalising' surgeries on intersex infants and children have currently been prohibited by law in Malta (2015),and with some nuances in Portugal (2018). Similar legislation is also currently being drafted in Germany and Iceland. As part of enacting laws, some countries have also set out guidelines for developing multidisciplinary clinical practices and other measures to promote intersex people's equality. The situation in these countries will be discussed in more detail below in this chapter.

Another issue relevant to some intersex people is the legal recognition of gender, i.e. changing the gender marker on identity documents. Consequently, changes made to legal gender recognition procedures over recent years have also made a positive impact on the

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[156] European Union Agency for Fundamental Rights (2015): The fundamental rights situation of intersex people.

[157] European Union Agency for Fundamental Rights (2015).

[158] European Union Agency for Fundamental Rights (2015).

[159] Swiss and German healthcare ethics advisory bodies, for example, have taken a stand on clinical practices applied to intersex children (ETENE 2016). The theme has also emerged on the agenda at the French Senate, which published a report recommending that clinical practice guidelines be prepared with due consideration for children's best interests (Sénat 2016-2017: Rapport d'information no 441 [*Senate 2016-2017: Information report No. 441*]: Variations du développement sexuel : lever un tabou, lutter contre la stigmatisation et les exclusions [*Variations in sexual development: lifting a taboo, fighting stigma and exclusions*]).

situation of those intersex individuals who wish to change the gender marker assigned to them at birth.

Legal gender recognition based on self-determination is currently possible at least in Belgium, Denmark, Norway, Malta, Ireland and Argentina[160]. Registration of a gender other than 'female' or 'male' is currently possible at least in Malta, Australia[161] and Nepal.[162]

In recent years, progress has also been made in terms of stronger anti-discrimination protections for intersex people. South Africa was the first country in the world to mention intersex people in its revised Promotion of Equality and Prevention of Unfair Discrimination Act of 2005[163], which was followed by reforms of anti-discrimination laws at least in Germany (2006), Australia (2013), Malta (2015), Finland (2015), and the Netherlands (2018).

7.1 Malta

Malta is the first European country to have legislated to protect intersex people's right to bodily integrity and physical autonomy. The 2015 Gender Identity, Gender Expression and Sex Characteristics Act criminalises any surgical or other intervention on the sex characteristics of a minor without the child's informed consent.[164]

The Act applies to any surgical or other interventions on sex characteristics that can be deferred until the child can provide informed consent to such interventions[165]. The punishment imposed on medical professionals for breaching the Act is equivalent to the sanctions imposed for female genital mutilation[166].

The Act allows such interventions on sex characteristics if a minor can give informed consent through a parent or some other guardian. The child's consent is to be assessed in accordance with their age and maturity. The final decision is to be based on an assessment of the child's best interests as expressed in the UN Convention on the Rights of the

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[160] Transgender Europe (2018): Trans Rights Map & Index.

[161] From 2011 onwards. Australian Government Guidelines on the Recognition of Sex and Gender (2013).

[162] Germany and New Zealand also have a practice in place according to which an intersex child's gender marker may be registered as 'other' or left blank by a physician's decision. The practice has been criticised for leading to discrimination against intersex people and for potentially putting increased pressure on parents to consent to genital surgery.

[163] Republic of South Africa. Government Gazette vol 487 no 28391 dated 13 January 2006.

[164] Gender Identity, Gender Expression and Sex Characteristics Act (the 'GIGESC Act').

[165] GIGESC Act, art. 14.

[166] Act No. XIII of 2018, art. 31. The punishment is imprisonment not exceeding five years or a fine of €5,000–€20,000.

Child.[167] The child has to understand what intervention is being proposed and express their wish to receive such treatment in a way that can be documented[168].

In exceptional circumstances, the child's parents or other guardians and the interdisciplinary team responsible for the child's treatment may decide on medical interventions without the child's informed consent[169]. In addition to medical professionals, such teams consist of a psychologist, a social worker, an expert in human rights and a patients' representative. However, the Act does not allow any interventions driven by social factors. If the child requires urgent treatment for health reasons, it must be provided.[170]

The Act also allows for the importance of counselling and psychosocial support offered to intersex children and their parents. It requires public authorities to organise sensitive and individually tailored psychosocial support for everyone seeking medical interventions to modify sex characteristics or psychosocial counselling and support on issues relating to sex or gender. The Act also recognises the importance of peer support and the psychosocial support to which it refers covers both expert support and peer support.[171] In addition to public psychosocial support services, the government also gives financial aid to support and counselling services provided by Maltese NGOs[172].

Following the enactment of the Act, the Maltese Ministry for Health appointed a working group to prepare revision of the medical treatment protocols applied to intersex children. The interdisciplinary working group consists of medical experts, psychosocial professionals, experts in human rights issues, and a representative of intersex people. The working group was due to complete its recommendations by the end of 2018.[173]

Besides the right to bodily integrity and physical autonomy, the Act also covers other rights. The Act guarantees everyone the right to the recognition of their gender identity; to free personal development according to their gender identity; to be treated according to their gender identity and to be identified accordingly in relevant documents. It prohibits any discrimination based on gender identity, gender expression or sex characteristics and obliges public authorities to promote equality.[174]

Instead of using the word 'intersex', the Maltese Act refers to 'sex characteristics'. These are defined as "the chromosomal, gonadal and anatomical features of a person". Such features include primary characteristics, such as reproductive organs and genitalia,

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[167] GIGESC Act, art. 14.

[168] Council of Europe Parliamentary Assembly (2017b).

[169] GIGESC Act, art. 14.

[170] GIGESC Act, art. 14.

[171] GIGESC Act, art. 15.

[172] Gabriella Calleja, Ministry for European Affairs and Equality, Head of SOGIESC Unit. Interview on 22 June 2018.

[173] Calleja (2018).

[174] GIGESC Act, art. 3(1a–d) and art. 2; Council of Europe Parliamentary Assembly (2017b).

chromosomes and hormones; and secondary characteristics, such as muscle mass, hair distribution, breasts and/or body structure.[175]

This choice is noteworthy for two reasons. Firstly, it means that the Act applies to all people, as everyone has sex characteristics. In other words, it does not create any 'special rights'. Its purpose is to ensure that everyone is entitled to bodily integrity and physical autonomy. Secondly, there are varying definitions as to which bodily variations are counted as intersex. The legislators therefore considered it important to write the law so as to actually guarantee bodily integrity and physical autonomy for all children.[176]

The Act also includes provisions on the legal recognition of gender, i.e. changing the gender marker on identity documents. According to the Act, changing the recorded gender is an administrative process based on the right to self-determination[177]. For minors, i.e. those under the age of 16, the parents can file an application to change their child's recorded gender and first name. The Court responsible for making such decisions is obliged to ensure that the application was made in the best interests of the child as expressed in the UN Convention on the Rights of the Child. It must also give due weight to the views of the child in accordance with their age and maturity.[178]

Since September 2017, official Maltese documents have also included three gender markers to choose from: female ('F'), male ('M'), or 'X'[179]. A child's birth certificate must indicate their sex, but it may not be included until their gender identity is determined[180]. In practical terms, this means that, where necessary, the gender may be left blank up until the person reaches the age of 18.

Malta has also published an education policy document and related procedures for trans, gender variant and intersex students. The policy aims to promote learning of human diversity that is inclusive of trans, gender variant and intersex students and improve the opportunities of all students to study in a safe school environment free from harassment and discrimination regardless of sex, sexual orientation, gender identity, gender expression and/or sex characteristics.[181]

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[175] GIGESC Act, art. 3(1a–d) and art. 2; Council of Europe Parliamentary Assembly (2017b).

[176] GIGESC Act, art. 3(1a–d) and art. 2; Council of Europe Parliamentary Assembly (2017b).

[177] GIGESC Act, art. 3. For more information on legal gender recognition, please see Ihmisoikeuskeskus [Human Rights Centre] (2018): Sukupuolen oikeudellinen vahvistaminen – Tilanne Suomessa ja lainsäädännön kehityslinjoja Euroopassa [*Legal recognition of gender – Situation in Finland and legislative development trends in Europe*].

[178] GIGESC Act, art. 7; Ihmisoikeuskeskus [Human Rights Centre] (2018).

[179] Ministry of European Affairs and Equality 09/2017, PR171985en.

[180] Malta Civil Code, art. 278.

[181] Ministry for Education and Employment (2015): Trans, gender variant and intersex students in schools – Policy; Trans, gender variant and intersex students in schools – Procedures.

The policy recognises that schools play a significant role in both disseminating information on human diversity and supporting the development and well-being of all students, including trans, gender variant and intersex students.[182]

Schools are encouraged to evaluate gender-based practices and their necessity in the school world and instructed to disseminate factual and up-to-date information on intersex issues. This can be accomplished by means such as using contemporary instead of outdated terms and teaching about natural bodily variations in sex characteristics in lieu of pathologising and medical language. Schools are also instructed to respect all children's rights to privacy and self-determination and to intervene in bullying based on sex, sexual orientation, gender identity, gender expression or sex characteristics.[183]

Based on the policy, various training sessions have been organised for teachers and other professionals working at schools, such as social workers, head teachers and psychologists. A challenge regarding intersex children is that they remain largely invisible. Little information is as yet available on the impact of the policy on them.[184]

Malta's new LGBTIQ[185] Equality Strategy & Action Plan (2018–2022)[186] also continues to integrate the education policy as part of school practices. Furthermore, the Action Plan includes several other measures concerning intersex people's rights and status.

The Action Plan covers measures such as finalising and implementing the review of the intersex treatment protocols and setting up a Gender Wellbeing Clinic specialising in provision of health services for trans and intersex individuals, among other things. Under the Action Plan, Malta will also continue to encourage other countries to promote the rights of LGBTIQ people. Examples include depathologisation of trans and intersex people and other active foreign policy efforts in keeping with the EU Guidelines[187] for promoting LGBTI people's rights.[188]

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[182] Ministry for Education and Employment (2015).

[183] Ministry for Education and Employment (2015).

[184] Calleja (2018).

[185] The abbreviation comes from the words 'lesbian, gay, bisexual, trans, intersex and genderqueer'.

[186] LGBTIQ Equality Strategy & Action Plan 2018–2022.

[187] European External Action Service (2013): Guidelines to promote and protect the enjoyment of all human rights by lesbian, gay, bisexual, transgender and intersex (LGBTI) persons.

[188] LGBTIQ Equality Strategy & Action Plan 2018–2022.

7.2 Portugal

In July 2018, the Portuguese Parliament adopted a law on the right to self-determination of gender identity and gender expression and to the protection of sex characteristics[189].

The law prohibits any discrimination based on gender identity, gender expression or sex characteristics, while guaranteeing everyone the right to retain their primary and secondary sex characteristics. The law further provides that, with the exception of situations involving proven risk to their health, no surgical or other medical interventions on sex characteristics may be performed on an intersex minor until the person's gender identity is 'manifestated'. The punishment imposed on healthcare staff for breaching the law is equivalent to what is provided in the Portuguese Criminal Code on conducting an involuntary medical intervention[190].

The law also provides for legal gender recognition based on the right to self-determination for everyone aged 18 or over. It also allows those aged 16 to 18 to apply for the right to change their first names and gender registration. As part of the application process, they are required to present their parents' consent and a medical certificate attesting that the choice is the person's own and that there are no other barriers to recognition. Such applications must be processed with due consideration for the child's age and maturity as well as the child's best interests as expressed in the UN Convention on the Rights of the Child. An intersex person may apply for legal gender recognition and name change once their gender identity is manifested.[191]

The law also provides for development of clinical practices applied to intersex children. In addition, it sets out the intention to develop education policy measures.[192] No detailed information on these measures was as yet available at the time of writing this report in October 2018.

Intersex people's organisations have criticised the law for being unclear and contradictory while also expressing their concerns for its future interpretation. The law does not unequivocally prohibit any medical interventions aiming to modify intersex children's sex characteristics. Nor does it define what 'manifestation of gender identity' means and how this is to be established.[193]

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[189] Lei n.º 38/2018, Direito à autodeterminação da identidade de género e expressão de género e à proteção das características sexuais de cada pessoa [*Law No. 38/2018, on the right of every person to self-determination of gender identity and gender expression and to the protection of sex characteristics*].

[190] Luis Isidro, assistant, Office of the Minister of Justice, Portugal. Legal opinion of 15 October 2018.

[191] Lei n.º [*Law No.*] 38/2018, articles 3, 6–10.

[192] Lei n.º [*Law No.*] 38/2018, articles 11–12.

[193] OII Europe: Portugal adopts law protecting intersex people. PR 12 July 2018.

The organisations have also been concerned that the interpretation of the law may lead to situations where an intersex child will not receive treatment vital for their health because they are not yet capable of expressing their consent. They stress that, in cases where a child's health is at risk, the child must be provided with all treatments that they require. Furthermore, they underline that situations where an intersex child would require urgent care are very rare.[194]

7.3 Germany

Since 2013, Germany has had in place a practice requiring a newborn child to be registered without a gender marker if their gender cannot be determined at birth. The practice has been criticised for compromising intersex children's privacy, as a blank gender marker will be disclosed when communicating with a kindergarten or a school, for example. No information on how widely the practice is being implemented is currently available. However, in the first two years following its introduction, only twelve children were registered without a gender marker.[195]

In 2014, the German Federal Ministry for Family Affairs, Senior Citizens, Women and Youth (the 'Federal Family Ministry', BMFSFJ) appointed an interministerial working group for a period from 2014 to 2017 to explore the situation of intersex and trans people. The working group has published several research papers and reports on the subject. It has also organised a consultation concerning psychosocial support and counselling and produced information and training materials intended for parents of intersex and trans children and counselling professionals.[196]

In its final conclusions issued in November 2017 on the basis of the working group's work, the Federal Family Ministry proposed that the German Civil Code be revised to include provisions on interventions aiming to modify children's sex characteristics. According to the proposal, parents would not be allowed to give their consent to such interventions on their children without compelling medical necessity. The proposal also includes an obligation for intersex children's parents to participate in counselling regarding variations of sex characteristics.[197]

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[194] OII Europe: PR 12 July 2018.

[195] Amnesty International (2017, 52).

[196] Examples include brochures intended for intersex children's parents and a guide for professionals on providing psychosocial support and counselling to trans and intersex people, produced by Pro Familia, Germany's leading sexual and reproductive health organisation. All publications are available on the website of the Federal Ministry for Family Affairs, Senior Citizens, Women and Youth (Bundesministeriums für Familie, Senioren, Frauen und Jugend, BMFSFJ 2018).

[197] BMFSFJ (2017): Schutz und Akzeptanz von geschlechtlicher [*Protection and acceptance of gender diversity*]. Vielfalt Schlussfolgerungen des Bundesministeriums für Familie, Senioren, Frauen und Jugend aus der Arbeit der Interministeriellen Arbeitsgruppe Trans- und Intersexualität [*Conclusions of the Federal Ministry for Family Affairs, Senior Citizens, Women and Youth from the work of the Interministerial Working Group on Trans and Intersex Persons*].

At the time of writing this report in October 2018, the German Federal Ministry of Justice and Consumer Protection (BMJV) was drafting a bill to insert the relevant provisions into the German Civil Code in keeping with the policy guidelines of the new coalition government's programme. In derogation from Malta's model, Germany decided on laying down mandatory obligations for parents for two reasons.[198]

Firstly, a statistical analysis commissioned by the Federal Family Ministry for a period from 2005 to 2014 clearly showed that cosmetic genital surgeries on intersex children had not decreased since 2005, although several internal recommendations for the medical profession[199] had specifically aimed at that outcome ever since around 2005. However, as none of these guidelines are legally binding, they have failed to bring down the number of cosmetic surgeries performed on intersex children.[200]

Secondly, performing such involuntary and non-vital surgical interventions is already criminalised in the German Criminal Code at a general level as causing bodily harm[201]. However, this provision has failed to guarantee intersex children's rights to bodily integrity and self-determination. Nor was it considered likely that intersex children's parents would begin to bring charges against the doctors who had performed such surgery in the future. Any pre-operative information provided to parents is likely to have precisely the opposite effect, i.e. convince them that the cosmetic operation concerned is medically necessary.[202]

For these two reasons, it was concluded that civil law provisions, imposing the responsibility for not consenting to non-vital surgery on the parents, would offer better protections for intersex children's rights to bodily integrity and self-determination. At the time of writing this report, however, it was still unclear whether the law would also include the obligation recommended by the Federal Family Ministry for parents to participate in counselling regarding intersex issues. The Federal Ministry of Justice is expected to complete its bill during 2019.[203]

Based on the working group's contributions, the Federal Family Ministry also recommended revising the law governing legal recognition of gender and introducing a third,

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[198] Ina-Marie Blomeyer, German Federal Family Ministry (BMFSFJ), head of the unit for same-sex lifestyles and gender identity. Interview on 30 July 2018.

[199] Statements advocating for a more cautious approach have been issued by the German Society of Pediatrics and Adolescent Medicine (2007), the German Medical Association (2015), the German Society of Urology (2016), the German Association of Paediatric Surgeons (2016) and the German Society for Pediatric Endocrinology and Diabetology (2016), among others. The German Ethics Council (2012) has also recommended abandoning such surgeries on the grounds that, in light of current knowledge, cosmetic genital surgery no longer meets medical standards and that surgeries have led to serious harm to many of those subjected to such procedures.

[200] Klöppel, Ulrike (2016): Zur Aktualität kosmetischer Operationen „uneindeutiger" Genitalien im Kindesalter [*On the relevance of cosmetic surgery on 'ambiguous' genitalia in childhood*].

[201] German Criminal Code (StGB), Sections 223 and 226a. Blomeyer (2018).

[202] Blomeyer (2018).

[203] Blomeyer (2018).

positive gender category into the Civil Status Act. Furthermore, the working group recommended strengthening protections against discrimination based on gender identity, gender expression and sex characteristics; organising comprehensive national support and counselling services for trans and intersex people and their families; and developing measures to combat discrimination and promote equality.[204]

The first two of the proposed measures are making progress. Introducing a third positive gender category into the Civil Status Act was also required by the German Federal Constitutional Court in 2017. In its decision of November 2017, the Federal Constitutional Court found that Germany's Basic Law, i.e. its constitution, also protects the gender identity of those whose gender identity is neither 'male' nor 'female'. The Federal Constitutional Court ordered the Civil Status Act to be amended by the end of 2018 so as to allow for a positive entry for a third gender category alongside 'male' and 'female'. Alternatively, the Court proposed that gender registration be abolished altogether.[205]

However, the draft bill issued by the German Federal Ministry of the Interior, Building and Community (BMI) in August 2018 restricts the right to register a third gender only to those who present a medical certificate of a 'disorder of sex development'. The bill has been criticised for the fact that, if implemented in this way, a third gender category would only work to amplify the pathologisation of intersex people, rather than promoting their right to self-determination. The Federal Family Ministry has also criticised the bill, demanding that the possibility to register a third gender should not be restricted as proposed in the bill. At the time of writing this report, the draft bill was about to be submitted for consideration by the German Bundestag. There was also an ongoing process of reforming the law governing legal gender recognition, which is not as yet based on the right to self-determination.

7.4 Iceland

In its programme (2017), Iceland's coalition government outlined that it would make a strong contribution to the rights of LGBTI people by means such as strengthening the right to self-determination and the protection of bodily integrity. Its aim is to base the relevant legislative reform efforts on the resolutions of the Council of Europe Parliamentary Assembly on the theme.[206]

When the coalition government started its term in 2017, a draft bill for an Act governing gender identity, gender expression and sex characteristics was already available. The draft had been prepared in broad cooperation between NGOs and various political actors[207],

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[204] BMFSFJ (2017).

[205] Bundesverfassungsgericht [*Federal Constitutional Court*], BvR 2019/16.

[206] Agreement between the Progressive Party, the Independence Party and the Left Green Movement on collaboration in a coalition government and reinforcing the capacity of the Althingi (2017).

[207] Kitty Anderson, Chair of Intersex Iceland. Interview on 27 July 2018.

making use of the above-mentioned Maltese Act as well as various resolutions of the Council of Europe Parliamentary Assembly.

The draft bill guarantees protections against any discrimination based on gender identity, gender expression and sex characteristics. It also provides for legal gender recognition and name change based on self-determination. Furthermore, it allows for a third 'X' category for gender registration.

The draft bill guarantees everyone the right to bodily integrity. Similar to Malta's law, it prohibits any non-vital medical interventions to modify intersex children's sex characteristics. Any operations conducted for social, psychosocial and cosmetic reasons are also prohibited in the draft bill. It also provides that any deferrable interventions should be deferred until the child can provide their written informed consent to such interventions. All interventions must also be assessed from the perspective of the principle of the child's best interests.[208]

The draft bill also proposes that any invasive operations on children's sex characteristics be registered and reported to the Ministry of Welfare. According to the draft, this obligation would apply to all children, rather than only intersex children. The draft also proposes setting up a multidisciplinary working group with the responsibility for developing and monitoring clinical practices applied to intersex children. Similar to Malta's model, the working group should also include human rights experts, psychologists and intersex individuals as well as medical professionals.[209]

At the time of writing this report in October 2018, the draft bill had been sent for its first consultation round, but no further information was as yet available on the schedule for its progression. Moreover, the Icelandic Parliament was considering a motion to transfer all equality themes under the Office of the Prime Minister as of the beginning of 2019. While no decision had as yet been made, it is likely that the responsibility for drafting the law will move from the Ministry of Welfare to the Prime Minister's Office. The draft bill enjoys strong political support.[210]

In addition to the draft bill, the Icelandic Government has been preparing an action plan relating to LGBTI issues. The plan includes proposals on developing information provided to intersex children's parents and several other measures to promote LGBTI people's equality and non-discrimination, among other things. In keeping with the policies outlined in the draft action plan, the Icelandic Government is also planning to strongly promote LGBTI rights in international forums.[211]

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[208] Linda Rós Alfreðsdóttir, Senior Adviser, Ministry of Welfare. Interview on 25 October 2018.

[209] Alfreðsdóttir (2018).

[210] Alfreðsdóttir (2018).

[211] Alfreðsdóttir (2018).

8. Overview and recommendations

This report has explored the experiences of intersex individuals and parents of intersex children in Finnish healthcare services and society.

Its purpose has been to establish how the decisions made when intersex children were born and the intersex-related medical interventions that they were subjected to during childhood and adolescence have affected their lives. It has also discussed the types of information and support that parents of intersex children were offered and the kinds of information and support they feel that they need. Furthermore, the report has examined good practices for taking intersex children into account in daycare, school, leisure and healthcare settings. It has also reviewed relevant legislation and practices in Malta, Portugal, Germany and Iceland.

'Intersex' refers to congenital variations in bodily sex characteristics that are not unambiguously female-typical or male-typical. Intersex people's sex characteristics and bodies are healthy and natural variations of the human sexes. These natural variations of sex characteristics highlight the fact that sex is more of a continuum than a clear-cut dichotomy.

Estimates of the number of intersex people vary between 1:4,500 and 1.7%. Depending on how broadly the concept of intersex is defined, it is possible to estimate that there are somewhere between 1,200 and 93,000 intersex people in Finland. Being intersex does not only impact on those who were born in an intersex body, but also their parents, siblings, friends and wider social environment.

The study data primarily consisted of interviews with 12 intersex individuals and 6 parents and their responses to online surveys.

Experiences within healthcare services

The study participants had experiences of various intersex-related healthcare interventions, such as examinations of sex characteristics, medications, and surgical and other interventions.

The respondents had very different experiences. All of the respondents had both positive and negative experiences of treatments. However, their experiences clearly tended either towards the more positive or the more negative end of the spectrum. Whether a respondent's experience was positive or negative was essentially dependent on two factors: firstly, whether the medical intervention had clearly been vital for their health and, secondly, whether the respondent was allowed to participate in making treatment decisions.

Respondents' negative experiences of intersex-related medical interventions were related to situations where they felt that they had been treated as if their emotions and experiences did not make any difference, especially in childhood. Both intersex respondents and parents of intersex children reported that they had been subjected to different types of inappropriate and prejudiced treatment. By way of example, rather than being involved in discussions on different treatment options, they had merely been "informed" of the interventions; there had been attempts to put pressure on them to consent to treatments; or interventions had been performed on them without informing them in advance. Several respondents' experiences were steeped in an atmosphere of no alternatives, secrecy, pressure and compulsion.

Consequently, the fundamental experience was that respondents had not been given a chance to participate in making decisions concerning their own or their child's treatments. Negative experiences were also intrinsically associated with the fact that there were no clear health grounds for the treatments and interventions.

The negative impacts of medical interventions reported by respondents included traumatising experiences of feeling as if they and their bodies were somehow defective and deficient; various types of physical pain; issues with psychological wellbeing (incl. self-destructive behaviour, depression, anxiety, panic disorders, dissociative disorders); problems due to a wrong type of hormone therapy (incl. body dysphoria, considerable weight gain); stigmatisation; and feelings of secrecy, shame and embarrassment. The respondents who had undergone involuntary and non-vital surgeries to modify their sex characteristics in childhood described their experiences in terms of sexual violence and sexual abuse.

Respondents' positive healthcare experiences were related to situations where they had been dealt with appropriately and sensitively. In such situations, respondents had received up-to-date information on treatments and the treatments offered had clearly been necessary for their actual health. Moreover, they had not been kept in the dark about being intersex. Even in these situations, however, respondents frequently brought up a lack of information, such as the fact that, had they been properly aware of the possible effects of the treatments, they would have chosen otherwise. Positive experiences were also intrinsically associated with the fact that the respondent felt that they had personally made the decisions concerning their own or their intersex child's treatments.

The positive impacts of intersex-related healthcare interventions reported by respondents were related to maintaining their own or their child's health (such as vital hormone therapy or preventive monitoring the child's health). Positive experiences of interventions aiming to modify sex characteristics were reported by respondents when the treatment had been performed of their own free will (such as hormone therapy to make their bodies more 'masculine' or 'feminine').

A recurring theme in the experiences reported by all of the respondents was a lack of information concerning variations of sex characteristics and the diversity of the human sexes. As a general rule, the information received by respondents from healthcare professionals had been medicalised and in many cases, the information also tended to be somehow tinged with negative overtones.

A crucial moment for many respondents had been the time when they had heard the word 'intersex' for the first time. As a result, they had found information where intersex bodies were referred to as part of healthy and natural variations in sex characteristics. In many cases, respondents described this experience as a relief. As a general rule, they had found such information on the internet.

Experiences also repeatedly involved a lack of peer support and other psychosocial support. The respondents who had eventually found peer support frequently described it as their most important information source and support channel. In many cases, peer support had also decisively contributed to respondents' psychological wellbeing. Many of the respondents who had been offered psychological support within healthcare services had found it pointless. The most common reason was that the professional that they had seen had not known about the different aspects of being intersex and the diversity of human sexes, nor known how to help them deal with being intersex.

Some respondents reported that they currently avoided or delayed seeking healthcare services. The reason given by respondents was that they do not feel that they can trust healthcare professionals, or that they find it hard to have to 'educate' healthcare professionals on variations of sex characteristics and the diversity of human sexes when using healthcare services.

Intersex-related medical interventions in Finnish healthcare services are governed by general healthcare laws and principles. The best interests of the child must be a primary consideration for public authorities in all decision-making processes concerning children. As the right to self-determination also applies to children, they must be allowed to have a say in matters concerning them in accordance with their age and maturity. The child's right to self-determination intrinsically involves the primary responsibility of parents for the child's growth and development and the obligation of public authorities to support parents in fulfilment of this responsibility.

However, the child's right to privacy and physical integrity is not deferred until the child is capable of expressing their own consent or will. Early childhood is a particularly critical period for realising these rights. Children's earliest years create the foundation for their physical and mental health, emotional security and personal identity.

The intersex respondents who were born in the 1980s or earlier, in particular, stressed that their experiences should be mirrored against the zeitgeist of the past decades. They wanted to emphasise that it should not be automatically assumed that similar interventions, suppression and secrecy would still be going on.

However, the experiences that parents participating in the study had from the current decade go to show that the grave concerns about whether intersex children's rights are realised in Finnish healthcare services are still relevant. Some of the parents felt, for example, that they had simply been "informed" of the interventions, or that there had been attempts to put pressure on them to consent to these. What is particularly concerning is that parents had such experiences also of non-vital surgeries to modify children's sex characteristics. Moreover, healthcare professionals had failed to give any rationales for such procedures that would have been relevant to the children's actual health.

Parents' experiences also highlight how important it is that, when a child's body becomes visible as intersex, the parents – and eventually the child as well as they grow up – are provided with comprehensive information regarding variations of sex characteristics and the diversity of the human sexes as well as time and space to get used to a new situation. Learning about a child being intersex can be a confusing situation. From the perspective of safeguarding the child's fundamental rights, it is crucial that the parents are not forced to make urgent decisions about their child's treatment while being overwhelmed by confusion, without appropriate information and competent support.

Experiences of the impacts of being intersex on life

As part of this study, intersex individuals and parents of intersex children also reported their experiences of the impact of being intersex on their lives.

Some of the intersex respondents reported that, because of being intersex, they were “more aware than average” about various norms and assumptions relating to human sexes and genders, as well as to sexuality and intimate relationships. Some of the parents of intersex children also considered it possible that they dealt with their children in a more gender-sensitive way than usual.

The intersex individuals participating in the study defined their gender identity in different ways (such as “woman”, “intersex”, “masculine”, “transgender”, “a woman and intersex”). Some respondents reported having reflected on their gender identity a lot, whereas others had always been “clear” about their gender identity. Some found the entire question very uninteresting. Almost all of the respondents raised the point that they would like to see a society where they would only be asked about gender in the first place when there was an important reason for it.

The majority of both the intersex respondents and the parents of intersex children had only shared being intersex with a close circle of family and friends. Some had disclosed the matter more widely. Being open about being intersex had mostly been a positive experience for the respondents. It had helped respondents get over the shame and secrecy associated with being intersex, increased their sense of freedom, and reinforced their sense of living as who they are.

Respondents also reported the impacts of being intersex on their relationships. Some of the intersex respondents felt that intersex-related medical interventions and the secrecy involved had taken a toll on their relationships with their parents. Some recounted that their parents were still – often several decades after the events – unable to bring themselves to talk about the subject with them. Others, in turn, reported that it was precisely their parents who had been a major support for them as they were dealing with being intersex. Such experiences were especially shared by the respondents whose parents had not kept secret the fact that their children were intersex, who had not been subjected to non-vital intersex-related medical interventions (surgeries or medications), or who had been personally involved in making decisions about treatments.

Respondents had varying experiences of the impact of being intersex on their dating, intimate and sexual relationships. Some had faced negative impacts and experienced challenges relating to sexuality, intimacy and falling in love. For others, however, dating and intimate relationships had provided healing experiences, allowing them to feel lovable and valuable.

Being intersex or intersex-related medical interventions had also affected some respondents’ schooling and studies (e.g. absences, bullying, poor psychological wellbeing), as well as their working lives (career choices, gaps in educational history).

A key issue in experiences concerning daycare, school, studying, leisure interests and working life was openness about being intersex. Intersex individuals and parents of intersex children are forced to make this decision again and again. Many respondents felt that it was easier to keep the issue secret because they found it hard to have to keep educating other people on the topic or feared negative reactions.

Respondents had numerous practical ideas on how to promote intersex individuals' position at daycare centres, schools and other educational institutions, in the world of work and in society at large. A key point emerging in this respect was promoting factual information and debate concerning variations of sex characteristics and the diversity of human sexes. Respondents hoped that such factual information and debate would contribute to shaping being intersex and human diversity in general as a natural part of everyday life in society.

This study on intersex people's experiences was carried out from the perspective of fundamental and human rights. The approach inevitably also contributed to what respondents reported and how they described their experiences. They related what had been positive and what had worked, on the one hand, and what had been negative and what had not worked, on the other. Attention was focused on what should be done to ensure that intersex people's fundamental and human rights would be realised more effectively.

However, it is important to note that, while speaking about being intersex, the majority of the respondents emphasised that being intersex was not at all a problem for them in itself; they were not broken and they did not need to be fixed. They highlighted that, if anything, being intersex was a reason for joy, being one of the many things that made them special and unique.

Recommendations

The aim of the study was to provide concrete recommendations on how to improve intersex people's situation and rights in Finland and as part of Finland's international activities in the field of human rights policy.

The data and participants of the study do not constitute a quantitatively representative sample of intersex people in Finland. The information obtained from the respondents cannot be generalised; nor does the report provide a comprehensive picture of intersex people's experiences in Finnish healthcare services and society. Instead, the views and experiences presented in the report are profound and informed descriptions of the kinds of experiences and issues that intersex people and their parents are living with in Finnish society. The respondents' experiences of intersex-related medical interventions and the impacts of these on their lives also provide valuable information for the purposes of reforming intersex-related healthcare and safeguarding intersex people's fundamental and human rights more effectively.

Intersex people's fundamental and human rights situation has mostly emerged into public debate in the 21st century because international and European human rights actors have started to pay attention to the theme. As a result of increasing awareness, clinical practices and relevant legislation have been reformed in Malta and Portugal. Other European countries have also started to pay attention to intersex people's fundamental and human rights situation. In Finland, various parties have taken a stand on the issue, including the National Advisory Board on Social Welfare and Health Care Ethics (ETENE), the Ombudsman for Children, the Ombudsman for Equality and a number of NGOs.

In recent years, various human rights actors have issued a number of recommendations on how to improve the fundamental and human rights situation of intersex people. The ones especially relevant to Finland include those issued by the Council of Europe Human Rights Commissioner (2015), the European Union Agency for Fundamental Rights (2015) and the Council of Europe Parliamentary Assembly (2017).

The data collected through this study indicates that these recommendations are still topical in Finland. Consequently, in addition to the study respondents' experiences and background interviews, the recommendations put forward in this report for Finnish public authorities are also based on those previously issued to Finland by these human rights actors.

Recommendations

1. Intersex people's rights to bodily integrity and self-determination should be ensured. Any non-vital surgeries or other interventions performed to 'normalise' intersex children's sex characteristics without the child's informed consent should be prohibited. With the exception of situations where a child's health is at immediate risk, no interventions aiming to modify sex characteristics should be performed until the child is capable of making an independent decision on the matter.

2. Healthcare for intersex people should be provided by multidisciplinary teams. In addition to medical professionals, these should include professionals in psychological and psychosocial support; experts with competence in ethical and human rights issues; as well as representatives of intersex people. Healthcare for intersex children should be outlined in clinical practice guidelines taking full account of the child's best interests and rights to participate in making decisions concerning their treatment in accordance with their age and maturity, in keeping with the obligations of the Convention on the Rights of the Child. Intersex people and parents of intersex children must be guaranteed access to appropriate information regarding variations of sex characteristics and the diversity of human sexes. The clinical practice guidelines should also cater for ethical and human rights considerations. The clinical practice guidelines should be developed in multidisciplinary cooperation between professionals from different fields and representatives of intersex people.

3. Intersex people and their parents should be guaranteed access to psychosocial support and peer support. Adequate resources should be secured for organisations providing psychosocial and peer support.

4. Intersex people should be guaranteed access to the healthcare services that they require and the right to check records on their own treatment.

5. Healthcare professionals should be provided with training on variations of sex characteristics and the diversity of human sexes. Their awareness of the potential effects of intersex-related medical interventions on children's health and wellbeing should be raised.

6. Discrimination against intersex people should be prevented purposefully and systematically, in keeping with the obligations of the Equality Act. Sufficient resources should be allocated to equality promotion efforts.

7. Efforts should be made to increase awareness and information measures concerning variations of sex characteristics and the diversity of human sexes among all professionals working with children (daycare, education, leisure activities, healthcare), as well as at educational institutions, in workplaces and in society at large. Research should be conducted into the topic and information on being intersex and the diversity of human sexes should be communicated appropriately.

8. Legislation governing legal recognition of gender (the 'Trans Act') should be reformed such that the legal gender recognition procedure will be a quick and transparent administrative process based on the right to self-determination.

9. Resources should be allocated, both in Finland and internationally, to the activities of intersex people's organisations aiming to dismantle the stigma and silence associated with being intersex.

10. Finland should continue to play the role of an active supporter of LGBTI rights in international human rights forums. Finland should make an effort to promote the rights of LGBTI people in keeping with the EU Guidelines to promote and protect the enjoyment of all human rights by lesbian, gay, bisexual, transgender and intersex (LGBTI) persons, while also bringing issues relating to intersex people's rights increasingly to the fore.

GLOSSARY

Body dysphoria. The term refers to the feelings of alienation, anxiety and disgust towards the gendered characteristics of the body. Body dysphoria is part of gender dysphoria, which refers to profound discomfort caused by the incongruity between physical sex and gender identity. Gender dysphoria is often divided into body dysphoria and social dysphoria. Social dysphoria describes the sense of distress and discomfort manifesting in social situations which is linked to misgendering, i.e. not being seen for who one is in such situations.

Gender identity. The term refers to an individual's intrinsic experience of being of a particular gender or being agender.

Gender reassignment. The term refers to medical treatments allowing a transgender person to align their body with their gender experience. Other terms include 'gender affirmation', 'gender confirmation', etc.

Genderqueer (adj.). The term is often used to refer to non-binary gender identity or gender expression (cf. gender binary = the idea that there are only two genders or sexes).

Intersex. The term refers to congenital variations in bodily sex characteristics that are not unambiguously female-typical or male-typical. Intersex people's sex characteristics and bodies are healthy and natural variations of the human sexes.

Legal gender recognition. The term refers to changing the personal data recorded in the population register (generally both the name and gender) to align with one's gender identity.

LGBTI. An abbreviation used for referring to lesbian, gay, bisexual, trans and intersex individuals.

Pathologisation. To define something as a disease.

Sex. The combination of a person's bodily characteristics including chromosomes, hormones, internal and external reproductive organs, and secondary sex characteristics.

Sex characteristics/Variations of sex characteristics. Sex Characteristics is a term that refers to a person's primary sex characteristics such as: chromosomes, anatomy, hormonal structure and reproductive organs or a person's secondary sex characteristics which become apparent at puberty such as: breasts, facial and pubic hair, Adam's apple, muscle mass, stature and fat distribution. The term 'variations of sex characteristics', therefore, is seen by many intersex people as a more accurate term than 'intersex status', as it refers to a spectrum of possible characteristics instead of a single homogenous status or experience of being intersex.

Trans (adj.). An umbrella term often used to refer to anyone whose gender identity or gender expression is sometimes or always different from the expectations set for the sex/gender assigned to them at birth.

The Finnish glossary was compiled making use of the glossary at intersukupuolisuus.fi and the Rainbow Glossary of Seta – LGBTI Rights in Finland.

The English translation drew on the following glossaries:

- Digital Transgender Archive: Glossary
- ILGA-Europe: Glossary
- LGTBQIA Resource Center: Glossary
- MIT: Useful Terminology about Trans and Gender Variant People
- The Safe Zone Project: LGBTQ+ Vocabulary Glossary of Terms
- Transgender Equality Network Ireland (TENI): Trans Terms.
- IGLYO, OII Europe & European Parents' Association (2018). https://www.iglyo.com/wp-content/uploads/2018/10/Supporting-Your-Intersex-Child.pdf.

SOURCES

Amnesty International (2017). First, do no harm: Ensuring the rights of children with variations of sex characteristics in Denmark and Germany.

Australian Government Guidelines on the Recognition of Sex and Gender (2013).

Bastien-Charlebois, Janik (2015). My coming out: The lingering intersex taboo. Montreal Gazette, August 11, 2015.

Blackless, Melanie; Charuvastra, Anthony; Derryck, Amanda; Fausto-Sterling, Anne; Lauzanne, Karl & Lee, Ellen (2000). How Sexually Dimorphic Are We? Review and Synthesis. In: American Journal of Human Biology 12(2).

Callens, Nina; Yvonne G. van der Zwan; Stenvert L.S. Drop; Martine Cools; Catharina M. Beerendonk; Katja P. Wolffenbuttel & Arianne B. Dessens (2012). Do Surgical Interventions Influence Psychosexual and Cosmetic Outcomes in Women with Disorders of Sex Development? International Scholarly Research Network Endocrinology, 2012; 2012: 276742.

Council of Europe Commissioner for Human Rights (2015). Human rights and intersex people.

Council of Europe Parliamentary Assembly (2017a). Promoting the human rights of and eliminating discrimination against intersex people/Recommendation 2116 (2017).

Council of Europe Parliamentary Assembly (2017b). Explanatory memorandum 14404 (2017).

ETENE (2016a). Kannanotto intersukupuolisten lasten hoidosta.

Available in English: Position statement on care and treatment of intersex children.

ETENE (2016b). Intersukupuolisuus [*Intersex*]. Taustaraportti ETENEn kannanottoon [*Background report to ETENE's position statement*].

European External Action Service (2013). Guidelines to promote and protect the enjoyment of all human rights by lesbian, gay, bisexual, transgender and intersex (LGBTI) persons.

European Union Agency for Fundamental Rights (2015). The fundamental rights situation of intersex people.

Council of Europe Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine. Finnish Treaty Series 24/2010.

Fagerholm R. et al. (2011). Sexual Function and Attitudes Toward Surgery After Feminizing Genitoplasty. Journal of Urology, 2011/185.

Fagerholm R. et al. (2012). Mental health and quality of life after feminizing genitoplasty. Journal of Pediatric Surgery 2012/47.

Falhammar et al. dsd-LIFE research group (2018). Health status in 1040 adults with disorders of sex development (DSD): a European multicenter study. Endocr Connect. 2018 Mar;7(3).

Hakalehto, Suvianna. Intersukupuoliset lapset [*Intersex children*]. Lasten oikeuksien näkökulma [*The perspective of children's rights*]. Lecture on 26 March 2016.

Helander, Merike. Lapsen itsemääräämisoikeuden käyttäminen [*The child's exercise of the right to self-determination*]. Lecture on 25 November 2014.

Huttunen, Matti (2018). Dissosiaatiohäiriö [*Dissociative disorder*]. Terveyskirjasto [*Online health library*].

Hyvärinen, Sauli. Lastensuojelun keinot tukea intersukupuolisia lapsia [*Means available to child welfare services for supporting intersex children*]. Lecture on 11 June 2018.

IGLYO, OII Europe & European Parents' Association (2018). How to support your intersex child toolkit.

Ihmisoikeuskeskus [*Human Rights Centre*] (2018). Sukupuolen oikeudellinen vahvistaminen – Tilanne Suomessa ja lainsäädännön kehityslinjoja Euroopassa [*Legal recognition of gender – Situation in Finland and legislative development trends in Europe*].

Intersukupuolisuus.fi [*Finnish intersex website*].

Jones, Tiffany; Hart, Bonnie; Carpenter, Morgan; Ansara, Gavi; Leonard, William & Lucke, Jayne (2016). Intersex. Stories and Statistics from Australia. Open Book Publishers.

Kansallinen perus- ja ihmisoikeustoimintaohjelma 2017–2019. Oikeusministeriön julkaisu 9/2017.

Available in English: National Action Plan on Fundamental and Human Rights 2017–2019. Publication of the Ministry of Justice 25/2017.

Kreukels et al. dsd-LIFE research group (2018). Gender Dysphoria and Gender Change in Disorders of Sex Development/Intersex Conditions: Results From the dsd-LIFE Study. Journal of Sexual Medicine, 15/5.

Kärnä, Teemu; Nina Uusi-Mäkelä & Aino Mattila (2018). Sukupuolen moninaisuus – lähestymistapa sukupuoleen muuttumassa [*The diversity of gender identities – Is the concept of gender changing*]? Lääkärilehti [*Finnish Medical Journal*] 45/2018, VSK [*Vol.*] 73.

Kätilöliitto [*Finnish Federation of Midwives*] (2016). Intersukupuolisen lapsen tulee saada itse määritellä oma sukupuolensa [*Intersex children should be allowed to determine their own gender*]. Kannanotto [*Position statement*], 3 May 2016.

Laki hedelmöityshoidoista (1237/2006).

Available in English: Act on Assisted Fertility Treatments (1237/2006).

Laki naisten ja miesten välisestä tasa-arvosta (609/1986).

Available in English: Act on Equality between Women and Men (609/1986).

Laki potilaan asemasta ja oikeuksista. (785/1992).

Available in English: Act on the Status and Rights of Patients (785/1992).

Lapsiasiavaltuutettu [*Ombudsman for Children*] (2016a). Intersukupuoliset lapset ja hoitokäytännöt [*Intersex children and clinical practices*]. Round-table discussion on 26 April 2016.

Lapsiasiavaltuutettu [*Ombudsman for Children*] (2016b). Intersukupuolisten lasten oikeuksia vahvistettava [*The Rights of Intersex Children need to be strengthened*]. Kannanotto [*Statement*], 31 August 2016.

Lastensuojeluki (417/2007).

Available in English: Child Welfare Act (417/2007).

Lee et al. (2006). Consensus Statement on Management of Intersex Disorders. Cited in: Amnesty International (2017).

Lee et al. (2016). Global Disorders of Sex Development, Update since 2016: Perceptions, Approach and Care. Cited in: Amnesty International (2017).

Lehtonen, Jukka (2016). Sukupuolen ja seksuaalisuuden moninaisuus osana laaja-alaista seksuaalikasvatusta ja heteronormatiivisuuden purkamista [*Gender and sexual diversity as part of broad-based sex education and dismantling of heteronormativity*]. In: Bildjuschkin, Katriina (ed.). Seksuaalikasvatuksen tueksi [*In support of sexual education*]. Työpaperi [*Discussion Papers*] 35/2015. Terveyden ja hyvinvoinnin laitos [*Institute for Health and Welfare*].

Lehtonen, Jukka (2017). Hankala kysymys [*A difficult question*]. Intersukupuolisuus suomalaisissa koulu- ja työelämätutkimuksissa [*Intersex in Finnish school and working life studies*]. Sukupuolentutkimus [*Journal of Gender Studies*] 1/2017.

Lepola, Outi & Susan Villa (eds.) (2007). Syrjintä Suomessa 2006 [*Discrimination in Finland 2006*]. Ihmisoikeusliitto [*Finnish League for Human Rights*].

Liefaard, Ton; Aart Hendriks & Daniella Zlotnik (2017). From law to practice: Towards a roadmap to strengthen children's rights in the era of biomedicine. Report commissioned by the Committee on Bioethics of the Council of Europe.

MacKenzie, D., A. Huntington & J.A. Gilmour 2009. The experience of people with an intersex condition: a journey from silence to voice. In: Journal of Clinical Nursing 2009/18/12.

Mattila A. K., Fagerholm R. et al. Gender Identity and Gender Role Orientation in Female Assigned Patients with Disorders of Sex Development. Journal of Urology 2012/188.

Nordenström & dsd-LIFE research group (2018). Hormone therapy and patient satisfaction with treatment, in a large cohort of diverse disorders of sex development. Clinical endocrinology 88/3.

Norio-keskus [*Norio Centre*]. Palvelut [*Services*].
https://www.norio-keskus.fi/palvelut/keskustelutuki-ja-neuvonta.html

Opetushallitus [*Finnish National Agency for Education*] (2015). Tasa-arvotyö on taitolaji [*Gender equality work is a game of skill*]. Opas sukupuolten tasa-arvon edistämiseen perusopetuksessa [*Guide to promoting gender equality in basic education*]. Oppaat ja käsikirjat [*Tutorials and manuals*] 2015:5.

Organisation Intersex International (OII) Europe (2018). WHO publishes ICD-11 – and no end in sight for pathologisation of intersex people. Statement 06/2018.

Pleskacova, J; Hersmus R, Oosterhuis JW; Setyawati BA; Faradz SM; Cools M; Wolffenbuttel KP; Lebl J; Drop SL; Looijenga LH (2010). Tumor Risk in Disorders of Sex Development. Sexual Development 2010/4.

Rantala, Marjo (2016). Sukupuoleen sopeutetut: Intersukupuolisten ja transsukupuolisten henkilöiden oikeusasema Suomessa [*Adjusted to sex – legal status of intersex and transgender persons in Finland*]. Oikeus [*Law Journal*] 1/2016.

Republic of South Africa. Government Gazette vol 487 no 28391 dated 13 January 2006.
www.justice.gov.za/legislation/acts/2005-022.pdf

Röhle et al. dsd-LIFE research group (2017). Participation of adults with disorders/differences of sex development (DSD) in the clinical study dsd-LIFE: design, methodology, recruitment, data quality and study population. BMC Endocrine Disorders 2017/17:52.

Sénat [*Senate*] 2016–2017. Rapport d’information no 441 [*Information report No. 441*]. Variations du développement sexuel : lever un tabou, lutter contre la stigmatisation et les exclusions [*Variations in sexual development: lifting a taboo, fighting stigma and exclusions*].

Seta [*Seta – LGBTI Rights in Finland*]. Sateenkaarisanasto [*Rainbow Glossary*].
https://seta.fi/sateenkaaritieto/sateenkaarisanasto/

Seta [*Seta – LGBTI Rights in Finland*]. Tukea Intersukupuolisille, Keinoja Ammattilaisille (TIKA-hanke) [*Information for Intersex People, Means for Professionals (TIKA project)*].
https://seta.fi/tika-hanke/

Sosiaali- ja terveysministeriö [*Ministry of Social Affairs and Health*] (2015a). Tasa-arvolaki, viranomaiset ja sukupuolen moninaisuus [*The Equality Act, authorities and gender diversity*].

Sosiaali- ja terveysministeriö [*Ministry of Social Affairs and Health*] (2015b). Tasa-arvolaki, oppilaitokset ja sukupuolen moninaisuus [*The Equality Act, educational institutions and gender diversity*].

Sosiaali- ja terveysministeriö [*Ministry of Social Affairs and Health*] (2016). Sukupuolten tasa-arvo neuvolan asiakastyössä [*Gender equality when working with clients in maternity and child welfare clinics*]. Miten tukea vanhempia ja lapsia sukupuolten tasa-arvon näkökulmasta [*How to support parents and children from a gender equality perspective*]?

Sosiaali- ja terveysministeriö (2018). Tasa-arvobarometri 2017.
Available in English: Ministry of Social Affairs and Health (2018). Gender Equality Barometer 2017.

Suomen perustuslaki. (731/1999).
Available in English: The Constitution of Finland (731/1999).

Streuli, J. C., Vayena, E., Cavicchia-Balmer, Y. & Huber, J. (2013). Shaping Parents: Impact of Contrasting Professional Counseling on Parents' Decision Making for Children with Disorders of Sex Development. Journal of Sexual Medicine 2013/10.

Tasa-arvovaltuutetun toimisto [*Office of the Ombudsman for Equality*] (2012:1). Selvitys sukupuolivähemmistöjen asemasta [*Report on the status of gender minorities*].

Tasa-arvovaltuutettu ja Lapsiasiavaltuutettu [*Ombudsman for Equality and Ombudsman for Children*]. Intersukupuolisilla on oikeus omaan kehoonsa [*Intersex people have the right to their own body*]. Kannanotto [*Statement*], 26 October 2017.

Terveyden ja hyvinvoinnin laitos [*Institute for Health and Welfare*] (2018). Kouluterveyskysely [*School Health Promotion Study*] 2017.

Terveyden ja hyvinvoinnin laitos [*Institute for Health and Welfare*]. Sukupuolen moninaisuus [*Gender diversity*].
https://thl.fi/fi/web/sukupuolten-tasa-arvo/sukupuoli/sukupuolen-moninaisuus

Third International Intersex Forum (2013). Malta Declaration.

Thyen et al. dsd-LIFE research group (2018). Quality of health care in adolescents and adults with disorders/differences of sex development (DSD) in six European countries (dsd-LIFE). BMC Health Serv Res. 2018; 18: 527.

Toriseva, Roosa (2017). Intersukupuolisuus suomalaisten lääkäreiden käytännöissä ja puheessa [*Intersex in the practices and speech of Finnish doctors*]. Sukupuolentutkimus [*Journal of Gender Studies*] 1/2017.

Transtukipiste [*Trans Support Center*]. Palvelut [*Services*]. http://transtukipiste.fi/palvelut/

Transgender Europe. Trans Rights Map & Index 2018.

Trasek & Seta (2016). The cruel, inhuman and degrading treatment of trans and intersex people in Finland. Submission to the UN Committee against Torture.

Traumaterapiakeskus [*Centre for Trauma Therapy and Trauma Education*] 2018. www.traumaterapiakeskus.com

Finnish National Board on Research Integrity (TENK) (2012). Responsible conduct of research and procedures for handling allegations of misconduct in Finland. Guidelines of the Finnish Advisory Board on Research Integrity 2012.

United Nations Committee on the Elimination of Discrimination against Women. Concluding observations on the combined sixth and seventh periodic reports of Luxembourg. (CEDAW/C/LUX/CO/6-7).

United Nations Committee on the Rights of the Child. Concluding observations on the combined fifth and sixth periodic reports of Spain. (CRC/C/ESP/CO/5-6).

United Nations Committee against Torture. Concluding observations on the seventh periodic report of France. (CAT/C/FRA/CO/7).

United Nations Committee against Torture. Concluding observations on the seventh periodic report of Switzerland. (CAT/C/CHE/CO/7).

United Nations Free & Equal Campaign. Factsheet: Intersex.

United Nations General Assembly. Discriminatory laws and practices and acts of violence against individuals based on their sexual orientation and gender identity (A/HRC/19/41).

United Nations General Assembly. Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment Juan E. Méndez (A/HRC/22/53).

van der Have, Miriam, Co-Chairperson, OII Europe. Lecture on 11 June 2018.

van Lisdonk, Jantine (2014). Living with intersex/DSD. An exploratory study of the social situation of persons with intersex/DSD. The Netherlands Institute for Social Research.

Väestörekisterikeskus (2018). Suomen ennakkoväkiluku 2017.

Available in English: Population Register Centre (2018). Preliminary population statistics 2017.

World Health Organisation (2014). Eliminating forced, coercive and otherwise involuntary sterilization: An interagency statement.

World Health Organisation (2015). Sexual health, human rights and the law.

UN Committee on the Rights of the Child:
- General Comment No. 7 (2005): Implementing child rights in early childhood.
- General Comment No. 14 (2013) on the right of the child to have his or her best interests taken as a primary consideration.
- General comment No. 18 (2014) on harmful practices.

UN Convention on the Rights of the Child. Finnish Treaty Series 59/1991 and 60/1991.

Yogyakarta Principles (2006). Principles on the application of international human rights law in relation to sexual orientation and gender identity.

Yogyakarta Principles (2017). Additional Principles and State Obligations on the Application of International Human Rights Law in relation to Sexual Orientation, Gender Identity, Gender Expression and Sex Characteristics to complement the Yogyakarta Principles.

Zillén, Kavot; Jameson Garland & Santa Slokenberga (2017). The Rights of Children in Biomedicine. Challenges posed by scientific advances and uncertainties. Report commissioned by the Committee on Bioethics of the Council of Europe.

Malta

Act No. XIII of 2018. Gender-Based Violence and Domestic Violence Act, 2018.

Gabriella Calleja, Ministry for European Affairs and Equality, Head of SOGIESC Unit. Interview on 22 June 2018.

Gender Identity, Gender Expression and Sex Characteristics Act (GIGESC Act) 2015.

LGBTIQ Equality Strategy & Action Plan 2018–2022.

Malta Civil Code.

Ministry for Education and Employment (2015). Trans, gender variant and intersex students in schools – Policy; Trans, gender variant and intersex students in schools – Procedures.

Ministry of European Affairs and Equality 09/2017, PR171985en.

Portugal

Lei n.º 38/2018, Direito à autodeterminação da identidade de género e expressão de género e à proteção das características sexuais de cada pessoa [*Law No. 38/2018, on every person's right to self-determination of gender identity and gender expression and to the protection of sex characteristics*].

Luis Isidro, assistant, Office of the Minister of Justice, Portugal. Legal opinion of 15 October 2018.

OII Europe. Portugal adopts law protecting intersex people. PR 12 July 2018.

Germany

Ina-Marie Blomeyer, German Federal Family Ministry (BMFSFJ), head of the unit for same-sex lifestyles and gender identity. Interview on 30 July 2018.

Bundesministeriums für Familie, Senioren, Frauen und Jugend [*Federal Ministry for Family Affairs, Senior Citizens, Women and Youth*] (BMFSFJ). Gleichgeschlechtliche Lebensweisen und geschlechtliche Vielfalt [*Same-sex Lifestyles and Gender Diversity*]. https://www.bmfsfj.de/bmfsfj/themen/gleichstellung/gleichgeschlechtliche-lebensweisen-geschlechtsidentitaet

BMFSFJ (2017). Schutz und Akzeptanz von geschlechtlicher [*Protection and acceptance of gender diversity*]. Vielfalt Schlussfolgerungen des Bundesministeriums für Familie, Senioren, Frauen und Jugend aus der Arbeit der Interministeriellen Arbeitsgruppe Trans- und Intersexualität [*Conclusions of the Federal Ministry for Family Affairs, Senior Citizens, Women and Youth from the work of the Interministerial Working Group on Trans and Intersex Persons*].

Bundesverfassungsgericht [*Federal Constitutional Court*], BvR 2019/16.

Klöppel, Ulrike (2016). Zur Aktualität kosmetischer Operationen „uneindeutiger” Genitalien im Kindesalter [*On the relevance of cosmetic surgery on 'ambiguous' genitalia in childhood*].

Iceland

Agreement between the Progressive Party, the Independence Party and the Left Green Movement on collaboration in a coalition government and reinforcing the capacity of the Althingi (2017).

Linda Rós Alfreðsdóttir, Senior Adviser, Ministry of Welfare. Interview on 25 October 2018.

Kitty Anderson, Chair of Intersex Iceland. Interview on 27 July 2018.

Background interviews with experts

The interviews were conducted over the phone and face-to-face between May and September 2018.

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