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**LEGAL ASPECTS ON MEDICAL INTERVENTIONS ON
INTERSEX CHILDREN'S GENDER FROM THE PERSPECTIVE
OF THE BEST INTEREST OF THE CHILD**

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I hereby declare that I have compiled the thesis independently and all works, important standpoints and data by other authors have been properly referenced and the same paper has not been previously presented for grading.
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TABLE OF CONTENTS

ABSTRACT	4
LIST OF ABBREVIATIONS	5
INTRODUCTION	6
1. INTERSEX, WHAT IT IS?	9
1.1. Terminology and nomenclature.....	9
1.2. Medical classifications of DSD	12
2. CONVENTION ON THE RIGHTS OF THE CHILD	15
2.1. Best Interest of the child.....	16
2.2. The right to enjoy the highest attainable standard of health and treatment.....	21
2.3. Registration of intersex child.....	22
3. LEGAL STATUS OF INTERSEX CHILDREN IN FINLAND.....	23
3.1. The Healthcare Act.....	25
3.2. The Patient Act	28
3.3. Medical ethics supporting the rights of intersex children.....	30
4. INTERSEX CHILDREN AND CLINICAL PRACTICE	32
4.1 General aspects on the clinical practice.....	36
4.2. Treating units as an arbitrary decision-maker	37
5. THE POSITION STATEMENT OF NATIONAL ADVISORY BOARD ON SOCIAL WELFARE AND HEALTH CARE ETHICS “ETENE“	39
6. IS THERE NEED FOR NEW LEGISLATION FOR INTERSEX CHILD?.....	41
C ONCLUSION	47
LIST OF REFERENCES	50
APPENDICE	55
Appendix 1. Non-exclusive licence.....	56

ABSTRACT

This paper provides an answer to, what is the best interest of intersex children. The paper illustrates the insufficiency of the current Finnish legislation and suggests ways to enhance it. The legislation does not set a uniform way of treatment nor procedure for the treatment of intersex children. The practice holds to statements and opinions of organizations and individual healthcare practitioners and parents of intersex children. The paper aims at justifying why the issue should be regulated in the legislation. The research is done by analyzing legal, medical, and psychological literature and comparing it to Finnish legislation. The United Nations Convention on the rights of the child is the basis for the analysis since the Convention introduces the principle of the best interest of the child.

The research is formed to answer two questions. Firstly, Should the intersex children`s treatment be regulated by law. Secondly, Is prohibition to treat intersex children before receiving the child`s consent always in the best interest of the child. After analyzing the essence of the principle of the best interest of the child and the current procedure in Finland the research concludes that it is clear that amendments to the legislation are necessary. However, it should not be a clear prohibition on medical interventions at an early age. Such prohibition would be unproportionate strict and on some occasions, it would not be in the best interest of the child.

Intersex, DSD, Best interest of the child, Rights of the child, Medical Law

LIST OF ABBREVIATIONS

AIS	Androgen insensitivity syndrome
CAH	Congenital adrenal hyperplasia
CAIS	Complete Androgen Insensitivity Syndrome
CESCR	The Committee on Economic, Social and Cultural Rights
CRC	The Committee on the Rights of the child
DSD	A Disorder of sex Development
ECHR	European Court of Human Rights
ETENE	The National Advisory Board on Social Welfare and Health Care Ethics
KHO	Korkein Hallinto-oikeus (Supreme Administrative Court of Finland)
KKO	Korkein Oikeus (the Supreme Court of Finland)
PAIS	Partial Androgen Insensitivity Syndrome
UN	The United Nations
UNCRC	The United Nations Convention on the Rights of the Child

INTRODUCTION

Gender is visible on a daily bases on society and gender stereotypes are known by the young and old. Gender stereotypes are an ingrown part of society. We are so used to them that we might not even recognize the occurrence of them. Still, gender stereotypes are very clear at an unconscious level. Usually, gender stereotypes are best acknowledged when someone diverges from the stereotype. In the first steps of life, the forming of gender is a complex process that is affected by many factors. The complex process contains several phases where even a slight disorder might manifest itself later on as unclarity of gender. There is no single perfect way to define gender. Professionals of different fields tend to approach the gender definition from different angles. For example, among medical professionals, the concept of gender is considered mainly based on genes and biological features. At the same time, psychologists might emphasize the person's own experience of gender. Gender can be defined in different ways and the biological appearance of gender and gender identity might conflict with each other. However, for the research gender is considered merely a biological feature to avoid confusion with the gender identity and due to the medical aspects of the research.

Attitudes towards the concept of gender are changing because part of society has opened up to the possibility that the binary concept of gender does not cover every possibility of gender. The third sex has been a hot topic for discussion since it has been brought up that there exist other genders beyond the traditional male and female. Intersex children are continually born in every nation but it seems that they gain very little attention. Historically, it was thought that intersex is a disease and it should be treated and body repaired, as soon as possible, after birth into a woman or a man.¹ Nowadays, it is thought that one should be able to determine for himself, whether he wants his bodily sex characteristic to be medically repaired into ordinary female or male characteristics or not. The fixing of gender may include medication and surgical operations.² Fixing of gender characteristics without patients' consent is not in conformity with the right to self-determination. Infants are incapable of expressing their consent and a legal and ethical dilemma arises.

¹ Gruber, N. (2005). Ethics in medicine: With special focus on the concepts of sex and gender in intersex management. *Cardozo Journal of Law & Gender*, 12(1), 117-126. 120.

² Hughes, I. A., et al. (2006). Consensus statement on management of intersex disorders. *Journal of pediatric urology*, 2(3), 148-162. 152,153.

ETENE (The National Advisory Board on Social Welfare and Health Care Ethics) has guided in its position statement that the gender shall not be fixed before the child is capable of giving his informed consent.³ However, the ETENE'S position statement is not binding and there is no legally binding way to proceed with the treatment of intersex children. According to the UNCRC (United Nations Convention on the rights of the child), the child has the right to develop fully and the best interest of the child has to be protected. In practice, the UNCRC principle of the best interest of the children does not set clarity since it could be interpreted in multiple ways depending on the reasoning. Determining one's gender affects the rest of one's life and might have serious problems caused to one's mental health and development. Society is full of examples, where it becomes visible that we are forced into one of the genders: male or female. Typically, the first question imposed to a new mother is, whether the baby is a boy or a girl. Starting from that point unclear gender amuses the surrounding society. People who are born in neither of the binary genders have to face a lot of trouble, not to mention their parents who either have to keep the secret or face the social amusement caused by their child's atypical gender. Still, the bodies of intersex children shall not be intervened only to release the embarrassment of the parents. The legislation is completely mute about intersex persons and their treatment. Various bodies, besides ETENE, have introduced guidelines and statements on how the intersex should be treated and accepted in society. What is notable, nothing legally binding has been adopted and therefore it is important to analyze the issue.

In Finland, parents are generally entitled by the Patient Act to decide on underage children's treatment or non-treatment. As intersex treatment is not regulated separately the parents and treating unit personnel jointly hold the authority to decide on the treatment. The best interest of the child should be taken into account while making decisions affecting the child. The authority of the parents relies on the presumption that parents aim to serve the best interest of the child. However, it does not ensure that the best interests of the child are considered properly and objectively. Since parents and medical personnel naturally hold their personal opinion and the best interest of the child is extremely open to interpretation.

Legal research is carried out by using a qualitative method. The paper focuses on Finnish healthcare legislation and constitutional provisions that are related to intersex children. The analysis is based on the UNCRC which introduced the principle of the best interest of the child. The paper aims at justifying that the Finnish legislation shall be amended to recognize the intersex

³ The National Advisory Board on Ethics in Social and Health Care (2016) Intersukupuolisten lasten hoito. 22.3.2016.

condition and to regulate the medical treatment of intersex children to ensure the execution of the principle of the best interest of the child. In the end, the paper suggests a possible way that the legislation should adopt provisions granting an equal right to fair treatment for intersex children, under the principle of the right of the child. The paper will discuss situations where it would not be in the best interest of the child to let the intersex child develop and decide for themselves when they have reached a certain age.

The hypothesis states that there is an urgent need for new legislation to ensure the materialization of the best interest of the child principle. The paper will answer two questions. The main research question is the following: Should the procedure for intersexual child treatment be regulated by legislative means and what the legislation should include? As a secondary question, the research evaluates: Is it always in the best interest of the child to refrain from medical treatment before the child is capable of expressing his consent? The research is legal but it exploits medical and other literature as well. The research questions are closely related to medicine and therefore they can not be answered purely in the light of legal literature. It is necessary to include medical literature in the research data of the thesis to support the answers to the research questions. The best interest of the child includes all parts of the child's life, for example: physical, legal, social and medical. Therefore, the research data includes some multidisciplinary sources also besides legal and medical data. For instance, psychological- and medical literature shall also be part of the research data.

The paper is divided into five parts before the ultimate conclusion. The paper begins with a general overview of DSD (Disorder of Sex Development) and the most common forms of DSD. The second part will focus on the UNCRC especially in the best interest of the child principle and how it is related to the treatment of DSD patients. The third part will discuss the Finnish legislation and the clinical practice of intersex children as well as the role of treating unit personnel and their possibility to affect the treatment. The fourth part of the paper will analyze ETENE's position statement on the treatment of intersex children. Finally, the last part before the conclusion will reason why it is necessary to amend the legislation.

1. INTERSEX, WHAT IT IS?

1.1. Terminology and nomenclature

To define what intersex is, and for the understanding of the paper, it is essential to understand basic terminology related to intersex, especially the difference between sex and gender identity. Biological sex is commonly assigned in birth and it classifies people into male, female or intersex based on genitals and gonads and configuration of sex chromosomes.⁴ The concept of gender has evolved to include also the psychosocial aspects. Classically, the determination of gender consists of three parts: chromosome, gonadal and appearance.⁵ At the beginning Disorder of Sex Development (DSD) is biological and it appears in various forms. All variations of DSD can be defined to be: “congenital conditions in which development of chromosomal, gonadal or anatomical sex is atypical.”⁶ For evaluating the need for treatment it is necessary to understand that the level of atypicality varies. Anatomical atypicality may appear in the genital area for example as an enlarged clitoris to a penis.⁷ The range of variation among atypical gender cases is wide. Intersex is not always even noticed immediately at the time of the birth or childhood, it may appear not until puberty.⁸

Chromosomal, gonadal or anatomical appearance can not be solely considered to determine the gender and the gender identity can not always be predicted based on the before mentioned parts.⁹ Gender identity is a person`s own internal experience on how they experience and classify their gender.¹⁰ The gender identity and sex may contradict with each other but for the purposes of the research, it should be kept in mind not to mix the before mentioned concepts. Intersex and transgender are often mixed but the separation remains clear. Intersex is about the atypical biological sex and transgender means that the gender identity of a person is opposite to the

⁴ Gurney, K. (2007). Sex and the Surgeon`s Knife: The Family Court`s Dilemma ... Informed Consent and the Specter of Iatrogenic Harm to Children with Intersex Characteristics. *American Journal of Law & Medicine*, 33(4), 625–661. 625.

⁵ Välimäki, M., et al. (2009). *Endokrinologia*. 2009. (2nd ed.) Jyväskylä, Finland: Duodecim Kustannus Oy. 579.

⁶ Hughes I.A., et al. (2006), *Supra nota 2*, 149.

⁷ Alpern, A.N., et al. (2017). Development of Health-Related Quality of Life Instruments for Young Children With Disorders of Sex Development (DSD) and Their Parents, *Journal of Pediatric Psychology*, Volume 42, Issue 5, 544–558, 545.

⁸ Greenberg, J. A. (2012). *Intersexuality and the Law: Why sex matters*. New York: New York University Press.

⁹ Välimäki, M., et al. (2009), *supra nota 5*.

¹⁰ Picard, B. (2018). Gender Identity: Developments in the Law and Human Rights Protections. *University of New Brunswick Law Journal*. Vol. 69, 126-159. 128.

biological sex. The reasons for the occurrence of transgender remain unknown. After clarifying gender identity and sex, it is understandable to state that intersex means the “third sex” of which Finnish and many other national legislations remain silent about.

Nomenclature, such as intersex, pseudohermaphroditism, hermaphroditism, sex reversal is used concerning the atypical formation of gender.¹¹ According to some, these terms have defamatory tone and therefore the term Disorder of Sex Development (DSD) is preferred in some contexts. Updated nomenclature of different forms of DSD was published in 2006 in the European Society for Paediatric Endocrinology and Lawson Wilkins Pediatric Endocrine Society consensus report.¹² The purpose of the nomenclature reform was to minimize the use of defamatory terms.¹³ The consensus report established the terms DSD, 46, XY DSD, 46, XX DSD, ovotesticular DSD and 46, XX testicular DSD.¹⁴ DSD is a wider term than intersex, which is usually used about the ambiguity of external genitalia.¹⁵ In this paper, both terms are used to discuss the same issue and the terms DSD and intersex are understood widely. Besides, the unfortunate negative associations related to the terms as a hermaphrodite, they might cause misunderstandings. DSD could be seen as a natural variation of the human body but in medicine, the term ambiguity is used.¹⁶ The term DSD was introduced to stop the use of defamatory terms. It did not succeed perfectly since DSD has also gained criticism from classifying the condition precisely as a disorder and not as a normal variation of the human body. Unfortunately, there are only estimations on the number of intersex persons, which vary between 1:45000-1,7% of the population.¹⁷ To concretize, one estimation states that 1 of 4500 infants born alive has the ambiguity of genitals¹⁸. DSDs are not visible in the social interaction but it appears about as often as the well-know Down syndrome.¹⁹ Historically, the surgical intervention at the very early stage of infants' life was the standard of care. Even

¹¹ Hughes, I.A., et al. (2006), *supra nota 2*, 149.

¹² Välimäki, M., et al. (2009), *supra nota 5*, 577.

¹³ *Ibid.*

¹⁴ *Ibid*, 578.

¹⁵ Nor DSD or intersex is used as a term only for abnormality of external genitalia.

¹⁶ Kessler, S.J., (1998) *Lessons from the intersexed*. New Brunswick, USA: Rutgers University Press; 1998. 8.

¹⁷ Oikeusministeriö (2019). Ei tietoa eikä vaihtoehtoja selvitys intersukupuolisten ihmisten oikeuksista ja kokemuksista, oikeusministeriön julkaisuja, selvityksiä ja ohjeita Oikeusministeriö, Helsinki 2019.

¹⁸ Michala, L., et al. (2014) Practice changes in childhood surgery for ambiguous genitalia? *Journal of Pediatric Urology*. Volume 10, Issue 5, Pages 934-939, 935.; Thyen, U., et al. (2006). Epidemiology and initial management of ambiguous genitalia at birth in Germany. *Hormone research in paediatrics*, 66(4), 195-203, 196.

¹⁹ Preves, S. E. (2005). Out of the o.r. and into the streets: Exploring the impact of the intersex media activism. *Cardozo Journal of Law & Gender*, 12(1), 247-288. 248.; Desai, S. S. (1997). Down syndrome: a review of the literature. *Oral Surgery, Oral Medicine, Oral Pathology, Oral Radiology, and Endodontology*, 84(3), 279-285, 280.; Dreger, A. D. (1998). *Hermaphrodites and the medical invention of sex*. Harvard University Press.; Roberts, H. E., Cragan, J. D., Cono, J., Khoury, M. J., Weatherly, M. R., & Moore, C. A. (1998). Increased frequency of cystic fibrosis among infants with jejunoileal atresia. *American journal of medical genetics*, 78(5), 446-449, 447.

though there was no scientific reasoning for medical intervention necessity.²⁰ Early treatment was provided for social purposes to normalize DSD children. The clinical practice of DSD children will be described in detail in section four of the research.

²⁰ Dimond, M., Garland, J., (2014) Evidence regarding cosmetic and medically unnecessary surgery on infants. *Journal of Pediatric Urology*, Volume 10, Issue 1, 2-6, 3.

1.2. Medical classifications of DSD

The typical chromosome combinations are XX (female) and XY (male). Atypical chromosome variations include XXX, XXY, XXXY, XYY, and XYYY.²¹ IA Hughes proposed three-dimensional classification for DSD based on the cause of the disorder, which is in conformity with the consensus reports nomenclature reform: 1. Disorder of the development of sex chromosome 2. The disorder of the development of 46XY,²² who are called intersex boys. 3. The disorder of the development of 46XX,²³ who are called intersex girls. The term intersex boy or girl might seem confusing but it illustrates that the karyotype is basically clear but some disorders of developed in the sex chromosome have been detected. In the first category, the sex is not clear in gene-level it may appear as mixed chromosomal sex. In the second category, the sex on gene-level is male but disorders appear for instance as a disorder of testicular development or androgen synthesis. The third category represents genetic females, for example, whose ovarian development is atypical or maternal virilizing tumors appear.²⁴ To determine what is in the best interest of the intersex children the forms of intersex have to be understood in a more detailed manner. It seems to be common to picture intersex to appear only as extremely abnormal external genitalia. In truth, the external genitalia is only a fraction of reproduction organs, for instance, ovaries and uterus of the female reproductive organs are mainly internal and therefore not visible. Most of the intersex bodies include typical genitalia of female or male and only some atypical characteristics. Intersex appears in different forms, for the purpose of the research not all of them are expedient to describe. Therefore, only the most common forms, which are CAH, AIS, DG, turner, and Klinefelter syndrome, of atypical gender is described in the chapter. Turner and Klinefelter syndrome patient's gender is not unclear at the time of the birth. The abnormalities arrive usually at the time of puberty.²⁵ Therefore, they are not even always defined as intersex since sex is considered to be clear at birth. As the conditions are not noticed at an early age these conditions are not considered in detail because the research focuses on forms in which medical treatment is provided before the child can express consent to the treatment.

²¹ McDonald, E. (2015). Intersex people in aotearoa new zealand: The challenges for law and social policy: Part i: Critiquing gender normalising surgery. *Victoria University of Wellington Law Review*, 46(3), 705-724. 705, 708

²² 46XY karyotype is genetically male.

²³ 46XX karyotype is genetically female.

²⁴ Hughes, I. A. (2008). Disorders of sex development: a new definition and classification. *Best practice & research Clinical endocrinology & metabolism*, 22(1), 119-134. 122

²⁵ Välimäki, M., et al. (2009), *supra nota* 5, 587.

The deficiency of one or more enzymes involved in the production of steroid hormones in the body for genetic reasons is called Congenital adrenal hyperplasia (CAH) which leads to a reduction in cortisol secretion from the adrenal gland.²⁶ CAH is the most common cause of unclear sex.²⁷ Among CAH patients different variations of the condition are seen but for 90-95% of CAH patients, the cause is 21 hydroxylase deficiency.²⁸ In the case, hormone production begins to accelerate in the adrenal gland under the influence of the pituitary gland, resulting in XX chromosomal virilization of children before or after birth.²⁹ Untreated CAH can lead to masculinization at puberty. CAH patients need life long treatment for the cortisol secretion because of cortisol deficiency contributes to poor cardiac function, poor vascular response to catecholamines, decreased glomerular filtration rate, and increased secretion of antidiuretic hormone.³⁰ “Among classic CAH patients, about three-fourths cannot synthesize adequate amounts of aldosterone due to severely impaired 21-hydroxylation of progesterone. Aldosterone is essential for normal sodium homeostasis; deficiency of this hormone results in sodium loss via the kidney, colon, and sweat glands.³¹” (White, P. C., & Speiser, P. W. 2000, 252) Sodium malfunctioning is commonly called as salt wasting which might be fetal. In modern medicine, CAH can be detected at the time of pregnancy which enables the treatment to begin before the birth.³² “Later diagnosis is associated with greater difficulty in achieving hormonal control, abnormal tempo of puberty, and short stature.³³” Basically, from the medical perspective, the best functionality is achieved when the treatment is started immediately after detecting the condition. CAH patients are usually called intersex girls and it is an example of 46 XX DSD. CAH has been proved to cause infertility and reproductive problems for instance: oligomenorrhea and amenorrhea, which are menstrual disturbances³⁴. Due to medical treatment’s development more and more CAH diagnosed females have reproduced successfully.³⁵

²⁶ Merke, D. P., & Bornstein, S. R. (2005). Congenital adrenal hyperplasia. *The Lancet*, 365(9477), 2125-2136, 2126.

²⁷ White, P. C., & Speiser, P. W. (2000). Congenital adrenal hyperplasia due to 21-hydroxylase deficiency. *Endocrine reviews*, 21(3), 245-291. 245.

²⁸ Speiser, P. W., & White, P. C. (2003). Congenital adrenal hyperplasia. *New England Journal of Medicine*, 349(8), 776-788. 776.

²⁹ White, P. C., & Speiser, P. W. (2000), *supra nota* 27.

³⁰ Speiser, P. W., & White, P. C. (2003). *supra nota* 28,777.

³¹ White, P. C., & Speiser, P. W. (2000). *supra nota* 27, 252.

³² Merke, D. P., & Bornstein, S. R. (2005), *supra nota* 26, 2125.

³³ Speiser, P. W., & White, P. C. (2003), *supra nota* 28, 778.

³⁴ Rickenlund, A., Carlström, K., Jörn Ekblom, B., Brismar, T. B., von Schoultz, B., & Hirschberg, A. L. (2003). Hyperandrogenicity is an alternative mechanism underlying oligomenorrhea or amenorrhea in female athletes and may improve physical performance. *Fertility and sterility*, 79(4), 947-955. 947.

³⁵ Speiser, P. W., & White, P. C. (2003), *supra nota* 28, 778.

Androgen insensitivity syndrome (AIS) appears as an abnormality of cell reception of testosterone.³⁶ AIS patient's body does not react to testosterone which is the male hormone and it constitutes a possibility that XY-chromosome baby is born with feminine genitalia. AIS occurs as complete- (CAIS) or partial AIS (PAIS).³⁷ CAIS 46 XY children have typical female external genitalia but the gonadal is testicular, which typically remains in the abdomen.³⁸ CAIS patients are usually regarded as girls at the time of birth because the external genitalia is completely female, the problem is usually detected at the time of puberty because CAIS patients do not menstruate, typically at this point, the testicles are removed.³⁹ CAIS patient's testicle removal decreases the risk of cancer, which is the main reason why testicle removals are performed.⁴⁰ There is little research about the gender identity of CAIS patients even though it would be interesting as their genotype and phenotype differ. Partial AIS formulation is similar to complete AIS but the external genitalia can not be classified as female or male. PAIS children's external genitalia can be surgically treated to fit in the normal category of one of the ordinary sexes. CAIS patients are usually born infertile, but PAIS patients might have a slight chance for fertility.⁴¹

Gonadal dysgenesis (GD) refers to undevelopment of gonadal cells. Gonadal cells are the reproductive cells and due to their undeveloped GD patients are born infertile. A high percentage of tumor among GD patient has created it an interesting research topic. One study involved 25 patients with Turner's syndrome and 26 patients with gonadal dysgenesis without somatic malformations.⁴² From the group of 51 patients who categorized legally as female the study found out that in 26 cases tumors were detected.⁴³ From Turner's syndrome patient group of 26 patients, only 2 of the group members suffered from tumors.⁴⁴ The studies show that the risks of a tumour can be predicted based on the form of DSD, more particular even on the base of the type of GD.⁴⁵

³⁶ Hines, M., et al. (2003). Psychological outcomes and gender-related development in complete androgen insensitivity syndrome. *Archives of sexual behavior*, 32(2), 93-101. 93

³⁷ Bevan, C. L., et al, (1996). Functional analysis of six androgen receptor mutations identified in patients with partial androgen insensitivity syndrome. *Human Molecular Genetics*, 5(2), 265-273. 265.

³⁹ Hines, M., et al, *supra nota* 36, 93.

⁴⁰ Lloyd, E. (2005). From the hospital to the courtroom: statutory proposal for recognizing and protecting the legal rights of intersex children. *Cardozo Journal of Law & Gender*, 12(1), 155-196 260.

⁴¹ Bevan, C. L., et al, *supra nota* 37, 265.

⁴² Teter, J., & Boczkowski, K. (1967). Occurrence of tumors in dysgenetic gonads. *Cancer*, 20(8), 1301-1310.1301.

⁴³ *Ibid*,1305.

⁴⁴ *Ibid*.

⁴⁵ *Ibid*.

2. CONVENTION ON THE RIGHTS OF THE CHILD

UNCRC was adopted in 1989. After a long drafting process states were ready to adopt a comprehensive compilation of the minimum standard of civil-political, economic-social-cultural, and humanitarian rights that all governments should ensure for the children.⁴⁶ It is a widely ratified international treaty of which only two states, the United States of America and Somalia, have not signed.⁴⁷ Finland has ratified the UNCRC which means that it is legally binding document and national legislation has to be in accordance with the UNCRC. Children are human beings and all legal rights appertain, children, like adults. The difference is that children do not have the same capacity and knowledge to enforce their own legal rights.⁴⁸ Children have become autonomous holders of their rights. Parents' and governments role is to guarantee that children get to enjoy their rights. The key principles of the UNCRC are non-discriminatory and equality, the best interest of the child, survival and development and participation and inclusion.⁴⁹ The principles have been raised by the Committee on the Rights of the Child (CRC) at its first meeting in the autumn of 1991. The principles are derived from Articles 2, 3, 6 and 12 of the UNCRC.⁵⁰ According to UNCRC article 4, by ratifying the Convention the contracting parties undertake to take all measures to implement the Convention in the state. It means that the provision should be directly applicable and executed. It is necessary to make sure that national legislation is in conformity with the Convention.⁵¹

⁴⁶ Davidson, H. A. (1991). The child's right to be heard and represented in judicial proceedings. *Pepperdine Law Review*, 18(2), 255-278. 255

⁴⁷ Scherrer, J.L.(2012) The United Nations Convention on the Rights of the Child as Policy and Strategy for Social Work Action in Child Welfare in the United States, *Social Work*, Volume 57, Issue 1, January 2012, 11–22. 15.

⁴⁸ Hakalehto-Wainio, S. (2011). Lasten oikeudet lasten oikeuksien sopimuksessa. *Defensor Legis*, 4/2011.510-525. 510.

⁵⁰ Committee on the rights of the child, General guidelines regarding the form and content of initial reports to be submitted by states parties under article 44, paragraph 1 (a) of the Convention (CRC/C/5), 1.

⁵¹ Committee on the Rights of the Child, General comment no. 5 (2003): General measures of implementation of the Convention on the Rights of the Child, 27 November 2003, 1

2.1. Best Interest of the child

The Article 3 (1) of the UNCRC states: “In all actions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies, the best interests of the child shall be a primary consideration.” The Article 3 (1) established the principle of the best interest of the child which is a fundamental value of the entire UNCRC.⁵² The Committee on the Rights of the Child underlines on its general comment on the right of the child to have his or her best interests taken as a primary consideration that the article 3 (1), “creates an intrinsic obligation for States, is directly applicable (self-executing) and can be invoked before a court.”⁵³ The principle aims at ensuring the fulfillment of all other rights of the convention and holistic development of the child.⁵⁴ Holistic refers to all aspects of the children’s development, which contains: “physical, mental, spiritual, moral, psychological and social development”⁵⁵ Best interest means that all the essential interests of the child have to be taken into account while deciding on children related issues.⁵⁶ The determination of the best interests of the child is linked to the articles of the UNCRC. The best interest of the child is that all of the rights ensured by the UNCRC will be fully materialized.⁵⁷ The best interest of a child is to be determined at the end by adults but it is necessary to assess the child's perspective. The child's perspective has to be taken into account but the desire of the child does not necessarily indicate the best interest of the child. Children are not considered to be capable of deciding what is best for them. The decision making power is held by adults at the end of the day which creates a major responsibility to evaluate the situation fully. The best interest of the child has to be a primary consideration which means for example that for intersex treatment the parents' personal wish to raise a girl is not a proper reason for the medical treatment of an intersex child. The line of treatment that provides the optimum prerequisite for the holistic development of the child shall be executed.

⁵²Committee 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 art. 3, para. 1, (CRC /C/GC/14), 3.

⁵³ CRC/C/GC/14, 4

⁵⁴ CRC /C/GC/14, 3

⁵⁵ Committee on the Rights of the Children, General comment no. 13, The right of the child to freedom from all forms of violence, 18. April 2011.(CRC/CG/13), 24.

⁵⁶ Hakalehto-Wainio S (2011), *supra nota* 48, 516

⁵⁷ *Ibid.*

The CRC stated on the general comment that the best interest can be divided into three dimensions. It includes a substantive right according to which the child⁵⁸ is entitled to have his best interests assessed and taken into primary consideration.⁵⁹ A fundamental; interpretative legal principle according to which, legislation that enables various interpretation, should be interpreted in order to best serve the child and a rule of the procedure according to which while decision that will have an effect on children or individual child the positive and negative impacts affecting the child has to be evaluated.⁶⁰ In deciding on intersex children`s treatment the evaluation of the positive and negative effects is complex to balance between the different aspects. The main point of evaluation should contain an evaluation of the physical and social disadvantages and capability of reproduction. The positive and negative effects are analyzed later on in the paper. The rule of procedure sets the decision-making bodies of the state parties a compulsion to prove how the child`s interest is taken into account in the decisions. To comply with the Convention contracting states are obliged to take implementation measures according to articles 4,42,44 (6).⁶¹ The measures include, for example, reviewing and amending national legislation in case it does not serve the principle of the best interest of the child.⁶² In case contracting state`s national legislation does not comply with the principle of the best interest of the child the contracting state could be considered to be obliged to amend the national legislation.

The concept of the best interest of the child is flexible and it should be determined on a case by case basis in relation to one specific child. The flexibility of the principle can be used to manipulate the essential aims of it. For example, it has been used in a wrongful manner by governments and governmental officials in the context of defending racists politicians.⁶³ In the intersex children`s treatment, the surgical intervention could be reasoned to be in the best interest as it decreases social embarrassment or better success rate of the treatment. On the other hand, it could be reasoned that surgical interventions are not in the best interest of the child because they do not protect the right to self-determination and the child might suffer dysphoria while growing up if the gender is fixed on the opposite gender as the child`s gender identity develops. The flexibility of the principle allows it to be used for and against in many cases. While arguing what is in the best interest of the child the reasoning is the most relevant factor. Objective reasoning shall have taken into account

⁵⁸ Substantive right is applicable to individual child, defined or undefined group of children or children in general.

⁵⁹ CRC/C/GC/14, 4.

⁶⁰ CRC/C/GC/14, 4.

⁶¹ CRC/C/CG/14, 5.

⁶² CRC/C/CG/14, 6.

⁶³ CRC/C/CG/14, 10.

all possible options and their positive and negative aspects and evaluated them for the benefit of the child. The principle of the best interest of the child is applicable to an individual child, defined or undefined group of children or children in general. In a collective decision that is made for example by legislative bodies, the best interest shall be analyzed based on the interest of the defined group of children or children in general.⁶⁴ Due to the essence of the best interest of the child, it can not be treated as a scientific fact that is once determined and never challenged. The best interest of the child depends also on the surrounding society and it has to be challenged as the society or medical techniques develop. To concretize, the medical techniques have developed fast to the digitalization and the surgical results are now better than ever. If the success rate of a surgical fix of ambiguous genital was poor before but better it has to be taken into account while assessing what is in the best interest of the child.⁶⁵

The CRC has stressed the inseparable link between the Articles 3 (1) and 12 of the UNCRC. The article 12 states that the child should be able to freely express his views on a matter relating to him. The article 12 guarantees the child the right to participate and is usually referred to as “the child right to be heard”.⁶⁶ Article 3 (1) and 12 interpreted jointly and observing the inseparable link constitutes the child’s right to have his views taken into account while determining the best interest of the child. The rights granted by 3(1) and 12 are different in nature. The best interest of the child is usually a passive right that in the end is assessed by an adult and the right to be heard is an active right that involves active participation of the child.⁶⁷ Rebecca M. Stahl stated that the UNCRC contains contradicting provisions relating to the right to be heard and the best interest of the children.⁶⁸ The provisions indeed are overlapping but the jointly interpreted they form a balanced concept and actually, they can also be seen as completing each other. The both rights share a major amount of flexibility, as described in the previous chapter the best interest of the child is extremely open to interpretation and the same applies to the right to be heard. The right to be heard can come to fruition in different forms. In some cases, it could mean that child has received some amount of information about the matter or he can hold a significant amount of

⁶⁴ CRC/C/CG/14, 9.

⁶⁵ At this point, I am not stating that the fixing of genitalia is in the best interest of child is actually in the best interest of the child. The point is merely to illustrate by an example how the principle is open to change.

⁶⁶ Krappmann, L. (2010). The weight of the child's view (Article 12 of the Convention on the Rights of the Child). *The International Journal of Children's Rights*, 18(4), 501-513. 501.

⁶⁷ Lücker-Babel, M. F. (1995). The right of the child to express views and to be heard: An attempt to interpret Article 12 of the UN Convention on the Rights of the Child. *The International Journal of Children's Rights*, 3(3-4), 391-404. 393, 394.

⁶⁸ Stahl, R. M. (2007). Don't Forget about Me: Implementing Article 12 of the United Nations Convention on the Rights of the Child. *Arizona Journal of International & Comparative Law*, 24(3), 803-842. 804.

decision-making power.⁶⁹ The concept of the right to be heard in health-care shall be formed to suit the capacity of the child as well as the decision to be made. For instance, a toddler suffering a tumor can not be considered to make a decision or understand the condition but for a teenager, it is important to provide more information on the condition and take his or her opinion of the treatment into consideration.

All aged children hold a similar right to get their best interest taken into account. The children's views are taken into account in relation to the capacity of the child. Very young children do not enjoy the link between Article 3(1) and 12, since they are incapable of expressing their views or acknowledging the issue. However, the decision made in the best interests of the child is not necessarily the same as the one in the child's opinion. In principle, the best interests of the child are not the same as the will of the child. Although, they may result in the same outcome. The right to be heard relates to participation, it does not entitle the child the decision-making power. Children shall be consulted in decision-making processes concerning them but the decision-making power is held by someone else.⁷⁰ The child is also under no obligation to make decisions and should not be left with decision-making responsibilities in difficult decision-making situations. The primary direction of ensuring the best interest of the child traditionally was parents. The government shall be an option used in case the parents fail to protect the best interest of the child.

The UNCRC emphasizes the responsibilities and rights of parents to ensure the development and well-being of their children. The position of parents is quite strong on the basis of the treaty provisions. According to Article 3 of the UNCRC, the State must take into account the rights and obligations of parents. Article 5 of the UNCRC obliges States to respect the right of parents to direct their children in the exercise of the rights contained in the Agreement. On the other hand, the right of parents to raise and care for a child is limited by the obligation under Article 18 of the UNCRC. Thus, parents must ensure that all the rights of the child are exercised and cannot infringe on the rights of the child on the basis of their right to raise and take care of the child.⁷¹

⁶⁹ Donnelly, M., Kilkelly, U. (2011). Child-friendly healthcare: delivering on the right to be heard. *Medical Law Review*, 19(1), 27-54. 27.

⁷⁰ *Ibid*, 29.

⁷¹ Hakalehto, S., Helander, M. (2017). Poikien ei-lääketieteellinen ympärileikkaus lapsen oikeuksien näkökulmasta. *Defensor legis*, 6/2017, 942-961. 944.

From the perspective of the age of the UNCRC the link of the Article 12 to medical law is fairly new. The right to be heard of a child was originally planned for litigation processes. To ensure that children have a say in litigation process relating to matters that consider them.⁷² The principle should be fully applied in medical law as well as to the participation of children in the decision-making process of their healthcare.⁷³ The responsibility of fulfillment of the principle in healthcare fall in the shoulders of pediatrics who shall be able to inform children according to their capacity to understand. The decision-making power is shared between parents and physician and both hold the right to express their views. The communication between the actors is in a vital role for the materialization of the child's right to be heard. The actors should have undisturbed and genuine communication to enable the child to express his opinion.⁷⁴

⁷² Donnelly, M., Kilkelly, U, *supra nota* 69, 27.

⁷³ *Ibid*, 28.

⁷⁴ Bosisio, R. (2012). Children's right to be heard: What children think. *International Journal of Children's Rights*, 20(1), 141-154. 143.

2.2. The right to enjoy the highest attainable standard of health and treatment

According to article 24(1) of the UNCRC, the children should be able to enjoy equal possibilities to enjoy the best standard of health.⁷⁵ States Parties of the UNCRC must assure children the right to the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health and children shall not be denied from access to healthcare services.⁷⁶ The right to health shall be one of the key elements while assessing the best interest of the child.⁷⁷ If multiple lines of treatment are possible for one condition the line of treatment shall decision of the line of the treatment shall be based on the evaluation of possible risks and side effects and the child's view.⁷⁸ The risk and side effect evaluation is extremely hard to carry out for intersex children's treatment. It seems that the major risks are most likely to be rather mental than physiological since the medical practice has evolved fast and the treatment provides functionality and high success rates. As described later on in the research physicians are usually able to classify the physiological gender into one of the binary genders, regardless of the amount of atypicality. The gender identity, in turn, can not be evaluated at a young age because the gender identity has not developed yet. The detrimental side effects of the assignment of sex or surgical fixing of the atypical sex will occur if the gender identity does not match with the assigned gender.

⁷⁵ Committee on the Rights of the Children, On the right of the child to the enjoyment of the highest attainable standard of health/ General comment no. 15, 17. April 2013, 8.

⁷⁶ UNRCR article 24 (1)

⁷⁷ CRC/C/CG/14, 16.

⁷⁸ CRC/C/CG/14, 17.

2.3. Registration of intersex child

According to Article 7 of the UNCRC, a child must be registered immediately after birth and have the right to a nationality. In Finland, while an infant is registered, they are given personal identification code which indicates the date of the birth, birth decade and gender. The registration faces a problem with an intersex infant whose sex is atypical. At the time of the birth, the child is assigned to one of the ordinary sexes in the government database. It has been argued that discrimination among transgender individuals arises while their outer gender expression is abnormal than the gender established in their identification documents. The strict division of binary sex and its possible harmful effects touch intersex persons as well. KHO (Korkein hallinto-oikeus, Supreme Administrative Court) issued judgment relating to transgenders and the difficulties the concept of binary gender causes to transgenders. The same reasoning is relevant in the case of intersex children because the situation has similar elements. If children is assigned to unfitting gender the identification document remains to show misleading indication of gender. The KHO stated in its judgment that since transgender has reached a point of treatment that the phenotype of the person does not fit the personality indicated in the identification document the process of identification might reveal the medical condition. The reveal of a medical condition is not appropriate since medical conditions are special categorized personal data and such reveal might predispose to discrimination.⁷⁹

In a similar way, DSD patients' sex assigned in an identification document might be misleading and cause distress. It is an example of how the condition gets revealed in an unpleasant way and causes harm to the patient. In the case of transgenders, the court has made a ruling and the legislation is changed. It enables transgender to changed sex assigned at birth in the identification document. It does not provide a solution for DSD children who do not categorize as either of the sexes.

⁷⁹ Korkein Hallinto-Oikeus, KHO 2009:15, 3.2.2009.

3. LEGAL STATUS OF INTERSEX CHILDREN IN FINLAND

Finnish legislation and constitution are consistent with the UNCRC. However, there is no specific legal act or mention of the intersex children in the current legislation. The legislation does not constitute a definition of gender. Sex seems to be irrelevant concerning most of the legal Acts, only in the Asevelvollisuus laki 28.12.2007/1438 (Military Service Act)⁸⁰ different genders are considered independently and they hold different legal obligations.⁸¹ Suomen perustuslaki 11.6.1999/731 (Finnish Constitution) chapter two presents fundamental rights. Finnish Constitution article 6 states that children have to be treated equally and children shall have the possibility to participate in the decision making process considering matters related to them, according to the level of development of the particular child. Article 7 of the Constitution grants everyone the right to life, personal freedom, and integrity. Personal integrity can not be intervened or deprived without legal grounds or on arbitrary bases.⁸² Treatment of intersex children could constitute a violation of personal integrity the legal grounds for it are granted in the Patient Act article 7 where parents are given the possibility to legally consent for their child's treatment.⁸³ The right to personal integrity also protects against treatment that is infringing human dignity by interfering in the physical very essence of a person without his consent. Personal integrity covers also significant interference of integrity, even if the interference can not be considered infringing human dignity.⁸⁴ The starting point for the protection of private life is that the individual has the right to live his or her own life without arbitrary or unjustified interference in his or her private life by public authorities or other third parties. It is difficult to define precisely the dimension of private life. It includes, among other things, the individual's right to freely establish and maintain relations with other people and the environment, as well as the right to determine himself and his or her body.⁸⁵ Therefore, the right to private life reinforce the intersex children's legal status as well.

⁸⁰ Asevelvollisuus laki 28.12.2007/1438.

⁸¹ Suominen, K., (2018) Nainen, mies vai jotain muuta? Sukupuoleen liittyvästä sääntelystä ja sen ongelmista. *Urheilu ja Oikeus*. 222-245. 222,223. (Female, male or something else? Gender related regulations and their problematics)

⁸² Suomen perustuslaki 11.6.1999/731.

⁸³ Potilaslaki 17.8.1992/785.

⁸⁴ HE 309/1993, Hallituksen esitys Eduskunnalle perustuslakien perusoikeussäännösten muuttamisesta. 46-47. (Government's proposal to the Parliament on amending fundamental rights regulation).

⁸⁵ HE 309/1993, 52-53.

The general healthcare legislation, such as healthcare - and patient act, are applied to intersex treatment. The legal status of intersex children does not differ from those with any other medical condition. Potilaslaki 17.8.1992/785 (The Patient Act)⁸⁶, which establishes the rights and status of the patient, is the *lex generalis* in the field of medical law. It is applied in case *lex specialist* does not exist. Particular, *lex generalis*, Acts has been adopted for: mentally ill patients⁸⁷, those who are treated for substance abuse⁸⁸ or spreadable diseases⁸⁹, and for the disabled⁹⁰.

⁸⁶ Potilaslaki 17.8.1992/785.

⁸⁷ Mielenterveyslaki 14.12.1990/1116.

⁸⁸ Päihdehuoltolaki 17.1.1986/41.

⁸⁹ Tartuntatautilaki 21.12.2016/1227.

⁹⁰ Laki kehitysvammaisten erityishuollosta 23.6.1977/519.

3.1. The Healthcare Act

Terveydenhuoltolaki 30.12.2010/1326 (Health care act) was established to compound Kansanterveyslaki 28.1.1972/66 (Primary Health Care Act)⁹¹ and Erikoissairaanhoitolaki 1.12.1989/1062 (Special Medical Care Act)⁹² to restrain the expenses and enhance co-operation between primary and specialized healthcare.⁹³ Erikoissairaanhoitolaki 1.12.1989/1062 aimed at ensuring equal access to specialized medical care throughout the whole country.⁹⁴ The basic unit responsible for the organization of specialized medical care was the municipality. However, as a provider of specialized health care services, the municipality was too weak in terms of population and other resources to respond to the needs. It eventually leads to the establishment of municipal federations of the hospital district. According to, the Health care Act (2010/1326) municipalities are obliged to provide citizens health care services. Health care services include diagnostics, prevention and treatment of diseases and reducing suffering. Highly specialized health care and health care requiring highly advanced technology was concentrated under the municipal federations which possess University Hospitals.⁹⁵ For some diseases, it is necessary to centralize healthcare in one or two hospitals in order to guarantee that everyone has equal access to health care services regardless of the place of residence.⁹⁶

The purpose of the healthcare act is to enhance health, to narrow the health difference between different groups of the population and to set equality to the healthcare services quality, accessibility and safety.⁹⁷ Hospital Districts shall ensure the availability of specialized medical care. Treatment that requires highly specialized care is centralized at University Hospitals. Intersex is a rare condition and in Finland, there are not too many physicians specialized for intersex treatment. Demanding surgery cannot be performed in a high-quality and safe manner unless it is concentrated in hospitals with adequate surgical volumes, the necessary intensive care and inpatient capacity, and round-the-clock emergency preparedness in a sufficient number of medical

⁹¹ Kansanterveyslaki 28.1.1972/66

⁹² Erikoissairaanhoitolaki 1.12.1989/1062

⁹³ HE90/2010, Hallituksen esitys Eduskunnalle terveydenhuoltolaiksi sekä laeiksi kansanterveyslain ja erikoissairaanhoitolain muuttamiseksi sekä sosiaali- ja terveydenhuollon asiakasmaksuista annetun lain muuttamiseksi, 1.

⁹⁴ HE90/2010, 4.

⁹⁵ HE90/2010, 4

⁹⁶ HE90/2010, 4.

⁹⁷ Terveydenhuoltolaki 30.12.2010/1326, §3.

specialties.⁹⁸ Centralized care ensures the steady quality of the treatment, accessibility of treatment, synchronization and smooth collaboration between specialized fields. The specialized care is not dependent only on the skills of the individual surgeon, it requires collaboration between different medical fields specialists.⁹⁹ Larger surgical volumes of the hospital mean that the personnel has more experience. In surgical operations, the experience indicates better results as the surgery requires manual skills that evolve by operating volume. Globally, there have been examples where babies who are not born intersex are gone through the reassignment of sex procedures.¹⁰⁰ For instance, David Bremer's parents were convinced by physicians that he could not grow up as a functional male which drove the parents to consent for re sex assignment surgeries which were not successful. As a consequence, the patient suffered life-long trauma.¹⁰¹ Bremer's unfortunate case illustrates that deep knowledge already in the diagnosis phase of DSD patients treatment is essential for rare and new conditions as intersex.

Transgender treatment in Finland is regulated by law.¹⁰² Gender identity research and the coordination of rehabilitation treatments, as well as much of their implementation, are centralized in two university hospitals, the Helsinki University Central Hospital (HYKS) Gender Identity Research Outpatient Clinic and Tampere University Hospital (Tays) Trans Outpatient Clinic.¹⁰³ The aim has been to ensure the quality of research and treatment in the context of a relatively rare and previously poorly known phenomenon. According to article 3, For the examination, treatment and monitoring of a person's transsexuality, Helsinki University Central Hospital and Tampere University Hospital have a multi-professional working group specializing in the research and treatment of transsexuality. The composition of the working group should be such that it is able to properly take care of the diagnosis, treatment and monitoring of transsexuality. The psychiatrist is responsible for the work of the working group. Specialists in gynecology and internal medicine specializing in endocrinology should be available to the working group. In addition, a specialist in

⁹⁸ Haapiainen, R., & Virolainen, P. (2016). Kirurgia Suomessa 2020-luvulla: Operatiivisten erikoisalojen järjestämistä ja keskittämistä koskevat periaatteet. Loppuraportti 21.9. 2016. (Surgery in Finland in 2020: Organization of Operative special care and principle of centralization), 5.

⁹⁹ *Ibid*, 10.

¹⁰⁰ Ingram, X. P. (2018). Physician liability for sex-assignment surgeries on intersex babies. *Cumberland Law Review*, 49(1), 55-84. 62

¹⁰¹ *Ibid*.

¹⁰² See, Sosiaali- ja terveysministeriön asetus sukupuolen muuttamiseen tähtäävän tutkimuksen ja hoidon järjestämisestä sekä lääketieteellisestä selvityksestä transseksuaalin sukupuolen vahvistamista varten 3.12. 1053/2002. (Regulation of the Ministry of Social Affairs and Health on the organisation of research and treatment aimed at gender change and on medical research for the strengthening of transsexual sex)

¹⁰³ Sosiaali- ja terveysministeriön asetus sukupuolen muuttamiseen tähtäävän tutkimuksen ja hoidon järjestämisestä sekä lääketieteellisestä selvityksestä transseksuaalin sukupuolen vahvistamista varten 3.12. 1053/2002.

plastic surgery specializing in genital surgery must be available to the working group of Helsinki University Central Hospital.¹⁰⁴ The diagnosis and treatment of DSD patients shall be centralized to one hospital to ensure that the treating personnel has the best skills and experience.¹⁰⁵ The legislation does not centralize DSD treatment in any form. DSDs are rare and relatively new phenomena as well, and the centralization of DSD diagnosis and treatment would enhance the DSD children's right to attain the best health care. Therefore, the centralization of the DSD treatment and the responsibility to treat DSD patients of one or two University Hospitals shall be written down in the legislation.

Article 7 of the Health Care Act introduces the principle of harmonized treatment.¹⁰⁶ The provision grants The Ministry of Social Affairs and Health the power to coordinate the observe the national harmonized principles of medical and dental care.¹⁰⁷ The provision was established because major variations were detected on the procedure for treatment and deciding of treatment for non-emergency healthcare.¹⁰⁸ Harmonized principles are established by the Ministry of social affairs and health. The principles should be generally respected by doctors. However, the physician is entitled to diverge from the principles for justified reason.¹⁰⁹ The harmonized lines of treatment are categorized by the fields of specialty. In pediatric field harmonized lined of treatment have been established for example for the treatment of child diabetes, a disorder of growth of length and disorder of puberty.¹¹⁰ The treatment of intersex children is not harmonized within the means of the Article.

¹⁰⁴ Sosiaali- ja terveysministeriön asetus sukupuolen muuttamiseen tähtäävän tutkimuksen ja hoidon järjestämisestä sekä lääketieteellisestä selvityksestä transseksuaalin sukupuolen vahvistamista varten 3.12. 1053/2002. (Regulation of the Ministry of Social Affairs and Health on the organisation of research and treatment aimed at gender change and on medical research for the strengthening of transsexual sex)

¹⁰⁵ Kärnä, T., (2017) Transukupuolisuus. (Trangender) Retrieved from: https://www.terveyskirjasto.fi/terveyskirjasto/tk.koti?p_artikkeli=dlk01195 3.5.2020.

¹⁰⁶ Terveysturvalaki 30.12.2010/1326, §7.

¹⁰⁷ Terveysturvalaki 30.12.2010/1326, 1(7)

¹⁰⁸ HE 90/2010,95.

¹⁰⁹ HE 90/2010, 95.

¹¹⁰ The Ministry of Social affairs and Health (2019) Yhtenäiset hoidonperusteet.

3.2. The Patient Act

The Patient Act¹¹¹ was enforced in 1993 at the time it was the first legal act to secure patients' legal rights.¹¹² The Patient act's original aim was to strengthen the patient's status and rights, uniform the treatment and enhance the relationship between the patient and healthcare personnel.¹¹³ The Patient Act¹¹⁴ aims at securing the patients' status and their rights.

Article 6 of the Patient Act regulates the patients' right to self-determination. According to, it all patients shall the right to be treated in mutual understanding with him. To treat the patient in mutual understanding the doctor must share necessary information impartially and share the decision-making power with the patient.¹¹⁵ Medical professionals are not entitled to force patients into a form of treatment or decision unless under special circumstances. It should be noted that physicians have a duty to provide care for those in need. The duty and right to self-determination overlaps, while the patient is not able to express his will.¹¹⁶ The relationship between patient and physician is vital to successful treatment in mutual understanding. If the patient is not able to express his will the physicians' relationship with the legal representatives has significant power. They jointly hold decision-making power on a third person. In practice, the physician holds the power. The medical professional is the one introducing the examples and risks. Medicine is not straightforward science and it is common that doctors hold different opinions on the best ways of treatment. It is human that the physicians' personal point of view is visible in the presentation of the risk and recommended line of treatment and might have an influence on the decision on an unconscious or conscious level.

Article 7, regulates more specifically the status of underaged children. The underaged patient is under 18 years old. The underaged patient opinion shall be taken into account as far as he is capable of deciding for himself. If children are considered to be too young to decide for himself the treatment shall proceed in mutual understanding with the parents or legal presentative. An infant can not be anyway considered to express his will. The right to self-determination is fully enjoyable

¹¹¹ Potilaslaki 17.8.1992/785

¹¹² HE 185/1991, Hallituksen esitys Eduskunnalle laiksi potilaan asemasta ja oikeuksista. (Government's proposal to the Parliament on legal act for patient's status and rights), 7

¹¹³ HE 185/1991,1

¹¹⁴ Potilaslaki 17.8.1992/785

¹¹⁵ Hermer, L. (2002). Paradigms Revised: Intersex Children, Bioethics & (and) the Law. *Annals Health Law*, 11(1)195-236, 222.

¹¹⁶ Taylor, H. J. (2016). What are 'Best Interests'? A Critical Evaluation of 'Best Interests' Decision-Making in Clinical Practice. *Medical law review*, 24(2), 176-205. 177.

only by adults and therefore 18 years old is a natural limit for involuntary treatment.¹¹⁷ The legislation concerning underaged patients trusts totally on the assumption that parent has to wish the best for their children.

In ordinary cases the patient's desire shall be respected if the patient is not autonomous the best interest of the patient shall be evaluated; in some cases, public interest should be respected in favor of the patients' desire or interests.¹¹⁸ Determining the prevail of the public interest is the issue of courts.¹¹⁹ Usually the medical personnel and/or legal presentative of the patient are the ones who evaluated and determine the best interests of the patients if he is not capable of deciding for himself. Intersex children's legal presentative is entitled to make decisions on whether to treat infants atypical sex or not. The considerations are brainstormed with physicians and it is reasonable to suspect that physicians opinion affects the final decision. The general non-binding guidelines encourage to avoid medical interventions on young children but the right to self-determination of intersex children could be infringed with legal representatives consent.

¹¹⁷ HE185/1991, 17.

¹¹⁸ For example in case of spreadable diseases the public interests might become more relevant than the patients will not to be treated.

¹¹⁹ Huxtable, R. (2014). Autonomy, best interests and the public interest: treatment, non-treatment and the values of medical law. *Medical law review*, 22(4), 459-493. 459,476

3.3. Medical ethics supporting the rights of intersex children

In many occupations, professional ethics guidelines have been imposed.¹²⁰ Medical ethics are closely related to justice in clinical practice. Clinical practitioners are frequently faced with ethical questions. Generally ethical questions consider practical situations that are governed by well-justified ethics which end up conflicting in practice. Six core principles form the bases for medical ethics. The principles are: respect for life, dignity, self-determination, providing treatment, justice and maximizing the benefits.¹²¹ The ethical principles are also written in the legislation and they encourage physicians to act in compliance with the ethics as well as the legislation. The Finnish physicians association provided four physicians' ethical obligations. 1. The doctor always works for the best of his patient. 2. The doctor will inevitably respect the will of the patient however, responsibility for transmission. The patients require physicians to issue in clear and comprehensible manner information necessary for them to express informed wishes. 3. The doctor shall keep confidential any information he also receives while caring for patients. 4. The activities of a doctor shall contribute to compliance in the field of health care and treats its patients equally without discrimination.¹²²

Self-determination is described in physician's ethics in the following form: The patient has the right to refuse treatment, treatment procedure and examinations, and in that case he or she shall be treated in another medically acceptable manner in agreement with him. The patient can express their opinions on the examinations and treatments, but the doctor has no obligation to follow the patient's will here. If the patient has clearly expressed his or her will for treatment, for example, urgent treatment or with regard to intensive care, his will must be respected. In other words, a self-determining (competent) patient has the right to refuse the recommended treatment and examinations even when this endangers the patient's health or even life. The self-determination in ethical guidelines seems to be a clear right of a competent patient to refuse treatment. An intersex child naturally can not refuse from treatment but their parents are entitled to it. The physicians are ethically obliged to provide a sufficient amount of information for intersex children's parents of the treatment. It is not secure by additional mechanisms.¹²³ The practical realization of the right to

¹²⁰ Nieminen, L. M. (2018). Ammattieettiset ohjeet juristin haasteena. In *Viestintäoikeuden vuosikirja 2017: 15 vuotta viestintäoikeutta*, 18-44. Helsingin yliopisto, oikeustieteellinen tiedekunta. 18.

¹²¹ Launis, V., Lääkintä- ja hoitoetiikan perusperiaatteet Retrieved from: <https://www.laakariliitto.fi/laakarinetiikka/laakarinetiikan-filosofiset-perusteet/laakinta-ja-hoitoetiikan-perusperiaatteet/>, 2 May 2020.

¹²² Duodecim, S. L., Lääkäriliitto, S., & Läkaresällskapet, F. (2003). Physician's professional ethics and problems of the health care system. *Duodecim; laaketieteellinen aikakauskirja*, 119(8), 694-695. 694.

¹²³ Lääkärietiikka, 7th edition, Lahti: Suomen Lääkäriliitto, 43.

be heard is, at this point, secure by medical ethics. For fulfillment of the right to be heard the child should have achieved information about the issue in an understandable form. Medical reasoning might be incomprehensible to non-medical professionals. Medical reasoning more or less includes professional vocabulary, which is difficult to treat regular adults, let alone children.

A prerequisite for good and successful care is that the child may be cared for in agreement with his or her parents. However, there are limits to parental rights. If there is a clear conflict between the best interests of the child and the will of the parents. For instance, if the parents want to prohibit life-threatening treatment. It is up to the treating physicians to make treatment decisions primarily for the best interest of the child.¹²⁴ Jehovah's Witnesses set a clear example of the restriction of parental authority and ethical conflict. Jehovah's Witnesses are known for refusing even from lifesaving blood transfusing for themselves or for their children.¹²⁵ In the case of a life-threatening situation, there is a conflict between the rights of the patient, the duties and rights of the doctor and the ethical views of both parties.¹²⁶ The Social and Health Board has taken into custody of a child with lymph node cancer from Jehovah's Witnesses, whose care required the administration of blood products, and placed her partly in a hospital and partly home.¹²⁷ Taking a child into temporary custody is a very extreme restriction of parental authority but such measures are entitled to save the child's life. Ethical analysis of the treatment for intersex children is difficult to carry out since most of the intersex treatment are not saving children from a life-threatening condition. The DSD treatment provides, however, usually better functionality and enables normal development. The physician's ethics book notices that parental rights are limited. The statement that parental authority is limited if there exists conflict between the best interest of the child and will of the parents is an excellent example of how the ethical guidelines serve better fulfillment of the UNCRC principle of the best interest of the child than Finnish legal acts.

¹²⁴ *Ibid*, 95-96.

¹²⁵ Louderback-Wood, K. (2005). Jehovah's witnesses, blood transfusions, and the tort of misrepresentation. *Journal of Church and State*, 47(4), 783-822. 783.

¹²⁶ Louhiala, P., Rauhala, V. (2012). Kriittisesti sairaan, verituoiteista kieltäytyvän potilaan hoito – eettisiä näkökohtia. *Lääketieteellinen Aikakauskirja Duodecim*, Vol. 128, No. 12, 123 – 124. 123-124.

¹²⁷ Korkein Hallinto Oikeus, KHO 10.03.2000/530.

4. INTERSEX CHILDREN AND CLINICAL PRACTICE

The Western way to correct the sex of intersex children originates from the United States from the 1950s when it was believed that the child's personality was shaped by the environment and upbringing.¹²⁸ Before the 1950`s intersex children's bodies were not medically modified, the sex was doomed to be either female or male by the physicians' opinion on what would be the most appropriate gender.¹²⁹ In 1950`s technical progress of plastic surgery and endocrinology enabled the physicians to make female and male bodies from the intersex.¹³⁰ The surgical treatments on intersex begin, the practice of defining a child was strengthened sex as early as possible, either as a girl or as a boy.¹³¹ The child was not always even told that she or he is intersex.¹³² At the time it was thought that individuals are born as psychosexually neutral and the appearance of the genitals is essential to the development of a child.¹³³ The external genital organs were built or repaired in line with gender as defined in early childhood.¹³⁴ The surgical treatment began to fix the gender to cosmetically acceptable.¹³⁵ The perception of gender, and also of the development of the human personality, has changed significantly since then.¹³⁶ However, the sex of the child is still determined soon after birth and the external genitalia of intersex children are surgically modified during childhood and during his youth also in Finland.¹³⁷

At the moment clinical practice and treatment of intersex vary depending on the treating hospital.¹³⁸ Guidelines for clinical practice is published by different bodies, for instance: ETENE, Duodecim and Ministry for social affairs and health. From the before-mentioned bodies, only ETENE has stated its opinion with regards to the treatment of intersex children. Duodecim published Current Care Guidelines which are independent and evidence-based clinical practice

¹²⁸ The National Advisory Board on Ethics in Social and Health Care (2016), *nota supra* 3.

¹²⁹ Greenberg, J. A. (2012). Health care issues affecting people with an intersex condition or dsd: Sex or disability discrimination. *Loyola of Los Angeles Law Review*, 45(3), 849-908. 856.

¹³⁰ Gruber, N. (2005), *supra nota* 1, 120.

¹³¹ The National Advisory Board on Ethics in Social and Health Care (2016), *nota supra* 3.

¹³² *Ibid.*

¹³³ Nieves, F. (2010). The unarticulated premise underlying the medical and legal management of intersex people in puerto rico: Some constitutional and gender issues. *Revista Juridica Universidad de Puerto Rico*, 79(4), 1233-1246. 1234.

¹³⁴ The National Advisory Board on Ethics in Social and Health Care (2016), *nota supra* 3.

¹³⁵ Greenberg, J. A. (2012), *Supra nota* 129.

¹³⁶ The National Advisory Board on Ethics in Social and Health Care (2016), *nota supra* 3.

¹³⁷ *Ibid.*

¹³⁸ Sukupuolen osaamiskeskus (2020) Intersukupuolisuus. Retrieved from: <https://sukupuolenosaamiskeskus.fi/sukupuoli/sukupuolen-moninaisuus/intersukupuolisuus/>, 15. January 2020.

guidelines.¹³⁹ The lack of Duodecim's guidelines for intersex children is significant because they have published a comprehensive list of guidelines. One reason for the lack of Duodecim's intersex treatment guidelines is the remote amount of accessible scientific research data.

Physicians have not reached consensus on the nature of intersex, some consider it as a disorder that should be fixed and some are strongly against it. Formally Mika Venhola, a surgeon at Oulu University Hospital, has repeatedly opposed the appearance of intersexed genitalia in children. Seppo Taskinen, a surgeon in Helsinki University Hospital, in turn, comments that the surgeries are developed massively. At the Children's Clinic, babies are thought to be girls or boys, and the sex under the surface is uncovered by examination. According to Seppo Taskinen and his colleague Päivi Miettinen, it is very rare for doctors to be unable to determine sex with certainty.¹⁴⁰ Miettinen stated in a news article that it is thought that it is in the best interest of the children to develop according to other same-aged children.¹⁴¹ Taskinen stated that he has received feedback from intersex girl patients who complain that they have not been able to live "normal girl's childhood" because their enlarged clitoris was not fixed, such unnecessary procedure are not proceeded if the parents are unwilling.¹⁴²

Genitoplasty is a term for a wide range of surgical procedures performed in the genital area. It includes fixing the physical genitalia into a typical female or male form. From the medical perspective, the early genitoplasty is preferred, since the result of the medical and psychosocial forecast is preferable.¹⁴³ Children's tissue recovery rate is high and early reparation can be seen to minimize social battles and discrimination. Most physicians believe that the treatment is in the best interest of the child as the risk of treatment is lower than the risk of suffering psychological trauma from growing up with atypical gender.¹⁴⁴ In addition, it supports the child's coherent identity development. "DSDs are a heterogeneous group of rare diagnoses, making it difficult to obtain a sufficient sample size."¹⁴⁵ Therefore, studies on intersex infants operations show adverse results.

¹³⁹ Duodecim (2020) *Guidelines*. retrieved from: <https://www.kaypahoito.fi/en/guidelines>, 26.2.2020.

¹⁴⁰ Tiihonen, P. (2017) Miksi intersukupuolisia saa pienenä silpoa, kysyy veitsin ja hormonein naiselliseksi muokattu Aksu. Retrieved from: <https://www.kirkkojakaupunki.fi/-/miksi-intersukupuolisia-saa-pienena-silpoa-kysyy-veitsin-ja-hormonein-naiselliseksi-muokattu-aksu#ce0c56d6>, 15. January 2020.

¹⁴¹ *Ibid.*

¹⁴² *Ibid.*

¹⁴³ Harris, R. M., Chan, Y. M. (2019). Ethical issues with early genitoplasty in children with disorders of sex development. *Current Opinion in Endocrinology, Diabetes and Obesity*, 26(1), 49-53. 49.

¹⁴⁴ Greenberg, J. A. (2012), *Supra nota 129*, 866.

¹⁴⁵ Harris, R. M., Chan, Y. M. (2019). *Supra nota 143*, 51

KKO (Korkein Oikeus, Supreme Court) has issued judgment regarding the non-medical based surgical operation on a child who is not capable of expressing his will. In the case, a father who had organized her four year old son`s circumcision was prosecuted for abuse. The judgment is also important while analyzing intersex children's treatment because the main premises are partly the same. The issue was first processed in the District Court. District court stated that the treatment had no medical basis and the child could not express his will. The procedure was irrevocable and therefore the legal presentative of the child could not be considered to be capable of deciding on such unnecessary procedure. It was argued that the child's right to self-determination could not be violated on the basis of his parents' religion. Father had reached circumvention for his four-year-old son based on cultural and religious reasons.¹⁴⁶ The medical procedure was properly done but there were no medical bases for the circumvention which includes surgically removing skin and tissue.¹⁴⁷ The procedure correctly done does not constitute pain if it is done in local anesthesia as in the case. The procedure was not considered to be against the best interest of the child or violating his right to self-determination. The District Court held that, under Article 7 (3) of the Constitution, personal immunity could not be invoked without a legal basis. There was no law in Finland regulating the circumcision of boys. No such legislation existed in western countries other than Sweden. As far as is known, there was no court case in Finland concerning the circumcision of a man or a child. It was noticed that the legality of the male circumvention is however unclear in Finland. According to the Circumcision Task Force set up by the Ministry of Social Affairs and Health on April 11, 2003, approximately 200 non-medical circumcisions of boys are performed in Finland each year. In some hospital districts, this is done within the public health service, when the costs are borne by the municipalities. Some hospital districts had made a clear negative decision against non-medical circumcision. The Circumcision Task Force had decided that non-medical circumcision of boys should be allowed by special legislation. The charge was dismissed cause the legality is unclear and not uniform. It could be reasonable to suspect that circumvention is legal if it is carried out by a medical professional in a proper way. The case was forwarded to KKO which ruled accordingly the case was dismissed and act not considered unlawful. The roots of boys' circumvention among specific cultures and religions have old roots and it is cultural operation. The roots are similar to intersex operations which are operation for non-medical reasons just to fit in the binary gender concept and “the normal”.¹⁴⁸ Circumcision Task Force concluded

¹⁴⁶ Korkein Oikeus, KKO:2008:93, 17.10.2008.

¹⁴⁷ *Ibid.*

¹⁴⁸ *Ibid.*

that non-medical and medical boy circumcision should be allowed by law but the performance of them shall be regulated by law. The Ministry of Social Affairs and Health agreed with the working group`s position that all boys in need of circumcision should be allowed to appropriate medical expertise and to have the procedure performed safely under appropriate conditions.¹⁴⁹

¹⁴⁹ Sosiaali- ja terveysministeriö (2004) Poikien ympärileikkauksia koskevaa lainsäädäntötarvetta selvittäneen työryhmän muistio, 45.

4.1 General aspects on the clinical practice

Aspects that have to be considered while deciding on the intersex treatment include fertility potential, capacity for normal sexual function, endocrine function, malignant change, testosterone imprinting, and the timing of surgery.¹⁵⁰ Medical intervention normalizing the genitalia might be detrimental to the development of gender identity.¹⁵¹ Gender dysphoria as a concept is not understood sufficiently and it can not be predicted.¹⁵² In some forms of DSDs of the development of gender identity can be predicted comparatively precisely. In the case of CAH patients, it seems to be justified to assign the female gender to CAH patients. Since 90% of the female infants diagnosed with CAH develop female gender identity.¹⁵³ Another CAH patient study revealed that 86% of CAH patients affirmed a female gender identity in adulthood, 14% affirmed intersex identity but what is notable none identified themselves as males.¹⁵⁴

DSD has a significant effect on the fertility of the patient. If the testicular development is disordered and the testicular fail to settle. They remain in the abdomen which holds a higher temperature than the scrotum. Non-treated testicular development leads to failure to product semen, if the testicular are treated surgically 28% of the men have normal semen density.¹⁵⁵ It is an example that non-treatment of DSD can lead to infertility. In the case of AIS girls, the successful pregnancies are dependant on DSD treatment.

One aspect on defending the intersex children treatment focuses on the possible social obstacles it can ought the causing to the child in the future. The approach is weak since it can not be stated with absolute certainty that such obstacles will arise. It could be also thought that if treatment was not provided to anyone the condition would be part of society and accepted as normal. In medicine, the physical justifications are usually proposed.

¹⁵⁰ Benson, S. R. (2005). Hacking the gender binary myth: Recognizing fundamental rights for the intersexed. *Cardozo Journal of Law & Gender*, 12(1), 31-64. 35.

¹⁵¹ Horowicz, E. M. (2017). Intersex children: Who are we really treating?. *Medical Law International*, 17(3), 183-218. 184.

¹⁵² Välimäki, M., et al. (2009), *supra nota 5*, 594.

¹⁵³ *Ibid*, 594.

¹⁵⁴ Harris, R. M., & Chan, Y. M. (2019), *Supra nota 143*, 52.

¹⁵⁵ Välimäki, M., et al. (2009), *supra nota 5*, 597.

4.2. Treating units as an arbitrary decision-maker

Ministry of Justice carried out a survey, which consisted of 12 intersex children and their parents. The main issue that arises is the lack of knowledge. None of the survey group members felt that they had received enough information about the condition.¹⁵⁶ The decision making power is primarily withheld by the parents but the treating unit's personnel establish the options and reasoning for the options. Parents' evaluation of the risk and side effects are most likely to be affected by the physician's presentation of the facts and professional opinion. Parents of the survey admitted feeling pressured by the hospital staff to make the decision. The answers were collected in 2010 which is an indicator that the rights of intersex children are not in a satisfying condition in real life.

As there is no uniform legislation about the treatment of intersex people the decision of treatment is up to parents. Unless the condition is threatening the physical wellbeing of the child. The medical personnel have a great responsibility. The attitude of medical doctors presenting the issue might have a radical indication of what will the parents decide. Before, bioethics was established as discipline the ethical matter on the treatment of intersex did not bother physicians. Even when informed consent became the norm in medical treatment it did not influence intersex treatment effectively.¹⁵⁷ “Patient autonomy took a back seat as parents heeded physicians’ advice in an environment even more hierarchical than we know today.”¹⁵⁸ Patient autonomy is not primary as long as the parents' possibility to decide is not regulated by law. The hierarchy of the situation has to be taken into account and the physicians' personal opinion should not be overriding the child's interest. The CRC encourages the state parties to decrease the conflict of interest between medical personnel and parents.¹⁵⁹ It is not strange that parents feel pressured by the medical personnel. In the relationship between physician and the patient's parent the physician most likely acquire a more powerful status on the relationship due to the professional position. The situation is complicated as legally parents are able to make the decision as they are trusted to wish the best for

¹⁵⁶ Oikeusministeriö (2019). *supra nota 17*.

¹⁵⁷ Reis., E. (2019) Did Bioethics Matter? A History of Autonomy, Consent, and Intersex Genital Surgery, *Medical Law Review*, Volume 27, Issue 4, Autumn 2019, 658–674, 660.

¹⁵⁸ *Ibid*, 658

¹⁵⁹ Committee on the Rights of the Children, The right of the child to freedom from all forms of violence, General comment No. 13, 18. April 2011, 5.

their child but if they decide pressured by medical personnel the decision ends up being made by the treating physician.

In a major amount of cases, surgical or hormonal treatment is not necessary for health. However, it is seen to support the development of sexual identity and it, therefore, it is sometimes chosen by the parents. In Finland, DSD treatment is provided in two University Hospital Districts Oulu and Helsinki and practices in them differ. In some university hospitals, parents hear about research findings as investigations progress, in some parents will not be notified until the results are completed. Some university hospital emphasizes that health care professionals make decisions about urgent surgical treatments when in another it is stated that the parents ultimately decide on them. When determining the gender of a child, it is also stated similar differences in responses; in some university hospitals, the parents do not participate in the decision at all, on the other hand, the team involved in the studies makes a decision together with the parents about the gender of the child.¹⁶⁰

¹⁶⁰ Wahlman-Calderera, T., Halila, R. (2016) Intersukupuolisuus. Taustaraportti ETENE:n kannanottoon, Retrieved from:<https://etene.fi/documents/1429646/2056382/IS-raportti20160331.pdf/58bf2412-48a9-4521-b5ac-81a3ee3bc07b>, 5th May 2020.

5. THE POSITION STATEMENT OF NATIONAL ADVISORY BOARD ON SOCIAL WELFARE AND HEALTH CARE ETHICS “ETENE”

The National Advisory Board on Ethics in Social and Health Care (ETENE) is an Advisory Board on Ethics in Social and Health Care questions that give opinions and recommendations relating to social and health care and monitor national and international developments in the social and health field.¹⁶¹ ETENE’s actions are based on the Patient Act. They issued a position statement on intersex treatment in 22.3.2016 which is in line with many non-governmental organizations' opinions. For instance, UN Agencies and UN human rights committees, among other authorities, have requested action for prohibiting the invasion of gender at an early stage without the patient’s consent with similar reasoning to the ETENE’s.¹⁶²

The ETENE’s position statement states that: If the sex of the newborn cannot be determined by external examination, the child will usually be referred to a university hospital for further investigation. The primary consideration is whether the child has congenital adrenal hyperplasia which shall be treated with the hormone medication started as early as possible. The chromosomes of a child are also usually examined immediately after birth. If the findings are normal, other factors causing intersex will be examined. Follow-up is individually planned for the child according to his or her condition and findings of the examination. How closely parents are involved in the research and decision-making phase, varies according to the university hospital district.¹⁶³

ETENE point attention to the fact that the child can not affect the designation of the gender. The procedure is problematic, even though professionals and authorities aimed at arriving at the best result. ETENE state that the fixing processes are not necessary and might make the children feel defective. The fixing of the gender does not serve the best interest of the child or his development. The fixing process lessens the anxiety of the parents and the surrounding society. ETENE states that sharing information about intersex should be the first step to diminish the stigma related to it.

¹⁶¹ The National Advisory Board on Ethics in Social and Health Care (2016), *nota supra* 3.

¹⁶² Garland, J., Slokenberga, S. (2019). Protecting the rights of children with intersex conditions from nonconsensual gender-conforming medical interventions: the view from Europe. *Medical Law Review*, 27(3), 482-508. 484-485.

¹⁶³ The National Advisory Board on Ethics in Social and Health Care (2016), *nota supra* 3.

ETENE recommends that the right to child's right self-determination shall be strengthened in matter essential to his identity, as the gender is. The measures modifying the external gender features shall not be executed until the child has formed gender identity, affect the outcome by giving informed consent. The idea is similar is in the Ministry of Justice's statement, which contains the following idea. Intersex people's right to bodily integrity and self-determination should be guaranteed. Intersex targeting children medically unnecessary "normalizing" surgeries and other actions without the informed consent of the child shall be prohibited. Except in cases where there is an imminent danger to the health of the child, no action shall be taken to modify the sex characteristics before the child is able to decide for himself.¹⁶⁴

ETENE suggests that structural abnormalities that affect the health of the child shall be fixed, at its time. The recommendation remains vague the definition of at its time strikes no clarity. As an example, ETENE mentions the removal of glands to reduce the risk of cancer. They state that scheduling the procedure in a manner that respects the child's self-determination is not always easy and requires sensitivity and wisdom from those responsible for the care of the child. Some international organization recommends that the harmful structural abnormalities should be treated only after the child is able to make an expression of will.¹⁶⁵

ETENES`s position statement notices that the early treatment of CAH patients is necessary to begin immediately. Otherwise, they are in favor of prohibiting all treatment of DSD patients until they are capable of expressing their opinion. The position statement does not evaluate the risks of non-treatment. Therefore, the position statement does not sufficiently consider what indeed is in the best interest of the child. It clearly aims at respecting the child's right to self-determination but leaving the child without treatment does not necessarily serve the best interest of the child. Luckily, CAH patients' need for treatment is recognized.¹⁶⁶

¹⁶⁴ Oikeusministeriö (2019), *supra nota 17*, 14.

¹⁶⁵ The National Advisory Board on Ethics in Social and Health Care (2016), *supra nota 3*.

¹⁶⁶ *Ibid.*

6. IS THERE NEED FOR NEW LEGISLATION FOR INTERSEX CHILD?

Children are human beings as well as adults and they have the right to autonomy, integrity, and self-determination. They are not considered as property of their parents, as children historically might have been considered. The lack of legislation granting rights for intersex children supports the old concept of children. One might assume that parents are the ones who always wish for the best for their child. Notably, the concept of the best varies greatly. It would be as well a relief for the parent that legislation should take the burden from them to decide on behalf of the child for something that might have no knowledge about. Even if it would be possible to assume that parents always want the best for their child and have the knowledge required for the decision making. The parent has to be capable of processing the information and carry out objective rational thinking in stressful and emotional issue to make the decision solely for the benefit of the children. The parents are going to raise the child in the future but it does not necessarily mean that they are capable of making decisions solely for the best interest of the child in an overwhelming situation¹⁶⁷. The possibility of medical personnel to affect the decision-making process based on their personal opinion, rather than the best interest of the child can not be ignored or left unquestioned. As it was recovered in the thesis, that it is not rare that parents of DSD children feel pressured by the treating personnel. The medical professional has status and the impact of the physician's recommendations is usually taken strongly. Medical ethics guidelines demonstrate that the right to self-determination is not understood as a right to choose the treatment. Medical ethics encourage the physicians to kindly justify their viewpoint and get the patient to consent the physicians recommended line of treatment. Therefore, it seems incompatible with the best interest of the child principle that such competencies are held by the parents and, in practice affected by medical district and no legal safeguards exist.

In the case Korkein Oikeus, KKO:2008:93, 17.10.2008 circumcized boy's father was accused of abuse. The case illustrates that without legal regulation on non-medical circumcision the medical practice is not uniform and the legal basis and justification for treatment remain unclear and so does the treatment. In addition, acting in an unclear situation with no regulation is hardly punishable, even though act generally could be considered as violating underaged legal rights if it

¹⁶⁷ Muckle, C. (2006). Giving voice to intersex individuals through hospital ethics committees. *Wisconsin Law Review*, 2006(3), 987-1024. 988.

is however commonly perpetrated.¹⁶⁸ The Ministry of Social Affairs and Health has stated that the circumvention of boys has to be regulated by law because it violated their right to personal immunity which is fundamental right and restriction of fundamental rights should be regulated in the legislation.¹⁶⁹

The nonexistence of legislation in relation to intersex children infringes the principle of the best interest of children which is a fundamental value of the UNCRC. In practice, there is no warranty that the care of DSD children is made after proper risk analysis and in the best interest of the child. The principle is connected to the other principles and articles of the Convention as well. Infringement of the principle of best interest might also lead to additional infringements of the Convention. For example, if the parents of the intersex child decide not to allow any treatment to their child, which lead to infertility and hormonal problems for the child it does not respect the child's right to attain the best available health care or his or her access to health care services. Children should be able to enjoy the highest standard of health. Intersex is considered as a disorder and the treatment could be justified as fulfilling the obligation to ensure the children's right to enjoy the highest attainable amount of health. If the intersex condition would be considered as the third sex instead of "illness" the society would eventually adapt to it. It may sound odd that DSD could be defined to be third sex instead of disease. Historically de-classification as a disease have occurred, for instance homosexuality used to be considered as an disease. Nowadays, approaching homosexuality as an disease would be old-fashioned and wry. If intersex was regulated it would become thought as normal variation of the human body and the reason for unnecessary surgical interventions would not be needed for social purposes. Spreading awareness of the condition would eventually decrease the need for unnecessary operations. The legislation could take the first step and recognize intersex as a type of gender and enhance the normalization of the variation instead of enabling the unnecessary normalization of intersex bodies. Treatment of transgenders was regulated by legislation and it could be taken as an example for intersex legislation as well. The unclarity of treatment and procedure for children with DSD threatens the rights arising from the UNCRC.

¹⁶⁸ Korkein Oikeus, KKO:2008:93, 17.10.2008

¹⁶⁹ Sosiaali- ja terveysministeriö (2004) Poikien ympärileikkauksia koskevaa lainsäädäntötarvetta selvittäneen työryhmän muistio

It seems that various legal articles have been criticizing the fixing of intersex gender and only a few legal articles consider that in some instances the early medical treatment might be in the best interest of the child. On the contrary, medical literature seems to be in favor of early treatment due to the better success rates and quality of life. Medical literature has paid attention to the physiological risks that non-treated DSD cause, e.g. cancers, salt wasting and infertility. The best interest of the child means that the child is able to live a holistic life and develop. The overview of DSD indicated that some of the consequences are very unfortunate and argue in favor of DSD treatment in specific cases. Therefore, I am not in favor of the strong prohibition of medical interference with intersex children. Nevertheless, the interference should be taken into account in legislation and legal framework reform is demanded at human rights and equality's sake. It seems that the current procedure violates the fundamental rights of the children as personal integrity is interfered on arbitrary bases. The arbitrary interference is against the fundamental right derived for example, from the Constitution. The best interest of the child has to be the primary concern. Intersex bodies shall not be treated in order to fit society's concept of normal. The only reason for medical interference could be the genuine will to enhance the child's quality of life. The concept of the best interest of the child is vague. It should be safeguarded that the concept is not manipulated. The best interest of the child should be guaranteed by suitable legislation which would enable intersex children to access to the best standard of health and treatment according to the UNCRC. It would be probably unnecessary to try to classify different sexes since there are multiple opinions on the number of different sexes. An Act shall be adopted to safeguard that the best interests of the child materialize as well in the treatment or non-treatment of intersex children. Health is the one justification for the early medical treatment that everyone should be able to agree with. Legally, it is clear that everything shall be done to decrease suffering in medical care. However, the positive and negative affect on the child should be considered. Gender identity is impossible to predict. I think that the possibility of different gender identities should not play such a major role in defining the positive and negative outcomes of the treatment. The gender identity can not be predicted with 100% certainty in any case. For example, if an intersex girl is treated in order to maintain her fertility but in puberty, she turns out as a lesbian. It should not be considered as signs that the treatment failed to fit the persons' gender identity. Sexuality is seen as part of the gender identity, however, it is completely separate from the DSD. Homosexuality and similar stereotypical gender behavior can not be considered as gender identity. The evaluation of positive and negative effects should be concentrated on the issues that can be predicted scientifically. For instance, physical well-being and functionality and capacity to reproduce. If non-treatment of intersex conditions will lead to permanent infertility can it be considered as the best interest of the

children? I argue that to doom intersex children infertile due to the lack of consent before the age of 18 is unreasonable. UN High Commissioner for Human Rights stated: “Far too few of us are aware of the specific human rights violations faced by millions of intersex people. Because their bodies don’t comply with typical definitions of male or female, intersex children and adults are frequently subjected to forced sterilization and other unnecessary and irreversible surgery, and suffer discrimination in schools, workplaces and other settings.”¹⁷⁰ UN High Commissioner for Human Rights pointed out the forced sterilization that intersex children are forced into. In similar way, in some cases, non-treatment might lead to sterility and it should be prevented. To maintain the fertility of DSD, especially CAH patients could not be prohibited because infertility can cause problems to mental well-being as well and it has been proved that all most all CAH girls categorize as females the possibility to carry children should be protected by medical treatment. The best interest of the child in the case of intersex children should be evaluated based on risk analysis. ”It is worth considering the difference between mourning a loss and regretting a decision.” (Holmes M, 2005, 133) It is impossible to state anything certain relating to such a condition that has unique features. The risk and side effects analysis shall be fact-based.

Physical recovery shows better rates if the treatment is carried out at an early stage of life. The issue has several complexities even in biological terms it could be very easily solved. Ethical, Psychological and social aspect has to be taken into account while analyzing the best interest of the child. The studies have shown that the number of mental health problems is significantly higher among sex minorities than among the mainstream population. Atypicality of sex is justified to increase the risk of depression. On the other hand, the treatment of an infant might cause a feeling of the intervention of privacy or even genital mutilation. The best interest of the child is not unambiguous. Arguments against and on behalf of the fixing of intersex gender can be found. The fixing of gender might arise with feelings of depression, shame, and violence. The fixing of gender seems to be linked to genital mutilation in many of the modern articles. In essence, it is an understandable proposition. The link between genitalia cutting and intersex treatment is more illusionary than real. The common factor is that they both are both culture related.¹⁷¹ Although the best interests of the child should be decided on a case-by-case basis. It can not be secured that the

¹⁷⁰ Opening Statement by UN High Commissioner for Human Rights Zeid Ra'ad Al Hussein at the 30th session of the Human Rights Council.

¹⁷¹ Ehrenreich, N., Barr, M. (2005). Intersex surgery, female genital cutting, and the selective condemnation of cultural practices. *Harvard Civil Rights-Civil Liberties Law Review*, 40(1), 71-140. 73-74.

best interest of the children is always guaranteed by the decision making by the combination of legal representative and physicians.

“The Council of the European Union, and the European Parliament, as well as the Council of Europe, the UN High Commissioner for Human Rights, and the UN Special Rapporteur on Torture, have all pointed out that intersex people can suffer from discrimination that may result in ill treatment, especially during childhood.”¹⁷² Children have to be protected in all environments, for instance: home, kindergarten, and school. Abnormality is a usual cause of harassment in many social environments. If legislation would take intersex persons into account as their own group the abnormality of the phenomenon could evidently disappear. The best interest of the child is equal treatment and legal silence does not promote equality among intersex children. The possibility of being bullied in the future does not constitute a justified reason for infringement of the child’s integrity, it is an example. There is no dispute about the fact that intersex might lead to bullying and feeling outsider of social action. The most attention is focused on physical surgery and the concept of informed consent. The fact is that social life is a major part of a child’s development and feeling different is detrimental to a child’s integrity. In modern publications, it seems that many are strongly arguing that the patients informed consent is an only valid reason for DSD treatment. The topic remains emotional and arguable. The lack of legislation on intersex children forces parents to make an enormously hard decision. Professional attitudes and presentation of the issue can not be separated from the decision-making process. The future of children with DSD is determined individually based on the will of the parent and medical professional. It does not serve the best interest of the child. Generally, parents are considered to altruistically promote the best for their children. Under such and major and emotional decision the facts may dim. Medical personnel usually desire to treat non-autonomic patients according to the relatives' wishes. For the next of kind, it is easier to estimate for example what adult relative would wish and in the perfect situation, he had even expressed his will beforehand. To decide for new-born, it is impossible, even to the parent, to foresee the child’s opinion.¹⁷³ Parental fear of the discrimination, embarrassment and poor functioning of reproductive organs drive parents to admit to genioplasty.¹⁷⁴ ETENE’S statement is strictly against the treatment of atypical sex infants, excluding CAH patients. They do

¹⁷² European Union Agency for fundamental rights (2015) The fundamental rights situation of intersex people. Retrieved from: <https://fra.europa.eu/sites/default/files/fra-2015-focus-04-intersex.pdf> , 17 March 2020.

¹⁷³ Lloyd, E. (2005), *supra nota 40*, 168.

¹⁷⁴ Beh, H., Diamond, M. (2005). David reimer's legacy limiting parental discretion. *Cardozo Journal of Law & Gender*, 12(1), 5-30. 6.

pay attention to the fact that the form of atypicality varies nor do they take into account the risks of non-treatment.

The legislation recognized only binary sex and it constitutes problems for intersex persons on other levels as well. The registration has to be made in the early weeks but it only recognized two genders. The sex and personal identification code can be changed to fit in the gender that the person grows in. The problem is still present since if treatment is provided only for older DSD children on voluntary bases, some would most probably choose to remain at the birth condition. The identification issue was briefly mentioned in the research. Further research would be needed on the issues and possible solution for the problem of identification. For the benefit of intersex children, the registration to the governmental database could be also formatted, to accept the registration of an infant in a unisex way. According to the Article 7 of the UNCRC, children have to be registered immediately after birth. In Finland registration obligation is fulfilled. In practice, to be registered the child has to be assigned as male or female because the registration method requires gender information to generate personal identification code. The Supreme Administrative Courts' decision illustrated that the assignment of gender might cause distress to transgenders.¹⁷⁵ The identification document indication of gender is problematic for intersex children. It might very well be an example of other national procedure that does not take into account the best interest of intersex.

¹⁷⁵ see, Korkein Hallinto-Oikeus, KHO 2009:15, 3.2.2009.

C ONCLUSION

The best interest of the child is the base principle of UNCRC which connects to every other principle of the Convention. The best interest of the child forms the foundations of the UNCRC. The “fixing” of intersex children's bodies has been criticized and almost all legal literature argues for the total prohibition of medical interventions on intersex children. The best interest of the child principle can not be determined in an absolute manner. The best interest of the child has to be more or less evaluated on a case by case bases. The rights of the child granted by UNCRC are vague and adults play a major role in their materialization. The fulfillment of the obligations of the UNCRC should not be dependent on the individual adults, e.g. physicians or parents' readiness to change their personal opinion for the benefit of the child, it shall be granted by national legislation. Certain medical procedures on intersex children's bodies can not be prolonged until the child is capable of expressing his will, for example, CAH treatment shall be started early. It seems that legal research has strongly focused on the visible genitalia. In this research, it was found out that if certain intersex conditions are not treated the causes can be dangerous or lead to infertility in adulthood. Complete prohibition to treat intersex children would not automatically result in a situation when the best interest of the child materialized. The best interest shall be considered in a holistic manner and not only physical harm can put the children in a disadvantage. It is impossible to protect children from bullying or mental health problems which might be caused by the atypicality of gender or conflict between gender and gender identity. All the aspects that can be protected shall be taken into account while assessing what is in the best interest of the child. The fertility of DSD children is one of the aspects that nor ETENE`s position statement or Ministry of Justice statements has considered. The shared decision-making power of legal presentative and physicians does not grant sufficient fulfillment of the Convention. The fulfillment of the best interest of the child principle is not secured by Finnish national legislation and as a contracting party of UNCRC Finland should take appropriate measures to ensure the fulfillment of the principle. Legislation amendment would in the case be the appropriate measure since there are different opinion and not legally binding guidelines which have not achieved significant changes to treatment practice. The primary decision making power on the treatment of intersex children is held by parents unless it is legally changed.

The Committee on the Rights of the Child defined the best interest of the child to consider the physical, mental, spiritual, moral, psychological and social development of the child. Those aspects have to be analyzed in order to make a conclusion if the current Finnish legislation

infringes the principle of the best interest of the child. As mentioned, before it is natural to consider the best interest individually. However, in the case of intersex children, the group of children that the legislation would affect is easily defined. Therefore, it would be more beneficial to eliminate the harmful effects of personal opinions which might have affected the result by legislation rather than by ethical guidelines or trusting the parents' evaluation. The best interest of the children fails to protect the intersex children sufficiently because of its openness to interpretation. "Legal silence effectively legitimises the medical account of intersex as a purely material concern, permits attempts to 'normalise' these bodies and enables their social or cultural erasure." (Garland, F., & Travis, M. 2018, 589) Legal silence about DSD supports its classification as atypicality and not natural variation of gender. It also sets major pressure on the parents and treating unit employees and therefore, it can not be seen as serving the best interest of the children. It is necessary to adopt an Act on the treatment of intersex children, to guarantee that the best interest of the child principle is fulfilled so that also the other rights of the UNCRC materialize according to the Convention and personal integrity of the child is not deprived on arbitrary bases. Legal Act on medical treatment of intersex would notice intersex person as part of the society and hopefully, it will eventually release the stigma related to DSD. The Act should also determine the centralized treating unit for DSD. The transgender regulation for centralized treatment ensures that the best standard of health care can be provided for all the patients and similar regulations should be created for DSD patients.

The new legal Act should be imposed on DSD patients. It shall not be drafted extremely precise since DSD has several forms of appearance with different risks. The legal Act should include a compulsion to provide parents with information about the DSD and possible ways of treatment, including the evaluation of positive and negative outcomes. The treatment shall be uniform throughout Finland for equality and granting the best interest of the child. Different situations shall be taken into account in the legislation. Situations, where treatment is compulsory, should be limited to health and the possibility to reproduce.

The Act on DSD patient's treatment could include the following. Scope of application: The Act concerns the organization of research, diagnosis, and treatment provided for intersex patients. Responsibility of treatment: The responsibility for treatment shall be centralized to University hospitals of Helsinki and Oulu. Only physicians specialized in DSD treatment from before mentioned University hospitals shall be capable of diagnosing and treating a disorder of sex development. Definition of the condition: Disorder of development of sex means congenital conditions in which development of chromosomal, gonadal, or anatomical sex is atypical. The

obligations of the treating unit personnel: to provide sufficient impartial information of the condition to the legal representatives of DSD patients. Hearing of the patient: The DSD patient must be heard about the DSD treatment and given adequate information about the nature and effects of the circumcision, as required by his age and stage of development. Treatment shall not be made against the will expressed by the child if he or she is of age and based on their level of development able to understand the meaning of treatment. Self-Determination: Underaged DSD patient shall not be treated without the patient's consent unless if the condition remains untreated it will constitute: a) serious physical harm or pain b) infertility.

Since the research is legal it lacks sufficient medical analysis to define the physiological situations where the unnecessary medical interference would be justified before the child may express his will. To determine specific conditions or levels of atypicality for which the unnecessary genitoplasty could be justified high-level medical research should be carried out. There are many possibilities also for further legal research. It is important to ensure that the rights of the child are realized in health care practices, however intersex also affects our society more broadly. In the future, it shall resolved got proceed if intersex person at some point in their development feels that they belong to a different sex than they were originally defined as a newborn. Our current legislation allows for the correction of an identity number, if it is found to be incorrect. The ID identifies a person as either a woman or a man. Is this necessary still in the present and in the future, remains to be considered. In dealing with intersex literature it has been recommended for consideration by the possibility of transferring the determination of sex to a later age or even leave the matter completely open.

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