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CARE AND TREATMENT OF INTERSEX CHILDREN

The National Advisory Board on Social Welfare and Health Care Ethics ETENE is an advisory board tasked to deal with ethical questions related to social welfare and health care, to issue statements and recommendations about them and to keep an eye on the national and international development in the field.

ETENE has, out of its own initiative, taken up the issue of health care treatment practices related to intersex children. The issue has also received international interest in recent years. Among others, the European Union Agency for Fundamental Rights and the human rights commissioners of the Council of Europe and the United Nations have turned their attention to treatment practices that modify children's external genital organs and urged the member nations of their organisations to ensure that no unnecessary medical or surgical operations are done to children. The national ethics committees of Germany and Switzerland have also expressed their views about the matter, and the Committee on Bioethics (DH-BIO) of the Council of Europe is currently examining the treatment practises of intersex children in the member states of the Council of Europe. Some countries have introduced the so-called third gender, and in Malta surgical procedures for intersex children have been prohibited by law.

ETENE has taken up the subject of intersex in its meetings in December 2015 and in spring of 2016. The report by BTheol, L.D.S. Tuula Wahlman-Calderara, which is appended to this position statement, includes a summary of Finland's treatment practises, international and national regulations and ethical aspects concerning the treatment of intersex children. ETENE, in its meetings, has heard SETA's Secretary General Kerttu Tarjamo and its Senior Social Worker Maarit Huuska, Juha Kilpiä from intersukupuolisuus.fi online community and Terhi Viikki from Trasek ry. In addition, ETENE has participated in organising an intersex-related joint seminar with the Swedish National Council on Medical Ethics, www.smer.se, in April 2015 in Stockholm. In cooperation with the Ombudsman for Children, ETENE will organise a so-called round-table discussion on the topic in spring 2016.

Intersex, DSD

Intersex is a condition due to a congenital anomaly. Its most apparent characteristic is that a person's gender cannot be determined on the basis of physical properties of gender. The condition is most often observable in newborns but sometimes later when trying to find out why the changes typical for the gender in adolescence do not develop or when the growth and development of the child otherwise differ from normal. It is believed that between three and eight intersex children are born in Finland yearly.

The definition of the term intersex varies internationally. For this reason, there are no exact and comparable international figures about the prevalence or incidence of intersexuality. There have always been intersex people, and they have lived in every culture. Often they have been discriminated against, due to their characteristics, but in some societies they have had a high standing.

The Western way to correct the gender of intersex children originates from the 1950's U.S.A: it was believed that the child's personality is molded through the influence of the environment



and upbringing. In addition to surgical procedures, also the practice to determine, as early as possible, the child's gender as either girl or boy was strengthened. Often the child was not even told about being intersex. External genital organs were constructed or repaired already in early childhood to accord with the defined gender.

The idea about gender and also about the development of human personality has significantly changed since then. However, even now a child's gender is determined fairly soon after the birth, and external genitals of intersex children are surgically modified during childhood and adolescence also in Finland.

Legislation

The treatment of intersex children is regulated by general health care provisions. According to the Constitution of Finland, public service guarantees independent, equal and sufficient social and health care services to everyone regardless of their gender or state of health. The constitution safeguards the right to personal liberty and integrity, which can be interfered with only on the basis of law. In accordance with the age and the stage of development, the child has the right for self-determination in matters related to the child's own treatment. The parents and custodians of the child can use the self-determination of the newborn in accordance with the provisions of the law. The parents do not have right to refuse any necessary treatment which is given to prevent a threat to the life or health of the child. In their professional activities, health care professionals must apply generally accepted and empirically justified methods. They must weigh the benefits of their activities to the patient and the possible hazards involved.

Notifying of a birth or death belongs to the obligations of the health care professionals. In case of an intersex child, the child's gender can be left undetermined in the beginning. However, the Finnish population register system requires that the gender of the child be determined because the national identification number includes data about the gender of the person. A local register office can *correct* the identification number if it indicates a gender that is not the correct one. The national identification number can be *altered* under some special and strictly defined conditions, for example when a person changes gender.

Treatment practices

If the gender of a newborn cannot be determined in an external examination, the child will normally be sent to a university hospital for more exhaustive examinations. The examination primarily tries to find out whether the child has congenital adrenal hyperplasia to ensure that the hormone medication that is part of the treatment can be started as soon as possible. Also the child's genome is examined, often immediately after the birth. If the findings are normal, other factors giving rise to intersexuality will be examined.

Further measures are individually planned for the child in line with the child's condition and the findings of the examination. The degree to which the parents are integrated into the medical examination and decision-making stage varies according to the university hospital district. Surgical procedures that are seen as necessary are centralised to HUS Children's Hospital, but some procedures have taken place also in the Tampere University Hospital. Paediatricians and – if the child has undergone surgical procedures – also paediatric surgeons monitor the growth and development of the child. The responsibility for the determination of the child's gender falls to multi-professional groups whose composition varies regionally. It seems that the possibilities in health care units to offer psychological/psychiatric support are inadequate. Also the availability of peer support offered to families varies by region.



International developments

The UN Convention on the Rights of a Child is the world's most widely ratified human rights convention. It requires that the child's interests must be taken into account in all matters related to the child. In Article 24 of the Convention, it is stated that the child has the right to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health. In Article 3, the states that are parties to the convention are required to take measures to abolish traditional practices prejudicial to the health of children.

Article 6 of the Council of Europe Convention of Human Rights and Biomedicine (Biomedicine Convention, ETS 164) ratified by Finland in 2007 states that a medical intervention may be carried out on a person who does not have the capacity to consent, but only in cases when it is for that person's direct benefit.

In recent years, opinions on the treatment of intersex children have been expressed by the UN High Commissioner for Human Rights, the Commissioner for Human Rights of the Council of Europe and the European Union Agency for Fundamental Rights, among others. Also intersex people have become more active and have organised themselves, told about their experiences and strongly brought up the need to be accepted as they are. International organisations of intersex people have made strong efforts to enable the ending of gender-determining surgical operations.

Organisational activities

So far, there has not been any organisation of their own for intersex people in Finland. An online community, which published an internet support site for intersexuality, (www.intersukupuolisuus.fi), was established in October 2015. Of the non-governmental organisations, the Transgender Support Center and Trasek ry operating in Finland provide support also to intersex children and adults as well as to their parents. Finland's Turner association organises peer activities, and the Norio Centre has published on their pages information on rare hereditary diseases such as congenital adrenal hyperplasia and the Turner and Klinefelter syndromes.

ETENE's alignments

ETENE argues that gender is an important part of the person for every human being. According to current understanding, gender is not a clear-cut characteristic on the basis of which humans could be unambiguously classified into females and males. Gender is a continuum consisting of various genetic, developmental, hormonal, physiological, social and cultural characteristics. The gender diversity also includes the fact that a human can feel as being something else than merely a woman or man, girl or boy. Sex or gender is not the same as sexuality, and a person's gender identity does not determine that person's sexual identity.

Because gender is a multiform characteristic, appearance-changing interventions carried out to intersex persons as a child can push that person to another direction from the child's own idea about him/herself or from the final result of the child's gender and sexual identity development. Actions aimed to determine a person's gender might therefore be unnecessary and even harmful, and they could not only inflict a lot of suffering to the child but also incur costs to society.



ETENE raises the point that a child cannot influence the determination of that child's gender; it is in the power of the authorities to determine it. The method is problematic even though the authorities and experts aim to achieve the best possible result by drawing on their professional skills. The development of the child's own identity takes years, lasting the entire childhood and adolescence. It is now widely recognised that the gender experience is inborn and a part of a person in human beings. Interventions modifying external appearance cannot, in a straightforward manner, change the person's image about one's self and one's gender. They are not necessary from the viewpoint of the child's growth and development; on the contrary, they may make the child feel defective and insufficient as well as cause feelings of shame. This is how the grown intersex persons have described their own childhood.

It is problematic to try to influence a child's development with actions that cause pain. Determination of the child's gender as early as possible does not provide direct support for the child's own growth and development; rather, it helps to alleviate confusion and anxiety felt by the parents and the surrounding community and society. For this reason, we should give serious thought to finding out whether there might be other ways to act in the interest of intersex children than by modifying their appearance and external gender characteristics. Dissemination of information in the child's living and development environment is the first step in increasing the understanding and advances the possibility to protect children from unnecessary suffering. The adults involved in early childhood education and grown-ups at schools and later on in working life are the key persons to protect children and young people from discrimination and bullying for example.

From the viewpoint of intersex children, it is problematic that in the population register a child must be defined as a girl or as a boy during the first months of life. The national ID number has become genderised even though the legislation is otherwise fairly equal. According to the act concerning the population register, if the child's gender develops to a direction that is different from the one to which the child was defined as a newborn, the child's national ID can be corrected. There is no deadline for the correction of the national ID. Nevertheless, this will not fix the problem if the person does not feel, even later, as being accommodated by the two-way gender system.

ETENE's propositions

- Intersex is only a part of the gender and sexuality spectrum which applies to all human beings. Gender and sexuality are a central part of identity. It is important that a person can self-determine one's own gender identity. Gender identity and sexual orientation are different matters. A child's right for self-determination should be strengthened in matters that are important to the child's identity. A presupposition for this is that the measures modifying external gender characteristics are taken only when the child can define one's own gender and form an opinion about one's sexuality.
- Structural abnormalities affecting the child's health must be corrected in time. This includes the removal of glands affecting gender, due to increased risk of cancer. Timing of the intervention in a manner that respects the child's self-determination is not always easy and calls for sensitivity and wisdom from the side of the person responsible for the treatment of the child. Some international organisations propose that even these operations should be timed to take place in such a way that also the child would be able to express an opinion about carrying out the operation.



- The parents should be given a wide variety of information about intersex, and they should be explained how the condition affects the child's growth and development. The matters that intersex does not affect should be pointed out to them especially. The role of the parents is to support the child in the growth and development and make decisions on matters concerning the child's life and health when the child cannot participate in the relevant decision-making. The parents must be informed that by modifying external gender characteristics it is not possible to influence the child's later experience about one's gender and one's self. The parent's must be made aware that, on the contrary, experience of pain can traumatise and make the child's well-being and development more difficult. Intersex persons themselves have emphasised this.
- Health care nurses and professionals in early childhood education, especially, need to get information about the whole spectrum of gender development to safeguard the growth of intersex children and their development to their proper selves.
- ETENE encourages wide social debate about the basis by which the gender-linkage of the national ID number is seen necessary, about what benefits we derive from that and what kinds of drawbacks and problems there are with it. Most often, the national ID number is used for purposes where it is not necessary to identify the person as a woman or a man. In case of an intersex person, the national ID number expressing one's gender does not necessarily reveal who the person is and can even be misleading. Where the gender is deemed important, its identification can also be carried out by other means than by the ID.
- General knowledge about the gender as a human characteristic must be increased to make the people – in health care, day-care centres, schools, sports associations, parishes, non-governmental organisations and other associations involved with children – aware of the gender diversity and to make them able to give support to intersex children in their growth and development into equal citizens with full rights.

On behalf of the Advisory Board

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