



REPUBLIC OF SLOVENIA
ADVOCATE OF THE PRINCIPLE OF EQUALITY

The Situation of Intersex People in Medical Procedures

SPECIAL REPORT

Table of contents

SPECIAL REPORT SUMMARY	3
1 INTRODUCTION	7
1.1 Legal basis and purpose of the Special Report	7
1.2 Intersex people	7
1.3 The concept of intersex in the light of human rights and protection against discrimination	8
1.4 Legal protection of the rights of intersex people in the context of medical treatment.....	10
2 VIEWS OF INTERNATIONAL INSTITUTIONS, LEGAL REGULATIONS AND AWARENESS RAISING ACTIVITIES IN OTHER COUNTRIES	11
2.1 Position of the European Parliament	11
2.2 Position of the Parliamentary Assembly of the Council of Europe	11
2.3 Concerns expressed by the United Nations.....	12
2.4 Legal regulations in other countries	13
2.5 Examples of awareness-raising activities in other countries.....	15
3 THE ADVOCATE'S QUERIES ON THE SITUATION OF INTERSEX PEOPLE IN MEDICAL PROCEDURES	16
3.1 Reasons for the queries by the Advocate in Slovenia.....	16
3.2 Realisation of queries – purpose and methodological remarks.....	17
3.3 Content of the Advocate's queries	18
3.4 Summary of responses to Advocate's queries	22
3.4.1 Replies by health authorities at decision-making or professional level	22
3.4.2 The replies by key public health facilities	23
3.4.3 Responses by patients' rights representatives.....	26
3.5 Concluding analysis of the responses received to the Advocate's queries	27
4 ANNEXES	30
4.1 European Parliament resolution of 14 February 2019 on the rights of intersex people (2018/2878(RSP))	30
4.2 Resolution of the Parliamentary Assembly of the Council of Europe on Promoting the human rights of and eliminating discrimination against intersex people number 2191 (2017).....	34

Special Report Summary

In accordance with Article 22 of the Protection against Discrimination Act (hereinafter: PADA), the Advocate of the Principle of Equality (hereinafter: Advocate) shall report to the National Assembly of the Republic of Slovenia about their work and findings on the existence of discrimination involving specific groups of people with certain personal grounds in the framework of special reports. The present Report serves to draw the attention of the legislator and the public to the importance of respecting human rights and equal rights of persons born with such physical characteristics that – according to established medical and/or societal norms – their sex cannot be defined as female or male. The Advocate's decision to focus on the situation of intersex people in medical procedures was based on thematic resolutions of the Parliamentary Assembly of the Council of Europe¹ (2017) and the European Parliament² (2019). The resolutions tackle, among other things, the issue of the protection of human rights, more specifically equal rights of intersex people in medical procedures, and highlight the problem of medicalisation and pathologisation of intersexuality.

In the spring of 2019, the Advocate began to address the situation of intersex people in medical proceedings on the basis of Article 21 of the PADA, as there was a reason for suspicion that their human rights were being violated and they were subject to unequal treatment due to the personal ground of sex characteristics. Based on the resulting findings, a Special Report was drawn up by the Advocate to stress some important issues related to the right of intersex people to equal treatment, and to raise awareness of the significance of planning and adopting legal regulations and measures to prevent any possibility of discriminatory treatment.

The Advocate wishes to draw attention to the situation of intersex people, especially children and adolescents, in medical procedures. In accordance with the respective competences and task, which include raising public awareness, the Advocate wishes to underline the aim of this Special Report, which is to highlight a particular and specific aspect of what is otherwise a much wider issue, namely the situation of intersex people in society. The selected aspect refers to the highly sensitive issue of respect for bodily and mental integrity and the right to make informed decisions on treatment or interventions in the body. Hence, this Special Report does not cover all aspects of protection against discrimination against intersex people at societal level, but focuses on how the protection of human rights, specifically equal rights of intersex people, primarily children and adolescents, who are a particularly vulnerable social group, is ensured in procedures of intersex medical interventions, which the Advocate categorises under other personal grounds under Article 1 of the PADA, whereas being a physical/body/sexual characteristic of individuals.

And because participants in medical procedures for the so-called sex-normalising treatments, are mainly intersex children or adolescents, the Advocate supports the European Parliament's (EP's) concerns³, namely that the treatment of intersex as a medical condition or disease (pathologisation) is contrary to the objective of ensuring the highest attainable standard of health provided for children by the United Nations Convention on the Rights of the Child.⁴

¹Resolution of the Parliamentary Assembly of the Council of Europe No. 2191 (2017) on promoting the human rights of and eliminating discrimination against intersex people, adopted on 12 October 2017. Available at: <http://semantic-pace.net/tools/pdf.aspx?doc=aHR0cDovL2Fzc2VtYmx5LmNvZS5pbmQvbnRvcveG1sL1hSZWYyWDJILURXLWV4dHluYXNwP2ZpbGVpZD0yNDIzMiZsYW5nPUVQ&xsl=aHR0cDovL3NlbWFudGlicGFJZS5uZXQvWHNsC9QZGYyWFJlZi1XRC1BVC1YTUwYUJERGLnhzbA==&xsltparams=ZmlsZWlkPT10MjMy>

²European Parliament resolution of 14 February 2019 on the rights of intersex people (2018/2878(RSP)); available at: https://www.europarl.europa.eu/doceo/document/TA-8-2019-0128_EN.html

³Ibid.

⁴Available at: <https://www.ohchr.org/en/professionalinterest/pages/crc.aspx>

The Advocate also wishes to emphasise the importance of independent research concerning intersex people, taking a sociological and human rights perspective rather than (exclusively) a medical one. The EP also called on Member States to contribute to such research.⁵

The term intersex refers to persons born with physical (sex) characteristics that do not fit medical or societal norms for female or male bodies, and concern physical variations which may manifest themselves in the inner and outer genitalia, chromosomal or hormonal structure, muscle mass, hair distribution and stature.

Due to variations from established medical and societal norms relating to the male or female body, including sex characteristics, intersex people (in this case primarily children) may be subject to various forms of human rights violations, stigmatisation and discrimination, often experienced in areas of health care, education and employment.

In the area of health care, the problem is reflected through various aspects, such as:

- non-essential and medically unnecessary surgical procedures to normalise sex characteristics which can lead to permanent infertility, pain, incontinence, loss of sexual desire, and varying degrees of mental distress;
- concealing the actual nature of the surgeries performed;
- difficult access to appropriate treatment, necessary medications and medical records;
- insufficient understanding of the complexity of the phenomenon of intersex among medical staff.

An important step in understanding intersex and the rights of intersex people was the Resolution on Promoting the human rights of and eliminating discrimination against intersex people, adopted by the Parliamentary Assembly of the Council of Europe in 2017, and Resolution on the rights of intersex people⁶ adopted by the European Parliament (EP) in 2019.

An example of good practice in addressing rights of intersex people is Malta, which, with the adoption of the Gender Identity, Gender Expression and Sex Characteristics Act, became the first country in the world to prohibit all non-essential surgeries of intersex people without their consent, thus ensuring the protection of their bodily integrity. With such an arrangement, Malta ensures a high level of protection of human rights and equal treatment of intersex people.

In May 2019, the Advocate received a letter from a group of non-governmental organisations⁷ regarding the level of compliance with the EP recommendations set out in the EP Resolution on the rights of intersex people. The Advocate has taken note of the essential facts regarding the treatment of intersex people in medical procedures in Slovenia and with the trends of addressing the issue of (human) right protection of intersex people at the political level in the European Union. As a result, the Advocate's associates met with representatives of these non-governmental organisations, who presented them in more detail the challenges faced by intersex people, especially children and adolescents, in particular in regard to protection against discrimination.

⁵ European Parliament resolution of 14 February 2019 on the rights of intersex people (2018/2878(RSP)); available at: https://www.europarl.europa.eu/doceo/document/TA-8-2019-0128_EN.html

⁶The Slovenian term equivalent to "intersexuality" is used in the official Slovenian translation of the Resolution, but in the opinion of the Advocate and a group of non-governmental organisations, the term "intersex" is more appropriate, so the Slovenian equivalent for intersex is used in the Slovenian version of this Report only in cases of direct reference to the Resolution. The English word consists of the word inter and sex, which is, in this case, understood as gender (as it describes people whose gender cannot be medically determined).

⁷These are: the Amnesty International Slovenia, DIH – Equal Under the Rainbow Association, Legebitra Information Centre Association, Pride Parade Association, ŠKUC Association and Transfeminist Initiative TransAkcija Institute.

Based on an underlying analysis of available information on the protection of human and other rights of intersex people, the Advocate drew up written queries aimed at examining the situation regarding the equal treatment of intersex people in medical procedures.

In total, the Advocate sent 31 written queries, namely to patients' rights representatives, Ministry of Health, Medical Ethics Committee, National Institute of Public Health, Maternity Hospital Ljubljana, Clinic of Gynaecology at the University Medical Centre Ljubljana (UMC Ljubljana), Clinic of Gynaecology and Perinatology⁸ at the University Medical Centre in Maribor (UMC Maribor) and the Clinic of Paediatrics in Maribor.

Upon receipt of the responses, the Advocate addressed additional questions to some institutions, which were not answered until the end of December 2019 and the preparation of the present Special Report – with the exception of the Clinic of Paediatrics of the University Medical Centre Ljubljana.

The key findings from the analysis of the responses received from health-care institutions suggest the following:

- lack of familiarity with the term intersex among some health-care institutions, including patients' rights representatives;
- unfamiliarity with cases of medical treatment of intersex people;
- surgical procedures are performed in childhood or adolescence;
- the sex of the child is determined within a few days after birth on the basis of examination, genetic testing and diagnosis;
- the decisions taken by the competent departments of health-care institutions are based on current medical guidelines, while there is a lack of adherence to an approach that would ensure comprehensive protection of human rights (*human rights-based approach*);
- surgical interventions are also performed for reasons of "social acceptability", in spite of not being necessary to ensure the health of the baby or child or even survival;
- some planned ways of informing parents of intersex children suggest that intersex may be stigmatised and pathologised;
- protocols for decision-making on medical interventions for intersex people that are not absolutely necessary are unclear and inconsistent.

Based on the available information, the Advocate formulated several recommendations of a systemic character, intended for the executive branch, responsible for planning and implementing policies (the Government and competent ministries), as well as health-care institutions and the health and medical professionals, who are directly in contact with intersex people.

⁸Perinatology is "a multidisciplinary science relating to the health care of pregnant women, the fetus, the mother, and the newborn." SSKJ, Ljubljana, 2014. Available at: <https://fran.si/iskanje?View=1&Query=perinatologija>

The Advocate's recommendations regarding the situation of intersex people in medical procedures

The Advocate makes the following recommendations to competent ministries as policy makers:

- **to the Ministry responsible for health**, to appoint an independent interdisciplinary working group to revise the current protocols for medical treatment of intersex people, to design a uniform protocol which would be in line with modern medical guidelines and practices, including (international) human rights standards for intersex people;
- **to the Ministry responsible for the Interior**, to examine possible administrative arrangements for flexible procedures for the registration of births and legal recognition of gender on the basis of self-determination;
- **to the Ministries responsible for health and education**, in cooperation with the professionals and civil society, to carry out activities aimed at raising awareness among the general and specific public about the human rights of intersex people and the various forms of discrimination they (may) face;
- **to the Ministries responsible for health and education**, to improve the opportunities for additional professional training on the concept of intersex for professionals in health-care institutions and in health and medical educational institutions at all levels;
- **to the Ministry responsible for education**, to update educational materials to include modern educational content on the phenomenon of intersex and protection against discrimination against intersex people.

The Advocate makes the following recommendations to **health-care institutions**:

- to refrain from implementing any non-essential medical interventions affecting the sex characteristics of intersex children which would be carried out without their consent with the purpose of determining their sex or/and could be deferred until the child can give informed consent;
- to ensure that intersex children and their parents or legal guardians are properly informed of the course of such interventions, all potential consequences and of the possibility of psychosocial and psychological consultancy before the medical intervention in their body is carried out;
- to take due account of definitions and terms related to intersex that aim at depathologising of this condition and respecting for human rights of intersex people, while relying also on the relevant Resolution of the EP and the Parliamentary Assembly of the Council of Europe.

1 Introduction

1.1 Legal basis and purpose of the Special Report

In accordance with Article 22 of the Protection against Discrimination Act⁹ (hereinafter: PADA), the Advocate of the Principle of Equality (hereinafter: Advocate) shall report to the National Assembly of the Republic of Slovenia about their work and findings on the existence of discrimination involving specific groups of people with certain personal grounds in the framework of special reports.

In the spring of 2019, the Advocate began to address the situation of intersex people in medical proceedings on the basis of Article 21 of the PADA, as there was a suspicion that their human rights were being violated and they were subject to unequal treatment due to their sex characteristics.

The key objective of preparing this Special Report is to obtain basic information, which would reveal:

- the situation of intersex people in medical procedures in the public health-care system;
- the conduct of medical staff in cases of treatment of intersex persons;
- the attitude of key health-care institutions towards the issue of intersex in the context of human rights and protection against discrimination;
- the international context of addressing intersex; and
- examples of good practice.

With the present Special Report, the Advocate wishes to stress some important issues related to the right of intersex people to equal treatment, and to raise awareness of the significance of planning and adopting legal regulations and measures to prevent any possibility of discriminatory treatment.

1.2 Intersex people

The term **intersex**¹⁰ refers to persons born with physical (sex) characteristics that do not fit medical or societal norms for female or male bodies. At birth, it is difficult to attribute to such a baby exclusively female or male sex. **Intersex people** have diverse sex characteristics. They may have underdeveloped or atypically developed external genitalia, mismatch of anatomical structures of the internal and external genitalia, abnormalities of sex chromosomes and disorders in the development of the gonads.¹¹

The term intersex covers several physical characteristics that can manifest in different ways, namely:

- **primary characteristics** (such as internal or external sexual organs, chromosomal and hormonal structure) and/or
- **secondary characteristics** (such as muscle mass, hair distribution and stature)¹².

⁹Official Gazette of the RS, No. 33/16 in 21/18 – Non-Governmental Organisations Act.

¹⁰As a rule, the medical profession in Slovenia does not use the term intersex. The term "persons with a disorder of sex development" is used.

¹¹Taken from P. Kotnik, T. Battelino: Obravnava otroka z motnjo v razvoju spola, Društvo medicinski razgledi, year 51, No. 1, available at: <https://www.dlib.si/details/URN:NBN:SI:DOC-5JMBBNQA>, p. 2.

¹²Taken from the European Parliament resolution of 14 February 2019 on the rights of intersex people (2018/2878(RSP)); available at: https://www.europarl.europa.eu/doceo/document/TA-8-2019-0128_EN.html

Being intersex refers to physical or sex characteristics that an individual does not choose for oneself, but acquires at birth. Being intersex does not (necessarily) relate to the individual's sexual orientation or gender identity.

An intersex person can be heterosexual or homosexual, bisexual, or asexual, and can identify as male, female, both, or none of the above.¹³ In this respect, it is worth adding that – in terms of gender identity – these people may be cisgender¹⁴ or transgender¹⁵.

According to the United Nations (UN), the number of newborns showing sexual signs of intersex is between 0.05 and 1.7 percent of the total population,¹⁶ approximately 4–5 intersex children are expected to be born in Slovenia every year.¹⁷

1.3 The concept of intersex in the light of human rights and protection against discrimination

Towards the end of the 1990s, an increasing number of people with a variation in sex characteristics began to report on surgical and other medical procedures to which they were exposed in childhood or adolescence with the aim of normalising their sex,¹⁸ which has encouraged many organisations, activist groups and human rights advocates to contribute to the efforts for greater visibility of both intersex people and the interventions to which they have been subjected.¹⁹

In the last decade, attention given to human rights of intersex people and discrimination based on sex characteristics, gender expression and gender identity has been increasing significantly. In addition to the United Nations (UN), this issue has been addressed by many regional organisations, such as the Council of Europe, Organisation of American States²⁰ and African Commission on Human and People's Rights.²¹

Despite a marked improvement of the situation, intersex people in Europe are, according to the European Commission, still subject to discrimination and violence and pushed to the margins of society.²²

¹³Office of the High Commissioner for Human Rights. 2017. Fact Sheet – Intersex, p. 1.

Available at: <https://www.unfe.org/wp-content/uploads/2017/05/UNFE-Intersex.pdf>

¹⁴The Office of the UN High Commissioner for Human Rights defines cissexuality as a term used to describe people whose gender identity matches the gender attributed to them at birth. Available at: <https://www.unfe.org/definitions/>.

¹⁵Transsexuality (sometimes abbreviated trans) is an umbrella term used to describe a wide range of identities whose appearance and characteristics are perceived as atypical with regard to the gender they were born with – including transgender people, transvestites and non-binary people. Transgender women are identified as women but have been assigned a male gender at birth, transgender men are identified as male but have been assigned a female gender at birth, while other trans persons are not identified as male or female. Some transgender people take hormones or go for surgery to adjust their body and appearance to their gender identity, others do not. *Ibid.*

¹⁶Office of the High Commissioner for Human Rights. 2017. Fact Sheet – Intersex, p. 1.

Available at: <https://www.unfe.org/wp-content/uploads/2017/05/UNFE-Intersex.pdf>

¹⁷As part of the enquiries within the preparation of this Special Report, the Advocate received information from the Clinic for Paediatrics of the University Medical Centre Maribor that the frequency of the disorder of sex development was 1:4500. In 2018, 19,585 children were born alive in Slovenia, which means that approximately 4–5 intersex children are expected to be born in Slovenia annually. Statistical Office of the Republic of Slovenia (2018). Available at: <https://www.stat.si/StatWeb/Field/Index/17/95>

¹⁸ Reis, A. and McCarthy, M. (2017). *Perspectives in Biology and Medicine*. What hospitalists should know about intersex adults, 59(3), p. 391–398.

Available at: https://interactadvocates.org/wp-content/uploads/2017/06/09_59.3reis.pdf

¹⁹Amnesty International (2017). First, do no harm – ensuring the rights of children with variations of sex characteristics in Denmark and Germany.

Available at: <https://www.amnesty.org/download/Documents/EUR0160862017ENGLISH.PDF>

²⁰ OAS (2017) IACHR Urges States to End Violence and Harmful Practices against Intersex Persons, available at: http://www.oas.org/en/iachr/media_center/preleases/2017/189.asp

²¹At the 26th Extraordinary Session, the African Commission on Human and Peoples' Rights addressed the rights of intersex people as a special item on the agenda. Available at:

https://www.achpr.org/public/Document/file/English/Final%20communiqu%2026EOS_ENG.pdf

²² European Commission (2018). Trans and intersex equality rights in Europe – a comparative analysis. Available at: https://ec.europa.eu/info/sites/info/files/trans_and_intersex_equality_rights.pdf

In the area of medical treatment of intersex people in conjunction with respect for human rights, children's rights and the right to protection against discrimination, the following represents a problem:

- **non-essential and medically unnecessary surgical procedures** for the normalisation of sex characteristics;
- **inadequate information** on the actual nature of the surgeries carried out;
- **difficult access** to necessary medications and medical records; and
- **insufficient understanding of the** intersex phenomena, also in society in general.

The UN Committee against Torture has expressed concerns about “unnecessary and, in some cases, irreversible surgical procedures carried out with intersex persons without their consent” and called on States parties to enact legal regulations to protect the bodily integrity of intersex persons and ensure that, in childhood, no one will be exposed to unnecessary medical and other surgical procedures for the purpose of sex attribution.²³ The Council of Europe also points out that such surgical and other medical interventions on intersex children intended to align their sex characteristics with binary sexual perceptions of men and women based on sociocultural motives can be observed all over the world.²⁴

Moreover, particular studies exist that shed light on various problems faced by intersex people. The results of a British survey (2018)²⁵ show that more than a third (38 percent) of intersex people sought to access mental health services in the last twelve months prior to the survey, of which 13 percent were unsuccessful. This study also demonstrates that intersex people are more likely to visit a doctor with concern, shame and anxiety, compared to non-intersex, while many intersex people also report insufficient support from a doctor.²⁶

An increased level of understanding of the individual and collective barriers faced by intersex people can stimulate public debate on their marginalisation and situation in society, including the protection of their human rights and the right to equal treatment; while increased awareness of medical and other health professionals would facilitate their access to the exercise of health-care rights.

Some research shows that intersex people also face discrimination **in the field of education**, which is reflected in the invisibility of intersex pupils as well as high school and university students in the educational curriculum. They are completely ignored by the latter, except being mentioned as an example of “abnormality”, at the same time, sex education does not include bodies that cannot be categorised in a binary classification.²⁷

Intersex people from across Europe report discrimination and intimidation in educational institutions, including the use of derogatory language and physical and psychological violence. Research shows that victims of bullying often drop out of formal education, which has negative consequences for both the victims and the wider society, as inadequate formal education can later lead to higher levels of exclusion and poverty.²⁸

²³UN Committee against Torture. 2015. Concluding Observations of the Seventh Periodic Report of Switzerland, CAT/C/CHE/CO/7, para. 20; UN Committee against Torture. 2016. Concluding Observations of the Seventh Periodic Report of France, CAT/C/FRA/CO/7, para. 34–35

²⁴Council of Europe. *Human Rights and Intersex People*, p. 51. Available at: <https://book.coe.int/en/commissioner-for-human-rights/6683-pdf-human-rights-and-intersex-people.html>

²⁵The aim of a national survey conducted in the UK in 2017 was to obtain answers from LGBT and intersex people about their perceptions of the overall quality of their life in the UK. Government Equalities Office (2018). National LGBT survey – Summary report. Available at:

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/722314/GEO-LGBT-Survey-Report.pdf

²⁶Ibid, p. 24

²⁷Ibid, p. 27 **Napaka! Sklicna hiperpovezava ni veljavna.**

²⁸Ibid.**Napaka! Sklicna hiperpovezava ni veljavna.**

Discrimination faced by intersex people during education (can) later continue **during their employment**, where they may become victims of discrimination and harassment based on their appearance or gender expression.

For intersex people, mandatory pre-employment medical examinations can also prove to be extremely difficult, especially if health-care professionals are unaware of their condition or treat them as persons with a “developmental disorder”. Testimonies of intersex people show that they face intrusive interest, mistrust or rejection from co-workers at the workplace.

1.4 Legal protection of the rights of intersex people in the context of medical treatment

The Act governing patients’ rights is the **Patients’ Rights Act**²⁹ (PRA). In Article 7 of the PRA, **discrimination of patients is prohibited and a right to equal medical treatment for all patients is guaranteed** regardless of sex, nationality, race or ethnic origin, religion or belief, disability, age, sexual orientation or any other personal ground.

Article 3 of the PRA sets out the principles of exercising patients’ rights, which also apply to intersex people:

- **respect for physical and mental integrity and safety;**
- **the pursuit of maximum health benefits for patients, especially children;**
- **respect for autonomy in decisions on treatment;**
- **respect for personality and dignity** so as to prevent any social discrimination based on a health condition or causes, consequences or circumstances stemming from such condition or medical treatment incurred due to such condition.

Article 8 of the PRA which addresses the protection of children and other vulnerable groups, stipulates in the second indent of the third paragraph that children shall be provided with medical treatment appropriate to their age and health condition without unnecessary medical procedures and actions that could cause physical or emotional distress to children.

The right to be acquainted with medical documentation, as well as the right to independently decide on treatment, are only two of the patient rights listed exhaustively in Article 5.

Article 12 of the PRA, which regulates the entitlement to medical procedure or medical treatment, states that a patient shall be entitled to a medical procedure or medical treatment provided by public funds if such is required under the rules of the medical profession and if it can be reasonably expected, in accordance with current medical doctrine, that such will be beneficial and that the expected benefits for the patients are greater than the risks and burdens.

The Advocate notes that some of the EP’s recommendations from the Resolution, which relate to the adoption of national regulations governing the rights of intersex people in the field of health care, have already been partially implemented and that the rights of intersex people are regulated in the PRA. However, the question which remains open is whether the legal provisions are consistently, appropriately and effectively implemented in practice.

²⁹Official Gazette of the RS, No. 15/08 and 55/17

2 Views of international institutions, legal regulations and awareness raising activities in other countries

2.1 Position of the European Parliament

At the plenary session on 14 February 2019, the EP adopted a Resolution on the rights of intersex people,³⁰ in which, among other things, the EP:

- “... notes the urgent need to address violations of the human rights of intersex people, and calls on the Commission and the Member States to propose legislation to address these issues...” Article 1
- “...strongly condemns sex-normalising treatments and surgery; welcomes laws that prohibit such surgery, as in Malta and Portugal, and encourages other Member States to adopt similar legislation as soon as possible...” Article 2
- “...calls on the Member States to improve access for intersex people to their medical records, and to ensure that no one is subjected to non-necessary medical or surgical treatment during infancy or childhood, guaranteeing bodily integrity, autonomy and self-determination for the children concerned...” Article 6
- “...takes the view that pathologisation of intersex variations jeopardises the full enjoyment by intersex people of the right to the highest attainable standard of health as enshrined in the UN Convention on the Rights of the Child; calls on the Member States to ensure the depathologisation of intersex people...” Article 7

In this Resolution, the EP also notes, inter alia, that:

- “...there is a high prevalence of surgeries and medical treatments carried out on intersex infants, although in most cases these treatments are not medically necessary; whereas cosmetic surgeries and urgent surgeries can be proposed as a package, preventing parents and intersex people from having full information on the impact of each...” Point C;
- “...surgeries and medical treatments are performed on intersex children without their prior, personal, full and informed consent; whereas intersex genital mutilation can have lifelong consequences, such as psychological trauma and physical impairments...” Point D;
- “...in many cases parents and/or legal guardians are strongly pressured to make decisions without being fully informed of the lifelong consequences for their child...” Point G;
- “...some intersex people will not identify with the gender they are medically assigned at birth; whereas legal gender recognition based on self-determination is only possible in six Member States; whereas many Member States still require sterilisation for legal gender recognition...” Point J.

2.2 Position of the Parliamentary Assembly of the Council of Europe

Resolution of the Parliamentary Assembly of the Council of Europe on Promoting the human rights of and eliminating discrimination against intersex people number 2191 (2017),³¹ also highlights:

³⁰European Parliament resolution of 14 February 2019 on the rights of intersex people (2018/2878(RSP)), see points No. 1., 2., 6., 7. in C., D., G., J.. Available at: https://www.europarl.europa.eu/doceo/document/TA-8-2019-0128_EN.html

³¹Resolution of the Parliamentary Assembly of the Council of Europe No. 2191 (2017) on the promotion of human rights and the elimination of discrimination against intersex people; adopted 12 October 2017. Available at: [http://semantic-pace.net/tools/pdf.aspx?doc=aHR0cDovL2Fzc2VtYmx5LmNvZS5pbmQvbncveG1sL1hSZWYvWDJILURXLWV4dHluYXNwP2Z](http://semantic.pace.net/tools/pdf.aspx?doc=aHR0cDovL2Fzc2VtYmx5LmNvZS5pbmQvbncveG1sL1hSZWYvWDJILURXLWV4dHluYXNwP2Z)

- **the importance of general identification of problems** faced by intersex people, which contributes to the acceptance of intersex people without stigmatisation or discrimination;
- **the importance of specialised, interdisciplinary team**, which, in addition to medical staff, also consists of psychologists, social workers, and ethics experts.

2.3 Concerns expressed by the United Nations

The Office of the United Nations High Commissioner for Human Rights (OHCHR) and various UN treaty-based bodies have previously fiercely criticised cosmetic and other non-essential surgeries on children's sexual and reproductive organs.³²

In many cases, such medical interventions are performed at a time when intersex children are still too young to be able to fully and effectively participate in the decision-making process regarding these interventions, and parents in most cases do not have comprehensive information and are not aware of positive perceptions of physical diversity.

In an interinstitutional statement by seven UN bodies and agencies, including the World Health Organisation, a warning was made that sex-“normalising” treatments could have irreparable and lifelong negative consequences for the physical and mental health of intersex people.³³

As early as 2009, the UN Special Rapporteur on the Right to Health called on health-care professionals to strive for the postponement of non-essential invasive and irreversible interventions until children are mature enough to give their consent based on prior information. It was emphasised that surgeries involving sexual organs of intersex children are particularly problematic, as they cause great pain, are risky, and at the same time do not bring proven health benefits.³⁴

Furthermore, in his 2013 Report, the UN Special Rapporteur on Torture assessed that the abuse of medical procedures which exceed a certain threshold constitutes torture or cruel, inhuman and degrading treatment or punishment. It was also pointed out that such gross violations of reproductive rights as forms of torture or ill-treatment are often based primarily on gender prejudices (both from the social and biological perspective). Furthermore, the Report criticised the medically unnecessary and irreversible surgeries on infants and children performed without their consent, and called on all countries to ban such interventions.³⁵

In 2015, the OHCHR held the first expert meeting on the topic of ending human rights violations of intersex people. At the opening of the event, the former OHCHR pointed out that intersex people are subject to very serious human rights violations. Such violations include surgeries that are not necessary for the child's health and other non-essential invasive interventions on intersex infants and children, infanticide of intersex infants, and lifelong

[pbGVpZD0yNDIzMiZsYW5nPUVO&xsl=aHR0cDovL3NlbWFudGlicGFjZS5uZXQvWHNsdC9QZGYvWFJiZi1XRC1BVC1YTUwyUERGLnhzbA==&xsltparams=ZmlsZWlkPTI0MjMy](https://www.who.int/reproductivehealth/publications/gender_rights/eliminating-forced-sterilization/en/)

³²OHCHR. 2011. *Discriminatory laws and practices and acts of violence against individuals based on their sexual orientation and gender identity*, A/HRC/19/41, Par. 57; the Committee on the Rights of the Child. 2015. Concluding Observations: Switzerland, CRC/C/CHE/CO/ 2-4; Committee against Torture. 2011. Concluding Observations: Germany, CAT/C/DEU/CO/5.

³³Office of the OHCHR, UN Women, UNAIDS, UNDP, UNFPA, UNICEF and WHO. 2014. *Eliminating Forced, Coercive and Otherwise Involuntary Sterilization, An Interagency Statement*, p. 7. Available at:

https://www.who.int/reproductivehealth/publications/gender_rights/eliminating-forced-sterilization/en/

³⁴Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health. 2009. A/64/272.

³⁵Report of the Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment. 2013. A/HRC/22/53.

discrimination in various areas.³⁶ A year later, on the *Intersex Awareness Day*, which is on October 26, the OHCHR made a call³⁷ for the cessation of violations of human rights of intersex children and adults.

And again, governments were called upon to prohibit harmful medical interventions, including surgeries not medically necessary and surgeries without consent.³⁸

In 2019, the OHCHR issued an even more extensive contribution to human rights violations of intersex people.³⁹ In this contribution, it is pointed out that a common reason for performing non-urgent medical procedures is the fear of divergence of societal norms. At the same time, it is highlighted that the fear of discrimination against people with atypical sex characteristics must not be used as an excuse to justify such abuses, hence, individual countries need to tackle discrimination in different ways and address its causes. Moreover, similarities between the stigmatisation of intersex people and people with disabilities are underlined. In both cases, these are groups that do not fully comply with the established societal and medical norms and hence also face forced medical interventions and discrimination.⁴⁰

The contribution also highlights the negative consequences of irreversible medical interventions, including terminal infertility, sterilisation, incontinence, and experience similar to rape, which can lead to lifelong physical pain and psychological suffering, including depression and shame.⁴¹ The early performance of non-urgent medical interventions is criticised, as they may lead to trauma, while this way, possible future restorative surgeries are not considered.⁴² Parallels between female genital mutilation and alteration of genitals in case of children with atypical genitals are drawn.⁴³ At the same time, the importance of work by organisations dealing with the rights of intersex people is emphasised, as without their contribution, the OHCHR would not be able to adequately draw attention to such problems.

2.4 Legal regulations in other countries

The best example of advanced treatment and protection of the rights of intersex people is **Malta**, where by adopting the *Gender Identity, Gender Expression and Sex Characteristics Act*⁴⁴ in 2015, protection of bodily integrity and self-determination of intersex people was ensured, hence Malta became the first country in the world to legally ban non-essential operations on intersex children and adults.

The Act, adopted unanimously by the Maltese Parliament, was drafted under the auspices of the Maltese Ministry of Social Dialogue, Consumers and Freedoms.

³⁶OHCHR, Opening remarks by Zeid Ra'ad Al Hussein, United Nations High Commissioner for Human Rights at the Expert meeting on ending human rights violations against intersex persons, Geneva 16. September 2015, available at: <https://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=16431>.

³⁷OHCHR Office: End violence and harmful medical practices on intersex children and adults, UN and regional experts urge, available at: <https://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=20739&LangID=E>.

³⁸The signatories of the call are *UN Committee against Torture (CAT)*, *UN Committee on the Rights of the Child*, *UN Committee on the Rights of People with Disabilities*, *UN Subcommittee on Prevention of Torture and other Cruel, Inhuman or Degrading Treatment or Punishment*, *UN independent experts*

³⁹ United Nations Human Rights Office. 2019. *Background Note on Human Rights Violations against Intersex people*, at: <https://www.ohchr.org/Documents/Issues/Discrimination/LGBT/BackgroundNoteHumanRightsViolationsagainstIntersexPeople.pdf>.

⁴⁰*Ibid.*, p. 4

⁴¹*Ibid.*, p. 11

⁴²*Ibid.*, p. 15

⁴³*Ibid.*, p. 14

⁴⁴ Maltese Gender Identity, Gender Expression and Sex Characteristics Act (2015).

Available at: <http://justiceservices.gov.mt/DownloadDocument.aspx?app=lom&itemid=12312&l=1>

Gender Identity, Gender Expression and Sex Characteristics Act:

- guarantees all citizens of Malta the right to the recognition of their gender identity, bodily integrity and physical autonomy (Article 3);
- establishes a distinction between interventions addressing the actual health needs of a person and other medical interventions that are cosmetic in nature, can be postponed and are performed for social/cultural reasons (Article 1);
- prohibits any attempts of sex-“normalising” treatments, “sex attribution” and other interventions in the sex characteristics of minors that may be postponed until the latter is able to make his or her own decisions on the basis of informed consent (Article 14);
- allows surgeries and other medical interventions in the sex characteristics of the infant or child if his or her life is endangered, while surgeries and medical interventions performed for social/cultural reasons are considered a violation of the law,
- provides for legal consequences in case of violation of the law (Article 11);
- allows a mature adolescent with a consent given to request a change in sex characteristics (Article 4);
- guarantees the right to individual, adapted and lifelong psychological and psychosocial support to intersex people, their parents and families (Article 15).

Malta is currently the only European country prohibiting non-essential medical procedures by the law. Some European countries have legal regulations pertaining to the recognition of the sex of intersex children.⁴⁵

One of them is **Germany**. Since 2013, there has been a possibility in Germany that in case of newborns whose sex could not be clearly determined, the determination of sex is postponed and sex is (temporarily) indeterminate. However, in 2017, the Federal Constitutional Court ruled that such an arrangement violated the rights of a group of persons who did not identify as a man or a woman, and at the same time stressed that it was a violation of the prohibition of discrimination based on sex and gender identity.

The Third Gender Act⁴⁶ was adopted to amend the previous unconstitutional Civil Status Act in such a way that, in addition to males and females, the category “different” shall be introduced.⁴⁷ This Act is in force from January 1, 2019.

In **Finland** and **Portugal**, the registration of a child whose sex cannot be determined at birth may be postponed for an unlimited period of time, while in **France**, it is possible, in some cases, to postpone sex registration until the third year of age, in **Belgium** however, this is possible only until the third month of age.⁴⁸

In **Austria**, a constitutional interpretation of the term sex was adopted by the Constitutional Court, which, according to this interpretation, also includes individuals who do not identify as men or women.

⁴⁵Legal recognition of gender is also an important aspect of the treatment of intersex people. This Special Report focuses on the health/medical aspect of the treatment of intersex people, so the Advocate does not give further comments on this issue in this document. However, in order to understand the wider context, it is relevant to highlight certain good practices in regulating legal recognition of gender in European countries, as these are related topics.

⁴⁶The German Act *Gesetz zur Änderung der in das Geburtenregister einzutragenden Angaben*, Bundesgesetzblatt Teil I Nr. 48. Available at:

https://www.bgbl.de/xaver/bgbl/start.xav?startbk=Bundesanzeiger_BGBI&jumpTo=bgbl118s2635.pdf#_bgbl_%2F%2F%5B%40attr_id%3D%27bgbl118s2635.pdf%27%5D_1579419967284

⁴⁷German Act NJW 2017, 3643 – *Third Gender in Civil Status Law* (Excerpts). Available at:

<https://germanlawarchive.iuscomp.org/?p=1960>

⁴⁸Summary of the Good Practice Map 2018 Organisation Intersex International Europe (OIIEurope), April 2019. Available at: https://oiieurope.org/wp-content/uploads/2019/05/gpmap2018_web.pdf

By acknowledging this, the Court recognised the third gender and contributed to the respecting of human rights of intersex people without the legislation having to be amended. In **Italy**, however, the Court of Cassation and then the Constitutional Court rejected a surgical intervention as a precondition for recognising sex.⁴⁹

2.5 Examples of awareness-raising activities in other countries

In **Luxembourg**, the organisation Intersex & Transgender Luxembourg, organised Intersex Days in 2017 under the auspices of the Luxembourg Ministry of Health, the main purpose of which was to draw attention to the problems of intersex people around the world, surgeries and hormonal therapies to which these people are exposed, all this with the aim of breaking taboos related to the intersex.⁵⁰

In **Denmark**, the organisation Pride, in collaboration with Intersex Denmark, hosted the second meeting and conference of European intersex activists, which was the largest meeting of activists for the rights of intersex in Europe.⁵¹

In **Iceland**, a queer organisation Samtökin 78 operating since 2014, has been integrating problems faced by intersex people in its educational programmes and activities.⁵²

The Netherlands government is currently the only one to provide financial support to organisations who concern themselves with the rights, interests and problems of intersex people. The Netherlands Ministry of Education, Culture and Science provides a five-year financial support to the Netherlands Netwerk Intersekse/dsd Foundation (NNID) with the intention of promoting their work in promoting the human rights of intersex people and raising awareness of the problems they face.

The Netherlands Ministry of Foreign Affairs provides a three-year financial support in an international environment (outside Europe), enabling the NNID Foundation to employ five people who perform their work under both national and international programs.⁵³

⁴⁹ European Commission (2018) Trans and intersex equality rights in Europe – a comparative analysis.

Available at: https://ec.europa.eu/info/sites/info/files/trans_and_intersex_equality_rights.pdf

⁵⁰ European Union Agency for Fundamental Rights (2018) Fundamental Rights Report, p. 59.

Available at: https://fra.europa.eu/sites/default/files/fra_uploads/fra-2018-fundamental-rights-report-2018_en.pdf

⁵¹ Summary of the Good Practice Map 2018 Organisation Intersex International Europe (OI Europe), April 2019. Available at: https://oiieurope.org/wp-content/uploads/2019/05/gpmap2018_web.pdf

⁵² Ibid.

⁵³ Summary of the Good Practice Map 2018 Organisation Intersex International Europe (OI Europe), April 2019. Available at: https://oiieurope.org/wp-content/uploads/2019/05/gpmap2018_web.pdf

3 The Advocate's queries on the situation of intersex people in medical procedures

The Advocate is an autonomous national body which, in line with the sixth indent of Article 21 of the PADA, monitors the overall situation in the Republic of Slovenia with regards to the protection against discrimination and situation of persons with particular personal grounds.

The Advocate prepared written queries, which were addressed to relevant stakeholders in the field of health policy and health care in Slovenia, as means to examine the situation in the area of equal treatment of intersex people in medical procedures and, where needed and in accordance with legal competences, also take special measures or issue recommendations for improving the situation of a group of persons with a certain personal ground or otherwise takes action at the systemic level.

3.1 Reasons for the queries by the Advocate in Slovenia

At the end of May 2019, in the framework of consultations with non-governmental organisations (NGOs), the Advocate met with representatives of Amnesty International Slovenia, Legebitra Information Centre Association and Transfeminist Initiative TransAkcija Institute.

At the meeting, challenges faced by intersex people in the health-care system and in medical treatments were presented. Representatives of NGOs pointed out that at least in some cases, human rights violations could have occurred as well as unequal treatment based on the personal ground of sex characteristics, i.e., discrimination within the meaning of the Protection against Discrimination Act (PADA).

A wider group of NGOs⁵⁴ has also notified the Advocate in writing of intersex persons born with physical sex characteristics that do not fit medical or societal norms for female or male bodies. These variations in sex characteristics may manifest themselves in primary characteristics (such as the inner and outer genitalia and the chromosomal and hormonal structure) and/or secondary characteristics (such as muscle mass, hair distribution and stature).

In their letter, the NGOs also pointed out that the EP's Resolution on the Rights of Intersexual Persons⁵⁵ ("the Resolution") drew attention to discriminatory practices and weaknesses in legislation, as well as to the issue of surgical practices that are not strictly necessary from a health point of view.

Besides the fact that no child should be subjected to non-urgent, invasive and irreversible surgical interventions or treatment with harmful consequences, the non-governmental organisations also drew attention to several issues related to the current state of medical treatment of intersex people in Slovenia in areas addressed by the Resolution:

- What surgeries and other medical procedures are performed on intersex children? Are these interventions necessary, in other words, do they eliminate a condition that endangers life or health?
- In what ways are intersex children and their parents or legal guardians informed about such interventions?

⁵⁴Amnesty International Slovenia, DIH – Equal Under the Rainbow Association, Pride Parade Association, Legebitra Information Centre Association, ŠKUC Association and Transfeminist Initiative TransAkcija Institute.

⁵⁵European Parliament resolution of 14 February 2019 on the rights of intersex people (2018/2878(RSP)). Available at: http://www.europarl.europa.eu/doceo/document/B-8-2019-0101_EN.html

- How is the consent of children, their parents or legal guardians obtained to perform such interventions?
- How do health facilities provide access to health records for intersex people?
- How do intersex people become familiar with their condition?
- How does medical staff classify intersex conditions? How many such classifications have been recorded in the last year and in the last five years?

3.2 Realisation of queries – purpose and methodological remarks

With the queries, the Advocate pursued the purpose of establishing **what is the understanding the concept of intersex** and, **in particular, what is the perception of potential violations of the right to equal treatment of intersex people by health-care institutions** in the light of the recommendations formulated in the EP Resolution. The Advocate's objective was to **obtain information on the perception of discriminatory practices within the medical profession, understanding of rights**, and functioning in terms of **medical treatment of intersex persons**.

On 24 June 2019 and on 4 July 2019, the Advocate addressed written requests to 23 addresses of health-care institutions for the submission of information related to medical treatment of intersex people. On 30 July 2019, the Advocate once again forwarded requests for information to 9 health institutions, which did not respond to the first query by 29 July 2019. Up to and including 24 September 2019, 21 institutions, that is 91 percent of all addressed health-care institutions, responded and submitted their clarifications.

On 21 November 2019, after receiving responses from most of the requested institutions and examining them, the Advocate addressed a written request to the Medical Ethics Committee (Ministry of Health), Clinic of Paediatrics (University Medical Centre Maribor) and Clinic of Paediatrics (University Medical Centre Ljubljana) for additional clarifications regarding the replies given in the context of the first query.

Subsequently, on 17 January 2020, the Advocate addressed a written request for information also addressed to assist. dr. Andreja Štolfa, dr. med. The Advocate decided to do so after one of the Advocate's expert colleagues attended the expert conference "Ethical challenges in gynaecology, perinatology and reproductive medicine" on 5 December 2019, at which dr. Štolfa held a lecture on gynaecological treatment of people with congenital genital disorders.

Hence, the Advocate forwarded written queries to the following **relevant public institutions**, which are responsible for the formulation and implementation of health policy and the implementation of health-care activities:

- **The Ministry of Health (MH) and within its framework, the Extended Professional College of Paediatrics, the Extended Professional College of Gynaecology and Obstetrics, the Medical Ethics Committee and the National Institute of Public Health** as key health policy makers and enforces. In accordance with Article 40 of the State Administration Act,⁵⁶ the activities of MH include tasks in the field of public health and health care. The National Institute of Public Health, which is a central national institution whose primary purpose is to study, protect and increase the level of public health in the Republic of Slovenia through awareness-raising activities and other preventive measures.⁵⁷

⁵⁶Official Gazette of the RS, No. 113/05 – official consolidated text, 89/07 – decision by the Constitutional Court, 126/07 – ZUP-E (Act Amending the General Administrative Procedure Act), 48/09, 8/10 – ZUP-G (Act Amending the General Administrative Procedure Act), 8/12 – ZVRS-F (Act Amending the Government of the Republic of Slovenia Act), 21/12, 47/13, 12/14, 90/14 and 51/16

⁵⁷NIPH. Available at: <https://www.nijz.si/en/identity-card>

- **The Clinic of Paediatrics, Maternity Hospital Ljubljana and Gynaecology Clinic within the University Medical Centre Ljubljana** (in January 2020, the Advocate also sent a separate request to assist. dr. Andreja Štolfa, dr. med.) and **Clinic of Gynaecology and Perinatology and Clinic of Paediatrics within the University Medical Centre Maribor**. Both university medical centres are key public health institutions performing health-care activities.⁵⁸
- **To all 13 patients' rights representatives**, which appeared on the list of the Ministry of Health of the Republic of Slovenia on 24 June 2019⁵⁹. In accordance with Article 49 of the PRA, their activities include, inter alia, counselling on the content of rights in the field of health care, health insurance and implementation of health-care activities, methods and possibilities of their enforcement in the period before or during treatment, and when these rights are violated, also help and representation of the patients.

In the written queries, the Advocate clarified that the term intersex was used even when referring to medical diagnoses, taking into account the fact that the medical profession does not use the term intersex but uses the term disorder of sex development.

The Advocate uses the term intersex, in the same way as the European Parliament in its Resolution, when referring to persons born with physical/sex characteristics that do not fit medical or societal norms for female or male bodies.

These variations in sex characteristics may manifest themselves in primary characteristics (such as the inner and outer genitalia and the chromosomal and hormonal structure) and/or secondary characteristics (such as muscle mass, hair distribution and stature).

3.3 Content of the Advocate's queries

Questions raised by the Advocate in the queries to various public institutions functioning in the field of health policy and health care varied according to the different competencies in the context of medical treatment of intersex people.

Questions raised with the Ministry of Health:

- Is the Ministry of Health aware of any cases of medical treatment of intersex persons? If so, how many such cases of newborns born with physical sex characteristics that do not fit medical or societal norms for female or male bodies have been recorded in the past year and how many in the last five years?
- Is the Ministry of Health familiar with the way how medical staff classifies intersex conditions?
- What are the attributed diagnoses, symptoms or medical conditions on the basis of which medical doctors decide to perform a surgery on intersex newborns? Are such interventions necessary in the light of sustaining life? Do intersex people who underwent medical procedures (surgeries) also receive other therapies (e.g. hormonal)?
- Is there any special medical protocol for cases when a newborn has symptoms or one of the diagnoses which are understood as intersex?

⁵⁸UMC LJ and UMC MB. Available at: https://www.kclj.si/index.php?dir=ukc_ljubljana/o_nas in <https://www.ukc-mb.si/bolnišnica/ukc-maribor-danes-poslanstvo-in-vizija>

⁵⁹Patient rights. Available at: <https://www.gov.si teme/pacientove-pravice/>

- Has the Ministry of Health so far provided public health institutions with any information or instructions regarding the (medical) treatment of intersex persons and their parents or legal representatives? If so, please forward the instructions to us.
- Is the Ministry of Health aware of how access to medical records is provided in these cases and when are intersex persons formally informed of their situation? If access is not enabled, are you familiar with reasons for such an approach?
- Is the Ministry of Health aware of whether the parents or legal representatives of intersex children are in any way specially informed or approached during medical treatment of these intersex children? Are they informed about the possible consequences of the surgery, and how much time do the parents have to decide on their consent for such a surgery? Are the parents or legal guardians asked for their consent which they sign after receiving all the information on the symptoms?

Questions raised with the Extended College of Paediatrics, the Extended College of Gynaecology and Obstetrics and Medical Ethics Committee (MEC):

- What is the position of the expert College on medical interventions and other therapies (e.g. hormonal) in newborns born with physical sex characteristics that do not fit medical or societal norms for female or male bodies?
- Have you discussed this at any of your previous meetings within your College? If not, will you discuss this at any of the forthcoming meetings?
- Have you taken note of the practices in other countries regarding the medical interventions in persons born with sex characteristics do not fit medical or societal norms for female or male bodies, and are you aware of the European Parliament's recommendations given in the Resolution on the rights of intersex people?

Additional questions raised with the MEC:

- What is the position of the MEC on medical interventions and other therapies (e.g. hormonal) in newborns born with physical sex characteristics that do not fit medical or societal norms for female or male bodies?
- Has MEC already considered this issue and adopted a position? If not, does MEC have an intention to address this issue in the future?
- Are you aware of practices in other countries regarding the medical interventions in persons born with sex characteristics do not fit medical or societal norms for female or male bodies, and are you aware of the recommendations laid down in the European Parliament's Resolution?

Questions raised with the National Institute of Public Health:

- Do you collect and process data on how many people are born with physical sex characteristics that do not fit medical or societal norms for female or male bodies? In other words, on how many intersex people are born in the Republic of Slovenia every year?
- Have you possibly already carried out any analysis of the situation or research on this subject matter?
- Do you recognise any challenges or specifics in this area that could support such research or analysis in the future?

Questions raised with individual clinics⁶⁰ within both university medical centres in Ljubljana and Maribor:

- How does medical staff classify intersex conditions?
- How many such cases of newborns born with physical sex characteristics that do not fit medical or societal norms for female or male bodies have been recorded in the past year and how many in the last five years?
- What are the attributed diagnoses, symptoms or medical conditions on the basis of which medical doctors decide to perform a surgery on intersex newborns? Are all such interventions necessary in the light of sustaining life? Do intersex people who underwent medical procedures (surgeries) also receive other therapies (e.g. hormonal)?
- Is there any special medical protocol for cases when a newborn has symptoms or one of the diagnoses which are understood as intersex? If there is, please forward it to us.
- In what ways are parents or legal representatives informed in such cases? Are they informed about the possible consequences of the surgery? How much time do the parents have to decide on their consent for such a surgery? Are the parents or legal guardians asked for their consent which they sign after receiving all the information on the symptoms?
- How does your health-care institution provide access to medical records in these cases? When do intersex persons get formally acquainted with their condition?

Additional questions raised with the Clinic of Paediatrics within the University Medical Centre Ljubljana which are linked to the replies received by the Advocate:

- Is the composition of the multidisciplinary team for the treatment of children with gender development changes permanent? Who is responsible for appointing the members, how does the appointment take place, and is there a list of the multidisciplinary team members' names that could be provided to the Advocate? (This question refers to the reply by the Clinic of Paediatrics: *"Children with changes in gender development are treated by a multidisciplinary team consisting of endocrinologists, gynaecologists, urologists, psychologists, andrologists, neonatologists, clinical geneticists, and, where appropriate, also pathologists and molecular geneticists."*)
- A booklet with written information is also available for parents of a child with changes in gender development. Is the booklet available to the general public on your website? If not, we would ask you to forward us the said booklet. (This question refers to the reply by the Clinic of Paediatrics: *"Parents who have a child with changes in gender development, are presented a booklet with information in writing."*)
- Parents are offered psychological support. How is the psychological support carried out, who provides it? Do intersex people also have access to such support later in life? (The question refers to the reply by the Clinic of Paediatrics: *"Based on all the information, parents take part in the decisions taken regarding therapeutic measures. Also, psychological support is provided."*)

Additional questions raised with the Clinic of Paediatrics within the University Medical Centre Maribor which are linked to the answers received by the Advocate:

⁶⁰The Advocate addressed the questions to the Clinic of Paediatrics at the UMC Ljubljana, Maternity Hospital Ljubljana – Clinical Department for Perinatology at the University Medical Centre Ljubljana, Gynaecology Clinic at the UMC Ljubljana, Clinic for Gynaecology and Perinatology of the UMC Maribor and the Clinic for Paediatrics of the UMC Maribor.

- We are additionally interested in who are the experts of which the team is made up and what are their professions? Is the composition of such a team permanent? Who appoints the team members and what is the procedure?
(The question relates to the original reply by the Clinic of Paediatrics: *"The decision on the gender in which the child will be raised is taken by the parents in cooperation with the multidisciplinary team..."*)
- We are additionally interested in who are the experts of which the team is made up? Are they just members of the psychological professions or other professions too? Is the composition of such a team permanent? Who appoints the team members and what is the procedure?
(The question relates to the original reply by the Clinic of Paediatrics: *"... a team of psychologists is always involved in the treatment, even if the question of gender identity is raised later."*)
- We are additionally interested in what you mean by the term "cultural peculiarities of the environment"? How does the assessment of cultural specifics of the environment take place and who is involved?
(The question relates to the original reply by the Clinic of Paediatrics: *"The decision on the sex in which the child will be raised is made by the parents... according ...to the views of the family and the cultural specifics of the environment in which the child will live."*)

Questions raised with assist. dr. Andreja Štolfa, dr. med .:

- Is the composition of the multidisciplinary team for the treatment of children with gender development changes permanent? Who is responsible for appointing the members, how does the appointment take place, and is there a list of the multidisciplinary team members' names that could be provided to the Advocate?
- How many such cases of newborns born with physical sex characteristics that do not fit medical or societal norms for female or male bodies have been recorded in the past year and how many in the last five years?
- What are the attributed diagnoses, symptoms or medical conditions on the basis of which medical doctors decide to perform a surgery on intersex newborns and at what age such surgeries take place?
- Are such interventions necessary in the light of sustaining life? If not, do you consider that they are deferred until the child can give informed consent in accordance with the Act governing patients' rights? Do intersex people who underwent medical procedures (surgeries) also receive other therapies, and, if so, which?
- Is there any special health-care protocol on medical treatment of intersex children in the institution where you are employed? If so, please forward it to us. Are you familiar with cases of other health-care institutions that have such protocols?
- How does communication with parents or legal representatives of the treated intersex children take place? Are they informed about the course and possible consequences of the surgery? How much time do the parents have to decide on their consent for such a surgery? Are the parents or legal guardians asked for their consent which they sign after receiving all the information on the possible complications and consequences?
- Have you taken note of the practices in other countries and the recommendations of the European Parliament regarding the medical treatment of intersex people? Would you highlight any of the good practices you know?

Questions raised with patients' rights representatives:

- Have you ever encountered the described issues in the course of your work? If so, due to which specific problems did intersex people approach the patient's rights representative?
- Are you aware of any situations where health-care facilities do not allow access to the files of persons who have been subject to surgeries on physical sex characteristics that do not fit medical or societal norms for female or male bodies?
- Are you aware of any situations where intersex persons, their parents or legal representatives are not or have not been adequately informed about the possible interventions and the consequences of these interventions?
- What are your competences to intervene in such cases?

3.4 Summary of responses to Advocate's queries

The Advocate received replies from all health authorities at the decision-making and professional level (Medical Ethics Committee at the Ministry of Health, Ministry of Health and National Institute of Public Health), and also obtained replies from all public institutions (Clinic of Paediatrics, University Medical Centre Maribor, Clinic of Gynaecology and Perinatology UMC Maribor, Clinic of Paediatrics UMC Ljubljana and Gynaecology Clinic – Clinical Department (CD) for Perinatology UMC Ljubljana) and replies from 12 of the 13 patients' rights representatives. The replies received are presented in more detail below.

3.4.1 Replies by health authorities at decision-making or professional level

At the Advocate's request of the Advocate, three substantive replies were received, namely from:

- Medical Ethics Committee at the Ministry of Health;
- Ministry of Health and
- National Institute of Public Health.

The Extended Professional College of Paediatrics informed the Advocate that the answers of competent professional associations will be submitted after 20 September 2019, however, the Advocate did not receive them. The Extended Professional College of Gynaecology and Obstetrics also did not submit any reply.

MEC replied to the additional query by the Advocate as follows: "medical treatment of intersex children (or children with a change in gender development) in Slovenia is provided in accordance with applicable international professional standards. MEC welcomes the existence of an appropriate multidisciplinary team for the treatment of children with gender development, which includes experts from various disciplines (endocrinologists, gynaecologists, urologists, psychologists, andrologists, neonatologists, clinical geneticists, and, where appropriate, also pathologists and molecular geneticists)... MEC has an appointed permanent representative in the Committee on Bioethics of the Council of Europe (DH-BIO), and through participation in DH-BIO actively participates in international discussions in the field of treatment of intersex people and is kept updated in this regard."

MH did not provide replies of the Advocate's questions, but stated that they **are not particularly aware of cases of medical treatment of intersex people**. Nevertheless, the Ministry stressed that, in line with the provisions of PRA, these persons are treated on an equal standing with others, as their rights are not specifically regulated.

Additionally, it was added that information will be requested from professional associations and submitted to the Advocate when received. Until the end of the preparation of this Special Report, the Advocate did not receive any additional clarifications from the Ministry of Health.

National Institute of Public Health (NIPH) replied to the query stating that **data on intersex persons are not processed separately and such analyses are not carried out**. Moreover, it was added in the reply, that there is an extremely small number of intersex people in Slovenia, hence it is not a major phenomenon. Instead of keeping statistics, **focusing on case-by-case analyses is, according to NIPH, considered more reasonable**. At the same time, the Advocate was also advised to contact the Ljubljana Maternity Hospital and the Ljubljana Paediatric Clinic for more information.

3.4.2 The replies by key public health facilities

The Advocate received written replies of the Clinic of Paediatrics at University Medical Centre Maribor, Clinic of Gynaecology and Perinatology at⁶¹ UMC Maribor, Clinic of Paediatrics at the University Medical Center Ljubljana and Clinic of Gynaecology – Clinical Department (CD) of Perinatology, University Medical Centre Ljubljana.⁶²

The Clinic of Gynaecology and Perinatology of the University Medical Centre Maribor did not answer to any of the questions. In the reply, it was stated "all newborns with unclear genitals" are referred to the Clinic of Paediatrics in Ljubljana for multidisciplinary treatment. Additionally, it was stated, that such cases are very rare, as there is one case every few years.

The Clinic of Paediatrics at the University Medical Centre Maribor also explained that a child born "with ambivalent genitals" is sent for further treatment to the Paediatric Clinic in Ljubljana due to the rarity of such pathology and the need for a multidisciplinary approach. Moreover, it was stated that the decision on the gender in which the child will be raised is made by the parents in cooperation with a multidisciplinary team, with regard to: "the cause of the disorder of sex development, visual characteristics of outer genitalia, surgical options of correction of genitalia, functionality, the possibility of a spontaneous puberty, the capability of a fulfilling sexual life, potential fertility and views of the family as well as cultural peculiarities of the environment in which the child will live." A team of psychologists is always involved in the treatment, even if the question of gender identity is raised later. Regarding the frequency of disorders of sex development, it is estimated that: "it is 1:4500, which means that around 4–5 such children are born in Slovenia every year." In conclusion, it was stated that patients' medical records are available at the treatment unit to anyone who comes in person with appropriate documents, and for older records, it is necessary to write a request for the records to be accessed.

The Advocate received more extensive answers to the questions raised from the Clinic of Gynaecology – Clinical Department of Paediatrics and the Clinic of Paediatrics in Ljubljana.

⁶²The Advocate sent separate letters to the Gynaecology Clinic of the UMC Ljubljana and the Ljubljana Maternity Hospital – Clinical Department of Perinatology, but the answers received showed that the Clinical Department of Perinatology operates within the Gynaecology Clinic, actually one reply was received from the Gynecology Clinic – Clinical Department of Perinatology.

To answer the question how medical staff classifies intersex conditions, the Paediatric Clinic of the University Medical Centre Ljubljana stated: "Medical staff classifies changes in gender development in line with the international classification published in Cools M et al. *Nat Rev Endocrinol* 2018,14: 415-29, and encrypts the conditions according to ICD 10"; and the Gynaecology Clinic responded that if gender is not "phenotypically determinable, karyotyping is performed⁶³ to determine the genotypic gender.

To the questions how many such cases of newborns are recorded in the past year and how many in the last five years, the Clinic of Paediatrics answered that, in 2018, there were nine such cases of children with changes in gender development and, in the last five years, around 30. The Clinical Department of Perinatology replied to the same question that there is 1 such case per year. The data on the number of newborns born with physical sex characteristics that do not fit medical or societal norms for female or male bodies vary considerably (from 1 to 9 per year), so it is difficult to speak with certainty about the numbers in Slovenia.

When asked about diagnostics, surgical procedures and their urgency, the Paediatric Clinic at **UMC Ljubljana and Clinical Department of Perinatology UMC Ljubljana** replied that **newborns are not subject to surgeries on and that surgeries are performed in childhood or adolescence.**

At the Clinic of Paediatrics of the University Medical Centre Ljubljana, surgeries and possible hormonal treatments or other treatments are initiated according to international guidelines, it is pointed out that the time of the procedure may be important for maintaining fertility and/or significant reducing of malignancy risks.⁶⁴ The Clinical Department of Perinatology stated that, in Slovenia, there is an agreement that the gender of a child is determined within two days after birth on the basis of an examination, genetic examination or on the basis of a diagnosis. It was also communicated that "surgical interventions are not necessary, but in some cases they are needed and recommended."

At the Clinical Department for Perinatology there is no special medical protocol in place and each patient is treated individually, and, for the Clinic of Paediatrics, it was stated that international "UpToDate" recommendations are followed. The Advocate notes that this is an online database that is publicly accessible⁶⁵.

To the questions how parents are informed in such cases, whether they are aware of the consequences of the surgery, how much time do they have to decide on their consent for such intervention, if the legal guardians are asked for their consent which they sign after receiving all the information on the symptoms, both institutions answered that parents and legal representatives are immediately informed of the fact that their child is intersex. They are also immediately acquainted with all the results of the examinations, treatment plan and potential need for surgery as well as its consequences. Parents give their consent for the procedure before the planned procedure, during the preoperative preparation. They are presented the consent form, at the same time, the doctor performs the duty to provide explanations. The Clinic of Paediatrics additionally noted that a booklet with written information is available to parents who give birth to a child with a change in gender development. Both institutions state that intense communication takes place with the parents before the surgery, and an interdisciplinary team of medical doctors is involved in the treatment. The Clinical Department of Perinatology did not specify the detailed composition of the multidisciplinary team, but the composition of the team was specified by the Clinic of Paediatrics.

⁶³Karyotyping means creating a karyotype. A karyotype depicts chromosomes according to number, size and shape. Taken from the Microbiological Dictionary (3rd edition), 2013, Slovenian Microbiological Society, Kamnik. Available at: <https://www.termania.net/slovarji/mikrobioloski-slovar/6722480/kariotip?sl=61&query=kariotip&SearchIn=All>

⁶⁴Malignancy means a malignant change. Taken from the Slovenian Medical Dictionary. 2012–2020 University of Ljubljana, Faculty of Medicine. Available at: <https://www.termania.net/slovarji/slovenski-medicinski-slovar/5525653/malignizacija?sl=61&query=malignizacija&SearchIn=All>

⁶⁵Available at: <https://www.uptodate.com/contents/search>

The team consists of endocrinologists, gynaecologists, urologists, psychologists, andrologists, neonatologists⁶⁶, clinical geneticist, and where appropriate also pathologist and molecular geneticist. At the same time, parents are offered psychological support.

Regarding **access to medical records** both clinics provided the same answers. These patients receive the same treatment as others in accordance with the legal regulations on medical records and personal data protection.

In response to additional questions by the Advocate, the Clinic of Paediatrics of the University Medical Centre Ljubljana⁶⁷ submitted another reply on 20 January 2020. The Advocate was interested to know whether the composition of the multidisciplinary team is permanent. Who appoints its members and whether there is a list of experts who form such a team. The answer received was that the composition of the team is mostly permanent, younger colleagues are also participating, who are gaining experience, however, no list was presented to the Advocate.

According to the first answer received, which stated that a booklet with written information is available to parents of children with a change in gender development, the Advocate asked for a copy of such booklet if publicly available. This time, the response was different from the first. The Advocate was provided with a link to the English booklet "First days, when your baby is born with genitals that looks different",⁶⁸ and it was stated that the Slovene translation was still under preparation, namely, in the design phase. Once published, it should be available on the website of the National Contact Point for Rare Diseases⁶⁹ and on the website of the Society for Helping Children with Metabolic Disorders. As of June 2020, the booklet is not publicly available on these websites.

The last of the additional question concerned psychological support. In what ways is psychological support provided, who ensures it and do intersex people also have access to it later in life? Psychological support for parents, children and adolescents is provided by clinical psychologists at the Clinic of Paediatrics in Ljubljana and at the Clinical Department of Paediatric Surgery at the UMC Ljubljana, who are a part of the multidisciplinary team. In adulthood, access to a psychologist is complicated, as the Clinical Department of Endocrinology, Diabetes and Metabolic Diseases at the Clinic of Internal Medicine in Ljubljana does not currently have its own psychologist.

The replies by individual clinics and departments show, that as regards addressing intersex people, there is no consistent terminology.

The Clinic of Gynaecology and Perinatology at the UMC Maribor uses the term "neonates with unclear genitals" in their response, the Clinic of Paediatrics at the UMC Maribor uses the term "same-sex persons", the Clinic of Paediatrics at the UMC Ljubljana uses the term "children with changes in gender development", and the Clinical Department of Perinatology at the UMC Ljubljana used the term "intersex persons", emphasising that they are not involved in any treatment but only in the identification of unclear outer genitalia.

⁶⁶A neonatologist is a specialist who specialises in neonatology. It is "the science of preventing, recognising, and treating disease in newborns." Slovenian Medical Dictionary, 2012–2020 University of Ljubljana, Faculty of Medicine. Available at: <https://www.termania.net/slovarji/slovenski-medicinski-slovar/5528853/neonatologija?sl=61&query=neonatologija&SearchIn=All>

⁶⁷The Advocate subsequently included this response by the Paediatric Clinic of the UMC Ljubljana in this special report.

⁶⁸Booklet available at: <http://www.bchildrens.ca/endocrinology-diabetes-site/documents/firstdays.pdf>.

⁶⁹National contact point for rare diseases: <https://www.redkebolezni.si/>.

The Clinic of Paediatrics at the University Medical Centre Maribor stated in the reply submitted among other things: "The decision on the gender in which the child will be raised is made by the parents in cooperation with a multidisciplinary team, with regard to the cause of the disorder of sex development, visual characteristics of outer genitalia, surgical options of correction of genitalia, functionality, the possibility of a spontaneous puberty, the capability of a fulfilling sexual life, potential fertility and views of the family as well as cultural peculiarities of the environment in which the child will live. A team of psychologists is always involved in the treatment..."

3.4.3 Responses by patients' rights representatives

The Advocate addressed a written request for information to the publicly available e-mail addresses of 13 patients' rights representatives, of which 12 responded to the query, however, until the end of the preparation of this Report, one still did not provide any answers.

Of all the answers received, 10 patients' rights representatives, which represent **91 percent**, **stated that**, during their work, **they have not yet come across issues related to intersex people, and intersex people have not yet approached them**. Only one patients' rights representative wrote that she had encountered complaints by intersex persons three times in her nearly decade-long career. She explained that two cases concerned lengthy procedures for treatment, in particular the lack of access to psychological support for such patients as there is a lack of professionals to address these issues. The third case concerned allegedly inappropriate communication and medical treatment of a patient who underwent sex reassignment surgery abroad. She noted that in her experience, intersex turn to patients' rights representatives only in exceptional cases. According to her opinion, this subject is still **taboo and rarely considered even among health-care professionals**.

The question of **whether they are aware of any situations where health-care facilities do not allow access to the files of persons** who have been subject to surgeries on physical sex characteristics that do not fit medical or societal norms for female or male bodies was answered only by three patients' rights representatives.

Two representatives stated that they were not informed of any cases in which patients or their relatives, if the patients were unable to make independent decisions about themselves, would be denied access to medical records or were unaware of treatment options.

One patients' rights representative pointed out that health-care organisations or health-care providers often violate the right of patients to be acquainted with medical records, even though they are required to ensure the accessibility of these records under the Patients' Rights Act.

To the question if they are familiar with **situations where intersex persons, their parents or legal representatives are not or have not been adequately informed about possible interventions and the consequences of such interventions**, only two patient rights representatives replied, both answering that are not aware of any such cases.

Four of the eleven representatives who responded to the Advocate's query explicitly referred to the **Patients' Rights Act as a basis for their competence to act when approached by intersex persons**. One patients' rights representative emphasises that as far as the type of medical treatment is concerned, all patients have the same rights.

3.5 Concluding analysis of the responses received to the Advocate's queries

In the analysis of the responses received from health-care institutions, the Advocate establishes the following:

- The Clinic of Paediatrics of the UMC Ljubljana does not apply the latest, 11th revision of the International Classification of Diseases (ICD 11), which is welcomed by the European Parliament (EP) due to the partially eliminated pathology of transgender identities, but the previous one (ICD 10). In any case, even the 11th revised international classification "treats childhood behaviour that is not in accordance with sexual norms as pathological...", hence the Resolution of the European Parliament under point 8 calls for changes.
- The Clinical Department of Perinatology of the UMC Ljubljana was the only one to write that interventions in intersex newborns are not necessary, but in some cases needed and recommended, while other clinics stated that they follow international guidelines and the circumstances (even after consulting parents) and do not perform surgeries on newborns. It therefore follows from the answers of all clinics that the medical profession does not doubt the existing practice, namely that it is permissible and necessary to determine the sex of intersex persons by surgical interventions. Meanwhile, under point 2 of the Resolution, the EP "... strongly condemns sex-normalising treatments and surgery; welcomes laws that prohibit such surgery,..." and encourages other Member States to prevent unnecessary medical and surgical interventions. The Resolution also call for ensuring the physical integrity, independence and self-determination of children.
- In their answers addressed to the Advocate, the Clinics indicate that they provide parents and legal representatives of intersex children with appropriate counselling and inform them on the consequences of treatment for the normalisation of sex. In order for the finding to be relevant, it would be necessary to verify the statement at least with parents, legal guardians and intersex people. This matter is related to point 3 of the EP Resolution, which highlights "the need to provide adequate counselling and support to intersex children and intersex individuals with disabilities, as well as to their parents or legal guardians, and fully inform them of the consequences of sex-normalising treatments".
- Clinics are obliged to provide access to medical records in accordance with the law. The implementation of the provision in practice should be examined by querying at parents or legal representatives of intersex children and intersex people, as the EP calls on Member States in Article 6 of the Resolution to improve access to health records for intersex people. One patients' rights representative pointed out in her answer that health-care organisations or health-care providers often violate the right of patients to be acquainted with medical records, even though they are required to ensure the accessibility of these records under the Patients' Rights Act.
- All the patient's rights representatives who responded to the Advocate's queries but one reported that they did not encounter any medical treatment of intersex people in the course of their work, and that intersex people did not approach them. Under point 1 of the Resolution, the EP states that there is an "... urgent need to address violations of the human rights of intersex people...", therefore, it is necessary to consider the establishment of (additional) mechanisms to ensure the protection of human rights and equal treatment of intersex persons.

- Several of the surveyed health-care institutions are not familiar with the meaning of the term intersex. In several cases, the representatives of health-care institutions confused the meaning of the term intersex with the term transsexuality, which means that the understanding of the rights of intersex people to equal health treatment is also questionable.
- Intersex people are not specifically defined as such in health terms for statistical analysis and consequently are not included in databases. The stated reason is also the small number of such persons. Under point 12 of the Resolution, the EP "...calls on all relevant stakeholders to carry out research concerning intersex people, taking a sociological and human rights perspective rather than a medical one...". Under point 13, the EP calls on "... calls on the Member States to support and fund research on the human rights situation of intersex people".
- The pathologisation and medicalisation of intersex people are problematic, which is also evident from the narratives in the responses by health-care institutions. Under point 7, the EP states that "...pathologisation of intersex variations jeopardises the full enjoyment by intersex people of the right to the highest attainable standard of health..." and call on Member States to ensure the depathologisation of intersex people.
- Medical assessment does not arise exclusively from scientific and professional findings, but also from sociological and cultural influences of the environment, as indicated by the response of the Clinic for Paediatrics at the UMC Maribor, namely that "The decision on the gender in which the child will be raised is made by the parents in cooperation with a multidisciplinary team /.../ and views of the family as well as cultural peculiarities of the environment in which the child will live..." The answers do not clearly indicate the role of other (social science) professions outside the area of medicine, civil society advocacy organisations and state institutions for the protection of human rights or protection against discrimination in the treatment of intersex people.
- The Clinic of Paediatrics at the UMC Maribor and the Clinic of Gynaecology and Perinatology at the UMC Maribor refer intersex newborns to the Clinical Department of Endocrinology, Diabetes and Metabolic Diseases at the Clinic of Paediatrics of the UMC Ljubljana (it can be concluded that other clinics and maternity hospitals in Slovenia do the same) which means that the treatment of intersex persons is determined by a relatively narrow circle of experts, and it is not clear whether there is a special uniform protocol even within the UMC Ljubljana.
- The replies of health-care institutions show a practice and orientation of the medical profession towards identifying intersex persons according to the logic of the binary male and female sex system (as early as possible). This must also be understood in the light of the fact that the health institution in which the child is born is obliged, in accordance with the Register of Deaths, Births and Marriages Act,⁷⁰ to report the birth of every child to the competent administrative unit within 15 days. Article 13 of the Rules on the implementation of the Civil Register Act⁷¹ explicitly stipulates that at the registration of birth, information on the sex of the child must be provided. Based on the birth registration, the registrar then enters the data on the child's birth in the registry. Point 2 of Article 3 of Rules on the implementation of the Civil Register Act sets out that the sex of a child is a piece of data entered in the register of births.

⁷⁰Official Gazette of the RS, No. 11/11 – official consolidated text and 67/19. See Articles 3, 4, 7 and 8 of the Act.

⁷¹Official Gazette of the RS, No. 40/05, 69/09 and 77/16

- The queries by the Advocate of the Principle of Equality were mostly positively received among health-care institutions, at the same time, additional attention was paid to this topic as a result.

4 Annexes

4.1 European Parliament resolution of 14 February 2019 on the rights of intersex people (2018/2878(RSP))

The European Parliament,

- with regard to Article 2 of the Treaty on European Union,
- with regard to Articles 8 and 10 of the Treaty on the Functioning of the European Union,
- with regard to the Charter of Fundamental Rights of the European Union, and in particular Article 21 thereof,
- with regard to the European Social Charter, and in particular Article 11 thereof,
- with regard to Directive 2012/29/EU of the European Parliament and of the Council of 25 October 2012 establishing minimum standards on the rights, support and protection of victims of crime⁽¹⁾,
- with regard to the report published by the Commission in 2011 entitled ‘Trans and intersex people’,
- with regard to the final reports of the Commission-funded ‘Health4LGBTI’ pilot project on health inequalities experienced by LGBTI people,
- with regard to its resolution of 4 February 2014 on the EU Roadmap against homophobia and discrimination on grounds of sexual orientation and gender identity⁽²⁾,
- with regard to its resolution of 13 December 2016 on the situation of fundamental rights in the European Union in 2015⁽³⁾,
- with regard to the paper published in May 2015 by the European Union Agency for Fundamental Rights (FRA) entitled ‘The fundamental rights situation of intersex people⁽⁴⁾,
- with regard to the FRA’s online publication of November 2017 entitled ‘Mapping minimum age requirements concerning the rights of the child in the EU⁽⁵⁾,
- with regard to the FRA Fundamental Rights Report 2018,
- with regard to the European Convention on Human Rights,
- with regard to the European Convention for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment,
- with regard to Resolution 2191 of the Council of Europe Parliamentary Assembly, adopted in 2017, on promoting the human rights of and eliminating discrimination against intersex people,
- with regard to the 2015 report of the Council of Europe Commissioner for Human Rights on human rights and intersex people,
- with regard to the Universal Declaration of Human Rights,
- with regard to the UN Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment,

- with regard to the UN Convention on the Rights of the Child,
- with regard to the UN Convention on the Rights of Persons with Disabilities,
- with regard to the 2013 report of the UN Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment,
- with regard to the Yogyakarta Principles ('Principles and State Obligations on the Application of International Human Rights Law in Relation to Sexual Orientation, Gender Identity, Gender Expression and Sex Characteristics') adopted in November 2006, and the 10 complementary principles ('plus 10') adopted on 10 November 2017,
- with regard to the questions to the Council and to the Commission on the rights of intersex people ([O-000132/2018](#) – B8-0007/2019 and [O-000133/2018](#) – B8-0008/2019),
- with regard to the motion for a resolution of the Committee on Civil Liberties, Justice and Home Affairs,
- with regard to Rules 128(5) and 123(2) of its Rules of Procedure,

A. whereas intersex individuals are born with physical sex characteristics that do not fit medical or societal norms for female or male bodies, and these variations in sex characteristics may manifest themselves in primary characteristics (such as the inner and outer genitalia and the chromosomal and hormonal structure) and/or secondary characteristics (such as muscle mass, hair distribution and stature);

B. whereas intersex people are exposed to multiple instances of violence and discrimination in the European Union and these human rights violations remain widely unknown to the general public and policymakers;

C. whereas there is a high prevalence of surgeries and medical treatments carried out on intersex infants, although in most cases these treatments are not medically necessary; whereas cosmetic surgeries and urgent surgeries can be proposed as a package, preventing parents and intersex people from having full information on the impact of each;

D. whereas surgeries and medical treatments are performed on intersex children without their prior, personal, full and informed consent; whereas intersex genital mutilation can have lifelong consequences, such as psychological trauma and physical impairments;

E. whereas intersex individuals and intersex children who belong to other minority and marginalised groups are further marginalised and socially excluded and are at risk of violence and discrimination, because of their intersecting identities;

F. whereas in most Member States surgery can be performed on an intersex child or an intersex individual with disabilities with the consent of their legal guardian, regardless of the capacity of the intersex person to decide for themselves;

G. whereas in many cases parents and/or legal guardians are strongly pressured to make decisions without being fully informed of the lifelong consequences for their child;

H. whereas many intersex people do not have full access to their medical records and therefore do not know that they are intersex or are not aware of the medical treatments they have been subjected to;

I. whereas intersex variations continue to be classified as diseases, as in the World Health Organisation's International Classification of Diseases (ICD), in the absence of evidence supporting the long-term success of treatments;

J. whereas some intersex people will not identify with the gender they are medically assigned at birth; whereas legal gender recognition based on self-determination is only possible in six Member States; whereas many Member States still require sterilisation for legal gender recognition;

K. whereas anti-discrimination legislation at EU level, and in most Member States, does not include discrimination based on sex characteristics, whether as a standalone category or interpreted as a form of discrimination based on sex;

L. whereas many intersex children face human rights violations and genital mutilation in the EU when undergoing sex-normalising treatments;

1. notes the urgent need to address violations of the human rights of intersex people, and calls on the Commission and the Member States to propose legislation to address these issues;

Medicalisation and pathologisation

2. Strongly condemns sex-normalising treatments and surgery; welcomes laws that prohibit such surgery, as in Malta and Portugal, and encourages other Member States to adopt similar legislation as soon as possible;

3. Stresses the need to provide adequate counselling and support to intersex children and intersex individuals with disabilities, as well as to their parents or guardians, and fully inform them of the consequences of sex-normalising treatments;

4. Calls on the Commission and the Member States to support organisations that work to break the stigma against intersex people;

5. Calls on the Commission and the Member States to increase funding for intersex civil society organisations;

6. Calls on the Member States to improve access for intersex people to their medical records, and to ensure that no one is subjected to non-necessary medical or surgical treatment during infancy or childhood, guaranteeing bodily integrity, autonomy and self-determination for the children concerned;

7. Takes the view that pathologisation of intersex variations jeopardises the full enjoyment by intersex people of the right to the highest attainable standard of health as enshrined in the UN Convention on the Rights of the Child; calls on the Member States to ensure the depathologisation of intersex people;

8. Welcomes the depathologisation, however partial, of trans identities in the eleventh revision of the ICD (ICD-11); notes, however, that the category of 'gender incongruence' in childhood pathologises non-gender-normative behaviours in childhood; calls, therefore, on the Member States to pursue the removal of this category from the ICD-11, and to bring future ICD revision into line with their national health systems;

Identity documents

9. Stresses the importance of flexible birth registration procedures; welcomes the laws adopted in some Member States that allow legal gender recognition on the basis of self-determination; encourages other Member States to adopt similar legislation, including flexible procedures to change gender markers, as long as they continue to be registered, as well as names on birth certificates and identity documents (including the possibility of gender-neutral names);

Discrimination

10. Deplores the lack of recognition of sex characteristics as a ground of discrimination across the EU, and therefore highlights the importance of this criterion in order to ensure access to justice for intersex people;

11. Calls on the Commission to enhance the exchange of good practices on the matter; calls on the Member States to adopt the necessary legislation to ensure the adequate protection, respect and promotion of the fundamental rights of intersex people, including intersex children, including full protection against discrimination;

Public awareness

12. Calls on all relevant stakeholders to carry out research concerning intersex people, taking a sociological and human rights perspective rather than a medical one;

13. Calls on the Commission to make sure that EU funds do not support research or medical projects that further contribute to violating the human rights of intersex people, in the context of the European Reference Networks (ERNs); calls on the Commission and the Member States to support and fund research on the human rights situation of intersex people;

14. Calls on the Commission to take a holistic and rights-based approach to the rights of intersex people and to better coordinate the work of its Directorates-General for Justice and Consumers, for Education, Youth, Sport and Culture, and for Health and Food Safety, to ensure consistent policies and programmes supporting intersex people, including training of state officials and the medical profession;

15. Calls on the Commission to reinforce the intersex dimension in its multiannual LGBTI list of actions for the current period, and to begin preparing as of now a renewal of this strategy for the next multiannual period (2019-2024);

16. Calls on the Commission to facilitate the sharing of best practices among Member States on protecting the human rights and bodily integrity of intersex people;

17. Instructs its President to forward this resolution to the Council, the Commission, the governments and parliaments of the Member States and the Parliamentary Assembly of the Council of Europe.

(1) OJ L 315, 14.11.2012, p. 57.

(2) OJ C 93, 24.3.2017, p. 21.

(3) OJ C 238, 6.7.2018, p. 2.

(4) <https://fra.europa.eu/en/publication/2015/fundamental-rights-situation-intersex-people>

(5) <https://fra.europa.eu/en/publication/2017/mapping-minimum-age-requirements-concerning-rights-child-eu>

4.2 Resolution of the Parliamentary Assembly of the Council of Europe on Promoting the human rights of and eliminating discrimination against intersex people number 2191 (2017)⁷²

1. Intersex people are born with biological sex characteristics that do not fit societal norms or medical definitions of what makes a person male or female. Sometimes a person's intersex status is detected at birth; sometimes it only becomes apparent later in life, notably during puberty. Despite the wide variety of situations concerned, the majority of intersex people are physically healthy. Only a few suffer from medical conditions that put their health at risk. Yet the situation of intersex people has for a long time been treated as an essentially medical issue. The prevailing medical view has been that intersex children's bodies can and should be made to conform to either a male or a female paradigm, often through surgical and/or hormonal intervention; that this should be done as early as possible; and that the children should then be raised in the gender corresponding to the sex assigned to their body.
2. The Parliamentary Assembly considers that this approach involves serious breaches of physical integrity, in many cases concerning very young children or infants who are unable to give consent and whose gender identity is unknown. This is done despite the fact that there is no evidence to support the long-term success of such treatments, no immediate danger to health and no genuine therapeutic purpose for the treatment, which is intended to avoid or minimise (perceived) social problems rather than medical ones. It is often followed by lifelong hormonal treatments and medical complications, compounded by shame and secrecy.
3. Parents are often under pressure to make urgent, life-changing decisions on behalf of their child, without having a full and genuine understanding of the long-term consequences for the child of the decisions made about their body during their infancy and early childhood.
4. Understanding of these issues is gradually increasing, but concerted efforts are still needed to raise public awareness as to the situation and rights of intersex people to ensure that they are fully accepted in society, without stigmatisation or discrimination.
5. The Assembly emphasises that it is crucial to ensure that the law does not create or perpetuate barriers to equality for intersex people. This includes ensuring that intersex people who do not identify as male or female have access to legal recognition of their gender identity, and that where their gender has not been correctly recorded at birth, the procedure for rectifying this is simple and based on self-identification only, as set out in [Assembly Resolution 2048 \(2015\)](#) on discrimination against transgender people in Europe. Anti-discrimination laws may also need to be amended to ensure that the situation of intersex people is effectively covered.
6. The Assembly considers that the above may raise important issues under a number of provisions of the European Convention on Human Rights (ETS No. 5), notably Articles 3 and 8.
7. In the light of the above, and bearing in mind the provisions of the Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine (ETS No. 164, "Oviedo Convention") and the relevant recommendations made in its [Resolution 1952 \(2013\)](#) on children's right to physical integrity, as well as those by the Council of Europe

⁷²Unofficial translation by the Advocate of the Principle of Equality. The original (English) text is available at: <https://assembly.coe.int/nw/xml/XRef/Xref-XML2HTML-EN.asp?fileid=24232&lang=en>

Commissioner for Human Rights and numerous treaty bodies of the United Nations, the Assembly calls on Council of Europe member States to:

- 7.1. with regard to effectively protecting children's right to physical integrity and bodily autonomy and to empowering intersex people as regards these rights:
 - 7.1.1. prohibit medically unnecessary sex-"normalising" surgery, sterilisation and other treatments practised on intersex children without their informed consent;
 - 7.1.2. ensure that, except in cases where the life of the child is at immediate risk, any treatment that seeks to alter the sex characteristics of the child, including their gonads, genitals or internal sex organs, is deferred until such time as the child is able to participate in the decision, based on the right to self-determination and on the principle of free and informed consent;
 - 7.1.3. provide all intersex people with health care offered by a specialised, multidisciplinary team taking a holistic and patient-centred approach and comprising not only health-care professionals but also other relevant professionals such as psychologists, social workers and ethicists, and based on guidelines developed together by intersex organisations and the professionals concerned;
 - 7.1.4. ensure that intersex people have effective access to health care throughout their lives;
 - 7.1.5. ensure that intersex people have full access to their medical records;
 - 7.1.6. provide comprehensive and up-to-date training on these matters to all medical, psychological and other professionals concerned, including conveying a clear message that intersex bodies are the result of natural variations in sex development and do not as such need to be modified;
- 7.2. with a view to assisting intersex people, their parents and the people around them in dealing with the challenges posed, inter alia, by social attitudes towards variations in sex characteristics:
 - 7.2.1. ensure that adequate psychosocial support mechanisms are available for intersex people and their families throughout their lives;
 - 7.2.2. support civil society organisations working to break the silence around the situation of intersex people and to create an environment in which intersex people feel safe to speak openly about their experiences;
- 7.3. with regard to civil status and legal gender recognition:
 - 7.3.1. ensure that laws and practices governing the registration of births, in particular as regards the recording of a newborn's sex, duly respect the right to private life by allowing sufficient flexibility to deal with the situation of intersex children without forcing parents or health-care professionals to reveal a child's intersex status unnecessarily;
 - 7.3.2. simplify legal gender recognition procedures in line with the recommendations adopted by the Assembly in [Resolution 2048 \(2015\)](#) and ensure in particular that these procedures are quick, transparent and accessible to all and based on self-determination;

- 7.3.3. ensure, wherever gender classifications are in use by public authorities, that a range of options are available for all people, including those intersex people who do not identify as either male or female;
 - 7.3.4. consider making the registration of sex on birth certificates and other identity documents optional for everyone;
 - 7.3.5. ensure that, in accordance with the right to respect for private life, intersex people are not prevented from entering into a civil partnership or marriage or from remaining in such a partnership or marriage as a result of the legal recognition of their gender;
 - 7.4. with regard to combating discrimination against intersex people, ensure that anti-discrimination legislation effectively applies to and protects intersex people, either by inserting sex characteristics as a specific prohibited ground in all anti-discrimination legislation, and/or by raising awareness among lawyers, police, prosecutors, judges and all other relevant professionals, as well as intersex people, of the possibility of dealing with discrimination against them under the prohibited ground of sex, or as an "other" (unspecified) ground where the list of prohibited grounds in relevant national anti-discrimination provisions is non-exhaustive;
 - 7.5. collect more data and carry out further research into the situation and rights of intersex people, including into the long-term impact of sex-"normalising" surgery, sterilisation and other treatments practised on intersex people without their free and informed consent, and in this context:
 - 7.5.1. conduct an inquiry into the harm caused by past invasive and/or irreversible sex-"normalising" treatments practised on individuals without their consent and consider granting compensation, possibly through a specific fund, to individuals having suffered as a result of such treatment carried out on them;
 - 7.5.2. in order to build a complete picture of current practice, keep a record of all interventions carried out on children's sex characteristics;
 - 7.6. carry out campaigns to raise awareness among the professionals concerned and among the general public as regards the situation and rights of intersex people.
8. Finally, the Assembly invites national parliaments to work actively, with the participation of intersex people and their representative organisations, to raise public awareness about the situation of intersex people in their country and to give effect to the recommendations made above.

The Situation of Intersex people in Medical Procedures - Special Report

Issued by

The Advocate of the Principle of Equality of the Republic of Slovenia

On behalf of the Advocate

Miha Lobnik, Head of the Institution, Advocate of the Principle of Equality

Contributors

Miha Lobnik, mag. Jelena Aleksić, Nika Stroligo Urankar, Nevenka Prešlenkova, Boštjan Vernik Šetinc, Samo Novak, Janja Pečan

Translation and proofreading

K&J Group, storitve d.o.o.

Ljubljana, April 2022

Use of the contents of the Report is permitted with citations.

The grammatical gender used in the report refers to any gender.

The publication is free-of-charge and freely available.

The original text of the Special Report is in the Slovenian language. In the case of unclear translation, the original shall prevail.

The Special Report was published in Slovene language in June 2020.

Annual and special reports by the Advocate of the Principle of Equality are published online at www.zagovornik.si

Kataložni zapis o publikaciji (CIP) pripravili v Narodni in univerzitetni knjižnici v Ljubljani

COBISS.SI-ID 112071683

ISBN 978-961-95155-3-2 (PDF)