

The Rights of Intersex Children in Greece



NGO submission for the 85th session of the Pre-Sessional Working Group of
Committee on the Rights of the Child

List of Issues for Greece

Joint NGO submission by:

Intersex Greece

NNID Foundation - Netherlands organisation for sex diversity

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Executive summary

Harmful practices for intersex children in Greece include non-necessary medical interventions, and intrusive and irreversible treatments, that can be safely deferred until a later age where these children can provide personal, prior, free, and fully informed consent. These treatments include medical and surgical interventions to 'normalize' the external genitalia of these intersex children. Photographs have been made of intersex children's genitalia, which has been proven harmful to their development. Psychosocial support for intersex children and their parents is lacking. Furthermore, coerced termination of intersex fetuses takes place as 'standard procedure' when these can be detected prenatally.

Therefore, intersex children in Greece seek protection under Articles 2, 6, 16, 19, and 24 of the Convention and General Comments no. 13, 15, and 18.

Intersex Greece and NNID request the Committee to consider these issues for the compilation of the List of Issues and suggest the following questions for the Committee to request the government of Greece to provide information on:

- **What medical treatments are provided to intersex children and clarify whether their free, prior and fully informed consent is ensured?**
- **How is the right to privacy ensured in the case of photographs taken from intersex children's genitalia?**
- **what prenatal tests are performed, and what information and support are provided to the parents of intersex children, and to clarify if this is done in a comprehensive and respectful manner to prevent coerced terminations.**

Introduction

This NGO report is a joint submission by Intersex Greece, and NNID Foundation to highlight key issues faced by intersex children in Greece. This submission does not provide information regarding all issues faced by intersex children in Greece. Intersex Greece and NNID would greatly appreciate the consideration of these issues by the Committee on the Rights of the Child for the List of Issues (LOI). The paragraphs give contextual information on topics that specifically affect intersex children, followed by links to the Convention and General Comments, and suggestions for questions which can be used for the preparation of the LOI. Appendix 1 contains statements from two parents of intersex children. Appendix 2 contains background on intersex and harmful practices.

Intersex Greece is an informal network of Greek intersex adults and parents of intersex children. Intersex Greece provides support to intersex people and their families and works on community building, awareness-raising, visibility and the rights of intersex people in Greece. NNID Foundation is an intersex-led human rights organization working for the equality, rights, and visibility of intersex people, and is based in the Netherlands.

Intersex in Greece

Intersex refers to the experiences of people who are born with a body that does not meet the normative definition of male and female.

Greece has prohibited discrimination of intersex people in employment and education under the term ‘sex characteristics’ and has included this term in the Criminal Code to criminalize violence and hate speech based on sex characteristics.¹ Naturally, Intersex Greece and NNID Foundation appreciate these efforts.

However, human rights violations still take place for intersex children. As a result, many try to remain invisible out of fear of social stigma, pathologization and discrimination.

Harmful practices and health [art. 16, art. 24, GC no. 13, 15 & 18]

Harmful practices for intersex children include non-necessary medical interventions, and intrusive and irreversible treatments, that can be safely deferred until a later age when these children can provide personal, prior, free, and fully informed consent. For more general background on intersex and harmful practices, see appendix 2.

Intersex Greece has received reports that non-necessary medical interventions are advised for many intersex babies. Galli-Tsinopoulou et al.² describe a case study of a new-born intersex child from Greece born with ambiguous genitalia. The decision was made to raise the child as a boy. The article describes the growth of the child’s ‘phallus’ under the influence of hormone treatment and the plans to perform at least three non-necessary surgeries in the first three years of the child’s life to make the child’s genitalia appear more male. A joint study of three French endocrinologists and one Greek gynecologist by Bougnères et al.³ on intersex children describes how ‘clitoral’ size was reduced in seven intersex children between 1 and 8 years old who are raised as girls with fludrocortisone and hydrocortisone injected between one and four times a day. These treatments have been conducted without the possibility to ascertain what the future gender identity of these children will be. Recent research has shown that five percent of all intersex children, including those with forms of sex diversity that are usually not recognized at birth, change sex before puberty⁴. Furthermore, the articles include images of the children’s genitalia,

¹ Law 4356/2015 & Law 4443/2016.

² Galli-Tsinopoulou A, Serbis A, Kotanidou EP, et al. 46,XY Disorder of Sex Development due to 17-Beta Hydroxysteroid Dehydrogenase Type 3 Deficiency in an Infant of Greek Origin. *J Clin Res Pediatr Endocrinol*. 2018;10(1):74–78. doi:10.4274/jcrpe.4829.

³ Bougnères P, Bouvattier C, Cartigny M, Michala, L. Deferring surgical treatment of ambiguous genitalia into adolescence in girls with 21-hydroxylase deficiency: a feasibility study. *Int J Pediatr Endocrinol*. 2017;3. doi:10.1186/s13633-016-0040-8.

⁴ Falhammar H, Claahsen-van der Grinten HL, Reisch N, Slowikowska-Hilczner J, Nordenstrom A, Roehle R, et al. Health status in 1040 adults with disorders of sex development (DSD): a European multicenter study. *Endocrine Connections*. 2018. <https://doi.org/10.1530/ec-18-0031>

which is a violation of the child's right to privacy. It has been shown by Creighton et al.⁵ that medical photographs of intersex children's genitalia are damaging to their development.

The parents of Thomas (appendix 1) describe how they regret consenting to non-necessary interventions on their child that have been stressful, painful and repetitive. If they had been fully informed they would have chosen to delay these decisions until Thomas could provide personal, prior, free, and fully informed consent. Intersex Greece has received reports that medical interventions are often advised at very young ages, between 3 months and three years old.

These practices are in violation of Article 24 of the Convention which recognizes the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health. Additionally, these practices fall under the criteria of harmful practices, as described in General Comment no. 18, Articles 15 and 16. GC 18 Art. 15 states: 'Harmful practices are persistent practices and forms of behavior that are grounded in discrimination on the basis of, among other things, sex.' GC 18 Art. 16 (d) states: "They are imposed on women and children by family members, community members or society at large, regardless of whether the victim provides, or is able to provide, full, free and informed consent." The consequences are comparable to the effects of female genital mutilation as described in Joint General Comment no. 18, art. 19, which describes amongst others, severe pain, infections, long-term gynecological problems such as fistula, psychological effects and death. Furthermore, these practices are contrary to Article 16 of the Convention on the right to privacy.

Intersex Greece and NNID request the Committee to ask the government of Greece to provide information on what medical treatments are provided to intersex children and clarify whether their free, prior and fully informed consent is ensured. And how the right to privacy is ensured in the case of photographs taken from intersex children's genitalia.

Discrimination and Health [art. 2, art. 24]

Discrimination of intersex children in medical settings in Greece can begin before these children are born. Medical tests performed before birth on specific types of intersex can lead to coerced abortions based on outdated assumptions about intersex. Statements from the parents of Jason and Alex (appendix 1) respectively from 2008 and 2018 describe how they were strongly recommended to terminate their desired pregnancies. The mother of Jason describes how physicians made derogatory remarks about her unborn child, including referring to the fetus as a freak and a monster. The mothers of these intersex children refused to undergo these procedures. Intersex Greece has received reports that recommendations to terminate pregnancies are 'standard procedure' for certain types of intersex that can be detected prenatally.

⁵ Creighton S, Alderson J, Brown S, Minto C. Medical Photography: Ethics, Consent and the Intersex Patient. *BJU international*. 2002;89(1):67-71. <https://doi.org/10.1046/j.1464-410X.2002.02558.x>.

Furthermore, psychosocial support is lacking for intersex children and people in Greece, which can have severe consequences. Intersex Greece has received many reports from intersex people that they were not treated respectfully by their physicians. Stigmatization remarks and lack of appropriate support for intersex children and their parents leads to fear of further stigmatization, shame and secrecy. Lakis⁶ describes in an interview that his parents strongly objected to openly speaking about intersex and in a heated argument, suggested that it would be better if he were to end his life.

These practices are a violation of Article 2 of the Convention, as it falls under discrimination on the basis of sex. Article 24.2(f), as explicated in General Comment no. 15 article 67 and 68 specifically requires guidance for parents and recognizes parents as the most important source of early diagnosis and primary care for small children. Furthermore, Article 19 requires State parties to take all appropriate legislative, administrative, social and educational measures to protect the child from all forms of physical or mental violence, injury or abuse, neglect or negligent treatment, maltreatment or exploitation.

Intersex Greece and NNID request the Committee to ask the government of Greece to provide information on what prenatal tests are performed, and what information and support are provided to the parents of intersex children, and to clarify if this is done in a comprehensive and respectful manner to prevent coerced terminations.

⁶ **Thanopoulos V**, Συνέντευξη: Λάκης Κανδύλλης. Antivirus Magazine 26 October 2019. <https://avmag.gr/81298/synentefxi-lakis-kandyllis/>

Appendix 1: Statements

Thomas

The parents of three-year-old Thomas* state:

'The standard protocol for babies born with hypospadias like ours is the surgical correction of the urethral opening, doctors told us, because "otherwise your child couldn't pee standing, or impregnate his future wife (20+ years from now) ", so "it is a social emergency". We weren't told how stressful, painful and repetitive these operations could be, let alone the danger to lose his sexual sensation as an adult. We were not informed that this is a natural and common intersex condition, that could be delayed to a time that he could give his fully informed consent. We wish we could know better and had all the relevant information, beforehand...'

Alex

The parents of one-year-old Alex* say:

'At 2018, our doctor suggested we should terminate our healthy fetus, as a "nature's fault" because he had two X-chromosomes and one Y-chromosome... We felt very sad, lost, and confused at first. Before deciding what we should do, we searched for other parents of children born with XXY chromosomes in Greece. Thankfully we found a few, very willing to share their info and knowledge. Our baby has been born, healthy and perfect, a real blessing. We keep educating ourselves, hoping Greek society is getting more and more aware and accepting of intersex children's rights.'

Jason

The mother of ten-year-old Jason* tells:

'This is our family story. At 2008, while 5m pregnant, after an amniotic karyotype testing revealed that our baby boy had an extra X-chromosome (47xxy karyotype). As this was something new to us, we went online and gathered every possible, updated information about it so that we would be prepared properly. We also met through the internet with many adults born with XXY-chromosomes from around the globe, happy to share their personal stories with us and very willing to support us psychologically. Unfortunately, my first obstetric doctors in the local hospital called us into a hospital counselling meeting and insisted that the "standard procedure" was to terminate ANY XXY fetus, cause they will be: "A freak! A monster! Nature's fault! A "dumb" person incapable of living on its own! A boy with a phallus so small, better not to be at all" (these were their exact words...). Since we were informed that all these statements were false and outdated, we insisted on keeping our baby. They refused to deliver him, so they made us sign a form that we'll continue at our own responsibility, and they send me to an Athens central hospital to find new doctors.'

Appendix 2: Intersex and Harmful Practices

In 2013, the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment called on states to repeal any law allowing intrusive and irreversible treatments, including forced genital-normalizing surgery, involuntary sterilization, “reparative therapies” or “conversion therapies”, when enforced or administered without the free and informed consent of the person concerned. He also called on states to outlaw forced or coerced sterilization in all circumstances.⁷

The UN Human Rights Office Background Note on Human Rights Violations against Intersex People states: ‘In recent years, awareness of intersex people, and recognition of the specific human rights abuses that they face, has grown, thanks to the work of intersex human rights defenders. These include risks of forced and coercive medical interventions, harmful practices and other forms of stigmatisation due to their physical traits. To date, only a handful of countries have implemented measures to prevent and address such abuses, and the effectiveness of existing measures remains to be fully documented.’⁸

Intersex children are at risk of medically unnecessary, intrusive and irreversible surgery, hormone treatments, other “normalizing” treatments and “normalizing” psychotherapy, without the free and fully informed consent of the child. These interventions may even start before their birth, with experimental medical treatment for which only very limited information is available about the results, while there even are proven negative long-term health consequences.⁹

Medical and surgical treatment of intersex children is based on ‘*predict and control*’: when an intersex child is born, health professionals try to predict the future gender of the child and control the outcome of this prediction by means of medically unnecessary, intrusive and irreversible treatments, that can be safely deferred until a later age where these children can provide personal, prior, free, and fully informed consent.¹⁰

The ‘*predict and control*’ method is a violation of the right of self-determination, bodily integrity, and the right to the highest attainable standard of physical and mental health. These rights are not guaranteed for intersex children, because they are victims of unnecessary, unproven and unscientific medical treatments.

⁷ Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, Juan E. Medez, Human Rights Council, 1 February 2013 (A/HRC/22/53).

⁸ UN Human Rights Office. Background Note on Human Rights Violations against Intersex People. 25 October 2019.

⁹ **Dreger A, Feder EK, Tamar-Mattis A.** Prenatal dexamethasone for congenital adrenal hyperplasia. *Journal of bioethical inquiry.* 2012;9(3):277-294.

Wallensteen L, Zimmermann M, Sandberg MT, Gezelius A, Nordenström A, Tatja J, et al. Sex-dimorphic effects of prenatal treatment with dexamethasone. *Journal of Clinical Endocrinology & Metabolism.* 2016; 101(10) 3838-3846.

¹⁰ **Wolffenbuttel KP.** Disorders of sex development: méér dan alleen een andere naam. *Tijdschrift voor Urologie.* 2015;5(1):8-12.

Wolffenbuttel K, Crouch NS. Timing of feminising surgery in disorders of sex development. *Understanding Differences and Disorders of Sex Development (DSD).* 27: Karger Publishers; 2014. p. 210-221.

Furthermore, a lack of support for intersex people combined with non-necessary, intrusive, involuntary, and irreversible treatments on intersex children can have a severe impact: 45 percent of adult intersex people experience mental health problems, almost 20 percent have suicidal thoughts and almost 7 percent have tried to commit suicide¹¹ – in general, intersex people suffer from physical and mental health issues throughout their lives.¹²

¹¹ **De Vries ALC, Roehle R, Marshall L, Frisé L, van de Grift TC, Kreukels BPC, et al.** Mental Health of a Large Group of Adults With Disorders of Sex Development in Six European Countries. *Psychosomatic Medicine*. 2019;81(7):629-640. DOI: 10.1097/psy.0000000000000718

¹² **Falhammar H, Claahsen-van der Grinten HL, Reisch N, Slowikowska-Hilczer J, Nordenstrom A, Roehle R, et al.** Health status in 1040 adults with disorders of sex development (DSD): a European multicenter study. *Endocrine Connections*. 2018. (<https://doi.org/10.1530/ec-18-0031>).