

REPORT OF THE SEMINAR  
EARLY INTERVENTION ON INTERSEX CHILDREN  
PROMOTING THE RIGHTS OF THE CHILD



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## Introduction

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*"Why to intervene on children's bodies if the problem is in adults' heads?"*

Council of Europe Commissioner for Human Rights

The seminar organised by the Steering Committee for Human Rights in the fields of Biomedicine and Health ([CDBIO](#)) of the Council of Europe on early intervention on intersex children took place in Strasbourg on 31 May 2022.

This action is foreseen in the **Strategic Action Plan on Human Rights and Technologies in Biomedicine**<sup>1</sup> (2020-2025) and is in line with the Committee's work on children's participation in decision-making about their health.

Ritva HALILA, Chair of the CDBIO, recalled that the objectives of this action were to promote and protect the rights of children with regard to medical practices that have future or long-term implications for them. It takes as its starting point **Article 14 of the UN Convention on the Rights of the Child**<sup>2</sup> which states that every child has individual rights, i.e. to have his/her own and autonomous existence and that his or her best interests should always be protected.

The **notion of child autonomy**, which can be conceptualised as "the child's right to an open future", means that the child's choices must be able to remain intact until such time as he or she is able to make his or her own decisions. It is therefore a question of the child and of everyone keeping the possibility of self-determination. This capacity is regularly restricted, sometimes by necessity, by the choices that parents and third parties can make for the child. The possibility of an open future therefore implies that choices must be weighed in accordance with this principle.

It is these issues that are at the centre of concerns about what interventions parents and others should not be allowed to choose in order to preserve a child's health, particularly in the case of so-called "intersex" children.

Thanks to the richness of the participants' interventions, the seminar organised by the Committee made it possible to return to the ethical and human rights (children's rights) issues, which are both significant and sensitive, raised by the early surgical care of these children, in order to open up new avenues of reflection and areas of work for the Council of Europe's Steering Committees: Steering Committee on Anti-discrimination, Diversity and Inclusion ([CDADI](#)), chaired by Sophie ELIZEON, the CDBIO and the Steering Committee on the Rights of the Child ([CDENF](#)).

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<sup>1</sup><https://rm.coe.int/strategic-action-plan-final-e/1680a2c5d2>

<sup>2</sup><https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-rights-child#:~:text=Article%2014,-1.&text=Les%20Etats%20parties%20respectent%20le,au%20d%C3%A9veloppement%20de%20ses%20capacit%C3%A9s>

## The need for intervention

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**Resolution 2191(2017) of the Parliamentary Assembly of the Council of Europe**<sup>3</sup> on the promotion of human rights and the elimination of discrimination against intersex persons, calls to "prohibit medically unnecessary sex-“normalising” surgery," on intersex children, as well as other treatments performed on intersex children and young people without their informed consent. It recommends further research into the long-term impact of such treatments to ensure that, unless there is an immediate risk to the child's life, the alteration of the child's sex characteristics is postponed until the child can participate in the decision

Ruzica BOSKIC, representative of the Steering Committee for the Rights of the Child, recalled **the decision rendered on 19 May 2022 by the European Court of Human Rights in the case of M. v. France.**

In this case, the applicant claimed that she had undergone feminising procedures and treatments before she was old enough to participate in the decision and that these had caused her severe psychological suffering and social consequences, while her parents had received fragmentary and inaccurate information about her situation and the necessary treatments. While the Court considered that all domestic remedies had not been exhausted and therefore considered the application inadmissible, it left open the question of whether an intervention carried out without medical necessity and without the person's consent could amount to degrading and inhuman treatment as described in Article 3 of the European Convention on Human Rights.

In her turn, Dunja MIJATOVIC, Council of Europe Commissioner for Human Rights, noted that many member states now seem to agree that many procedures performed early on these children amount to a violation of the rights of the child and that the bodily integrity of these children should be protected. Indeed, it called on Member States to **legislate to explicitly prohibit unnecessary interventions** performed early on these children and without their consent, as Malta, Iceland, Germany and Portugal have already done.

Laurence BRUNET, a lawyer specialising in bioethics, family law and fundamental rights and a researcher at the Institute of Legal and Philosophical Sciences at the Sorbonne in Paris, then recalled how the issue of **assessing the medical necessity of interventions** was at the heart of the debates surrounding Article 30 of the latest revision of the bioethics laws in France. France's highest administrative court thus considered already in 2018 that non-medically necessary interventions should wait until the child is old enough to participate in the decision. **Since the sole purpose of conforming the child's atypical genitalia to representations of the feminine and masculine does not constitute a medical necessity, it was appropriate to wait until the minor was able to participate in the decision.**

Kristof VAN ASSCHE, Associate Professor and Researcher at the University of Antwerp in Belgium, confirmed that there is currently no consensus on the type, age and surgical treatment of these children. Assignment surgeries are often performed before 24 months. Some interventions are obviously urgent, for example to create a urinary opening, but **how can we determine which interventions are necessary outside of an emergency?** Hormonal treatment often raises the same issues as surgical interventions.

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<sup>3</sup><http://assembly.coe.int/nw/xml/XRef/Xref-XML2HTML-EN.asp?fileid=24232>

The arguments put forward for early surgery have long been in the majority and include the prevention of poor urinary function or blood retention and the supposedly better psychosocial development and sexual satisfaction in adulthood.

Over time, the arguments against performing these early surgical treatments have grown: They include pain and numerous surgical complications, the need for frequent reoperations, long-term sexuality disorders, fertility disorders and psychological trauma for the children on whom these procedures were carried out, the possibility of postponing these surgeries to a later age when the child could participate in the decision, the high rates of "misassignments" (i.e. when the sex assigned to the child does not correspond to the gender in which he or she perceives him- or herself), and non-medical motives for these procedures that are most often societal demands

In terms of medical necessity, it is increasingly recommended to take into account the state of the art, not to remove healthy tissue, to ensure preservation of innervation and to postpone vaginal and phalloplasty until adulthood. These recommendations are currently applied in a very heterogeneous way.

Katharina LUGANI, from the Law Faculty of the Heinrich Heine University in Düsseldorf confirmed the restrictions that exist in Germany for the performance of early surgical intervention on intersex children since the law of 2021 (Bürgerliches Gesetzbuch (BGB) § 1631e Behandlung von Kindern mit Varianten der Geschlechtsentwicklung). In practice, in the absence of the child's consent or a medical emergency, the intervention is prohibited. Assessment of necessity by a special commission is possible. This **commission is multidisciplinary**.

Gaby CALLEJA, Head of the LGBTIQ Unit at the Human Rights Directorate of the Maltese Ministry for Equality, Research and Innovation, began by recalling the long-standing Maltese commitment to the rights of intersex people, in particular through the 2013 Malta Declaration (adopted at the [conclusion of the 3rd International Intersex Forum](#)) calling for an end to discrimination against intersex people and the defence of the right to bodily integrity, physical autonomy and self-determination. This commitment was reflected in the passage of the Gender identity, gender expression and sex characteristic act (GIGESC) in 2015.

The latter established the right to gender identity based on self-determination, and the right to bodily integrity (Article 14 prohibiting normalising interventions) and bodily autonomy based on the State's duty to protect children whose parents seek interventions that manifestly violate the child's welfare or decision-making rights. Thus all sex reassignment treatment decisions that have irreversible but deferrable consequences should not be made until the person to be treated can decide for themselves. This includes genital surgery and gonadal ablation, unless there is an urgent medical indication for these procedures.

The present Maltese legislation also provides for the establishment of a multidisciplinary working group of medical, psychosocial and human rights experts to review intersex treatment protocols and to assist parents and health professionals in decision-making. These assessments should ensure that the principle of the best interests of the child prevails at all stages of the discussion.

In turn, Kári HOLMAR RAGNARSSON, Assistant Professor of Law at the University of Iceland in Reykjavík, presented the Icelandic legal framework with the adoption in 2020 of Act 154/2020 concerning children under 16 years of age, born with variations of sexual characteristics or atypical sexual characteristics. The main issues of this law are to guarantee

the physical integrity, self-determination and the right to the best available health care for these children.

If the child is too young to give consent (or is not able to do so): the law does not allow any permanent modification of sexual characteristics, unless there are compelling 'health reasons' for doing so. This excludes social, psychosocial and appearance-related reasons.

As in the previous examples, the decision-making process involves an interdisciplinary team of experts who have to carry out a detailed assessment of the short and long term risks and benefits. However, there are exceptions to this rule in some situations (hypospadias and drug treatment of micropenis).

It should be noted that, like French law, Icelandic law provides additional guarantees for the information of the child, in particular the obligation to record the elements of the decision-making process in the individual medical files.

All the speakers pointed out **the importance of a collegial and multidisciplinary evaluation of the medical necessity** of interventions, whether they be medicinal (hormonal) or surgical, as well as the importance of access to information during the decision-making process, in particular by recording the evaluations and opinions formulated in the child's medical file.

## **The decision-making process, the place of law, the notion of consent**

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- **The notion of consent and parental responsibility**

Early surgical interventions make it impossible to obtain the consent of the child concerned. The responsibility of adults: parents and professionals, what does the law say?

In several Member States, Portugal, Iceland, Germany and Cyprus, early interventions that are not a vital emergency are prohibited. In Germany it is possible to appeal to an administrative court. However, not all Member States have legislated on the issue of early intervention for intersex children.

Article 4 of the **Oviedo Convention**<sup>4</sup> states that "*Any intervention in the field of health, including research, must be carried out in accordance with relevant professional obligations and standards,*" as well as the rules of conduct applicable in the case, and in States that have not specifically legislated on the issue, reference should be made to local codes of ethics or general public health laws.

Kristof VAN ASSCHE recalled that three ethical obligations exist in all Member States: to provide information, to obtain the informed consent of the individual and to take into account the state of the art of medical knowledge.

### **In this context, should informed consent be given by parents and other representatives?**

According to articles 5 and 6 of the **Oviedo Convention**<sup>5</sup>, "Where, according to law, a minor does not have the capacity to consent to an intervention, it shall not be carried out without the authorisation of his or her representative, an authority or a person or body designated by law. The opinion of the minor is taken into account as an increasingly determining factor, depending

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<sup>4</sup><https://rm.coe.int/168007cf98>

<sup>5</sup><https://rm.coe.int/168007cf98>

on his/her age and degree of maturity. Representatives should then receive the same full and adequate information, useful for decision-making.

Parents obviously have the right to make decisions about their child's health. They must act in the best interests of the child. However, these decisions should be taken with **full and sufficient information and independently of social or medical pressure**. What legitimacy do parents have to authorise irreversible interventions such as sterilisation? This debate is still ongoing.

Jameson GARLAND, Associate Professor of Medical Law and Senior Lecturer in Family Law at Uppsala University, discusses how the Swedish legislator has been confronted with the issue of consent in the care of intersex children, and in particular for surgical care. The prerequisite for consent is good and understandable information.

Sweden now has non-legally binding recommendations making it possible to ensure that many surgical procedures on intersex children are postponed to an age when the child is able to participate in the decision.

Jameson GARLAND recalled that Sweden had worked on the possibility for a child to receive advice and information autonomously and independently of his or her parents, but this subject was still largely poorly known and implemented.

- **The decision-making process**

Vladimir KOJOVIC, Professor at the Faculty of Medicine in Belgrade and paediatric surgeon at the Centre for Reconstructive Urology in Serbia, shared his experience of the decision-making process for surgery on intersex children. He recalled that at the beginning of his training some twenty years ago, the dogma prevailed that no child should leave the maternity ward without being assigned a gender and having completed surgery. Since then, his team has been committed to respecting the fundamental rights of the child, notably by working regularly with NGOs, and tries to avoid all unnecessary interventions. To achieve this, his team follows a defined decision-making process. This process must never be rushed because there is no emergency. The decision-making process is organised around a multidisciplinary team of doctors, but also lawyers, associations, support groups and paramedics, and is based on three main questions: Is the surgery necessary and why? When should it be performed? What are the expected benefits and risks?

In this process, clear and concrete objectives should be pursued. First of all, the objectives should be functional. Then come the objectives that can be qualified as aesthetic, such as the conformity of the appearance of the genitals to the subject's gender identity (which may be different from that of his or her marital status) and the search for minimal scarring.

Several speakers then pointed out the difficulties posed by the legal framework and the obligation in many countries to declare the birth of a child and therefore its sex very quickly after birth. This constraint is a source of pressure in the decision-making process. The deadline is 30 days, particularly in Serbia. In France, Laurence BRUNET explained the flexibility newly authorised by the latest revision of the bioethics laws. The deadline can now be extended but, above all, the sex indicated can be modified without any trace of the modification in the birth certificate. Such flexibilities aim to reduce the pressure and give time to the decision-making process.

- **The ethics of decision making**

Jurg STREULI, Head of the paediatric palliative and advanced care team at the Children's Hospital of Eastern Switzerland, Head of the research group in paediatric bioethics at the Institute of Biomedical Ethics of the University of Zurich, proposes the principles that should guide any medical decision concerning intersex children. In his view, the threshold of acceptable harm should be clarified in any decision-making process. This principle should result in less discussion of the "medical necessity" of intervention (which is rare in intersex children) and more discussion of the limits of the medical indication.

These decisions should be taken within multidisciplinary teams and with the involvement of the child and his/her family as much as possible for a shared decision.

He invites everyone to bear in mind that the absence of a decision or intervention remains a decision and will have consequences.

- **The place of professionals**

Lih-Mei LIAO, Consultant clinical psychologist in the UK, observes that the responsibility for carrying out child surgery is increasingly placed on parents, with health professionals seeing their advice as neutral and free of framing effects. She therefore encourages an understanding of systemic factors in medical services, such as the effects of pathologisation and objectification, but also of techno-centrism in intersex services, on the choice of care and training of carers.

## **Information and training: family, carers, society**

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During this session, Mika VENHOLA, Paediatric surgeon at the University Hospital of Oulu in Finland, referred to the work of the National Federation of Voluntary Bodies in Ireland in developing recommendations on how to inform and support families with a disabled child. The project, initiated in 2004, has identified six key principles that should be also applied in the very specific case of families with an intersex child. The initiative provides information materials for professionals and families to illustrate these principles on its website.

The guiding ideas she puts forward are echoed in the words of many of the seminar speakers.

According to these principles, information should be tailored specifically to each family and take into account all the particularities of the family, in particular, the members of the family and their need for support by a trusted third party or interpreter, but also their culture and beliefs.

Throughout the process, the professional should consider how best to support the participants in understanding and accepting the information provided, particularly by taking into account their emotions and adopting an empathetic mode of communication, while ensuring that the content of the information is as accurate and precise as possible.

During the morning session, the mother of an intersex child, born XXY 13 years ago, spoke of her suffering at not receiving any congratulations or reassurance of her child's good health from the doctors when he was born. She emphasised the need for parents to receive a positive first message when their child arrives.

Finally, whatever the situation, the message should be positive and realistic about the child's prospects and natural history.



- **The choice of words and the weight of representations**

From the outset of the seminar, the representative of the Parliamentary Assembly of the Council of Europe, Christophe LACROIX, General Rapporteur on the rights of lesbian, gay, bisexual, transgender and intersex (LGBTI) people, reminded the meeting of the invisibility of so-called intersex children and people and the need to open up the debate, to understand and raise awareness of the many issues raised by this subject. He said that this invisibilisation is the result of the commonplace reflex that *"any body that cannot be easily classified is immediately considered abnormal and hidden"*.

Gary BUTLER, Professor of Paediatric and Adolescent Endocrinology at University College Hospital, London, reviewed the definitions of sex and gender, the context of the appearance of a biological sex during embryological development and the weight of this determinism in our representations.

In his turn, François ANSERMET presented the long debates of the French National Consultative Ethics Committee on the terminology to be used: are they variations or disorders? Sexual or genital? According to him, semantics is also important for the way society looks at these children. He recalled the well-known examples of the shame felt by some parents at the time of depositing their children in a crèche and the ease that normalising surgery can represent for them.

Katharina LUGANI confirmed the semantic debates that also exist in Germany. She also mentioned the recognition of a third category. The associations and activists for the recognition of intersex children have different opinions themselves. Some do not want "pathologisation" but claim recognition of a certain difference.

The question of pathologisation remains open: to what extent can we depathologise children with these variations. What level of medical is desirable?

Jurg STREULI in turn calls for the demedicalisation of information for non-medical problems.

Gary BUTLER also stressed the need to combat the confusion that sometimes exists among the general public between gender dysphoria and intersex children, by providing clear information on the concepts of sex and gender.

- **Support**

Ružica BOSKIC, representative of the Steering Committee for the Rights of the Child, underlined the immense role of professionals not only in avoiding unnecessary early intervention, but also and above all in reassuring and guiding parents.

In his turn, Mika VENHOLA, a paediatrician at the University Hospital of Oulu in Finland, insisted on the rarity of emergencies (apart from hormone supplementation for adrenal insufficiency) and the imperative need to reassure parents. He stressed the need to seek to be an ally of the family at every stage of care and to see care as a journey that family and professional will embark on together. The quality of the family's support should be assessed in order to propose the best support options.

As François ANSERMET indicated, the National Consultative Ethics Committee had also insisted on the content and methods of the information provided to parents. This should be reassuring, complete and exhaustive, covering the characteristics of the variation in the child's genital development and the possible physiological and psychological consequences, in the short, medium and long term, with and without treatment.

François ANSERMET also pointed out that when a specific treatment of genital developmental variation is envisaged, the child and his parents should be given all the information allowing them to appreciate the reason for it and its consequences.

Laurence BRUNET, in turn, recalled the important place given to support in the French law, which now stipulates that parents are **informed of the existence of associations specialising in** supporting people with a variation in genital development.

In all cases, long-term psychological care and support should be systematically offered to parents and children to enable them to have an appropriate development.

- **Transparency and information media**

Jameson GARLAND, Associate Professor of Medical Law and Senior Lecturer in Family Law at Uppsala University, emphasised the need for more information materials and documents for the persons concerned and their families. These materials must provide reliable and understandable information, document what the medical team has said and ensure transparent communication.

They also make it possible to ensure that consent is informed when decisions are taken. However, he notes that this information is rarely available, either to the persons concerned or to professionals. The few tools available are still, in his opinion, very superficial and should be the subject of in-depth work to highlight, in particular, the social factors that can influence parents, as well as the benefits and limits of early surgical process.

Jameson GARLAND mentioned the examples of the interACT association in the United States, which has contributed to positive discrimination in hospitals and is developing information materials for the general public, and the National Board of Health and Welfare in Sweden in 2022, which has focused on scientific information and available treatments.

Several speakers, including Jurg STREULI, called for the development of adequate information material to help parents inform the child, but also his or her grandparents and society at large.

- **Training of professionals**

Jurg STREULI emphasised the need to develop training for professionals. The latter should learn how to implement a decision-making process that involves all the actors concerned, and also how to implement this shared decision.

Beyond the multidisciplinary, it encourages cross-professional teamwork (including support groups).

Gary BUTLER, in his turn, insisted on the importance of general training and the establishment of a basic knowledge base on intersex children, sex and gender for all health students and professionals as well as for the general public, but also on the need for advanced and specialised training on this subject for all paediatricians or neo paediatricians, obstetricians, midwives and paediatric nurses. These trainings should address the need for emerging professionals to address sensitive issues (e.g. should sex/gender be decided in infancy? who should decide on sex and the performance of interventions?)

## **Recommendations**

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The interventions of the participants and the exchanges with the audience allowed to put forward many ideas and recommendations to promote the rights of the child. The main points were as follows

- Information
  - o Informing parents and representatives in a comprehensive and appropriate manner
  - o Adopt a reassuring and positive attitude
  - o Developing information materials
  - o Enable the child to benefit from dedicated information
  - o Ensuring support for the child and his/her family: trusted third party, associations
  - o Better informing society
- Training of professionals
  - o Better training for professionals in parenting and decision-making
  - o Better understand the role of professionals in decision-making
- Decision-making process
  - o Assessing the benefits and limitations of surgical indications
  - o Don't make any decisions in a hurry
  - o Postpone medical and surgical interventions as far as possible to an age when the child can participate in the decision
  - o In case of discussion of intervention and in the absence of a life-threatening emergency, resort to collegial and multidisciplinary decision-making, favour shared decisions
  - o Promoting multidisciplinary and trans-professional decision-making
- Societal and legal factors
  - o Postpone and limit the pressure on the family and health care team to declare the child's sex
  - o Promoting positive discrimination and diversity in society

## **Avenues for work**

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The various presentations highlighted numerous and varied avenues of work.

A priority should be the development and promotion of shared decision-making models involving health professionals, families and representatives of affected persons (e.g. through associations), to ensure that any intervention or its postponement has been assessed in the best interests of the child.

Later, when a decision to postpone intervention may have been made, the family and health professionals should be provided with tools and guidelines to seek and ensure the child's consent to possible care.

Support for families and professionals is another essential issue. Training should be proposed and good practices developed for healthcare professionals to inform families.

It would also be useful to consider the nature and methods of support for families: support from third-party carers, associations, psychologists or social workers.

More generally, it seems essential to encourage and support all initiatives that promote the dissemination of knowledge about intersexuality and encourage its acceptance in society.

## References

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France - Council of State - Revision of the bioethics laws: options for the future, 2018 - [Bioethics study](#)

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Sweden - Recommendations for decision-making and care of intersex children: <https://www.socialstyrelsen.se/globalassets/sharepoint-dokument/artikelkatalog/kunskapsstod/2020-4-6695.pdf>

UK - <https://interconnecteduk.org>

UK: Gender Support Association: <https://gids.nhs.uk>

UN - Office of the High Commissioner for Human Rights - [Convention on the Rights](#) of the Child

USA - interACT Association - Advocates for Intersex Youth - <https://interactadvocates.org>