

Indicators for effective protection of the rights of intersex people, in particular protection from IGM

Contents

Introduction & Explanatory Notes.....	3
Prohibition of non-vital, non-consensual interventions or treatments.....	4
Comprehensive definition of prohibited treatments and interventions	5
Inclusion of all variations of sex characteristics	5
Accountability for healthcare professionals.....	5
Effective monitoring mechanism.....	6
Access to truth, justice and reparations	6
Accessibility of medical records.....	7
Provision of tailored support	7
Human rights compliant access to health	8
Provision of training for professionals	9
Prohibition of other harmful practices.....	9
Clarity about the scope of vital interventions or treatments.....	10
Prior, free, explicit and fully informed consent.....	10
Provision of comprehensive information	11



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Indicators for effective protection of the rights of intersex people, in particular protection from IGM

The following indicators were prepared by OII Europe on the basis of extensive consultations and research (see below) and adopted by the OII Europe Steering Board representing OII Europe member organisations in 23 countries across Europe.

It aims to give policy makers and law makers a useful tool when preparing legislation to ensure

- ▶ **legal protection of persons with a variation of sex characteristics from intersex genital mutilation**
- ▶ **effective implementation of such legal protection**
- ▶ **clarity and functionality of legislation prohibiting intersex genital mutilation**
- ▶ **access to truth, justice and reparations**
- ▶ **the right to health**
- ▶ **that a human rights based and de-pathologizing perspective on persons with a variation of sex characteristics is being mainstreamed among professionals**

This checklist has been developed by OII Europe building on:

1. The joint demands that have been expressed by the European intersex community in the past 10 years (see [Malta Declaration](#), [Riga Statement](#), [Vienna Statement](#)), and which have informed other OII Europe publications (e.g. the toolkit [Protecting Intersex People in Europe: A toolkit for law and policy makers](#)).
2. The analysis of the IGM bans already in force, based on legal research and consultations with national intersex NGOs, intersex activists and ally NGOs of the countries who have established a ban.
3. A consultation about the essential elements of an IGM ban with European intersex civil society that took place at the intersex pre-meeting of the ILGA-Europe Conference 2022. The consultation took place in hybrid format to allow for maximum participation.



Explanatory Notes:

Intersex persons are persons born with a variation of sex characteristics, that is with sex characteristics (sexual anatomy, reproductive organs, hormonal structure and/or levels and/or chromosomal patterns) which do not fit the typical definition of male or female bodies. The fact that someone has an intersex body can become apparent at different times in their life: through prenatal testing, at birth, during childhood, in puberty or even in adulthood.

List of Indicators:

Elements 1, 2, 3 and 4 are essential to ensure comprehensive protection of persons with a variation of sex characteristics from intersex genital mutilation

1

Prohibition of non-vital, non-consensual interventions or treatments

This indicator is met under the following circumstances:

- ▶ if an individual with a variation of sex characteristics is legally able to provide consent, a prohibition exists for interventions or treatments on that person's sex characteristics unless the person has provided their prior, free, explicit and fully informed consent (as laid out in indicator 13).
- ▶ if an individual with a variation of sex characteristics is not legally able to provide consent, all interventions or treatments on that person's sex characteristics are prohibited unless the intervention or treatment is vital (as laid out in indicator 12); with the following exception:
 - › the individual has expressed their explicit wish for such an intervention or treatment;
 - › the individual's capacity to consent has been assessed positively by an independent third party with the necessary professional qualification who is not connected with the health practitioner, the multidisciplinary medical team or the health care facility providing medical care related to the persons' variation of sex characteristics and/or performing the potential intervention or treatment;
 - › the individual has provided their prior, free, explicit and fully informed consent;
 - › a system is set up to monitor the compliance with the above steps; the steps have been documented; and the documentation is easily accessible to the intersex person.

i

Explanatory Notes (cont.):

Intersex Genital Mutilation (IGM)

IGM is a harmful practice which entails surgical and medical procedures, or hormonal treatments on the sex characteristics of an intersex person, often performed at a very early age, without the person's free, personal, prior and fully informed consent.

IGM has been identified as a harmful practice by the UN High Commissioner for Human Rights, UN treaty bodies, the Commissioner for Human Rights of the Council of Europe, the Parliamentary Assembly of the Council of Europe, the European Commission and the European Parliament, among others. As of this date (11.5.2023) already 6 Council of Europe Member States have adopted laws to prohibit IGM.

Comprehensive definition of prohibited treatments and interventions

2

This indicator is met when the law targets all kinds of non-vital, non-consensual medical and/or surgical interventions on the person's sex characteristics and/or hormonal treatments on the person's sex characteristics, including medical interventions or treatments performed before the birth of the child. Sex characteristics include the person's sexual anatomy, hormone levels, reproductive organs, and/or chromosome patterns.

Inclusion of all variations of sex characteristics

3

This indicator is met when no variation is excluded from the prohibition as set out in indicators 1 and 2, for example by excluding specific diagnoses, related to variations of sex characteristics.

"Variation of sex characteristics" refers to any innate variation of a person's primary or secondary sex characteristics that is not aligned with societal norms of female or male sex characteristics in appearance or function, including sexual anatomy, reproductive organs, hormonal structure and/or levels and/or chromosomal patterns.

Accountability for healthcare professionals

4

This indicator is met when penalties exist for healthcare professionals who commit, attempt to commit or assist in performing any non-vital, non-consensual medical treatments or interventions on the sex characteristics of persons with a variation of sex characteristics.

Legal sanctions should also be envisioned for the conduct of healthcare professionals referring the parents or legal guardians of an intersex minor to healthcare professionals abroad for the purpose of having the latter perform a prohibited intervention or treatment (as set out in indicators 1 to 3).

Element 5 is essential to ensure effective implementation of a legal prohibition of intersex genital mutilation.

5

Effective monitoring mechanism

This indicator is met when an independent and effective monitoring mechanism is established to assess the implementation of the prohibition of non-vital, non-consensual interventions on persons with a variation of sex characteristics. This includes:

- ▶ Establishing a monitoring body tasked with submitting an evaluation report. The report should include
 - › an evaluation of the implementation of the law and, where suitable, proposals for closing gaps, including but not limited to amending provisions;
 - › a monitoring of the number and nature of interventions performed in the country;
 - › a monitoring of the consent process (as laid out in indicator 1);
 - › consultations with organisations representing the national intersex community as part of the evaluation process.

Elements 6, 7 and 8 are essential to ensure access to truth, justice and reparations (6 and 7) and to guarantee their right to health (7 and 8).

6

Access to truth, justice and reparations

This indicator is met when the law ensures that access to effective complaints procedures and remedies, including reparation for past harm, is guaranteed. This includes:

- ▶ The provision of psychological and other support tailored to the specific needs of the person, including medical treatment needed as a consequence of having been subjected to a prohibited intervention or treatment.
- ▶ The extension of the statutes of limitation to ensure that the person is able to access redress and to enable investigation, prosecution,

trial and judicial decision – the extension should accommodate the fact that intersex persons subjected to violations of their bodily integrity and self-determination may need a significantly long time to recover from trauma. The limitation period for violations which occurred when the person was a minor, should only start on the day the person reaches maturity.

- ▶ The issuing of a public apology which provides adequate acknowledgement of the suffering and injustice caused to intersex people in the past.
- ▶ The establishment of a compensation fund for past harm.
- ▶ Effective monitoring and evaluation of the effectiveness of the procedures and remedies which have been established to account for past harm caused by non-vital, non-consensual medical treatments or interventions.

Accessibility of medical records



This indicator is met when all relevant medical information is easily accessible to the person with a variation of sex characteristics, or to their parents or legal guardians through the person's medical records. To this aim:

- ▶ The full information, including information about the diagnoses related to the person's variation of sex characteristics, the decision-making process in relation to the intervention or treatment and the intervention or treatment itself, should be mandatorily recorded in the person's patient file.
- ▶ The retention period for accessing medical records should be such that a person who may have been subjected to a treatment or intervention as a minor can access their files also as an adult. This will allow for comprehensive health care throughout their life and allow for seeking redress, if relevant.
- ▶ In order to ensure the latter the retention period should at minimum be extended to match the statutes of limitation.

Provision of tailored support



This indicator is met when persons with a variation of sex characteristics are entitled to receive quality healthcare based on the individual's physical needs, along with individually tailored psychological or psychosocial counselling by trained professionals, and peer support and counselling.

This support should be available to the person and their parent(s) or guardian(s) / families, from the moment the variation is determined, including before birth, and throughout the person's life, if necessary.

Elements 9, 10 and 11 are essential to ensure that a human rights based and de-pathologizing perspective on persons with a variation of sex characteristics is being mainstreamed among professionals and the general public and that “othering” of persons with a variation of sex characteristics is put to an end.

9

Human rights compliant access to health

This indicator is met when a human rights compliant and human rights affirming framework for healthcare services is set up, which upholds the intersex person’s right to bodily integrity and self-determination. This includes:

- ▶ Provision of mandatory training for healthcare professionals - such as doctors, midwives, psychologists and other professionals working in the health sector.
- ▶ Creation of an independent working group to review and revise relevant national medical protocols and guidelines from a de-pathologizing, patient-centred perspective.
 - › The working group should be composed in equal parts of human rights experts, intersex peer experts, psycho-social professionals and medical experts.
 - › It should carry out its work within a limited period of time laid down in the law.



Provision of training for professionals

This indicator is met when the law establishes educational and awareness raising measures, including sensitivity training, for professionals working in the field of education, law, including health law, and law enforcement, among others.

Such measures should ensure the inclusion of comprehensive, affirmative, accurate, human-rights based information about the specific needs of persons with a variation of sex characteristics.

10

Prohibition of other harmful practices

This indicator is met when, in addition to the rights granted to all patients, special protection from other harmful practices is given to persons with a variation of sex characteristics, especially by ensuring the prohibition of bodily examinations and bodily exposure that do not have a therapeutic scope.

11

12

Clarity about the scope of vital interventions or treatments

This indicator is met when interventions and treatments on persons with a variation of sex characteristics are only considered vital if they are being performed to avert a threat to the life or serious damage to the person's physical health. Interventions and treatments that are performed for social, cultural or aesthetic reasons are not to be considered vital.

13

Prior, free, explicit and fully informed consent

This indicator is met when free, explicit and fully informed consent is required as a prerequisite for any non-vital intervention or treatment on the sex characteristics of a person with a variation of sex characteristics. This includes that the person:

- ▶ Is given comprehensive information about the treatment or intervention.
- ▶ Is given reasonable assistance in order to understand the information.
- ▶ Has been given reasonable opportunity, including reasonable time, in order to make a decision about the treatment or intervention.
- ▶ Has not been subjected to undue pressure or coercion by another person.

In addition, if the person is a minor:

- ▶ An independent assessment is conducted to establish whether the minor who expresses the wish to undergo the intervention/treatment, has the capacity to provide consent, and the minor is given adequate support (as set out in indicator 8).
- ▶ Free, explicit and fully informed consent cannot be substituted by authorisation ("consent") of parents or legal guardians.

A person with a variation of sex characteristics should be deemed to have the capacity to consent to an intervention or treatment on their sex characteristics if they are able to understand the facts, assess the risks and benefits and weigh up the short- and long-term consequences of the possible choices and make a decision.



Elements 12, 13 and 14 are essential framework definitions which ensure clarity and functionality of legislation prohibiting intersex genital mutilation

Provision of comprehensive information

14

This indicator is met when, prior to performing any interventions or treatments on persons with a variation of sex characteristics, healthcare professionals are required to provide them and, where applicable, their legal guardian(s), with

- ▶ up-to-date, accurate, comprehensive and objective medical information in a way that the person can understand, including, as a minimum,
 - › information about the diagnosis related to the person's variation of sex characteristics;
 - › the common or likely risks of an intervention or treatment, including the mid-term and long-term consequences;
 - › the existence of alternative options, including the option to not undergo any interventions or treatments;
- ▶ empowering and supportive information about living with a variation of sex characteristics;
- ▶ information about how to access peer counselling.



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