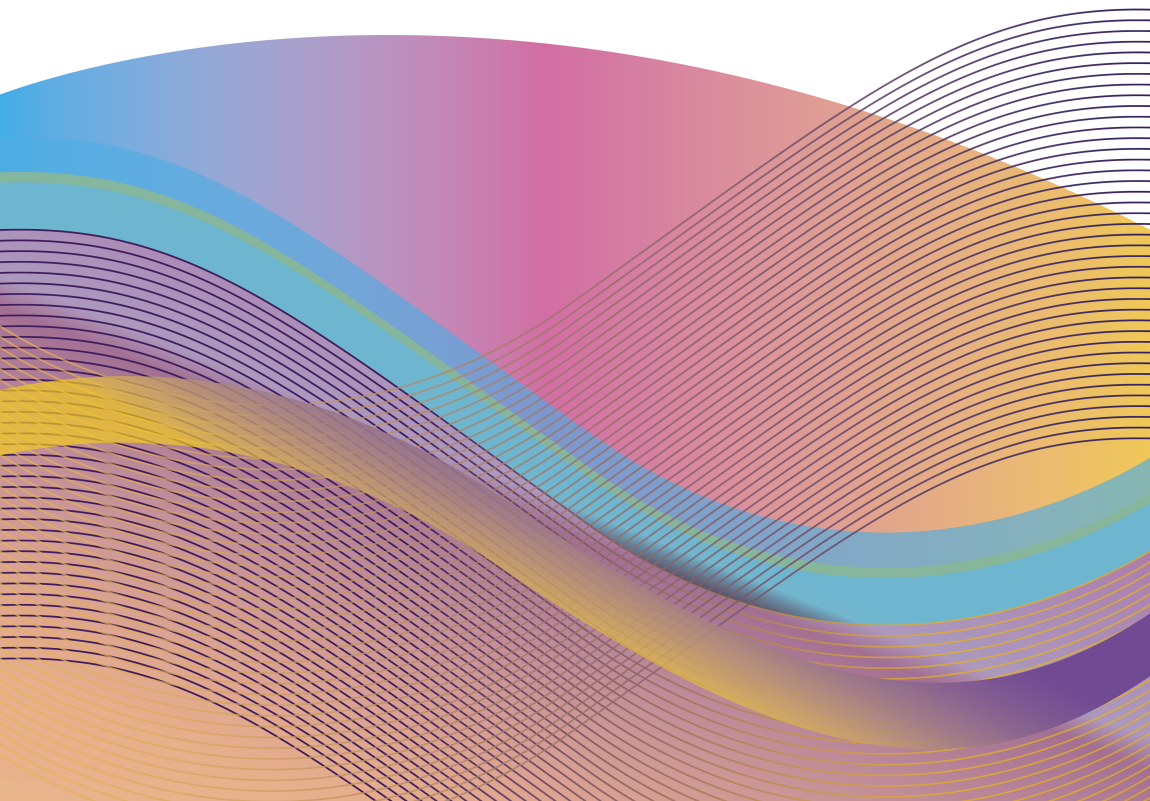


**Ethical Communication:
Guidelines and terms to know about people
with variations of sex development**



Julia Pustovit

Intersex People are like everyone else

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The definitions and recommendations in this guide aim to summarize key concepts in protecting the rights of people with variations in sex characteristics and to promote the consistent, ethical use of language by human rights advocates, medical professionals, and society.

This will help to:

1. Raise awareness – to understand that intersex variations are a natural form of biological diversity, not a pathology.
2. Standardize terminology – to move away from medicalized and/or stigmatizing terms such as “DSD” or “abnormalities” in favor of neutral terms like “sex characteristics” or “variations.”
3. Protect rights – to create a foundation for developing clinical protocols that guarantee bodily autonomy, informed consent, and the prohibition of forced interventions.
4. Promote solidarity – to provide activists, lawyers, and allies with tools for informed communication, education, and advocacy at both national and international levels.

Thus, this guide not only explains key concepts but also outlines practical steps toward a safer, rights-based approach to intersex people.

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KEY TERMS AND THEIR DIFFERENCES

Intersex

Short definition:

An intersex person is someone born with sex characteristics – such as genitals, gonads, and chromosomes – that do not fit typical binary notions of male or female bodies.

These characteristics may relate to chromosomes, gonads, hormone levels, or internal/external sex organs. Intersex is a natural biological variation. It may be visible at birth, appear during puberty, or remain unnoticed throughout life.

Intersex is not the same as being transgender or part of LGBT identities, as it refers not to gender or orientation, but to physical traits.

Context of use:

Intersex people often face discrimination in healthcare systems due to forced medical interventions. Because their bodies differ from others, they are frequently stigmatized and experience numerous human rights violations in both childhood and adulthood, including violations of the right to health, bodily integrity, protection from torture and ill-treatment, and equality and non-discrimination.

Note:

The term “intersex” is a self-identification that many people consciously choose. Medical terms such as DSD (Disorders/Differences of Sex Development) are not recommended in activist or educational contexts.

DSD (Disorders of Sex Development) / DSD (Differences of Sex Development)

DSD (Disorders of Sex Development) is a medical term introduced in 2006 to describe various variations in

sex development that do not align with typical notions of “female” or “male” bodies.

DSD (Differences of Sex Development) was introduced as a less pathologizing alternative to “disorders,” replacing earlier terms such as “sexual abnormalities.” However, despite the use of “differences,” many intersex people still consider this term problematic, as it maintains a medicalized framework where bodily diversity is seen as something that requires correction or treatment.

Definition:

These terms are mainly used in medical contexts to describe intersex variations—that is, natural diversity in the development of sex characteristics.

Context of use:

In many countries, a DSD diagnosis serves as justification for forced surgical interventions on intersex children. Alternatively, some intersex people reject the term DSD as stigmatizing.

Note:

DSD is not a self-identification for most intersex people. In educational, human rights, and activist contexts, it is preferable to use more neutral terms such as “intersex,” “variations of sex development,” or simply “sex characteristics.”

Sex Characteristics (synonym: sex traits)

Biological features related to a person’s sex—chromosomes, gonads, hormones, and internal and external sex organs – which may appear in many different combinations and variations.

The term “sex characteristics” refers to bodily traits traditionally used to assign sex at birth. In reality, these characteristics do not always fit neatly into the categories of “male” or “female.” The existence of different combinations of these traits is precisely what underlies intersex variations.

These characteristics are divided into:

- Primary – gonads (ovaries, testes), genitals
- Secondary – changes appearing during puberty (breast development, voice changes, body hair, etc.)
- Genetic – chromosomal patterns (XX, XY, XXY, XO, and others)

Using the term “characteristics” instead of “traits” or “features” emphasizes natural diversity rather than pathology. It is a politically and ethically conscious language choice that avoids stigmatizing intersex bodies.

Context of use:

Intersex is a variation in sex characteristics, not a disease. We recognize bodily diversity – including sex characteristics – as part of the human norm.

Note:

Some legal or medical documents still use terms like “sexual characteristics” or “abnormalities of sex development,” but the intersex community advocates replacing pathologizing language with neutral or positive terminology.

Intersex Variations

Natural diversity in human sex characteristics that does not conform to traditional medical ideas of “male” or “female” bodies.

Intersex variations encompass a wide range of biological conditions related to chromosomes, hormones, gonads, and/or internal or external sex organs. These variations may be identified:

- at birth;
- during puberty;
- in adulthood;
- or never, if they do not attract medical attention.

These variations are not a disease, not a diagnosis, and not an “abnormality.” They are part of normal biological diversity observed in all human populations. According to various estimates, intersex people make up approximately 1.7% of the population – comparable to the number of people with red hair.

Context of use:

Intersex variations are natural and do not require “correction.” Human rights advocates call for recognizing intersex variations as part of human diversity rather than as a medical problem.

Note:

The medical system often classifies intersex variations as “Disorders of Sex Development” (DSD), but this terminology is stigmatizing and pathologizing. The intersex community advocates for the use of the neutral and accurate term “variations.”

BIOLOGICAL COMPONENTS

Karyotype

The complete set of chromosomes present in a person's cells is typically described by their number, shape, and structure.

A karyotype is a full map of chromosomes showing:

- how many chromosomes are in the cells (humans usually have 46);
- how they are arranged in pairs (22 pairs of autosomes + 1 pair of sex chromosomes);
- possible variations (e.g., XX, XY, XXY, XO, XYY, etc.).

Determining a karyotype is often used in medical contexts, including:

- investigating causes of infertility;
- diagnosing genetic conditions;
- cases where external traits do not align with typical binary biological classifications of “female” or “male.”

In the context of intersex experience:

Intersex people may have karyotypes different from XX or XY, but not always. Some intersex variations occur with typical binary karyotypes. Therefore, a karyotype alone does not determine sex; it is just one of many biological components.

Context of use:

This person's karyotype is 46, XX, but they have external traits typically associated with male sex. It is important to understand that karyotype variations are not a pathology, but part of biological diversity.

Chromosome

A structure within the cell nucleus that carries genetic information. Chromosomes contain DNA and determine various biological traits – from eye color to aspects of body development.

Humans typically have 46 chromosomes, including 2 so-called sex chromosomes that influence the development of sex characteristics. The common general model is:

- XX – “female” pattern;
- XY – “male” pattern.

However, in reality, there is a wide range of variations, including:

- XXY (Klinefelter syndrome);
- XO (Turner syndrome);
- XXX, XYY, XXYY, etc.

These variations may be:

- present from birth;
- undetected throughout life;
- not associated with visible traits.

In some intersex people, chromosomal patterns do not align with external sex characteristics or hormonal profiles – and this is a natural part of human diversity.

Context of use:

An XX body does not always have a vagina, just as an XY body does not guarantee a penis. Intersex variations show that chromosomes do not strictly determine sex.

Note:

Chromosomal information is only one layer in the development of sex characteristics. Others include hormones, gonads, and anatomy. Reducing sex to chromosomes is not a scientific fact but an oversimplified and often politicized idea.

Chromosomal Variations

A type of intersex variation related to the chromosomal makeup of a person. Instead of “typical” XX or XY, a person may have, for example, XXY, XO, XXX, or XY with androgen insensitivity.

Important to know:

- These variations are often not visible at birth and may be discovered later (e.g., during medical examinations, delayed puberty, infertility, or inability to conceive).
- Chromosomal variations may not affect appearance or health, yet the medical system often still seeks to “correct” them.
- People with such variations are intersex, even if their external sex characteristics do not raise “concerns” among doctors.

Examples:

- **Turner syndrome (XO)** – a person has only one X chromosome; often associated with absence of ovaries, lack of menstruation, and shorter stature.
- **Klinefelter syndrome (XXY)** – a person assigned male at birth has an extra X chromosome.
- **Androgen Insensitivity Syndrome (CAIS/PAIS)** – a person has XY chromosomes, but the body does not respond to “male” hormones, resulting in development along a typically “female” pattern.

The presence of chromosomal variation is not a “mistake of nature,” but one form of human biological diversity.

Hormonal Variations

Intersex variations that arise due to differences in the production, perception, or balance of hormones involved in the development of sex characteristics.

What this means:

The human body produces various hormones (including androgens and estrogens) that influence the development of internal and external sex traits. If the body:

- produces hormones in amounts that do not match the “normative” model for the assigned sex; or
- does not respond to certain hormones (due to lack of receptors), which can lead to unexpected combinations of sex characteristics.

Examples of hormonal variations:

- **Congenital Adrenal Hyperplasia (CAH)** – the most common hormonal intersex variation. The adrenal glands produce excess androgens, which may cause masculinization of the external genitalia in children with an XX karyotype.
- **Androgen Insensitivity (CAIS, PAIS)** – the body does not respond or partially responds to “male” hormones despite having XY chromosomes. A person may have a typically female appearance but no uterus and internal testes.
- **5-alpha-reductase deficiency (5ARD)** – the body does not convert testosterone into its active form, affecting genital development.

Important to know:

- Hormonal variations are often discovered during adolescence, when the body does not develop “as expected.”
- They do not require “correction” unless there is a direct health risk. The person themselves should make decisions about interventions.
- These variations may be invisible to others but still significantly affect identity, bodily experience, and self-perception.

Hormonal diversity is not a “problem,” but part of biological variation that should be respected rather than automatically “treated.”

Anatomical Variations

A type of intersex variation related to the structure of the body, internal or external sex organs that do not correspond to standard notions of “female” or “male” anatomy.

What this means:

- Some people are born with genitals that are not considered clearly “female” or “male” according to medical expectations.
- Some may have both ovarian tissue and partially developed penile structures, or a vulva with internal testes.
- Some people may not have a uterus, may have an underdeveloped vagina, or a vagina that ends blindly.

Examples of anatomical intersex variations:

- **Cloacal exstrophy** – a complex congenital condition where parts of the urinary and reproductive systems are not fully formed or are located outside the body.
- **Mayer-Rokitansky-Küster-Hauser (MRKH) syndrome** – a person assigned female at birth lacks a uterus and part of the vagina despite having a typically female external appearance.
- **Severe hypospadias** – the urethral opening is located in a non-typical position, sometimes accompanied by other atypical traits.

Important to know:

- Many of these variations are not life-threatening and do not require intervention unless they cause pain or problems with urination.

- Often, it is the decision by doctors and parents to “correct” genitals that leads to long-term physical and psychological harm.
- People with anatomical intersex variations have the right to know the truth about their bodies and decide for themselves whether they want any changes.

Variability in body structure is part of natural diversity, not a “defect” to be hidden or “fixed.”

Genitals

The external sex organs of a person are body parts related to the reproductive system and urination.

These include:

- for people assigned female at birth: the vulva (labia, clitoris, vaginal opening);
- for people assigned male at birth: the penis, scrotum, and urethral opening.

In biology, there is a wide range of variation in the shape, size, and structure of genitals, and this is a normal part of human diversity.

In the context of intersex experience:

- Intersex people may be born with genitals that do not match typical expectations of “female” or “male,” or that combine features of both.
- Because of this, their genitals are often subjected to forced “normalizing” surgeries in childhood, aimed at making the body conform to a binary model and assigned sex.
- These interventions can have long-term consequences: loss of sensitivity, complications with urination, painful sexual experiences, and issues with self-perception.

Context of use:

Doctors said my genitals were “ambiguous” and decided to “fix” them – I had no choice. Variation in genitals is not a disease, but a biological reality.

Social taboo around genitals:

In many cultures, genitals are considered “shameful” or “private,” which leads to:

- silence and lack of open discussion;
- stigma around “atypical” genitals;
- pressure on parents to “fix” a child early;
- psycho-emotional consequences for people whose bodies do not fit social norms.

As a result, intersex people are often forced to remain silent, feel ashamed of their bodies, or experience isolation.

Hormones

Chemical substances produced by endocrine glands that regulate various bodily functions: growth, development, metabolism, sexual function, and more.

In the context of bodily development, hormones:

- play a key role in the formation of secondary sex characteristics (body hair, breasts, voice, etc.);
- influence the reproductive system, mood, muscle growth, and fat distribution;
- are not inherently “male” or “female”—all people have both estrogens and androgens, just in different proportions.

Typical examples:

- **Testosterone** – often called a “male hormone,” but present in all people;
- **Estrogen and progesterone** – commonly associated with female bodies, but also present in everyone.

In the context of intersex variations:

- Some intersex people have hormonal systems that function differently. For example, the body may:
 - ◇ produce testosterone but not respond to it (as in androgen insensitivity syndrome);
 - ◇ not produce sufficient sex hormones during puberty;
 - ◇ have different hormone ratios without affecting health.
- Because of this, intersex people are often subjected to hormonal interventions even when there is no medical necessity, solely for “normalization.”

Context of use:

I was given hormones to “successfully feminize” my body. This condition does not affect health, but hormone levels may not match what is expected in typical XX or XY development.

Hormone Therapy

A medical intervention in which a person is given hormones (such as estrogens or androgens) to alter or support certain processes in the body.

Hormone therapy may serve different purposes:

- **medical** – when the body lacks certain hormones (e.g., gonadal insufficiency);
- **gender-affirming** – for transgender people who wish to align their hormonal profile with their gender identity;
- **“normalizing”** – for intersex children and adolescents, when doctors attempt to adjust bodily development to match an assigned sex.

In the context of intersex experience:

- often administered without the person’s informed consent;

- may continue for years (e.g., for “feminization” or “masculinization” according to assigned sex);
- may have side effects or be psychologically harmful, especially when a person is forced to take hormones that do not align with their identity or desired state of health.

Context of use:

After the surgery, I was told I would have to take hormones for life, but I didn’t understand why. Hormone therapy can be beneficial, but only when based on the person’s informed choice.

PROCESSES OF MEDICALIZATION

Sex Assignment at Birth (often confused with “gender assignment”)

A formal process in which medical professionals assign a legal sex to a newborn immediately after birth, based solely on a visual assessment of external genitalia.

In most countries, including Ukraine, a child's sex is recorded in the birth certificate as a binary category – “male” or “female.” This decision is made without considering the full range of sex characteristics, such as chromosomes, gonads, or hormonal profile.

In the case of intersex children, sex assignment is often accompanied by pressure on parents – or even medical interventions – to make the child's body conform to the chosen marker. Such actions may violate the child's rights to bodily autonomy, protection from discrimination, and self-determination.

Sex assignment is not a biological “fact” – it is an administrative decision based on cultural ideas about two sexes.

Context of use:

Sex assignment at birth is not a neutral medical act, but a culturally conditioned process. Intersex people are often forced to live with an assigned sex that does not correspond to their sex characteristics or identity.

Note:

The term “gender assignment” is often used in English-language activist contexts. Still, in this context, it is more accurate to refer to sex assignment followed by gender expectations that arise from it.

Sex Marker in Official Documents

A sex marker is an entry in official documents (such as a birth certificate or passport) that records one of two categories: “male” or “female.”

This entry is based on a visual examination of a newborn’s body – without additional testing, even when signs of intersex variation are present.

Why this matters for intersex people:

In cases of “ambiguous” bodies, medical professionals and parents are expected to choose between “M” and “F,” rather than recognize intersex variation. This often becomes the basis for forced surgeries or hormonal interventions aimed at aligning the body with the chosen sex marker. Intersex people themselves do not influence this decision, yet must live with its consequences.

What intersex activists advocate for:

- the possibility to delay assigning a sex marker;
- the right to change a sex marker without being forced into medical interventions;
- some also advocate for removing sex markers as a mandatory category altogether, prioritizing human rights over binary expectations.

A sex marker is not about biology. It is a socio-administrative decision with serious consequences for intersex people.

The Cycle of Intersex Medicalization

1. **Sex assignment at birth**
 - determining sex based on external traits
2. **Diagnosis**
 - pathologization: DSD, “abnormalities,” “disorders”
3. **Interventions**
 - surgeries, hormonal treatments, injections
 - without the person’s consent

4. Taboo and silence

- lack of information
- pressure on families “not to tell anyone”

5. Consequences:

- physical (pain, complications);
- psychological (trauma, anxiety);
- legal (lack of recognition, document changes);
- social (stigma, isolation, discrimination).

“Normalizing” Sex Surgeries

Medical interventions aimed at altering the sex characteristics of intersex children or adolescents so that they conform to societal expectations of “male” or “female” bodies.

These may include surgical or hormonal interventions performed without medical necessity, often at an age when the child cannot give informed consent. Such procedures include clitoral reduction, vaginoplasty, gonad removal (gonadectomy), reconstructive surgeries on the penis, and others. The primary goal is to make the body appear more typically male or female.

These surgeries are often justified by the belief that it will be easier for the child to socialize if their body conforms to binary norms. In reality, these interventions frequently result in traumatic experiences, violations of bodily integrity, loss of sensitivity, infertility, and psychological harm.

Typical examples:

- so-called “clitoral reduction”;
- “reconstruction” of the vagina or penis;
- removal of gonads;
- hormone therapy without necessity or consent.

Such interventions are usually performed in early childhood or adolescence, without the child’s participation or understanding, which constitutes a violation of their rights to bodily autonomy, informed consent, and protection from torture or cruel treatment.

Context of use:

Intersex activists oppose “normalizing” surgeries on children without their informed consent. International human rights organizations condemn such practices as violations of human rights.

Note:

These surgeries are not necessary for survival or health. International human rights standards recognize them as violations of children’s rights, bodily autonomy, and in some cases even as forms of torture (according to UN assessments).

Gonadectomy

The surgical removal of gonads – ovaries, testes, or mixed gonadal tissue – often performed on intersex children or adolescents without their consent.

In cases where doctors consider gonads “unnecessary” or “dangerous” (e.g., due to a perceived cancer risk), gonadectomy is used as a preventive measure. However, scientific evidence shows that the risk of cancer in intersex gonads is often exaggerated, making such interventions medically unjustified in many cases.

Consequences of gonadectomy include:

- lifelong hormonal dependency (hormone replacement therapy);
- infertility;
- loss of bodily autonomy and sexual sensitivity;
- traumatic experiences due to violation of bodily integrity.

Context of use:

Gonadectomy performed on intersex children without their informed consent is a violation of human rights. Human rights organizations call for banning non-essential gonadectomies in childhood.

Note:

Gonadectomy without medical necessity and without consent is considered by many human rights institutions to be a form of forced sterilization, which violates international human rights law.

Medical Intervention Without Consent

Any medical action performed on a person's body without their free, informed, and voluntary consent.

In the case of intersex children, this includes surgeries, hormonal "treatments," or examinations carried out before the person is able to understand, agree to, or refuse them.

Examples include:

- "correction" of clitoral or penile size;
- creation or closure of a vagina;
- removal of internal sex organs (e.g., gonads);
- administration of hormones to "reinforce" the assigned sex.

Important to know:

Such interventions violate human rights, including the right to bodily integrity, autonomy, and protection from torture. Many intersex people have experienced serious psychological and physical consequences due to such "treatments." International organizations – such as the UN, Amnesty International, and the World Health Organization – call for an end to non-consensual medical interventions.

The right to consent is fundamental. A child should not lose the right to their own body simply because they were born intersex.

HUMAN RIGHTS PRINCIPLES

Informed Consent

A conscious, voluntary, and well-founded decision by a person to agree to a medical intervention after receiving complete, accurate, and accessible information.

Informed consent is not just a formality. It is a process that guarantees a person's right to know, understand, and choose: what will happen to their body, what the risks are, what alternatives exist, and what the consequences and benefits may be. It is the foundation of medical ethics.

In the case of intersex people, this right is often ignored, especially in childhood. Parents cannot fully provide consent on behalf of a child when the intervention is not life-saving but aimed at “normalizing” appearance.

True informed consent requires:

- sufficient age and capacity for conscious decision-making (e.g., adolescence or adulthood);
- access to independent opinions, not only a doctor's perspective;
- time to reflect and decide without pressure.

Context of use:

Intersex activists advocate for mandatory informed consent before any intervention. Without informed consent, surgery becomes a form of violence.

Note:

International instruments, including the UN Convention on the Rights of the Child, emphasize that consent to medical procedures should be given by the child when they are capable of understanding. Otherwise, it constitutes a violation of bodily autonomy and, in some cases, may be legally recognized as torture.

BODILY AUTONOMY

Bodily autonomy is the right of every person to control their own body and make decisions about it independently, without coercion, pressure, or interference from others, the state, or medical professionals.

What this means in practice:

No one has the right to alter, operate on, or use your body without your voluntary consent. A person has the right to say “no,” even when others believe it would be “better.” This includes:

- the right to refuse surgery or treatment;
- the right to define what feels normal for one’s own body;
- the right not to justify one’s bodily characteristics.

In relation to intersex people:

Many intersex individuals are deprived of bodily autonomy from childhood. Their bodies are altered without consent, without explanation, and without waiting until they can decide for themselves. They are raised with the idea that their bodies must be “fixed” in order to be “normal.”

This is not only a medical issue – it is a human rights violation.

What the intersex community demands:

Recognition of bodily autonomy from childhood.

Abandon all non-essential, non-consensual interventions.

Respect for bodies as they are – without “correction.”

Autonomy is not about “being allowed to be different.”

It is about the right to be oneself without needing permission.

Right to Bodily Integrity

The right to bodily integrity is a fundamental human right not to be subjected to physical interventions without voluntary consent, including medical procedures, violence, or experimentation.

What this means:

Every person's body belongs to them. No one has the right to change it, harm it, or interfere with it without clear, informed, and voluntary consent. This right:

- is guaranteed by international conventions (including the UN Convention on the Rights of the Child and the Convention Against Torture);
- has no exceptions based on age, sex, diagnosis, or family circumstances.

What happens to intersex people:

In many countries, including Ukraine, intersex children undergo surgeries or medical interventions without informed consent, often without sufficient medical justification.

This violates the right to bodily integrity, because the body is not simply being treated – it is being altered to fit societal norms.

Common features of such practices:

- lack of adequate information for parents;
- exclusion of the child from decision-making;
- absence of urgent medical necessity.

Position of the intersex community:

All people, including intersex individuals, have the right to protection from interventions without consent. Practices aimed at “normalization” are a form of systemic violence and must be stopped.

Integrity is not only a physical right. It is recognition that:

Your body is yours – not medical, not parental, not state-owned.

Medical Necessity

Medical necessity refers to situations in which, without intervention, a person's health or life is at real risk, and medical assistance is urgently or reasonably required under specific conditions.

This includes:

Treatment that genuinely saves lives or prevents serious physical deterioration.

Interventions supported by evidence, clinical justification, and chosen as the least invasive option available.

Example:

Surgery for appendicitis is medically necessary because, without it, a person may die.

What about intersex children?

Most interventions performed on intersex people are not medically necessary, but are based on aesthetic or social considerations, such as:

- clitoral reduction or reconstruction;
- creating a “typical” vagina or penis;
- hormonal interventions to “confirm” an assigned sex.

In most cases, there is no threat to life or health – the decision is based on the desire to make the body appear more typically male or female.

What the intersex community emphasizes:

- clearly distinguish between real medical necessity and social pressure or stigma;
- do not present cosmetic or gender-motivated interventions as “treatment”;
- require clear clinical protocols separating medical indications from bias.

Not every medical intervention is medically necessary – especially when it is about conformity, not survival.

SYSTEMIC FRAMEWORKS

ICD Codes (International Classification of Diseases) and Intersex Variations

The ICD is an international system used to classify diseases, conditions, and medical events. It is developed and updated by the World Health Organization (WHO) and serves as the basis for medical documentation, statistics, and patient records worldwide.

What about Ukraine?

At the time of this guide's publication, Ukraine officially uses ICD-10, which is largely outdated. Meanwhile, WHO has introduced a newer version – ICD-11 – which is gradually being implemented globally but has not yet been fully adopted in Ukraine's healthcare system. The Ministry of Health allows reference to international protocols, including ICD-11, but this is not systematic yet.

How does this relate to intersex people?

In ICD-11, a separate group of conditions has been created to describe intersex variations, including:

- androgen insensitivity syndrome (AIS);
- 5-alpha-reductase deficiency;
- ovotesticular variations;
- congenital adrenal hyperplasia (CAH), etc.

These are typically classified under “Conditions related to sexual development,” often grouped as VSD (Variations of Sex Development).

What is the problem?

1. Pathologization:

Many of these variations are still classified as “disorders,” reinforcing the idea that intersex people are “ill” or “defective.”

2. Stigmatization through language:

Medical terminology shapes social perception and creates pressure – and justification – for interventions without consent.

3. Mechanical application of protocols:

In practice, this often means: “diagnosis → intervention,” especially harmful for children who undergo surgeries or hormonal procedures without consent.

What intersex activists propose:

- shift from “Disorders of Sex Development (DSD)” to “Variations” or “Differences” (VSD);
- include notes in ICD that intersex variations do not always require medical intervention;
- explicitly state that interventions without informed consent violate human rights;
- prioritize support over “normalization.”

Note:

Although ICD-11 is not yet officially implemented in Ukraine, it reflects a global shift toward depathologizing intersex people. The intersex community in Ukraine calls for adopting these approaches even before formal healthcare reform.

SOCIAL ASPECTS AND SUPPORT

Psychosocial Support

Psychosocial support refers to assistance aimed at a person's emotional, psychological, and social well-being. It is especially important for intersex people, who often:

- grow up in environments of taboo, silence, or shame;
- lack access to truthful information about themselves;
- experience isolation, discrimination, or stigma;
- live with the consequences of non-consensual medical interventions.

This may include:

- psychological support that acknowledges intersex experiences;
- family counseling to help parents avoid fear-driven decisions and rushed interventions;
- peer support;
- access to intersex communities and allies;
- creating safe environments in schools, hospitals, and society.

In Ukraine, such support is still largely absent at the systemic level. Intersex people are often left alone with their experiences or must seek support abroad or within activist communities.

Important:

Psychosocial support is not an “alternative to treatment.”

It is a person's right to live with dignity – without shame, fear, or violence.

CISNORMATIVITY

Cisnormativity is the assumption that all people have identities, bodies, and experiences that align perfectly with the sex assigned to them at birth.

This implies:

- that everyone is either “male” or “female,” with no variation;
- that everyone should have “normal” genitals;
- that bodies must conform to gendered expectations (e.g., “female bodies” = certain breasts, “male bodies” = certain genital forms).

How this affects intersex people:

Cisnormativity excludes intersex people from definitions of “normality” and creates pressure to:

- “normalize” bodies through surgeries and hormones;
- hide variations;
- maintain silence in families and secrecy in medicine;
- accept coercive or medicalized practices in childhood.

Intersex people are often not allowed to be themselves because their bodies do not fit cisnormative expectations.

Fertility / Reproductive Capacity

Fertility is a person’s ability to have children – that is, to produce offspring using their own reproductive cells (sperm or eggs).

In a broader sense, reproductive capacity includes not only the biological ability to conceive or fertilize, but also:

- the ability to carry a pregnancy;
- access to reproductive technologies;
- the right to raise children regardless of bodily characteristics.

Intersex People and Fertility

Some intersex people have full or partial fertility, while others do not have the biological ability to have children, for example, due to:

- absence of functional gonads (ovaries or testes);
- surgical removal of organs in childhood;
- consequences of hormonal “treatment.”

Loss of fertility in intersex people is often not natural, but the result of early interventions performed without consent.

What is important:

Reproductive rights are not only about “giving birth,” but about the right to make decisions regarding one’s body and reproductive future.

Genetic Testing

Genetic testing is the analysis of tissue samples (usually blood, saliva, or mucous membrane) that makes it possible to identify the characteristics of a person’s karyotype – that is, the set of chromosomes, which may differ from the standard 46,XX or 46,XY.

Regarding intersex individuals, such testing is often:

- conducted to identify variations in sexual development or chromosomal characteristics of the body’s structure;
- used as a basis for further interventions, particularly surgical or hormonal, often without the informed consent of the individual themselves or their parents;
- are not always explained in an accessible and honest manner, especially regarding the consequences or the person’s right to know or not know the results.

Important to know:

- The results of such a test do not determine a person’s “true sex”.

- Intersex people may have non-standard chromosome combinations (e.g., 47,XXY; 45,X; mosaicism), but this does not make them “abnormal” or sick.

Good practice means respecting the rights of intersex people to privacy, to informed consent, and to refuse tests unless they are medically necessary.

STEREOTYPES AND MYTHS

Common Myths About Intersex People

Intersex people are often the subject of misinformation, fantasies, or myths. This compromises their visibility, rights, and dignity. Here are some of the most harmful myths and explanations of why they are not true:

Myth 1: “Intersex is always visible at birth.”

Fact: Many intersex variations are only discovered during adolescence or adulthood – for example, due to delayed puberty, infertility, genetic testing, or they may remain unnoticed throughout life.

Myth 2: “Intersex is rare.”

Fact: Intersex variations occur in approximately 1–2% of the population – much more common than most people think. Society often silences or replaces this reality with stigmatizing concepts.

Myth 3: “It’s just a medical problem that needs fixing.”

Fact: In most cases, intersex variations are not diseases and do not require intervention. The issue lies not in the body, but in societal expectations of what bodies “should” be.

Myth 4: “Intersex is the same as being transgender.”

Fact: Intersex relates to innate physical characteristics, not identity or transition. It is not about gender nonconformity, but about physiological diversity beyond the binary model.

5. Myth: “Intersex is the same as transgender.” »

Fact: Intersex refers to physical characteristics that are congenital, not a change or a choice. It is not a transition, not “gender nonconformity,” but a variation in physiology that goes beyond the limits of the biological binary system.

Debunking these myths is key to acceptance, respect, and real protection of intersex people's rights.

Intergender Medicalization

A process in which the bodily sex characteristics of intersex people are viewed as pathologies that require medical intervention or "correction."

Medicalization is not only about surgeries or hormones.

It is, above all, about how medicine and society frame intersex variations as a problem to be eliminated, rather than as a natural part of human diversity.

Within this process, doctors often become "arbiters" of sex, making decisions about an intersex child based on external traits or predictions about future gender identity.

This practice includes:

- forced diagnostic procedures involving invasive and excessive data collection;
- psychological pressure on parents to "choose" a sex;
- early prescription of hormone therapy or surgeries without the child's informed consent;
- creation of medical records and labels that depersonalize the individual.

Context of use:

Intersex medicalization places bodily differences within a framework of "normality" and "deviation," often leading to a loss of autonomy. Activists advocate for the demedicalization of intersex variations as a natural part of human biology.

Note:

Medicalization is often framed as "help" or "care," but in reality, it can have long-term negative consequences for mental health, self-esteem, and a person's relationship with their own body

Intersex Medicalization

A system of medical approaches and decisions in which intersex variations are perceived as pathologies requiring treatment or “correction,” often without necessity, consent, or consideration of the person’s well-being.

Intersex medicalization is a process in which:

- natural bodily variations are labeled as “disorders of sex development”;
- decisions are made by medical professionals rather than by the person concerned;
- the primary goal of interventions is not health, but conformity to norms (binary, cisnormative, heteronormative).

This practice includes:

- diagnostic labeling (e.g., DSD);
- “normalizing” surgical and hormonal interventions;
- secrecy, silence, and isolation of families;
- lack of adequate information, support, and alternatives.

Context of use:

Intersex medicalization is not a medical necessity, but a form of social pressure embedded in clinical practice. Human rights organizations call for an end to intersex medicalization without consent.

Note:

This is a critical term, used to analyze and challenge existing medical systems and approaches. It is commonly used by intersex people, human rights advocates, researchers of the body, and legal professionals.

Person with Experience of Bodily Intervention Due to Intersex Variations

A person who has undergone surgical, hormonal, or other medical interventions aimed at altering their body

to conform to binary notions of sex – typically without their own consent.

This definition encompasses the experiences of intersex people who have been subjected to interventions such as “normalizing” surgeries or other forms of medical treatment, often intended to make the body appear “more female” or “more male.”

Such interventions typically occur:

- in childhood or adolescence;
- without the person’s informed consent;
- with long-term consequences – physical, psychological, and legal.

Context of use:

This person has experience of bodily intervention in childhood due to an intersex variation. Human rights advocates call for compensation for individuals who have undergone forced medicalization of intersex bodies.

Note:

This term is not a medical diagnosis, but rather reflects a form of lived experience – often traumatic – associated with violations of bodily autonomy. Individuals may choose whether or not to use this term, depending on how they understand and identify their own experience.

Examples of such features:

- Genitalia that do not appear clearly “male” or “female” (e.g., a clitoris larger than typical, a smaller penis, fused labia, or genitalia with an “androgynous” appearance).
- Presence of characteristics of both types of sex organs simultaneously.
- Urethra not located in the “standard” position (e.g., opening not at the tip of the penis).
- Absence of, or unusual positioning of, the testes in the scrotum.

- During adolescence – atypical development of secondary sexual characteristics for the assigned sex (e.g., absence of menstruation or breast growth in a person assigned male at birth).
- Absence of, or unusual location of, the vaginal opening.
- Unexpected findings during ultrasound (e.g., detection of a uterus in a person assigned male at birth).

Important to know:

- These features are not a disease or a “defect”, but one form of natural variation in sex development.
- They are not always visible externally; some only become apparent with age or incidentally during medical examinations.
- Often, it is precisely these external features that lead to medical interventions without the person’s consent, such as surgeries, hormone therapy, examinations, or legal changes of sex.

Context of use:

“My parents learned about my variation because of ‘atypical genitalia,’ and doctors then suggested surgery. For many intersex people, external features have been the reason for early medicalization.”

Normality ≠ fitting a template

The fact that a person’s body does not match doctors’ or society’s ideas of “female” or “male” **does not mean that anything is “wrong”** with it.

Normal means: not a pathology, does not pose a threat to life, and does not require mandatory intervention.

Typical or standard is **just one of many possible forms** – what occurs most often, but is not the only correct way.

Intersex variations are part of **natural diversity**. It is not the body that must “fit” norms – norms need to **adapt to include everyone**.

What doctors say → What it may actually mean

- **“Genital development anomaly”** → A medical label that devalues bodily variation. Intersex traits are not pathological in themselves.
- **“We need to urgently ‘fix the problem’ before the child grows up.”** → Refers to cosmetic or “normalizing” interventions without the child’s consent, often with irreversible consequences for bodily and psychological integrity.
- **“You don’t want the child to be laughed at, do you?”** → A manipulative statement that transfers societal stigma onto the child to justify intervention.
- **“This is a rare case, better not tell anyone.”** → Creates shame and isolation instead of support. There are millions of intersex people worldwide, but they are just not talked about.
- **“The child won’t understand what’s wrong with them.”** → Instead of honest conversation, the child is excluded from decisions about their own body – but they will feel it anyway.

Intersex variation

This is a general term for natural variations in body development related to sex characteristics – chromosomes, hormones, genitalia, internal organs – that do **not fit typical female or male criteria**.

What this means:

People with intersex variations may:

- Have unexpected combinations of sex characteristics (e.g., a female appearance with an XY karyotype).

- Be born with “atypical” genitalia.
- Learn about their intersex variation during adolescence or even adulthood, for example, due to the **absence of menstruation, infertility**, or other reasons.

Important to know:

- Intersex variations are **not a disease**, but a form of biological diversity.
- There are **over 30 medical terms** that describe different intersex variations (e.g., CAIS, MRKH, hypospadias), but not all intersex people identify with these medical labels.
- Not all intersex people know about their variation – especially if information was hidden during childhood or “treated” without consent.
- Using the term **“intersex variation”** acknowledges **naturalness and uniqueness**, rather than labeling a body as “wrong.”

“Normalization” of the body

“Normalization” of the body refers to **medical interventions aimed at making an intersex body appear more like a typical female or male body according to doctors’ or parents’ expectations, rather than medical necessity.**

What this can involve:

- **Surgical interventions** (e.g., “clitoral reduction” or “vagina/penis reconstruction”).
- **Hormone therapy.**
- **Other actions** that do not treat a disease but only modify the body to fit **binary expectations** (“girl” / “boy”).

Such interventions are often performed **without the person's informed consent, during childhood or at an early age**, when the child cannot yet express their own views.

Consequences:

- **Physical complications** (loss of sensitivity, pain, urinary problems, infertility).
- **Psychological trauma** (feeling that your body was “wrong” and needed fixing).
- **Lost opportunity** to choose for yourself what your body will be like.

Position of the intersex community:

- Any intervention on an intersex person's body should occur **only with their free and informed consent**.
- The concept of “normalization” is **problematic and stigmatizing**, as it assumes that an intersex body is abnormal.
- An intersex body is a **natural variation of human bodies**, not an “anomaly” that needs fixing.

“Normalization” is a word that often hides surgeries that change a person's life. It should not be confused with medical treatment.

Hormone Therapy

Also: hormonal treatment / hormonal intervention

Hormone therapy refers to the use of hormones or medications that affect the body's hormonal balance. In the context of intersex people, hormone therapy is often used to “adjust” or “normalize” hormonal levels in accordance with what medical professionals consider a “female” or “male” model.

Що це означає на практиці?

- What does this mean in practice?
 - ◊ Intersex children may be prescribed hormonal medications without their consent in order to:
 - stimulate or suppress sexual development,
 - reduce the “visibility” of variation,
 - “align” the body with binary norms.

Intersex adults who received such treatment in childhood or adolescence are often required to take hormones for life – sometimes not by choice, but as a result of decisions made without their involvement.

Issues:

- 1. Lack of informed consent** is a key problem. Intersex individuals were often not given adequate explanations of the nature, risks, and consequences of hormone therapy.
- 2. Psychological and physiological consequences:**
 - depression, anxiety,
 - impaired sexual function,
 - chronic pain,
 - metabolic disorders,
 - difficulties with body acceptance.
- 3. Interference with autonomy** – especially when doctors or parents make decisions without considering the perspective of the intersex person themselves.

Position of the intersex community:

Hormone therapy should be voluntary. It should only be provided after:

- full information has been given;
- alternatives have been considered;
- informed consent has been obtained.

People have the right to refuse therapy, discontinue it, or modify their hormonal care in accordance with their own needs.

Diversity of Experience

Intersex people are very diverse. Some of them:

- have never undergone any medical intervention;
- others, however, have experienced surgical, hormonal, or other procedures carried out in childhood without their consent, and without the possibility to understand the consequences or to refuse

Such interventions were typically aimed at “normalizing” the body in line with notions of biologically binary sex, rather than addressing actual medical needs. They may have resulted in deep psychological trauma, as well as long-term physical consequences, including pain, infertility, loss of sensitivity, and hormonal imbalance, among others.

In other words, even within the intersex community, experiences can be more or less painful – depending on whether a person has undergone bodily interventions and how exactly these have affected their life.

Non-binary Sex (in the Context of Intersex Variations)

Non-binary sex is a conditional term used to describe situations in which a person’s biological sex characteristics do not clearly fit into the defined categories of “female” or “male,” and therefore fall outside the traditional binary system of sex classification.

In the context of intersex variations, this may include:

- the presence of mixed or variable sex characteristics (for example, partial development of both ovarian and testicular tissue),
- karyotypes that do not correspond to the standard 46,XX or 46,XY,
- genitalia that are considered aesthetically or functionally “ambiguous” from a medical perspective,
- hormonal profiles that do not conform to either of the binary norms

What this is not:

This is not a synonym for non-binary gender identity (as in the case of trans people).

It is not about how a person feels or identifies.

Rather, it refers to a bodily reality that medical systems and society often attempt to “fit” into binary frameworks.

Medical Errors in the Context of Intersex People

Medical errors refer to actions or omissions by healthcare professionals that result in harm to the health, rights, or dignity of intersex individuals. In the context of intersex people, these are not merely “technical mistakes,” but rather consequences of systemic misunderstanding, bias, and the deliberate or unconscious disregard for bodily autonomy.

Common forms of such errors include:

- **forced or early interventions** (surgical, hormonal) carried out without informed consent – most often in childhood;
- **pathologization of intersex bodies**, where variations in sex characteristics are treated as “abnormalities” or “defects” requiring “correction”;
- **withholding or distorting information** about a child’s or patient’s condition, including from parents or from the individual later in adulthood;
- **denial of experiences of pain, trauma, or depression** associated with intersex experiences – especially when these consequences are the direct result of medical interventions.

Regrettably, many intersex people remain unaware of their own characteristics for years because doctors deliberately withheld the truth – this, too, constitutes a form of medical violence.

Within a responsible approach, acknowledging medical errors is not a “shame for doctors,” but a step toward justice, accountability, and the restoration of trust.

What Matters to Know If You Are Not Intersex

Intersex people are not an exception, not a “medical case,” and not someone’s mistake. They simply exist—and always have. If you are not intersex, that is not a reason to be indifferent. It is a reason to become an ally.

How to offer support:

- 1. Respect bodily autonomy** – do not ask questions you would not want to be asked yourself.
- 2. Do not confuse intersex with transgender identity, LGBT, or “otherness”** – intersex variations relate to the body, not identity.
- 3. Do not romanticize or sensationalize** – avoid phrases like “that’s interesting” or “oh, how strange!”
- 4. Educate yourself and correct others** – especially when you hear jokes, stigmatizing myths, or misinformation.
- 5. Support intersex organizations** – informationally, financially, and publicly. This helps combat invisibility.
- 6. Do not stay silent when silence supports injustice** – the voice of an ally can challenge systems.

You do not have to be an expert. But you can stand alongside. You can be the one who does not turn away. You can be the one who affirms intersex people’s right to be themselves – without “but.”

INTERNATIONAL APPROACHES AND DOCUMENTS

1. UN Committee Against Torture (CAT)

Document: CAT/C/DEU/CO/5 (Germany, 2011)

Essence of the document:

The Committee reviewed Germany's fifth periodic report on the implementation of the Convention Against Torture and, for the first time, explicitly identified forced medical interventions on intersex children as "potentially a form of torture or cruel, inhuman or degrading treatment."

Key positions:

- The Committee expressed concern about surgical and hormonal interventions performed on intersex children without their informed consent.
- It called on Germany to ensure compensation for individuals who have suffered as a result of such procedures.
- It recommended imposing a moratorium on non-medically necessary interventions.

Why this matters:

This was one of the first international human rights documents to equate interventions on intersex individuals with torture. It elevated the issue beyond a "controversial medical practice" to a human rights concern – opening the way for potential legal accountability by states.

2. World Health Organization (WHO)

"Sexual Health, Human Rights and the Law" (2015)

Essence of the document:

This WHO report is an analytical study examining how healthcare systems should integrate human rights into their practice, particularly in sexual and reproductive health.

What it says about intersex people:

The WHO explicitly recognized “normalizing” surgeries performed on intersex children as a violation of human rights.

The organization expressed concern about the lack of informed consent, noting that such practices violate the rights to bodily autonomy, health, and dignity.

It recommends the provision of psychosocial support services for intersex individuals as an alternative to surgical interventions.

Why this matters:

The WHO is the leading global authority in the field of medicine. The fact that it criticizes unethical medical practices and explicitly identifies intersex children as a vulnerable group provides a strong basis for revising clinical protocols at the national level (including in Ukraine).

3. Parliamentary Assembly of the Council of Europe (PACE)

Document: Resolution 2191 (2017) – Promoting the human rights of and eliminating discrimination against intersex people.

Essence of the document:

This resolution is one of the most progressive statements in Europe from an interparliamentary institution. It consolidates the position of the Council of Europe on the rights of intersex people.

Key provisions:

- Condemns “normalizing” interventions carried out without consent, recognizing them as human rights violations.
- Calls for a ban on surgical and hormonal interventions that are not medically necessary and are performed without full consent.

- Recommends that member states:
 - ◇ ensure proper information and support for parents,
 - ◇ establish legal mechanisms to protect intersex individuals,
 - ◇ implement anti-discrimination measures in education, healthcare, and official documentation.
- Proposes considering legal sex markers to allow greater flexibility in registration systems.

Why this matters:

This is the official position of the Council of Europe, of which Ukraine is a member. While the resolution is not legally binding, it carries significant authority and should be used in advocacy. It provides a structured roadmap for reforms in medical, legal, and educational spheres.

General conclusion:

These three documents together form an emerging international consensus:

Forced interventions on intersex people are not “treatment,” but a form of violence that must be stopped.

Intersex activists, lawyers, and human rights advocates have full grounds to demand action from states, relying on these documents as:

- ethical standards (WHO),
- legal guidance (PACE),
- and even a basis for legal accountability for torture (UN CAT).

HOW TO TALK ABOUT INTERSEX

Guidelines for Journalists

Journalists play a powerful role in shaping public perception. When speaking or writing about intersex people, careful and precise language is essential.

Key guidelines:

1. Avoid sensationalism

“Shocking story,” “mysterious sex,” “born between male and female” – all such phrases are stigmatizing.

Instead, use neutral language: *“people with intersex variations,” “intersex person,” “born with variations of sex development.”*

2. Respect privacy

Do not ask questions about genital appearance, surgeries, or hormones. This can be traumatic.

Focus on lived experience, rights advocacy, and systemic challenges – not on the body.

3. Intersex is not the same as trans, LGBT, or gender identity

Do not conflate these concepts, even if it seems “simpler.”

Intersex relates to biological diversity, not transition or identity.

4. Align terminology with the individuals themselves

If you are conducting an interview, ask which terms the person prefers. Not everyone uses the same language.

5. Avoid stigmatizing terms

Avoid: *“intersexual,” “hermaphrodite,” “anomaly,” “defect.”*

Use: *intersex people, intersex variations, sex characteristics.*

Guidelines for Activists and Allies

Activism is not only about action – it is also about language. Those who are not intersex but want to be supportive should keep in mind:

1. Speak with intersex people, not for them

Intersex individuals should have space to speak for themselves. You are support – not the “main expert.”

Avoid speaking *on behalf of* others.

2. Use community-preferred terminology

Use: *intersex, intersex people, sex characteristics.*

Avoid: “*intersexuality, “intersexual,” “hermaphrodite,” “sex anomalies,” etc.*

3. Do not reduce intersex experience to tragedy

Do not focus solely on “pain, struggle, suffering.”

This is part of the experience – but not the whole of it. Intersex people are not only victims; they are whole, diverse individuals.

4. Educate, but do not patronize

Explaining basics is part of allyship. But avoid turning it into lecturing or performative “awareness.”

5. Defend correct language use

If people hesitate to use or decline the word *intersex*, set an example: *intersex people, intersex individuals, etc.*

Guidelines for the General Public

You do not need to be an expert in medicine or human rights to be respectful. Here’s how to avoid harm in everyday communication:

1. Do not ask about the body

Questions like “What are your genitals like?” or “Are you a boy or a girl?” are not neutral.

If a person wants to share, they will.

2. Avoid “normalizing” advice

Phrases like “What matters is that you’re human,” “It’s just a quirk,” or “Everyone has it hard” can invalidate experience.

Better: *“I don’t know what that’s like, but I’m here.”*

3. Do not mock or trivialize

Intersex is not a meme, a curiosity, or a “taboo topic.”

Respond as you would to discrimination against any group – with dignity and intervention.

4. Respect the choice to remain silent

Some intersex people may not want to share their experiences.

That is not an obligation – it is a right.

5. Learn independently

Do not place the burden of explanation on intersex people.

If you encounter a new term, look it up or seek resources from intersex communities.

Guidelines for Medical Professionals

Healthcare providers deal not only with bodies, but with human rights. In the context of intersex people, the medical system has often been a source of trauma. These guidelines are about both ethics and dignity:

1. Do not “treat” intersex variations without real necessity

Intersex variations are not inherently pathological.

If there is no immediate threat to life, do not rush into surgery or hormone treatment.

2. Ensure genuine informed consent

A parent’s signature under pressure is not consent.

Saying “this will be better” is not an explanation.

Explain all consequences, alternatives, and the right to refuse or delay interventions.

3. Collaborate with psychologists, human rights experts, and communities

Consult those with experience working with intersex individuals. Avoid isolated decision-making.

4. Respect the patient regardless of age

Children also have the right to be heard – adolescents even more so.

Provide age-appropriate explanations; do not conceal or obscure information.

5. Maintain transparent documentation

Do not falsify records (e.g., regarding sex or interventions). Ensure patients have access to their full medical history.

6. Preserve future choice

It is often better to do nothing than to perform irreversible procedures.

Not all decisions must be made immediately.

Common Language Mistakes: What to Avoid

Avoid → Use instead → Why

Incorrect / outdated term	Recommended alternative + explanation
intersexual / intersexuality	intersex / intersex people → The former creates misleading associations with sexuality.
hermaphrodite	intersex person → Outdated, inaccurate, and offensive term.
sex development anomaly	variation of sex development / sex characteristics → "Anomaly" implies deviation and stigmatizes.
wrong sex / undefined sex	intersex variation / not typical of binary model → Sex is not "wrong."
born without sex	has an intersex variation → Everyone has sex characteristics; "without sex" is incorrect.
sex correction	surgical or hormonal intervention → Sex is not a defect to be "fixed."

Intersexphobia

Intersexphobia refers to prejudice, fear, rejection, or hostility toward intersex people because of their natural sex characteristics, which do not fit typical notions of “male” or “female” bodies. It can manifest both at the individual level (bullying, stigmatization, mockery) and at the systemic level (non-consensual medical interventions, lack of legal recognition, exclusion from human rights policies).

Discrimination Based on Sex Characteristics – What Does It Look Like?

This is a broader concept that encompasses all forms of unacceptable treatment of people due to their variations in sex development. Key manifestations include:

- Medical discrimination: “normalizing” surgeries on intersex children without consent; imposition of hormone therapy without full information.
- Legal discrimination: lack of mechanisms for registration without forcing a sex assignment or “correction.”
- Social discrimination: exclusion from educational, sports, gender-related, or LGBTQ+ programs.
- Cultural discrimination: pathologization and portrayal as “abnormal” in media, science, and school curricula.
- Everyday discrimination: disrespect, microaggressions, breaches of confidentiality.

Intersexphobia

Because silence conceals violence, when people lack the language to name injustice, it begins to appear as a “normal reality.” It is not.

Intersexphobia is just as unacceptable as homophobia, transphobia, racism, or ableism. It leads to trauma, depression, suicide, and a loss of trust – in medicine, in one’s body, and in the world.

TERMS FROM INTERSEX ACTIVISM

Intersex Experience

Definition:

The totality of a person's personal, bodily, psychological, social, and cultural experiences as an intersex individual. It is not limited to a medical diagnosis or anatomical traits. This concept includes self-awareness, interactions with systems (medicine, education, law), social position, identity, the presence or absence of stigma, and the right to be oneself.

Comment:

In many cases, the medical system reduces intersex people to “patients with variations of sex development,” ignoring their subjective experiences, emotions, social realities, and right to self-definition. The term intersex experience restores the wholeness of the individual as a subject – not an object – of “treatment.” It also emphasizes that medical categorization is only one part of the picture, not its center.

Usage context:

Intersex experience should be recognized as a life experience, not merely a biological one. We use this term to highlight individuality and diversity – not a medical standard.

Self-Identification / The Right to Self-Definition

Definition:

The right of individuals to choose the language that describes their experience, body, and identity. When it comes to people with variations in sex characteristics, this includes the right to use the term intersex – or not use it – based on their personal perspective, experience, and sense of belonging.

Comment:

The term intersex can function as a political identity and a form of solidarity, uniting those who have experienced “normalizing” practices, medical violence, or enforced silence. However, not all individuals with diagnoses within the spectrum of variations of sex development (DSD) identify – or wish to identify – as intersex.

Some people may not have undergone bodily interventions or pressure and therefore don't share the same experiences. Others might prefer not to politicize their bodies or may feel discomfort with umbrella terminology.

For this reason, the right to self-definition includes both the right to be intersex and the right not to be.

At the same time, imposing terms like DSD (Disorders of Sex Development) without consent violates principles of dignity and autonomy.

Usage context:

I am intersex because my experience of bodily violence is political. I do not use the term “intersex,” and that is my choice – not a medical one, but a personal one.

Silencing / Enforced Silence

Definition:

A condition in which an intersex person is compelled to conceal their experience and is denied the opportunity or right to speak about their body, diagnosis, surgeries, trauma, identity, or to name themselves openly. This silence is often shaped not only by fear or shame but also by active pressure from medical institutions, family, society, and educational systems.

Comment:

Silencing is not merely the absence of speech – it is a structured, imposed prohibition that arises when a person is directly or indirectly deprived of the right to speak about their reality. For example:

- “Don’t tell anyone” (after surgery),
- “You’re not like others – it’s better not to say it out loud” (at school),
- “This is a medical secret” (told to parents),
- “Intersex people don’t exist” (at the state level).

Such silence functions as a form of social control, contributing to isolation, stigmatization, and loss of agency.

Enforced silence is not a personal choice – it is the result of systemic pressure.

Usage context:

I stayed silent because I was made to feel that my body should not exist. Silence is part of the operation. It is not written in the medical record, but it lasts for years.

TERMS FOR CONTEXTUALIZATION UKRAINE

Silent System

Definition:

A conditional term used to describe a state, institutional, or administrative system that does not recognize the existence of intersex people, does not record them in statistics, does not include them in policies or legal categories, and does not establish any official mechanisms for protection or support.

It is a system that acts as if intersex people do not exist.

Comment:

The “silent system” is not overt discrimination, but a deliberate silencing or “neutral” ignoring that has the following consequences:

- no separate records in medical statistics;
- reluctance to document violations of the rights of intersex children, adolescents, and adults;
- absence of policies, legislation, or services that acknowledge the vulnerability of this group;
- erasure of intersex experiences from educational programs, academic sources, and public discourse.

This is silencing, institutionalized as “if we don’t see it, we don’t have to respond.”

Intersex people exist, but the state “remains silent” about it and, through this, avoids responsibility.

Context of use:

A silent system is when you don't even have a column in a form to represent yourself. When statistics don't see you, no one sees you – this is the silencing of truth.

Manipulation of Diagnosis Regarding Intersex People

Definition:

This is a deliberate or systemic practice in which medical professionals:

- conceal the child's actual condition (for example, intersex variations),
- instead, assign other "convenient" or "socially acceptable" diagnoses,
- or, conversely, impose a diagnosis of "transsexualism" in cases related to updating documents after an intersex experience, rather than a transgender process.

Comment:

In children, this often occurs under the guise of "protecting from psychological trauma" (but in reality, it's due to stigma and fear of the truth). A child might be formally diagnosed with "cryptorchidism," "hypospadias," or "congenital anomaly" instead of honestly identifying an intersex variation.

In adults, this appears as administrative pressure: a person who wants to update their passport gender marker is forced to accept a diagnosis of "transsexualism," even though their experience has nothing to do with being transgender.

This is not simply a mistake. It is a form of medical violence.

The person is deprived of truth, dialogue, consent, and agency.

This practice creates a distorted picture of experience, and also causes repeated erasure of intersex identity – or worse: its denial through someone else's category.

Context of use:

I was not told I am intersex. I was told: anomaly. Everything is fine, we've already fixed it. I am not trans. But to change my passport, I was forced to accept a diagnosis of transsexuality, as if I were not who I had been all my life.

“Intersex Is Not a Problem”

Definition:

A political and ethical statement that challenges the medical and social narrative of “anomalies.”

The phrase “intersex is not a problem” means that intersex bodies, in themselves, are not a disorder, do not require correction or intervention – they are one of the natural forms of human bodily diversity.

Comment:

This statement is a form of refusal to accept the “pathologizing” framework, in which intersex children and adults are viewed as “clinical cases,” “risks,” or “medical anomalies.”

The phrase also challenges the institutional view that frames the body as the “problem,” rather than the system that treats it violently.

It is a counter-narrative that restores subjectivity, dignity, and the normalcy of an intersex person’s body – not through justification, but through self-determination.

Context of use:

Intersex is not a problem. The problem is intervention without consent. I am not a risk. I am a human being.

Coercion into Silence

Definition:

A system of overt or covert actions, words, or directives that pressure an intersex person (or their parents) not to speak about their body, medical interventions, identity,

or experience. Such coercion may originate from family, doctors, school administrators, or religious and social environments.

Comment:

Coercion into silence can take direct or indirect forms, for example:

- “Just don’t tell anyone” (from a doctor or parent),
- “It’s shameful, it’s private” (from relatives),
- “There’s no need to make it public” (from a teacher or psychologist),
- “You’re normal – don’t stand out” (from friends or a priest).

This is not just a cultural taboo; it is a means of control and separation, often reinforced by fears of losing safety, love, or acceptance.

Coercing someone into silence causes a traumatic muteness, where a person cannot even recount their experience to themselves – because “people don’t talk about it.”

Context of use:

“I didn’t stay silent – I was forced to be silent.” Coercion into silence is also a form of violence, just wrapped in a softer package.

Diagnosis as a Tool of Control

Definition:

A practice in which a medical diagnosis is used not only to describe a condition, but as a means of normalization, coercion, or justification for interventions on an intersex person without their consent, participation, or understanding.

Comment:

Through a diagnosis, doctors and institutions can:

- deprive a person of choice (“this must be operated on because the protocol says so”);
- impose a single “correct” model of the body;
- justify early interventions;
- create a sense of “urgency” for parents’ decisions.

In such cases, a diagnosis is not a helpful tool, but a power move that shuts down alternative options and creates reliance.

Context of use:

My diagnosis was used against me as an excuse to alter who I am. By calling it a “disorder,” they gained control over my body.

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**Ethical Communication: Guidelines and Terms to Know
About People with Variations of Sex Development**

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