Recommendations on human rights of intersex people for health professionals

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This eBrief is part of the INIA: Intersex - New Interdisciplinary Approaches project and specifically, part of the research project "The right to bodily integrity, autonomy and self-determination: Demands and strategies of international and regional intersex activist networks and human rights bodies." It is based on findings from a literature and legal review, the project fieldwork which consisted in semistructured interviews with intersex activists from different world regions, and a previous publication[1] (for more information: https://www.intersexnew.co.uk/).

Basic Facts

What does intersex mean?

'Intersex' is an umbrella term used to describe a number of bodily variations of sex characteristics (VSCs). Intersex people are born with sex characteristics that do not fit typical social and medical definitions of male or female bodies, including sexual anatomy, reproductive organs, hormonal, and/or chromosomal patterns.

Language in this space is very contested. Within medical circles, VSCs have many diagnostic labels but are collectively known as 'Disorders of Sex Development (DSD)' or 'differences of sex development (dsd).' In this brief, the terms 'intersex' or VSCs are preferred to be inclusive of human rights perspectives.

Is there a problem?

Throughout Europe and around the world, intersex people face a wide range of human rights violations because of the diversity of their sex characteristics, and are often subjected to stigma, misrecognition, pathologisation, violence (including medical violence), and degrading, humiliating, and inhumane treatments.

Likewise, intersex persons are exposed to different forms of discrimination that they experience through their life cycles, for example, in healthcare, education, or employment settings, among others.

One of the main concerns of intersex activists and civil society organisations continues to be surgical interventions performed during childhood (including to newborns) with the aim of 'normalising' intersex bodies to fit the socially and medically accepted male/female binaries. These surgeries are often framed as forms of medical violence, harmful treatments, torture or 'intersex genital mutilation' by intersex activists.

Are intersex 'normalising' surgeries harmful?

Intersex genital surgery is the main concern by human rights activists and has been considered as a practice that contradicts many current human rights standards.

International human rights monitoring bodies within the United Nations, have highlighted some aspects that contradict international human rights standards, for example that these surgeries and treatments:

(a) are medically unnecessary
(b) are non-urgent
(c) are carried out too early or mostly on children
(d) are intended to decide or assign sex

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[1] Zelayandía-González E. The Growing Visibility of Intersex Demands at the United Nations: A Review of the Treaty Bodies' Concluding Observations. Social Sciences. 2023;12(2):73.

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(e) are irreversible or have long-lasting consequences

(f) entail pain or suffering

(g) are carried out without the person's informed consent

Are harmful surgeries and treatments allowed in Europe?

Unconsented medical treatments that are often harmful, including surgeries, are performed upon intersex persons all over the world. Regarding the European region, according to the European Union Agency for Fundamental Rights (FRA),[2] 'normalisation' surgeries are carried out on intersex children in at least 21 member states of the European Union (EU). Among the member states of the EU and the Council of Europe (CoE), by October 2023, only six countries (Malta, Portugal, Iceland, Germany, Greece and Spain) have legislation that provides some form of protection against these types of interventions during early childhood.

Recommendations for health professionals

What can health professionals do?

Get informed. The research outcomes suggest that health practitioners often do not know about variations of sex characteristics. From nurses to GPs, health practitioners should have a basic knowledge about VSCs and not expect their patients to educate them**.**

Be aware of the pathologisation of intersex bodies. A great number of medical professionals and medical literature still has pathologising views of intersex bodies. The ICD-11 for example classifies most intersex bodily variations as '*Disorders of Sex Development (DSD).'* Many intersex persons consider that viewing their bodies as 'disordered' contributes to the idea that they are in need of a 'fix' to their bodies via medical treatments, including extensive hormonal therapy or genital surgery. Only in a small number of cases early interventions are needed for life-saving purposes. The pathologisation of intersex bodies also contributes to the secrecy and stigma that exist around being an intersex person.

Health professionals treating intersex persons *because of* their sex characteristics should look for non-pathologising sources of information. The research findings suggest that biased medical knowledge founded upon the idea of fixing or normalising bodies tend to see intersex variations as a problem, however most of these bodily variations are not harmful or life-threatening.

It is crucial that health professionals treating persons because of their intersex variations are aware of the history of pathologisation in this area and are up to date in the most ethical and human-rights sensitive forms of treatment.

Invasive and non-reversable treatments should always be discussed with the patient, and if the patient is too young to understand and therefore consent to any treatments, these conversations and treatments should be delayed**.**

Take measures to guarantee intersex persons access to healthcare services. Like everyone intersex persons have healthcare needs. Intersex persons should be able to access high-quality specialist and individualised healthcare services throughout their life. Health professionals should have training and knowledge about bodily, sex and gender diversities. Appropriate healthcare should be provided according to the specific person's needs to enjoy a healthy life.

Support access to information about being intersex and intersex persons' experiences and human rights. The invisibility of intersex people's issues and realities supports a climate of secrecy, stigma and/or ignorance. This only harms intersex persons' life experiences, as they often need to justify their realities and 'come out' to different persons when needing access to public services, for example in school, to access healthcare or at work.

Promoting a culture of basic information and education about bodily variations and diverse sex characteristics is a first step towards creating a more inclusive and accepting society and can make it easier for intersex persons to speak about their experiences when they want to do so.

Do not engage in harmful medical practices. Surgeons and other health professionals should abstain from advising or performing treatments and surgeries that may cause harm and irreversible damages to patients. Urgent treatments should be discussed and explained to parents, all other treatments that can wait should wait and be discussed directly with the intersex persons when they are mature enough to fully understand and provide consent.

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[2] EU Agency for Fundamental Rights (FRA). The Fundamental Rights Situation of Intersex People. Vienna: FRA, 2015.

Be an ally. If you are a health professional providing services to an intersex person talk to them about their experiences and needs, in a non-pathologising or non-paternalising way, if they are open to it. Aim to understand them to provide the best possible care.

Be aware that there is nothing shameful or wrong with having a diverse body with variations of sex characteristics. Secrecy and hiding should be discouraged, instead, the intersex persons' right to disclose or not information about their bodies should be affirmed.

Refer parents, families and intersex persons to peer support groups. While professional psychosocial services should be available and provided to patients and their families, the research findings suggest that people may need to talk to other persons with lived experience. Doctors are often the first point of information parents, families and patients have about intersex bodily variations. It is therefore recommended that doctors become aware of local groups and refer patients and families to those groups, these can be for example human rights groups, support groups, family groups, etc. You can also support the financial remuneration of the services provided by these groups.

You can also direct patients and families to affirming resources and literature about intersex variations. If you don't know about local organisations, several resources are available on the INIA project website (more information below).

If you are engaged in the teaching or training of other health professionals, educate yourself and promote and facilitate their education about intersex issues. If possible, talk to education and training bodies such as hospitals, residency programs, medical faculties, etc., about the importance of providing basic information to healthcare practitioners about intersex bodily variations.

Promote medical protocols that are respectful of human rights. Medicine is often and in many contexts a self-governing institution in the sense that medical protocols are often created for doctors by doctors. The research outcomes suggest however that intersex persons have many needs that go beyond medical treatment plans and that many problems and human rights violations are the result or directly linked to current pathologising medical protocols.

To promote a change in medical practice towards a more respectful one based on human rights, it is recommended that new protocols for the attention and treatment of intersex persons are designed with the direct inclusion and participation of intersex persons with lived experience and other experts such as human rights experts, bioethicists, psychosocial support experts, amongst others, to create specific guiding protocols that can address the needs of intersex persons in the specific context at hand.

The right to access medical information should be guaranteed and advocated for. Provide parents and/or guardians the full medical information pertaining their child in a comprehensible way, this includes information about treatments that are or have been conducted on their child, plans for future treatments, risks, necessity, and alternatives of such, including the possibility of deferring treatments until an older age. Likewise, provide your patients with all their medical information in a way that is comprehensible for them according to their age and maturity.

It is also important to advocate for the patients' right to have access to their medical records for the longest time possible. In the case of intersex persons, it is recommended that medical records be as detailed as possible and stored for the longest time available, giving them the opportunity to request such information in adolescence or adulthood.

Promote the active participation of patients as rights bearers in the healthcare system. This starts by not thinking of patients as passive persons with no agency within their healthcare processes. For intersex persons this is particularly important as life-changing decisions have been made for them since a very early age and many have suffered from medical paternalism and violence.

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For more information, please check https://www.intersexnew.co.uk/

*We acknowledge that there are differences of opinion amongst INIA Consortium members and more widely amongst people with VSCs.

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