Recommendations on human rights of intersex people for law and policymakers

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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 a legal review, the project fieldwork which consisted of semi-structured 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 to describe a number of bodily variations in 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 persons 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 inhuman 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 norms, 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 carried 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 performed 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 law and policymakers

What can law and policymakers do?

Listen to intersex persons. The research findings suggest that intersex persons and civil society groups have a hard time making their concerns heard when they engage with local politicians and with law and policymakers.

Meet with intersex persons. Intersex issues might be a complicated topic to understand, therefore it is recommended that law and policymakers meet and listen to intersex persons directly to understand their needs and demands. Consider also that different contexts may bring different situations that need to be addressed locally.

Believe intersex people. Even when intersex persons gain access to law and policymakers their claims are often dismissed as non-important or more value is given to medical views that often are pathologising and in conflict with intersex persons' concerns.

When working on law or policy, consider holding separate meetings for health practitioners and intersex advocates. If meetings are taken place jointly, warn intersex persons about the presence of doctors as some might find it triggering (and they might choose not to participate).

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).'* Biased medical knowledge founded upon the idea of 'fixing' or 'normalising' bodies tends to see intersex variations as a problem, however most of these bodily variations are not harmful or life-threatening, only in a small number of cases interventions on minors are needed for life-saving purposes.

Many intersex persons consider that viewing their bodies as 'disordered' contributes to the idea that they need a 'fix' leading to harmful and invasive medical treatments, including extensive hormonal therapy and/or genital surgery.

Take action. Design and implement policies and legislation to guarantee intersex persons' human rights. Intersex persons' rights are the same as everyone else's, for example the right to life, health, bodily integrity, etc. However, harmful practices on intersex bodies have been normalised, socially and medically accepted and turned into systemic and institutionalised forms of rights violations. Specific laws and policies may be necessary to counter this situation.

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.

End harmful medical practices performed upon intersex persons. Governments have a responsibility when harmful medical practices are allowed to be carried out rampantly and without regulation or safeguards, this is true in the case of intersex persons as it is for everyone else. Treatments and surgeries that are invasive, not urgent, have long-time consequences, and may inflict pain or prolonged medical interventions should only be

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

conducted with the patient's full, personal, prior and informed consent.

Law and policymakers should take action to end and prohibit harmful medical practices (e.g, surgeries, neovaginal dilations, or hormonal treatments) that are performed without the intervened person's consent if they are too young to understand and the interventions are not urgent or medically necessary to save the person's life.

In cases where there is doubt about the necessity of treatments (e.g., to improve health or bodily functions) governments should develop appropriate and transparent health protocols to determine this necessity and make sure these treatments are in line with non-pathologising ethical principles and human rights standards (in particular, autonomy, bodily integrity, and children's rights).

Governments must make sure these decisions are reviewed by independent, balanced and multidisciplinary bodies that take into consideration the human rights of the intervened person and do a fair balance between the necessity of the intervention and the risks, and possible consequences of the same.

Take measures to guarantee intersex persons' access to healthcare services. Like everyone intersex persons have healthcare needs. Law and policymakers should take steps to secure the right of intersex persons to access healthcare in conditions that respects their human rights, specially their right to informed consent throughout their life.

Likewise, governments should ensure the services of high-quality specialist and individualised healthcare for all intersex persons. Governments should invest in training and professional development for health professionals including knowledge about bodily, sex and gender diversities.

The right to medical information should be guaranteed. This includes the right of parents and/or guardians to have the full and comprehensible information about what treatments are or have been conducted on their child, plans for future treatments, risks, necessity, and alternatives of such, including the possibility of deferring treatment until an older age where the person can consent.

Persons' rights to have access to their medical records should be guaranteed. In the cases of intersex persons, it is recommended that medical records be as detailed as possible and stored for the longest time available, giving the opportunity for the person to request such information in adolescence or adulthood.

Support the renumeration of the active engagement of civil society actors. Sometimes intersex persons with lived experience provide services, like advice and counselling for intersex persons and their families. They may also be consulted in the design and development of legislation and public policies. Supporting their work financially helps keep these services available over time.

Take the necessary measures to repair the damage made. New provisions, policies and legislations can benefit intersex persons from the moment they are implemented. However, many already have suffered from surgeries or medical treatments performed in the past. Governments need to take steps to provide reparations and redress to those who already suffered because of these harmful medical practices.

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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 intersex people with VSC.

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