

## COMMENT

## Intersex/Differences of sex development: Human rights at the intersection of cure and care

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**Abstract**

Intersex people are viewed from the medicalised lens of having a “disorder” of sex development rather than a difference in sex development. This inherent indifference to diversity is also visible in LGBTQIA+ advocacy, as they were initially excluded from the Yogyakarta Principles promoting the human rights of sexual and gender minorities. This paper attempts to explore the issues of discrimination, social exclusion, and unnecessary medical treatments through the lens of the Human Rights in Patient Care framework to advance the human rights of the intersex community and highlight the need for the state to take responsibility. The discussion touches upon intersex people's right to bodily integrity; the right to freedom from torture and cruel, inhuman, and degrading treatment; the right to the highest attainable standard of health; and the right to legal and social recognition. The concept of human rights in patient care moves beyond the traditional philosophical principles of bioethics as it applies legal norms in a patient care context derived from judicial interpretations and international conventions upholding human rights at the intersection of cure and care. As socially accountable health professionals, it is our duty to defend the human rights of intersex people who are marginalised within the marginalised community.

*“As part of the surgical community who cares for intersex patients, I want to publicly apologize for our wrongdoings...the standard of care for intersex patients is inadequate. As a part of the medical community, we must*

*unify with our patients to better understand their desires and needs.” [1]*

-Dr Charles Osterberg, Chief of Urology at Dell-Seton Medical Center, Texas, USA  
(At Austin's first Intersex Awareness Day on Oct 26, 2019)

The Office of the United Nations High Commissioner for Human Rights defines intersex people as “those who are born with sex characteristics (including genitals, gonads, and chromosome patterns) that do not fit typical binary notions of male or female bodies” [2]. “Intersex” is an umbrella term used to depict a wide range of natural bodily variations. At times, intersex traits are noticeable at birth, while in others, they are not obvious until pubescence. Some chromosomal intersex varieties may not be physically noticeable at all. The medical model of disability is often applied to bodies that are non-normative. That is why such differences of sex development (DSD) or diverse sex development, or variation of sex development/characteristics are medicalised as “Disorders of Sex Development” (DSD) in the medical literature, that need to be “repaired” or “cured.” DSD is regarded as stigmatising by the Intersex community so in order to respect their voices and lived experiences, we shall be using the term intersex throughout.

**Deciding for others: When human rights matter**

The standards of bioethics, particularly non-maleficence (“do no harm”), have been pertinent to clinical care since 1979. Yet, intersex activists have been obliged to protest the surgical “correction” of intersex infants' genital differences. On October 26, 1996, a gathering of intersex activists along with transgender people assembled in Boston to dissent at the American Academy of Paediatrics' annual conference, demanding the right to bodily integrity. Their battle continues to this day, as October 26 is commemorated across the globe as Intersex Awareness Day. The statement quoted at the beginning of this paper, made by an esteemed urologist on October 26, 2019, as to how the surgical community has harmed intersex patients, was a much needed and long-awaited acknowledgment of intersex human rights.

The concept of human rights in patient care (HRPC) arose from an increasing discomfort with paternalism in medicine, along with advocacy by patients' and children's rights activists [3]. This concept broadens the scope of shared decision-making to examining systemic factors and State

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responsibility in patient care. The notion of HRPC supplements a reciprocal structure in bioethics by putting the spotlight on advocacy as a humanistic competency for health professionals [4]. Moving away from the philosophical construct of bioethics, this human rights framework proposes accountability through a set of legal norms based on the "best interests of the child" as a guiding principle derived from the UN Convention on the Rights of the Child. For instance, the conflict between the best interests of a juvenile and the existing law was the reason for the amendment of the Juvenile Justice (Care and Protection of Children) Act, 2000, in India in 2006. The said Act lacked measures for reporting abandoned children (many intersex infants are abandoned) and did not differentiate between children who needed protection and those who were in conflict with the law.

The well-being of a child, therefore, encompasses minimising both physical and psychosocial risk to the child. It is observed that "normalising" the child's anatomy is discussed more than the current problems surrounding early surgery (controversies, autonomy, fertility and long-term effects) and the child's autonomy in parent-clinician interactions [5]. Parents are often misinformed and are not given enough time or options to give fully informed permission [6]. In a country like India with a skewed sex ratio at birth and a preference for male children, especially in rural areas, it is important to consider how much autonomy should be given to parents to decide on intersex children who are incapable of making medical decisions for themselves. It is easy to prioritise parental wishes and concerns over the child's autonomy. The medical ethicist Lainie Ross describes an alternate constrained parental autonomy model which provides a robust framework

for intrafamilial decision making [7] and much-needed debate in developing countries. Best interests must guide paediatric decision-making.

### Right to bodily integrity (SOGIESC Principles)

Sexual and gender minorities often face human rights violations, but there is no United Nations (UN) convention to address them, as there are for children (Convention on the Rights of the Child) and people with disabilities (Convention on the Rights of Persons with Disabilities: CRPD). This led activists and ethicists to frame Sexual Orientation, Gender Identity, and Expression (SOGIE) human rights norms as the Yogyakarta Principles (YPs) in 2006 [8]. However, the intersex community is considered as part of the LGBTQIA+ (Lesbian, Gay, Bisexual, Transgender, Queer, Intersex, Asexual, and others) communities, it is often misunderstood as transgender or excluded from the SOGIE principles as it lacks the inclusion of sexual characteristics [9,10]. Morgan Carpenter a bioethicist and intersex activist, highlighted it succinctly when he said, "Protections for people with non-normative *identities* are presumed to benefit intersex people, but they provide no protection for people with non-normative *bodies*." [11]

In line with the disability rights movement motto "Nothing About Us, Without Us", the inclusion of intersex people led to the broadening of SOGIE into the SOGIESC principles with the inclusion of sex characteristics in 2017 as Yogyakarta Principles plus 10 (YP +10) [11]. The YP+10 also added new principles specific to the intersex community, like Principles on the Right to Bodily and Mental Integrity, the Right to Truth, and the Right to Legal Recognition [Table 1].

**Table 1: Human rights applicable to intersex individuals**

Human rights	Applicable international Conventions, Declarations, Principles
Right to life	Article 3 of the Universal Declaration of Human Rights (UDHR), Article 6 of the Convention on the Rights of the Child (CRC)
Right to bodily and mental integrity	Principle 32 of Yogyakarta Principles Plus 10 (YP+10)
Prohibition of torture and inhuman or degrading treatment	Article 5 of the UDHR, UN Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment 1984
Right to privacy	Article 12 of the UDHR, Article 16 of the CRC, Principle 6 of Yogyakarta Principles
Right to health	Article 25 of the UDHR, Articles 17, 23 and 24 of the CRC, Article 25 of the Convention on the Rights of Persons with Disabilities, Section 15, Transgender Persons (Protection of Rights) Act, 2019
Rights of the child	Articles 3, 7, 8, 12 and 13 of the CRC
Right to non-discrimination and equality	Section 3 of Transgender Persons (Protection of Rights) Act, 2019, Principle 2 of Yogyakarta Principles
Right to legal recognition	Sec 4 Transgender Persons (Protection of Rights) Act, 2019
Right to truth	Principle 37 of YP+10
Right to Promote Human Rights	Principle 27 of Yogyakarta Principles
Right to the Highest Attainable Standard of Health	Principle 17 of Yogyakarta Principles

Following this, after years of struggle by the intersex community, the Ann and Robert H Lurie Children's Hospital in Chicago became the first institution in the United States to apologise for conducting cosmetic genital surgery on intersex babies, acknowledging that their approach was "harmful and incorrect" and that the "medical profession had failed" those children [12]. Boston Children's Hospital, following their lead, said, "We will not conduct clitoroplasty or vaginoplasty in patients who are too young to engage in a serious discussion of the effects of these procedures unless anatomical differences endanger the child's physical health." [13]

In 2015, Malta became the first country in the world to pass legislation prohibiting nonconsensual medically unnecessary surgery on intersex children. In 2012, the Hon'ble Supreme Court of India, in the *National Legal Services Authority (NALSA)* judgment categorically stated that no one should be required to undergo medical procedures, such as sex reassignment surgeries (SRS), sterilisation, or hormone treatment, as a condition for legal gender recognition [14]. In a historic judgment of the Hon'ble Madurai Bench of the Madras High Court in 2019, on the plea of intersex activist Gopi Shankar Madurai, the Tamil Nadu Government became the first Indian State to ban SRS on intersex children except in life-threatening circumstances [15].

The United Nations Committee on the Rights of Persons with Disabilities in 2019, in its concluding observation while reviewing India's country report on the implementation of CRPD, expressed concerns over information about "mercy killings" of intersex children with disabilities and strongly recommended the government of India to safeguard the rights of intersex people:

*"The Committee recommends that the State party protect intersex children from attacks against their lives and any related harmful practices (Article 22), and ...adopt measures to prevent sex-assignment or "sex-normalizing" surgeries, bullying and stigmatization against intersex children, ensuring their rights to preserve their physical and mental integrity [Article 36(c)]."* [16]

Two of the authors of this paper (SS and AS) are medical professionals belonging to the disability and transgender communities and have had the lived experience of "medicalization". Our collective interest in the field of health humanities in general, and disability studies in particular, has enabled us to view medicalisation as a process that transforms non-normative bodies into medical problems requiring fixation. This prompted the two of us (SS and AS) to write to the Delhi government citing the Madurai Court judgment and the concluding observation of the CRPD to ban unnecessary surgeries on intersex children except in medical emergencies [17]. We later petitioned the Delhi Commission for Protection of Child Rights (DCPCR) [18] and the Delhi Medical Council, the statutory body regulating medical practitioners in Delhi, responded to the Commission in the hearing stating:

*The Delhi Medical Council agrees with the complainants*

*that Differences of Sex Developments/Intersex (DSD) issues are [a] human rights issue as it pertains to bodily integrity and autonomy. Surgical interventions and gender-related medical interventions for DSD that are not deemed medically necessary should be delayed until the patient can provide meaningful informed consent/assent to these interventions.* [19]

This is a major statement coming from a regulatory authority in India, as none of the medical associations or health professionals in India had shown such support till this point. In contrast, GLMA: Health Professionals Advancing LGBTQ Equality (previously known as the Gay & Lesbian Medical Association), the American Academy of Family Physicians, Physicians for Human Rights, two paediatric professional bodies (North American Society for Pediatric and Adolescent Gynecology, and Pediatric Endocrine Society), along with Human Rights Watch, the World Health Organization, UN experts, and intersex-led organisations worldwide (InterACT, AIS-DSD Support Group, Srishti Madurai, Intersex Human Rights India, and Intersex Children's Foundation of India) have a clear stand against unnecessary intersex surgeries [13].

The DCPCR in its final order recommended that the Government of Delhi declare a ban on medically unnecessary, sex-selective surgeries on intersex infants and children except to overcome life-threatening circumstances [19]. Further, on our previous plea, the Directorate of Health Services instructed the Dean, Maulana Azad Medical College, Delhi to constitute a committee of experts to examine the matter regarding the plea to ban sex reassignment surgeries on intersex children (except to overcome life-threatening situations). While the committee seems to have had good intentions, it makes a mockery of rights-based understanding and normality of intersex persons. The lack of understanding can be gauged from the first recommendation by the committee, which is to replace the widely recognised and respectful word "intersex" with the one that is pathologised — Disorders of Sexual Differentiation [20]. It further conflates sex and gender by referring to chromosomal gender and genetic gender. It also recommends that risky and often irreversible surgeries may be planned on intersex children before the age of consent for non-life-threatening conditions to help the child fit into the binary norms of society. These recommendations are classic examples of the juxtaposition of a total lack of understanding about healthcare and ingrained social dogma, and totally fail to live up to the spirit of "Do no harm" and "In the best interest of the child". The advocacy on bodily integrity has now reached the Delhi High Court in the case *Srishti Madurai Educational Trust vs Government of NCT of Delhi & Ors* appealing for an order directing the Delhi government to implement recommendations issued by the DCPCR. The Court has now granted the Delhi government eight weeks to make an appropriate decision on the said recommendations made by DCPCR [21].

## Right to freedom from torture and cruel, inhuman, and degrading treatment

In the current International Classification of Diseases (ICD-11), at least 40 different variations of intersex have been identified, which are described using terms like "malformations," and "defects," and categorised together under the fractious clinical term "disorders of sex development." ICD-11 codes, in some cases, explicitly necessitate genitoplasties or gonadectomies, as well as gender assignment, "in which either masculinizing or feminising surgery is indicated based on technical and heteronormative expectations for surgical outcomes". [22] Gender stereotypes underpin such initiatives. These interventions, according to intersex organisations, are harmful practices and abuses of the right to bodily integrity, as well as to freedom from torture, ill-treatment, and experimentation. Certain historical cultural traditions in the global South, like Sati and female genital mutilation, some of which are banned now, were socially accepted assaults on bodily integrity and amounted to torture. We argue that medically unnecessary and forced sex reassignment surgeries are current socially accepted assaults on bodily integrity and should also be banned.

Surgical interventions might be either necessary (urgent) or optional (elective). There are no objections to urgent surgeries for medical emergencies. However, controversy remains for elective surgical intervention. Intersex surgery involves procedures directed at the gonads, internal reproductive anatomy, or external genitalia [23]. Critics of early elective surgery say such operations do not address parental fear, guilt, and concealment about the child's sex anatomy. Activists and providers know parents may feel ostracised and want to "normalise" their child's external appearance before learning all the alternatives and balancing risks and advantages. Patient autonomy has also brought out legal and ethical issues.

The majority of varied sex characteristics are not unhealthy, but rather healthy physiological variations of the human body. The Special Rapporteur on Torture underscored the torture and ill-treatment protection framework in health-care settings when they mentioned: "Fixing" sex can result in permanent, lifelong harm, producing sterility, genital insensitivity, impaired sexual function, chronic pain, bleeding, and infections, post-surgical depression, trauma, massive internal and external scarring, and metabolic imbalances [24]. The definition of torture in the Convention against Torture includes at least four basic elements: a physical or mental act inflicting significant pain or suffering; the element of intent; the specified goal; and the involvement of a State authority. Many intersex individuals call such surgical interventions on their bodies "torture in medical healthcare settings" [25]. Genital normalisation operations marketed as "reparative therapies" are rarely medically required. Torture prohibition is a *jus cogens*, an inviolable law. Analysing abuses in healthcare contexts via a torture protection lens exposes these violations

and highlights the affirmative responsibility of States to prohibit, punish, and rectify them. However, India is one of only five countries that has yet to ratify the 1987 Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment [26]. In addition, genetic de-selection and selective abortion are increasingly preventing the births of intersex babies [25]. Hence, there is an urgent need to address intersex genital mutilation and the abandonment of intersex children as a grave violation of inalienable human rights and adequately sanction such practices.

## Right to the highest attainable standard of health

The highest attainable standard of health is a fundamental right of every human being, as per the WHO constitution [27]. As with other rights, the right to health encompasses both freedoms (sexual and reproductive rights; freedom from torture and non-consensual medical experimentation) and entitlements (the right to a healthcare system on an equal basis with others). Recently, the US Food and Drug Administration has warned that non-urgent procedures involving general anaesthesia should not be conducted on children under the age of three because this may impact their brain growth [28]. Preliminary research suggests that intersex people who were previously thought to be infertile may actually have a biological viable capacity [29]. However, fertility preservation (FP) in the intersex field is still in its infancy. Patients suffer physical and emotional failure as well as loss of identity as a result of prophylactic gonadectomy. Furthermore, the probability of germ cell cancer (GCC) can now be stratified [30] based on a particular diagnosis (intersex conditions with different phenotypes-partial or complete- androgen insensitivity syndrome) which makes FP a source of "frozen hope" that can improve the quality of life, as well as mental wellbeing [31]. However, it is too costly and no insurance company in India is covering it currently despite section 15(g) of the Transgender Persons (Protection of Rights) Act (TPA), 2019, mandating provision for coverage [32]. Regardless of positive and negative health impacts, and the debate on future fertility versus GCC risk, people with intersex variations have the right to the highest attainable standard of health [33].

We call for the development of multidisciplinary intersex management teams in India, which must embrace support groups, individuals with lived experience, and medical ethicists. Intersex people and their families need interdisciplinary care, including peer support. The professional associations from the specialities of endocrinology, urology, gynaecology, andrology, psychology, genetics, and medical ethics should come up with consensus statements on the best practices from within and outside the country. Merely writing an editorial once in a while will not help this vulnerable population, as none of the professional associations have written any consensus statements so far.

## Right to legal recognition

It may be noted that there is no national-level legislation specifically identifying and acknowledging intersex persons and their human, socio-economic and legal rights. However, under Section 2(k) of the TPA 2019, persons with intersex variations have been wrongly clubbed in the definition of transgender persons [32]. This does not take into consideration that intersex persons are not necessarily transgender and that their issues and needs are different. As a result, a one-size-fits-all solution would fail. Gender nonconformity in early childhood is often linked to intersex conditions but may not lead to gender incongruence. Parents of intersex children often face problems in rural areas while enrolling in schools. In many places, there is only one option of "third gender" and using that puts the child at risk of being bullied. As a co-author of this paper, KC shares her personal reflection:

*In my personal experience of parenting an intersex child in Bangalore, the discrimination has been no less nor less cruel, despite the higher education levels and socio-economic strata that defines the urban areas. I have come across highly qualified paediatric surgeons advocating sex reconstruction surgeries on my five-year-old child through emotional blackmail of potential gonadal cancer. There have been endocrinologists who have recommended that I raise my child as a girl in order to avoid social awkwardness due to their external sex characteristics. When considering schools for enrolling my child, a principal of a renowned school told me that they have a toilet for the handicapped that my child can use. It is important to note here that the Delhi Government has already issued a circular to create separate toilets for transgender people or till they are built, to use existing toilets meant for people with disabilities. As both transgender and disabled people share a similar history of oppression, neither of these parties have objected to this provision as on date.*

*Some of the systemic issues that we faced as a parent-child team were a) not having intersex recognised as a legal option for sex selection in the birth certificate. If I were to pinpoint exactly at what point the discrimination started, I would have to say, "at birth," where without legal recognition of intersex variations and adequate education of medical and healthcare professionals on this subject, gender is assigned at birth as one of the two binaries – male / female. In my child's case, they were assigned male at birth, but she chose to identify as a girl at 4.5 years old. Intense familial pressure to conform to one of the binary genders to fit into the current social construct was seen. I was not able to find trained psychologists / counselors with understanding about intersex variations who could support me psychologically. Can we then really blame parents for either abandoning their children or unilaterally deciding to put their children through sex reconstruction surgeries and /*

*or hormone replacement therapies? My child was also abandoned at birth and I adopted her when she was 3.5 years old. It is not fair to expect every parent to stand up and proclaim that their children's health and happiness is more important to them than social acceptance, not unless we as a nation and the State as its principal authority can back them up with appropriate legal and medical infrastructure and support. The intersex community promotes non-binary and different sex identities that are optional and opt-in. They should have the same legal rights as cisgender, transgender, or gender non-conforming people. There is a need to rectify the definition anomaly in the Indian legislation but not at the expense of removal of Intersex people from the provisions of TPA 2019.*

## Conclusion

The more vocal rainbow community has advanced the rights of sexual and gender minorities. However, intersex human rights get lost under the overall umbrella of LGBTQIA+. The concept of human rights in patient care moves beyond the traditional philosophical principles of bioethics as it applies legal norms in patient care contexts derived from judicial interpretations and international conventions. We look forward to an inclusive India where intersex children are guaranteed their legal and social rights through ratified laws; where all health professionals are trained to support intersex children and their parents, respecting dignity and bodily integrity; and where hospitals have intersex-affirming policies. This paper is our endeavour and contribution towards the building of that India. We hope the readers take note of the struggles of intersex children and adults and their families, enough to take action towards ensuring protection of their human rights. As socially accountable health professionals, it is our duty to defend the human rights of intersex people who are marginalised within the marginalised community.

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