

The human rights of intersex people: addressing harmful practices and rhetoric of change

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Abstract: *Intersex people and bodies have been considered incapable of integration into society. Medical interventions on often healthy bodies remain the norm, addressing perceived familial and cultural demands, despite concerns about necessity, outcomes, conduct and consent. A global and decentralised intersex movement pursues simple core goals: the rights to bodily autonomy and self-determination, and an end to stigmatisation. The international human rights system is responding with an array of new policy statements from human rights institutions and a handful of national governments recognising the rights of intersex people. However, major challenges remain to implement those statements. Human rights violations of intersex individuals persist, deeply embedded in a deliberate history of silencing. Rhetoric of change to clinical practices remain unsubstantiated. Policy disjunctions arise in a framing of intersex issues as matters of sexual orientation and gender identity, rather than innate sex characteristics; this has led to a rhetoric of inclusion that is not matched by the reality. This paper provides an overview of harmful practices on intersex bodies, human rights developments, and rhetorics of change and inclusion. © 2016 Reproductive Health Matters. Published by Elsevier BV. All rights reserved.*

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Introduction

Intersex people are born with sex characteristics that do not meet medical and social norms for female or male bodies.¹ People with intersex variations are heterogeneous, with varied bodies, sexes, and sexual and gender identities. Intersex traits comprise “at least 40 different entities of which most are genetically determined”.² Disclosed by a doctor to a parent or an individual, an “exact diagnosis is lacking in 10 to 80% of the cases”,² including the author’s own medical papers which include the terms hypogonadism, gynaecomastia and indeterminate sex.

Between 0.5 and 1.7% of people may have intersex traits.¹ Numbers are vague, not only due to diagnostic challenges and the growing impact of genetic selection,³ but also stigma. The consequences of being born with intersex characteristics are profound. Historicised as hermaphrodites, gods and monsters,⁴ visibly intersex people have been subjects of infanticide and freak shows.^{5,6} Dan Ghattas remarks that, everywhere in the world, people with intersex bodies have been deemed incapable of integration into society.⁷

In a repeated historical pattern,⁸ terms have changed over the last century as clinical decision-makers have determined pre-existing language to be imprecise or pejorative: that affected persons are not hermaphrodites, not pseudo-hermaphrodites, not intersex, but disordered children whose bodies need finishing⁹ or disambiguating.¹⁰

Human rights violations take various forms. In places without accessible medical systems, abandonment, infanticide, mutilation, and stigmatisation of children and their mothers may occur if an intersex trait is obvious.¹¹ Recent cases include mutilation and murder of an adolescent in Kenya,¹² and abandonment of an infant in Shandong, China.¹³ In places with accessible medical systems, human rights violations take place in medical settings, intended to make intersex bodies conform to narrow social norms for females or males.⁷ Lack of necessity, autonomy and valid consent mean that such “normalising” interventions violate “rights to health and physical integrity, to be free from torture and ill-treatment, and to equality and non-discrimination”.^{1,14}

Medicalisation

Intersex bodies became medicalised from the end of the 19th century, alongside the medicalisation of women's bodies and of homosexuality. From the 1950s, a new belief in the malleability of infants' gender identities brought an "optimal gender model" into being: intersex children identified at or close to birth could be "normalised" by aligning their bodies, gender roles and sex of rearing. Surgical limitations meant that most affected intersex infants were assigned female. "Successful" cases were heterosexuals, who identified with their assigned gender.¹⁵

Sex assignment of infants diagnosed at birth is now typically based on visual inspection, genetic and hormonal testing. While there are some common rules, based on chromosomes and sensitivity and exposure to androgens,¹⁶ social attitudes favouring male children can influence assignments in some regions.¹⁷

Sex "normalising" interventions, to reinforce a sex assignment, include feminising and masculinising surgical and hormonal interventions, and gonadectomies, often during infancy, childhood and adolescence,¹⁸ before the recipient can consent and without firm evidence of necessity or good surgical outcomes. However, initial sex assignment need not be reinforced, permanent, or irreversible.

In some cases, other interventions may be necessary for physical health, notably for endocrine issues in congenital adrenal hyperplasia.¹⁹ Surgical interventions may sometimes be necessary to tackle elevated gonadal cancer risks or urinary issues.^{16,36} These surgical interventions should not be contentious, but firm supporting data are lacking. Moreover, clinical decisions on these interventions entwine therapeutic with "normalising" non-therapeutic rationales.³²

Feminising interventions include clitoral surgeries (such as "clitoridectomies"), construction of a vagina, and related genital surgeries, for example, in infants and children with larger clitorises or ambiguous genitalia. Masculinising interventions include surgeries for "hypospadias", diagnosed in boys when the urethra opens between the glans of the phallus and the perineum.

Clitoral cutting is considered female genital mutilation, an abhorrent and harmful practice,²⁰ and a form of gender-based violence prohibited in many countries, yet exemptions may apply to intersex girls.^{20,21} Adults are also vulnerable: a medical journal reported in 2013 that four elite women athletes from low- and middle-income countries were

discovered to have intersex traits during routine testosterone testing. They were subjected to "partial clitoridectomies" and sterilisation under duress, to enable their return to competition.²²

Vaginal construction necessitates regular post-surgical dilation by the insertion of an instrument; this may in some cases be experienced as rape.⁸ Follow-up examinations may include sensitivity testing on minors,¹⁷ such as with a cotton bud or vibrator.

Surgeries for hypospadias are typically undertaken in infancy, despite evidence that outcomes are not determinable until adulthood.²³ Construction and maintenance of a urinary tube may involve multiple surgeries with significant impact on sensitivity, high complication rates and particularly poor long-term outcomes, and even genital "resurfacing".^{8,23} Evidence of the necessity of early intervention is lacking.²⁴

Risks of gonadal cancer have been overstated or poorly evidenced, resulting in sterilisations.³² During a 2013 Australian Senate inquiry into the involuntary or coerced sterilisation of intersex people, it was revealed that routine sterilisations of women with complete androgen insensitivity syndrome no longer take place because of overstated risks. There has been no attempt at reparations for individuals who consequently need a lifetime of hormone replacement.

Solid data on the prevalence of "normalising" interventions are scarce but, despite media reports stating the contrary,^{25,26} interventions remain routine and central to the management of intersex traits.²⁷ For example, although FGM is prohibited in the UK, Creighton et al note an increasing number of clitoral surgeries on under-14s in the UK; "it is not clear if this is secondary to an increase in the detection or incidence" of intersex traits.²⁸ According to a 2015 neonatal handbook by the government of Victoria, Australia, an intersex birth event remains "distressing" for all in the delivery room; "[c]orrective surgery is usually undertaken within the first year of life",¹⁸ despite contrary earlier ethical guidance by the same government.²⁹

Rationales and outcomes of medical intervention

Current medical protocols on the paediatric management of intersex traits were set out in the Chicago "consensus" statement in 2006.¹⁶ It framed intersex as "disorders of sex development", recommending interventions to "minimise family

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