The OHCHR background note on human rights violations against intersex people

Morgan Carpenter ©

Co-executive director, Intersex Human Rights Australia, Sydney, Australia; Master of Bioethics, Sydney Health Ethics, Faculty of Medicine and Health, The University of Sydney, Sydney, Australia. Correspondence: morgan@morgancarpenter.com

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Introduction

The Office of the High Commissioner for Human Rights (OHCHR) has published a background note on ending human rights violations against intersex people.¹ The report provides a detailed analysis of human rights violations affecting intersex people and the way forward in addressing them, with a focus on: forced and coercive medical interventions; violence and infanticide; discrimination in healthcare, education, sport and other settings; legal recognition, and access to justice. It situates intersex people in relation to sexual and reproductive health and rights, gender stereotypes, female genital mutilation (FGM), and the rights of children, LGBT, and disabled people. In doing so, the report brings together and expands on a range of actions by UN bodies over the last decade. These actions include statements by UN Special Rapporteurs, Treaty Body recommendations to countries in all regions, publication of a website and fact sheet by the OHCHR, and an expert meeting. The note provides a report of this expert meeting on ending human rights violations against intersex persons, held in Geneva in 2015. The meeting gathered representatives of UN agencies and Treaty Bodies, human rights experts, and experts from civil society, clinical and biomedical ethics institutions and academia. The following paragraphs summarise some of the key messages, including in sections on understanding intersex, specific human rights violations affecting intersex people, and conclusions and a way forward.

Understanding intersex

Intersex people have any of a diverse range of innate physical variations in sex characteristics that differ from medical and social norms for female or male bodies. These traits mean that intersex people risk or experience stigmatisation, discrimination and violence, including in medical, education and other settings. In many legal systems, intersex people were historically acknowledged using terms like hermaphrodite or barren women, with related jurisprudence governing marriage and inheritance. In modern times, the word hermaphrodite has narrowed in meaning, and given way to the umbrella terms intersex and, controversially, “disorders of sex development” or the ameliorative “differences of sex development”. Intersex bodies have become medicalised and atomised, with individual underlying variations each becoming associated with specific diagnostic terms.

The report makes the opposite point that personal preferences for nomenclature should be respected, while it also challenges misconceptions that intersex people have a single particular kind of body or a single particular kind of identity. Indeed, intersex populations include infants and children who lack agency to freely express any kind of identity. This problematises associations with LGBT populations based on perceptions of sexual orientation or gender identity, rather than experiences of stigma due to dominant sex and gender norms. Medicalisation and the disordering of intersex characteristics is intended to deconstruct or “fix” “abnormal” bodies and promote development of individuals with heterosexual, cisgender identities – this experience of medicalisation highlights common ground between intersex people and both LGBT people and people with disabilities.

The background paper identifies commonalities and distinctions between these populations and rights issues, but also with children’s rights, sexual
and reproductive health and rights, and the elimination of discrimination based on sex and gender. In doing so, it may benefit institutions working on these issues, and support specific attention to the relevant but distinct characteristics and needs of intersex populations.

**Forced and coercive medical interventions**

Forced and coercive medical interventions affecting intersex people include practices performed without their prior, personal informed consent that have been variously described as “gender assignment” or “reassignment”, “normalization” surgeries, genital “enhancement”, clitoral recessions, vaginoplasties, phalloplasties and hypospadias repairs, gonadectomies and associated genital examinations, genital sensitivity testing and medical photography. These can be distinguished from urgent medical interventions that may be necessary for physical health or with personal, free, and prior informed consent; the report notes that inappropriate “loose conceptions of medical necessity or therapeutic treatment may facilitate social and cultural rationales” for treatment. Such practices violate rights to security, bodily and mental integrity, health, sexual and reproductive rights, privacy, legal capacity and non-discrimination. They violate rights to freedom from torture, ill-treatment and violence.

The report identifies a range of rationales for such practices, including social and cultural rationales such as risks of stigmatisation, parental distress, gender identity “confusion”, marriageability, as well as weak health risks or benefits, claims about surgical timing, and financial rationales. Social and cultural rationales are compared with rationales for FGM: these practices may reflect “normative ideas about women’s bodies” and eligibility for marriage; and parents and persons subjected to such practices may promote conformity. Legislation prohibiting FGM may sometimes contain exemptions permitting such practices on children with intersex variations. Parents may receive limited or partial disclosure of risks, lack access to non-surgical pathways, lack affirmative portrayals of intersex bodily diversity, and lack access to independent peer support.

Over a twenty-five year period, claims of change to clinical practices have been made in response to the demands of a growing intersex movement. There remains no clear evidence of change to clinical practices, and such interventions have lifelong consequences that remain poorly understood. Generally, clinical practices lack transparency and accountability, and attempts at self-regulation have failed. Human rights defenders, led by intersex human rights organisations, have called “for prohibition of unnecessary or deferrable medical interventions”, effective independent oversight, and the development of rights-affirming standards of care. Malta and Portugal have implemented legislation intended to end these practices; while these are important developments, their implementation is mixed or lacks evidence. Reflecting statements by Special Rapporteurs and Treaty Bodies, the Office of the High Commissioner for Human Rights supports such efforts, calling for recognition of the rights of intersex children “to bodily integrity, autonomy and self-determination”, ensuring “that no-one is subjected to harmful practices or unnecessary medical treatment during infancy or childhood”. The Committee on the Rights of the Child and the Committee on the Elimination of Discrimination Against Women have called on states to abolish “harmful practices”, tackle impunity and provide redress. Research, too, should meet human rights standards. Clinical research should not justify human rights violations. The report calls for the development of rights-based lifetime medical protocols, access to independent support, and oversight.

**Violence and infanticide**

Children, adolescents and adults are at risk of violence due to their physical characteristics. Infants are at risk of infanticide in some regions, particularly resource-poor and low-income regions. Infanticide appears linked to obvious physical difference, and beliefs in curses or witchcraft experienced also by parents of children with disabilities. Reports in high-income countries also show an association between intersex variations that are evident to strangers and experiences of discrimination.

**Discrimination and stigmatisation**

Discrimination in healthcare impacts on intersex persons’ right to health, including through bias, lack of training and awareness, lack of research on long-term health outcomes in adolescents and adults, and lack of human rights-affirming standards of care. Many intersex persons may lack
information to help them manage their health. An undue focus on sex or gender may overshadow specific health needs, including psychosocial and fertility-related needs. Stigmatisation, bullying, developmental delays and medical interventions during puberty may contribute to limited access to education and, in an East African study, access to sanitation. Women athletes with variations of sex characteristics face potential disqualification and humiliation due to their innate characteristics. Intersex people face particular challenges in humanitarian protection and places of detention.

Significantly, the report supports calls to disaggregate data on sexual and gender minorities and promote specific actions to support intersex people and their families. Anti-discrimination laws typically fail to prohibit discrimination against intersex persons, including through measures and programmes on grounds of sexual orientation or gender identity. Measures to prohibit discrimination on grounds of “sex characteristics” reflect an emergent norm. Reasonable accommodations are beneficial for some individuals.

**Legal recognition**

In relation to legal gender recognition, the background paper identifies no obligation in the Conventions on the Rights of the Child or Persons with Disabilities, nor the International Covenant on Civil and Political Rights, for registration of sex or gender; this is a position that underpins a recommendation in the Yogyakarta Principles plus 10. Nevertheless, singling out intersex people for special registration rules can be expected to be discriminatory with adverse consequences.

Systemic barriers take multiple forms. In some countries, parents and individuals have found it difficult to obtain birth registration and, in some cases, birth registration has been made contingent on parental consent to medical intervention. In other contexts, those intersex individuals who seek to change sex marker have been rejected or subjected to punitive requirements.

While some intersex and non-intersex people have sought legal recognition for a third or non-binary sex category, it is crucial to note that others feel forced into association with such categories—particularly when such categories are named or framed around the needs of intersex people. The report recommends that attempts to reform sex classifications should take account of the diversity of both intersex and non-intersex populations, and ensure no adverse impact on intersex women and men. Naming new categories “intersex” forces this association and has adverse impacts. Naming new categories “non-binary” does not have this impact.

**Access to justice and remedies**

Access to justice and remedies have been limited, including due to stigma, unnecessary statutes of limitations, appeals to non-existent clinical consensus regarding specific medical practices, and the effects of limited clinical disclosure to individuals on their capacities to obtain justice. Courts in Colombia, Chile, Germany and India have sometimes recognised some rights of people with intersex variations and provided redress, while courts in Australia have not. Inquiries in multiple countries have lacked implementation. Alleged perpetrators of human rights violations have not faced prosecution. Misconceptions, stigma and lack of awareness limit access to affirmative information and peers. Nevertheless, an inadequately resourced global intersex movement has made important strides in documenting human rights violations, and in providing education and support.

The OHCHR calls for investigation of human rights violations and actions to hold perpetrators to account, together with statements of apology, and redress and compensation. It also calls for action to address root causes of human rights violations, including taboos, harmful social and cultural norms and stereotypes.

**Conclusions**

The report draws upon a diverse array of reports, case studies and examples, providing a global analysis. It describes some distinct regional differences, perhaps relating to the accessibility of surgery in resource-poor and low-income settings, but the overall situation reflects an impunity and lack of action to protect the rights of a marginalised and often misunderstood population. The paper is an essential tool for human rights practitioners, policy-makers, advocates, physicians and academics, including those working on sexual and reproductive health, disability, child rights, women’s rights, and the rights of sexual and gender minorities.
Disclosure statement

Morgan Carpenter has been contracted as a consultant to the Office of the High Commissioner for Human Rights, and participated in a 2015 United Nations expert meeting on ending human rights violations against intersex people.

ORCID

Morgan Carpenter http://orcid.org/0000-0001-6166-7018

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