

Reproductive Health Matters



An international journal on sexual and reproductive health and rights

ISSN: 0968-8080 (Print) 1460-9576 (Online) Journal homepage: http://tandfonline.com/loi/zrhm20

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

Morgan Carpenter

To cite this article: Morgan Carpenter (2016) The human rights of intersex people: addressing harmful practices and rhetoric of change, Reproductive Health Matters, 24:47, 74-84, DOI: <u>10.1016/j.rhm.2016.06.003</u>

To link to this article: https://doi.org/10.1016/j.rhm.2016.06.003

9	© 2016 Elsevier Inc.
	Published online: 12 Jul 2016.
	Submit your article to this journal 🗷
ılıl	Article views: 2912
CrossMark	View Crossmark data 🗗
4	Citing articles: 2 View citing articles 🗹



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

Morgan Carpenter

Founder, Intersex Day Project; Co-chair, Organisation Intersex International Australia Limited

Correspondence: morgan@morgancarpenter.com

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.

Keywords: intersex, human rights, harmful practices, hermeneutical injustice, disorders of sex development

Introduction

Intersex people are born with sex characteristics that do not meet medical and social norms for female or male bodies. 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". Disclosed by a doctor to a parent or an individual, an "exact diagnosis is lacking in 10 to 80% of the cases", 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. Numbers are vague, not only due to diagnostic challenges and the growing impact of genetic selection, but also stigma. The consequences of being born with intersex characteristics are profound. Historicised as hermaphrodites, gods and monsters, visibly intersex people have been subjects of infanticide and freak shows. Dan Ghattas remarks that, everywhere in the world, people with intersex bodies have been deemed incapable of integration into society.

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. 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 illtreatment, and to equality and 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. Surgical interventions may sometimes be necessary to tackle elevated gonadal cancer risks or urinary issues. hese 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.

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 postsurgical 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. It framed intersex as "disorders of sex development", recommending interventions to "minimise family

concern and distress", facilitate parental bonding and "mitigate the risks of stigmatisation". ¹⁶ The statement recommended caution on surgical treatment, but nevertheless facilitates such interventions. A 2016 follow-up statement does the same. ³⁰ The authoritativeness and "consensus" in the Chicago statement lies not in comprehensive clinician input or meaningful community input, but in its utility to justify any and all forms of clinical intervention. Clinical practices have not been impacted by the statement; they have been validated.

Local ethical guidelines, such as in Victoria, Australia, extend that framework, suggesting that medical interventions address cultural risks including "reduced opportunities for marriage". ²⁹ A clinician submission to the Australian Senate inquiry recommended surgeries justified as therapeutic for "functional reasons such as to allow a male individual to urinate while standing, and for psychosocial reasons such as to allow the child to develop without the psychosocial stigma or distress which is associated with having genitalia incongruous with the sex of rearing". These rationales express cultural norms, in much the same way as rationales for female genital mutilation.

In a clinician submission to the Australian Senate committee inquiry, rationales for sterilisation included "sex of rearing, estimated capacity of the gonad to produce hormones in accordance with or opposite to sex of rearing and/or (developing) gender identity, likelihood of gender dysphoria". The committee was disturbed by this entanglement of different justifications. 32

The Australian Senate inquiry found in 2013 that psychosocial and cultural rationales for surgical interventions are a "circular argument that avoids the central issues".³² A 2012 Swiss national bioethics report concluded that interventions addressing stigma, familial and social integration "run counter to the child's welfare".³³

There are only a few large quantitative data sources on outcomes, due in part to limited follow-up, a lack of comparative data on individuals who have avoided early intervention, and the low frequency of many intersex traits. These mean that there is little evidence to support either medical intervention or non-intervention.⁴³ A decade after the Chicago Consensus statement, there are no credible alternative clinical pathways that avoid early surgical intervention.³⁸

A rhetoric of improved surgical techniques and outcomes has been evident for more than two

decades, at least since 1995.34 without evidence. Lloyd et al in 2005 noted that evidence of benefit from early surgical interventions "is conspicuous by its absence". 37 A 2013 submission by the Royal Children's Hospital Melbourne to the Australian Senate inquiry acknowledged that "outcomes related to current [surgical] practices remain to be established". 35 However, there is evidence of harm from early surgical practices: a submission by the Australasian Paediatric Endocrine Group identified "particular concern regarding sexual function and sensation" as a consequence of recommended surgeries.³⁶ In the UK, Creighton et al remark that "a schism has developed between clinicians working in paediatric and in adolescent/adult services" due to lack of evidence of benefits from early surgeries.²⁸ Clinical claims about improved surgical techniques are used to justify surgeries early in life, 28 but surgical improvements over time should mean that surgeries on infants be deferred, so that consenting adults can later benefit from those improvements if they choose.

According to Lloyd et al, clinical decision-making on the necessity of genital surgeries can be "entirely subjective". The 2013 Australian Senate inquiry found "no medical consensus around the conduct of normalising surgery" on intersex children. As noted by Liao et al, parents "may not realise that they are de facto opting for experimental surgery on their children" and so they are unable to provide valid consent; "parental regret can be high" for interventions aimed at tackling parental and social issues. Second Second

In addition to issues of sensation and sexual function, and the possibility of incorrect sex assignment, surgeries create physical differences that inhibit intimacy. 39 Iain Morland, for example, describes being anatomically "both glaringly unusual and yet brutally normalised". 40 A clinical study of 439 intersex adults, children and parents of intersex children in Germany undertaken between 2005 and 2007 showed that 81% of adults and children with intersex traits had undergone surgeries related to those traits: two-thirds of adults linked sexual problems to those surgeries. 41 A recent Australian survey of 272 adults born with atypical sex characteristics found "strong evidence" of "institutionalised shaming and coercive treatment". 42 Of the study population, 60% reported receiving medical interventions related to their intersex traits, and a majority experienced negative consequences, not simply medical or sexual: early school leaving (by 18% of respondents compared to a national average of 2%) was coincident with puberty and pubertal medical interventions.

Key ethical and human rights concerns with current medical practices are often portrayed as matters of surgical timing, degree of physical difference from sex norms, ³⁶ and sex assignment. ¹⁸ The intersex movement poses more fundamental concerns of valid consent, self-determination and bodily autonomy. ⁴³

The intersex movement

Intersex advocates have been active since the 1990s. The early establishment of Australian and UK Androgen Insensitivity Syndrome Support Groups was followed by the Intersex Society of North America (ISNA), a Latin American consortium, national groups and international networks.

In just a few years, ISNA moved from demonstrating outside a paediatric conference in 1996 to delivering a plenary address at the same conference. He defical authority was subsequently reasserted in the Chicago statement of 2006: an invite-only group led by US clinicians, with peripheral involvement by ISNA, changed clinical language from intersex to "disorders of sex development" (DSD). ISNA hoped this would open doors for closer collaboration with clinicians, and improved medical practices to but instead it has led to greater biomedicalisation.

The shift to DSD never received widespread acceptance by intersex individuals, advocates and organisations; the term is regarded as pathologising and poorly translatable. A decade later, a survey of Australians born with atypical sex characteristics shows low acceptance of the term. Only of respondents use DSD by choice, while 60% use terms including the word intersex. Interestingly, 21% use DSD when accessing healthcare, indicating a perceived need to use disordering language to obtain appropriate care.

The intersex movement of the mid-2000s divided acrimoniously between those accommodating to clinical leadership and those favouring human rights approaches. ISNA folded in 2008.⁴⁸ Voices accommodating of clinical leadership have found themselves co-opted⁴⁹ and disappointed.⁵⁰

The intersex human rights movement engages with international and national human rights and ethics institutions, engages in discussions with

policy-makers, and demonstrations, ⁵¹ and instigates legal action. Its core human rights goals are simple: the rights to bodily autonomy and self-determination, and an end to stigmatisation.

Human rights developments

Clinical practices have been scrutinised in a few countries. A 2012 national Swiss bioethics inquiry recommended substantive changes to clinical practice, to defer non-urgent treatments and recognise human rights norms,³³ as did the 2013 Australian Senate inquiry.³² Neither has been implemented. In 2008. Christiane Völling won legal action following involuntary medical treatment at age 18 in Germany.⁵² Michela Raab won a similar case in Germany in 2015.⁵³ In the US. the case of a child, MC, has been pursued since 2013 with no conclusion to date.⁵⁴ Bauer and Truffer note that there have been no successful legal actions by intersex persons subjected to interventions during infancy or childhood, due in part to statutes of limitations, 55 and claims of clinical consensus.

National legislation has begun to act on discrimination and bodily autonomy. South Africa first added intersex to the attribute of "sex" in discrimination law in 2005, through work by intersex and anti-apartheid activist Sally Gross. Australians secured an independent attribute of "intersex status" in discrimination law in 2013. In 2015, Malta became the first country to legally recognise the right of all individuals to "bodily integrity and physical autonomy", adding a more encompassing attribute of "sex characteristics" to discrimination law, and prohibiting social, cultural and other unnecessary interventions on the sex characteristics of minors. S8,59

A series of International Intersex Forums took place between 2011 and 2013. Out of these came a landmark statement in Malta in 2013. ⁶⁰ This was followed in 2014 by a first submission to the World Health Organization, by advocates from six continents outlining concerns with the International Classification of Diseases (ICD). ⁸

Advances in international human rights forums have been made as a result of purposeful advocacy. In 2013, the UN Special Rapporteur on torture first acknowledged the existence and harmful consequences of irreversible, involuntary medical treatment to "fix" intersex children. In 2015, the Council of Europe's Human Rights Commissioner first recognised the right of intersex people *not* to

undergo sex assignment treatment.⁶² The same year, the Council of Europe, the European Union Agency for Fundamental Rights,⁶³ and the Inter-American Commission for Human Rights⁶⁴ called for the reassessment of medical classifications that pathologise intersex traits.

UN Treaty Bodies are now responding to these developments. The Committee against Torture has commented on early unnecessary and irreversible sex determining surgeries, consent and long-term impact in Switzerland, 65 in China 66 and in Hong Kong. 7 The Committee on the Rights of the Child has commented on non-discrimination, right to identity and harmful practices in Chile, 68 and harmful practices in France 9 and Ireland. 70 The Committee on the Rights of Persons with Disabilities has commented on protecting the integrity of the person in Germany. As a result of comments on Chile, in late 2015 the Chilean Health Ministry issued instructions suspending early medical interventions.

Zeid Ra'ad Al Hussein, UN High Commissioner for Human Rights, opened an intersex expert meeting in September 2015 stating:

"All human beings are born equal in dignity and rights... regardless of our sex characteristics." 73

Policy disjunctions

Despite human rights advances, many challenges remain, not least in implementation of reforms to ensure that clinical practices meet human rights norms. Disjunctions are evident between social and medical policy and, in both domains, between rhetoric and reality. This disjunction differentiates between the medical treatment of "individuals with DSDs" and social policy advances for the intersex or broader LGBTI communities. Fundamentally, addressing DSD and intersex populations as separate is deeply flawed, and may even permit medical policy to disregard the intersex human rights movement.

For example, in 2014 an Australian territory introduced three additional birth sex classifications, 74 in part considered suitable for intersex children. Communications between the author and the Territory's chief/health minister on that policy and on the medical treatment of children elicited divergent, unrelated responses, drafted by different policy teams with different policy goals. The government was not able to create a

well-formed policy because it does not possess a coherent understanding of the population affected. A similar bifurcation between DSD and intersex is evident in US medical schools. Distinctions between rhetoric and reality are evident in Victoria, Australia, where 2013 ethical guidelines on the care of children with intersex traits are ignored and contradicted by the same government's current neonatal handbook materials on ambiguous genitalia and hypospadias. Revisions to those ethical guidelines are in hand, and these are likely to remove marriageability as a rationale for medical intervention, but the ethical guidelines are irrelevant to actual clinical practice.

Policy disjunctions extend to public resourcing. Australian genetic research on intersex traits is partially justified by "psychological trauma", 77 yet, no health services offer psychological support for adults. While peer and advocacy groups support intersex populations, they lack sufficient funding. 78

Disjunctions are also evident in media reporting. Reporters continue to contrast intersex perspectives with medical perspectives, typically those of paediatric endocrinologists or geneticists. Media reports frequently and uncritically present an unsubstantiated narrative of fewer surgical interventions, and improved medical practices. Peppers that frame intersex within LGBTI contexts frequently, and incorrectly, and incorrectly, the distinction of the contexts frequently, and incorrectly, and incorrectly, the distinction of the contexts frequently, and incorrectly, and incorrectly, the distinction of the contexts frequently, and incorrectly, and incorrectly, the distinction of the contexts frequently and incorrectly.

From an intersex perspective, the LGBT movement appears preoccupied with identity and relationship recognition, without recognition of bodily autonomy, and deeper challenges posed by sex and gender norms. Discussions within LGBT spaces may suggest that intersex groups do not want inclusion; some intersex-led organisations seek it, while others simply fear becoming overwhelmed and instrumentalised. Many "LGBTI" organisations treat intersex inclusion as an inconsequential goal, rather than a deliberate strategic process, resulting in a reality that fails to match the rhetoric of inclusivity.⁸³ Regardless, aggregation of our issues is progressing, including in health,⁸⁴ foreign policy, 85 and human rights. 1,64 If "LGBTI" is to work, it has to work for all constituent populations. Dan Ghattas suggests that LGBT organisations seeking to become inclusive should adopt the statement of the Third International Intersex Forum⁶⁰ as a key first step.⁸⁶

In Australia, a shift from LGBT to LGBTI occurred early, but with little deliberate attention to its implications. The few institutions that have responded to "intersex status" in law have typically focused on the same issues of honorifics, pronouns and toilets that they address in responding to discrimination based on gender identity. This is troubling. Not only does this approach obscure issues of medicalisation and bodily autonomy, it treats intersex as no more than a gender identity issue.

In practice, intersex as identity is polymorphic, but asserts the dignity of stigmatised embodiment. The gender identities of intersex people may match sexes assigned at birth, or may not. As with transgender persons, intersex persons can suffer "misgendering", a failure to acknowledge the validity of individuals' gender identities. Uniquely, intersex people also face failures to acknowledge the validity of sexes assigned at birth. 88,89

Misconceptions often frame intersex as a third sex.⁸⁷ For example, in 2015, an Australian State agency saw no contradiction in proposals simultaneously calling for a third sex classification and promoting intersex human rights via a poster stating "sex is a spectrum". A Chilean LGBT group proposed a third sex for intersex infants in 2016, with similar proposals elsewhere.⁹⁰

Identities are frequently informed by bodily characteristics, but while some intersex people use intersex or non-binary as gender labels, most intersex adults are female or male. 42 Suppositions that sex characteristics dictate gender identity not only deny the existence of trans people, they deny agency to intersex people to autonomously determine sex and gender. Third sex classifications pose added difficulties for infants: parents may feel increased pressure to avoid stigma, disclosure and social incomprehension through physical interventions, ensuring an unequivocal, familiar sex assignment. As Mauro Cabral comments, it is necessary to challenge and expand narrow definitions but also the reduction of intersex issues to matters of gender identity.91

The statement of the Third International Intersex Forum calls for initial male or female assignment, recognising physical integrity, with openness to changes in sex assignments, and non-binary and multiple options for people able to consent. The statement also calls for the removal of sex and gender, like race and religion, from official documentation as a more universal, long-term policy goal.

Hermeneutical injustice

Underlying these policy disjunctions and misconceptions is a broader issue, described by philosopher Miranda Fricker as "hermeneutical injustice"; a form of injustice in knowing that prevents a person from making sense of their own lived experience due to a lacuna in social understanding. This arises due to the "relative powerlessness" of the subject's social group. For intersex people, this hermeneutical injustice arises in two distinct ways: through clinical secrecy and terminology, and through societal discourse on identity.

Clinical secrecy was most profound from the 1950s: a deliberate culture of secrecy withheld diagnoses to "enable the child have a 'normal' physical and psychosexual development". 93 That silence gave people with intersex traits no words to describe our sutures, scars and lack of sensation, and no words to understand commonalities shared across the diversity of lives and histories. This culture changed with the introduction of DSD. but clinical language still prevents parental understanding of a child in positive, non-pathological ways, and the individualisation of each condition separates people from intersex communities. Morgan Holmes states that the shift to DSD. "reinstitutionalises clinical power to delineate and silence those marked by the diagnosis; ... this silencing is precisely the point of the new terminology".9

Identity-focused language mischaracterises intersex human rights issues as matters of sexual orientation and gender identity. It prioritises issues of performativity and identity over deeper, more intractable issues of bodily autonomy. These act as barriers to familial and self-understanding, and to the social connectedness that can help individuals overcome stigma.

Conclusions

International human rights institutions have begun to address intersex human rights issues, acting on testimonies from a growing and decentralised global movement. While this progress is welcome, effective implementation of policy and change in clinical practice remain a priority. This means challenging an unsubstantiated rhetoric of changing clinical practice on one hand, and an inconsequential rhetoric of inclusion on the other.

Structural change is needed to end the pathologisation and stigmatisation of healthy intersex

bodies. Current rhetoric of changed clinical practices demonstrates a focus on the appearance or optics of those practices; unsubstantiated claims of change must be evidenced. Harmful practices in medical settings must be eliminated; the right of intersex people not to undergo medical intervention for social and cultural reasons must be recognised, ensuring the right to make autonomous informed choices about irreversible treatments. The development of rights-based clinical pathways must be prioritised. Where individuals are unable to provide consent for necessary treatment, physical health issues need scrutiny, careful

justification, and distinguishing from "normalising" cultural practices. Diagnoses in the International Classification of Diseases must change to ensure that treatments meet human rights norms.

Rhetorics of inclusion and a focus on performativity need to be challenged by human rights bodies and funders. Resourcing models that advance intersex-led initiatives need to be supported and extended. Above all, bodily autonomy, stigmatisation and medicalisation are human rights issues. Intersex-led advocacy and peer support groups must be at the heart of efforts to manage and resolve them.

References

- United Nations, Office of the High Commissioner for Human Rights. Free & Equal Campaign Fact Sheet: Intersex [Internet]. 2015 [cited 5 September 2015]. Available from: https://unfe.org/system/unfe-65-Intersex_ Factsheet ENGLISH.pdf.
- Hiort O. DSDnet: Formation of an open world-wide network on DSD. In: Proceedings of the 4th International Symposium on Disorders of Sex Development. Glasgow: University of Glasgow, 2013.
- Carpenter M, Organisation Intersex International Australia. Submission on the Review of Part B of the Ethical Guidelines for the Use of Assisted Reproductive Technology in Clinical Practice and Research, 2007 [Internet]. Sydney: Organisation Intersex International Australia, 2014. [cited 30 April 2014]. Available from: http://oii.org.au/25621/submission-ethics-geneticselection-intersex-traits/.
- Diodorus Siculus. Library of History in twelve volumes. IV: books IX-XII,40. Cambridge, Mass.: Harvard University Press, 2007. 467.
- Ambrose J. I Thought People Like That Were Clip Art/A Modern Minstrel Show [Internet]. 2014 [cited 12 January 2016]. Available from:. http://interfaceproject.tumblr.com/ post/115256095866/i-thought-people-like-that-were-clipart-a
- 6. Illustrating such concerns, Rachel Moss wrote in 2014 about a married Chinese man, described as female by his doctors, "Mr Chen is reported to have told doctors that he and his wife have had intercourse we can't help but wonder how that worked." Moss R. Married Man Sees His Doctor About Stomach Cramps Finds Out He's a Woman With Period Pains. Huffington Post UK [Internet]. 28 July 2014 [cited 1 September 2014]; Available from: http://www.huffingtonpost.co.uk/2014/07/24/married-manperiod-pains-woman_n_5616359.html.

- Ghattas DC. Human Rights between the Sexes A preliminary study on the life situations of inter* individuals. Berlin: Heinrich-Böll-Stiftung, 2013.
- 8. In: Cabral, Carpenter, editors. Intersex Issues in the International Classification of Diseases: a revision [Internet] [cited 25 October 2015]. Available from: http://transactivists.org/?attachment_id=652.
- Hester JD. Intersex(es) and informed consent: How physicians' rhetoric constrains choice. Theoretical Medicine and Bioethics, 2004;25(1):21–49.
- 10. German Ethics Council. Intersexuality, Opinion. Berlin. 2012
- Kaggwa J. A general overview on lived realities of being intersex in Uganda and the Eastern African region. In: Presentation at Intersex Expert Meeting, Office of the High Commissioner for Human Rights, Geneva.
- Odero J. Intersex in Kenya: Held captive, beaten, hacked. Dead. [Internet]. 76 CRIMES. 2015 [cited 28 December 2015]. Available from: http://76crimes.com/ 2015/12/23/intersex-in-kenya-held-captive-beatenhacked-dead/.
- Lau M. Baby born with male and female genitals found abandoned in Chinese park [Internet]. South China Morning Post. 2015 [cited 13 January 2016]. Available from: http://www.scmp.com/news/china/society/article/ 1851891/baby-born-male-and-female-genitals-foundabandoned-chinese-park.
- Sandberg K. The Rights of LGBTI Children under the Convention on the Rights of the Child. Nordic Journal of Human Rights, 2 October 2015;33(4):337–352.
- Intersex Society of North America. What's the history behind the intersex rights movement? [Internet]. [cited 11 March 2015]. Available from: http://www.isna.org/faq/ history.

- Houk CP, Hughes IA, Ahmed SF, et al. Writing Committee for the International Intersex Consensus Conference Participants. Summary of Consensus Statement on Intersex Disorders and Their Management. Pediatrics, 2006;118(2):753–757.
- Lee PA, Wisniewski A, Baskin L, et al. Advances in diagnosis and care of persons with DSD over the last decade. International Journal of Pediatric Endocrinology, 2014;2014(1):19.
- Department of Health and Human Services. Neonatal ehandbook: Ambiguous genitalia in neonates – disorders of sexual differentiation. Victoria, Australia. 9 April 2015. Available from: http://www.health. vic.gov.au/neonatalhandbook/congenital/ambiguousgenitalia.htm.
- Arlt W, Willis DS, Wild SH, et al. Health Status of Adults with Congenital Adrenal Hyperplasia: A Cohort Study of 203 Patients. The Journal of Clinical Endocrinology and Metabolism, 2010;95(11):5110–5121.
- Attorney General's Department, Australia. Review of Australia's Female Genital Mutilation legal framework – Final Report. Attorney General's Department, May 2013.
- Ehrenreich N, Barr M. Intersex Surgery, Female Genital Cutting, and the Selective Condemnation of "Cultural Practices.". Harvard Civil Rights – Civil Liberties Law Review. 2005 Winter;40(1):71–140.
- 22. Jordan-Young RM, Sonksen PH, Karkazis K. Sex, health, and athletes. BMJ, 2014;348(apr28 9):g2926.
- Barbagli G, Sansalone S, Djinovic R, et al. Surgical Repair of Late Complications in Patients Having Undergone Primary Hypospadias Repair during Childhood: A New Perspective. Advances in Urology, 2012:1–5.
- 24. Carmack A, Notini L, Earp B. Should Surgery for Hypospadias Be Performed Before an Age of Consent? Journal of Sex Research, 2015; in press.
- Gorman G. Born intersex: The people who are biologically neither male nor female. News.com.au [Internet]. 29 November 2015 [cited 29 November 2015]; Available from: http://www.news.com.au/lifestyle/real-life/truestories/born-intersex-the-people-who-are-biologicallyneither-male-nor-female/news-story/ 5bd9ce6debf9c8b4ab7ca919fb04526c.
- Graves J. Boy, girl or ...? Dilemmas when sex development goes awry [Internet]. The Conversation. 2016 [cited 10 March 2016]. Available from: http:// theconversation.com/boy-girl-or-dilemmas-when-sexdevelopment-goes-awry-49359.
- Liao L-M, Simmonds M. A values-driven and evidence-based health care psychology for diverse sex development. Psychology & Sexuality, 2014;5(1):83–101.

- Creighton SM, Michala L, Mushtaq I, et al. Childhood surgery for ambiguous genitalia: glimpses of practice changes or more of the same? Psychology & Sexuality, 2014;5(1):34–43.
- Victoria, Department of Health. Decision-making principles for the care of infants, children and adolescents with intersex conditions. Melbourne: Victorian Government, February 2013.
- 30. Lee PA, Nordenström A, Houk CP, et al. Global Disorders of Sex Development Update since 2006: Perceptions, Approach and Care. Hormone Research in Pædiatrics, 28 January 2016;85(3).
- 31. Cools M, Dessens A, Drop S, Hewitt J, Warne G. Answers to questions on notice (received 27 September 2013) in Australian Senate Community Affairs References Committee. Involuntary or coerced sterilisation of intersex people in Australia. Canberra: Community Affairs References Committee, 2013.
- 32. Australian Senate, Community Affairs References
 Committee. Involuntary or coerced sterilisation of intersex
 people in Australia. Canberra: Community Affairs
 References Committee, 2013. Available from: http://www.
 aph.gov.au/Parliamentary_Business/Committees/Senate/
 Community_Affairs/Involuntary_Sterilisation/Sec_Report/
 index.
- Swiss National Advisory Commission on Biomedical Ethics NEK-CNE. On the management of differences of sex development. Ethical issues relating to "intersexuality". Opinion No. 20/2012. Berne. 2012.
- Devore H. Endless Calls for "More Research" as Harmful Interventions Continue. In: Hermaphrodites with Attitude, Fall/Winter 1995–1996.
- 35. Royal Children's Hospital Melbourne. Submission to the Senate Inquiry into the Involuntary or Coerced Sterilisation of People with Disabilities in Australia: Regarding the Management of Children with Disorders of Sex Development. July 2013. p. 8.
- 36. Hewitt J, Warne G, Hofman P, et al. Submission to the Senate Inquiry into the Involuntary or Coerced Sterilisation of People with Disabilities in Australia: Regarding the Management of Children with Disorders of Sex Development. Australasian Paediatric Endocrine Group, June 2013.
- Lloyd J, Crouch NS, Minto CL, et al. Female genital appearance: "normality" unfolds. BJOG: An International Journal of Obstetrics & Gynaecology, 2005; 112(5):643–646.
- Liao L-M, Wood D, Creighton SM. Parental choice on normalising cosmetic genital surgery. British Medical Journal, 28 September 2015:h5124.
- Australian Senate Community Affairs References Committee. Involuntary or coerced sterilisation of people with disabilities in Australia, transcript of

- hearing on Thursday 28 March 2013 [Internet]. Canberra. 2013. Available from: http://www.aph.gov.au/hansard.
- Morland I. What Can Queer Theory Do for Intersex?
 GLQ: A Journal of Lesbian and Gay Studies, 2009;15(2): 285–312.
- Jürgensen M. "Klinische Evaluationsstudie im Netzwerk DSD/Intersexualität: Zentrale Ergebnisse", Slide 6. In: Presentation 27.05.2009 at Jenseits der zwei Geschlechter
 – Wie kann ein Situation intersexueller Menschen verbessert werden?. UK-SH, Lübeck: Klinik für Kinder- und Jugendmedizin, 2009.
- 42. Jones T, Hart B, Carpenter M, et al. Intersex: Stories and Statistics from Australia. Cambridge, UK: Open Book Publishers. 2016.
- Tamar-Mattis A. Patient advocate responds to DSD surgery debate. Journal of Pediatric Urology, 2014;10(4): 788–789.
- Davis G. "DSD is a Perfectly Fine Term": Reasserting Medical Authority through a Shift in Intersex Terminology. In: McGann, Hutson, editors. Advances in Medical Sociology. Bingley: Emerald Group Publishing, 2011. p. 155–182.
- AISSG UK. DSD Terminology [Internet]. 2014 [cited 30 April 2015]. Available from: http://www.aissg.org/ DEBATES/DSD.HTM.
- Intersex Society of North America. Why is ISNA using "DSD"? [Internet]. 2006 [cited 3 February 2015].
 Available from: http://www.isna.org/node/1066.
- 47. See the acknowledgements in Consortium on the Management of Disorders of Sex Development. Clinical guidelines for the management of disorders of sex development in childhood. Whitehouse Station, N.J.: Accord Alliance; 2008. And also Consortium on the Management of Disorders of Sex Development. Handbook for parents. Whitehouse Station, N.J.: Accord Alliance; 2008.
- 48. Intersex Society of North America. Dear ISNA Friends and Supporters [Internet]. 2008 [cited 3 February 2015]. Available from: http://www.isna.org/.
- Dreger A. Tiger Devore's Statement [Internet]. 2015[cited 25 November 2015]. Available from:. http://alicedreger. com/Tiger_Devore.
- Dreger A. Malta Bans Surgery on Intersex Children. The Stranger SLOG [Internet]. 3 April 2015 [cited 4 April 2015]; Available from: http://www.thestranger.com/blogs/ slog/2015/04/03/22001053/malta-bans-surgery-onintersex-children.
- Zwischengeschlecht. Ending IGM: Dialogue with ESPE Representatives, Dublin 19.09.2014 [Internet]. 2014 [cited 26 December 2015]. Available from: http://stop. genitalmutilation.org/post/Ending-IGM-Dialogue-with-ESPE-Representatives-Dublin-19-09-2014.

- 52. Re: Völling. Cologne: Regional Court Cologne. 2008. Available from: http://icj.wpengine.netdna-cdn.com/wp-content/uploads/2008/02/ln-re-Volling-Regional-Court-Cologne-Germany-English.pdf.
- 53. Zwischengeschlecht.org. Nuremberg Hermaphrodite Lawsuit: Michaela "Micha" Raab Wins Damages and Compensation for Intersex Genital Mutilations! [Internet]. 2015 [cited 21 December 2015]. Available from: http://stop.genitalmutilation.org/post/Nuremberg-Hermaphrodite-Lawsuit-Damages-and-Compensation-for-Intersex-Genital-Mutilations.
- 54. Southern Poverty Law Center. Groundbreaking SPLC lawsuit accuses South Carolina, doctors and hospitals of unnecessary surgery on infant [Internet]. 2013 [cited 21 July 2015]. Available from: http://www.splcenter.org/get-informed/news/groundbreaking-splc-lawsuit-accuses-south-carolina-doctors-and-hospitals-of-unnece.
- Zwischengeschlecht.org. IntersexUK, OII-UK, The UK Intersex Association. NGO Report to the 5th Periodic Report of the United Kingdom on the Convention on the Rights of the Child (CRC) [Internet]. Zurich. 2016 [cited 23 May 2016]. Available from: http://intersex.shadowreport. org/public/2016-CRC-UK-NGO-Zwischengeschlecht-Intersex-IGM v2.pdf.
- Mokoena N. Remembering Sally, and the intersex movement in South Africa [Internet]. Intersex Day. 2015 [cited 25 October 2015]. Available from: http:// intersexday.org/en/remembering-sally-south-africa/.
- Australia. Sex Discrimination Amendment (Sexual Orientation, Gender Identity and Intersex Status) Act 2013. Canberra. 2013. Available from: http://www. comlaw.gov.au/Details/C2013A00098/.
- 58. Cabral M. Making depathologization a matter of law. A comment from GATE on the Maltese Act on Gender Identity, Gender Expression and Sex Characteristics [Internet]. Global Action for Trans* Equality. 2015 [cited 4 July 2015]. Available from: http://transactivists.org/2015/04/08/making-depathologization-a-matter-of-law-a-comment-from-gate-on-the-maltese-act-on-gender-identity-gender-expression-and-sex-characteristics/.
- Malta. Gender Identity, Gender Expression and Sex Characteristics Act: Final version [Internet]. 2015 [cited 15 April 2015]. Available from: http://justiceservices.gov. mt/DownloadDocument.aspx?app=lp&itemid= 26805&l=1.
- Public statement by the third international intersex forum [Internet]. Malta. December 2013 [cited 26 October 2015].
 Available from: http://intersexday.org/en/third-international-intersex-forum/.
- Méndez J. Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, A.HRC.22.53. February 2013.

- Council of Europe, Commissioner for Human Rights. Human rights and intersex people, Issue Paper. Strasbourg. 2015.
- European Union Agency for Fundamental Rights. The fundamental rights situation of intersex people. Vienna. 2015.
- Comisión Interamericana de Derechos Humanos. Violencia contra Personas Lesbianas, Gays, Bisexuales, Trans e Intersex en América. Comisión Interamericana de Derechos Humanos, 2015.
- Committee on the Rights of Child. Concluding observations on the seventh periodic report of Switzerland. In: Report No.: CAT/C/CHE/CO/7. Geneva: United Nations, 2015.
- Committee against Torture. Concluding observations on the fifth periodic report of China. In: Report No.: CAT/C/ CHN/CO/5. Geneva: United Nations, 2015.
- Committee against Torture. Concluding observations on the fifth periodic report of China with respect to the Hong Kong Special Administrative Region. In: Report No.: CAT/ C/CHN-HKG/CO/5. Geneva: United Nations, 2015.
- Committee on the Rights of the Child. Concluding observations on the combined fourth to fifth periodic reports of Chile. In: Report No.: CRC/C/CHL/CO/4-5. Geneva: United Nations, 2015.
- Committee on the Rights of the Child. Concluding observations on the fifth periodic report of France. In: Report No.: CRC/C/FRA/CO/5. Geneva: United Nations, 2016.
- Committee on the Rights of the Child. Concluding observations on the combined third to fourth periodic reports of Ireland. In: Report No.: CRC/C/IRL/CO/3-4. Geneva: United Nations, 2016.
- Committee on the Rights of Persons with Disabilities.
 Concluding observations on the initial report of Germany.
 In: Report No.: CRPD/C/DEU/CO/1. Geneva: United Nations, Apr 2015.
- Ministerio de Salud. Circular No. 18: Instruye sobre ciertos aspects de la atención de salud a niños y niñas intersex. Chile: Ministerio de Salud, 2015.
- United Nations High Commissioner for Human Rights.
 Opening remarks by Zeid Ra'ad Al Hussein, United Nations High Commissioner for Human Rights at the Expert meeting on ending human rights violations against intersex persons [Internet]. 2015 [cited 16 September 2015]. Available from: http://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID= 16431&LangID=E.
- Australian Capital Territory Government, Office of Regulatory Services. Birth Registration Statement (form 201-BRS) [Internet]. 2014 [cited 6 February 2015].
 Available from: http://www.legislation.act.gov.au/af/ 2014-46/current/pdf/2014-46.pdf.

- 75. Association of American Medical Colleges. Implementing Curricular and Institutional Climate Changes to Improve Health Care for Individuals Who Are LGBT, Gender Nonconforming, or Born with DSD [Internet]. 2014 [cited 11 November 2014]. Available from: https://members.aamc.org/eweb/upload/AAMC_ R.pdf.
- Department of Health and Human Services. Neonatal ehandbook. Congenital abnormalities. Victoria, Australia [Internet]. 16 October 2015 [cited 20 May 2016].
 Available from: https://www2.health.vic.gov.au/ hospitals-and-health-services/patient-care/perinatalreproductive/neonatal-ehandbook/congenitalabnormalities.
- National Health and Medical Research Council. Program Grants for funding in 2015 [Internet]. [cited 5 February 2015]. Available from: https://www.nhmrc.gov.au/_files_ nhmrc/file/grants/funding/2013/program_grants_ outcomes_for_funding_2015_140217.pdf.
- Eisfeld J, Gunther S, Shlasko D. The State of Trans* and Intersex Organizing: A case for increased support for growing but under-funded movements for human rights. New York: Global Action for Trans* Equality and American Jewish World Service, 2013.
- Ghorayshi A. Intersex Surgeries are a Human Rights Violation, Says U.N. Group. Buzzfeed [Internet]. 20 September 2015 [cited 20 September 2015]; Available from: http://www.buzzfeed.com/azeenghorayshi/intersexsurgeries-human-rights-violation.
- Reardon S. The spectrum of sex development: Eric Vilain and the intersex controversy. Nature, 2016;533(7602): 160–163.
- Medhora S. Domestic violence affects LGBTIQ communities at alarming levels report. The Guardian [Internet].
 November 2015 [cited 12 January 2016]; Available from: http://www.theguardian.com/society/2015/nov/03/domestic-violence-affects-lgbtiq-communities-at-alarming-levels-report?CMP=soc_568.
- Davidson H. No data exists on suicide among gay and trans Indigenous Australians [Internet]. The Guardian. 5 May 2016 [cited 14 May 2016]. Available from:. http:// www.theguardian.com/australia-news/2016/may/05/nodata-exists-on-suicide-among-gay-and-trans-indigenousaustralians.
- 83. See, for example, the rhetoric of inclusion at ACON. LGBTI Health | ACON Here for Health [Internet]. [cited 17 January 2016]. Available from: http://www.acon.org.au/lgbti-health/.
- 84. National Institutes of Health Sexual and Gender Minority Research Coordinating Committee. NIH FY 2016-2020 Strategic Plan to Advance Research on the Health and Well-being of Sexual and Gender Minorities [Internet]. National Institutes of Health, 2015.

- 85. United States of America, Department of State. Joint Government and Multilateral Agency Communique from Conference to Advance the Human Rights of and Promote Inclusive Development for LGBTI Persons [Internet]. Washington, DC: Department of State. November 2014 [cited 21 November 2014]. Available from: http:// www.state.gov/r/pa/prs/ps/2014/11/234308.htm.
- 86. Ghattas DC. Standing up for the human rights of intersex people. ILGA-Europe, OII Europe: Brussels, 2015.
- 87. Yoosuf M. Recognition and protection for intersex persons. Law Institute Journal, April 2015:52–56.
- 88. For example Martínez-Patiño MJ. Personal Account A woman tried and tested. Lancet, December 2005:366–538.
- Karkazis K, Jordan-Young R, Davis G, et al. Out of Bounds? A Critique of the New Policies on Hyperandrogenism in Elite Female Athletes.
 The American Journal of Bioethics, 2012;12(7):3–16.

- El Mostrador. Proponen al Minsal iniciar debate sobre la creación de un tercer sexo registral [Internet]. 8 February 2016. Available from. http://www.elmostrador.cl/noticias/ pais/2016/02/08/proponen-al-minsal-iniciar-debate-sobrela-creacion-de-un-tercer-sexo-registral/.
- 91. Cabral M. The marks on our bodies [Internet]. Intersex Day. 2015 [cited 25 October 2015]. Available from: http://intersexday.org/en/mauro-cabral-marks-bodies/.
- 92. Fricker M. Epistemic Injustice: Power and the Ethics of Knowing. Oxford: Oxford University Press, 2007.
- Holmes M. Is Growing up in Silence Better Than Growing up Different? [Internet]. Intersex Society of North America. [cited 30 December 2013]. Available from: http://www.isna.org/node/743.
- Holmes M. The Intersex Enchiridion: Naming and Knowledge. Somatechnics, September 2011;1(2):388–411.

Résumé

Les personnes et corps intersexués ont été considérés comme incapables d'intégration dans la société. Les interventions médicales sur des corps souvent sains demeurent la norme. Elles répondent à des besoins familiaux et culturels ressentis, en dépit des inquiétudes quant à la nécessité et aux résultats, à la réalisation et au consentement à ces interventions. Un mouvement intersexué mondial et décentralisé recherche des objectifs de base simples : les droits à l'autonomie et l'autodétermination des corps, et la fin de la stigmatisation. Le système international des droits de l'homme répond avec un éventail de nouvelles déclarations politiques adoptées par les institutions des droits de l'homme et une poignée de gouvernements nationaux qui reconnaissent les droits des personnes intersexuées. Néanmoins, de grands obstacles demeurent à l'application de ces déclarations. Les violations des droits des personnes intersexuées persistent, profondément enracinées dans une histoire délibérée de mise sous silence. La rhétorique des changements de la pratique clinique reste non étayée. Les disjonctions politiques apparaissent dans un cadre de guestions intersexuées comme les thèmes de l'orientation sexuelle et de l'identité de genre, plutôt qu'en tant que caractéristiques sexuelles innées ; cela a abouti à une rhétorique d'inclusion qui ne correspond pas à la réalité. Cet article donne un apercu des pratiques nuisibles sur les corps intersexués, le développement des droits de l'homme et la rhétorique du changement et de l'inclusion.

Resumen

Las personas y cuerpos intersexuales han sido considerados incapables de integrarse a la sociedad. Las intervenciones médicas en cuerpos a menudo saludables continúan siendo la norma, abordando exigencias familiares y culturales percibidas, a pesar de las inquietudes sobre la necesidad, los resultados, la conducta v el consentimiento. El movimiento intersexual mundial y descentralizado procura lograr metas fundamentales sencillas: los derechos a la autonomía corporal y la autodeterminación, y el fin de la estigmatización. El sistema internacional de derechos humanos está respondiendo con una variedad de nuevas declaraciones de políticas de instituciones de derechos humanos y un puñado de gobiernos nacionales están reconociendo los derechos de las personas intersexuales. Sin embargo, aún existen retos importantes para poner en práctica esas declaraciones. Persisten las violaciones de derechos humanos de las personas intersexuales, arraigadas en una historia deliberada de silenciamiento. La retórica de cambios a la práctica clínica continúa sin fundamento. Las disyuntivas en políticas surgen al plantear los asuntos intersexuales como cuestiones orientación sexual e identidad de género, v no como características sexuales innatas; esto ha producido una retórica de inclusión que no coincide con la realidad. Este artículo ofrece una visión general de las prácticas dañinas en cuerpos intersexuales, sucesos relacionados con los derechos humanos y las retóricas de cambio e inclusión.