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Intersex Variations, Human Rights, and the International Classification of Diseases

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Abstract

Over time, the World Health Organization (WHO) has reviewed and removed pathologizing classifications and codes associated with sexual and gender minorities from the International Classification of Diseases (ICD). However, classifications associated with intersex variations, congenital variations in sex characteristics or differences of sex development, remain pathologized. The ICD-11 introduces additional and pathologizing normative language to describe these as "disorders of sex development." Current materials in the ICD-11 Foundation also specify, or are associated with, unnecessary medical procedures that fail to meet human rights norms documented by the WHO itself and Treaty Monitoring Bodies. This includes codes that require genitoplasties and gonadectomies associated with gender assignment, where either masculinizing or feminizing surgery is specified depending upon technical and heteronormative expectations for surgical outcomes. Such interventions lack evidence. Human rights defenders and institutions regard these interventions as harmful practices and violations of rights to bodily integrity, non-discrimination, equality before the law, privacy, and freedom from torture, ill-treatment, and experimentation. WHO should modify ICD-11 codes by introducing neutral terminology and by ensuring that all relevant codes do not specify practices that violate human rights.

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Introduction

In 2015, the World Health Organization (WHO) published a paper on sexual health, human rights, and the law. This paper described sexual health as "a state of physical, emotional, mental and social well-being in relation to sexuality" where "achievement of the highest attainable standard of sexual health" is linked to enjoyment of the rights to non-discrimination, privacy, freedom from violence and coercion, and rights to education, information, and access to health services.[1] WHO described how harmonizing laws and regulations with human rights standards can "foster the promotion of sexual health" while laws that contradict human rights principles have a negative impact.[2] It concluded by advising that "States have obligations to bring their laws and regulations that affect sexual health into alignment with human rights laws and standards."[3] In this paper, I argue that these same principles apply to WHO's International Classification of Diseases (ICD) in relation to the impact of ICD codes on the health and well-being of people born with intersex variations. I conclude that WHO should bring ICD classifications and standards into line with existing WHO and UN human rights standards and agreements applicable to the situation of intersex people.

Background

In recent years, Topic Advisory Groups established and administered by WHO on genito-urinary reproductive medicine, and on other matters, have engaged in a re-evaluation of classifications and codes associated with sexual and reproductive health, including the sexual health of both sexual and gender minorities. The trend has been to depathologize codes associated with sexual minorities, reflecting both human rights norms, and the poor-quality evidence and social rationales that justified their existence.[4] Thus, though a code for egodystonic sexual orientation was retained in the ICD with endorsement of the ICD-10 in 1990, homosexuality, *per se*, was removed.

The ICD-11 was formally introduced on June 18, 2018, drawing a structure and a subset of material from an ICD-11 Foundation Component into a first release of the ICD-11 for Mortality and Morbidity Statistics (ICD-11-MMS).[5] The World Health Assembly is expected to approve the ICD-11 in May 2019, and further changes are likely to occur prior to this approval.

The ICD-11 has reconceptualized or deleted codes relating to sexual and gender minorities. Remaining diagnostic classifications related to sexual orientation have been deleted entirely. In relation to gender minorities, Chou and others stated in 2015:

> *The ICD-10 categories 'Transsexualism' and 'Gender Identity Disorder of Childhood' have been proposed to be re-conceptualized in ICD-11 as 'Gender Incongruence of Adolescence and Adulthood' and 'Gender Incongruence of Childhood', respectively.*[6]

Chou notes that broader changes have also been introduced, including a new chapter on sexual health.[7] The new chapter brings together a range of sexual health issues, including codes enabling the classification of female genital mutilation, unwanted pregnancy, sexually transmitted infections, and violence against women.

This reconceptualization of the ways in which concepts relating to the health of sexual and gender minorities are classified has not, however, extended to concepts relating to intersex persons, that is, persons with congenital variations in sex characteristics/differences of sex development. This population is sometimes aggregated with other sexual and gender minorities to comprise an "LGBTI" community, including in publications by WHO and other international institutions.[8] Rather than ending the unnecessary pathologization of all LGBTI populations, the ICD-11 layers pathologizing new language describing such variations as "disorders of sex development" (DSD) onto existing language such as "pseudo-hermaphrodite" that has often been critiqued as pejorative.[9] As I will later show, current ICD Foundation codes specify and are associated with unnecessary medical procedures that fail to meet human rights norms detailed by WHO and other UN organizations, and recommendations of UN Treaty Monitoring

Bodies, and are not underpinned by an appropriate evidence base.

Umbrella terms

Objections to the language of "disorders of sex development" began immediately after it was clinically adopted in 2006 and have continued to the present time.[10]

Populations described by the term "disorders of sex development" (DSD) find this language pejorative and inappropriate, a finding borne out consistently in research by clinical teams and peer support bodies. This language unnecessarily pathologizes often benign characteristics. Amongst persons seeking healthcare, whether due to innate or iatrogenic causes, a 2017 study found that DSD nomenclature may "negatively affect access to healthcare and research": "the use of DSD and related terms is causing distress and avoidance of medical care among some affected individuals and caregivers."[11]

The research team found these findings "consistent with previous studies that demonstrated negative perceptions of DSD nomenclature."[12] Among those, a CARES Foundation survey on issues relating to congenital adrenal hyperplasia in the US found that "more than half of those surveyed said they would not choose to receive care from centers or participate in research studies that use the term DSD."[13] US youth and advocacy organization interACT and Australian and New Zealand advocates have taken similar positions.[14]

Australian research based on a survey of 272 people born with atypical sex characteristics found that participants engaged in code-switching: 3% used the term "disorders of sex development" to describe themselves, while 21% used the term to access medical services.[15] This shows not only that such individuals feel it necessary to disorder themselves in order to access appropriate care, but also that clinicians may not be aware of or exposed to the terms that individuals prefer to use.

Human rights institutions have linked the terminology used to describe innate variations of sex characteristics with human rights violations. The Office of the High Commissioner for Human Rights, the Inter-American Commission on Human Rights, the Human Rights Commissioner of the Council of Europe and other human rights experts have recommended that medical codes that pathologize all variations of sex characteristics should be reviewed and modified, to "ensure that intersex persons can effectively enjoy the highest attainable standard of health and other human rights."[16] These echo recommendations to WHO from intersex human rights defenders.[17]

In a 2016 joint statement, multiple UN Treaty Monitoring Bodies, Special Rapporteurs, the Office of the High Commissioner for Human Rights, African Commission on Human and Peoples' Rights, Council of Europe, Office of the Commissioner for Human Rights, and the Inter-American Commission on Human Rights called for the combatting of root causes of human rights "violations such as harmful stereotypes, stigma and pathologization," and so, "it is critical to strengthen the integration of these human rights principles in standards and protocols issued by regulatory and professional bodies."[18] Changing nomenclature from "disorders of sex development" to neutral terminology is necessary to achieve this goal.

An umbrella term is necessary. Variations of sex characteristics are known to be heterogeneous, with at least 40 different known variations; there is also wide agreement that a significant proportion of people born with variations of sex characteristics do not have a specific or clear diagnosis.[19] Aggregation facilitates the provision of services for people with otherwise disparate variations of sex characteristics.[20] Individuals have frequently also received multiple different diagnostic labels, not only due to change in nomenclature over time, but also due to diagnostic error and the availability of new genetic tests. Umbrella terms help to establish continuity.

An umbrella term can also help individuals without a clear genetic diagnosis find peers and persons with shared lived experience. In situations where individual variations of sex characteristics are statistically rare or uncommon, umbrella terms provide a vital connection with other individuals with related or common experience. By helping in-

dividuals to find common ground, umbrella terms also help facilitate collective action, for example, to tackle shame, stigma, and discrimination.

Indeed, in recent decades, it is the term "intersex," along with specific diagnostic codes, that have facilitated peer connection and collective action, in contrast with the term "disorders of sex development." The term "intersex" is increasingly popular, with intersex communities, advocacy groups, and peer support groups now developing across the globe, and this can be expected to continue. Such peer support, advocacy, and other community groups undertake critical work to support individuals, tackle stigma associated with being born with variations of sex characteristics, tackle misconceptions, combat human rights violations, and hold policy makers and practitioners to account. A proportion of these groups are identified in a 2016 clinical update noting that peer support "is a key component of the 2013–2020 WHO Mental Health Action Plan," and that routine inclusion of peer support is necessary in "clinical care at the earliest possible time."[21]

Nevertheless, using the term "intersex" in clinical settings repathologizes a term increasingly used in social, advocacy, and human rights settings. It has become an affirmative term, available irrespective of diagnostic code, gender identity, or legal sex; despite this, and like all stigmatized populations, language is contested, and misunderstandings and instrumentalization affect its acceptance.[22]

A term other than "intersex" may recognize contention regarding terminology, while also acknowledging that persons can acceptably use different terms in clinical and social settings. Well chosen, a change in clinical terminology can help narrow the distance between community and clinical organizations. In line with a community submission to WHO, I propose that umbrella nomenclature in the ICD-11 be modified from "disorders of sex development" to neutral terminology, such as "congenital variations of sex characteristics" or, failing that, "differences of sex development," a term already used by some intersex people and organizations, clinicians, and rights institutions.[23]

Specific ICD codes

Individual codes in the ICD-11-MMS and ICD-11 Foundation typically contain both a title and description. In some cases, additional information is provided. In relation to a range of codes relating to intersex variations, these details in the ICD 11 Foundation provide the preconditions for medically unnecessary and often irreversible interventions. Further, for some ICD codes, additional information attached to those codes explicitly specifies such interventions. Consequently, adoption of a neutral umbrella term alone is not sufficient; changes to specific codes are also necessary.

Forced and coercive medically unnecessary interventions on the bodies of intersex children may sometimes be described critically or euphemistically as "normalization" surgeries, but also as "corrections," treatment for "malformations," genital "enhancement," "genital reconstruction," "sex assignment" or "gender assignment," or "gender reassignment."[24] The procedures involved may include labiaplasties, vaginoplasties, clitoral "recession" and other forms of clitoral cutting or removal, gonadectomies, hypospadias "repairs," phalloplasties and other forms of penile augmentation surgeries, other forms of urogenital surgeries, and prenatal and postnatal hormone treatment.[25] Associated practices may include dilation, repeated genital examinations, post-surgical sensitivity testing, and medical photography.[26] Many of these procedures have been found to be direct violations of a right to bodily integrity and, when conducted without informed consent by the person concerned, may be regarded as torture or ill treatment.[27]

The World Health Organization paper on sexual health summarizes concerns regarding the sexual health and rights of intersex persons, distinguishing between "medically unnecessary, often irreversible, interventions" resulting from "so-called sex normalizing procedures" to ensure that children's bodies "conform to gendered physical norms" and procedures that "may sometimes be justified in cases of conditions that pose a health risk or are considered life-threatening," noting that some of these may be poorly justified.[28]

Multiple intersex variations may be associated with specific genital characteristics at birth. In each case, genital appearance may be atypical but benign, with that appearance having no consequences for physical health.[29] Nevertheless, descriptions for ICD-11 Foundation codes may promote or specify surgical intervention to modify those sex characteristics. Among these, the ICD-11 Foundation codes for congenital adrenal hyperplasia, 5-alpha-reductase 2 deficiency (5a-RD2), and 17-beta-hydroxysteroid dehydrogenase 3 deficiency (17ß-HSD3) are notable. Each of these variations are associated with specific genital characteristics at birth, and each ICD-11 classification contains supporting descriptions that promote or explicitly require surgical interventions.

The ICD-11-MMS code for congenital adrenal hyperplasia notes that: "Genital anomalies may be noted at birth in affected females," while ICD-11 Foundation code information remarks that genital surgery may be required without specifying why or under what conditions, stating: "Genital anomalies in females may require surgical intervention(s)."[30]

The ICD-11 Foundation code information for 5a-RD2 deficiency remarks that surgery is necessary, with the type of surgeries dependent on sex assignment and the likely outcomes of masculinizing surgery:

> *Gender assignment is still debated and must be carefully discussed for each patient, depending on the expected results of masculinizing genitoplasty. If female assignment is selected, feminizing genitoplasty and gonadectomy should be performed. Prenatal diagnosis is available for the kindred of affected patients if the causal mutations have been characterized.*[31]

The ICD-11 Foundation code information for 17ß-HSD3 makes similar assertions:

> *If the diagnosis is made at birth, gender assignment must be discussed, depending on the expected results of masculinizing genitoplasty. If female assignment is selected, feminizing genitoplasty and gonadectomy must be performed. Prenatal diagnosis is available for the kindred of affected patients if the causal mutations have been characterized.* [32]

The statements in codes for both 5a-RD2 and 17ß-HSD3 favoring genitoplasties share a heritage evident in a 1993 paper on clinical practices by Hendricks that shared the idea that: "You can make a hole but you can't build a pole."[33] This rationale is based upon the technical possibilities of surgery, but it also reflects heteronormative norms about physical function: the idea that someone cannot be a man if they cannot penetrate a woman, and that someone cannot be a woman without being penetrated by a man. The same attitudes are also evident in narrow expectations for male and female bodies expressed in the idea that "real men" have to be able to stand to urinate.[34]

Human rights defenders question those attitudes as surgical intervention is dictated by social and cultural factors. Indeed, no potential quality of life issues are indicated in the ICD-11 information, other than those that might be derived from an associated minority status and, in the case of 17ß-HSD3, infertility. In the cases of both 5a-RD2 and 17ß-HSD3, genetic deselection is described as an option. This suggests the possibility of a pre-emptive elimination of bodies with intersex variations in place of surgical intervention, but neither surgery nor prenatal deselection are adequately justified.

A series of clinical papers has outlined risks of gonadal tumors as rationales for monitoring gonads in children with 5a-RD2 and 17ß-HSD3. For example, a 2006 clinical statement calls for the monitoring of gonads in children with 17ß-HSD3 due to a "medium" risk of gonadal tumors.[35] A later clinical review reduced the associated risk level.[36] However, the mention of gonadectomies in ICD-11 clinical descriptions for both 17ß-HSD3 and 5a-RD2 is dependent not on tumor risk but instead on gender assignment. This gendering of gonadectomies contradicts assertions made about tumor risk management and highlights the role of gender stereotypes in determining clinical practices. This gendering of gonadectomies also constrains children's future possibilities and choices, including those associated with gender identification, and for hormone production, and access to novel reproduc-

tive technologies.

A 2016 Australian legal case provides a specific example to illustrate the rationales and gender stereotyping that underpin the content of these ICD-11 codes. The case was taken before the Family Court of Australia to approve the gonadectomy of a 5-year-old child with 17ß-HSD3, described as having a "sexual development disorder" (that is, a "disorder of sex development"). The case documented the judge's view that a prior clitoral "recession" (a form of clitorectomy) and labioplasty had "enhanced the appearance of her female genitalia."[37] The judgment also disregarded evidence recommending monitoring of gonads, and made no reference to new evidence on reduced risks.

The rationale for the child's gonadectomy was substantively comprised of gender stereotypes, observed by a treating doctor in her multidisciplinary team and recounted by the judge:

> a. *Her parents were able to describe a clear, consistent development of a female gender identity;*
> b. *Her parents supplied photos and other evidence that demonstrated that Carla [a pseudonym] identifies as a female;*
> c. *She spoke in an age appropriate manner, and described a range of interests/toys and colours, all of which were stereotypically female, for example, having pink curtains, a Barbie bedspread and campervan, necklaces, lip gloss and 'fairy stations';*
> d. *She happily wore a floral skirt and shirt with glittery sandals and Minnie Mouse underwear and had her long blond hair tied in braids; and*
> e. *Her parents told Dr S that Carla never tries to stand while urinating, never wants to be called by or referred to in the male pronoun, prefers female toys, clothes and activities over male toys, clothes and activities, all of which are typically seen in natal boys and natal girls who identify as boys.*[38]

This evidence describes parental descriptions, and culturally specific, socially constructed ideas of femininity associated with a child too young to freely articulate a gender identity, for an irreversible medical intervention. Given that the surgeries in this case were each predicated on the initial gender assignment, the timing of the gonadectomy was deliberate: "it will be less psychologically traumatic for Carla if it is performed before she is able to understand the nature of the procedure."[39] Yet, at the same time, the heteronormative nature of the gender stereotypes involved in clinical and judicial decision-making led the judge to comment: "Carla may also require other surgery in the future to enable her vaginal cavity to have adequate capacity for sexual intercourse."[40]

The evidence in support of these medical interventions is lacking. A 2006 clinical statement cited clinician feelings, and a "belief" that early surgery "relieves parental distress and improves attachment between parents and child."[41] In the decade since, the quality of available evidence has not improved. A 2016 clinical review found that there is no consensus on surgery timing, indications, procedures, or outcome evaluation, and no evidence on the impact of intervention or non-intervention during childhood for the affected person, their family, or society.[42] A 2017 Council of Europe bioethics committee report summarized key research to state that:

> *(1) "quality of life" studies on patients into adulthood are lacking and are "poorly researched", (2) the overall impact on the sexual function on children surgically altered is "impaired" and (3) the claim that gender development requires surgery is a "belief" unsubstantiated by data.*[43]

The same paper makes a point, directly relevant to the Family Court case *Re: Carla*, that there is no guarantee that "infant surgery will be certain to coincide with the child's actual identity, sexual interests, and desires for bodily appearance" or function.[44]

Clinicians have argued that the practices documented in Carla's case and described in the ICD-11 no longer take place routinely, but such claims lack evidence, and so lack merit.[45] Governments have similarly attributed change to clinical practices. For example, the state where Carla lived had previously, in 2012, offered a reassurance that:

> *Previously it was an accepted practice to assign the external genitalia of a child during their childhood, often through surgical intervention … Research and investigation now advises against any irreversible or long-term procedures being performed on intersex children, unless a condition poses a serious risk to their health.*[46]

Similarly, a local clinical organization has suggested "a trend toward consideration of less genital and gonadal surgery" without providing supporting evidence.[47] The recent nature of the medical history detailed in Carla's case does not support such assurances, and nor does the ICD-11 Foundation code for 17ß-HSD3.

Human rights standards

In recent years, UN Treaty Monitoring Bodies have responded to testimonies by survivors of such practices provided by institutions and individuals in countries around the world. They have cited Treaty Articles on non-discrimination and protection from torture and experimentation, and on liberty and security, privacy, and equality before the law, issuing multiple recommendations in relation to such interventions.[48] These include the observations listed below.

- States must guarantee bodily integrity, autonomy, and self-determination to intersex children, and ensure that no one is subjected to unnecessary medical treatment during infancy or childhood.[49]
- States must protect intersex persons from violence, and harmful practices such as intersex genital mutilation.[50]
- States must adopt legislation to prohibit the performance of surgical or other medical treatment on intersex children unless such procedures constitute an absolute medical necessity, and until they reach an age at which they can provide their free, prior and informed consent.[51]
- States must repeal all types of legislation, regulations, and practices allowing any form of forced intervention or surgery, and ensure that the right to free, prior, and informed consent to treatment is upheld and that supported decision-making mechanisms and strengthened safeguards are provided.[52]
- States must ensure that no one is subjected to undocumented medical or surgical treatment during infancy or childhood.[53]
- States must ensure that intersex people's personal integrity and sexual and reproductive health rights are respected.[54]

These examples indicate a growing consensus by international human rights institutions in opposition to unnecessary irreversible surgeries on infants and children with intersex variations. At present, the ICD-11 Foundation code materials specify or otherwise facilitate such practices.

Reframing intersex-related codes and classifications

Given demands to review diagnostic terminology to avoid unnecessary medicalization, terminology in diagnostic codes should be changed to ensure that it does not predicate surgical interventions. At the same time, individuals able to provide consent need to able to access medical interventions. A more neutral language is needed in order to balance these needs. For example, the ICD-11 classification of "malformative disorders of sex development" could be replaced with "structural congenital variations of sex characteristics" or "structural differences of sex development." Descriptions facilitating medical interventions based on gender stereotypes or social norms should be deleted, including requirements, specifications, or suggestions for surgical intervention or genetic deselection.

Individuals subjected to unwanted medical interventions to modify their genitals may suffer consequences including impaired sexual function and sensation, incontinence, scarring, a need for further surgery, and lifelong hormone treatment.[55] For such persons, the introduction of a new ICD-11 code for "intersex genital mutilation" analogous to

an existing code on female genital mutilation may, like the code on female genital mutilation, facilitate access to consequential and reparative treatments.

Conclusion

Over time, WHO has consistently reviewed and removed pathologizing classifications and codes associated with sexual and gender minorities from the International Classification of Diseases (ICD). However, classifications associated with intersex variations, or differences of sex development, remain pathologized. As a result, the ICD-11 facilitates, and specifies, procedures that are regarded by UN and other institutions as violating human rights. Intersex advocates have made multiple collaborative submissions to WHO on these issues.[56]

WHO should reconsider the introduction of unnecessarily pathologizing language of "disorders of sex development" into the ICD. It should instead adopt alternative language such as "congenital variations of sex characteristics" or, failing that, "differences of sex development."

Codes and clinical information relating to all individual variations in sex characteristics should be reviewed to ensure that they do not specify or facilitate interventions that fail to meet human rights norms and that lack adequate supporting evidence. Terminology predicating unnecessary medical interventions without the consent of the recipient should be replaced.

To assist persons subjected to irreversible medical interventions, the addition of a new code for "intersex genital mutilation" may facilitate access to reparative treatments.

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