

Intersex Issues in the International Classification of Diseases: a revision

1. Introduction

On 8-9 September 2014 a group of intersex activists and experts met in Geneva to discuss the revision and reform of the International Classification of Diseases (ICD) at the World Health Organization. The meeting had three goals:

- To develop a collective analysis of intersex issues in the context of the ICD, including an analysis of significant changes between ICD-10 and ICD-11 (beta).
- To identify the key connections between intersex-related diagnoses, and current protocols and treatments aimed at “normalizing” intersex bodies.
- To highlight human rights issues related to current biomedical management approaches.

The meeting was organized by the GATE International Initiative on the ICD Reform Process, in partnership with ILGA. It was planned and coordinated by Mauro Cabral (GATE), facilitated by Ruth Baldaccino (ILGA) and attended by the following intersex activist participants:

Janik Bastien-Charlebois (Canada); Morgan Carpenter (Australia); Dan Ghattas (Germany); Holly Greenberry (UK); Natasha Jimenez (Costa Rica); Ev Blaine Matthigack (Germany); Nthabiseng Mokoena (South Africa); Daniela Truffer (Switzerland) and Markus Bauer (Switzerland).

The meeting was also attended by Michael van Gelderen (OHCHR); Eszter Kismödi (Human Rights lawyer); Doris Chou (WHO); Rajat Khosla (WHO); Sara Cotter (WHO); Robert Jakob (WHO); André Du Plessis (ILGA) and Renato Sabadini (ILGA).

As a first stage follow up to the meeting, the intersex participants have prepared this **introductory document** for the WHO Topic Advisory Group for Genitourinary, Reproductive & Maternal Health (GURM TAG) for the ICD revision, addressing specific concerns related to intersex issues in the ICD reform process. The document is intended as an invitation for a critical dialog between intersex activists and the World Health Organization.¹ It is grounded in the following **principles**:

- Intersex bodies are a healthy manifestation of human bodily diversity.
- Intersex people’s health and wellbeing depend on the distinguishing of medical necessity from established cultural norms that relate to sexual difference.
- Diagnostic classifications of intersex bodies have a direct impact on socio-medical management, including protocols, treatments and procedures regarding informed consent.
- The human rights of people with intersex variations must be taken into account in any revision and reform process concerning the diagnostic classifications of intersex bodies.
- Intersex people must be involved in all decision-making processes concerning them.
- Data, analysis and the production of knowledge concerning the socio-medical management of intersex bodies must be subject to scrutiny and critical revision.

2. Matters of terminology

2.1 Definitions

Intersex people are born with atypical variations in physical sex characteristics, including atypical genetic, hormonal or anatomical characteristics. The World Health Organization genomic resource centre utilizes a broad definition: “*Intersex is defined as a congenital anomaly of the reproductive and sexual system.*”² The UN Office of the High Commissioner for Human Rights states: “*An intersex person is born with sexual anatomy, reproductive organs, and/or chromosome patterns that do not fit the typical definition of male or female.*”³

Many forms of intersex exist; it is a spectrum or umbrella term, rather than a single category. It includes different numbers of sex chromosomes, different tissue responses to hormones, a different hormone balance or combination during prenatal development, and a range of atypical anatomical sex characteristics. Intersex traits also include developmental differences due to environmental factors. At least 30 or 40 different variations are known to science; 10-80% of cases are idiopathic, with no exact diagnosis⁴. Some common intersex variations are diagnosed prenatally, others may be apparent at birth. Some intersex traits become apparent at puberty, or when trying to conceive, or through random chance. However, most intersex characteristics are not pathological, but express healthy variation amongst human bodies.

2.1.1 Intersex and DSD

The term intersex originated in the early 20th century⁵, distinguishing intersex from the term “*hermaphrodite*”, increasingly associated in biology with organisms that can perform both “*male*” and “*female*” functions. Definitions and the scope of the word intersex vary, such as in response to arguments that the term is imprecise or pejorative, that affected persons are not intersex but girls and boys who need disambiguating⁶, or a difference that needs “*fixing*”⁷. This follows a historical pattern. For example, many intersex persons are not “*true*” hermaphrodites, they may be considered to be “*pseudo hermaphrodites*”⁸. In 2006, a *Clinician Consensus Statement* replaced the term intersex with *Disorders of Sex Development* or DSD⁹. DSD, and particularly the framing as “*disorders*”, has proved controversial; the term intersex is itself now far more widespread than in 2006, including in national legislation and regulation, medical guidance¹⁰, and usages by international institutions.

In an evolution of terminology driven by assertions of imprecise or pejorative wording, there is no evidence that new terms have resolved stigma¹¹ or led to better treatment or patient outcomes¹². Nevertheless, a full gamut of stigmatizing language persists in the ICD-11 draft, with the striking omission of the most commonly used word, the word most commonly used by national and international institutions and the community itself: intersex.

Intersex activists have been visible since the 1990s, including through the establishment of the Intersex Society of North America, Androgen Insensitivity Syndrome support groups, a Latin American consortium, national and international networks, and other actions aimed at changing dominant medical treatment protocols and promoting the rights of the child.

Scholars in medical sociology have identified that the rationale for a shift in terminology was a reassertion of medical authority in the face of community criticism. Georgiann Davis states:

*Medical professionals needed to maintain their authority in the face of intersex activism, and they did so linguistically through a reinvention of the intersex diagnosis. The new DSD terminology constructs "sex" as a scientific phenomenon, and a binary one at that...This places intersexuality neatly into medical turf and safely away from critics of its medicalization.*¹³

Morgan Holmes states that the terminology shift “reinstitutionalises clinical power to delineate and silence those marked by the diagnosis”¹⁴

In many situations, the introduction of Disorders of Sex Development also produces a disorder where no disorder otherwise exists. A Swiss National Advisory Commission on Biomedical Ethics report on intersex published in November 2012 stated:

*not all cases of DSD involve a (pathological) "disorder", i.e. a functional impairment associated with suffering. Not infrequently, a case of DSD may involve a variation from a norm of sex development which does not require medical treatment. From the perspective of those affected, the term "disorder" may thus appear stigmatizing*¹⁵

Similarly, a 2013 Australian Senate Community Affairs References Committee report on the *Involuntary or coerced sterilisation of intersex people in Australia* remarked that:

*2.4 Not everyone who is intersex has a health problem: whether they experience a 'disorder' is not defined by whether they are biologically 'intersex'. A person might have a form of Androgen Insensitivity Syndrome and present as having an uncommon physiology that appears neither completely female nor completely male, and they may or may not experience health issues.*¹¹

This document uses the term intersex to describe a broad range of congenital physical traits or variations that lie between stereotypical standards of male and female and to address human rights issues affecting intersex issues. The document scope extends to relevant diagnoses in the ICD-10 and ICD-11 (beta).

3. Intersex issues and the International Classification of Diseases

The ICD revision and reform process has a key relevance for the intersex movement. Diagnostic categories play a central role in expressing scientific understandings, establishing medical approaches, informing clinical protocols, defining surgical, hormonal and other treatments¹⁶. Diagnostic categories defining intersex bodies reify differences between stereotypical female and male bodies on the one hand, considered to be healthy, and bodies that vary from female and male standards on the other hand, considered to be “disordered”, or “abnormal”. Current classifications therefore contribute to stigma and discrimination against intersex people; they endow appropriateness¹⁷ to medical attempts to “fix” or “normalize” intersex bodies through surgical and hormonal means. They play a direct role in determining how intersex bodies are treated in society at large.

Everywhere in the world, people born with intersex traits are subjected to “normalizing” procedures, including clitoridectomies, labioplasties, vaginoplasties, gonadectomies, hypospadias “repair”, and treatment with steroids or sex hormones. Many of these procedures are performed during infancy and early childhood when intersex individuals cannot provide their informed consent. Intersex babies, infants, children and adolescents are also subjected to related practices in medical settings, such as continued exposure. In

different parts of the world, treatments also include socio-legal measures, including a lack of birth certificates.

Most of these treatments have lifelong consequences: they produce sterility, genital insensitivity and impaired sexual function¹⁸, chronic pain, chronic bleeding, and chronic infections, post-surgical depression, and trauma (in many cases associated with the experience of rape), massive internal and external scarring, metabolic imbalances. These procedures have been internationally denounced as institutionalized forms of genital mutilation^{19 20 7}. They reproduce and reinforce the cultural sense of intersex bodies as disordered and shameful; they produce coercive social environments.

The ICD reform process would benefit from a in-depth revision of assumptions and conceptions around sex, and the connection between clinical language and treatments. In our review of both ICD-10 and ICD-11 (Beta), it is notable that the term intersex is not explicitly included; however, intersex-related diagnoses are contained in both versions, with many common characteristics:

- Both ICD versions share the same implicit and normative conception of sex as binary, rendering all bodies that vary from female or male standards as pathological by definition.
- While heterogeneous in their application, both ICD versions share the same negative definitional approach to intersex bodies, employing pathologizing and stigmatizing diagnostic descriptions such as “*disorder*”, “*disease*”, “*malformation*”, “*pathologic*”, “*defect*”, and “*abnormality*”. Multiple such terms may be employed in the same diagnosis.
- Both ICD versions combine different diagnostic languages (such as, ‘hermaphroditism’ and ‘DSD’).

Intersex-related diagnoses in **ICD-10** are included under the following chapters:

- Chapter IV on Endocrine, nutritional and metabolic diseases.
- Chapter XIV on Diseases of the genitourinary system
- Chapter XVII on Congenital malformations, deformations and chromosomal abnormalities.

In the case of **ICD-11 (Beta)**, intersex-related categories can be found in the following chapters:

- Chapter 5. Endocrine, nutritional and metabolic diseases
- Chapter 6. Conditions related to sexual health
- Chapter 17. Diseases of the genitourinary system
- Chapter 20. Developmental anomalies

The most evident changes between ICD-10 and ICD-11 are:

- The introduction of *Disorders of Sex Development* as the main diagnostic category. This introduction, compatible with the language proposed by the 2006 *Clinician Consensus Statement*, represents an epistemological turn to genetics in the definition of intersex-related categories, but also a re-assertion of medical authority and a re-medicalization of intersex bodies.
- The introduction of Chapter VI on Conditions Related to Sexual Health.

In regard to Chapter VI we consider necessary to call the attention of WHO on two particular issues:

- The introduction of the proposed category of 'gender incongruence of childhood', is strongly opposed by trans* activists and experts.²¹ Their opposition is based on two main grounds: the notion of '*gender incongruence of childhood*' has no medical utility, and it pathologizes healthy gender diversity in childhood, with the concomitant risk of reinforcing the gender binary, promoting stigma and discrimination, and justifying reparative therapies and other compulsive treatments. For the same reasons, the proposed category of '*gender incongruence of childhood*' poses a serious risk for intersex children. '*Normalizing*' procedures are frequently justified by the imperative of creating bodily congruence –for example, by removing '*incongruent*' organs, such as gonads that do not match assigned sex, or reducing '*incongruent*' tissue to make organs congruent with stereotypical male and female anatomies. As a consequence, the evaluation of this proposed category must include its potential negative effects on intersex children's health and rights.
- The introduction of the proposed categories of "*changes in male anatomy*" (6A50-6A5Z) and "*changes in female anatomy*" (6A40-6A4Z) and, in particular, the introduction of "*female genital mutilation*" (6A40) indicate a clear intention to address genital cutting. This material should additionally include a new section on "*changes affecting intersex anatomy*".

4. Selected specific issues with the ICD framework and diagnoses

A non-exhaustive selection of specific concerns with the ICD and diagnoses of intersex variations in the ICD is presented in this section.

4.1 Rationales for treatment

4.1.1 Psycho-social rationales

The 2006 *Clinician Consensus Statement* places the justifications for "*psychosocial*" interventions on minors with intersex variations with society, and in particular with parents; its rationales included "*minimizing family concern and distress*" and "*mitigating the risks of stigmatization and gender identity confusion*".⁹ In a 2014 review, Hiort *et al* describe how the "*Disorder*" in DSD reflects clinical and societal understanding: "*Inclusion of the term 'disorder' reflects the fact that most parents and medical professionals have a traditional binary concept of sex development*"²². A 2013 paper by Creighton *et al* makes the same point, that surgical interventions are for families, and surgeries should be targeted accordingly⁴⁹.

In what appears to be a circular argument, Pasterski *et al*, 2014, describe an intersex birth as a "*challenging clinical emergency*" due to issues such as sex assignment and genital surgeries, remarking that parents are as traumatised as parents of a child diagnosed with cancer²³. Professor Julie Greenberg notes that parents find it difficult to "*objectively determine the treatment that would be in their child's long term best interests, especially because the issue may affect sexuality when the child becomes an adult... most parents believe that "normal" appearance and not potential erotic response would be more important to their child's well-being*"²⁴.

In many times and places, sex assignments encapsulate cultural and religious biases toward the social and economic standing of men and women. In Malaysia, research showed that assignments of infants with the same intersex variation differed depending on their parent's culture and attitudes towards dowries²⁵. Similarly, Lee *et al* report in 2014:

*Religious and cultural factors influence medical decisions and quality of life in CAH. For example, a study from Vietnam recognized that expectations of future marriage and reproduction were main worries of parents with CAH children. Other cultures in the Middle and Far East favor male over female offspring, and these views have been reported to influence sex assignment in DSD.*²⁶

A 2013 framework document for decision-making published by the Victorian Department of Health in Australia defines psychosocial rationales for medical intervention as including “*risk of social or cultural disadvantage to the child, for example, reduced opportunities for marriage or intimate relationships, or reduced opportunity for meaningful employment and capacity to earn an income*”²⁷. In a critique of such rationales, the Swiss National Advisory Commission on Biomedical Ethics stated in 2012: “*If such interventions are performed solely with a view to integration of the child into its family and social environment, then they run counter to the child’s welfare. In addition, there is no guarantee that the intended purpose (integration) will be achieved.*”²⁸ The ICD-11 (beta) draft contains no provision for the treatment of parental distress or discomfort associated with the birth of an infant with an intersex variation.

4.1.2 Tumor risk

Rationales for surgical intervention also include risk of cancer. However, there is evidence that issues such as sex of rearing are interpolated into decision making processes, undermining their neutrality²⁹. Risk assessments are highly variable³⁰, subjective³¹ and based on small sample sizes and the repetition of out-dated data³². It is unclear whether or not widespread early surgical interventions have undermined the ability to perform accurate risk assessments associated with ageing³³.

4.2 ‘Normalizing’ treatments

4.2.1 ‘Feminizing’ treatments

In 19th Century Western medicine, clitoridectomies on girls were prevalent as a “*harmless*” “*cure*” for masturbation, hysteria, and “*enlarged clitoris*”³⁴ – today such surgeries are recognized as Female Genital Mutilation (“FGM”) on non-intersex girls. While clitoris amputations motivated by rationales of masturbation and hysteria attracted mounting criticism within the medical community, and were mostly abandoned between 1900 and 1945³⁵, amputations of “*enlarged clitorises*” rose after 1950. In the 1960s they became the predominant medical standard for intersex newborns³⁶. For decades, doctors claimed, “*removal of clitoris does not interfere with the ability to achieve orgasm*”, and would reportedly facilitate “*normal sexual function in these females*”^{37 38 39} Only in the 1980s and 1990s were clitoris amputations replaced by more modern “*better*” techniques of partial amputations described as “*clitoris reduction surgeries*” amid claims of improved outcomes⁴⁰. Howard Devore in 1995⁴¹, Crouch *et al* in 2004⁴², and the Victoria Department of Health in 2013⁴³ each reflect on unsubstantiated claims of improved surgical techniques, yet in 2013 the Royal Children’s Hospital Melbourne recognises that “*outcomes related to current practices remain to be established*”⁴⁴. The necessity for non-consensual “*sex normalizing*” interventions remains to be established^{45 46}. In Victoria, Australia, for example, cultural rationales such as improving marriage prospects remain explicitly valid¹⁰, even while such rationales are prohibited in non-intersex girls⁴⁷.

Ahmed *et al*, 2014, suggest that the 2006 Clinician Consensus Statement encourages, “[a]n emphasis on functional outcome rather than, simply, cosmetic appearance”, however, “there is little published evidence that surgical practice has changed”⁴⁸. Creighton *et al* reported in 2013 that UK health service statistics show “an increase in the number of operations on the clitoris in under-14s since 2006”; surgeon attitudes towards surgical interventions are fixed and medical literature continues to focus on surgical technique, rather than patient experience⁴⁹.

In ICD-11 (beta) “5A60.2 Congenital adrenal hyperplasia”, states: “*Genital anomalies in females may require surgical intervention(s).*” In the case of infants with Congenital Adrenal Hyperplasia, surgical interventions are based on a presumed need to reinforce a binary gender assignment, and prepare for heterosexual intercourse, with surgeries recommended in a child’s first year. Individual capacity for cortisol production varies widely, but only the reference range for women may be considered. Hormone treatment to suppress testosterone, for example Cyproterone acetate, has side effects including libido suppression, cognitive impairment, edema, myoma and weight gain⁵⁰.

Adults, as well as children, may be subjected to “*partial clitoridectomies*”. The IOC mandates that national sports authorities “*actively investigate any perceived deviation in sex characteristics*”⁵²; other sports codes follow suit. Journal articles in 2013 and 2014 documented how four elite women athletes from developing nations were subjected to clitorectomies and removal of their gonads as part of a process deemed necessary for them to compete in sport – and with no guarantee of continued access to medical treatment for the rest of their lives^{51 52}. Jordan-Young *et al* note that the elite women athletes “*may have no health complaints stemming from the androgen excess itself*”, but:

*The most striking and troubling illustration of these concerns is that all of the athletes in the recent report had “partial clitoridectomy.” Clitoridectomy is not medically indicated, does not relate to real or perceived athletic “advantage,” and is beyond the policies’ mandate. Moreover, this technique is long eschewed because it has poor cosmetic outcomes and damages sexual sensation and function. Clitoral surgery should have no role in interventions undertaken for athletes’ eligibility or health.*⁵²

Medical treatment is predicated on the assumption that bodies must fit a stereotypical standard of normality, and that bodies that develop differently are defective or disordered. The definition of “*clitoromegaly*” in ICD-11 is a “*congenital abnormality*” described in HA84 as: “*an abnormal enlargement of the clitoris (not to be confused with the normal enlargement of the clitoris seen during sexual arousal)*”.

Such stereotypical sex standards are subjective. Jillian Lloyd *et al*, at the University College London Hospitals note enormous variation in the size of women’s genitals⁵³, yet recent literature only describes “*a clitoris that is in the right position and of the right size*”⁵⁴. In a 2009 study of 210 Dutch physicians, Welmoed Reitsma *et al* examined the dispositions of general practitioners, gynaecologists and plastic surgeons to refer or perform a surgical labia minora reduction, along with their experience of performing such surgeries and their beliefs about societal ideals. The study found that attitudes towards surgical interventions change according to both medical specialism and clinician gender: male doctors were more inclined to recommend surgical intervention⁵⁵.

Vaginoplasties are another common feminizing treatment, performed on girls affected by CAH, by complete or partial Androgen Insensitivity Syndrome, or by Mayer Rokitansky Kuster Hauser Syndrome. Vaginoplasties, as well as other associated genitoplasties, are also performed to feminize intersex bodies when an infant has been assigned female at birth—for example, in cases of penile agenesis.⁵⁶ Early surgical interventions are known to have significant negative consequences:

*In children with ambiguous genitalia assigned female, vaginoplasty is commonly performed during the first year of life even though the child will not menstruate for a further 10 or so years and is unlikely to be sexually active until after puberty. High rates of introital stenosis of up to 100% have been demonstrated as well as frequent requirements for repeated reconstructive surgery in adolescence before tampon use or intercourse. Given that there is no available data to suggest early infant vaginoplasty has a better long-term outcome than a later delayed surgery, vaginoplasty in infancy is, then, chiefly to create a reassuring appearance for parents and clinicians’.*⁵⁷

Vaginoplasties usually require regular follow-up treatment through dilation⁵⁸, a procedure that has been repeatedly identified as an experience comparable with rape by intersex people forced to undergo it after non-consensual interventions, or following interventions where consent was not fully informed. The latter cases are characterized by inadequate or incomplete access to proper information regarding follow up treatment and long-lasting consequences. “[D]ense scarring and the closing of the vagina opening are common complications [in addition to] chronic pain during intercourse, excessive vaginal secretion and total closure of the vagina”⁵⁹, complicated by other factors “including poor communication, inadequate follow-up, humiliating encounters with health professionals including medical photography, poor treatment outcome, and inadequate psychological support”.⁶⁰

4.2.2 ‘Masculinizing’ treatments

Research indicating unreasonable expectations of normality in men’s genitalia does not provide a breakdown of clinician responses by gender or specialism. Hypospadias is diagnosed where the urethra opens anywhere from the glans of the penis to the perineum, rather than at the tip of the penis. Clinician organisations such as the Australasian Paediatric Endocrine Group regard the surgical “correction” of hypospadias as simply a physical (rather than cultural) necessity, primarily to enable urination while standing⁶¹. Incidence data varies dramatically. Professor Alice Dreger referenced a 1995 German study⁶² and concluded that:

*...urologists have unreasonably strict expectations for penises. These physicians looked at a group of 500 men and found that only 55 percent could be labeled “normal,” according to medical standards. Of the 500, fully 225 counted as having hypospadias... The physicians also questioned whether surgical “correction” of hypospadias was necessary, given what they admitted was the “significant complication rate” of “reparative” surgeries*⁶³

Only 6 of the 225 men with hypospadias were aware of any physical anomaly, yet surgical interventions are challenging, and complications frequent. Singh report research showing that “commonest sexual complaints included short penis, increased curvature, painful erection, and no erection”⁶⁴; nearly half of patients were ridiculed for their genital appearance; with no non-surgical control group. Chrzan *et al* report complications in 31% of cases. Barbagli *et al* report that failures can arise “many years after achieving successful functional and cosmetic results”; in a study of 1,176 cases reported in 2012, 11.9% were considered “failures”, and the majority of these were said to “require surgical reconstruction

to fully resurfacing the glans and penile shaft”.⁶⁵ Chertin *et al* and others note a “growing industry” of treatment of urethral strictures in “hypospadias cripples”; the reasons for strictures are not completely known but may, at least in part, be “inherent to hypospadias itself”⁶⁶ or a “natural evolution over time”⁶⁷.

Surprisingly given the occurrence of long term failures, long-term follow up is rare, for example, because pediatric urologists do not follow patients into adulthood, and because patients “have been shown to be reluctant to seek further medical advice despite significant distress”; clinicians acknowledge that such data are necessary “to provide an honest and meaningful account” of results⁶⁸. Given the limitations of such data, a “common weakness of the existing literature is that most studies have been based on surgeon impressions of outcome, as opposed to patient satisfaction”⁶⁸.

Surgical complications and poor functional results and sensation are typically regarded as a rationale for further investigation and refinement of surgical techniques, rather than a case for fundamentally questioning the rationales for these cosmetic surgeries. Disclosure of complications is often limited, for example, to statements that the incidence of “complications has decreased with modern techniques”⁶⁹. Documentation of complication rates has declined in the last decade⁷⁰.

4.2.3 Prenatal treatment

Dexamethasone, a steroid, is used to prevent homosexuality and physical “virilization” in infants with CAH assigned female^{71,72}. This is defended as a means of preventing post-natal elective surgical treatments, and is considered to be of greater benefit than established cognitive and physical risks to the children exposed to such treatment⁷³. Dexamethasone treatment does not address the more critical issue of salt wasting associated with CAH, an issue which may necessitate urgent medical attention to ensure the health of an infant. Genital variation is seen as a social emergency.

4.2.4 Sterilization

Sterilization is a consequence of treatment rationales related to tumor risk. The fertility of persons with intersex variations is not valued in the same way as that of other persons – and sterilizations may not be viewed as such if a child’s capacity for fertility does not match a gender assignment or reassignment⁷⁴ removing a person’s only route to biological parenthood.

4.2.5 Genetic selection

The four elite women athletes subjected to partial clitoridectomies are known to have 5-alpha-reductase deficiency. Despite their capacity for elite athletic performance, this intersex variation is one of several listed as appropriate for genetic de-selection via IVF in the UK⁷⁵. 5-alpha-reductase deficiency solely has implications for fertility and cosmetic effects on sex development⁷⁶.

The health impacts of sex chromosome differences such as 47,XXY and 45,X0 are typically considered to be cognitive differences, infertility and differences in stature and physical appearance. In some cases there may be other concurrent health concerns – nevertheless, the World Health Organization states that sex chromosome anomalies are “compatible with normal life expectancy and often go undiagnosed”⁷⁷. Indeed, a 2010 consensus statement on diagnosis and clinical management of Klinefelter syndrome (47,XXY) reports “only 25% of estimated cases are diagnosed post-natally, and <10% are detected at or before birth”⁷⁷. Such low rates of diagnosis skew reported health impacts of diagnosis as non-diagnosed,

often asymptomatic, persons do not come to the attention of clinicians. Despite these low rates of diagnosis, termination rates for 47,XXY once diagnosed during pregnancy are known to reach up to 88%.^{78 79} The framing of this diagnosis as a major genetic disorder thus has a dramatic impact on the percentage of pregnancies carried to term.

As differing forms of sex and gender non-conformity, sexual orientation, gender identity, gender expression and intersex variations are closely intertwined. The genetic de-selection of intersex traits is based upon heteronormative expectations of future identities and behaviours, as well as expectations of different social roles for men and women. Behrmann and Ravitsky comment that sex, gender and sexual orientation are “intertwined”. “Parental choice against intersex may thus conceal biases against same-sex attractedness and gender nonconformity”.⁸⁰

5. Human Rights issues

Intersex people face gross human rights violations everywhere; very many are committed in medical settings, and associated with treatments described above. ‘Normalizing’ procedures violate right to physical and mental integrity, the right to freedom from torture and medical abuses, the right to not being subjected to experimentation, the right to take informed choices and give informed consent, the right to privacy and, in general, sexual and reproductive rights. Those procedures violate the rights of people with intersex variations to health and wellbeing, by altering bodies through irreversible procedures with long-lasting negative consequences. Therefore, treatments described in the previous section of this document fall into the scope of the ICSRC Comment 15, which “right to control one’s health and body, including sexual and reproductive freedom”⁸¹, as well as the “right to be free from interference, such as the right to be free from torture, non-consensual medical treatment and experimentation”.⁸²

As many medically unnecessary and unconsented ‘normalizing’ treatments are performed during infancy and early childhood, intersex children suffer a constant violation of their human rights, including Articles 2, 3, 7, 8, 12, 17 and 39 of the *Convention on the Rights of the Child*. Para. 101 of the General Comment 12 on CRC establishes that

States Parties need to introduce legislation or regulations to ensure that children have access to confidential medical counseling and advise without parental consent, irrespective of the child’s age, where this is needed for the child’s safety or well-being (...) The right to counseling and advise is distinct from the right to give medical consent and should not be subject to any age limit.

The recent Joint General Comment recently produced by CRC and CEDAW on harmful practices define them in terms perfectly consistent with ‘normalizing’ treatments applied to intersex people, including intersex girls, boys and women. In paragraph 14 of the General Comment, harmful practices are introduced as:

... persistent practices and behaviours that are grounded on discrimination on the basis of sex, gender, age and other grounds as well as multiple and/or intersecting forms of discrimination that often involve violence and cause physical and/or psychological harm or suffering. The harm that these practices cause to the victims surpass the immediate physical and mental consequences and often has the purpose or effect of impairing the recognition, enjoyment and exercise of the human rights and fundamental freedoms of women and children. There is also a negative impact on their dignity, physical, psychosocial and moral integrity and development, participation, health, educational, economic and social status.

These practices are therefore reflected in the work of both the CEDAW and CRC Committees.

In that sense, clitoridectomies, labioplasties, vaginoplasties and other genitoplasties performed for ‘normalizing’ reasons and without intersex people’s informed consent fall into the definition of Female Genital Mutilation provided by the same CRC and CEDAW General Comment on its paragraph 18:

‘Female genital mutilation, female circumcision or female genital cutting is the practice of partially or wholly removing the external female genitalia or otherwise injuring the female genital organs for non-medical or non-health reasons. In the context of this GR/GC, it will be referred to as female genital mutilation (FGM). FGM is performed in every region of the world and within some cultures, is a requirement for marriage and believed to be an effective method to control women’s and girls’ sexuality. The practice may lead to a variety of immediate and long-term health consequences, including severe pain, shock, infections and complications during childbirth affecting both the mother and child, long-term gynaecological problems such as fistula as well as psychological consequences and death. WHO and UNICEF estimate that between 100 and 140 million girls and women worldwide have been subjected to one of the types of FGM.’

The Yogyakarta Principles on the Application of International Human Rights Law in relation to Sexual Orientation and Gender identity includes Principle 18 on Protection from Medical Abuses.⁸³ According to that Principle, States shall:

‘ensure that no child’s body is irreversibly altered by medical procedures in an attempt to impose a gender identity without the full, free and informed consent of the child in accordance with the age and maturity of the child and guided by the principle that in all actions concerning children, the best interests of the child shall be a primary considerations’.

At the international level there have been recent and positive developments in the identification of intersex issues as human rights issues. In 2009 the Special Rapporteur on right of everyone to the enjoyment of the highest attainable standard of physical and mental health⁸⁴ presented a report explicitly focused on informed consent. Paragraph 49 affirms:

Health-care providers should strive to postpone non-emergency irreversible interventions until the child is sufficiently mature to provide informed consent.

In the same Report, footnote #67:

This is particularly problematic in the case of intersex genital surgery, which is a painful and high-risk procedure with no proven medical benefits.

In 2011, the Office of the High Commissioner for Human Rights published its report on *Discriminatory laws and practices and acts of violence against individuals based on their sexual orientation and gender identity*⁸⁵. Paragraph 57 affirms that:

...Intersex children, who are born with atypical sex characteristics, are often subjected to discrimination and medically unnecessary surgery, performed without their informed consent, or that of their parents, in an attempt to fix their sex.

In 2012, the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment published a ground-breaking report on violence in medical settings. It included specific mention of intersex issues:⁸⁶

Children who are born with atypical sex characteristics are often subject to irreversible sex assignment, involuntary sterilization, involuntary genital normalizing surgery, performed without their consent or that of their parents, ‘in an attempt to fix their sex leaving them with permanent, irreversible infertility and causing severe mental suffering.

The Special Rapporteur calls upon all States to repeal any law allowing intrusive and irreversible treatments, including forced genital-normalizing surgery, involuntary sterilization, unethical experimentation, medical display, “reparative therapies” or “conversion therapies”, when enforced or administered without the free and informed consent of the person concerned. He also calls upon them to outlaw forced or coerced sterilization in all circumstances and provide special protection to individuals belonging to marginalized groups.

And under its recommendations:

B.85.(e) Safeguard free and informed consent on an equal basis for all individuals without any exception, through legal framework and judicial and administrative mechanisms, including through policies and practices to protect against abuses. Any legal provisions to the contrary, such as provisions allowing confinement or compulsory treatment in mental health settings, including through guardianship and other substituted decision-making, must be revised. Adopt policies and protocols that uphold autonomy, self-determination and human dignity. Ensure that information on health is fully available, acceptable, accessible and of good quality; and that it is imparted and comprehended by means of supportive and protective measures such as a wide range of community-based services and supports (A/64/272) Instances of treatment without informed consent should be investigated; redress to victims of such treatment should be provided.

Following presentations at the Human Rights Commission and the Human Rights Council, on 11 March 2014, the first panel on intersex issues took place.⁸⁷ Also in 2014, OHCHR, UN Women, UNAIDS, UNDP, UNFPA, UNICEF and WHO published a *Interagency Consensus Statement on Eliminating forced, coercive and otherwise involuntary sterilization*⁸⁸ addressing human rights violations against people with intersex variations:

Intersex persons may be involuntarily subjected to so-called sex-normalizing or other procedures as infants or during childhood, which, in some cases, may result in the termination of all or some of their reproductive capacity. Children who are born with atypical sex characteristics are often subjected to cosmetic and other non-medically indicated surgeries performed on their reproductive organs, without their informed consent or that of their parents, and without taking into consideration the views of the children involved. As a result, such children are being subjected to irreversible interventions that have lifelong consequence for their physical and mental health.

Medical procedures that might result in sterility may sometimes be justified because of benefits to health, including the reduction of cancer risk. Such treatments may be recommended for transgender or intersex persons; however, they may be proposed on the basis of weak evidence, without discussing alternative solutions that would retain the ability to procreate. Parents often consent to surgery on behalf of their intersex children, including in circumstances where full information is lacking.

It has been recommended by human rights bodies, professional organizations and ethical bodies that full, free and informed consent should be ensured in

connection with medical and surgical treatments for intersex persons and, if possible, irreversible invasive medical interventions should be postponed until a child is sufficiently mature to make an informed decision, so that they can participate in decision-making and give full, free and informed consent. It has also been recommended that health-care professionals should be educated and trained about bodily diversity as well as sexual and related physical diversity, and that professionals should properly inform patients and their parents about the consequences of surgical and other medical interventions.

At the regional level there have been other promising developments. In March 2013 the Inter American Human Rights Commission held, for the first time, a Thematic Hearing on intersex issues and human rights.⁸⁹ In the same year, the European Parliamentary Assembly passed *Resolution 1952 (2013) on Children's right to physical integrity*⁹⁰; it mandates States:

undertake further research to increase knowledge about the specific situation of intersex people, ensure that no-one is subjected to unnecessary medical or surgical treatment that is cosmetic rather than vital for health during infancy or childhood, guarantee bodily integrity, autonomy and self-determination to persons concerned, and provide families with intersex children with adequate counselling and support.

5.1 Addressing intersex human rights at national level

In 1999 the Colombian Constitutional Court ruled in case SU-337⁹¹ that a mother should not be able to consent to a 'normalizing' surgical procedure on behalf of her eight years old intersex child. This land-marking affirmation of intersex people's right to self-determination opened the way for other successful cases at the same jurisdiction.

In 2004, the San Francisco Human Rights Commission conducted a hearing on intersex issues, and in 2005 launched the report titled *Human Rights Investigation Into The Medical 'Normalization' of Intersex People*.⁹² The report stated that "Infant genital surgeries and sex hormone treatments that are not performed for the treatment of physical illness ... are unnecessary and are not medical or social emergencies... "Normalizing" interventions done without the patient's informed consent are inherent human rights abuses."

In 2012 the Swiss National Advisory Commission on Biomedical Ethics published the report *On the management of differences of sex development. Ethical issues relating to 'intersexuality'*⁹³. It states:

- 1. The suffering experienced by some people with DSD as a result of past practice should be acknowledged by society. The medical practice of the time was guided by sociocultural values which, from today's ethical viewpoint, are not compatible with fundamental human rights, specifically respect for physical and psychological integrity and the right to self-determination.*
- 4. Protection of the child's integrity is essential. Given the uncertainties and imponderables involved, a psychosocial indication cannot in itself justify irreversible genital sex assignment surgery in a child who lacks capacity.*
- 12. There should be a legal review of the liability implications of unlawful interventions in childhood, and of the associated limitation periods. Questions of criminal law, such as the applicability of offences of assault (Art. 122 and 123, StGB) and the prohibition on genital mutilation (Art. 124, StGB), should also be investigated.*

In October 2013, the Australian Senate published a report stating “*Normalising appearance goes hand in hand with the stigmatisation of difference.*”¹¹ It identified “*disturbing*” issues with current medical practices affecting children with intersex variations, finding that there is no medical consensus about the conduct of surgical interventions, and standards of “*normality*” are subjective. The report recommended deferring interventions that are not medically necessary until the persons affected can consent. It also called for national human rights-based standards, effective oversight, long term follow-up, and linkages between community organizations and hospitals.

In 2014 the Emancipation department of the Dutch Ministry of Education, Culture and Science commissioned the production of an exploratory report on the social situation of intersex people in the Netherlands, titled *Living with intersex/DSD. An exploratory study of the social situation of persons with intersex/DSD.*⁹⁴

In October 2014, the Maltese government published a consultation paper on a proposed Gender Identity, Gender Expression and Sex Characteristics Bill providing for a “*right to bodily integrity and physical autonomy for all persons*”, and proposals to make “*non-medically necessary treatment on the sex characteristics of a person without informed consent unlawful*”⁹⁵.

6. Epistemological analysis

Despite the clear evidence of a need for changes to diagnoses and treatment protocols provided by intersex activists and experts, as well as their allies in different fields, there is still strong resistance to change. An epistemological analysis was documented during the meeting in Geneva.

Intersex medical management practices were instigated and developed without prior long-term impact studies⁹⁶. Doctors utilized educated guesses to initiate or modify medical interventions, and regarded their own judgment as intrinsically better than the judgments of persons with Intersex variations. Claims include suggestions that no large-scale study demonstrates negative impact⁹⁷; evidence based research is required to revise current practices^{98 97}, and clinical appraisals purport a “*satisfied silent majority*”^{99 106}.

In a pilot study that attempted to manage issues of sample and selection bias present in previous studies, Schützmann et al (2009) report that adults with intersex variations “*are markedly psychologically distressed with rates of suicidal tendencies and self-harming behavior on a level comparable to non-DSD women with a history of physical or sexual abuse*”¹⁰⁰. All but one participant in this study had received some form of surgical or hormonal “*sex normalizing*” intervention.

In a study in Lübeck conducted between 2005 and 2007, the *Klinische Evaluationsstudie im Netzwerk DSD/Intersexualität: Zentrale Ergebnisse*“, 81% of 439 individuals had been subjected to surgeries due to their intersex diagnoses¹⁰¹. Almost 50% of participants reported psychological problems. Two thirds of the adult participants drew a connection between sexual problems and their history of surgical treatment. Participating children reported significant disturbances, especially within family life and physical well-being – these are areas that the medical and surgical treatment was supposed to stabilize. 75% of participating teenagers had *no* experience with petting and masturbation; even though these are habitual for 82% of girls and 77% of boys of the same age¹⁰². Despite alarming statistics, and clear statements about surgeries and medical treatment, the research groups

still hesitated to draw obvious conclusions. While admitting that complications following the surgeries were high, „die Komplikationen infolge von Operationen trotz verbesserter Operationstechniken „immer noch recht hoch“ liegen“, they opted for further studies to research the reasons for stated psychological and sexual difficulties¹⁰³.

In 2013, the UN Special rapporteur on torture referenced “*structural inequalities, such as the power imbalance between doctors and patients, exacerbated by stigma and discrimination, result in individuals from certain groups being disproportionately vulnerable to having informed consent compromised*”¹⁰⁴. This is evident not simply in the age of most intersex persons at times of medical interventions, but also in the production of knowledge on intersex health and wellbeing.

The studies do not simply depict a significant lack of contentment amongst participating intersex persons in regard to the treatments they had undergone, they also show that studies conducted by the medical establishment, or produced within a medical framework, are in danger of reproducing the hegemonic medical discourse which opts for surgeries as *the* solution. Furthermore such studies only include intersex people who are willing to engage with the medical establishment. Engagement levels are known to be low¹⁰⁵.

From an epistemological perspective, the following observations can be made of the production of knowledge on intersex health and wellbeing:

- Medical researchers do not lead research from a neutral and disinterested position¹³⁹⁹, or from a reflexive position, open to fundamental re-evaluation and self-critique¹⁰⁶. Power-dynamics influence data-collection^{107 108 109}. Clinician decision making is influenced by characteristics such as their specialism and gender⁵⁵.
- Researchers interpret their own results, often in their own hospitals, assessing the outcomes of their own treatment paradigms¹⁰⁰; there is selection and sampling bias^{108 109 110 111}.
- Conclusions that do not meet study expectations of successful patient outcomes serve not to prompt a fundamental review of reassessment of clinical practices, but instead serve to promote further clinical research and study²⁶.
- When doctors are in control of the terms of evaluation, and interpretation of data⁹⁶, intersex persons and community groups are in no position to provide acceptable data. Testimonials of negative experiences by people with intersex variations, and intersex human rights claims, are regarded as insufficient to change medical discourse and practice^{112 113 114 115}. The voices and perspectives of persons with intersex variations are filtered through a medical lens, and independent evidence-based research is virtually impossible.
- Clinicians claim that there is no evidence children can develop successfully without surgical interventions despite a lack of conclusive evidence in favor of such interventions¹⁸. This is misleading and unscientific,¹¹⁶ in part a product of selection and sampling bias.
- There is no evidence of clinician consensus on the conduct of “*normalizing*” surgeries¹¹⁷.
- Controversies in the treatment of infants and children with intersex variations are portrayed by clinicians as a dispute over degree of genital ambiguity necessitating intervention, and the timing of interventions¹⁸, rather than the case made by intersex activism and the UN interagency statement on forced sterilization: a case for patient autonomy through full, free and informed decision-making, non-discrimination and access to remedies⁸⁸.

For research and data collection to be valid, legitimacy requires closeness to the studied population, to indicators and dimensions that intersex persons consider relevant, and to the meanings they attach to them^{118 119}. Medical researchers must not superimpose their own meaning, for example, through adopting a biomedical framework which focuses on bodily outcome and ignores psychological and social outcomes¹²⁰.

7. Conclusions

Intersex bodies are a healthy manifestation of human bodily diversity. People with intersex variations, like other people, may have health issues, however, the disordering and pathologization of intersex creates disorders where no disorder may otherwise exist. The human rights of intersex people must be taken into account in the ICD reform process, in healthcare diagnoses, rationales for treatment, treatment protocols, and the production of knowledge. The reform process must critically review assumptions and conceptions regarding sex.

We recommend that the WHO and GURM TAG:

1. Comprehensively review and consider intersex issues within the context of human rights of intersex people, and in the context of the medical ethical principle of “*do no harm*”.
2. Engage with intersex activists regarding intersex-related diagnoses in the ICD reform process.
3. Conduct a critical review of assumptions regarding the sex binary norms underlying those diagnoses.
4. Ensure that diagnoses focus on issues of clear and evidenced medical necessity, rather than social, cultural and/or normative understandings of sex.
5. Remove diagnostic categories arising from social or cultural norms regarding sexual difference from the ICD. Social stigma, gender or sexual stereotypes and/or parental distress must not drive the classification of intersex-related diagnoses.
6. Introduce references to enable the management and mitigation of distress arising from stigma and discrimination, including parental distress.
7. Introduce references to mitigate trauma and distress arising from “*changes in intersex anatomy*”, such as intersex genital mutilation.
8. Introduce references to grant intersex people full access to healthcare in different institutional settings, including access to information, counseling and support.
9. Consider with particular attention those diagnoses affecting newborns, infants and children.
10. Contribute to the dismantling of the pathologization and stigmatization of bodily diversity.

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