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Submission by GATE to the World Health Organization: Intersex codes in the International Classification of Diseases (ICD) 11 Beta Draft

A major concern for intersex people is that so-called sex normalizing procedures are often undertaken during their infancy and childhood, to alter their bodies, particularly the sexual organs, to make them conform to gendered physical norms, including through repeated surgeries, hormonal interventions and other measures. As a result, such children may be subjected to medically unnecessary, often irreversible, interventions that may have lifelong consequences for their physical and mental health, including irreversible termination of all or some of their reproductive and sexual capacity. Medical procedures may sometimes be justified in cases of conditions that pose a health risk or are considered life-threatening. Such procedures, however, are sometimes proposed on the basis of weak evidence, without discussing and considering alternative solutions

- World Health Organization. "Sexual health, human rights and the law". 2015.

[No clinically-accepted intersex] protocol has emerged to explain, as a matter of science, how infant surgery will be certain to coincide with the child's actual identity, sexual interests, and desires for bodily appearance

- Committee on Bioethics of the Council of Europe. "The Rights of Children in Biomedicine". 2017.

Those whose oath or conscience says "do no harm" should heed the simple fact that, to date, research does not support the practice of cosmetic infant genitoplasty.

- Elders, Satcher, and Carmona (15th, 16th and 17th US Surgeons General). 2017.

It shall be unlawful for medical practitioners or other professionals to conduct any sex assignment treatment and/or surgical intervention on the sex characteristics of a minor which treatment and/or intervention can be deferred until the person to be treated can provide informed consent

- Malta. Gender Identity, Gender Expression and Sex Characteristics Act. 2015.

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.

- World Health Organization. ICD 11 Beta Draft: "46,XY disorder of sex development due to 17-beta-hydroxysteroid dehydrogenase 3 deficiency". 2017.

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2 Summary

This submission is made by the Intersex ICD project of GATE,¹ in consultation with intersex participants in meetings and webinars that have taken place specifically on intersex issues in the ICD, from 2014 to present. Participants have included health and human rights advocates from every continent. GATE remains responsible for the proposals made, acknowledging that respondents shared varying personal perspectives. The submission builds upon an earlier joint submission to the World Health Organization, made in November 2014.²

Our concerns include the unnecessary pathologisation of often benign physical variations, including through new terminology, and proposed unlawful medical interventions.

In particular, “additional information” in the following codes requires treatment that is unlawful in at least one jurisdiction, of international concern to community organisations, and of international concern to human rights institutions:

- 5-alpha-reductase 2 deficiency³
- 17-beta-hydroxysteroid dehydrogenase 3 deficiency⁴
- congenital adrenal hyperplasia (5A61.12)⁵

Such interventions are also criticised for their weak evidence, and irreversible physical and mental health consequences, in the WHO report on *Sexual health, human rights and the law*;⁶ these interventions are not compatible with such statements, and it is contradictory and inappropriate for the proposed ICD revision to require them. They should be removed.

We recommend changing the proposed new text “disorders of sex development” throughout the ICD-11 beta to “congenital variations of sex characteristics”. We recommend additional systemic changes to all diagnoses currently proposed to be “disorders of sex development”, and an additional code.

¹ Morgan Carpenter, project consultant; Mauro Cabral Grinspan, executive director of GATE.

² Cabral M, Carpenter M, editors. Intersex Issues in the International Classification of Diseases: a revision [Internet]. 2014 [cited 2015 Oct 25]. Available from:

<https://transactivists.org/2015/10/26/intersex-issues-in-the-international-classification-of-diseases-icd/>

³ World Health Organization. 46,XY disorder of sex development due to 5-alpha-reductase 2 deficiency. In ICD-11 Beta Draft (Foundation). 2017 Jun 22. Available from: <http://apps.who.int/classifications/icd11/browse/f/en#http%3a%2f%2fid.who.int%2fid%2fentity%2f1028755501>

⁴ World Health Organization. 46,XY disorder of sex development due to 17-beta-hydroxysteroid dehydrogenase 3 deficiency. In ICD-11 Beta Draft (Foundation). 2017 Jun 22. Available from: <http://apps.who.int/classifications/icd11/browse/f/en#http%3a%2f%2fid.who.int%2fid%2fentity%2f887793448>

⁵ World Health Organization. Congenital adrenal hyperplasia. In ICD-11 Beta Draft (Foundation). 2017 Jun 22. Available from: <http://apps.who.int/classifications/icd11/browse/f/en#http%3a%2f%2fid.who.int%2fid%2fentity%2f172733763>

⁶ World Health Organization. Sexual health, human rights and the law. Geneva; 2015.

3 Human rights obligations

In recent years, multiple UN institutions including the World Health Organization, and also regional human rights institutions, have issued comments on human rights issues associated with medical interventions on intersex children.

In October 2016, multiple UN Treaty Bodies, Special Rapporteurs on health, torture and violence against women, and 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, Inter-American Commission on Human Rights issued a joint statement condemning human rights violations, stating:

In countries around the world, intersex infants, children and adolescents are subjected to medically unnecessary surgeries, hormonal treatments and other procedures in an attempt to forcibly change their appearance to be in line with societal expectations about female and male bodies. When, as is frequently the case, these procedures are performed without the full, free and informed consent of the person concerned, they amount to violations of fundamental human rights.

Parents of children with intersex traits often face pressure to agree to such surgeries or treatments on their children. They are rarely informed about alternatives or about the potential negative consequences of the procedures, which are routinely performed despite a lack of medical indication, necessity or urgency. The rationale for these is frequently based on social prejudice, stigma associated with intersex bodies and administrative requirements to assign sex at the moment of birth registration.⁷

The joint statement called for the combatting of “root causes of these violations such as harmful stereotypes, stigma and pathologisation”, and “In this connection, it is critical to strengthen the integration of these human rights principles in standards and protocols issued by regulatory and professional bodies”.

Multiple UN Treaty Bodies have made similar comments, calling for an end to forced and coercive practices. The Committee on the Rights of Persons with Disabilities issued General Comment 3 in November 2016, on women and girls with disabilities:

Certain forms of violence, exploitation and abuse may be considered as cruel, inhuman or degrading treatment or punishment and as breaching a number of

⁷ 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, Inter-American Commission on Human Rights, Special Rapporteur on torture and other cruel, inhuman, or degrading treatment or punishment, Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, et al. Intersex Awareness Day – Wednesday 26 October. End violence and harmful medical practices on intersex children and adults, UN and regional experts urge [Internet]. Office of the High Commissioner for Human Rights; 2016 [cited 2016 Oct 24]. Available from:

<http://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=20739&LangID=E>

*international human rights treaties. Among them are: ... any medical procedure or intervention performed without free and informed consent, including ... invasive and irreversible surgical practices such as psychosurgery, female genital mutilation and surgery or treatment performed on intersex children without their informed consent*⁸

In May 2016, the Committee on Economic, Social and Cultural Rights issued General Comment 22, on the right to sexual and reproductive health:

*Violations of the obligation to protect occur when a State fails to take effective steps to prevent third parties from undermining the enjoyment of the right to sexual and reproductive health. This includes the failure to prohibit and take measures to prevent all forms of violence and coercion committed by private individuals and entities, including ... harmful practices such as ... medically unnecessary, irreversible and involuntary surgery and treatment performed on intersex infants or children.*⁹

Concluding observations condemning harmful practices, or forced and coercive medical interventions on children have been published by the Committee on the Rights of the Child, Committee on the Rights of Persons with Disabilities, the Committee against Torture, and the Committee on the Elimination of all Forms of Discrimination Against Women.¹⁰

The WHO report on *Sexual health, human rights and law* also commented in detail on “normalising” interventions, their justifications and lack of evidence:

*A major concern for intersex people is that so-called sex normalizing procedures are often undertaken during their infancy and childhood, to alter their bodies, particularly the sexual organs, to make them conform to gendered physical norms, including through repeated surgeries, hormonal interventions and other measures. As a result, such children may be subjected to medically unnecessary, often irreversible, interventions that may have lifelong consequences for their physical and mental health, including irreversible termination of all or some of their reproductive and sexual capacity. Medical procedures may sometimes be justified in cases of conditions that pose a health risk or are considered life-threatening. Such procedures, however, are sometimes proposed on the basis of weak evidence, without discussing and considering alternative solutions*⁶

In 2017, the Committee on Bioethics of the Council of Europe published a report examining the rights of children in biomedicine. The authors reviewed clinical literature and examined outcomes, and situations where necessity for treatment is evidenced:

⁸ CRPD/C/GC/3, 25 November 2016

⁹ E/C.12/GC/22, 2 May 2016

¹⁰ CAT/C/DEU/CO/5, CRC/C/CHE/CO/2-4, CRPD/C/DEU/CO/1, CAT/C/CHE/CO/7, CRC/C/CHL/CO/4-5, CAT/C/AUT/CO/6, CAT/C/DNK/CO/6-7, CAT/C/CHN-HKG/CO/4-5, CRC/C/IRL/CO/3-4, CRC/C/FRA/CO/5, CAT/C/FRA/CO/7, CRPD/C/CHL/CO/1, CRC/C/GBR/CO/5, CRC/C/NPL/CO/3-5, CEDAW/C/FRA/CO/7-8, CRPD/C/ITA/CO/1, CRPD/C/URY/CO/1, CRC/C/ZAF/CO/2, CRC/C/NZL/CO/5, CEDAW/C/CHE/CO/4-5, CEDAW/C/NLD/CO/6, CEDAW/C/DEU/CO/7-8, CEDAW/C/IRL/CO/6-7.

(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...

On the scientific question of whether intervention is necessary, only three medical procedures have been identified as meeting that criteria in some infants: (1) administration of endocrine treatment to prevent fatal salt-loss in some infants, (2) early removal of streak gonads in children with gonadal dysgenesis, and (3) surgery in rare cases to allow exstrophic conditions in which organs protrude from the abdominal wall or impair excretion¹¹

In addition to impaired sexual function as a result of such interventions, the report of the Committee on Bioethics of the Council of Europe states that no clinically-accepted standard of care:

has emerged to explain, as a matter of science, how infant surgery will be certain to coincide with the child’s actual identity, sexual interests, and desires for bodily appearance¹¹

In June 2017, the 15th, 16th and 17th Surgeon Generals of the United States published a statement, *Re-Thinking Genital Surgeries on Intersex Infants*:

First, there is insufficient evidence that growing up with atypical genitalia leads to psychosocial distress... Second, while there is little evidence that cosmetic infant genitoplasty is necessary to reduce psychological damage, evidence does show that the surgery itself can cause severe and irreversible physical harm and emotional distress... Finally, these surgeries violate an individual’s right to personal autonomy over their own future. In short, surgeries whose purpose is to ensure physical and psychological health too often lead to the opposite result... Those whose oath or conscience says “do no harm” should heed the simple fact that, to date, research does not support the practice of cosmetic infant genitoplasty.¹²

Additionally, at least one jurisdiction has made such interventions unlawful. Malta has recognised a right to “bodily integrity and physical autonomy”:

It shall be unlawful for medical practitioners or other professionals to conduct any sex assignment treatment and/or surgical intervention on the sex

¹¹ Zillén K, Garland J, Slokenberga S, Committee on Bioethics of the Council of Europe. The Rights of Children in Biomedicine: Challenges posed by scientific advances and uncertainties. 2017.

¹² Elders MJ, Satcher D, Carmona R. Re-Thinking Genital Surgeries on Intersex Infants [Internet]. Palm Center; 2017 [cited 2017 Jun 28]. Available from: <http://www.palmcenter.org/wp-content/uploads/2017/06/Re-Thinking-Genital-Surgeries-1.pdf>

characteristics of a minor which treatment and/or intervention can be deferred until the person to be treated can provide informed consent¹³

3.1 Implications for proposed ICD codes

These developments have implications for all codes that unnecessarily pathologise intersex bodies without clear rationales based on evidenced medical necessity. Later sections of this submission discuss the proposed “disorders of sex development” nomenclature, and a subset of proposed ICD codes. The following proposed codes in the International Classification of Diseases that require described procedures. The following codes must be updated, removing treatments, and ensuring conformity with now-established human rights norms.

3.1.1 5-alpha-reductase 2 deficiency

The additional information for 5-alpha-reductase 2 deficiency currently states that feminising or masculinising surgeries should take place based on discussions about (but not with) a patient, with gender assignment dependent upon expected results of masculinising surgeries:

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.³

3.1.2 17-beta-hydroxysteroid dehydrogenase 3 deficiency

The additional information for 17-beta-hydroxysteroid dehydrogenase 3 deficiency currently states that surgery should be performed associated with gender assignment:

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.⁴

3.1.3 Congenital adrenal hyperplasia

The description and additional information for congenital adrenal hyperplasia (5A61.12) mention genital anomalies that may be noted at birth. Coupled with a statement that surgical intervention may be required to manage genital anomalies, the two statements promote early surgical management:

*Genital anomalies may be noted at birth in affected females
Genital anomalies in females may require surgical intervention(s)⁵*

¹³ Malta. Gender Identity, Gender Expression and Sex Characteristics Act. 2015.

4 Replacing “disorders of sex development”

The current beta draft version 11 of the International Classification of Diseases introduces a new terminology of “disorders of sex development” into the ICD. The term “disorders of sex development” (DSD) has proven controversial since first adopted at a clinical “Intersex Consensus Meeting” in Chicago in October 2005.¹⁴

Two community group representatives participated in that event, amongst around 50 clinicians predominantly from the US. Neither community organisation representative participated in a working group on nomenclature. Barbara Thomas, one of those participants, remarked in her report on the event that the two were marginalised and outnumbered at the meeting, and that term “disorders of sex development” translated very poorly into German.¹⁵ Indeed, the German group she represented is still called XY-Frauen (“XY-Women”), a part of the organisation Intersexuelle Menschen e.V. (“Intersex People Association”)¹⁶

The Intersex Consensus Meeting has been criticised by some other clinicians as “a self-selected group”,¹⁷ nevertheless, participation in the event by two community group representatives is often framed as a validation of both nomenclature and other outcomes of the meeting.¹⁸

Ongoing issues evident with the terminology of “disorders of sex development” proposed for ICD-11 include a lack of standardisation, and avoidance of treatment, both attributable to controversy about the term, and concern over the way that nomenclature endows often unnecessary procedures with appropriateness.¹⁹

4.1 Lack of standardisation

Since the formal introduction of “disorders of sex development” in clinical settings in 2006, the terminology has been contentious, with no consensus about nomenclature shared by clinicians, patients, families and community organisations. Thus, instead of promoting a standardisation or homogenisation of clinical terminology, clinical and associated literature

¹⁴ Hughes I, Lee P. Intersex Consensus Meeting [Internet]. 2005 [cited 2016 Oct 24]. Available from: <http://www.aissg.org/PDFs/Chicago-Agenda-Oct-05.pdf>

¹⁵ Thomas B. Report to AISSG on Chicago Consensus Conference October 2005 [Internet]. 2006 [cited 2017 Mar 30]. Available from: <http://www.aissg.org/PDFs/Barbara-Chicago-rpt.pdf>

¹⁶ XY-Frauen Selbsthilfegruppe. Intersexuelle Menschen e.V. | xy-frauen [Internet]. [cited 2017 Jun 22] Available from: <http://xy-frauen.de/verein/>

¹⁷ Diamond M. Human Intersexuality: Difference or Disorder? Archives of Sexual Behavior. 2009;38(2):172–172.

¹⁸ Meyer-Bahlburg HFL. Intersex Care Development: Current Priorities. LGBT Health. 2017;4(2):77–80.

Hughes IA. Disorders of sex development: a new definition and classification. Best Practice & Research Clinical Endocrinology & Metabolism. 2008;22(1):119–34.

¹⁹ Nisker J. Informed Choice and PGD to Prevent “Intersex Conditions.” The American Journal of Bioethics. 2013;13(10):47–9.

has instead spawned numerous alternatives to “disorders of sex development”, sometimes using the same acronym, such as:

- disorders of sexual development,²⁰
- disorders of sexual differentiation,²¹
- differences of sex development,²²
- diverse sex development,²³ and
- sexual development disorder²⁴

The latter term, “sexual development disorder”, is currently included in the ICD10 to refer to psychological and behavioural disorders and recommended for deletion in ICD11.²⁵ This highlights the close similarity of DSD terminology to words associated with stigmatised sexual behaviours, orientations and identities.

Clinical literature also uses other terms such as “variations of sex development”,¹⁷ or concatenates or persists with the term intersex.^{22,26} Draft ICD-11 codes, like ICD-10 codes before them, sometimes also include terms such as “male pseudo-hermaphroditism”.^{3,4}

Literature focusing on social groups and populations comprised of people born with variations of sex characteristics typically uses the term intersex. This includes World Health Organization and interagency documents on eliminating coercive sterilisations,²⁷ and on sexual health, human rights and the law.⁶

²⁰ Deans R, Berra M, Creighton SM. Management of Vaginal Hypoplasia in Disorders of Sexual Development: Surgical and Non-Surgical Options. *Sexual Development*. 2010;4(4–5):292–9.

Wunsch, L. Checklist for the structural description of the deep phenotype in disorders of sexual development. *Int. J. Endocrinol.* 2012, 816365 (2012).

²¹ Shawky RM, Nour El-Din SM. Profile of disorders of sexual differentiation in the Northeast region of Cairo, Egypt. *Egyptian Journal of Medical Human Genetics*. 2012;13(2):197–205.

²² Wiesemann C, Ude-Koeller S, Sinnecker GHG, Thyen U. Ethical principles and recommendations for the medical management of differences of sex development (DSD)/intersex in children and adolescents. *European Journal of Pediatrics*. 2010;169(6):671–9.

²³ Liao L-M, Simmonds M. A values-driven and evidence-based health care psychology for diverse sex development. *Psychology & Sexuality*. 2013;5(1):83–101.

²⁴ Family Court of Australia. Re: Carla (Medical procedure) [2016] FamCA 7 (20 January 2016). Available from: <http://www.austlii.edu.au/cgi-bin/sinodisp/au/cases/cth/FamCA/2016/7.html>

²⁵ Cochran SD, Drescher J, Kismödi E, Giami A, García-Moreno C, Atalla E, et al. Proposed declassification of disease categories related to sexual orientation in the International Statistical Classification of Diseases and Related Health Problems (ICD-11). *Bulletin of the World Health Organization*. 2014;92(9):672–9.

²⁶ Jordan-Young RM, Sonksen PH, Karkazis K. Sex, health, and athletes. *BMJ*. 2014;348(apr28 9):g2926–g2926.

Liao L-M, Roen K. Intersex/DSD post-Chicago: new developments and challenges for psychologists. *Psychology & Sexuality*. 2014;5(1):1–4.

Behrmann J, Ravitsky V. Queer Liberation, Not Elimination: Why Selecting Against Intersex is Not “Straight” Forward. *The American Journal of Bioethics*. 2013;13(10):39–41.

²⁷ World Health Organization, OHCHR, UN Women, UNAIDS, UNDP, UNFPA, et al. Eliminating forced, coercive and otherwise involuntary sterilization, An interagency statement [Internet]. Geneva; 2014

4.2 Avoidance of medical care and other consequences

Objections to the language of “disorders of sex development” began early, and has continued to the present time. In the first published papers describing first-hand experiences of people described as having “disorders of sex development”, disclaimers had to be added because of objections to that terminology.²⁸

Research by clinical bodies and peer support has persistently found that the term is regarded as pejorative and inappropriate.

A 2017 study of members of the Androgen Insensitivity Syndrome-Differences of Sex Development Support Group (AISDSD SG) by staff of Lurie Children’s Hospital of Chicago in collaboration with the AISDSD SG found that:

Use of this nomenclature by medical professionals may unintentionally negatively affect access to healthcare and research for individuals with DSD conditions

the medical community may have inadvertently exchanged one controversial term for another²⁹

Most significantly, the researchers report that:

our data suggest that the use of DSD and related terms is causing distress and avoidance of medical care among some affected individuals and caregivers²⁹

The research team stated that “These study findings are consistent with previous studies that demonstrated negative perceptions of DSD nomenclature”.³⁰ The CAH-focused CARES Foundation in the US refuses to participate in research using “disorders of sex

[cited 2014 Dec 1]. Available from:

http://apps.who.int/iris/bitstream/10665/112848/1/9789241507325_eng.pdf?ua=1

²⁸ Consortium on the Management of Disorders of Sex Development. Clinical guidelines for the management of disorders of sex development in childhood. Accord Alliance; 2006. Whitehouse Station, N.J.

²⁹ Johnson EK, Rosoklija I, Finlayso C, Chen D, Yerkes EB, Madonna MB, et al. Attitudes towards “disorders of sex development” nomenclature among affected individuals. Journal of Pediatric Urology. 2017 May; In press.

³⁰ Lin-Su K, Lekarev O, Poppas DP, Vogiatzi MG. Congenital adrenal hyperplasia patient perception of “disorders of sex development” nomenclature. International Journal of Pediatric Endocrinology. 2015;2015(1).

development” terminology.³¹ US youth and advocacy organisation interACT³² and Australian advocates³³ have taken similar stands on terminology.

Australian research based on a survey of 272 people born with atypical sex characteristics found that 3% used the term “disorders of sex development” to describe themselves, but 21% used the term to access medical services. 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 hear the terms that individuals prefer to use.³⁴

4.3 Nomenclature is linked to treatment

Multiple institutions, organisations and authors, including organisations of affected individuals, bioethicists and researchers,³⁵ and parliamentarians³⁶ have linked terminology to these human rights violations. For example, the Commissioner for Human Rights of the Council of Europe recommended, in 2015, that:

*National and international medical classifications which pathologise variations in sex characteristics should be reviewed with a view to eliminating obstacles to the effective enjoyment, by intersex persons, of human rights, including the right to the highest attainable standard of health.*³⁷

³¹ CARES Foundation. For Researchers [Internet]. Cares Foundation. 2014 [cited 2017 Jun 20]. Available from: <https://www.caresfoundation.org/clinical-trials-an-overview/for-researchers/>

³² interACT. interACT Statement on Intersex Terminology [Internet]. interactadvocates. 2016 [cited 2016 May 26]. Available from: <http://interactadvocates.org/interact-statement-on-intersex-terminology/>

³³ Black E, Bond K, Briffa T, Carpenter M, Cody C, David A, et al. Darlington Statement: Joint consensus statement from the intersex community retreat in Darlington, March 2017 [Internet]. Sydney, NSW; 2017 Mar [cited 2017 Mar 17]. Available from: <https://eprints.qut.edu.au/104412/>

³⁴ Organisation Intersex International Australia. Demographics [Internet]. 2016 [cited 2016 Aug 9]. Available from: <https://oii.org.au/demographics/>

³⁵ Holmes M. The Intersex Enchiridion: Naming and Knowledge. Somatechnics. 2011;1(2):388–411. Davis G. “DSD is a Perfectly Fine Term”: Reasserting Medical Authority through a Shift in Intersex Terminology. In: McGann P, Hutson DJ, editors. Advances in Medical Sociology. Bingley: Emerald Group Publishing; 2011. p. 155–82.

Karkazis K, Feder EK. Naming the problem: disorders and their meanings. The Lancet. 2008 Dec 13;372:2016–7.

Feder EK. Imperatives of Normality: From “Intersex” to “Disorders of Sex Development.” GLQ: A Journal of Lesbian and Gay Studies. 2009;15(2):225–47.

³⁶ Australian Senate, Community Affairs References Committee. Involuntary or coerced sterilisation of intersex people in Australia [Internet]. Canberra; 2013 [cited 2013 Oct 26]. Available from: http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Involuntary_Sterilisation/Sec_Report/index

³⁷ Council of Europe Commissioner for Human Rights. Human rights and intersex people, Issue Paper [Internet]. 2015 [cited 2015 May 12]. Available from: [https://wcd.coe.int/ViewDoc.jsp?Ref=CommDH/IssuePaper\(2015\)1&Language=lanEnglish&Ver=original](https://wcd.coe.int/ViewDoc.jsp?Ref=CommDH/IssuePaper(2015)1&Language=lanEnglish&Ver=original)

In 2016, multiple UN Treaty Bodies, Special Rapporteurs, and 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, Inter-American Commission on Human Rights called for the combatting of "root causes of these violations such as harmful stereotypes, stigma and pathologisation", and "In this connection, it is critical to strengthen the integration of these human rights principles in standards and protocols issued by regulatory and professional bodies".⁷

Changing proposed nomenclature in the International Classification of Diseases from "disorders of sex development" to a different term is necessary to achieve this.

4.4 An umbrella term is necessary

Sources vary in describing population figures, but variations of sex characteristics are known to be heterogeneous, with at least 40 different variations known.³⁸ 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. In 2013, Hiort suggested that this was the case for 10-80% of persons with DSDs.³⁸ This is particularly true of people with variations associated with XY sex chromosomes.³⁹

In many cases, diagnostic labels have changed over time, with not only the systemic introduction of new clinical nomenclature but also, on an individual basis, diagnostic error and the availability of new genetic tests. In this context, an umbrella term is necessary, helping individuals who don't have a clear genetic diagnosis to find peers. In situations where individual variations are statistically rare or uncommon, umbrella terms provide a vital connection with other individuals with related or common experience. Umbrella terms also identify connections between populations that are stigmatised because of sex characteristics.

Umbrella terms can assist in establishing continuity over time and, indeed, it is the term intersex that has achieved this rather than terms associated with DSD. The term intersex is increasingly popular, with communities, advocacy groups and peer support groups now developing and growing across the globe, and this will not go away.

Peer support, advocacy and other community organisations 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 both policy-makers and practitioners to account. A proportion of these organisations are identified in a 2016 clinical "Global Disorders of Sex Development Update" which notes that peer support "is a key component of the 2013– 2020 WHO Mental Health Action Plan" and

³⁸ Hiort O. I-03 DSDnet: Formation of an open world-wide network on DSD at clinician conference, "4th I-DSD Symposium" [Internet]. 2013 [cited 2013 Jul 1]. Available from http://www.gla.ac.uk/media/media_279274_en.pdf

³⁹ Warne G, Hewitt J. Disorders of sex development: current understanding and continuing controversy. *Med J Aust.* 2009 Jun 1;190(11):612–3.

routine inclusion of peer support is necessary in “clinical care at the earliest possible time”.⁴⁰

A change in clinical terminology can help narrow the distance between community and clinical organisations.

4.5 Proposed replacement terminology

We propose the term “congenital variations of sex characteristics”, for use in clinical settings.

This proposal is made in good faith, recognising significant contention about terminology, and calling for some shift in thinking from both advocacy groups and clinicians.

While there is overwhelming community opposition to “disorders of sex development”, including overwhelming opposition to the term “disorders” because of its association with an inherent problem that needs to be “fixed”, there are a range of perspectives on replacement terms for use in clinical settings.

The term intersex is increasingly popular, but we do not propose to replace the term “disorders of sex development” with the term intersex in clinical settings. We acknowledge the likelihood of strong opposition to use of the term by some clinicians and some parent-led groups. We also believe that all parties should acknowledge that persons in clinical and social settings can acceptably use different terms.

To be clear, it is evident that the word intersex is a preferred term in social and community settings; while still often misunderstood, it is the most widespread and the most understood term in popular literature and we expect this to continue. In human rights settings, the terms intersex and a universal attribute of “sex characteristics” are becoming widespread.⁴¹ This, too, must be accepted.

As with some other populations and social groups, it is not necessary for the same term to be used in popular and community settings and also in clinical settings. Indeed, the Lurie/AISDSD-SG study found that affected individuals prefer the term intersex, but also found that respondents preferred alternative terms in naming relevant clinics.

In surveys by GATE, “sex characteristics” ranked slightly ahead of “intersex” as a preferred clinical umbrella term. There was unanimous and strong opposition to “disorders”.

⁴⁰ Lee PA, Nordenström A, Houk CP, Ahmed SF, Auchus R, Baratz A, et al. Global Disorders of Sex Development Update since 2006: Perceptions, Approach and Care. *Hormone Research in Paediatrics*. 2016;85(3):158–180.

⁴¹ ARC International, ILGA, International Bar Association. Sexual Orientation, Gender Identity and Expression, and Sex Characteristics at the Universal Periodic Review [Internet]. 2016 [cited 2016 Dec 21]. Available from: <http://arc-international.net/research-and-publications/research-and-analysis/sexual-orientation-gender-identity-and-expression-and-sex-characteristics-at-the-universal-periodic-review/>

A distinction between congenital and acquired sex characteristics is helpful in our view.

- Congenital variations are present at birth, even where they may become apparent later in life, such as at puberty.
- Acquired variations can be freely chosen or not; iatrogenic or caused through illness, trauma or accident.
- Some people born with intersex variations may seek reparative treatments where iatrogenic changes are not desired.
- Not all acquired variations may require clinical intervention or management; the same is true of congenital variations of sex characteristics.

5 Systemic changes to codes for “disorders of sex development”

We propose the following systemic changes to all codes currently proposed to be “disorders of sex development”.

- Proposed insertion of language around “disorders of sex development” should be **replaced** with “congenital variations of sex characteristics”.
- The term “affected females” should be **replaced** by “person with 46,XX sex chromosomes” or “person with 46,XX genotype”. This detaches the chromosomes from a presumed gender, and confusion regarding whether or not “females” refers to phenotype, genotype or identity. It does not presume that being affected is pathological.
- The words “malformations” and “defects” should be **replaced** by “structural variations”.
- The term “disease” should be **replaced** by “condition”.
- The term “abnormal genital development” should be **replaced** by “genital variation of sex characteristics”.
- The terms “genital ambiguity” and “sexual ambiguity” should be **replaced** by “genital variations”.
- The term “phenotype male” should be **replaced** by “appears phenotypically male”.
- The terms “virilisation” and “defects of virilisation” should be **replaced** by “variation of sex characteristics”. These terms are loaded with culturally-dependent assumptions of masculinity and femininity. We note, too that the word “feminization” is rarely evident in proposed ICD codes because of culturally-dependent pejorative associations.

6 Selected codes

There follows a non-exhaustive subset of relevant codes, aiming to include an indicative range of codes proposed to be included as “disorders of sex development” and additional relevant codes. The code proposals are self-contained, written to enable reading independently of this full submission.

6.1 LC1A.5 Androgen insensitivity syndrome

We propose changes to bring the headings and description of this code into line with the systemic changes proposed for all congenital variations of sex characteristics.

The current headings:

- LC1A Malformative disorders of sex development
- LC1A.5 46,XY disorder of sex development due to androgen resistance

Should be changed to:

- LC1A Structural congenital variations of sex characteristics
- LC1A.5 46,XY Congenital variation of sex characteristics due to androgen resistance

The description should be changed from:

Androgen insensitivity syndrome (AIS) is a disorder of sex development (DSD) characterized by the presence of female external genitalia, ambiguous genitalia or variable defects in virilization in a 46,XY individual with absent or partial responsiveness to age-appropriate levels of androgens. It comprises two clinical subgroups: complete AIS (CAIS) and partial AIS (PAIS).

To:

Androgen insensitivity syndrome (AIS) is characterized by the presence of phenotypically female external genitalia or genital variations in an individual with testes, 46,XY sex chromosomes, and absent or partial responsiveness to age-typical levels of androgens. It comprises two subgroups: complete AIS (CAIS) and partial AIS (PAIS).

6.1.1 Complete peripheral androgen resistance syndrome

- Index entity at <http://apps.who.int/classifications/icd11/browse/f/en#http%3a%2f%2fid.who.int%2fid%2fentity%2f1497511971>

The description should be changed from:

Complete androgen insensitivity syndrome (CAIS) is a form of androgen insensitivity syndrome (AIS), a disorder of sex development (DSD), characterized by the presence of female external genitalia in a 46,XY individual with normal testis development but undescended testes and unresponsiveness to age-appropriate levels of androgens.

To:

Complete androgen insensitivity syndrome (CAIS) is a form of androgen insensitivity syndrome (AIS), a congenital variation of sex characteristics characterized by the presence of phenotypically female external genitalia in an individual with 46,XY sex chromosomes, testis development, undescended testes and unresponsiveness to age-appropriate levels of androgens.

6.1.2 Partial peripheral androgen resistance syndrome

- Index entity at <http://apps.who.int/classifications/icd11/browse/f/en#http%3a%2f%2fid.who.int%2fid%2fentity%2f1302802480>

The description should be changed from:

Partial androgen insensitivity syndrome is a disorder of sex development (DSD) distinct from complete AIS characterized by the presence of abnormal genital development in a 46,XY individual with normal testis development and partial responsiveness to age-appropriate levels of androgens.

To:

Partial androgen insensitivity syndrome is a congenital variation of sex characteristics distinct from complete AIS characterized by the presence of variations in genital development in an individual with 46,XY sex chromosomes, testis development and partial responsiveness to age-appropriate levels of androgens.

6.2 LC73 Chimaera

The current heading:

- LC73 Chimaera 46, XX, 46, XY

Should be changed to:

- LC73 Chimaera 46,XX; 46,XY

The description should be changed from:

A disease caused by XX and XY embryonic fusion or two distinct loss event of a sex chromosome from a XXY embryo early in development. This results in a subset of cells in the body having a XX karyotype, while other cells demonstrate a XY karyotype. This disease may present with abnormal genital development.

To:

A congenital variation of sex characteristics caused by XX and XY embryonic fusion or two distinct loss events of a sex chromosome from an XXY embryo early in development. This results in a subset of cells in the body having an XX karyotype, while other cells demonstrate an XY karyotype. This condition may present with a genital variation of sex characteristics.

6.3 LB41 Structural developmental anomalies of clitoris

The current heading:

- LB41 Structural developmental anomalies of clitoris

Should be changed to:

- LB41 Congenital structural variations of clitoris

The description:

A deformation established before birth of an anatomical structure of the clitoris.

Should be changed to:

A variation established before birth of an anatomical structure of the clitoris.

6.3.1 LB41.3 Clitoromegaly

Synonym: Congenital hypertrophy of clitoris

This code does not have a description. The code should be **deleted**.

6.4 5A61.12 Congenital adrenal hyperplasia

The proposed code for congenital adrenal hyperplasia (CAH) is unusual with an inappropriate, excessive “additional information” section that also includes treatment recommendations.

We propose changes to the headings for the code and its parent code. We propose changes to the description and **deletion** of the “additional information” section.

The description currently states, “Genital anomalies may be noted at birth in affected females.” The treatments described in the “additional information” section include prenatal diagnosis that “allows treatment to be established for preventing virilization in affected females”, and the statement that “Genital anomalies in females may require surgical intervention(s).” These should be **deleted**.

6.4.1 Prenatal treatment

Proposed prenatal interventions have been discontinued in Sweden, and are restricted in other jurisdictions, on the grounds that they do, or may, incur adverse effects. In 2012, a Swedish team stated:

we do not consider it ethical to initiate further treatment ... We find it unacceptable that, globally, fetuses at risk for CAH are still treated prenatally with DEX without follow-up⁴²

in 2016, an Australian state remarked that such interventions should be rarely employed:

Prenatal use of dexamethasone treatment of the mother has been used in the past, to try to reduce virilisation of an affected female fetus but this may have potential adverse effects and is now only used rarely.⁴³

In the absence of clear health benefits with no adverse effects, prenatal interventions should not be listed in ICD-11.

6.4.2 Surgical management of “genital anomalies”

The mention of genital anomalies that may be noted at birth, coupled with a statement that surgical intervention may be required to manage genital anomalies, promotes early surgical management.

⁴² Hirvikoski T, Nordenström A, Wedell A, Ritzén M, Lajic S. Prenatal Dexamethasone Treatment of Children at Risk for Congenital Adrenal Hyperplasia: The Swedish Experience and Standpoint. *The Journal of Clinical Endocrinology & Metabolism*. 2012;97(6):1881–3.

⁴³ Department of Health & Human Services. Congenital adrenal hyperplasia (CAH) in neonates [Internet]. 2015 [cited 2016 Jun 2]. Available from: <https://www2.health.vic.gov.au:443/hospitals-and-health-services/patient-care/perinatal-reproductive/neonatal-e-handbook/conditions/congenital-adrenal-hyperplasia>

However, the 2006 summary clinical “consensus statement” states that “Appearance-altering surgery is not urgent”,⁴⁴ and the 2016 clinical global DSD update to the 2006 “consensus statement” demonstrates that there remains no clinical consensus regarding any surgical management:

*There is still no consensual attitude regarding indications, timing, procedure and evaluation of outcome of DSD surgery. The levels of evidence of responses given by the experts are low ... Timing, choice of the individual and irreversibility of surgical procedures are sources of concerns. There is no evidence regarding the impact of surgically treated or non-treated DSDs during childhood for the individual, the parents, society or the risk of stigmatization.*⁴⁵

In 2017, the Committee on Bioethics of the Council of Europe commissioned a report examining the rights of children in biomedicine. The report authors stated 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...

*On the scientific question of whether intervention is necessary, only three medical procedures have been identified as meeting that criteria in some infants: (1) administration of endocrine treatment to prevent fatal salt-loss in some infants, (2) early removal of streak gonads in children with gonadal dysgenesis, and (3) surgery in rare cases to allow exstrophic conditions in which organs protrude from the abdominal wall or impair excretion*⁴⁶

This analysis does not support surgical management of genital anomalies associated with CAH.

Surgical interventions are typically predicated on a female gender identity. However, Furtado and others have stated in a 2012 clinical review that generally “between 8.5–20% of individuals with DSDs” will experience distress associated with their gender assignment, including one in ten individuals with CAH.⁴⁷ Some individuals with 46,XX sex chromosomes and CAH will be raised male and/or consider themselves to be male when freely able to express an identity.

⁴⁴ Houk CP, Hughes IA, Ahmed SF, Lee PA, Writing Committee for the International Intersex Consensus Conference Participants. Summary of Consensus Statement on Intersex Disorders and Their Management. *PEDIATRICS*. 2006;118(2):753–7.

⁴⁵ Lee PA, Nordenström A, Houk CP, Ahmed SF, Auchus R, Baratz A, et al. Global Disorders of Sex Development Update since 2006: Perceptions, Approach and Care. *Hormone Research in Paediatrics*. 2016;85(3):158–180.

⁴⁶ Zillén K, Garland J, Slokenberga S, Committee on Bioethics of the Council of Europe. *The Rights of Children in Biomedicine: Challenges posed by scientific advances and uncertainties*. 2017.

⁴⁷ Furtado PS, Moraes F, Lago R, Barros LO, Toralles MB, Barroso U. Gender dysphoria associated with disorders of sex development. *Nature Reviews Urology*. 2012;9:620–7.

The report of the Committee on Bioethics of the Council of Europe states that no clinically-accepted standard of care:

*has emerged to explain, as a matter of science, how infant surgery will be certain to coincide with the child's actual identity, sexual interests, and desires for bodily appearance*⁴⁶

*all evidence-based reviews concur that gender identity and sexual orientation of children with differences in sex development cannot be predicted with accuracy*⁴⁶

In 2017, a first feasibility study has shown surgery to be not necessary. The study on deferral of (or no) genital surgeries for ambiguous genitalia in seven children with the 21-hydroxylase deficiency form of congenital adrenal hyperplasia in France. The study authors acknowledge:

*Multiple scientific voices have joined those of patients and support groups to question long term results of early genital surgery ... Decreased genital sensitivity and need for further surgery in adulthood, as well as poor cosmetic results in the long run have been proven by studies in multiple institutions, suggesting dissatisfaction in a significant proportion of patients irrespective of geographical provenance*⁴⁸

The authors of this study point to inertia as a rationale for continued early genital surgery. While the report authors still had a “normalising” intent, they concluded that, in their population:

*deferring genital operation is acceptable among patients and families*⁴⁸

Widespread concern about the human rights issues associated with early surgical interventions for reasons of appearance means that multiple UN institutions and Treaty Bodies have issued statements condemning such practices.⁷ The World Health Organization report on Sexual health, human rights and the law is cited in the section “Nomenclature is linked to treatment”. In 2016, the World Health Organization paper on *Sexual health, human rights and law* has recognised these concerns:

A major concern for intersex people is that so-called sex normalizing procedures are often undertaken during their infancy and childhood, to alter their bodies, particularly the sexual organs, to make them conform to gendered physical norms, including through repeated surgeries, hormonal interventions and other measures. As a result, such children may be subjected to medically unnecessary, often irreversible, interventions that may have lifelong consequences for their physical and mental health, including irreversible termination of all or some of

⁴⁸ Bournières P, Bouvattier C, Cartigny M, Michala L. Deferring surgical treatment of ambiguous genitalia into adolescence in girls with 21-hydroxylase deficiency: a feasibility study. *International Journal of Pediatric Endocrinology*.2017(3).

their reproductive and sexual capacity. Medical procedures may sometimes be justified in cases of conditions that pose a health risk or are considered life-threatening. Such procedures, however, are sometimes proposed on the basis of weak evidence, without discussing and considering alternative solutions⁴⁹

It is inappropriate for the ICD to facilitate or promote such cosmetic practices.

Additionally, at least one jurisdiction has made such interventions unlawful. Malta has recognised a right to “bodily integrity and physical autonomy”:

It shall be unlawful for medical practitioners or other professionals to conduct any sex assignment treatment and/or surgical intervention on the sex characteristics of a minor which treatment and/or intervention can be deferred until the person to be treated can provide informed consent⁵⁰

The ICD-11 should not include language promoting unlawful actions.

Human rights institutions in jurisdictions across multiple continents are raising similar concerns. In contrast, psychological support and counseling may benefit parents and individuals.⁵¹

Code headings

The current headings:

- 5A61.1 46,XX disorders of sex development induced by androgens of fetal origin
- 5A61.12 Congenital adrenal hyperplasia

Should be changed to:

- 5A61.1 46,XX congenital variations of sex characteristics due to androgens of fetal origin
- 5A61.12 Congenital adrenal hyperplasia

Description

- “diseases” should be **replaced** by “conditions”.

⁴⁹ World Health Organization. Sexual health, human rights and the law [Internet]. Geneva: World Health Organization; 2015. Available from:

http://apps.who.int/iris/bitstream/10665/175556/1/9789241564984_eng.pdf?ua=1

⁵⁰ Malta. Gender Identity, Gender Expression and Sex Characteristics Act: Final version [Internet]. 2015. Available from:

<http://justiceservices.gov.mt/DownloadDocument.aspx?app=lp&itemid=26805&l=1>

⁵¹ Liao L-M, Simmonds M. A values-driven and evidence-based health care psychology for diverse sex development. *Psychology & Sexuality*. 2013;5(1):83–101.

Liao L-M, Wood D, Creighton SM. Parental choice on normalising cosmetic genital surgery. *BMJ*. 2015;351:h5124.

- "Genital anomalies may be noted at birth in affected females" **replace** by "Genital variations may be noticed in a neonate with 46,XX sex chromosomes. Parents may require counseling."

Change description from:

Congenital adrenal hyperplasia (CAH) refers to a group of diseases associated with either complete (classical form) or partial (non-classical) anomalies in the biosynthesis of adrenal hormones. The disease is characterized by insufficient production of cortisol, or of aldosterone (classical form with salt wasting), associated with overproduction of adrenal androgens. In the classical form, metabolic decompensation (dehydration with hyponatremia, hyperkalemia and acidosis associated with mineralocorticoid deficiency, and hypoglycemia associated with glucocorticoid deficiency) may be life-threatening from the neonatal period onwards. Genital anomalies may be noted at birth in affected females.

To:

Congenital adrenal hyperplasia (CAH) refers to a group of conditions associated with either complete (classical form) or partial (non-classical) variations in the biosynthesis of adrenal hormones. The condition is characterized by insufficient production of cortisol, or of aldosterone (classical form with salt wasting), associated with overproduction of adrenal androgens. In the classical form, metabolic decompensation (dehydration with hyponatremia, hyperkalemia and acidosis associated with mineralocorticoid deficiency, and hypoglycemia associated with glucocorticoid deficiency) may be life-threatening from the neonatal period onwards. Genital variations may be noticed in a neonate with 46,XX sex chromosomes. Parents may require counseling.

Additional Information

Our recommendation is for this section to be **deleted** in its entirety, as it contains treatments that are not lawful in some countries, and treatments known to have been discontinued in some jurisdictions due to adverse effects. Experimental treatments and non-essential treatments with adverse consequences should not form part of the ICD.

If section deletion is not possible then:

- "Prenatal diagnosis is possible through molecular analysis of fetal DNA and allows treatment to be established for preventing virilization in affected females" should be **deleted**. These interventions have been discontinued in some jurisdictions due to actual or potential adverse effects.^{42,43}
- "Genital anomalies in females may require surgical intervention(s)" should be **deleted**. These interventions are not supported by clear scientific evidence, and may be unlawful in some jurisdictions.⁵⁰

6.5 LC1A.2 46,XY gonadal dysgenesis

The current headings:

- LC1A Malformative disorders of sex development
- LC1A.2 46,XY gonadal dysgenesis

Should be changed to:

- LC1A Structural congenital variations of sex characteristics
- LC1A.2 46,XY gonadal dysgenesis

The description should be changed from:

This is any congenital developmental disorder of the reproductive system characterized by a progressive loss of primordial germ cells on the developing gonads of an embryo.

To:

This is any congenital variation of sex characteristics characterized by a progressive loss of primordial germ cells on the developing gonads of an embryo.

6.5.1 Complete 46,XY gonadal dysgenesis

- Index entity at <http://apps.who.int/classifications/icd11/browse/f/en#http%3a%2f%2fid.who.int%2fid%2fentity%2f2109073646>

The description should be changed from:

46,XY complete gonadal dysgenesis (46,XY CGD) is a disorder of sex development (DSD) associated with anomalies in gonadal development that result in the presence of female external and internal genitalia despite the 46,XY karyotype.

To:

46,XY complete gonadal dysgenesis (46,XY CGD) is a congenital variation of sex characteristics associated with variations of gonadal development that result in the presence of phenotypically female external and internal genitalia with 46,XY sex chromosomes.

6.5.2 Partial 46,XY gonadal dysgenesis

- Index entity at <http://apps.who.int/classifications/icd11/browse/f/en#http%3a%2f%2fid.who.int%2fid%2fentity%2f1658995864>

The description should be changed from:

46,XY partial gonadal dysgenesis is a disorder of sex development (DSD) associated with anomalies in gonadal development that results in genital ambiguity of variable degree ranging from almost female phenotype to almost male phenotype in a patient carrying a male 46,XY karyotype.

To:

46,XY partial gonadal dysgenesis is a congenital variation of sex characteristics associated with gonadal development that results in genital variations ranging from almost phenotypically female to almost phenotypically male phenotype in an individual with XY sex chromosomes.

6.6 LB53.5 Hypospadias, perineal

The current headings:

- Structural developmental anomalies of the male genital system
- LB53 Hypospadias
- LB53.5 Hypospadias, perineal

Should be changed to:

- Structural congenital variations in the 46,XY genital system
- LB53 Hypospadias
- LB53.5 Hypospadias, perineal

The description should be changed from:

A condition of the urethra affecting males, caused by determinants arising during the antenatal period. This condition is characterized by a malformation of the urethra and the ventral side of the penis and an abnormally placed urinary meatus that opens in the perineum. This condition may also present with an incomplete foreskin that forms a hood.

To:

A condition of the urethra caused by determinants arising during the antenatal period. This condition is characterized by a structural variation of the urethra and the ventral side of the penis and a urinary meatus that opens in the perineum. This condition may also present with a partial foreskin that forms a hood.

6.7 LC43.1 Klinefelter syndrome

- LC43.1 Klinefelter syndrome with karyotype 47,XXY, regular

The description should be changed from:

Karyotype 47 XXY; gonads: testes (hypogonadism) small and firm with decreased spermatogenesis; phenotype male with associated congenital abnormalities (decreased virilization due to decreased testosterone production, long arms and legs, short trunk, psychosocial problems)

To:

Karyotype 47,XXY; gonads: testes, small and firm with low spermatogenesis; hypogonadism; long arms and legs with short trunk. Possible taurodontism. Often phenotypically male with some breast development. Psychosocial issues may be evident.

6.8 LC1A.1 Ovotesticular disorder of sex development

The current headings:

- LC1A Malformative disorders of sex development
- LC1A.1 Ovotesticular disorder of sex development

Should be changed to:

- LC1A Structural congenital variations of sex characteristics
- LC1A.1 Ovotesticular variation of sex characteristics

The description should be changed from:

Ovotesticular disorder of sex development, formerly called true hermaphroditism, is a rare cause of genital ambiguity characterized by the presence of ovarian and testicular tissue in an individual, leading to development of both male and female structures.

To:

Ovotesticular variation of sex characteristics is a rare cause of genital variations characterized by the presence of ovarian and testicular tissue in an individual, leading to development of phenotypically male and female structures.

6.9 LB44 Structural developmental anomalies of uterus, except cervix

The current heading:

- LB44 Structural developmental anomalies of uterus, except cervix

Should be changed to:

- LB44 Structural congenital variations of uterus, except cervix

The description should be changed from:

A deformation established before birth of an anatomical structure of the uterus or cervix.

To:

A variation established before birth of an anatomical structure of the uterus or cervix.

6.9.1 Müllerian agenesis

- Index entity at <http://apps.who.int/classifications/icd11/browse/f/en#http%3a%2f%2fid.who.int%2f%2fentity%2f1098660435>

The current headings:

- Certain specified disorders of genital development

Should be changed to:

- Certain specified congenital genital variations

The description should be changed from:

Absent vagina, absent or hypoplastic uterus (sometimes with areas of functional endometrium), and normal or hypoplastic fallopian tubes, mostly associated with normal ovaries and urologic abnormalities and skeletal malformations. Presenting symptoms and signs typically include primary amenorrhea, absent vagina, and normal breast and pubic hair development.

To:

Absent vagina, absent or hypoplastic uterus (sometimes with areas of functional endometrium), and typical or hypoplastic fallopian tubes, mostly associated with typical ovaries and urologic variations and skeletal variations. Presenting symptoms and signs typically include primary amenorrhea, absent vagina, and typical breast and pubic hair development.

6.10 LC1F.25 MURCS association

The current headings:

- LC1F.2 Syndromes with multiple structural variations, not of environmental origin
- LC1F.25 MURCS association

Should be changed to:

- LC1F.2 Multiple structural variations, not of environmental origin
- LC1F.25 MURCS association

The description should be changed from:

MURCS association, which stands for Müllerian duct aplasia (MU), congenital renal dysplasia (R), cervical somite anomalies (CS), is the atypical (or type II) form of Mayer-Rokitansky-Küster-Hauser syndrome, characterized by utero-vaginal atresia in otherwise normal females as well associated kidney and skeletal abnormalities and hearing problems.

To:

Müllerian duct aplasia (MU), congenital renal dysplasia (R), cervical somite anomalies (CS), is the atypical (or type II) form of Mayer-Rokitansky-Küster-Hauser syndrome, characterized by utero-vaginal atresia in persons with XX sex chromosomes as well associated kidney and skeletal abnormalities and hearing problems.

6.11 Testosterone-related variations

6.11.1 5A71.2 Testicular hypofunction

The current heading:

- 5A71 Testicular dysfunction or testosterone-related disorders

Should be changed to:

- 5A71 Testicular dysfunction or testosterone-related conditions

The description should be changed from:

In pre-puberty, a disorder characterized by atrophied testes and sterility, abnormal height and absence of secondary sex characteristics. In post-puberty, a disorder characterized by depressed sexual function, loss of sex drive and sterility, muscle weakness and osteoporosis (due to loss of the androgen anabolic effect).

To:

In pre-puberty, a condition characterized by atrophied testes and sterility, atypical height and absence of secondary sex characteristics. In post-puberty, a condition characterized by depressed sexual function, loss of sex drive and sterility, muscle loss and osteoporosis (due to loss of the androgen anabolic effect).

6.11.2 46,XY disorder of sex development due to 5-alpha-reductase 2 deficiency

- Index entity at <http://apps.who.int/classifications/icd11/browse/f/en#http%3a%2f%2fid.who.int%2fid%2fentity%2f1028755501>

The 2006 summary clinical “consensus statement” states that “Appearance-altering surgery is not urgent”,⁵² and the 2016 clinical global DSD update to the 2006 “consensus statement” demonstrates that there remains no clinical consensus regarding any surgical management:

There is still no consensual attitude regarding indications, timing, procedure and evaluation of outcome of DSD surgery. The levels of evidence of responses given by the experts are low ... Timing, choice of the individual and irreversibility of surgical procedures are sources of concerns. There is no evidence regarding the impact of surgically treated or non-treated DSDs during childhood for the individual, the parents, society or the risk of stigmatization.⁵³

In 2017, the Committee on Bioethics of the Council of Europe commissioned a report examining the rights of children in biomedicine. The report authors stated 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...

On the scientific question of whether intervention is necessary, only three medical procedures have been identified as meeting that criteria in some infants: (1) administration of endocrine treatment to prevent fatal salt-loss in some infants, (2) early removal of streak gonads in children with gonadal dysgenesis, and (3) surgery in rare cases to allow exstrophic conditions in which organs protrude from the abdominal wall or impair excretion⁵⁴

This analysis does not support surgical management of genital anomalies associated with 5-alpha reductase deficiency.

The “addition description” states that:

Gender assignment is still debated and must be carefully discussed for each patient, depending on the expected results of masculinizing genitoplasty. If

⁵² Houk CP, Hughes IA, Ahmed SF, Lee PA, Writing Committee for the International Intersex Consensus Conference Participants. Summary of Consensus Statement on Intersex Disorders and Their Management. PEDIATRICS. 2006;118(2):753–7.

⁵³ Lee PA, Nordenström A, Houk CP, Ahmed SF, Auchus R, Baratz A, et al. Global Disorders of Sex Development Update since 2006: Perceptions, Approach and Care. Hormone Research in Paediatrics. 2016;85(3):158–180.

⁵⁴ Zillén K, Garland J, Slokenberga S, Committee on Bioethics of the Council of Europe. The Rights of Children in Biomedicine: Challenges posed by scientific advances and uncertainties. 2017.

*deferring genital operation is acceptable among patients and families*⁴⁸

Widespread concern about the human rights issues associated with early surgical interventions for reasons of appearance means that multiple UN institutions and Treaty Bodies have issued statements condemning such practices.⁷ The World Health Organization report on Sexual health, human rights and the law is cited in the section “Nomenclature is linked to treatment”. In 2016, the World Health Organization paper on *Sexual health, human rights and law* has recognised these concerns:

*A major concern for intersex people is that so-called sex normalizing procedures are often undertaken during their infancy and childhood, to alter their bodies, particularly the sexual organs, to make them conform to gendered physical norms, including through repeated surgeries, hormonal interventions and other measures. As a result, such children may be subjected to medically unnecessary, often irreversible, interventions that may have lifelong consequences for their physical and mental health, including irreversible termination of all or some of their reproductive and sexual capacity. Medical procedures may sometimes be justified in cases of conditions that pose a health risk or are considered life-threatening. Such procedures, however, are sometimes proposed on the basis of weak evidence, without discussing and considering alternative solutions*⁵⁸

We note that no evidence is provided of necessity for early surgical interventions in the “additional information” section, and nor are alternative solutions entertained. It is thus contradictory and inappropriate for the ICD to facilitate or promote such cosmetic practices.

Additionally, at least one jurisdiction has made such interventions unlawful. Malta has recognised a right to “bodily integrity and physical autonomy”:

*It shall be unlawful for medical practitioners or other professionals to conduct any sex assignment treatment and/or surgical intervention on the sex characteristics of a minor which treatment and/or intervention can be deferred until the person to be treated can provide informed consent*⁵⁹

The ICD-11 should not include language promoting unlawful actions.

Human rights institutions in jurisdictions across multiple continents are raising similar concerns. In contrast, psychological support and counseling may benefit parents and individuals.⁶⁰

⁵⁸ World Health Organization. Sexual health, human rights and the law [Internet]. Geneva: World Health Organization; 2015. Available from:

http://apps.who.int/iris/bitstream/10665/175556/1/9789241564984_eng.pdf?ua=1

⁵⁹ Malta. Gender Identity, Gender Expression and Sex Characteristics Act: Final version [Internet]. 2015. Available from:

<http://justiceservices.gov.mt/DownloadDocument.aspx?app=lp&itemid=26805&l=1>

⁶⁰ Liao L-M, Simmonds M. A values-driven and evidence-based health care psychology for diverse sex development. *Psychology & Sexuality*. 2013;5(1):83–101.

In our view, the statement in the “additional information” that “Prenatal diagnosis is available for the kindred of affected patients if the causal mutations have been characterized” is grounded in social stigma and gender stereotypes, and not any innate disadvantage.

Code headings

The current headings:

- LC1A.4 46,XY disorder of sex development due to a defect in testosterone metabolism
- 46,XY disorder of sex development due to 5-alpha-reductase 2 deficiency

Should be changed to:

- LC1A.4 46,XY congenital variation of sex characteristics due to a variation in testosterone metabolism
- 46,XY congenital variation of sex characteristics due to 5-alpha-reductase 2 deficiency

Description

The following description should be changed:

Steroid 5-alpha-reductase 2 deficiency is a rare disorder of sex development (DSD), characterized by incomplete differentiation of male genitalia in 46X,Y patients.

To:

Steroid 5-alpha-reductase 2 deficiency is a rare variation of sex characteristics, characterized by genital variations in a person with 46,XY sex chromosomes.

Additional Information

The following “Additional Information”:

Steroid 5-alpha-reductase 2 deficiency is a rare disorder leading to male pseudohermaphroditism (MPH), a condition characterized by incomplete differentiation of male genitalia in 46X,Y patients. The enzyme 5-alpha-reductase 2 catalyses the conversion of testosterone (T) to dihydrotestosterone (DHT), which is essential for normal differentiation of the external male genitalia and development of the urogenital sinus. The classical syndrome (pseudovaginal perineoscrotal hypospadias) is characterized at birth by ambiguous external genitalia with a clitoral-like phallus, hypospadias, bifid scrotum and persistent

Liao L-M, Wood D, Creighton SM. Parental choice on normalising cosmetic genital surgery. BMJ. 2015;351:h5124.

urogenital sinus with a perineal blind vaginal pouch. However, external genitalia phenotypes may range from complete female to male with hypospadias and/or micropenis. Testes are found in the labioscrotal folds or inguinal canals. The internal urogenital tract is well developed and Müllerian duct derived structures are absent. At puberty, unless gonadectomy has already been performed, significant virilization without gynecomastia occurs, due to the action of testosterone. Most patients are infertile. The disorder is transmitted as an autosomal recessive trait. The enzyme 5-alpha-reductase 2 is encoded by the SRD5A2 gene localized to 2p23. More than 40 mutations have been reported in all five exons of the SRD5A2 gene. These are mainly amino-acid substitutions, but complete gene deletion, small deletions, nonsense mutations and splice site mutations have also been detected. Baseline and post-hCG (human chorionic gonadotropin) stimulation hormonal investigations reveal normal or elevated testosterone levels, low DHT and an increased T/DHT ratio (> 20). The conversion of T to DHT can be assessed in cultured genital skin fibroblasts, but false negative results are frequent. 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.

Should be **deleted** in its entirety.

If deletion is not possible, this section should be changed to:

Steroid 5-alpha-reductase 2 deficiency is a rare variation characterized by genital variations in a person with 46,XY sex chromosomes. The enzyme 5-alpha-reductase 2 catalyses the conversion of testosterone (T) to dihydrotestosterone (DHT), which is essential for phenotypical external male genitalia and urogenital sinus. The classical variation (pseudovaginal perineoscrotal hypospadias) is characterized at birth by diverse variations in external genitalia including phallus, hypospadias, bifid scrotum and persistent urogenital sinus with a perineal blind vaginal pouch. Testes are found in the labioscrotal folds or inguinal canals. The internal urogenital tract is present and Müllerian duct derived structures are absent. Parents and caregivers may benefit from counseling.

6.11.3 46,XY disorder of sex development due to 17-beta-hydroxysteroid dehydrogenase 3 deficiency

- Index entity at <http://apps.who.int/classifications/icd11/browse/f/en#http%3a%2f%2fid.who.int%2f%2fentity%2f887793448>

The 2006 summary clinical “consensus statement” states that “Appearance-altering surgery is not urgent”,⁶¹ and the 2016 clinical global DSD update to the 2006 “consensus statement” demonstrates that there remains no clinical consensus regarding any surgical management:

There is still no consensual attitude regarding indications, timing, procedure and evaluation of outcome of DSD surgery. The levels of evidence of responses given by the experts are low ... Timing, choice of the individual and irreversibility of surgical procedures are sources of concerns. There is no evidence regarding the impact of surgically treated or non-treated DSDs during childhood for the individual, the parents, society or the risk of stigmatization.⁶²

In 2017, the Committee on Bioethics of the Council of Europe commissioned a report examining the rights of children in biomedicine. The report authors stated 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...

On the scientific question of whether intervention is necessary, only three medical procedures have been identified as meeting that criteria in some infants: (1) administration of endocrine treatment to prevent fatal salt-loss in some infants, (2) early removal of streak gonads in children with gonadal dysgenesis, and (3) surgery in rare cases to allow exstrophic conditions in which organs protrude from the abdominal wall or impair excretion⁶³

This analysis does not support surgical management of genital anomalies associated with 5-alpha reductase deficiency.

The “additional information” section states that:

⁶¹ Houk CP, Hughes IA, Ahmed SF, Lee PA, Writing Committee for the International Intersex Consensus Conference Participants. Summary of Consensus Statement on Intersex Disorders and Their Management. PEDIATRICS. 2006;118(2):753–7.

⁶² Lee PA, Nordenström A, Houk CP, Ahmed SF, Auchus R, Baratz A, et al. Global Disorders of Sex Development Update since 2006: Perceptions, Approach and Care. Hormone Research in Paediatrics. 2016;85(3):158–180.

⁶³ Zillén K, Garland J, Slokenberga S, Committee on Bioethics of the Council of Europe. The Rights of Children in Biomedicine: Challenges posed by scientific advances and uncertainties. 2017.

The authors of this study point to inertia as a rationale for continued early genital surgery. While the report authors still had “normalising” intent, they concluded that, in their population:

*deferring genital operation is acceptable among patients and families*⁴⁸

A 2016 case before the Family Court of Australia controversially described feminizing interventions on a young (circa 3-year old) child with 17 β -hydroxysteroid dehydrogenase-3 as having “enhanced the appearance of her female genitalia”.⁶⁷ A legal scholar has condemned this as describing both “the culpability of health systems and the medical profession” and a “failure of the state to protect the rights” of children with intersex variations.⁶⁸

Widespread concern about the human rights issues associated with early surgical interventions for reasons of appearance means that multiple UN institutions and Treaty Bodies have issued statements condemning such practices.⁷ The World Health Organization report on Sexual health, human rights and the law is cited in the section “Nomenclature is linked to treatment”. In 2016, the World Health Organization paper on *Sexual health, human rights and law* has recognised these concerns:

*A major concern for intersex people is that so-called sex normalizing procedures are often undertaken during their infancy and childhood, to alter their bodies, particularly the sexual organs, to make them conform to gendered physical norms, including through repeated surgeries, hormonal interventions and other measures. As a result, such children may be subjected to medically unnecessary, often irreversible, interventions that may have lifelong consequences for their physical and mental health, including irreversible termination of all or some of their reproductive and sexual capacity. Medical procedures may sometimes be justified in cases of conditions that pose a health risk or are considered life-threatening. Such procedures, however, are sometimes proposed on the basis of weak evidence, without discussing and considering alternative solutions*⁶⁹

We note that no evidence is provided of necessity for early surgical interventions in the “additional information” section, and nor are alternative solutions entertained. It is thus contradictory and inappropriate for the ICD to facilitate or promote such cosmetic practices.

Additionally, at least one jurisdiction has made such interventions unlawful. Malta has recognised a right to “bodily integrity and physical autonomy”:

⁶⁷ Family Court of Australia. Re: Carla (Medical procedure) [2016] FamCA 7. Available from <http://www.austlii.edu.au/cgi-bin/sinodisp/au/cases/cth/FamCA/2016/7.html>

⁶⁸ Jones M. Children’s Health Rights and Gender Issues. In: Children’s Rights in Health Care. Leiden: Brill; 2017 (forthcoming).

⁶⁹ World Health Organization. Sexual health, human rights and the law [Internet]. Geneva: World Health Organization; 2015. Available from: http://apps.who.int/iris/bitstream/10665/175556/1/9789241564984_eng.pdf?ua=1

It shall be unlawful for medical practitioners or other professionals to conduct any sex assignment treatment and/or surgical intervention on the sex characteristics of a minor which treatment and/or intervention can be deferred until the person to be treated can provide informed consent⁷⁰

The ICD-11 should not include language promoting unlawful actions.

Human rights institutions in jurisdictions across multiple continents are raising similar concerns. In contrast, psychological support and counseling may benefit parents and individuals.⁷¹

In our view, the statement in the “additional information” that “Prenatal diagnosis is available for the kindred of affected patients if causal mutations have been characterized” is grounded in social stigma and gender stereotypes, and not any innate disadvantage.

Code headings

The current headings:

- LC1A.4 46,XY disorder of sex development due to a defect in testosterone metabolism
- 46,XY disorder of sex development due to 17-beta-hydroxysteroid dehydrogenase 3 deficiency

Should be changed to:

- LC1A.4 46,XY congenital variation of sex characteristics due to a variation in testosterone metabolism
- 46,XY congenital variation of sex characteristics due to 17-beta-hydroxysteroid dehydrogenase 3 deficiency

Description

The following description should be changed:

17-beta-hydroxysteroid dehydrogenase isozyme 3 deficiency is a rare disorder leading to male pseudohermaphroditism, a condition characterized by incomplete differentiation of the male genitalia in 46X,Y males.

To:

⁷⁰ Malta. Gender Identity, Gender Expression and Sex Characteristics Act: Final version [Internet]. 2015. Available from:

<http://justiceservices.gov.mt/DownloadDocument.aspx?app=lp&itemid=26805&l=1>

⁷¹ Liao L-M, Simmonds M. A values-driven and evidence-based health care psychology for diverse sex development. *Psychology & Sexuality*. 2013;5(1):83–101.

Liao L-M, Wood D, Creighton SM. Parental choice on normalising cosmetic genital surgery. *BMJ*. 2015;351:h5124.

17-beta-hydroxysteroid dehydrogenase isozyme 3 deficiency is a rare variation of sex characteristics characterized by genital variations in a person with 46,XY sex chromosomes.

Additional Information

The following “Additional Information”:

17-beta-hydroxysteroid dehydrogenase isozyme 3 (17betaHSD III) deficiency is a rare disorder leading to male pseudohermaphroditism (MPH), a condition characterized by incomplete differentiation of the male genitalia in 46X,Y males. The estimated incidence of this disease is 1 in 147 000 in The Netherlands. The 17betaHSD III enzyme catalyzes the conversion of androstenedione to testosterone in the testis. Lack of testosterone in the fetal testis leads to genetic males with female external genitalia. Patients usually present at birth with female or ambiguous external genitalia, characterized by clitoromegaly, posterior labioscrotal fusion and perineal blind vaginal pouch. Testes are inguinal or in the labioscrotal folds. The internal urogenital tract (epididymides, vasa deferentia, seminal vesicles, ejaculatory ducts) is well developed; prostate and Müllerian structures are absent. Although some patients with less severe defects are brought up as males, affected males are usually brought up as females. However, at puberty they develop signs of virilization (phallic enlargement, male secondary sexual characteristics) and gynecomastia as the result of increases in serum testosterone, due to the conversion of androstenedione to testosterone by extra-gonadal 17b-HSD isoenzymes. All affected individuals are infertile. The disorder is transmitted as an autosomal recessive trait. At least 20 mutations have been reported in the 17-beta-HSD type 3 isozyme gene (HSD17B3), localized to 9q22. These are mainly missense/nonsense mutations, without significant genotypic/phenotypic correlation. Baseline and post-hCG (human chorionic gonadotropin) stimulation hormonal evaluation demonstrates increased androstenedione and low testosterone levels, with an elevated androstenedione/testosterone ratio. Before puberty, a hCG stimulation test is often necessary for diagnosis, since basal levels may be uninformative. Deficiency of 17-ketosteroid reductase is often misdiagnosed in infancy and detected at puberty in genetic males who have been either raised as females and develop hirsutism and primary amenorrhoea, or raised as males and have gynecomastia and incomplete male genital development. 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 causal mutations have been characterized.

Should be **deleted** in its entirety.

If deletion is not possible, it should be replaced by:

17-beta-hydroxysteroid dehydrogenase isozyme 3 deficiency is a rare variation of sex characteristics characterized by genital variations in a person with 46,XY sex chromosomes. The estimated incidence of this condition is 1 in 147 000 in The Netherlands. The 17betaHSD III enzyme catalyzes the conversion of androstenedione to testosterone in the testis. Lack of testosterone in the fetal testis leads to phenotypically female or variations of external genitalia in persons with 46,XY sex chromosomes, including clitoromegaly, posterior labioscrotal fusion and perineal blind vaginal pouch. Testes are inguinal or in the labioscrotal folds. The internal urogenital tract (epididymides, vasa deferentia, seminal vesicles, ejaculatory ducts) is present; prostate and Müllerian structures are absent.

6.12 46,XY disorder of sex development due to environmental chemical exposure

- Index entity at <http://apps.who.int/classifications/icd11/browse/f/en#http%3a%2f%2fid.who.int%2f%2fentity%2f1039516049>

Change code headings from:

- Malformative disorders of sex development
- Congenital non genetic 46,XY disorder of sex development
- 46,XY disorder of sex development due to environmental chemical exposure

Change code headings from:

- Structural congenital variations of sex characteristics
- Congenital non genetic 46,XY variation of sex characteristics
- 46,XY congenital variation of sex characteristics due to environmental chemical exposure

7 Proposed additional classification

7.1 Proposed code: Intersex Genital Mutilation

We propose a code to capture changes to congenital variations of sex characteristics that take place without the informed consent of the recipient. This code would apply in situations where early surgical intervention results in impaired sexual health, and/or occurs despite a high probability that the intervention assumes a gender or sexual orientation that does not match actual gender identity or sexual orientation.⁷²

This code may be used where such interventions take place in medical or non-medical settings.⁷³

Proposed description:

A condition caused by procedures or other interventions to modify congenital variations of sex characteristics without the informed consent of the patient. This condition is characterized by the partial or total removal or modification of external or internal genitalia or other injury to genital organs or secondary sex characteristics.

⁷² Cohen-Kettenis PT. Gender Change in 46,XY Persons with 5 α -Reductase-2 Deficiency and 17 β -Hydroxysteroid Dehydrogenase-3 Deficiency. Archives of Sexual Behavior. 2005;34(4):399–410. Carpenter M, Organisation Intersex International Australia. Shadow Report submission to the Committee on the Rights of Persons with Disabilities on the situation of intersex people in Australia [Internet]. 2017 Jun [cited 2017 Jun 19]. Available from: <https://oii.org.au/31467/submission-crpd-2017/>

Justicia Intersex, Zwischengeschlecht.org. NGO Report to the 6th and 7th Periodic Report of Argentina on the Convention against Torture (CAT) [Internet]. Buenos Aires; 2017 Mar [cited 2017 Apr 26]. Available from: <http://intersex.shadowreport.org/public/2017-CAT-Justicia-Intersex-Zwischengeschlecht-IGM.pdf>

Zwischengeschlecht.org. Intersex Genital Mutilations Human Rights Violations Of Children With Variations Of Sex Anatomy: NGO Report to the 2nd, 3rd and 4th Periodic Report of Switzerland on the Convention on the Rights of the Child (CRC) [Internet]. Zurich; 2014 Mar [cited 2014 Jun 1]. Available from: http://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf

⁷³ Kaggwa J. A general overview on lived realities of being intersex in Uganda and the East African region. Expert meeting on ending human rights violations against intersex persons; 2015 Sep 16; Geneva.