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DRAFT FOR COMMENT

Submission on the World Professional Association for Transgender Health 7th Standards of Care, and the draft Diagnostic and Statistical Manual of Mental Disorders 5th edition

Summary

About this submission

This is a submission by OII Australia to ANZPATH on the proposed World Professional Association for Transgender Health 7th Standards of Care with respect to its application to intersex people. It is also a submission to the APA with respect to the application of the draft Diagnostic and Statistical Manual of Mental Disorders 5th edition to intersex people.

The proposed Standards of Care include intersex people for the first time, and do so in a manner that pathologises intersex people, at a time when WPATH is de-pathologising trans people. Yet, in *all* cases concerning intersex people there is a biological basis for any gender non-conformity. In *very many* cases, gender presentation is iatrogenic – it arises from medical treatment.

The paper reviews peer-reviewed medical research and other papers, and makes a series of recommendations to ensure the appropriate, patient-centred treatment of intersex people, that takes account of our personal needs, and our histories, including both pre-existing diagnoses and the iatrogenic consequences of previous treatment.

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Introduction

The term intersex was adopted by science in the early 20th century and applied to human beings whose biological sex cannot be classified as clearly male or female. An intersex person may have the biological attributes of both sexes or lack some of the biological attributes considered necessary to be defined as one or the other sex. Intersex is always congenital and can originate from genetic, chromosomal or hormonal variations. Environmental influences such as endocrine disruptors can also play a role in some intersex differences.

Intersex people represent a significant percentage of the population. Anne Fausto-Sterling puts the intersex prevalence figure at a minimum of 1.9 % of the population and a maximum, derived from research by John Money, of up to 4%¹. Australian registers of birth anomalies have newborns with visible and reportable differences of sex anatomy at around 29:1000 live births. The introduction of prenatal screening has reduced this number considerably for some intersex differences, due to pregnancy terminations

OII Australia

The Organisation Internationale des Intersexués (OII) is the world's largest intersex organization with members representing almost all known intersex variations. OII has affiliates in twenty countries, on six continents, speaking ten languages including Mandarin Chinese and Arabic.

OII is represented in Australia by **Organisation Intersex International Australia Limited**, a not-for-profit company. The organisation is referred to as **OII Australia** in this submission.

Our mission² is:

- To support intersex individuals by providing information and contact with other intersex people.
- Campaign in favour of human rights for intersex people.
- Encourage an exchange of ideas and different perspectives about intersex from various groups and geographical regions.
- Provide information concerning actual life experiences of people with intersex variations to medical personnel working with infants with atypical sex anatomy, to psychological experts, sexologists, sociologists and specialists in feminism.
- To assist families and friends of intersex individuals to understand intersex and to cope with the specific problems related to their role as a support person.

Our interest in this submission

The proposed Standards of Care include intersex people for the first time, and do so in a manner that pathologises intersex people, at a time when WPATH is de-pathologising trans people. It does so in reference to the Diagnostic and Statistical Manual of Mental Disorders 4th and draft 5th editions.

The SOC states the rationale for including intersex people as

Previously, individuals with a DSD who also met the *DSM-IV-TR*'s behavioral criteria for Gender Identity Disorder (American Psychiatric Association, 2000) were excluded from that general diagnosis. Instead, they were categorized as having a "Gender Identity Disorder - Not Otherwise Specified." They were also excluded from the WPATH *Standards of Care*.

The current proposal for *DSM-5* (www.dsm5.org) is to replace the term *gender identity disorder* with *gender dysphoria*. Moreover, the proposed changes to the *DSM* consider gender dysphoric people with a DSD to have a subtype of gender dysphoria. This proposed categorization – which explicitly differentiates between gender dysphoric individuals with and without a DSD – is justified: In people with a DSD, gender dysphoria differs in its phenomenological presentation, epidemiology, life trajectories, and etiology (Meyer-Bahlburg, 2009).³

OII Australia has significant concerns about the pathologisation and diagnosis as mentally disordered of intersex people. Intersex people have a natural, biological basis for any gender non-conformity, and intersex people are often in a situation where their gender presentation at time of diagnosis with a mental disorder in accordance with the DSM is iatrogenic – it arises from medical treatment.

Mission Creep in the Standards of Care

OII Australia regrets the inclusion of intersex in the WPATH Standards of Care, regrets the manner in which intersex was incorporated, explicitly for the first time, without consultation with intersex representative bodies. OII Australia questions the capacity of WPATH in matters of intersex health. Indeed, the brevity and physical location of the SOC's 3.5 page statement on intersex, which closes that document, demonstrates that capacity.

We are aware that Milton Diamond and some others argue that,

“transsexuality is a form of intersexuality”.

Diamond states that

“I believe that transsexuals are intersexed in their brains as others are or might be more obviously so”⁴.

However, brain differences have also been noted in studies of gay men and lesbians^{5,6}, and very few would argue that this makes them intersex. The inclusion of intersex should not occur through scope- or mission creep.

Intersex health is not a matter of transgender health, should not appear in a Standards of Care manual for transgender people.

This is not to claim that intersex people do not have issues with their gender assignment. we review, later in this submission, research on this issue and present recommendations for a suggested protocol. However, the gender identity issues of intersex people are not, we would argue, a matter of transgender health. They are often a matter where longstanding needs have not been met, where iatrogenic changes have caused discomfort, or where proposed “gender confirming” treatments are as life changing as “cross gender” treatments.

Where intersex people are presenting themselves for treatment at centres for transgender health due to gender identity issues, their specific needs have to be met, and support services need to develop the capacity to assist with intersex health needs, rather than by conflating the very different life trajectories of intersex and trans individuals.

We acknowledge that clinicians experienced in treating intersex people may equally benefit from liaison with clinicians experienced in transgender health issues.

Recommendations on process and capacity

1. Treatment protocols for intersex people must only be developed with the full inclusion of intersex individuals and organisations, just as has been the case with the transgender Standards of Care.
2. Membership of WPATH should be extended to client organisations in the targeted population. OII Australia would welcome such an opportunity.
3. WPATH must canvas widely amongst intersex organisations for membership and offer reasonable affordable rates, given that most are unfunded and financially stretched.
4. Professionals involved in developing protocols and standards must have on-the-ground experience with intersex clients.
5. The naming of the Standards of Care, and the membership and naming of the organisation, are not intersex-inclusive. We recommend that an extended remit and membership of WPATH be reflected in the organisation's name and outputs.

Value-Free Terminology

OII Australia welcomes the de-pathologisation evident in a shift from “Gender Identity Disorder” to “Gender Dysphoria”. However, we have strong objections to terminology in the Standards of Care, and draft Diagnostic and Statistical Manual of Mental Disorders 5th edition, that are used to describe intersex.

Disorders of Sex Development

Version 7 of the Standards of Care introduces the term “People With Disorders of Sex Development”:

Although the terminology was changed to *DSD* during an international consensus conference in 2005 (Hughes et al., 2006), disagreement about language use remains. Some people object strongly to the “disorder” label, preferring instead to view these congenital conditions as a matter of diversity (Diamond, 2009) and to continue using the terms *intersex* or *intersexuality*. In the *SOC*, WPATH uses the term *DSD* in an objective and value-free manner, with the goal of ensuring that health professionals recognize this medical term and use it to access relevant literature as the field progresses. WPATH remains open to new terminology that will further illuminate the experience of members of this diverse population and lead to improvements in health care access and delivery.³

The DSM-5 draft uses the same term. OII Australia uses the term “intersex”, or “intersex variation”. OII Australia rejects the terms ‘disorder’, ‘DSD’, or ‘Disorders of Sex Development’, as pathologising and stigmatising language that harm intersex people. We also reject “Differences of Sex Development” and similar terms because they will be interpreted as indistinguishable from DSD. The terminology can not be said to be “value-free” and “objective”.

We note WPATH’s own position on the depathologisation of gender variance and the effects of stigmatising language in their press release of May 26 2010:

The expression of gender characteristics, including identities, that are not stereotypically associated with one’s assigned sex at birth is a common and culturally-diverse human phenomenon which should not be judged as inherently pathological or negative... WPATH urges governmental and medical professional organizations to review their policies and practices to eliminate stigma toward gender-variant people⁷

Professor Milton Diamond states:

I refuse to use the acronym DSD to refer to Disorders of Sex Development as suggested by Hughes *et al.* Calling intersex conditions disorders is unnecessarily stigmatizing. The majority of persons with these conditions also hold this feeling as do intersex groups⁴.

Georgiann Davis recounts the history behind this shift thus:

By the 1990s, the medicalized treatment of intersexuality was heavily critiqued by intersex activists upset that they had been lied to about their medical condition, surgically modified in ways that left them with diminished sexual desire, minimal ability to reach sexual pleasure, and in some cases, an increased likelihood of incontinence. Intersex activists responded by protesting outside of pediatric medical association meetings accusing doctors of pediatric “mutilation.” While their confrontational strategies were initially ignored by the medical profession, by the year 2000, the

American Academy of Pediatrics (AAP) acknowledged that their historical treatment of intersexuality left their profession in a state of “social emergency”

...By the year 2000, Chase was delivering a plenary address to the Lawson Wilkins Pediatric Endocrine Society, a group she was once protesting against. This successful activist encroachment into medical turf was highly unusual for two overlapping reasons. It marked the first time an activist’s perspective was solicited by organizers of a major medical conference. And, it was “the first time that the society’s annual symposium was devoted to intersexuality”.⁸

Morgan suggests that a value-free term was sought in the shift to “DSD”, but not the outcome – a consequence of a flawed strategy:

The aim was to create a non-pejorative, value-neutral term to replace “intersex” and “hermaphrodite”. In a very literal sense it was homophobic: it aimed to eliminate a parental and social fear of homosexuality and queerness in an attempt to improve patient outcomes.

It failed... The 2006 Consensus Statement on management of intersex itself describes the current “rationale for early reconstruction” on infant genitals as including

“minimizing family concern and distress, and mitigating the risks of stigmatization and gender-identity confusion...”⁹

OII Australia disputes an assertion made by the DSD consensus group that the word “intersex” is perceived as pejorative and is stigmatizing. We contend that the consensus body asserted that position without any factual evidence before it. OII Australia contends that, according to our own polls and surveys amongst a substantial number of intersex people, none has indicated a preference for “DSD” or “disorder”.

The presence of a genetic disorder does not only impact on minors, as reviewed later in this submission, it is also grounds for termination, including late termination. De Crespigny and Savulescu state, in 2008 research, that:

Most women will request abortion after the diagnosis of a major fetal abnormality — 95% do so after the diagnosis of Down syndrome in Victoria (J Halliday, Head, Public Health Genetics, Murdoch Children’s Research Institute, Melbourne, personal communication). When a major fetal abnormality is diagnosed, clinical experience shows that even women who consider themselves to be antichoice commonly reevaluate their in-principle opposition to abortion...

The late abortion case at the RWH in Melbourne in 2000 was widely publicised. A woman requesting pregnancy termination was referred at 31 weeks’ gestation; her fetus had been diagnosed with skeletal dysplasia, most likely achondroplasia. Termination was performed at 32 weeks on the grounds that the woman was acutely suicidal¹⁰

In research by the AIS Support Group Australia, presented to the ACT government in 2003:

A report about prenatal diagnostic testing in Victoria by the Victorian Department of Human Services found that of all birth ‘defects’ from 1983 to 1998:

- 213 had Turners Syndrome;
- 77 had Klinefelter Syndrome;
- 189 had other sex chromosomes; and

- 229 were of 'indeterminate sex'.

The data of termination following diagnosis before 20 weeks gestation was only available for the reduced period of 1989 to 1998, and of these the following were terminated because of their condition:

- 98 Turner Syndrome;
- 28 Klinefelter Syndrome; and
- 39 Conditions due to other sex chromosome anomalies.¹¹

Georgiann Davis describes the term 'Disorder of Sex Development' as a reassertion of medical authority:

I argue this shift was a reaction to activist challenges to medical jurisdiction over intersexuality, and doctors' insistence on the DSD terminology was a reassertion of their medical authority⁸.

She concludes:

The new DSD terminology constructs "sex" as a scientific phenomenon, and a binary one at that. Under such frame, intersex experts neatly link intersexuality to science, and thus are able to justify surgery. This places intersexuality neatly into medical turf and safely away from critics of its medicalization. At the same time, the connection to science increases medical credibility, which in light of intersex activism, is necessary.

...With the new DSD terminology, intersexuality has been returned to medical turf where medical professionals, notably surgeons, are able to reclaim authority over the intersex body...

Intersex as a condition

OII Australia regards intersex as a matter of natural human biological variation, present in myth and legend, for example, giving rise to the term hermaphrodite; history, for example, Herculine Barbin (Foucault¹²); and all human societies.

OII Australia does not favour the terms intersex condition or hermaphrodite, but we recognise that some intersex people reclaim or use these terms to describe themselves.

We also recognise that some intersex variations, such as CAH, have on-going (but manageable) health needs that are not associated with cosmetic differences. However, OII Australia believes that conceiving of natural human variation as a "condition" is pathologizing simply because it creates an impulse to correct an error.

Recommendation on terminology

6. OII Australia believes that a desire for "objective, value-free" terminology necessitates the use of terms other than DSD. OII Australia recommends use of the term "intersex".

Intersex, gender nonconformity and gender dysphoria

Definitions

The definitions of gender nonconformity and dysphoria given in the SOC are:

Gender nonconformity refers to the extent to which a person's gender identity, role, or expression differs from the cultural norms prescribed for people of a particular sex (Institute of Medicine, 2011). *Gender dysphoria* refers to discomfort or distress that is caused by a discrepancy between a person's gender identity and that person's sex assigned at birth (and the associated gender role and/or primary and secondary sex characteristics) (Fisk, 1974; Knudson, De Cuypere, & Bockting, 2010b). Only *some* gender nonconforming people experience gender dysphoria at *some* point in their lives.³

The DSM-5 draft discusses gender assignment and actual sex characteristics rather than the congruence of gender identity and sex. These are defined in dyadic terms. The rationale, similarly, describes gender dysphoria as having "unusual status as a mental condition treated with *cross-sex hormones*" (our emphasis)¹³. The proposed text for the 'condition' is as follows:

Gender Dysphoria (in Adolescents or Adults)**

A. A marked incongruence between one's experienced/expressed gender and assigned gender, of at least 6 months duration, as manifested by 2* or more of the following indicators: [2, 3, 4]**

1. a marked incongruence between one's experienced/expressed gender and primary and/or secondary sex characteristics (or, in young adolescents, the anticipated secondary sex characteristics) [13, 16]
2. a strong desire to be rid of one's primary and/or secondary sex characteristics because of a marked incongruence with one's experienced/expressed gender (or, in young adolescents, a desire to prevent the development of the anticipated secondary sex characteristics) [17]
3. a strong desire for the primary and/or secondary sex characteristics of the other gender
4. a strong desire to be of the other gender (or some alternative gender different from one's assigned gender)
5. a strong desire to be treated as the other gender (or some alternative gender different from one's assigned gender)
6. a strong conviction that one has the typical feelings and reactions of the other gender (or some alternative gender different from one's assigned gender)

B. The condition is associated with clinically significant distress or impairment in social, occupational, or other important areas of functioning, or with a significantly increased risk of suffering, such as distress or disability**

Subtypes

With a disorder of sex development [14]

Without a disorder of sex development

See also: [15, 16, 19]

Specifier**

Post-transition, i.e., the individual has transitioned to full-time living in the desired gender (with or without legalization of gender change) and has undergone (or is undergoing) at least one cross-sex medical procedure or treatment regimen, namely, regular cross-sex hormone treatment or gender reassignment surgery confirming the desired gender (e.g., penectomy, vaginoplasty in a natal male, mastectomy, phalloplasty in a natal female).¹³

Intersex people have a biological sex that is not clearly male or female, and intersex people may possess characteristics of both or neither binary sexes. Intersex people are invariably assigned a binary gender that, even at best, can only approximate our actual sex. As a result, gender nonconformity is widespread, and non-standard gender identities are common.

OII Australia welcomes the recognition in both SOC and DSM-5 that intersex people may not be happy with an earlier assignment, and may wish to pursue options to live more comfortably as male or female. We particularly welcome the recognition that some people, including intersex people, may not feel comfortable living as either gender.

Gender dysphoria, as defined in the SOC, is likely to be widespread amongst intersex people. Gender dysphoria, as defined by the DSM-5, in its references to “natal male”, “natal female” and “cross-sex” medical treatments is a very poor fit with the intersex experience.

OII Australia shares the concerns of the British Psychological Society (BPS), that this approach medicalises our natural individual variation and normal responses to our human experience. The BPS response to the DSM-5 (P00-03 Gender Dysphoria) reads:

As stated in our general comments, we are concerned that clients and the general public are negatively affected by the continued and continuous medicalisation of their natural and normal responses to their experiences; responses which undoubtedly have distressing consequences which demand helping responses, but which do not reflect illnesses so much as normal individual variation.

We believe that classifying these problems as ‘illnesses’ misses the relational context of problems and the undeniable social causation of many such problems. For psychologists, our well-being and mental health stem from our frameworks of understanding of the world, frameworks which are themselves the product of the experiences and learning through our lives.¹⁴

The etiology of intersex people who seek to change gender or appearance is markedly different from that of non-intersex people. In *all* cases there is a biological basis for any gender non-conformity. In *very many* cases, gender presentation is iatrogenic – it arises from medical treatment. Sex characteristics may have been surgically or hormonally modified before assessment as having dysphoria, to conform to societal, familial and medical pressures.

This is recognized by the SOC, which states:

However, certain criteria for treatment (e.g., age, duration of experience with living in the desired gender role) are usually not routinely applied to people with a DSD; rather, the criteria are interpreted in light of a patient’s specific situation (Meyer-Bahlburg, in press). In the context of a DSD, changes in birth-assigned sex and gender role have been made at any age between early elementary-school age and middle adulthood.

One reason for these treatment differences is that genital surgery in individuals with a DSD is quite common in infancy and adolescence. Infertility may already be present due to either early gonadal failure or to gonadectomy because of a malignancy risk.

In cases of iatrogenic gender presentation, it is insulting and damaging for people who have been made to more closely conform to an arbitrary binary gender to be told they have a psychiatric disorder or condition if they reject that assignment.

OII Australia considers gender non-typical behaviour or desires by intersex people to be the result of inappropriate societal, familial or medical preferences and standards, not a medical condition.

Intersex has a biological basis

Assigning a binary gender role to a person with intersex biology must be regarded as an approximation of reality and must not be pathologised as non-conformist, or disordered.

Gender non-conformity has often been constructed as “abnormal”. Congenital Adrenal Hyperplasia (“CAH”), is a manageable salt wasting condition that requires lifelong treatment. In women, it’s also associated with higher levels of prenatal testosterone, and a degree of physical and mental “masculinisation”. In 1999, Columbia University psychologist Heino Meyer-Bahlburg published a paper entitled *What Causes Low Rates of Child Bearing in CAH?*:

CAH women as a group have a lower interest than controls in getting married and performing the traditional child-care/house-wife role. As children, they show an unusually low interest in engaging in... maternal play, motherhood...¹⁵

Similarly, a 2008 Swedish study reported:

When comparing pregnancy history, significantly fewer women with CAH had ever been pregnant, 16 compared with 41 in the control group. A total of 31 pregnancies were seen among the 62 women with CAH compared with 76 among the 62 women in the control group. Only 25 children were born in the CAH group compared with 54 in the control group”

“The number of term pregnancies among the CAH women was clearly related to the severity of the mutation...”

The number of women living in a steady heterosexual relationship was also significantly lower.¹⁶

Alice Dreger *et al* tell how Meyer-Bahlburg and Dr Maria New of Mount Sinai School of Medicine in NY published research in 2008 stating:

Most women were heterosexual, but the rates of bisexual and homosexual orientation were increased above controls... and correlated with the degree of prenatal androgenization¹⁵.

Dreger *et al* describe how New and fellow pediatric endocrinologist Saroj Nimkarn (Weill Cornell Medical College) construct:

low interest in babies and men – and even interest in what they consider to be men’s occupations and games – as “abnormal,” and potentially preventable with prenatal dex”¹⁵

This is shocking, given that the APA declassified homosexuality as a mental disorder in 1973.

Most research on people with XXY chromosomes and other variants has assumed that such people are men. A.S. Herlihy and L. Gillam of Murdoch Children's Research Institute, Department of Obstetrics & Gynaecology at Monash University, Andrology Australia, Prince Henry's Institute of Medical Research, Centre for Health & Society and Royal Children's Hospital, Parkville, acknowledge this in a letter to the International Journal of Andrology in 2011:

Over the course of our recruitment period, from November 2008 to December 2009, a number of inquiries came through, some from clinicians, but mostly from the support group Organisation Intersex International Australia Ltd. Were we just looking for male XXY participants? Or were we also interested in XXY participants who were female, intersex, or at least did not identify as male? This initially caused some concern amongst the research team – we certainly had not intended to exclude anyone with XXY chromosomes, regardless of their gender identity, and we had lacked awareness of the possibility of this occurring, by assuming that all XXY individuals are male.¹⁷

John Parkinson similarly identifies a number of cases of XXY and other hypogonadal people with non-male gender identities¹⁸.

Many people might seek assistance to resolve their difficulties with iatrogenic changes to their bodies. It is inappropriate for them to be diagnosed as dysphoric.

For intersex people who have not experienced iatrogenic changes, gender affirming, or gender-related, treatments should be regarded as equally valid regardless of whether or not these are considered to be aligned with that person's gender presentation at start of treatment.

Surgical and other treatment on minors

Surgery, on infants, children or adolescents, is a standard protocol where an early diagnosis of intersex is made, despite the inability of a minor to freely give prior, fully informed consent.

The age of first surgery varies, depending in large part on the age of diagnosis and the particular type of intersex. From the Consensus statement on management of intersex disorders:

The birth of an intersex child prompts a long term management strategy that involves a myriad of professionals working with the family¹⁹

On infants Creighton reports:

The traditional management of the virilized female infant has centred on restoring 'normality'. Once the diagnosis has been made and the infant assigned to a female sex of rearing, feminizing genital surgery almost inevitably follows.²⁷

The SOC comments on early genital surgery, albeit in an ambiguous statement that we hope might be related to reparative surgery, rather than infant cosmetic surgeries:

Even genital surgery may be performed much earlier in these patients than in gender dysphoric individuals without a DSD if the surgery is well justified by the diagnosis, by the evidence-based gender-identity prognosis for the given syndrome and syndrome severity, and by the patient's wishes.³

The 2006 Consensus Statement on managing intersex describes how such surgeries are cosmetic in nature:

Rationale for early reconstruction includes beneficial effects of estrogen on infant tissues, avoiding complications from anatomic anomalies, satisfactory outcomes,

minimizing family concern and distress, and mitigating the risks of stigmatization and gender-identity confusion of atypical genital appearance¹⁹

Assumed “complications from anatomic anomalies” aside, the rationale betrays a focus on the arbitrary assignment of children based on societal objectives: family distress, stigmatization, gender identity confusion. Intersex bodies are still treated as if they are queer and distressing.

Such treatments lack a sound ethical or research basis. Creighton and Minto report:

Genital surgery is one of the most controversial interventions in current intersex management. A large proportion of infants with ambiguous genitalia are raised as girls, and surgically feminising the genitalia usually involves a clitoral reduction and a vaginoplasty. In the absence of clinical trials and with minimal objective cohort studies providing data on outcomes on cosmetic, gender, social, or sexual function after this surgery, along with anecdotal evidence of dissatisfaction of adult patients with childhood surgery, both clinicians and parents face huge dilemmas. Current theories of gender development say that both prenatal factors (for example, testosterone) and postnatal factors, including the social environment, are important, and that genital appearance is less relevant.²⁰

Further, too early surgery can affect accurate diagnosis and later treatment. In a cross-sectional review of XY female diagnoses, Minto *et al* report:

Inaccurate and wrong diagnoses were surprisingly high in this study, with only 47.8% of patients considered to have an accurate diagnosis. Of more immediate concern were the 13% of patients with a wrong diagnosis, in some cases leading to irreversible virilising changes or high risk of gonadal malignancy...

In this study 13% of patients were assigned an inconclusive diagnosis due to inadequate investigation prior to gonadectomy. The vital information from hormonal assays must be performed with the gonads *in situ*. It is much more difficult, if not impossible, to make an accurate diagnosis after gonadectomy.²¹

Birgit Köhler, *et al*¹⁴ report that:

Prenatal deficit of androgens or androgen action results in atypical genitalia in individuals with XY disorders of sex development (XY,DSD). XY,DSD include mainly disorders of gonadal development and testosterone synthesis and action. Previously, most XY,DSD individuals were assigned to the female sex. Constructive genital surgery allowing heterosexual intercourse, gonadectomy, and hormone therapy for feminization were often performed. However, outcome studies are scarce.²²

This scarcity of outcome studies is a matter of great concern to OII Australia. Those that do exist show that the effects of infant surgeries are long lasting, including a legacy of shame, distorted family dynamics, and insensate genitalia that deeply affect adult relationships and life satisfaction.

Birgit Köhler *et al* report:

Dissatisfaction with function of the surgical result (47.1%) and clitoral arousal (47.4%) was high in XY,DSD partially androgenized females after feminization surgery. Dissatisfaction with overall sex life (37.5%) and sexual anxieties (44.2%) were substantial in all XY,DSD individuals. Problems with desire (70.6%), arousal (52.9%), and dyspareunia (56.3%) were significant in XY,DSD complete females. 46,XY partially androgenized females reported significantly more often partners of female (9.1%) or both sexes (18.2%) and dyspareunia (56.5%) compared with controls.

Individuals with complete androgen insensitivity syndrome stated significant problems with desire (81.8%), arousal (63.6%), and dyspareunia (70%).²²

Creighton, Minto and Steele analysed the cosmetic results of surgery performed for cosmetic reasons, and found results to be poor, and almost all required further surgical treatment:

Cosmetic result was judged as poor in 18 (41%) of these patients. 43 (98%) of 44 needed further treatment to the genitalia for cosmesis, tampon use, or intercourse. 23 (89%) of 26 of genitoplasties planned as one-stage procedures required further major surgery...

The outcomes of childhood genital surgery are substantially poorer than reported previously with nearly all children requiring further treatment. All surgery was done at specialist units and should give the best results available. This study is retrospective, but because of the numbers of patients involved, we believe it is representative. Nevertheless, despite planned routine referrals for all relevant adolescents, these patients may be those with the poorest outcomes. Additionally these children had surgery between 1979 and 1995. There have been changes in surgical techniques, equipment, sutures, and antibiotics since that time. More up-to-date procedures may have better outcomes, although there are few data to support this.

This study prompts a re-evaluation of cosmetic genital surgery in children. Most vaginal surgery can be deferred until after adolescence unless haematocolpos is a risk. Repeated clitoral surgery may be more damaging to sexual function than a single procedure.²³

Alice Dreger, former co-director of the Intersex Society of North America has said that “I have never met an intersex adult who was entirely happy with their surgery”, reported by Karkazis²⁴.

Assignment is arbitrary, dictated by societal preferences and changing medical beliefs. Milton Diamond reports:

Regarding the management of infants with intersex conditions and ambiguous genitalia, David Diamond (no relation) and colleagues reported in 2006 on a survey they conducted of pediatric urologists. They asked how these specialists would clinically deal with infants diagnosed with CAH. The respondents overwhelmingly favored female gender assignment for females with CAH even if they were extensively masculinized (Prader V). They recommended feminizing surgery—reducing the size of an enlarged clitoris—and considered that preservation of female fertility was of foremost importance and the masculinization of behaviors or inclinations, was of lesser importance. There was a great difference of opinion as to the age it would be best to do the surgery.

In that same survey Diamond *et al* asked how these pediatric urologists might treat cases of cloacal exstrophy. For a case involving a male with cloacal exstrophy, a condition in which all external genitalia might be absent, notwithstanding retention of the gonads, 70% of respondents recommended male assignment and 30% a female one.

These 70 and 30 percent figures, in themselves, are crucial. They represent a dramatic reversal of how male infants with cloacal exstrophy would have been assigned just a decade earlier. These males then would all have been assigned as females.⁴

Yet Davis reports how parents who might choose not to pursue surgical options are pressured into it, by doctors who stand to financially benefit from the practice.

Medical professionals made it clear during the interview that parents welcomed their professional opinion with little resistance or hesitation. However, such wasn't true for all families. Dr. C. recounted a recent consultation with a family that was very critical of his recommendations:

"The father said, '[Doctor], can I ask you a question?' I said, 'Absolutely, this is your forum. I'm at your disposal. You're hiring me.' He said, 'Why should we do anything?' And I acted physically surprised, I'm sure I did. And I said, 'Well, I'm concerned that if you raise this child in a male gender role without a straight penis, he's not going to see himself as most other males and he's not going to certainly be able to function as most other males.' And the father said, 'Well, in our family we like to celebrate our differences and not try to all be the same and feel the social pressure to do everything like everyone else does.'... I said, I do have to say one thing, and I think it's of key importance that you both see a psychiatrist." ⁸

Where medical treatment or investigation takes place, it can cause major interference in family dynamics and behaviour, and in the development of a child. DSD Guidelines on "timing of surgeries" for patients with CAH in 2006 stated:

Operations designed to normalize genital appearance may undermine the multidisciplinary team's central message to the parents that the child is unconditionally acceptable and lovable ²⁷

Creighton *et al* state:

Chase (quoted by Hegarty) describes families with an intersex child as 'distorted and unusual' and refers to 'all the trauma that intersexed children and their families experience'. That is, the 'degrading and shaming experience' of medical sexing, and patient care before and after can profoundly alter individual and family functioning. Thus although the biology of intersex conditions can influence sexuality, as intersex people have also been subjected to major developmental interference, their sexuality (normative or variant) can say little about the relative contributions of genetic, anatomical, hormonal or environmental influences ²⁵

Dreger and Feder reported in 2010 on post-surgery examinations by Dix Poppas, presented in the 2007 *Journal of Urology* paper, "*Nerve Sparing Ventral Clitoroplasty: Analysis of Clitoral Sensitivity and Viability*" by Jennifer Yang, Diane Felsen, and Dix P. Poppas:

At annual visits after the surgery, while a parent watches, Poppas touches the daughter's surgically shortened clitoris with a cotton-tip applicator and/or with a "vibratory device," and the girl is asked to report to Poppas how strongly she feels him touching her clitoris. Using the vibrator, he also touches her on her inner thigh, her labia minora, and the introitus of her vagina, asking her to report, on a scale of 0 (no sensation) to 5 (maximum), how strongly she feels the touch. Yang, Felsen, and Poppas also report a "capillary perfusion testing," which means a physician or nurse pushes a finger nail on the girl's clitoris to see if the blood goes away and comes back, a sign of healthy tissue. Poppas has indicated in this article and elsewhere that ideally he seeks to conduct annual exams with these girls. He intends to chart the development of their sexual sensation over time...

Zucker said that we could quote him as saying this: “Applying a vibrator to a six-year-old girl’s surgically feminized clitoris is developmentally inappropriate.” We couldn’t find a clinician who disagreed with Zucker.²⁶

Even in 2006, DSD Guidelines prepared by the Consortium on the Management of Disorders of Sex Development on “timing of surgeries” for patients with CAH recognized that:

There is a consistent and growing body of evidence that children raised with “ambiguous” sex anatomy are at no greater risk for psychosocial problems than the general population... Meanwhile, there is surprisingly little published evidence to the contrary... As a consequence, there is a lack of demonstrated need for early cosmetic genital surgeries. Interventions have tended to be based on fears about “worst case scenarios,” not demonstration of medical need.²⁷

Yet surgeries remain part of standard protocols for the management of “disordered” intersex patients. Dreger and Feder stated in 2010:

We still know of no evidence that a large clitoris increases psychological risk (so is the surgery even necessary?), and we do know of substantial anecdotal evidence that it does not increase risk. Importantly, there also seems to be evidence that clitoroplasties performed in infancy do increase risk – of harm to physical and sexual functioning, as well as psychosocial harm.²⁸

In many cases, medical professionals fail to disclose the nature of treatment to the individuals concerned, and seek the collusion of family members. Creighton and Minto describe the impact of a widespread policy of non-disclosure:

A paternalistic policy of withholding the diagnosis is still practised by some clinicians. No objective work has analysed the widespread effects of such non-disclosure, but the impact on individual patients has been eloquently described. There are more than just medicolegal reasons for abandoning non-disclosure. Most patients eventually become aware of their diagnosis through a variety of ways—from mortgage applications to television and magazine articles on intersex. Some articulate feelings of anger, distrust, and betrayal directed towards their doctors and families. Surely if a patient is going to learn the truth whatever happens, it would be more appropriate if they learnt it from their doctor and were given accurate information and appropriate psychological input. Policies of non-disclosure also prohibit access to genetic screening and the important option of peer support groups for shared learning and experiences.²⁹

In conclusion, Creighton and Liao report that sex assignment by genital surgery:

represents an experiment involving invasive, risky and irreversible intervention. We are unsure how the absence of rigorous evaluation of the intended outcome could ever have been justified in interventions with such grave consequences³⁰.

The experience of intersex people who have undergone infant surgeries prompts us to question the ability of children and adolescents diagnosed with gender dysphoria to consent to their treatment with hormone blockers and subsequent actions. While considered reversible, such treatments delay psychological maturation and so delay the ability of the minor to properly consent to subsequent treatments.

Adult surgical and hormone treatments

Current protocols for the treatment of intersex adolescents and adults are similarly problematic, due to:

- Medicalization where an individual does not seek treatment.
- Treatments deemed to be aligned with gender presentation generally proceeding without counselling or support. Such treatments can result in discomfort, especially when they are inadequately patient-centred.
- Treatments that are not aligned with gender presentation resulting in diagnosis as disordered or dysphoric. Such diagnosis is based on the inaccurate assumption that one gendered set of gender affirming treatments are necessarily more valid or appropriate than another.

John Parkinson reports that:

47XXY males and other cases of hypogonadism are usually treated with testosterone at adolescence or on diagnosis, often with surgery for gynaecomastia. These procedures are usually found helpful in affirming a male gender identity.¹⁸

However, he describes a set of case studies of people who

...regretted having had mastectomy and wanted breast reconstruction...

These cases give food for speculation as to the relation of body to body image and as to possible antenatal hormonal influence on gender identity. They might also illustrate academic notions of gender fluidity. However, the main purpose of this paper is clinical – a plea for careful assessment of gender identity *before* launching on physical treatments¹⁸

An OII Australia board member says:

I was one of Parkinson's cases, I'm hypogonadal and I generally present as masculine, although most of my documentation now doesn't specify a gender. In 2003, I sought a breast reduction, in the hope of better balancing my own understanding of my body with social demands. I'd recently moved for a time to Australia, a much warmer country than where I grew up and, due to my increasing age and the climate, my differences were becoming far more noticeable. Despite written exchanges with the surgeon before the surgery, the reduction turned out to be a mastectomy. Surgical consent statements were ambiguous, although the paper trail leading to surgery is not. A second surgery, provided at no charge by the surgeon, was necessary after three months, but failed to address my loss of sense of self. The week after surgery, I was diagnosed with reactive depression, and this persisted for around three years.

I wasn't treated according to my expressed wishes. It was as if the surgeon had done what he thought I must need according to the way I presented. He tried to make me into a 'normal' man, although the scarring and other characteristics about my body belie that.

I still struggle with what was done to me, close to a decade later. It was the most difficult period of my life, and led directly to the break-up of a longstanding relationship and employment stress.²⁸

Willem de Ronde et al report in the European Journal of Endocrinology that "quality of life is reduced in patients with Klinefelter syndrome on androgen replacement therapy"²⁹. Such therapy is a standard protocol for XXY people.

Chris Somers *et al* also write about the pressure that primary care providers feel to act in such cases, here quoting a public health doctor:

I suppose we have such an idea about kids growing up and such a bi-polar idea about males and females and what we expect physically from them, and that I can say it would be pretty tough if we had...a male with Klinefelter who had breasts as they were growing up; that would be very difficult not to do anything.³⁰

Michael Noble has documented his own experience, initially presented at the Gay and Lesbian Feast Festival, Adelaide, South Australia in 2002:

Around the age of 23, an endocrinologist discovered that my body had never produced enough testosterone for me to undergo a full puberty. He therefore suggested I commence testosterone therapy. Initially, I resisted the pressures placed on me to commence therapy. Yet, eventually, I crumbled under the constant onslaught of threats and horror stories of what my future would be like if I didn't undergo therapy, which the doctors claimed would turn me into a 'real man'. It was insinuated, even blatantly stated on occasions, that my life would be worthless; that I would be a freak; that I would never achieve my potential, and that I would never have any self-esteem (apparently the self-esteem I already had was invalid as it existed outside of the predefined paradigm of being a real man). So, eventually, from the age of 28, after about 6 years of constant threats and 'counseling' by my medical specialists, I began testosterone therapy. And I found it to be a horrifying experience.

Testosterone therapy generated profound and traumatic changes in me. I lost contact with who I was and thus my sense of self. I was mortified when I began to grow large amounts of hair, where hair had never been. My voice dropped. I developed a very strong libido, but found the feelings unwelcome. I lost contact with my heart and the ability to relate to people in a nonsexual manner. Yet, most frustratingly, while I developed a sex drive and ability to sustain an erection, orgasms eluded me. I just couldn't function as a 'normal' male, and this caused me significant psychological and physical distress.

Worst of all, however, was that the therapy turned me into someone I was not...

Michael Noble writes on his experience in discussion with other people with XXY, and about his own body image, as it has changed due to hormone treatment:

While it seems that most XXYs receive some degree of benefit from testosterone therapy, my traumatic experience is not unique. Some XXYs who found the attempts to turn them into 'real men' psychologically devastating, have also either ceased, or drastically reduced their testosterone intake. A few report they feel they are more female than male and have sought female sex reassignment...

Sadly though, most intersex people cannot completely revert back to their pretherapy states. I only reverted back to about 75% of what I was prior to commencing therapy. While my true self quickly re-emerged after the overwhelming and oppressive weight of the drugs had dissipated, testosterone therapy has irreversibly damaged my body. Therefore, gone are the days when I looked like a teenager, and gone is the slim build and smooth face. These days, fully dressed, I appear very much like a male. I have a deep male voice; my physique generally appears like a slightly overweight male; and I walk, talk and, for the most part, conduct myself as a male.

Yet I am more than a male.³¹

Medical treatment to make him a “real man” has “irreversibly damaged” his body. These body changes – crucially – took place to make his body conform to medical assumptions about an appropriate gender identity and physiology.

Milton Diamond reports on people with AIS who experience a similar one-size-fits-all medical strategy:

The management of cases of androgen insensitivity syndrome (AIS) also has its unknowns. While it is true that those with the complete AIS condition most often prefer to live as women, this is not equally true for all those with the partial condition. Some minority of those with partial AIS will elect to live as males and yet often have had their testes removed in a prophylactic effort by their physicians to prevent future testicular tumors. Such men are angry that they were brought up as girls and are particularly distressed that they were, without their knowledge, and often without their or their parents' informed consent, at an early age, castrated and subjected to vaginal reconstructive surgery. And then, from puberty on, were given estrogens to feminize them somatically. Without their gonads such individuals are forced to take medicinal steroids the remainder of their lives.⁴

Existing diagnoses typically provide for hormone treatment, but treatment protocols are not patient-centred, and there is little or no evidence of prior, informed consent, freely given without coercion, by the people involved.

Access to appropriate healthcare is an on-going issue for intersex people. Somers *et al* report:

Interviewer: Do you think by not disclosing to their doctor that they had any kind of intersex condition, this will have an impact on their health and how the GP will manage them?

Respondent: I really think this is case by case...If you look at the physical health, then if someone has got ovaries and testes...and then develop abdominal pain, you know in their sixties or something, *we may not do the appropriate ultrasound scan looking for ovarian cancer because we don't know the ovaries are there* So, yes, physically it is going to be a problem; if you have illnesses specific to the fact the person who may have the opposite sex type, that you know will have combination sex types, they may be all the things that you did not think were there...³⁰

Neither Michael nor the OII Australia board member has “transitioned” in a medical or legal sense, nor intends to. Nevertheless, the adult bodies of each have changed dramatically, iatrogenically, in ways that can not be described to be consensual.

Further, their bodies and identities are clearly non-normative, formed in part as a response to iatrogenic change; and body and identity are arguably congruous with each other.

Very many intersex people are hypogonadal, whether due to iatrogenic changes or otherwise, and hormone treatment is generally a lifelong commitment. It is an absurdity, should either person choose to take estrogen instead of, or as well as, testosterone, that they be subject to transgender protocols. There is, in our opinion, no wrong way for them to define or express their identities, and no wrong medical path for them to choose, when given a free choice.

We believe that it is inappropriate for people seeking assistance to resolve their difficulties with iatrogenic changes to be diagnosed as dysphoric.

For intersex people who have not experienced iatrogenic changes, gender affirming, or gender-related, treatments should be permissible with fully informed prior consent whether

or not these are considered to be aligned with that person's gender presentation at start of treatment. Medical professionals should never make assumptions about what treatment outcomes, if any, are desired or desirable.

Changing documentation

The current SOC contains the implication that WPATH SOC practitioners are gatekeepers for establishing and recognising a person's legal gender identity.

OII Australia believes that any need for documentation in a different gender role should not require any mental health diagnosis.

Indeed, intersex people are currently able if we wish, in several Australian states and territories, to obtain an administrative correction of their birth certificate simply on the basis that there was a mistaken assignment at birth.

The NSW Registry of Births Deaths and Marriages (BDM) has provided us with this case study example:

Customer was born intersex in the late 1960s in New South Wales. Customer was registered with BDM as female but over the next forty years this was to prove to be incorrect. Customer supplied medical documentation outlining to the Registrar various diagnosis and procedures he had endured over a long period of time. Registrar amended the birth record of this person to show the correct gender. Registrar also added the person's details to a child he had fathered regardless of the original birth registration as female.³²

The main exception to this is Western Australia. Under Western Australian law, intersex people who reject their birth assignments have no choice but to comply with the rules contained in the *Gender Reassignment Act 2000 (GRA)*. That entails, as it does for transsexual and transgender individuals, that sufficient parts of an intersex person's anatomy should be removed or modified so that they might be seen to be appropriately bodied for a binary gender they may seek to live as. This legal requirement was the subject of an appeal to the High Court of Australia in the case of AB and AH v. State of Western Australia:

The construction placed upon s 15(1)(b)(ii) and the identification which is its concern, does not mean that a recognition certificate is to be provided based only upon a person's external appearance, and that person's belief about his or her gender. Section 14 must be satisfied before a person can apply for a certificate. But that is the only provision in the Act which requires a surgical or other reassignment procedure. Once that condition and those of s 15(1)(a) are met, the Board is directed by s 15(1)(b) to other enquiries relating to the person's perception of themselves and to social perceptions about them.³³

It remains the law that a "reassignment procedure" is required to "alter the genitals and other gender characteristics of a person"³⁴. Bearing in mind the tendency for intersex people to be subjected to medical treatment without fully informed, freely given consent, we regard this approach – where further surgery is required to confirm a different gender identity – as wholly inappropriate.

Changing the sex identifier on a passport is currently possible with evidence from a single doctor indicating the applicant lives as the preferred identifier. Consequently, intersex people, and other people with a preference for an unspecified sex identifier, are able to choose an 'X' identifier on their passport. In the case of an OII Australia board member, this was provided on request by their GP.

(We note that X does not indicate a third sex; rather it indicates the holder of the passport has not specified their sex. That is, they exercised their right to remain silent on the question of their sex. OII Australia would like to see the criteria for accessing a non-gender specific passport relaxed further, so that any individual could obtain this on request without medical confirmation.)

Intersex healthcare needs

While recognizing that intersex people may have already undergone medical treatment aimed at reinforcing an assigned gender, the SOC advises a diagnosis of gender dysphoria:

Even so, it is advisable for patients with a DSD to undergo a full social transition to another gender role only if there is a long-standing history of gender-atypical behavior, and if gender dysphoria and/or the desire to change one's gender role has been strong and persistent for a considerable period of time. Six months is the time period of full symptom expression required for the application of the gender dysphoria diagnosis proposed for *DSM-5* (Meyer-Bahlburg, in press).³

OII Australia questions the need for such diagnosis. How is a gender role congruent with an intersex biology defined?

Intersex people need:

An end to pathologisation

7. The Standards of Care and DSM must not pathologise intersex biologies and consequential gender identities.

An end to non-consensual and experimental treatment

8. An end to all non-consensual medical treatment, including (but not limited to) infant cosmetic surgeries.
9. The ability to give fully informed prior consent to any and all treatment.

Patient centred³⁵ treatment that recognises our history and needs

10. Practitioners should act as facilitators in a client-centred model of patient care, enabling the ability to choose an appropriate path for hormone and, should we desire it, surgical treatment, regardless of the social acceptability of the desired path.
11. Non-cosmetic treatment must be freely available without regard to the gender noted on Medicare and other health records.

Hormone treatment

12. Practitioners should recognise that hormonal treatments for intersex people are simply an aspect of a pre-existing diagnosis.
13. Intersex individuals should not be subjected to real life tests or waiting periods to have access to hormone treatments.
14. Intersex people should be able to freely choose hormone treatments that are congruent and/or incongruent with their gender presentation. The most important criteria in the choice of hormone treatment for an intersex person are to be comfortable with their own body, and to be able to tolerate treatment effectively.

Surgical treatment

15. Practitioners should recognise that surgical treatments for intersex people are an aspect of a pre-existing diagnosis.

16. Intersex individuals should not be required to subject themselves to trans-like standards so that they should not be required to undertake affirmation surgery, or any other surgery unless that surgery is life preserving.
17. Life preserving surgery must be validated with factual long term research. The removal of gonads, for instance, should only be done if it can be factually shown that they will become health problems. Practitioners should never recommend a specific surgical course of action as proven unless they have substantial evidence that the long term outcomes are known.
18. Infant cosmetic genital surgeries, like other cosmetic treatments, should not be covered by healthcare insurance or Medicare.

(While infant surgery is a very serious issue, such surgeries are not the only medical issue for intersex people, and an overemphasis on infant surgery is regarded by OII Australia as an Infantilization of intersex.)

Counselling

19. Practitioners should not encourage clients down a treatment path without themselves being fully aware of the consequences and able to articulate those consequences in a meaningful way to the client.
20. Counselling for intersex people may be desirable prior to commencement of hormonal or surgical treatment, but such counselling should not be a prerequisite for commencing treatment. Counselling prior to hormone or surgical treatment should not necessitate a psychiatric evaluation. Counselling should always be available where discomfort with treatment gives rise to depression or other mental health issues. Counselling should be sensitively provided, given the non-consensual iatrogenic changes that many intersex people have experienced.
21. Counselling must not prejudge an outcome, or take a different path, based on whether proposed treatment is regarded as congruent with gender identity, or not. Counselling must not direct an individual to an outcome based on preconceptions regarding their anatomical differences or sex binary expectations. An individual should be able to decide freely to choose a gender other than man or woman.

Research

22. We recommend that ANZPATH request the government to commission and fund research on all aspects of the health and wellbeing of intersex people in Australia and New Zealand.

Recommendations

The following summarizes OII Australia recommendations for the SOC-7 and DSM-5.

Process and capacity

1. Treatment protocols for intersex people must only be developed with the full inclusion of intersex individuals and organisations, just as has been the case with the transgender Standards of Care.
2. Membership of WPATH should be extended to client organisations in the targeted population. OII Australia would welcome such an opportunity.
3. WPATH must canvas widely amongst intersex organisations for membership and offer reasonable affordable rates, given that most are unfunded and financially stretched.
4. Professionals involved in developing protocols and standards must have on-the-ground experience with intersex clients.
5. The naming of the Standards of Care, and the membership and naming of the organisation, are not intersex-inclusive. We recommend that an extended remit and membership of WPATH be reflected in the organisation's name and outputs.

Terminology

6. OII Australia believes that a desire for "objective, value-free" terminology necessitates the use of terms other than DSD. OII Australia recommends use of the term "intersex".

Protocols

An end to pathologisation

7. The Standards of Care and DSM must not pathologise intersex biologies and consequential gender identities.

An end to non-consensual and experimental treatment

8. An end to all non-consensual medical treatment, including (but not limited to) infant cosmetic surgeries.
9. The ability to give fully informed prior consent to any and all treatment.

Patient centred treatment that recognises our history and needs

10. Practitioners should act as facilitators in a client-centred model of patient care, enabling the ability to choose an appropriate path for hormone and, should we desire it, surgical treatment, regardless of the social acceptability of the desired path.
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