



Daniela Truffer, Markus Bauer (StopIGM.org)

**Bias in intersex research and the lack of implementation of intersex human rights.
Analysis and proposals to ensure good practices.**

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Presentation at Centring Intersex Conference, 21.02.2023: Slides + Script

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Conference Programme and Abstracts:

<https://research.hud.ac.uk/media/assets/document/hhs/CentringIntersexIssuesConferenceProgrammeDelegateVersion.pdf>

Hi, we are Daniela Truffer and Markus Bauer from the intersex NGO StopIGM.

We want to talk to you today about intersex research and human rights.

“At intersex human rights conferences, I hear time and again representatives from different countries describe the same **circular, self-perpetuating problem.**

The medical profession won't listen to the arguments of intersex activists appealing to human rights.

Lawmakers defer to the medical profession.

The medical profession sees it as its job to surgically alter intersex bodies.”

Valentino Vecchietti (2018)

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We'd like to start with a quote by intersex human rights campaigner Valentino Vecchietti, on what she calls the circular, self-perpetuating problem:
Doctors do not want to hear about intersex human rights.
Politicians follow the doctors' lead.
Doctors will be doctors, wanting to do more surgery on intersex children.

“At intersex human rights conferences, I hear time and again representatives from different countries describe the same **circular, self-perpetuating problem.**

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Valentino Vecchiotti (2018)

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We see this a lot too, and not just at intersex rights conferences.

We will argue that not only the medical profession, but also academia in general and all fields of intersex research are biased against intersex human rights, thus contributing to said self-perpetuating problem.

And we argue that this medical and scientific bias against intersex people further reflects harmful societal notions and prejudice.

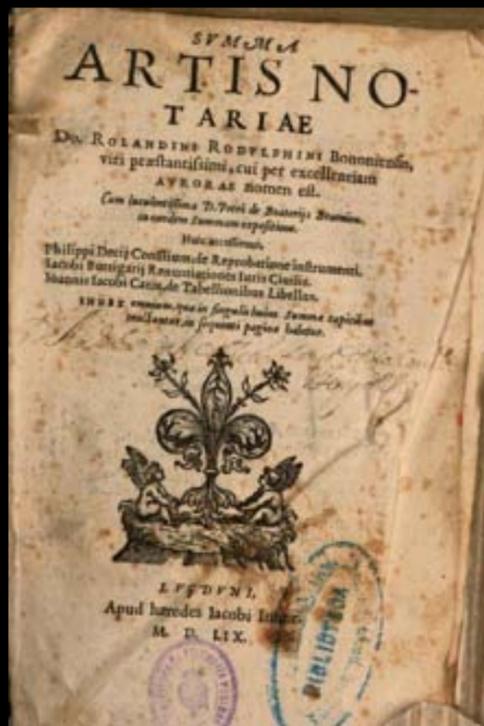


As an intersex person and IGM survivor I grew up under the medical gaze, watched and prodded, and left with scars, as also illustrated in my medical record.

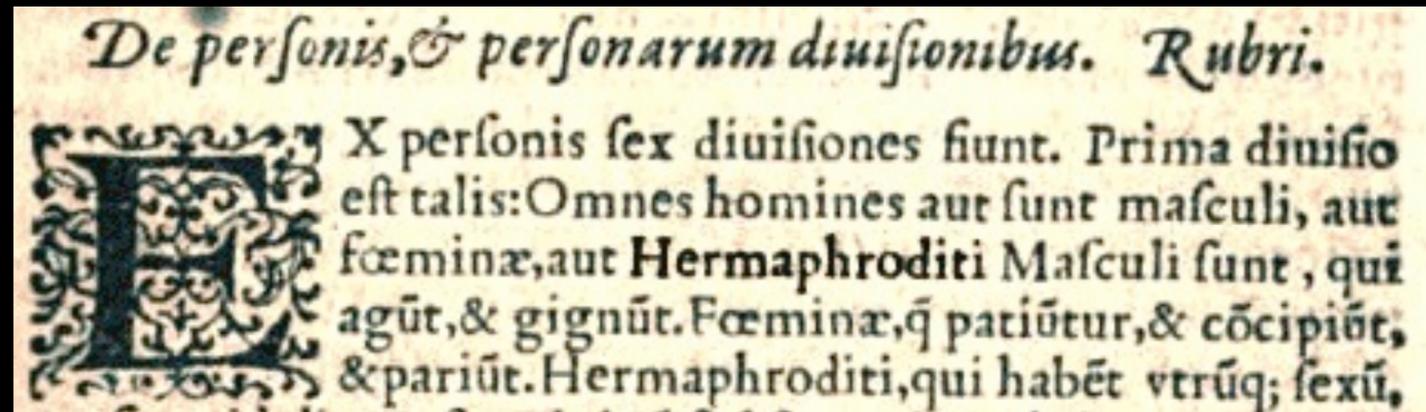
Unlike many others, at least I hadn't to strip for the photo.

To give you a better idea of the medical and scientific view of intersex bodies, lets take a look at almost 1000 years of academic intersex research from our perspective, in time lapse.

Europe: Middle Ages – Early Modern Age



“All humans are men, women or hermaphrodites”



Rolandino de Passageri (ca. 1215-1300), Bologna

Law Textbook “Summa artis notariae”

(ca. 1255 – pictured: edition Lyon, 1559)

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Good Practice

In the European Middle Ages, we find a remarkable body of legal literature, recognising intersex people as human beings, affirming their rights, and even privileges.

SINCE THE ENLIGHTENMENT

Science + Medicine:

Intersex

=

Subhuman

With the enlightenment, the medical and scientific notion emerged, which still informs the harmful medical practice today:

That intersex is a subhuman species, and therefore most frequent in the less developed and more primitive sections of the human race ...



... as well as in primates,
as illustrated here....

Régulièrement, on rencontre de telles grandes verges chez les femelles des espèces ateles, en particulier chez *Atele coïta*, singe de grande taille déjà. Ce sont des animaux originaires du Sud-Amérique.

Nous avons pu constater nous-même cette disposition, grâce à l'amabilité du professeur Bourdelle, au Muséum d'histoire

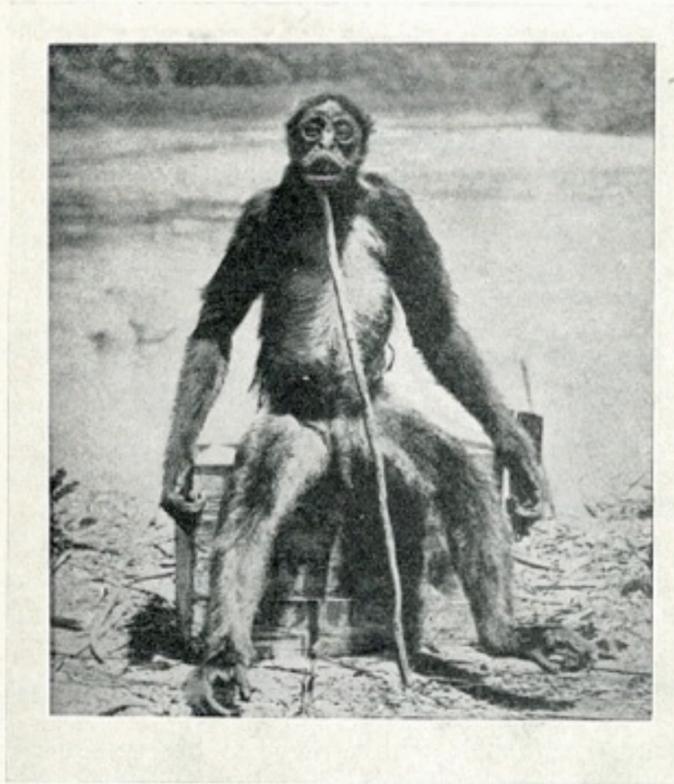


FIG. 26. — Femelle de *Ateles anthropoides Loysi* (d'après MONTANDON).

naturelle, non seulement chez des ateles, mais aussi chez des saïous (*Cebus*).

Bien plus, on a rencontré aussi ces grandes verges chez des espèces de haute taille.

Montandon signale au Yucatan une statue rappelant le gorille, dans ce pays où pourtant le gorille n'existe pas. Une de ces statues, haute de 5 pieds, semble bisexuelle, car, tandis qu'elle a les caractéristiques masculines, elle porte un enfant sur le bras gauche, comme une mère.

« Le grand nombre d'hermaphrodites dont on a parlé dans tous les temps ne sont que des femmes en qui le clitoris avait une étendue démesurée ; on a vu dans tous les temps des femmes qui en abusaient avec les personnes de leur sexe : les Grecs les nommaient *tribades*. Bartholin rapporte qu'il devint osseux à une courtisane vénitienne, pour en avoir fait un usage trop fréquent. »

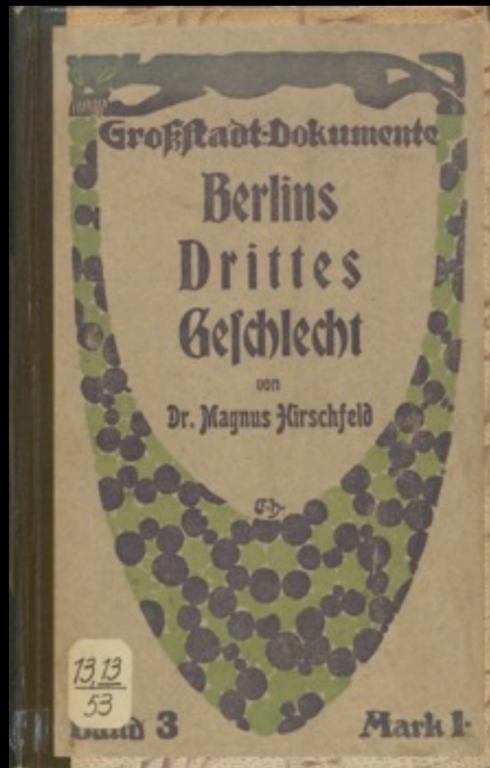
« On parle d'immenses clitoris qu'on a vus dans les pays chauds, » dit encore l'*Encyclopédie* d'Yverdon. Nous allons revenir sur cette notion.

Louis Ombrédanne: "Les Hermaphrodites et la Chirurgie", Paris 1939

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Since the Enlightenment, such "races" equipped with "enormous clitorises" have traditionally been located in the hotter climates, for example in Africa.

Early Gay Liberation + Sexology



Karl Heinrich Ulrichs (1825-1895):
Gays as “psychological hermaphrodites”

Magnus Hirschfeld (1868-1935):
Gays as “sexual intermediate stages”
and as the “Third sex”

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At the turn of the 19th century, hermaphrodites were repeatedly instrumentalised in early gay liberation and sexology texts.

Gay rights pioneer Ulrichs referred to homosexuals as “psychological hermaphrodites”, his successor and early sexologist Hirschfeld as “sexual intermediate stages” and as the “3rd sex”.

Early Genetics

Goldschmidt, Vorläufige Mitteilung etc.

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Vorläufige Mitteilung über weitere Versuche zur Vererbung und Bestimmung des Geschlechts.

Von Richard Goldschmidt.

In zwei früheren Arbeiten¹⁾ hatte ich den merkwürdigen Gynandromorphismus beschrieben, der bei Kreuzung des europäischen und japanischen Schwammspinners (*Lymantria dispar*) auftritt und versucht, die Erscheinung im einzelnen zu analysieren und daraus Schlüsse auf das Geschlechtsproblem zu ziehen. Trotzdem die Hauptpunkte klar erschienen, waren noch manche Schwierigkeiten vorhanden, vor allem die, dass die gleiche **Rassenkreuzung** nicht immer dasselbe Resultat ergab, wenn Material verschiedenen Ursprungs verwendet wurde. Es konnte als feststehend betrachtet werden,

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In 1915, geneticist and zoologist Richard Goldschmidt introduced the terms intersex and intersexuality into biology.

örterungen sein wird.) So erscheint es mir notwendig, für die hier behandelte Erscheinung eine andere Bezeichnung einzuführen. Ich werde in Zukunft die sexuellen Zwischenstufen als **Intersexe** bezeichnen und von männlichen oder weiblichen Intersexen reden, je nachdem es sich um Männchen auf dem Weg zur Weiblichkeit oder Weibchen auf dem Weg zur Männlichkeit handelt⁴); die Erscheinung selbst hieße dann **Intersexualität**.

Bevor ich über die neuen Versuche berichte, dürfte es gut sein, die verschiedenen mir bekannten **Stufen der Intersexualität** zu charakterisieren. Ich kenne nunmehr sämtliche Schritte, die von einem reinen Weibchen über die verschiedenartigen weiblichen Intersexe zu einem reinen Männchen führen; ferner die Stufen, die von einem Männchen über die männlichen Intersexe zum Weibchen führen, bis zu etwa $\frac{3}{4}$ des Wegs. Von beiden kann ich jetzt eine jede Stufe durch geeignete **Bastardierung** beliebig erzeugen. Weibliche Intersexualität beginnt mit einer ersten Stufe von Tieren mit

When cross-breeding "different races" of sponge moths, Goldschmidt noticed specimens with "ambiguous" sex markers. Like Hirschfeld, he called them sexual intermediate stages and intersexes, further describing them as the result of bastardisation due to racial mixing.

Since 1915:

“Ambiguous” sex markers

=

Intersex

=

“Degeneration due to racial mixing”

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So, speaking of harmful notions and prejudice against intersex people, let's note how deep they are ingrained in the very term itself: Intersex as a form of degeneration caused by racial mixing.

Gynaecology, 1920s-50s



Abb. 863. Intersex-Typ (Schizoid).

Der **Intersex-Typus** (M a n n w e i b, **S c h i z o i d**) (Abb. 863) ist körperlich und psychisch ausgedrückt. Es kommen auch sexuelle Zwischenstufen vor, wobei feminine Zeichen nur schwach ausgebildet sind. Die Behaarung ist übermäßig und atypisch, die Züge sind männlich, die Stimme ist tief. Die Pubertät tritt verzögert auf, es besteht Frigidität und eine herabgesetzte Fruchtbarkeit bei Hypoplasie der Keimdrüsen und Hyperfunktion der Hypophyse, manchmal ein eunuchoider Hochwuchs, ferner Störungen in der Funktion der Thyreoidea. Häufig wird Dysmenorrhöe beobachtet.

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In the 1920s, gynaecologists introduced intersex into human medicine, as a racist diagnosis for women with enlarged clitorises, described as prone to mental illnesses, unfit for marriage and procreation, and most frequent in jews.

Racial Hygiene, 1921-45

Menschliche Erblehre und Rassenhygiene

Von

Erwin Baur †, Eugen Fischer
und Fritz Lenz

Band I:

Menschliche Erblehre

Band II:

Menschliche Auslese und
Rassenhygiene
(Eugenik)

Accordingly, intersex diagnoses also featured prominently in the infamous Nazi textbook, “Human Heredity and Racial Hygiene”, ...

statt. Wenn einer oder beide Hoden dauernd in der Bauchhöhle oder im Leistenkanal liegen bleiben, spricht man von **Kryptorchismus**. Leistenhoden sind Druckschädigungen ausgesetzt und können sich nicht normal entwickeln. Wenn beide Hoden im Leistenkanal oder in der Bauchhöhle liegen, pflegt Unfruchtbarkeit zu bestehen. Für die Entstehung des Kryptorchismus ist die Erbanlage vermutlich von wesentlicher Bedeutung. Es sollten Zwillingsuntersuchungen darauf gerich-

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... including cryptorchidism,

Die **Hypospadie** ist eine erbbedingte Mißbildung des männlichen Gliedes bzw. der Harnröhre. Bei den daran leidenden Männern liegt die Öffnung der Harnröhre nicht am Ende des Gliedes, sondern an der Unterseite mehr oder weniger weit nach hinten. Etwa jede 300. männliche Person soll in geringerem oder höherem Grade damit behaftet sein. Das Leiden konnte in einigen Sippen durch mehrere Generationen männlicher Linie verfolgt werden. Bei weiblichen Personen kann es sich natürlich nicht äußern, kann aber durch gesunde Frauen auf männliche Kinder übertragen werden. Dieser Erbgang darf nicht mit dem rezessiven geschlechtsgebundenen (vgl. S. 332) verwechselt werden; er unterscheidet sich von diesem

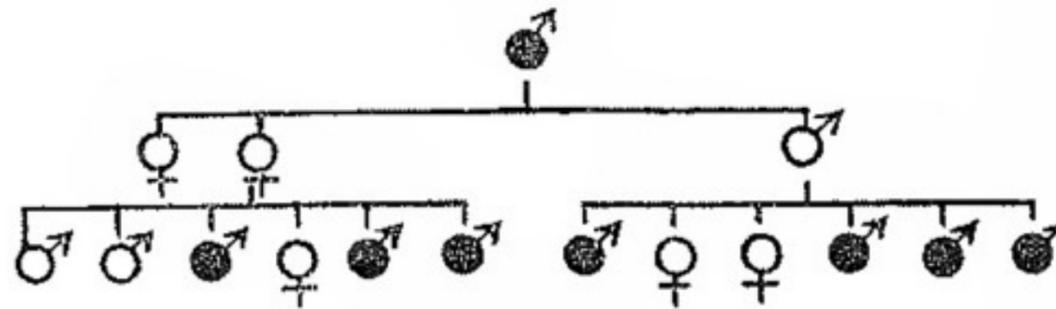


Fig. 116.

Hypospadie. Nach Lesser¹). (Ausschnitt.)

Epispadie, d. h. Spaltbildung an der Oberseite des männlichen Gliedes, die bis zur Spaltung der vorderen Bauchwand und der Blase gehen kann, ist gelegentlich bei neugeborenen Zwillingen beobachtet worden. Da derartige Kinder zugrundegehen, kommt dominanter Erbgang nicht in Frage.

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... epispadias,

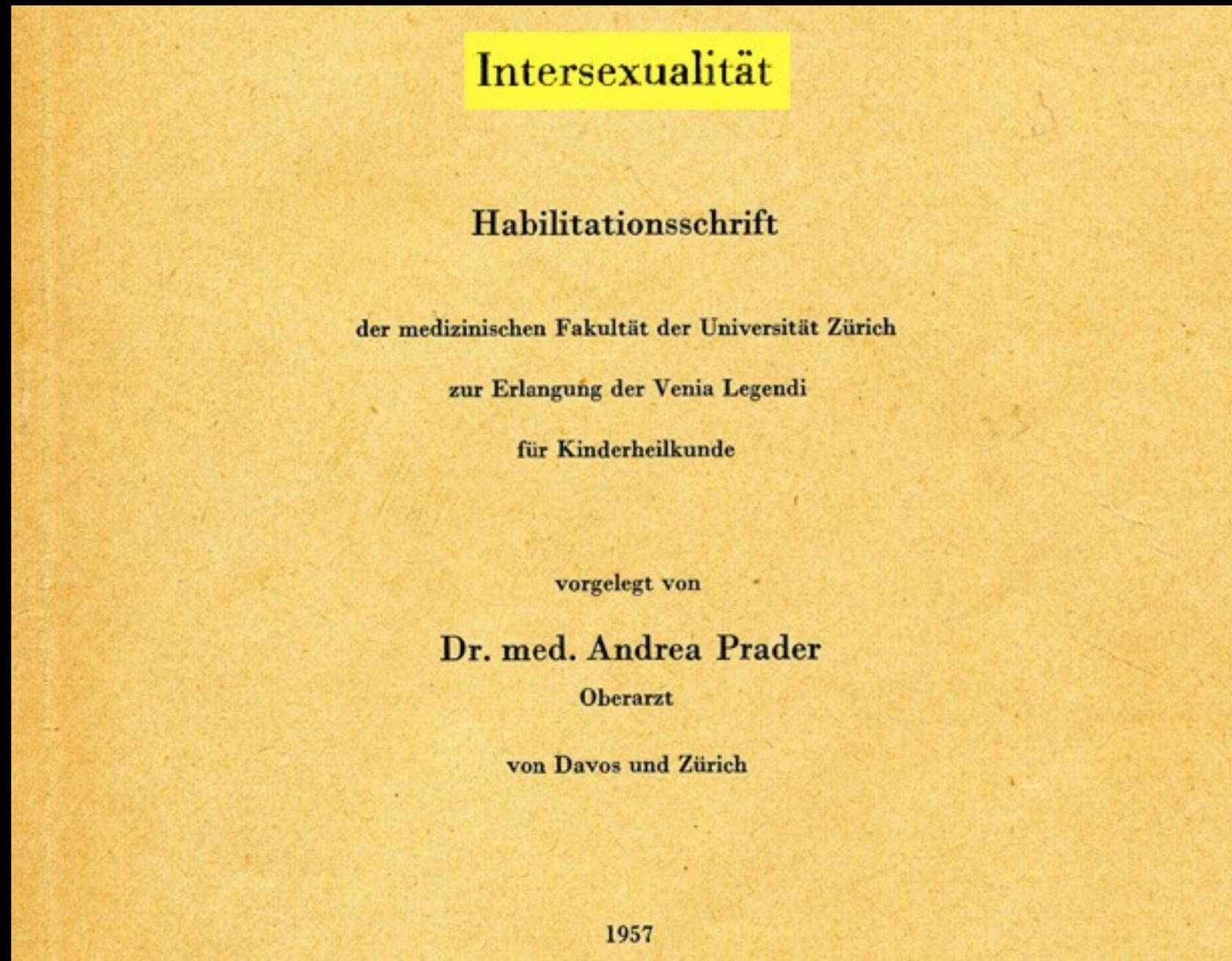
Von Scheinzwittertum oder **Pseudohermaphroditismus** spricht man, wenn das männliche Glied sehr klein ist oder ganz fehlt; der Hodensack ist dann in zwei Teile gespalten. Solche Individuen werden bei der Geburt oft in ihrem Geschlecht verkannt und als Mädchen aufgezogen, bis sich bei

Da das Geschlecht auch beim Menschen durch die Erbmasse bestimmt ist, ist anzunehmen, daß auch jene sehr seltenen Fälle, in denen männliche und weibliche Gonaden (Keiendrüsen) nebeneinander vorhanden sind, erbbedingt sind. Man spricht dann von echtem Zwittertum oder Hermaphroditismus. Wenn entweder nur männliche oder nur weibliche Gonaden vorhanden sind, das Individuum aber zum Teil Merkmale des andern Geschlechts zeigt, so spricht man von Pseudohermaphroditismus oder **Intersexualität**. Goldschmidt hat bei Schmetterlingen (Schwammspinnern) durch Kreuzung verschiedener Rassen **geschlechtliche Zwischenstufen (Intersexe)** verschiedenen Grades erzeugen können. Beim Menschen ist Intersexualität als Folge von **Rassenmischung** jedenfalls in der ersten Generation (F_1) nicht beobachtet worden. Auch ob sie in späteren Generationen vorkommt, ist fraglich. Wahrscheinlicher ist es, daß Erbanlagen, die beim Menschen Intersexualität bedingen, nicht aus der Erbmasse normaler geographischer Rassen stammen, sondern daß es sich um **abnorme**, durch **Mutation** entstandene Erbanlagen handelt.

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... and of course, referring to Goldschmidt, intersex and sexual intermediate stages caused either by racial mixing or mutation.

Paediatrics, 1950s



In the 1950s, the diagnosis intersex was established in paediatrics by the father of the infamous Prader Scale.

Baltimore and Zurich, 1950: The Beginning of Systematic Early Surgery

CONGENITAL ADRENAL HYPERPLASIA—FEMALE PSEUDOHERMAPHRODITISM



Normal age 9 yrs.



Age 2 yrs. 11 mos.

Ht. age 4-3
Bone age 6-0
17-KS:
2 yrs. 9-12 mg/d.
3 yrs. 15-25 mg/d.
Pubic hair appeared at 20 mos.

Small urogenital sinus.

Siblings:

1. ♀ pseudohermaphrodite.
2. Female—normal.
3. ♂—macrogenitosomia
4. ♂—macrogenitosomia

Clitoris amputated.

Raised as girl.
(H.L.H. A59183)



Age 4 yrs., 2 mos.

Ht. age 5-0
Bone age 7-6
17-KS: 16-22 mg/d.
No sexual hair.

Urogenital sinus non-communicating.

Raised as boy.
Plastic operations on hypospadiac penis and scrotum. (H.L.H. A52394)



Age 4 yrs., 5 mos.

Ht. age 7-0
Bone age 11-0
17-KS:
17-22 mg/d.
Pubic hair at 2 3/4 yrs.

Small urogenital sinus.

Raised as girl.
Clitoris excised. (H.L.H. A47344)



Age 9 yrs.

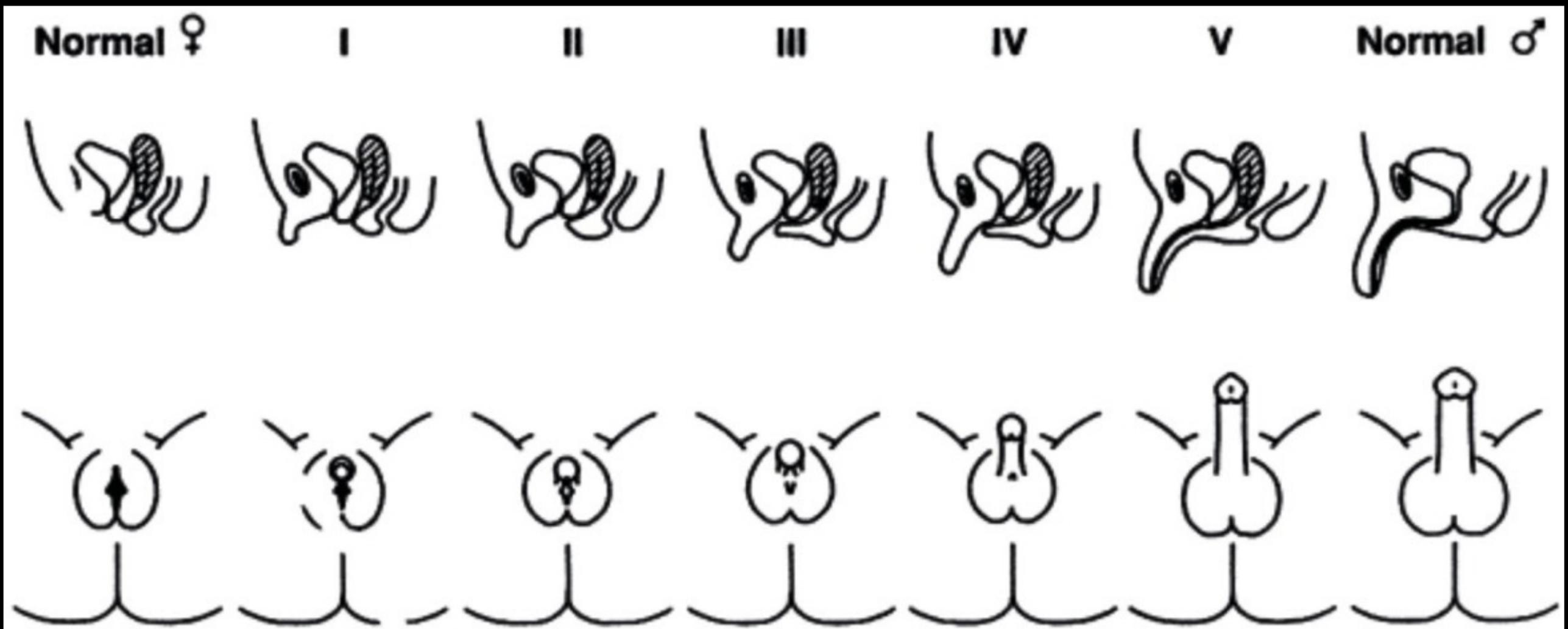
Ht. age 14-6
Bone age 15-0
17-KS: 14-22 mg/d.

Pubic hair at 4 1/2 yrs.

Axillary hair at 8 yrs.
Large urogenital sinus.
Raised as girl.
Clitoris excised. (H.L.H. A26544)

Patients all had enlarged phallus, urogenital sinus and absent vagina at birth. Patient B had been mistaken for a boy and raised as such.

By then, the first clinics had begun to systematically practice early genital mutilation of intersex children, here as opposed to “normal children”.



Figuur 1. *Vermannelijking van het uitwendig genitaal bij 46,XX (Prader)*

Verschillende mate van vermannelijking van het in eerste aanleg vrouwelijk genitaal; vergroting van de clitoris, inwendige fusie van de urethra en vagina en uitwendig fusie van de schaamlippen, dat de schaamlippen op een scrotum doet lijken.

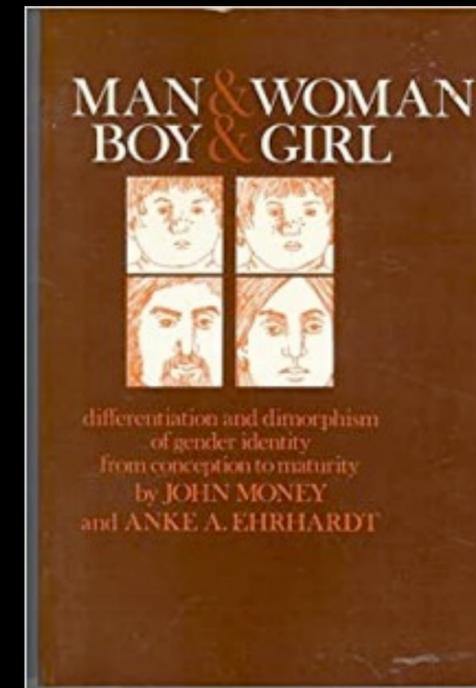
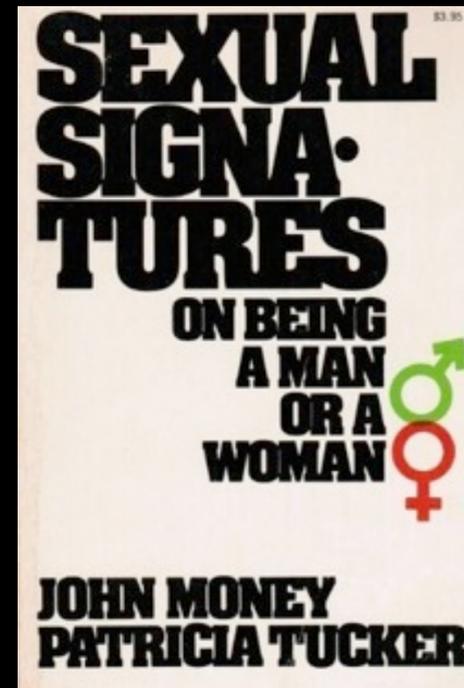
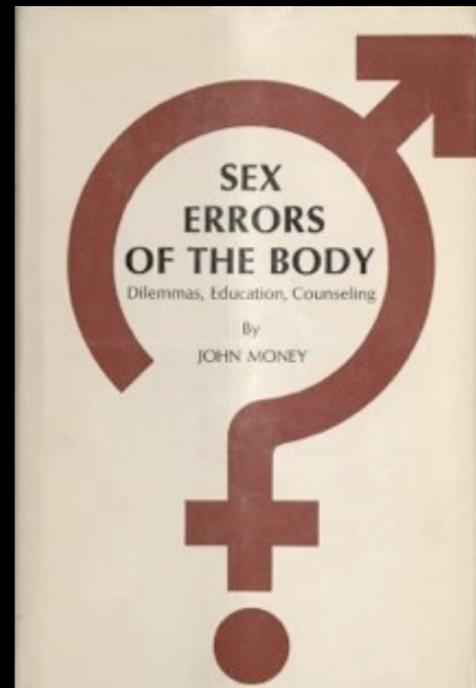
To this day, the Prader scale remains the diagnostic standard for prescribing surgery on children's "abnormal intermediate genitalia", pictured here in a 2017 publication.

Sexology (continued)

John Money (1921-2008)

Joan Hampson (1922-2005)

John Hampson (†1998)



Later in the 1950s, Baltimore-based sexologist John Money and colleagues produced their infamous policy justifying systematic early surgery on intersex children as well as the scientific claim amputation of the clitoris would not impair sexual function -- welcome news for IGM surgeons around the globe.

They also established the meaning of the word gender as we use it today.

Sexology (revisited)

Milton Diamond



In the 1990s, sexologist Milton Diamond followed up on Money's key evidence for systematic IGM, the infamous John/Joan case, finding David Reimer, and exposing Money as a fraud, causing a worldwide stir.

Title: Management of Intersexuality: Guidelines for dealing with individuals with ambiguous genitalia.

Author(s): Milton Diamond, Ph.D. and H. Keith Sigmundson, M.D.

Published: Archives of Pediatrics and Adolescent Medicine, 151 (Oct.)

7. **Perform no major surgery for cosmetic reasons alone;** only for conditions related to physical/medical health. This will entail a great deal of explanation needed for the parents who will want their children to "look normal." Explain to them that appearances during childhood, while not typical of other children, may be of less importance than functionality and **post pubertal erotic sensitivity of the genitalia.** Surgery can potentially impair sexual/erotic function. Therefore such surgery, which includes all clitoral surgery and any sex reassignment, should typically **wait until** puberty or after when the patient is able to give **truly informed consent.**

Good Practice

Diamond became the first prominent scientist to publicly oppose IGM, citing impaired sexual sensitivity, and the lack of informed consent.

Title: Pediatric Ethics and the Surgical Assignment of Sex

Author(s): Kenneth Kipnis, Ph.D. and Milton Diamond, Ph.D.

Published: *The Journal of Clinical Ethics*, Volume 9 (4):398-410 Winter 1998.

FIRST RECOMMENDATION: That there be a general moratorium on such surgery when it is done without the consent of the patient.

Accordingly, it is not possible for a patient's parents to give informed consent to these procedures precisely because the medical profession has not systematically assessed what happens to the adults these infant patients become. Doctors can't tell parents what the long-term risks and benefits are because they haven't done the studies and don't know.

Good Practice

Further highlighting the lack of evidence, Diamond famously called for a moratorium of early genital surgery, arguing parents don't have the right to consent on behalf of their children. Hardly surprising, IGM practitioners were having none of it.

Gender/Queer Studies

eminism.org
Putting the Emi back in Feminism since 1975

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What is "intersex"? A response to June42, a woman with Turner's syndrome

Date: February 14, 2013

The mistake queer theorists and activists often make (as Judith Butler did in her 2002 paper, "[Doing Justice to Someone](#)") is that they do not attempt to understand or address actual lived experiences of people with a specific intersex condition, but treat "intersex" as a homogenous group, or worse, a theoretical tool to advance their own theories about social construction of gender and sex (see my old paper, "[From Social Construction to Social Justice: Transforming How We Teach about Intersexuality](#)").

Good Practice: Emi Koyama (2002, 2013)

Today, most papers on intersex are published in the context of gender and queer studies.

All too often, they don't care about actual lived intersex experiences, but merely instrumentalise intersex people as a means to an end to deconstruct the notion of binary sexes.

Harmful Academic + Societal Notions:

- **suprematist**
 - **racist**
 - **ableist**

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So, to summarise the examples of harmful academic intersex research so far, we characterise the underlying societal notions and prejudice as suprematist, racist and ableist.

5. “Cultural Practice” or “Reconstructive Surgery”? U.S. Genital Cutting, the Intersex Movement, and Medical Double Standards

CHERYL CHASE

discourses continue a long tradition of making Africans into the “other,” suggesting that **ethnocentrism is a key factor** in the sometimes purposeful maintenance of ignorance about contemporary U.S. genital surgeries. This

have been treated by many feminists, and the **double standard regarding representations of genital cutting, depending upon who is cutting and where in the world the cutting is done.**

Good Practice

Intersex advocates like Cheryl Chase a.k.a. Bo Laurent have also criticised ethnocentrism, double standards ...

HERMAPHRODITES WITH ATTITUDE

Mapping the Emergence of Intersex Political Activism

Cheryl Chase

link the two forms of genital cutting have met with multiform resistance. Examining how first-world feminists and mainstream media treat traditional African practices and comparing that treatment with their responses to intersex genital mutilation (IGM) in North America exposes some of the complex interactions between ideologies of race, gender, colonialism, and science that effectively silence and render invisible intersex experience in first-world contexts. Cutting intersex geni-

Good Practice

... and racist ideologies as enablers of IGM.

Academic Complicity with IGM Practices

IGM in Africa = Mutilation,

IGM in University Clinics = Normalising Surgery?



Daniela Truffer (2016)

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In our experience, another enabler is academic complicity.

v2.0

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)

+ Supplement "Background Information on IGMs"

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Further examples of criticism of bias and prejudice in the medical literature include the appendices to our first NGO report to CRC ...

Intersex Day

Intersex Awareness Day, 26 Oct, & Intersex Day of Solidarity, 8 Nov

How medical discourse dehumanizes intersex people

18 October 2016

– by Janik Bastien Charlebois, PhD, sociology professor at the Université du Québec à Montréal.

Many valuable analyses have been developed by intersex activists and scholars on the medical management of intersex, where each look at discursive practices from medical professionals invested in them. As we know full well, medical professionals not only produce intervention techniques and protocols, but legitimate them to one another and to the public, as well as – and increasingly – to State officials and human rights organisations. Unveiling the assumptions and the prejudices underneath what they write

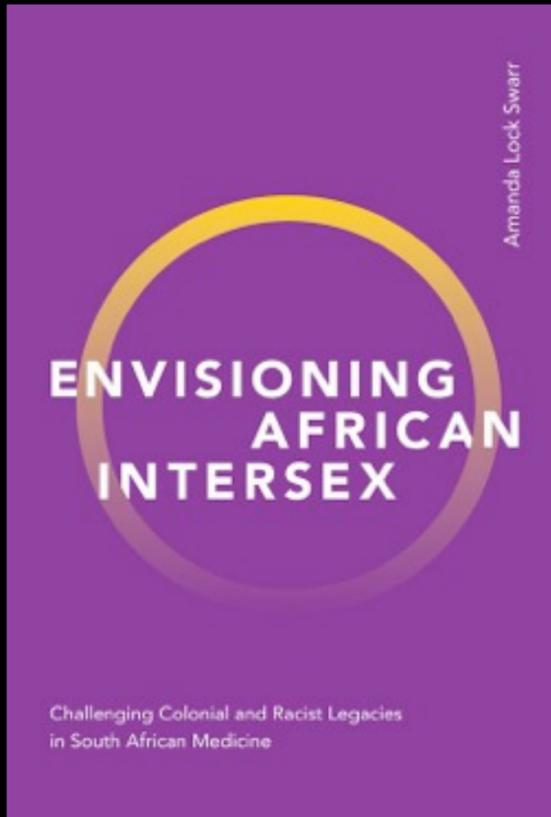
Good Practice

... as well as a paper by Janik Bastien Charlebois.

Despite being a professor,
her criticism wasn't published in an academic publication.

Ganie et al.: *Hormone Research in Paediatrics*, 2017

“The prevalence of OT DSD [true hermaphroditism] is particularly high in black South Africans [and] . . . disproportionately high compared to other centres worldwide” (cites Van Niekerk 1976; Wiersma and Ramdial 2009; and Wiersma 2004, 2011).



In these examples, scholars collaborate and cite each other, referencing scholarship repetitively and citing decades-old research with presentist assumptions. Note, for instance, the historical present assumed in Ganie’s 2017 citation of research published forty-one years prior (in 1976). References with scant evidentiary bases become codified through citation without substantive engagement with the original publications. They begin to create norms about Africans’ bodies, deriving power through their repetition. The sources in which these articles

Amanda Lock Swarr (2023)

Good Practice

Recent criticism from an African perspective has also exposed the persisting medical claims of intersex being most frequent in southern countries, as well as the academic fallacies enabling their persistence.

Current Medical Research: dsd-LIFE



Conclusion

The majority of participants were neutral to satisfied with the appearance and function in the long-term after masculinizing surgery. Given the initial severe phenotype and a risk of unsatisfactory results after masculinizing surgery in DSD, treatment should be handled by experienced multidisciplinary teams in order to optimize the postoperative results.

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Now, let's have a look at some recent examples of medical intersex research from the DSD-Life project funded by the European Union.

Evaluating patient-reported outcomes, this one conveniently groups patients reporting positive outcomes together with those reporting neutral ones, concluding that the majority was neutral to satisfied.

Current Medical Research: dsd-LIFE



Conclusion

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As an IGM survivor, I call this weaponising the trauma and the resulting decades of denial caused by IGM.

For the bigger part of my live, when asked about my surgeries in such a context, I'd say, I'm fine, can I go now?

And I know quite a few peers who said the same.

Masculinizing surgery in disorders/differences of sex development: clinician- and participant-evaluated appearance and functionTim C. van de Griff^{1,2} , Marion Rapp³, Gundela Holmdahl^{4,5}, Lise Duranteau⁶, Agneta Nordenskjold^{4,5} , on behalf of the dsd-LIFE group***Table 3** Hypospadias outcomes from genital examination and participant-reported measures in males

	All operated <i>n</i> = 74	Hypospadias <i>n</i> = 25	PAIS <i>n</i> = 15
Satisfaction postoperative genital function, <i>n</i> (%)			
(Very) Satisfied	25 (44.6)	9 (45.0)	5 (41.7)
Neither satisfied nor dissatisfied	20 (35.7)	6 (30.0)	2 (16.7)
(Very) Dissatisfied	11 (19.6)	5 (25.0)	5 (41.7) [‡]

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Despite trauma and the obvious sample bias in this study, less than the majority reported being satisfied.

Self- and proxy-reported outcomes after surgery in people with disorders/differences of sex development (DSD) in Europe (dsd-LIFE)

MD Marion Rapp, Lise Duranteau, MD, Tim C. van de Grift, PhD, Justine Schober, MD, Angelica L. Hirschberg, PhD, Susanne Krege, MD, Anna Nordenstrom, PhD, Robert Roehle, MSc., Ute Thyen, MD, MD Claire Bouvattier, Baudewijntje P.C. Kreukels, PhD, Agneta Nordenskjold, PhD, on behalf of the dsd-LIFE group



the study participants. Most participants reported no impact, or positive impact, of the surgical procedures on their lives, but 29% experienced a negative effect of gonadectomy on their life.

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The same trick of grouping patients reporting no impact together with positive impact, also in another DSD-Life publication.

Self- and proxy-reported outcomes after surgery in people with disorders/differences of sex development (DSD) in Europe (dsd-LIFE)

MD Marion Rapp, Lise Duranteau, MD, Tim C. van de Grift, PhD, Justine Schober, MD, Angelica L. Hirschberg, PhD, Susanne Krege, MD, Anna Nordenstrom, PhD, Robert Roehle, MSc., Ute Thyen, MD, MD Claire Bouvattier, Baudewijntje P.C. Kreukels, PhD, Agneta Nordenskjold, PhD, on behalf of the dsd-LIFE group



Table 5: Self-reported impact on life of specific types of surgery

	Number of participants with procedure	Percentage of available information	Impact on life by this type of surgery (n)		
			(Very) positively (%)	No effect (%)	(Very) negatively (%)
Vaginoplasty	184	76 %	67 (48)	55 (39)	18 (13)
Vaginal dilation	127	64 %	38 (47)	28 (35)	15 (18)
Clitoris reduction	153	67 %	51 (49)	37 (36)	15 (15)
Clitoridectomy	19	48 %	0	2 (22)	7 (78)
Hypospadias repair	85	78 %	33 (50)	18 (27)	15 (23)
Orchidopexy	76	71 %	28 (52)	21 (39)	5 (9)
Gonadectomy	217	76 %	37 (22)	80 (49)	47 (29)
Mullerian or uterus resection	42	50 %	14 (67)	5 (24)	2 (9)
Breast removal	34	82 %	24 (86)	2 (7)	2 (7)
Breast enlargement	12	92 %	9 (82)	1 (9)	1 (9)

Again, in fact it was less than the majority reporting a positive impact.

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Conclusions

Surgical treatment is a common component in DSD treatment and this study summarizes surgery in the largest cohort of DSD individuals. The general appearance after surgery was satisfactory in over 90% of females and males. The function was less satisfactory due to findings of vaginal stenosis, diminished sensation on the clitoris or the glans penis. The participants' view on appearance and function and the impact of surgery on their life was less positive than by the examiner. To further understand the influence of genital surgery on life, patient reported outcomes could be evaluated as a component of surgical care before, and after, surgical procedures, and included into standardized follow-up programs.

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Nonetheless, the conclusions claim a whopping 90% of satisfied patients, and call for more research to further understand the impact of IGM.

Counterpoint

Endless Calls for “More Research” as Harmful Interventions Continue

Howard Devore, Ph. D. is a licensed psychologist, certified by the American Board of Sexology as a sex therapist, and is a Life Clinical Fellow of the American Academy of Clinical Sexologists. Dr. Devore has extensive experience working with intersexed children, adults, and their parents. We are proud to have Dr. Devore as a member of ISNA’s Board of I

I was saddened and di
Sandberg’s article. During my post-doc-

current medical practice, and the unreliability of research conducted *in the setting where the harm was done.* Dr. Sandberg’s wish to “do better” for his intersexed patients is obstructed by several of his beliefs.

First, he seems to believe that useful information can be obtained only by for-

Good Practice

search, and dismisses
the many individual voices now made

public by ISNA. Certainly ISNA is

In other words, exactly what Tiger Devore aptly described as “endless calls for more research as harmful practices continue,” further denouncing the “unreliability of research conducted in the setting where the harm was done.”

Current Medical Research: Sexology



Also, let's have a look at intersex research out of the Ghent University Hospital commissioned and published by Belgian government agencies in 2016 and 17,

“A report by the United Nations, among others, condemned the practices of 'normalising' treatment in children and even used the words 'torture' and 'genital mutilation' to describe it (Méndez, 2013). Although the human rights commissioner of the Council of Europe was more cautious in his use of language ...” (Federal Study, p. 12)

English summary taken from 2019 CCPR Belgium NGO Report

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Please note the use of scare quotes around the words torture and genital mutilation, when referencing human rights criticism.

Correspondingly, intersex human rights NGOs and advocates are portrayed as *“a (small) group of human rights activists standing on the barricades for sexual diversity”* (Flemish Study, p. 8 = p. 10 in PDF) and as *“the (small) group of activists who are currently on the barricades”* (Federal Study, p. 12), unduly focusing on the *“battle with the scalpel”* (Flemish Study, p. 54 = p. 56 in PDF) and engaging in a *“vicious circle of non-collaboration, distrust and non-communication”* (Federal Study, p. 37).

English summary taken from 2019 CCPR Belgium NGO Report

StopIGM.org

Further how, both studies describe intersex human rights advocates as “standing on the barricades for sexual diversity,” and engaging in a “vicious cycle of non-collaboration, distrust and non-communication.”



Ghent University Hospital, 12.06.2015

Oops, we must have forgotten the barricades, and missed the gender memo!



Also, our Belgian colleagues are in fact quite open for discussions. However, they report being silenced and marginalised in hearings, including by some of the authors of the aforementioned studies.

This concludes our examples of bias against intersex human rights in medical and other studies and which we consider a part of the self-perpetuating problem mentioned earlier.

Human Rights Focus: Current Research



In recent years, arguably due to increasing verdicts issued by human rights bodies, a new type of scientific studies has emerged with a declared focus on intersex human rights.

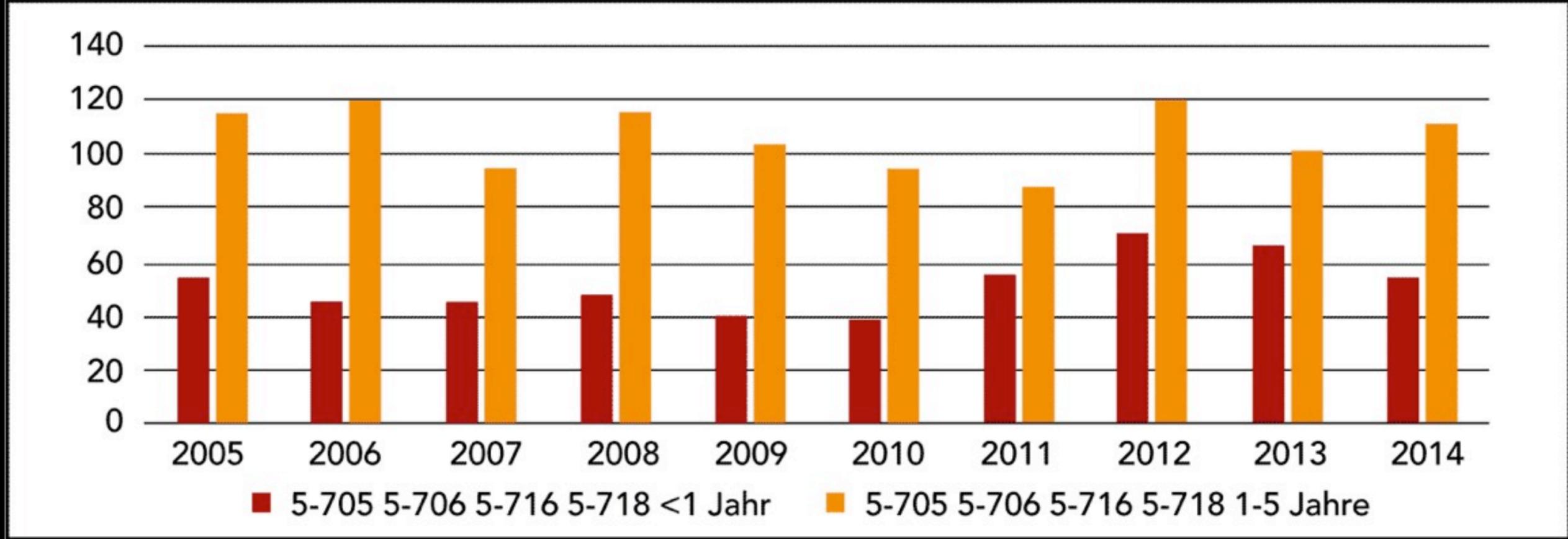
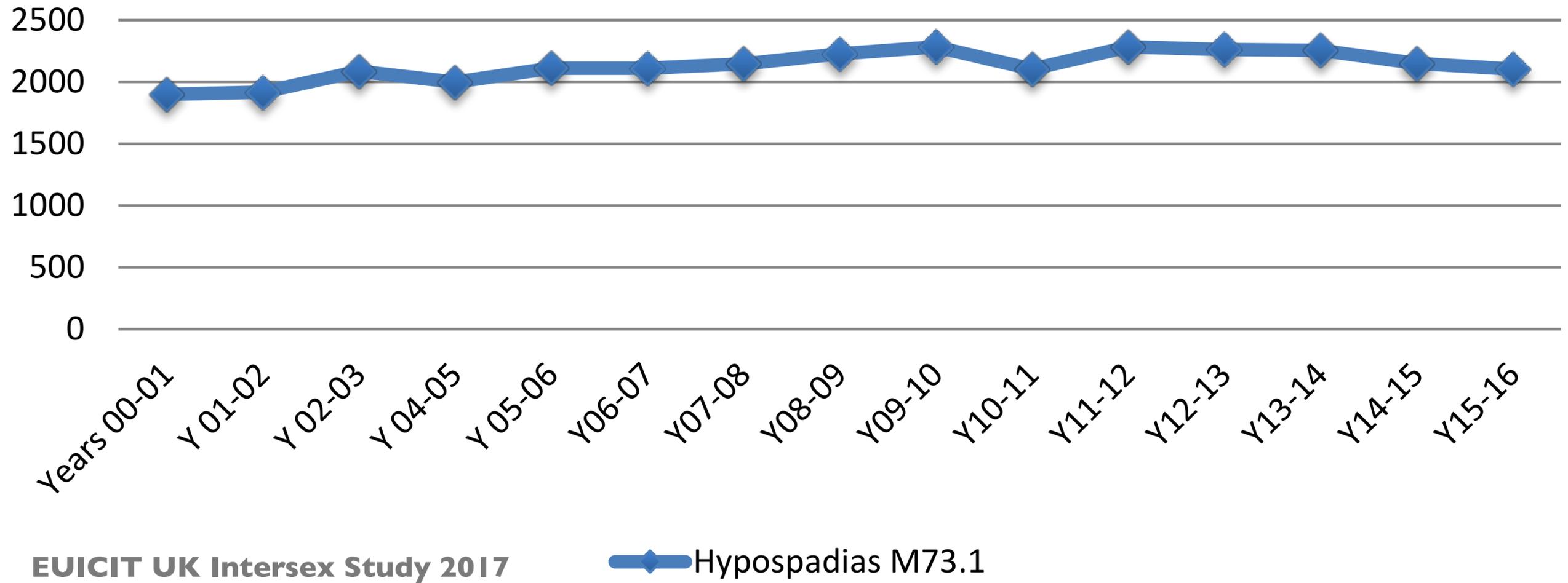


Abb. 1: DRG 5-705 Konstruktion und Rekonstruktion der Vagina, DRG 5-706 andere plastische Rekonstruktion der Vagina, DRG 5-716 Konstruktion und Rekonstruktion der Vulva, DRG 5-718 andere plastische Rekonstruktion der Vulva **KINDER- UND JUGENDARZT** 47. Jg. (2016) Nr. 5/16

Good Practice

For the first time, there were studies actually researching the frequency of IGM practices and publishing the relevant data.

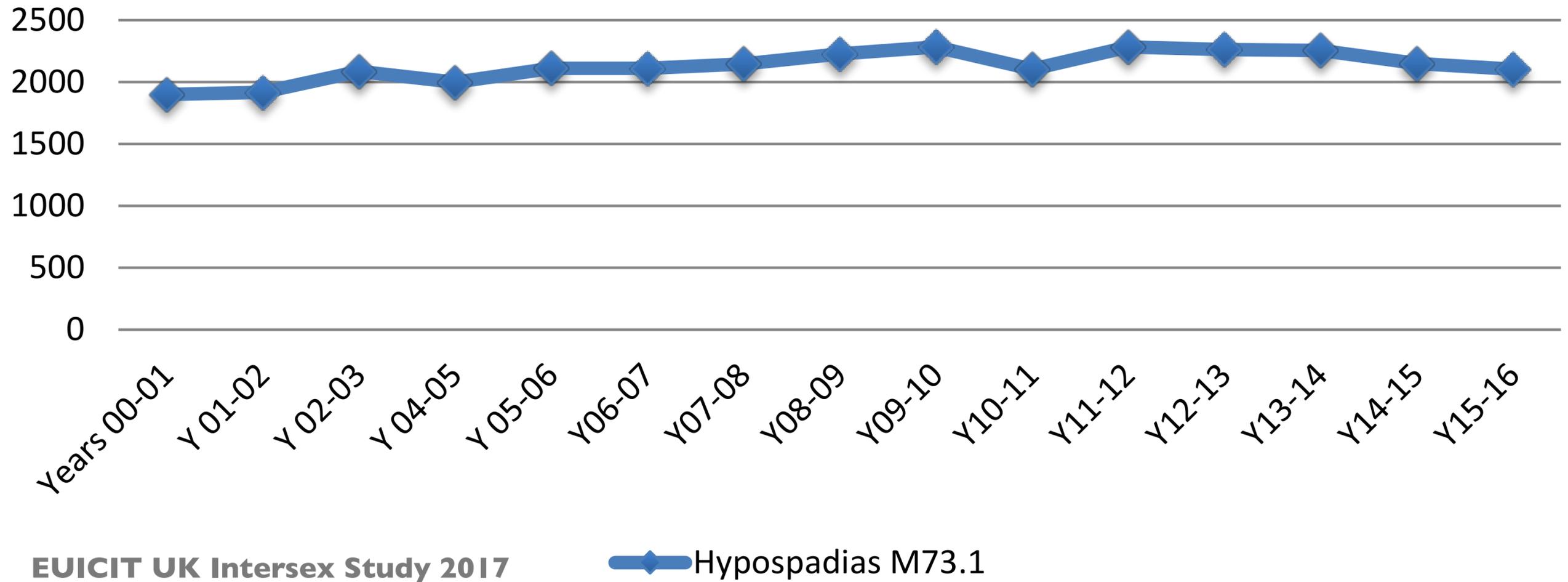
"Masculinizing" surgical procedures: Hypospadias Ages 0-14 from 2000 to 2016



Good Practice

Data, which doctors and health ministries don't want you to see, because it clearly refutes their claims that "we don't operate anymore". However, in our experience, also in human rights focused studies, medical and scientific bias and prejudice have a tendency of creeping back in. From our perspective, this is usually due to inadequate study design and/or researchers.

"Masculinizing" surgical procedures: Hypospadias Ages 0-14 from 2000 to 2016

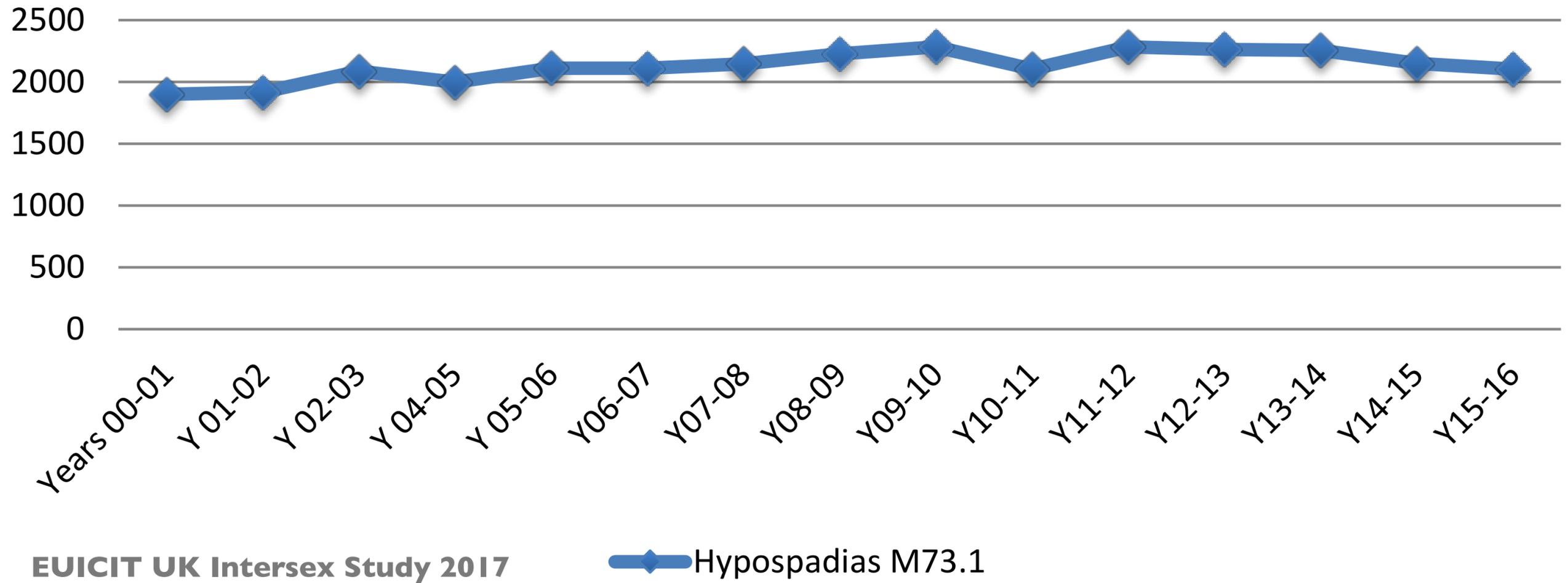


Good Practice

Inadequate study design may include taking a previous trans study as a template, despite that when it comes to genital surgery, the attitudes and experiences of trans persons are fundamentally different to those of intersex persons.

Inevitably, such studies will have an undue focus on gender identity, civil registration and discrimination issues, while falling short on IGM as a serious human rights violation, access to justice, case law, and more.

"Masculinizing" surgical procedures: Hypospadias Ages 0-14 from 2000 to 2016



Good Practice

Inadequate researchers include those whose specialty is not intersex issues, but for example gender identity, equality and discrimination, and/or with a history of collaboration with IGM practitioners and their institutions, which inevitably leads to medical and scientific bias creeping back in.

interACT Policy Statement on Participation in Research

Updated by interACT February 2, 2022

interACT: Advocates for Intersex Youth recognizes the value of high-quality, ethically conducted research as one avenue to improve the recognized disparities the intersex community faces in health-related outcomes and other areas of life.^[1] Accordingly, interACT is committed to supporting research that measures what matters to people with innate variations in their (intersex traits) and that meaningfully and needs.

Good Practice

Intersex NGOs have long identified issues with research as well as remedies, from medical studies harming the community to preventing such harm by involving intersex people from the beginning.

Good Practice Examples

5th I-DSD Symposium Programme. 11th-13th June 2015, Ghent, Belgium - Abstracts

Working Together in Raising Confident Young Men

Tiger Devore, Hypospadias/Epispadias Association

Precious little information exists about how to discuss early sexual exploration with young men with 46, XY DSD. This presentation offers a positive long-term communication model for fathers –in collaboration with the team- to talk to sons in a way that promotes self-esteem and confidence and reduces the anxiety of young men when sharing information with a potential sexual partner about their DSD

We'd like to conclude with some inspirational examples.

At a parallel session convened by self-help groups, Tiger Devore presented vital advice for grown-up intersex people to avoid what he called genital exposure trauma.

Tiger's pro tip: Make a drawing of your genitals and discuss it with your partner before you get into bed with them.

5th I-DSD Symposium Programme. 11th-13th June 2015, Ghent, Belgium - Abstracts

Informed consent: from ethical principles to ethical behaviour

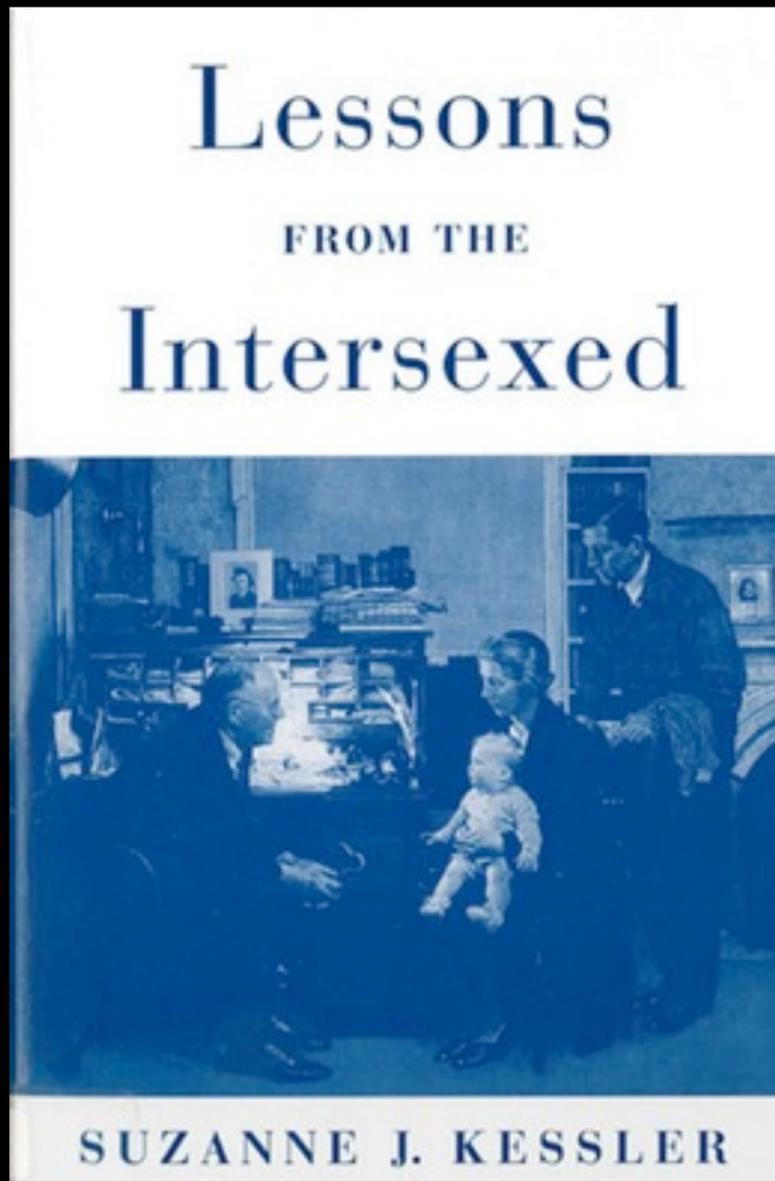
Lih-Mei Liao, University College London Hospitals

Informed consent has been described as communication between provider and recipient, whereby the recipient understands equally the immediate and longer term implications of the proposed intervention as well as the alternatives, including no intervention. This process may be compromised by a number of psychological factors. This paper outlines a behavioural checklist developed at UCLH to optimise quality and consistency in the consenting process for adult women electing to undergo (further) genital surgery.

Lih-Mei Liao presented on how to make sure that intersex can truly give consent without regretting it later.

Her findings: Not just have them sign a consent form, but have them watch a video of themselves explaining the procedure first.

2002

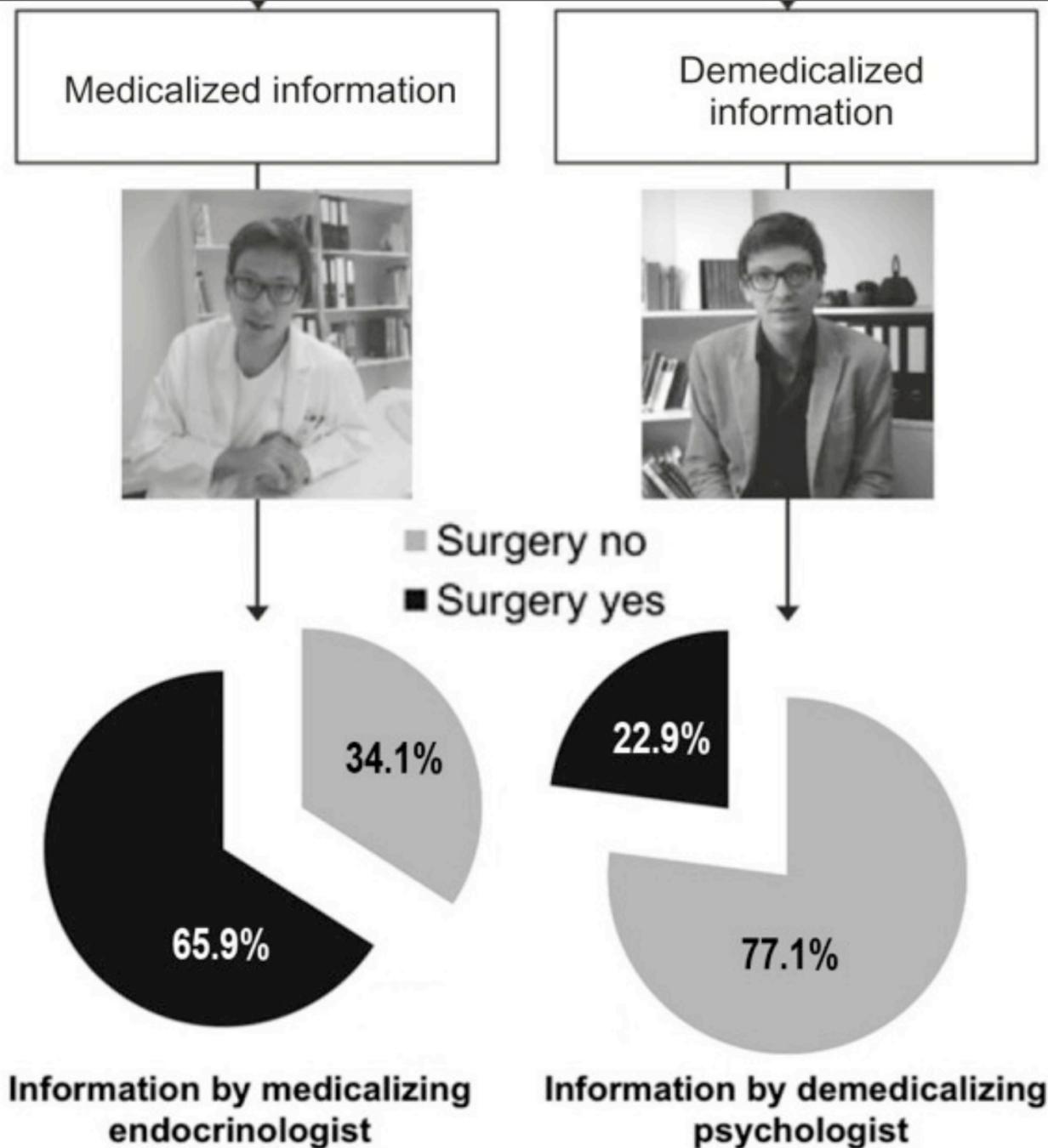


Prospective study on intersex genital surgery (p. 100-104):

- As parents, most would opt for early genital surgery for their intersex children
- As intersex women and men, most would not want their parents to make this decision for them

Prospective studies can be an inexpensive societal indicator.

Suzanne Kessler contrasts how parents want surgery for their children but would not want their parents to decide for them.



**Streuli JC, Vayena E, Cavicchia-Balmer Y, and Huber J.
 Shaping parents: Impact of contrasting professional counseling on
 parents' decision making for children with disorders of sex development.
 J Sex Med 2013;10:1953–1960**

This example illustrates the difference between medicalised and demedicalised counselling.



Article

The Growing Visibility of Intersex Demands at the United Nations: A Review of the Treaty Bodies' Concluding Observations

Ernesto Zelayandia-Gonzalez ^{1,2}

¹ Andalusian School of Public Health, 18011 Granada, Spain; e.ezelayandia@ms.ugr.es

² Doctoral School in Humanities, Social Sciences and Law, University of Granada, 18071 Granada, Spain

Abstract: In recent years, there has been an increasing visibility of intersex people's issues and experiences of human rights violations amongst international human rights institutions and monitoring bodies. At the United Nations, to date, there are more than 500 treaty bodies' concluding observations taking notice of human rights abuses against intersex persons and calling member states to fulfil their human rights obligations. This paper follows the inclusion and visibility of intersex issues in the text of the United Nations treaty bodies' concluding observations. I looked for explicit mentions of the word "intersex" in treaty bodies' report documents and reviewed how the concluding observations and recommendations of these bodies resonate with demands coming from intersex activist groups. I found that the main issues included in the treaty bodies' reports concern intersex genital surgeries (IGS)

Research on the currently 77 UN treaty body recommendations on IGM remains lacking. We welcome the first article opening this field

Addressing Intersex Genital Mutilation through the Universal Periodic Review: an emerging *opinio juris* ?

Dr Saskia Caroline Irene Ravesloot¹

Abstract

Intersex Genital Mutilation is a medical intervention imposed on individuals with perfectly healthy bodies. These interventions have only one goal in mind, namely to comply with the prevailing social, cultural and medical values and norms. Most societies rely on binary gender norms and values, distinguishing only girls and boys, women and men. Intersex persons have sex characteristics that do not fit into one of these mutually exclusive categories. Their ‘physical imperfections’ or ‘ambiguous’ variations in sex characteristics expose intersex persons to physical corrections. However, the international human rights framework considers Intersex Genital Mutilation (IGM) a human rights violation and promotes the rights of intersex persons.

The same goes for the Universal Periodic review.
We welcome the second dedicated analysis.

2023

PRESIDENCY OF ICELAND
Council of Europe
11/2022 – 05/2023



PRÉSIDENCE DE L'ISLANDE
Conseil de l'Europe
11/2022 – 05/2023



ADVANCING THE HUMAN RIGHTS OF INTERSEX PEOPLE

26 JANUARY 2023
13:00-18:00 CET
COUNCIL OF EUROPE STRASBOURG/ONLINE

Committee of Ministers Room, Palais de l'Europe
with English/French interpretation

A Conference hosted in the framework of Iceland's Presidency of the Committee of Ministers of the Council of Europe, organised by the SOGI Unit in co-operation with the Permanent Representation of Iceland to the Council of Europe

[Register here](#)

LIVE STREAM

BACKGROUND

The protection of the human rights of intersex persons has increasingly gained attention in many Council of Europe member states. Some have adopted legislation banning so-called "sex-normalising" surgeries while others have revised anti-discrimination legislation to include sex characteristics as a protected ground using different regulatory techniques. Along with Malta (2015), Portugal (2018), Germany (2021) and Greece (2022), Iceland (2019) has introduced legal provisions concerning children born with variations of sex characteristics (VSC) with its legislation on the "Amendment on the Act on Personal Autonomy" which prohibits unnecessary medical interventions on minors until the child can give informed consent. Belgium and Spain are currently in the process of creating their national regulations regarding intersex human rights.

AIM

This conference will seek to:

- raise awareness of the situation of intersex people in Europe
- share the most recent legal and policy best practices

Last but not least, we welcome conferences about intersex human rights featuring intersex researchers and truly dedicated experts only.

StopIGM.org

cc Daniela Truffer, Markus Bauer / Zwischengeschlecht.org

Thank you.