IGM – Intersex Genital Mutilations

Human Rights Violations of Children With Variations of Sex Anatomy

What are Variations of Sex Anatomy?

“Ambiguity” is possible on 3 levels or layers:
1. Genetic > Chromosomes / Karyotype (e.g. XX, XY, X0, XXY)
2. Hormonal > Gonads (e.g. Testes, Ovaries), and Response
3. Appearance > e.g. External Genitals, Secondary Sex Markers

“Ambiguity” means:
a) “atypical” characteristics on one or more layers
and / or
b) “incongruency”: layers “don’t match”

Presentation @ “Intersex People & Human Rights” - NGO Panel, Geneva 11.03.2014
Daniela Truffer, Co-founder and president international Human Rights NGO Zwischengeschlecht.org / StopIGM.org, co-founder Peer Support Group Intersex.ch (1/3): “I was born with so called atypical genitalia. The doctors couldn't tell if I was a boy or a girl. At two and a half months they castrated me, they threw my healthy testicles in the garbage bin. Later the castration was declared a mistake, one doctor said that I was a boy with hypospadias, however now they had to continue this way. When I was seven, they cut my genital to make me look more like a girl.”
Daniela Truffer (2/3):
“The doctors always lied to me and my parents. I spent my life in fear, pain and shame. I couldn't talk to anybody. Only after meeting others like me in my thirties, I found out that I wasn't alone. When I asked for my medical records, the hospital said they didn't exist anymore. Only when I threatened to return with a lawyer, I was eventually able to obtain them. At this point, all possibilities of legal redress had expired long ago due to the statutes of limitation.”
Daniela Truffer (3/3):
“I remain a patchwork created by doctors, bruised and scarred. Compared to many others I am still lucky insofar that I was able to learn the truth from my medical records, and that I still have some sexual feelings. I wish I could have grown up without surgery and decide myself. After more than a decade of trying to reason with doctors together with others from self help groups, I am convinced that this is futile, and only legislation will stop the ongoing mutilations.”
What are Intersex Genital Mutilations (IGM)?

Non-consensual, medically unnecessary, irreversible, cosmetic genital surgeries, and/or other similar medical treatments, including imposition of hormones, performed on children with variations of sex anatomy, without evidence of benefit for the children concerned, justified by “psychosocial indications” shaped by societal and cultural norms and beliefs.

Markus Bauer (Co-founder international Human Rights NGO Zwischengeschlecht.org / StopIGM.org):
I’m not an intersex person myself, but the partner of a person concerned. During the next minutes, I’d like to give you a short overview on IGM. Our definition of IGM in the forthcoming Swiss CRC NGO report is, that IGM consists of (see above).
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Variations of sex anatomy are more than just the so called “ambiguous genitals”. So called “ambiguity” is possible on tree levels: 1. on the genetic level 2. regarding the sex hormone producing organs, and the level of response to these hormones by the body, and 3. Appearance, which includes External Genitals and Secondary Sex Markers “Ambiguity” means: a) “atypical” characteristics on one or more layers, and / or b) while individual planes may appear “perfectly normal”, together they “don’t match”, for example a newborn with male exterior genitals, but an uterus, ovaries and karyotype XX.

Now, to understand how so called ambiguous genitals develop, we have to consider a fact of life usually omitted in biology classes:
All people were hermaphrodites ... 

... until the 7th week of pregnancy.

We all started out with precursors for ovaries and testicles, and we all had “ambiguous genitals”. Only after the 7th week male or female genitals develop – out of the very same “basic parts”.

Yes, we all started out with precursors for ovaries and testicles, and we all had “ambiguous genitals.” Only after the 7th week, male or female genitals develop – out of the very same “basic parts” as follows:
The right side of the diagram shows how most females develop. The left side shows how most males develop — note how the urethral opening only ascends to the tip of the penis during the very last stage. And if you ever wondered why male private parts have a fission, this is the explanation.
Genital Variation: Male, Female, and In-Between

Numbers represent the “Prader Scale”, after Andrea Prader, Zurich (1954):
"Der Genitalbefund beim Pseudohermaproditismus femininus des kongenitalen adrenogenitalen Syndroms. Morphologie, Häufigkeit, Entwicklung und Vererbung der verschiedenen Genitalformen."

Medicine counts 4 “in-between” stages. (Actually, it’s rather a continuum.)

Some, but not all intersex children are born with atypical genitals. Children with genitals resembling diagrams 3 and 4 may be diagnosed as “boys with hypospadias” and submitted to “masculinising hypospadias repair.” Children with genitals resembling diagrams 1–5 may be diagnosed as “girls with an enlarged clitoris” and submitted to “feminising clitoris reduction” and “vaginoplasty.”
**IGM 1 – Diagnosis “Hypospadias”: “Masculinising Genital Correction”**

<table>
<thead>
<tr>
<th>Layers</th>
<th>“Hypospadias”</th>
</tr>
</thead>
<tbody>
<tr>
<td>Karyotype</td>
<td>XY</td>
</tr>
<tr>
<td>Hormonal</td>
<td>Testicles (10% undescended)</td>
</tr>
<tr>
<td>Appearance</td>
<td>Urethral opening not at the tip of the penis,</td>
</tr>
<tr>
<td></td>
<td>sometimes +/- “chordee” +/- “micro penis”</td>
</tr>
<tr>
<td></td>
<td>“in-between”</td>
</tr>
</tbody>
</table>

Due to time restrictions, I will only outline the three most frequent forms of Intersex Genital Mutilations. The most common form today is hypospadias surgery. Hypospadias is, when the urethral opening is not at the tip of the penis, but somewhere below on the underside.
“My childhood was filled with pain, surgery, skin grafts, and isolation. And I still have to sit to pee.”

“It would have been just fine to have a penis that peed out of the bottom instead of the top, and didn’t have the feeling damaged.”

Tiger Howard Devore

The main justification for hypospadias surgery is that a real man must be able to pee standing, and to be able to impregnate women via penetrative sex. In comparison, a numbed glans due to repeat surgeries is considered a minor obstacle.
As you can see, hypospadias surgery is no minor surgery. The penis is sliced open, and from the foreskin or another skin graft an artificial urethra is formed.
Hypospadias surgery is fraught with complications, which can result in serious medical problems where none had been before, for example urethral strictures can lead to kidney failure requiring dialysis.

However, for doctors and hospitals, complications are lucrative.
Many children have major surgeries every year until they’re old enough to resist further treatments. The language of the doctors is telling, see for example the official diagnosis “hypospadias cripple” for persons with repeat “failed” surgeries which the doctors have given up as hopeless cases.
For decades, doctors again and again have been stating the lack of outcome studies, but still prefer to just go on with more and more surgeries by hook or by crook, relishing the “Surgical Challenge.” This is typical for all forms of IGM.
IGM 2 – Diagnoses “CAH” and “AIS”: “Feminising Genital Correction”

<table>
<thead>
<tr>
<th>Layers</th>
<th>“CAH”</th>
<th>“(C)AIS”</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>“Congenital Adrenal Hyperplasia”</td>
<td>“(Compl.) Androgen Insensitivity Syndr.”</td>
</tr>
<tr>
<td></td>
<td>2nd most comm. Diagn.</td>
<td>3rd most common Diagnosis</td>
</tr>
<tr>
<td>1. Karyotype</td>
<td>XX</td>
<td>XY</td>
</tr>
<tr>
<td>2. Hormonal</td>
<td>Ovaries</td>
<td>Testes</td>
</tr>
<tr>
<td></td>
<td>Adrenal glands produce Testo (instead of Cortisol)</td>
<td>(abdominal), body doesn’t “recognise” Testo</td>
</tr>
<tr>
<td>3. Appearance</td>
<td>“in-between”</td>
<td>“in-between”</td>
</tr>
<tr>
<td></td>
<td>(Prader Scales)</td>
<td>CAIS = “200% female” = “wrong”</td>
</tr>
<tr>
<td></td>
<td>in “severe cases” = “wrong”</td>
<td></td>
</tr>
</tbody>
</table>

Until the 2nd hypospadias boom, feminising corrections were the most frequent procedure due to surgical limitations, according to the infamous surgeon’s motto, “You can dig a hole, but you can’t build a pole.”

In above diagnoses, the atypical development was caused either by an excess of male sex hormones, for example CAH, or a low ability by the body to respond to them, for example AIS.
“... my micropenis was reduced to a ‘clitoris’, i.e. my penis was dissected, most thrown in the garbage can, the remains were stuffed inside me and sewn shut.”

“I’ll suffer for the rest of my life from the consequences of this inhumane treatment.”

Daniela “Nella” Truffer
Today, doctors use more modern techniques, aiming at sparing the main nerves, though they still cut away most tissue and persons concerned still deplore loss of sensitivity.
“Material Shortage’ while reconstructing a praeputium clitoridis and the inner labia”

Finke / Höhne: Intersexualität bei Kindern (2008)

Again, the language of doctors is telling, for example the “material shortage” mentioned here.
The 3rd most common practice is castration, justified by an alleged high cancer risk. Unnecessary castrations have been criticised also by some doctors for decades, however to little avail.
If a child is raised male, but has an uterus and/or ovaries, those are cut out in reverse.
While doctors claim to produce “normal looking genitals,” persons concerned still report being teased also in the so called “successful” cases because of scars and unusual appearance, let alone in cases of admittedly “bad results.”
Typical examples of traumatising non-surgical treatments include repeat forced medical display and unnecessary and brutal genital exams.
Since 1950, intersex genital mutilations have been practised systematically and on an increasingly industrial scale all over the “developed world.”
Since 1950, for children with sex anatomies considered “not normal” by doctors, it’s been mostly either “clitoris reduction” or “hypospadias repair.”
Since 1950, it's paediatric endocrinologists together with paediatric surgeons leading the treatments, garnering millions ...
... despite the obvious fact that medicalisation inevitably results in more and even more unnecessary genital surgeries on defenceless children.
“Unfortunately the surgery is immensely destructive of sexual sensation and of the sense of bodily integrity.”

For 20 years now, survivors and their organisations denounce Intersex Genital Mutilations publicly as grave human rights violations and demand justice.

Heidi Walcutt
20.10.1961–10.11.2010
About 90% Intersex Children are still submitted to often repeat surgeries:

“Lübeck Intersex Study” (439 participants from D, A, CH), 2009 (German)

E.g. in Germany, at least one child is mutilated every day, both in Austria and Switzerland at least another one every week in each country, and in the U.S. five per day.

However, despite silver tongued statements by doctors, today still about 90% of all children concerned get submitted to unnecessary and harmful surgeries.
2009-2011: UN-CEDAW and UN-CAT criticise Germany because of IGM. [http://intersex.shadowreport.org](http://intersex.shadowreport.org)

2013: The UN Special Rapporteur on Torture condemns “ involuntary genital normalizing surgeries” and “sterilization” on “Children who are born with atypical sex characteristics”, demands legislative measures (A/HRC/22/53), followed by the Council of Europe (Res. 1951/2013).

Only recently, some human rights bodies started to acknowledge the grave human rights violations caused by IGM, notably the Special Rapporteur on Torture and the Council of Europe who called for legislative measures to end it. However, up to now for example the UN Human Rights Council and the Committee on the Rights of the Child still have not yet acknowledged IGM, despite repeated calls for support by survivors.
“It’s a pity that, because of a lack of ethical clarity in the medical profession, we have to get legislators involved, but in my opinion it’s the only solution.”

Source: swissinfo.ch, January 23, 2013

2013:
Blaise Meyrat (Lausanne), one of only a handful of paediatric surgeons worldwide with a conscience, who refuse to do (most) unnecessary intersex surgeries:

Swiss surgeon Blaise Meyrat, while commenting on the 2012 Recommendations on Intersex by the Swiss National Advisory Commission on Biomedical Ethics calling for a legal review of IGM, was the first doctor to publicly highlight the urgent need for legislation to eventually end the mutilations. However, the Swiss federal government still refuses to implement the recommendations by its own commission.
Therefore, it is vital that international human rights bodies really raise the pressure on national governments, and relevant medical bodies. For more comprehensive information and sources, see the resources linked above, including the extensive 2014 CRC Intersex NGO report to the UN Committee for the Rights of the Child, our IGM Primer, and the Documentation on IGM History & Current Practice.

Thank you!

For more information:

StopIGM.org