Dear Committee on the Rights of the Child

We thank you for this opportunity to brief you on "Intersex Genital Mutilations on a global scale".

Intersex organisations have hoped for the Committee to get active on this issue and have invoked the Convention on the Rights of the Child to fight IGM practices for almost 17 years. (ctd.)
My name is Daniela Truffer. In 2007, together with Markus Bauer I co-founded the international intersex NGO Zwischengeschlecht.org, based in Zurich, Switzerland.

Before Markus will talk about the most common IGM practices and their history, I would like to give you a survivor’s perspective, and an overview of the intersex movement.

I’ll start with a few words regarding my personal experience.

For more on this, I refer you to the case study number 2 in our NGO report (p. 33–36), which is my story.

2014 CRC NGO Report: Case Studies 1–6 (p. 32–41)
I was born in Switzerland in 1965, with so called "ambiguous" genitalia. The doctors couldn’t tell if I was a girl or a boy.

First they cut me open between my legs to see, if they find a vagina.

At two months they opened my abdomen and found healthy testes, which they threw in the garbage bin, according to my medical records without the consent of my parents.

I spent a lot of time in doctor’s offices and hospitals, suffering countless examinations of my genital and urethral opening, often painful and leading to infections.
The Invisible “Dragon’s Tail” (Despite Surgical “Correction”)

When I was seven they cut my genital to the size of a "very small clitoris", allegedly with my informed consent.

At twelve I had to take estrogens to induce an artificial puberty, which I still have to take daily.

Like 50% of all XY-intersex, I don’t have an exact diagnosis.

If I was born today, they would probably make a boy out of me, which might mean even more surgeries.
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 I found out that I wasn't alone.

I wish I could have grown up without surgery and decided myself.
Globally, the first intersex organisations were CAIS and CAH self-help groups initiated by doctors in Australia, in the Americas and in Europe starting in the 1980s.

While the CAH groups were and are led by parents with heavy involvement by IGM doctors, many CAIS groups emancipated and opened themselves for other intersex people.

To this day, the latter try to change the current medical practice mostly through dialogue with sympathetic doctors, however to little avail.  (ctd.)

Hermaphrodites Speak! (35 min) http://www.youtube.com/watch?v=BwSOnqdR7kM
It was in such a self-help group that, at thirty-five I met other intersex people for the first time in my life.

After decades of isolation and denial, it felt like finally coming home.

At the same time I was shocked, because I became aware of the pattern in all the stories I heard, and that the surgeries still continue.
In 1993, the first intersex NGO was founded in North America with many more to follow on all continents. Due to the livelong traumatisation of survivors of IGM, most intersex NGOs only endure for a limited time. From the very beginning they described early surgeries as immensely destructive of sexual sensation, and as a violation of the right to physical integrity, and called for legislation.

ISNA [http://www.isna.org/articles/chase1995a](http://www.isna.org/articles/chase1995a)
AGGPG (German) [http://blog.zwischengeschlecht.info/pages/%22Vernichtung-intersexueller-Menschen-in-westlichen-Kulturen%22-Flugblatt-AGGPG-%281998%29](http://blog.zwischengeschlecht.info/pages/%22Vernichtung-intersexueller-Menschen-in-westlichen-Kulturen%22-Flugblatt-AGGPG-%281998%29)
1996 saw the first nonviolent intersex protest outside a pediatric conference, after doctors refused to let intersex activists be heard inside.

Hermaphrodites with Attitude [http://www.isna.org/books/chrysalis/beck](http://www.isna.org/books/chrysalis/beck)
1996: Reinforced Criticism by Survivors

1. It’s about ALL “corrective” early genital surgeries
2. Also “new surgical techniques” impair sensation
3. It’s a Western Form of Genital Mutilation
4. Systematic Intersex Erasure is a Form of Genocide
5. Survivors’ suppressed anger can be self destructive

Also since 1996 survivors describe what was done to them as a western form of genital mutilation, and the de facto erasure of intersex and intersex persons from public life and awareness as a form of genocide.

Hermaphrodites Speak! (1996, 35 min) http://www.youtube.com/watch?v=BwSOngdR7kM
In 1999 the Constitutional Court of Columbia partly restricted non-consensual, cosmetic genital surgeries on intersex children.

An Amicus Brief dated February 7, 1998 by the Intersex Society of North America marked the first time that an intersex NGO invoked the Convention on the Rights of the Child to fight IGM.

To this day, Columbia is still the only country worldwide to at least partly restrict IGM practices.

ISNA Amicus Brief [http://www.isna.org/node/97]
2007 marked the first time that a survivor succeeded in suing her former surgeon, eventually winning 100'000 Euros damages in Germany.

I knew Christiane Völling from the self-help group. For the first time I organised a nonviolent protest, which changed my life considerably. (ctd.)
District Court Cologne, 12.12.2007:
1st ever Trial against IGM Surgeon – WON!

To this day, we know of only two more civil cases, both ongoing.

In total, two cases were only possible because of surgeries on persons older than eighteen, while the third was filed by the foster parents of an intersex child.

This underlines the urgent need for review of statutes of limitation to end the factual impunity.

Justice for M.C. (USA) http://aiclegal.org/south-carolina-court-rejects-attempt-to-delay-justice-for-m-c/
Michaela Raab (Germany) http://zwischengeschlecht.info/post/2013/11/11/N%C3%BCrberger-Nachrichten-Zwitterprozess-Uniklinik-Erlangen
In 2008, an intersex organisation filed an NGO report to a UN Committee for the first time, resulting in intersex surgeries being criticised by a UN body.

Since then, many more followed suit.

CEDAW, CAT: 2014 CRC NGO Report, p. 28–29
With intersex issues slowly becoming more visible in public, unfortunately we are observing an increasing tendency of third party groups using intersex and the plight of intersex people as a means to advance their own agenda, for example to deconstruct the notion of binary sexes (and thus sexism and homophobia) in order to “abolish the two sex system”, or to advance LGBT issues, or to focus on discrimination while ignoring IGM practices, often by wrongly representing intersex NOT as a bodily variation, but, amongst others, primarily as a sexual orientation, or as a gender identity.

While it is a good thing to include intersex status when addressing discrimination, and while there are some intersex people who also experience intersex as a gender identity and position themselves within an LGBT context, and we should assert their human rights, this should NOT be done at the expense of addressing IGM practices. (ctd.)
It is important to note that intersex persons and their organisations around the world have spoken out clearly against instrumentalising intersex issues, and have maintained, that, although intersex children may face several problems, in the "developed world" the most pressing are the ongoing intersex genital mutilations, which present a distinct and unique issue, and constitute significant human rights abuses, which are different from those faced by the LGBT community, and therefore should be addressed adequately in a separate section.  

(ctrd.)

2014 CRC NGO Report: Intersex is NOT THE SAME as LGBT, p. 11–12
For the next part I'm now handing over to Markus, as I'm always glad if I don't have to present it myself.
What are Intersex Genital Mutilations?

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: Thanks.

I’m Markus Bauer. I’m not an intersex person myself, but the partner of a person concerned. I’ll bring an overview of some of the most common IGM practices, their justifications, and their history.
What are Intersex Genital Mutilations?

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Our definition from our NGO report (p. 13) is:

IGM practices consist of non-consensual, medically unnecessary, irreversible, cosmetic genital surgeries, and other treatments ...

2014 CRC NGO Report: What are Intersex Genital Mutilations (IGMs)? (p. 13)
What are Intersex Genital Mutilations?

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.

... justified NOT by evidence, but by psychosocial indications ...
What are Intersex Genital Mutilations?

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.

As referenced in our NGO report (p. 13), this is not just our impression but these are the exact words of various human rights and ethics bodies and experts.

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”

Variations of Sex Anatomy are not just the notorious “ambiguous genitals”. but include • genetics • sex hormone producing organs, and hormonal response by the body, as well as • Appearance, which includes External Genitals and Secondary Sex Markers.

“Atypical” characteristics may not only occur on one or more of the above layers, but 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 variations of sex anatomy 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 in the abdomen, 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 in our bellies, 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 (with the urethral opening and the vaginal opening only separating in the last stage).

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).

2014 NGO Report: What is Intersex?, p. 8–10
Genital Variation: Male, Female, and In-Between

Numbers represent the “Prader Scale”,

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 1–4 may arbitrarily be diagnosed as “boys with hypospadias” and submitted to “masculinising hypospadias repair.”
Children with genitals resembling diagrams 1–5 may arbitrarily be diagnosed as “girls with an enlarged clitoris” and submitted to “feminising clitoris reduction” and “vaginoplasty.”

Andrea Prader: 2014 NGO Report, p. 54-56, 86
The most common form of genital variation surgically “corrected” today is hypospadias.

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

TRIGGER WARNING! (next slide)

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 penetration.

In comparison, a numbed glans due to repeat surgeries is considered a minor obstacle. On the other hand, there are many unoperated persons with hypospadias who are grateful for having escaped surgery.

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 were before, for example urethral strictures can lead to kidney failure requiring dialysis.

However, for doctors and hospitals, complications can be lucrative.
Many children have major surgeries every year until they're old enough to successfully resist further treatments.

The language of the doctors is telling, see for example the official diagnosis “hypospadias cripple” for persons with repeat “failed” surgeries given up as hopeless cases.
For decades, doctors keep stating the obligatory lack of outcome studies, but nonetheless prefer to just go on with more and more risky surgeries, relishing the what they call “Surgical Challenge.”

This is typical for all forms of IGM.
What's more, a recent review on 30 years of hypospadias publications concluded ...

MATERIAL AND METHODS
The British Journal of Urology, Journal of Pediatric Surgery, Urology, Journal of Urology, British Journal of Plastic Surgery, European Journal of Plastic Surgery, Journal of Pediatric Urology and European Urology were systematically reviewed. Quality measures assessed were reporting rates of meatal location, chordee, follow up, meatal stenosis, fistula, urethral stricture, residual chordee and reoperation. Statistical analysis was performed using a Chi-squared test, taking a p value of <0.05 as significant.

RESULTS
184 articles were reviewed. From 1980s-2000s there was an improvement in reporting of meatal location and documentation of a length and duration of follow up. Reporting of presence of chordee was weak throughout especially in 2000s with 63.1% of articles not recording this variable. 13.1% and 22.6% of articles in the 2000s did not publish rates of meatal stenosis and urethral stricture respectively compared to 3-5% for the 1980s and 1990s for both parameters. Reporting of residual chordee has been poor, remaining static, with approximately 70% of articles from each decade not stating this outcome measure. Reoperation rate was absent in 50% of publications from 1980s, 37.5% from 1990s and 56% from 2000s.

CONCLUSIONS
Documentation of complication rates has declined in the last 10 years. At a time when outcome measures are increasingly being used to evaluate surgeons we advocate improved reporting by implementation of a standardised reporting model before a true assessment of performance can be made.

“Documentation of complication rates has declined in the last 10 years.”

Arguably until the 1990s, 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 the above diagnoses, the atypical development was caused either by an unusually high level of male sex hormones, for example CAH, or a low ability by the body to respond to them, for example AIS.
Since the 1930s, the justification given by doctors for cosmetic clitoris surgeries on intersex children remains the same:

An enlarged clitoris may appear bothersome and may lead to embarrassment for these girls in the changing room or while swimming, therefore, amputation or cutting is surely justified. (Max Grob, Zurich 1957)
As honest doctors admit, clitoris amputations were the most common intersex surgery for decades, and were practiced until the 1990s.

2014 CRC NGO Report, p. 50
While doctors today employ more modern techniques, aiming at sparing the main nerves, they usually still cut away most tissue and persons concerned still deplore impairment or loss of sensitivity.
Again, the language of doctors is telling, for example the “material shortage” mentioned here.
The 3rd most common IGM practice is castration, justified by an alleged high cancer risk, most frequently on persons with Androgen Insensitivity Syndrome (AIS).

Unnecessary castrations have been criticised also by some doctors for decades, however to little avail.
IGM 3 – Sterilising Procedures

b) Removal of Reprodoctive Structures
“Discordant to Sex of Rearing”,
e.g. Hysterectomy,
Removal of “Persistant Duct Structures”,
Partial Removal of Ovotestes, etc.

If a child is raised male, but has an uterus and/or ovaries, those are cut out in reverse, – same as with other so called “discordant structures”.

While doctors promise to produce “normal looking genitals,” persons concerned still report being teased because of scars and unusual appearance also in the so called “successful” cases, let alone in cases of admittedly “bad results.”

Captions:
“Ill. 1 a, b: Congenital Adrenal Hyperplasia (CAH) Prader 5 before and after surgery; c,d: Hypospadias scrotalis before and after surgery;
Ill. 2 a,b: Bad results of correction after feminisation and c,d: hypospadias repair”
Typical examples of harmful and traumatising non-surgical intersex treatments include repeat forced medical display and unnecessary and often brutal genital exams.
Further surgical and non-surgical IGM Practices include:

- forced mastectomy
- imposition of hormones
- human experimentation
- denial of needed health care
- prenatal “therapy”
- selective (late term) abortions
- preimplantation genetic diagnosis (PGD) to eliminate intersex fetuses
- misinformation and directive counselling
- systematic lies and imposition of “code of silence” on children

IGM covers a wide array of surgical and non-surgical practices.

Our NGO report explains 17 forms and attributes, including forced mastectomy, vaginal surgeries, imposition of hormones, human experimentation, denial of needed health care, selective abortions, misinformation and directive counselling.

2014 CRC NGO Report: The 17 Most Common Forms of IGMs, p. 63–76
About 90% Intersex Children are still submitted to often repeat surgeries:

“Lübeck Intersex Study”, 439 participants D/A/CH, 2009

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.

Despite claims by doctors, total numbers of early surgeries are still increasing.

Wherever there’s universal access to paediatric surgery, about 90% of all children concerned still get submitted to unnecessary and harmful genital surgeries, with current guidelines everywhere still advocating early “corrections”.

In regions with less access to paediatric services, the situation may be different.

Julius Kaggwa reports of intersex newborns being at risk of infanticide, however describes the lack of access to paediatric surgery as a blessing in disguise.

Julius Kaggwa BBC (Audio 1:59) [http://www.bbc.co.uk/programmes/p01krtg7](http://www.bbc.co.uk/programmes/p01krtg7)
Nthabiseng Mokoena
(Pretoria)

• “So, it took a long time for me to actually accept myself, and because I’ve never been operated on … the shame, the shame … all that I wanted to do was to get an operation for a long time in my life”

• “But the more I met other people like me the more I realized how privileged I am that I didn’t get an operation – that, I’m thankful that I did not get an operation when I was born.”

Video @ “The Interface Project”, recorded December 10, 2012

As a young adult, Nthabiseng Mokoena resented not having been able to get surgery, but today concludes:

“the more I met other people like me, the more I realized how privileged I am that I didn’t get an operation”.

Nthabiseng Mokoena @ Interface (Video 03:23 + Transcript) http://www.interfaceproject.org/nthabiseng-mokoena/
In regions where FGM is practised outside clinical contexts, also intersex persons assigned as females are at risk.

Note how above doctors seem taking issue with how non-medical cutters pre-empted IGM surgery.

Open Acces Pub (2006) [http://www.biomedcentral.com/content/pdf/1472-6874-6-6.pdf](http://www.biomedcentral.com/content/pdf/1472-6874-6-6.pdf)
Europe: Middle Ages – Early Modern Age

- increased risk of infanticide

BUT – surviving intersex people had it better than today:

- growing up intact
- legally and socially recognised + right to self determination
  (“Hermaphrodite Articles” in canon and civil laws)

• had the privilege to decide whether to live as male or female after reaching adulthood
  (“Sex Oath” at majority)

1900: End of legal self-determination in Europe

The history of IGM practises has still to be written.

It is striking to realise how in the so called “dark” middle ages, surviving intersex people were often better off than today, with their right to self determination asserted in canon and civil law, and the existence of hermaphrodites in society, of Intersex as a natural variation, was common knowledge.

2014 CRC NGO Report: Historical Overview, p. 49–51
“Western” Medicine, 19th Century:

Clitoris Amputations on Girls as “Cure” for a) Masturbation, b) Hysteria, and c) “enlarged Clitoris”

While amputations motivated by a) and b) attracted mounting criticism and eventually had been abandoned between 1900 and 1945, amputations of “enlarged clitoris” took a sharp rise after 1950 and became de facto medical standard on newborns in the 1960s, often in combination with gonadectomies / castrations.

It’s important to put intersex clitoral surgeries in relation with other historic surgical practices today widely accepted as constituting FGM.

While those clitoris amputations were soon criticised and eventually abandoned, amputations as a “cure” for “enlarged clitoris” took a sharp rise after 1950.

2014 CRC NGO Report: Historical Overview, p. 50
The racist and eugenic implications of the introduction of the term intersex in human medicine is still mostly ignored, same as persistent national socialist notions of intersex as biologically inferior and not fit for marriage.

2014 CRC NGO Report: Historical Overview, p. 52–53, 84
The actual beginning of IGM can be dated to 1950.

Since then, intersex genital mutilations have reportedly 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 ...

2014 CRC NGO Report: Lack of disinterested research, p. 19
... despite the obvious fact that medicalisation inevitably results in more and even more unnecessary genital surgeries on defenceless children.

2014 CRC NGO Report: Misinformation and directive counselling for parents, p. 70–71
2012: Swiss National Ethics Commission
Swiss National Advisory Commission on Biomedical Ethics NEK-CNE
criticises
“medical practice [...] guided by sociocultural values which [...] are not compatible with fundamental human rights, specifically respect for physical and psychological integrity and the right to self-determination” of “children with a sex variation”,
calls for
• Suffering of survivors should be acknowledged by society
• Psychosocial indication cannot in itself justify irreversible genital surgery in a child who lacks capacity
• Legal review of:
  - Liability implications of unlawful interventions in childhood
  - Limitation periods
  - Criminal law re: Assault and Genital Mutilation

On the other side, the 2012 recommendations by the Swiss National Ethics Commission (NEK-CNE) were welcomed by intersex organisations worldwide, because for the first time a national body recognised the harm done, and called for legal review, including criminal law and limitation periods.
2013: UN Special Rapporteur on Torture criticise “involuntary genital normalizing surgeries” and “sterilization” on “Children who are born with atypical sex characteristics” (A/HRC/22/53) followed by the Council of Europe (Res. 1951/2013).

... seconded in 2013 by the UN Special Rapporteur on Torture and the Council of Europe ...

2014 CRC NGO Report: Bibliography, p. 29–30
2014: WHO Interagency Statement

World Health Organisation (WHO), Office of the High Commissioner for Human Rights (OHCHR), UN Children's Fund (UNICEF), UN Women, UNAIDS, UN Development Program (UNDP), UN Population Fund (UNFPA)

criticises

“forced, coercive, involuntary sterilization” and “cosmetic and other non-medically indicated surgeries performed on [the] reproductive organs”
of “Children who are born with atypical sex characteristics”,

calls for

• Independent and impartial investigation of all incidents
• Recognize past or present policies, patterns or practices, issue statements of regret or apology to victims
• Collection of data and monitoring
• Provide appropriate and humane notification to people concerned
• Access, including through legal aid, to administrative and judicial redress.

... seconded by 6 more UN bodies in 2014, calling for legal review, data collection and monitoring, and recognition of harm done.

For the conclusion, I'm handing back to Daniela.

WHO Interagency Statement http://www.who.int/iris/bitstream/10665/112848/1/9789241507325_eng.pdf
Daniela Truffer: Thank you.

From a survivor's perspective it's self-evident that Intersex Genital Mutilations should be recognised as a harmful practice, and all appropriate measures should be taken to eliminate them.

We hope that we were able to give the committee enough evidence and testimonies to consider the case, and – if applicable – to consider an appropriate policy and general recommendations on the issue not only for Switzerland.
Legislation alone is not enough ...

“Toolbox” for Policy Development:

+ Truth & Reconciliation Commission

Our preferred “Toolbox” to develop a holistic policy would be the recommendations of
- the Swiss National Advisory Commission on Biomedical Ethics (NEK-CNE),
- the WHO Interagency Statement, and
- the CEDAW-CRC Joint general recommendation/general comment on Harmful Practices.

In addition, we would like to suggest to recommend establishing Truth and Reconciliation Commissions.

Legislation alone is not enough ...

“Toolbox” for Policy Development:

+ Truth & Reconciliation Commission

For short term recommendations, we refer to our initial NGO report (p. 27), and to our comment on the answers to the list of issues (p. 3).

2014 NGO Report: Recommendations, p.27

For 22 years now, survivors have been fighting to eliminate IGM practices, hoping that maybe this year will achieve results.

Thank you for listening.

Whenever you have questions or there is anything we can do for support, please don't hesitate to ask.

Translation of placard: “We demand: comprehensive information against manipulation!”
Katrin Ann Kunze, intersex activist, co-founder and board member XY-Frauen and Intersexuelle Menschen e.V., took her own life 2009.
StopIGM.org

http://StopIGM.org
http://intersex.shadowreport.org
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