

Intersex NGO Statement CRPD 12th PSWG Switzerland, 24.09.2019

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Daniela Truffer

Thank you.

I'm an intersex person born 1965 in Switzerland 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 cut out and threw in the garbage bin, without telling my parents.

Later the "castration" was declared a "mistake": one doctor said I was a boy with hypospadias, but as they had already removed the testes, now they would have "to continue this way and the small patient must be made a girl."

At seven they cut my genital, allegedly with my consent. Fortunately, they didn't amputate the glans, so I still have sexual feelings left. But I have a lot of scars, which often hurt and itch.

Today they probably would make a boy out of me, by even more surgeries and complications.

During my childhood, I spent a lot of time in doctor's offices and hospitals for countless examinations of my genitals. When I was two, a doctor stuck his finger into my urethral opening; I was screaming very loud. Afterwards, my mother had to put me into warm water because every time I had to pee, I screamed in pain. Eventually I was hurried to the hospital with a bad infection. Still today my urethra often hurts after going to the toilet.

The doctors always lied to me and my parents. I spent my life in fear, pain and shame. I couldn't talk to anybody. When I had to see a doctor, I was always scared stiff, but I never cried, and endured everything without any protest. I felt sick days in advance.

The doctors always told me I couldn't have a boyfriend without a proper vagina. I just wanted to be normal, and the Swiss Federal Invalidity Insurance, which finances all the surgeries, doesn't pay after one turns 20, so at 18 I quote-unquote "consented" to have a vaginoplasty. After surgery, I was bleeding and in pain, but I had to dilate my vaginal opening, and the doctors said, "best get a boyfriend soon."

I left home when I was twenty. I tried to lead a normal life, boyfriend, work, and university, but I always felt numb inside and always had to lie and pretend, for example when somebody asked if I wanted children. I didn't want to think about my childhood, and had little contact with my family.

An obsessive-compulsive disorder controlled my everyday life for decades. I couldn't study anymore; I was always exhausted and desperate, and I couldn't talk to anybody, for who would understand?

At 35, I had to pull the emergency brake. I started a psychoanalytic therapy, which lasted

ten years, otherwise I wouldn't be here now. And while the Swiss Federal Invalidity Insurance paid for all the surgeries, for the psychoanalytic rehabilitation, a third of the costs I had to pay myself.

I learned fragments of the truth of what was done to me only after decades of ignorance and denial. Only at 35 I discovered that I am not alone and that there are self-help groups. At 42, I was lucky to obtain my medical records, but only after a long struggle, and with statutes of limitations long expired.

Today, I still suffer from periodical pain between my legs, hypersensitivity, and painful scars. Because of the castration I have to take artificial hormones for the rest of my life. Already at 30 I was diagnosed with a beginning osteoporosis and as long as I can remember I suffered from metabolic and circulatory problems, which are all known negative effects of castration.

As substantiated in our **NGO report**, in Switzerland all forms of Intersex Genital Mutilation are still perpetrated with impunity, paid for by the Swiss Federal Invalidity Insurance. On the other hand, adequate psychosocial support and rehabilitation is still not available, and neither is access to redress and justice.

And this all despite that in the meantime, IGM practices have been denounced as a serious violation of non-derogable rights, namely as inhuman treatment and a harmful practice, by the **Swiss National Advisory Commission on Biomedical Ethics (NEK-CNE)** in 2012, by **CRC** and **CAT** in 2015, by **CEDAW** in 2016 and by **CCPR** in 2017, all of them urging Switzerland to

1. **prohibit the practice**
2. **ensure access to redress and compensation,**
3. **provide access to free counselling.**

Today, the **Swiss government** claims that the recommendations of the National Ethics Commission have been largely implemented, but explicitly

- **rejects the implementation of UN recommendations** on IGM,
- **rejects to facilitate psychosocial support and rehabilitation,**
- **refuses to facilitate data collection,** and
- **allows hospitals to destroy medical records** instead of facilitating a historical reappraisal.

I therefore urge the Committee to include **tough questions on IGM in the LOIPR**, to sternly remind Switzerland of its obligations under the Convention.

Thank you.