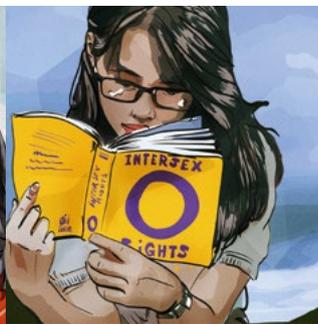




#MyIntersexStory

Personal accounts by intersex people
living in Europe

With a text by intersex scholar Janik Bastien Charlebois "On our own terms and in our own words": The value of first person accounts of intersex experience



IMPRINT



A big Thank You to all intersex people and parents for participating in this project and sharing their personal accounts!

We are thankful for the support by our donors and funders that make our work and this publication possible

oii
EUROPE

Published by: Organisation Intersex International Europe – OII Europe
www.oii-europe.org • www.intervisibility.eu

ISBN: 978-3-9821518-1-6

Layout & Illustrations: Ins A Kromminga

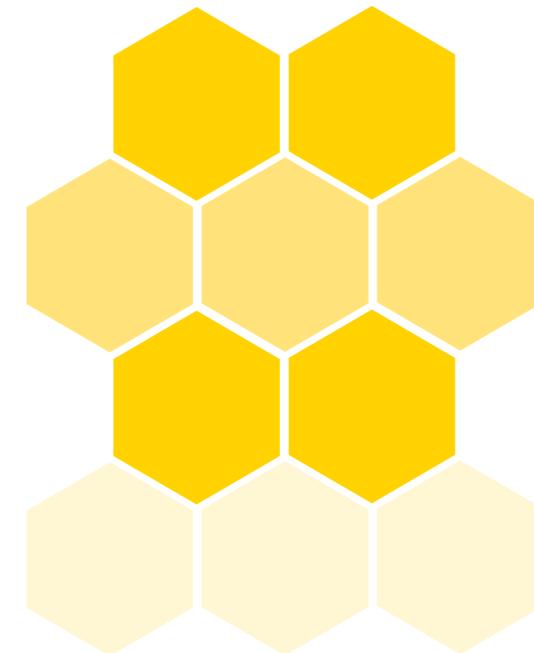
Editorial Team: Dan Christian Ghattas & Ins A Kromminga (staff);
Irene Kuzemko, Kitty Anderson, Audrey Aegerter (board)

1st Edition Nov 2019

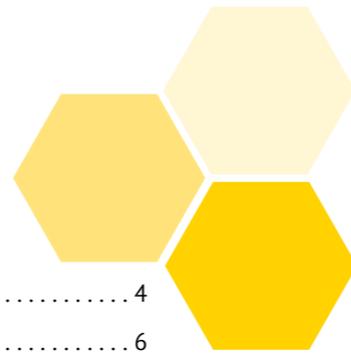
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<i>Janik Bastien Charlebois, Ph.D., professor of sociology, Université du Québec à Montréal</i>	

THE ILLUSTRATIONS OF THE PERSONAL ACCOUNTS IN #MyIntersexStory

The stories told by intersex people about their lived experiences can be hard to read, can be triggering, and they often are not happy stories.

But one thing they all have in common: They are being told by people who survived misfortunes and mistreatments, who found the strength to write their story down, and share insight of how being intersex has shaped their life.

For most of the drawings I decided to have the person look directly and proudly at the reader of this brochure. All of them can be interchangeable with anyone – as intersex people are found everywhere, we look the same as everyone, have as many diverse identities, sexual orientations and interests as the rest of the folks in our societies. Some images are inspired by segments or details of these testimonials, but they do not want to

represent one individual or one specific experience. The images want to empower by emphasizing the strength and resilience of intersex people, for example through vivid colours and bold outlines.

In combining the texts with images this brochure provides an additional non-textual layer of reflection, rest, and stimulus. Telling our stories is an emotional endeavour, can be a challenge, and definitely is a huge step out of invisibility. Deciding on what and how much we want to share with the world is part of reclaiming dignity, integrity, autonomy in our lives, our human rights, and it’s also about recognizing beauty in our lives.



Ins A Kromminga



MEDICAL REPORT:

I have no memories before the age of 8 and not much until I am 11, so I will start with when I was 11 years old. I was doing Judo so I often had to have medical tests. I remember that after my first blood test the doctor and my mother were confused and they told me that I would have to go to the hospital and have more tests.

So I went to the hospital for one week and they gave me a lot of blood tests including a diabetes test and many others but I was not told what they were. They took my blood six times a day but after a week in hospital they said everything was fine and I could go home. I do remember very shortly after this hospital stay I got very heavy abdominal pains and then my first period.

With my periods I had lots of troubles and it was always very painful, sometimes so painful that I often could not get up in the morning. One day my mother said we should go to the gynaecologist to sort out the pain and the doctor prescribed the birth control pill. He said that I had endometriosis and if I took the birth control pill it would alleviate the pain and my periods would become normal.

I continued to see this doctor until I was 19 but I stopped going to visit and just continued to take the pill for another 6 years. My mother then changed doctors and forced me to as well and to visit the new gynaecologist. I hated these visits as it was always very painful for me to be examined and often they could not examine or test me properly as my vagina was too small. The new doctor advised I stop taking the pill to see if things had improved – they had not.

As soon as I stopped the birth control pill the pain came back as hard as before, I bled very heavily for three months. So the doctor did a laparoscopy which revealed that my uterus and ovaries were very small and also that I had many tumours within them which needed to be removed.

Again I was prescribed the birth control pill but a new one which I had to take everyday, I was 25 at this time. I did not want to be on the pill but I did not want the pain to return so I did as the doctor suggested.

I continued to take the pill for years until when I suddenly started getting a lot of pain again in my ovaries and uterus but without my period. I went to a new doctor and after several tests it was recommended to have another operation. She found tumours again in my uterus and ovaries and after discussion I had my uterus removed along with the tumours but I kept my ovaries.

At the time of the operation the new doctor examined me and found scars around my clitoris and labia, I talked to my parents and after month of fights they told me that it is true, that I had a genital operation when I was a baby and at that moment a lot of things were suddenly clear in my life, now I understood why I did not have any sexual feeling or could have an orgasm. I also stopped taking the pill after the operation.

After 9 months I started to get more hair on my body, including a beard and my voice changed.

During all these years I often have troubles with my bladder where I cannot urinate and I get cystitis regularly. Additionally I suffer from migraines, skin disorders and blood pressure issues where I just collapse suddenly.

In few month I will have an operation again to take out my ovaries or my testicle (the doctors are not sure), because I have tumors there again. After that I hope I can move on without pain.

Country: Austria





EVERYONE HAS MISSED THE REAL CAUSE OF MY SUFFERING

Talking about my past may seem ridiculous. However, I was 100% organic and was born like many children, quite normally. I was built in-utero in a different way and I couldn't be, or become, quite a boy or quite a girl. The culture makes a problem with this because it only offers two labels.

Society is binary and everyone thinks it's always been that way! This ignorance is still present because it is maintained by medical and government authorities. I always thought I wasn't wanted as I was because I was transformed with surgeries and hormone injections. And then when I wasn't doing well because of all this, well, I was sent to psychiatry!

Everyone has missed the real cause of my suffering.

My parents did not understand what the doctors told them, but they were convinced that treatments were needed to correct the problem. So the problem was me! It is not easy to live when you feel that in your heart, when you are afraid of not being loved by your own parents and family, when you are mocked and rejected.

Adolescence is, for all of us, a time of great natural upheaval and it also serves as a foundation on which to build our personality and autonomy. But how do we build ourselves when our bodies are subjected to scalpels that transform you deeply and when you are forced to take artificial hormones? Who are you becoming?

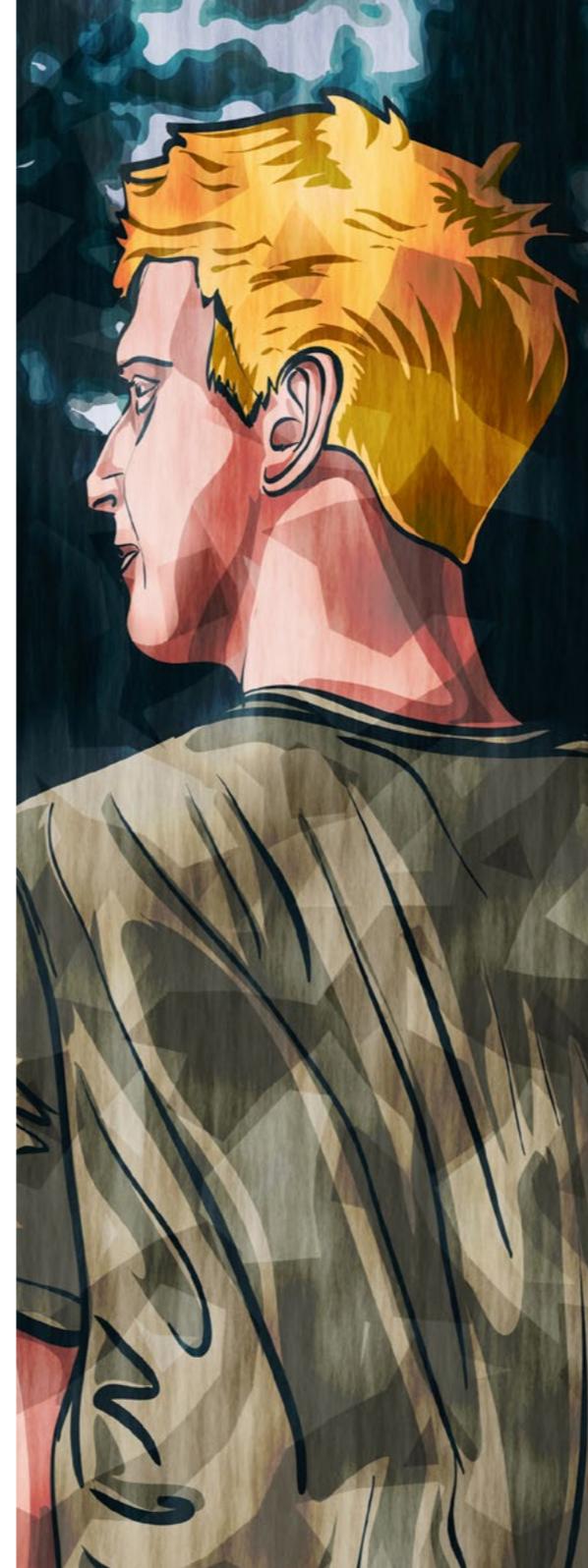
If my parents had been supported and better informed, they probably would not have acted as they did with me. The pediatrician told them to go to a university hospital where there were experts. So they believed 100% what the experts told them, without getting anything in return. The specialists did not want to listen to my mother, they forced her to accept everything, they scared her with scary words for my future and they made my father believe that medicine would fix everything to put it back in order.

However, my parents were emotionally overwhelmed and today, although they are 80 years old, they have not yet said everything. In 1980, without the Internet, no one was talking about this subject. The endocrinologist told them not to talk about it! So, having received no support, they ended up going very badly themselves. Fundamentally lacking in humility, these doctors deeply wound the bodies and minds of all intersex children and the damage is considerable!

I felt all my life invisible and unworthy to exist as I was. I have been an object for science and above all a very big problem for my whole family! When my parents talked about me, it was always to complain. My needs, my emotions, my opinion were not taken into account. I had to do as they wanted. I felt manipulated by everyone and everyone lied. I was abused because I was a vulnerable child and so were my parents.

I still have nightmares about all this.

Just as I told the United Nations to testify and explain the feelings of a child who, every morning, receives a visit from the surgeon surrounded by a group of students and everyone talks about his genitals aloud as if he were just a doll in a bed. Someone was lifting the sheets,



someone else was taking pictures. I was very embarrassed, I had to be wise and I was told that I was there to be cared for so that everything would be all right.

This way of suffering everything leaves its mark. I was lied to about who I was. I was told how to behave. I was lied to about the effects of the hormones injected and their consequences. The negative and irreversible effects have been deliberately overlooked.

My body couldn't stand all that and that's normal! I was made sick and now I have to go through all this alone! These are all complications and my life has been put in unnecessary danger. My physical and mental well-being has been seriously affected by all this.

I received "with love" everything the doctors had said to do to make me a "normal man". The reproaches I have since received have forced me to bow my back. For years I tried to express my distress and make my family understand it, but in vain.

My parents still feed their denial at 80. Every time I try to come back to this subject that obsesses me, they feel aggrieved and struggle, they prefer to relativize and marginalize me. Simply because nothing has healed at home either.

After the XXY diagnosis and infertility, my parents' behaviour changed dramatically. My father was totally desolate because his only son was not going to be able to give him natural offspring. And my mother was hit on the head when the doctor told her she was guilty of the problem because the extra x chromosome came from her!

To the pain of the treatments was added the guilt of relationships that had become tense at home and the fear of no longer being loved!

At 14, I had my chest removed by total mastectomy without the torsoplasty that we do today for trans people. The effects have been terrible, I keep this area lifeless and nipples insensitive.

I keep the complications such as periodically painful glandular masses on the flanks and under the arms.

I suffered from muscle tears and joint pain. I had little stamina and I was always very tired. My father said I was lazy and told my mother they wouldn't do anything good with me! My mother did the best she could despite the fact that my academic and learning difficulties were never recognized.

The classmates laughed at me openly and often made me fall down the stairs. Twice I had broken bones. I was afraid to go to school. I still hear my father telling me that if I was bored, I should fight "like a man". I experienced all this as deeply unfair.

The truth is, I wasn't allowed to be myself. I am still always afraid of what people think of me and afraid of how others look at me. When I have to go to the pool with my children, I often have to take an anxiolytic.

In conclusion, it is mainly my parents who should have been supported and the environment informed.

The good job of being a parent is to love, support and defend your child and not to obey inhuman social obligations defended by medicine. Instead, parents learn to be intrusive and control everything in their child, as if to give them the illusion that this is the only way to erase everything.

Thank you to all the intersex people and allies who have helped me and continue to support me today.

Age: 40-45

Country: Belgium





CHANGE SOCIETY, NOT OUR BODIES!!!!

My Intersex adventure started in 1958 right after I was born when doctors noticed a genital ambiguity but for the sake of convenience very quickly decided to assign me female without even consulting my parents. Diagnosis: PAIS.

From that moment, the first interventions and treatments were scheduled and went on for all of my childhood and adolescence. As doctors had very little experience with this kind of cases at the time and some gender theories were emerging (see John Money*), they took the opportunity to turn me into a case study. They never thought it necessary to explain my situation to me and they forbade my parents to reveal it.

The consequence for me was annual hospitalizations during school vacations to assess my psychological state sometimes combined with surgeries and other tests/treatments. The most

* John Money was one of the most influential figures in the history of medicalization and treatment of intersex people: His theory of gender and binary behaviour led to a systemic clinical and surgical management of persons born with variation of sex characteristics from the 1950's on. Up to this day this practice is still very much present, regardless of changes within medicine. To learn more about this read "Contesting Intersex – A Dubious Diagnosis", Georgiann Davis, 2015, P.58 – *editorial comment*

shocking to me were medical examinations as I was naked in front of the assistants/students and the pictures they would take at such occasions as if I were a “freak” in a circus. All of this without ever having been sick. Moreover, my parents were pressured into raising me as a “girl” whereas I would have rather been a boy. To that end, I was sent to a girls school and forced to study subjects I didn’t like. As a result I failed at school and only as an adult could I take classes that suited me and allowed me to find a job. I also stopped the feminizing treatments that I didn’t tolerate well and resulted in an early osteoporosis. Since then, I have been taking a masculinizing treatment and I feel comfortable in my own skin.

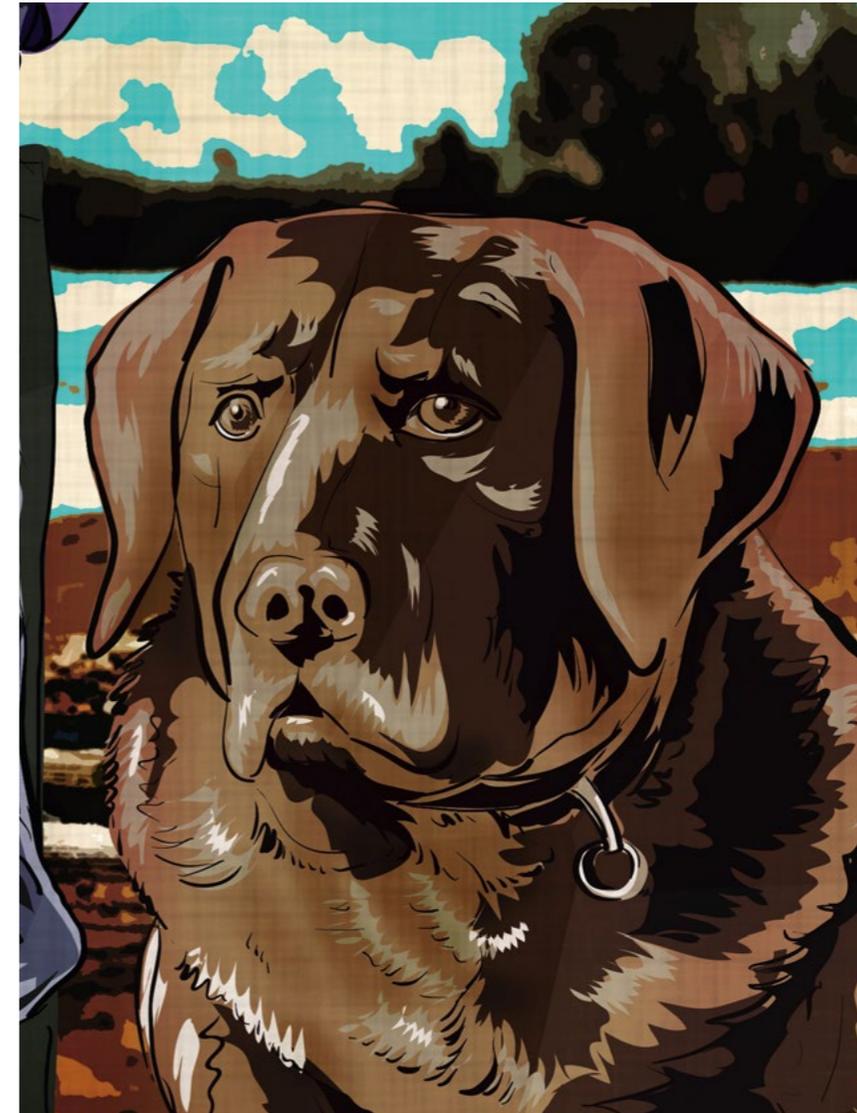
It is difficult for me to accept my body as it is and because of the various mutilations, my sexual life is very limited, non-existent even, and I end up pretty isolated which is heavy on me and puts me regularly in a depressed state.

Convinced I would have had a better future if I hadn’t had to go through all these unnecessary treatments – because I was in good health, I was just different from most people – I got involved in activism because still now this practice is carried out with similar results, as other intersex people testify.

Change society, NOT our bodies!!!!

Age: 60 -65

Country: Belgium





AM I NOT “INTERSEX ENOUGH”?

I write this piece because I read in an intersex facebook group a debate on whether PCOS (polycystic ovarian syndrome) should be considered as intersex or not, depending on the model of analysis we adopt. Having myself PCOS, I was very relieved and enthusiastic when I finally ended up hearing about intersex identities, movements and communities, and I have joined them for several years now. So you can imagine how hard it was for me to read that my very place in the group was debated upon. But feelings are not the point on which I build my activism, and after discussing with several older activists who were very supportive, I decided to write this. Not to discuss my feelings, but to feed the debate on what we are calling “intersex”.

According to the UN definition, with which all the intersex activists I know agree, “Intersex people are born with sex characteristics that don’t fit typical definitions of male and female.” Sex characteristics include “genitals, gonads, hormone levels and chromosome patterns”.

Many intersex activists point out that not only the variation but the social treatment of it defines their oppression. You would not be intersex only by carrying a variation of sex characteristics, but also because you have been stigmatised for it, especially that you went under medical violence, from harassment to mutilation (but you don’t need to be mutilated to identify as intersex), including hormonal treatment.

Let’s see now what I went through by having PCOS.

When I was 12, I was supposed to have my period, like my sister and my mother before me. I didn't. Months then years passed. I was 13, then 14 and still no period. No breast. Some new hair. Low growth. My mother started to worry; and read a lot about it. She found out that 95% of the girls had already their period when they were 14 years old. She brought me to the doctors, and to be more precise, since we didn't have a lot of money, to the hospital. There, the tests began. Blood tests, countless echographies, and the first medical rapes with different kind of tools, in my vagina and my anus – sometimes without even telling me in advance that they would penetrate me, to find out what was wrong. They started to give me pills, to “help the puberty to start”, but they always told me to be careful, that it was in no way contraceptive... they didn't know then that my sex life was with a person with a vagina too.

When I was 15 and a half, the summer before I enter high school, my growth arrived, along with my period. I was mostly relieved that my medical journey will end there. What a mistake! My sudden growth came with a brand new double scoliosis and I had to wear for a year an orthopedic corset to prevent it to worsen. And when I went out of the shower, my mother started to look at my genitals with a worrying look. She made me lay down on her bed to check it, manipulating it, frowning. And she took me back to the doctors.

I'm not really sure why we didn't go to the hospital yet. Maybe she was more worry and so more in a rush; but she took me to a private gynecologist, the same she and my grandmother had. It should be noted than he was also a member of the hospital team, and a surgeon working in a private clinic.

This doctor looked at my genital and explained that we had to do something about it, otherwise I would have trouble to have sex. If only I was brave enough then to tell him that I was already having sex and orgasms with my girlfriend... but I was still in the closet, afraid, crushed by my mother's concerns, and 15. I didn't say anything about it. He showed me some pictures of genitals, and I was too ashamed to look at them. I was kind of paralyzed, really, and you have to consider that all of this (the growth, the period, the corset and the proposal of surgery) hap-



pened over the course of two months. My body was changing too fast, betraying me, I had no idea what to do; so I did what most of us do in this circumstances: I agreed.

I was mutilated in October 1999, in his private clinic. I remember everything, from the shameful shaving of my sex to the gloomy awakening with a nurse shaking my stretcher to wake me sooner. Then I spend weeks and months cleaning my wounds – my mother did it at first, and it was so embarrassing. It was in the same months that I was wearing my corset and cleaning the wounds on my skin every night. I lose my sex life, of course, then my girlfriend. I started anorexia.

The mutilation was a dirty work. I still have folded scars, and parts of a “normal vulva” missing (I read, 16 years later in my medical records, that they talked about retraction). I went to several surgeons years after, to ask for something better. I'll never forget what one of them told me: “Well...fact is, there is not enough left to do anything better...”

Back to my 16, and back to the hospital. Remember when I told you I had my period? I had it. Once. Then it disappeared. The doctors said it was because of the trauma of the corset (nothing about the mutilation, nothing about anorexia). They ran other tests. I had new period, once, 10 months after the first. Back to echographies and blood tests, back to pills. My medical records stated than my levels of delta 4 androstenedione and of testosterone were too high – they didn't tell me. They gave me a progestogen, without telling me anything except that “it would help me having my period” and then, be a normal 17 yo girl. I read, later, that my medical record said “Stein-Leventhal” (which means PCOS) but they never told me.

So I kept going, with my scars and my strong acne and my pills stating to the world that I was not a normal girl, hiding my sex, and its occasional infections, then I was finishing high-school, my periods sometimes missing in spite of the pills, one month, one summer, two months without them, like a little reminder that I would never be a real woman and that I needed to go to the hospital at least twice a year... My breast finally showed up, I started to make peace with my body, I had a girlfriend again, and I finally asked to have a contraceptive instead of a strictly

medical pill, just to “pass” better, to be able to talk with the other girls of something common and normal, and not a treatment. I started it at 18, and kept it for 10 years.

At 20, in a different town, I went to a gynecologist for a renewal of my prescription. He was surprised by the story and made me go through the tests, always the same, external and internal echographies, and blood tests. He gave me oestrogen gel to apply on my belly. And he told me that I had PCOS with dystrophy, which would explain why I had irregular periods and why my ovaries were often so painful. I still can't believe it took me so long to learn why I was under so much pain so often, that I was so closely watched by so many doctors for so long and that not one of them cared enough to tell me.

I was 29 when I decided that I decided to stop the hormonal treatment. I was beginning to understand more politically what happened to me, and I was able to see that I had develop a serious uneasiness with my body, and that it had been so alienated to me that I was unable to set my boundaries and had been through several sexual assaults and rapes. I decided to stop the treatment in an attempt to connect better with my body. And it worked. My breast shrank a bit. I grew up a little. Yes, I did, because I suddenly develop more muscles in my back and my scoliosis decreased. How strange is it? The doctors were very angry and said it didn't make sense, and I was dancing on their rage, celebrating my new complicity with my body.

I had a better sex life, because my body reacted in a way which was closer to my state of mind.

My periods started again to be irregular, and I didn't really care... who wants more periods, honestly? But I wondered if I was sterile, and what it would mean to me.

And I started to look for people like me. I searched for failed female, for freaks, for the mutilated, for those who were told that they needed to be fixed, for those who wondered each time they met someone they like, how and when to tell them that they may find something disturbing down there, for those who hate the medical power, the socially constructed so-called “sex

binarism”, those who never recognized themselves in biology books in schools, the monsters in the shadows of the bright male/female system.

And I found the intersex community. And I wanted to know to I took new tests, I swallowed the violence and the traumas and the technician saying “there's something wrong with your ovaries... they don't seem to work the way they should”. I gathered my medical records. And I went to an endocrinologist who looked at my tests and told me that yeah, I had too much male hormones. I was so happy, because it was the first time I was not told that I was “not enough” but “too much”...

So tell me. Am I not “intersex enough”?

Age: 30-35

Country: France





SOCIETY NEEDS TO BE FIXED, NOT US!

I am an intersex man, who was assigned female at birth and has organs that do partly correspond to what is usually called “female” organs. Retrospectively I was lucky, as my mother, who raised me after my parent’s divorce, had a family history that prevented her from trusting the medical establishment too much. This said, she did feel the pressure for me to conform and that resulted in doctor’s visits during my adolescence, of which I will talk more about below. My father was a Muslim and though we never talked about it, it always felt to me that he, through his religious and cultural background, was more aware of the existence of people outside of the sex binary of male and female. Plus, he had a sister that, from all I know, is very likely to have been intersex too.

Looking back, it is very clear to me that I came into puberty much earlier than expected. People have interesting ideas about too early puberty. Early puberty does not mean that you wake up one morning with a deep voice and hair all over the place. Early puberty means that some body parts start to grow sooner than others (you might be bigger than average for some time and then get outgrown by your peers afterwards) or you might develop more muscle mass at an early age: Looking at old pictures I still wonder why people didn’t ask me about the closest fitness studio – instead they called me freak because I liked to test my strength with boys, and you were not supposed to do that as a girl; and they called me brutal because I didn’t realize that I was as a matter of fact stronger than most of the kids, as “girls” were not supposed to be actually physically stronger.

Coming into puberty earlier also can mean that your hormone level increases already around the age of six or seven and you might get some sexual feelings in your body earlier than your peers. I experienced this as a kid and it did not frighten me: It is a nice feeling and there is nothing wrong with it – except it seemed to be for adults who were looking at me with dis-

T-shirt slogan inspired by the #PositivelyIntersex project and the onepointseven project <https://onepointseven.org.uk/> by Magda Rakita

gust when I was trying to tell them about that feeling. Some were talking behind my back and suspecting a psychic disorder. The same happened when I tried to get more information about my growing muscle mass or told them that I didn't mean to be brutal, but that I was somehow stronger than other kids. No one explained to me that it was ok and what was happening with my body. Instead I got more and more worried that I was possibly nuts as everyone was telling me that I was making things up to get attention. The latest at the age of 10 I felt like having a mental disorder and I was panicking that at some point of my life it would break out completely and I would lose it.

So although I was lucky not to have been mutilated at birth by surgical or medical means I was mutilated psychologically by adults and children throughout my childhood and adolescence. This is what comes from lack of knowledge, from taboo and shame. And I knew that I was not only different "psychologically" as claimed by the adults and children around me, but I was different in regards to my body. I tried my best to contain my "nutness" inside of me, in order to prevent others from bullying me. But that is the point with an intersex body: it shows. I was deeply ashamed – not of my body itself – but of that neither my body nor my soul seemed to be able to conform, whatever I tried.

At the same time, I liked most of my body parts, especially those that seemed to be not totally complying with people's expectations. However, I thought, maybe I got that wrong too and was just imagining that difference. People already believed that I was nuts, so what if I was? My body did not really fit the description of female in the biology book, but if that was so why didn't people see that too? Why did they tell me over and over again that I needed to behave more female and sometimes claimed that there was something mentally wrong with me? Why was I not allowed to cut my hair? (Of course I know now, thanks to modern computer software; cutting my hair would have turned my appearance totally towards male in a second).



Fast forward to my period setting in. Yes, I had that. Sometimes. Very irregularly. As in 3 times a year. But then the pain was horrible. But no one believed me when I tried to make them understand the extent of my pain, neither teachers, neither doctors, interestingly not even my mother who sometimes witnessed it and acknowledged at least a part of it being true. But periods were supposed to only hurt a bit or at least be bearable. They were not supposed to cause you rolling around in pain on the cold floor (cold helps) for up to three hours. It took me two decades to find out that the reason why they were so painful has to do with my specific anatomy. And all I would have needed was a fucking pain killer.

Although to me the pain was the disturbing part, to others the lack of regularity was much more interesting. I can just assume that, other than muscles and appearance, this issue in the end cries "reproduction" and it seems that this is of much more general interest in society than what the person themselves considers to be important.

To make a long story short: During adolescence I was dragged to different gynaecologist to find the cause – not of the pain, but of the lack of regularity in my period. The latter of which I personally was zero interested in as having the period only so often felt very natural to me. I had been mostly spared from dealing with doctors in regards to my intersex body in the past, but now the nightmare began: Each and every time the gynaecologists I saw over the years would try to insert the speculum for adolescents and adults, then angrily change to the girl's speculum, when I yelled. Which they couldn't insert either. The latest at this point each gynaecologist got furious and told me that I had a psychological problem for not letting them in. They claimed that I was responsible. It took me 25 years to get confirmation that it is anatomically not possible to close this specific part of your body by your own will. But none of the gynaecologists I was pushed to see over the years acknowledged that. You don't acknowledge what is not supposed to exist, right. They did not acknowledge that my anatomy makes it impossible to insert a speculum without causing a lot of pain. After that they usually said that they would check from

behind. And I never understood how they could get any information from that. I suppose now that they were actually looking for something else, a prostate maybe? Again my mental state of mind was questioned. That I was not worried about my period was also proof that I was somehow psychologically disturbed. Finally, still in my teens, I found my own solution to the pain: strong painkillers, that I could obtain through a person that I was tutoring.

Would I have wanted to be operated on my anatomy – certainly not, not back then and not later. I wanted the pain to cease, not my body to be changed. Eventually some years later in my twenties the problem solved itself, when my body just stopped building up the tissue.

In addition to the gynaecological examinations there were other incidents that I won't dive into. Maybe one: around the age of 18 I was given a drug, which, as I was told, was small contraception pill that would help me to regulate my period and get it once a month. I was not at all keen to take it, but I was already mentally broken from years of bullying and questioning my own mental health, so I complied. However, luckily even in my state of severe depression that I was entering at that time (and took 6 years to get out without any real help available) there was some resistance left. I took that "contraception pill" for three months feeling awful each and every day. My body felt like being spammed with something that was not genuinely part of it, I felt totally wobbly physically and emotionally, my vision seemed to fray. I don't remember if I actually got my period. After three months I threw the remaining drugs in the trash bin. And never regretted it since. I know that many of my peers weren't so lucky.

A quick fast forward to the time a decade later when I was trying to find out more about my body and was looking for a diagnose – just to be told by two doctors, who were considered to have expertise with intersex bodies, that, in fact, I should not exist. Why? Because all the findings didn't match up with any of their diagnostic manuals.

I am the survivor of mental abuse by doctors and by society, that do not acknowledge the fact that people like us exist. I am also the survivor of the attempt of doctors to turn my body towards female by hormonal treatment. Hormonal treatment that was given to me without my free and fully informed consent. I am the survivor of a severe depression caused by these and other related incidents, like society not accepting my male gender identity, that come from lack of knowledge, from taboo and shame.

My body was and has been healthy all that time. Currently I take some testosterone to make sure my hormone levels are balanced as they sometimes are a bit low now. There are also one or two things that come with my specific intersex body e.g. one that I need to make people aware of when put under anesthesia. That is it.

So to me it is very clear who needs to be fixed: It is society, not us. What we need is that our bodies are acknowledged as they are. And that we, as individuals, are enabled to take care for our actual physical needs, if there are any. Instead of other people doing that for us without our consent from their non-intersex perspective.

Country: Germany





BEING BORN INTERSEX IN GREECE 2009

The difficulties, the struggles and the violations for a family with an intersex child and for the child itself.

This is our family story. At 2008, while five months pregnant, I was asked to do an amniotic karyotype testing, due to our age (I was 43 and my husband was 40). The test revealed that everything was normal, except that the baby had an extra X in the sex chromosome, that is a 47,XXY (intersex) karyotype. As this was something new to us, we went online and gathered every possible, updated information about it, so we would be prepared properly. We also met through the internet with many XXY people around the globe, happy to share their personal XXY stories with us and very willing to support us psychologically. Unfortunately my first obstetric doctors in the local hospital were not that well-informed: they call us on a hospital counselling meeting (two of them) and insisted that the “standard procedure” was to terminate ANY XXY foetus, cause they will be “A freak! A monster! A nature’s fault! Someone like with Down syndrome, a dumb person incapable of living on its own! A boy with a so small phallus, so better not to be at all” (these were their exact words...) Since we were informed that all these was false and outdated, we insisted on keeping the baby and they refuse to deliver it, so they made us sign papers that we continue on our own responsibility and they send me to an Athens central hospital to find new doctors to carry on. So, even before T was born, we had to struggle with medical ignorance for his safety and his profound right to be born. As I am hearing from other local hospitals, this “standard procedure” (to terminate healthy intersex foetuses) is still valid... So we can’t say how many XXY’s have already been “terminated” before being even born. This is an ignorant and racist genocide that has to be stopped, in Greece and globally.

Next (3,5 years later) T was denied attending the local public nursery school, cause again they thought “he is not normal”, out of plain ignorance (before they even met him physically). After we strongly insisted to his right to attend, they accepted him and he went without any further problem.

But in primary school things got nasty: As many intersex children are, T is also a gender creative child, that since 3-4 years old he steadily identifies as “mostly I’m a boy, but I am a little girl too”, he loves lego, ballet dancing, long hair, dresses and skirts and prefers to play with girls. Because in greek schools the norm is “There are only boys and girls and that’s all”, the kids found it very strange for a boy to have ballet classes, to have long hair, to like girl-playing and have soft manners and high-pitched voice. So they gave him a hard time teasing and bullying him to the extend he cut his hair in tears and refuse to go to school. With a lot of work with the teachers and the psychologist there were created a little acceptance and space for him, so he made it to the end of the year.

As T entered elementary school in Sept. 2016, we as parents provided every possible and valid info about intersex traits (social and physical) to all his school teachers and the headmaster, to create awareness and acceptance. But in fact, the teachers are refusing (or declare themselves unable, “unqualified”) to accept his gender fluidity and create positive awareness to his co-students, by just telling them that “it’s ok to be a pink-boy, or a tomboy girl. Its ok to be different than distinct male/female, cause gender is a colourful spectrum that everybody can fit in”. They are refusing this scientific valid info to the kids, because (as they told us) 1) they don’t have such orders and guidelines from the Greek Ministry of Education and 2) they are very afraid of the possible bad reactions of other homophobic/transphobic or religious parents, who don’t want this info to reach their kids.

So my kid is being teased and bullied (again) because educators deny to offer kids valid and updated scientific info, and deny him acceptance and support for

freely express his gender, like every other kid. He is just in first grade and already wants to quit school if things don’t change to the better.

These problems we face, that probably will be harder in years to come, this social and educational ignorance and rights violations, it would all be stopped if the Greek Government makes the right step now to INCLUDE intersex (and trans) children in the new legislation (May 2017) about gender identity.

Gender is a spectrum. Gender-fluid children do exist. Intersex and trans children do exist. They are all perfectly normal human children that deserve respect. Either intersex in their physiology/ anatomy/hormonal & chromosome profiling, or not, they do exist and have human rights and they need us to support their rights to develop safe and free to create their true, unique gender. They have to have the right to decide/create their gender at their own pace as they grow and not be pushed to identify strictly as males/females only. This social pushing towards the only-two-accepted-as-“normal” gender stereotypes, while excluding in shame and harm all the others, is adding a lot of social and inner stress to these kids and compromises their physical and psychological health, due to a lot of well-documented dangers (as gender bullying, harassment, personality assaulting, physical violence, depression, school quitting and even youth suicides).

For our child and all of these children we ask the Greek Government to include them in the new legislation. Also it is urgently needed for them to be included in the Greek Educational System, through clear inclusive guide lines to all school-levels educators, from the nursery schools to universities.

Country: Greece





DO YOU KNOW WHAT IT IS LIKE TO BE AN INTERSEX PERSON IN ANATOLIA, IN A VILLAGE IN TURKEY?

I know that pain, I know what it is like to be the kid who got called names or heard a mother's sigh when she was asked about it. Listen to it from someone like me who once could not speak Turkish at all.

I guess I was 5 or 6 years old, I remember some women from our village and my mother forcing me to lie down and touching me between my legs while I was crying and screaming, making comments like they were doctors. They were consoling my mother by saying: "Look, it is right there. Doctors will open it with the grace of God" and my mother would agree with them with gratitude and say, "Amen, please God."

For the first time I sensed that a part of me was bad. A connection between my mind and that area had started. I stayed away from the adults and was scared of them for days. It was the spring of 1978.

Because I was physically stronger, I used to win all the games. My friends who could not stand this used to call me names. Kurdish nicknames one after another, nicknames that implied that I was both a boy and a girl, and words that described my genitals. I felt like I was going crazy. I

used to leave that cacophony, run home and tell my mother about it. My mother used to curse them and console me by saying “You are better than them” and she usually fought them.

When I was old enough to go to school, I learned what it means to be excluded. I learned to keep people at a distance and that was when I started to have conversations with myself. The new school year was about to begin, all of my peers’ school supplies were ready and they were showing them to me. I ran home from the square. My father, mother and brother were at home. I was panting heavily and I asked them when they were going to buy my school supplies. There was a silence for a while and then I barely heard my mother saying “Let’s let her go.” My father angrily told my mother, without even looking at me, “Stop growling. Children from three different villages will go to the same school, the child will come home with a new problem every single day, other children will not give them a rest. They will be harassed; should we be disgraced even more?” I remember my mother saying in response, “They should take a look at themselves. There is nothing wrong with my child.” My brother supported my father and defended the idea that I should not be sent to school. He looked at me with disgust and grumbled, “Get out! School is not allowed!” He pushed me, then slapped me so hard that I fell down. He had a say in it, after all his wedding was only a week later. He also warned me strictly, “While the teachers are passing through the village do not let them see you, hide. Or else I will trash you.” I had to say, “OK brother.” It was not only that. There were trucks that carried workers to the factory. I used to hide when I saw them as well because the truckers also used to call me with my famous nicknames. Every morning and every evening, those were the times that I used to die.

I did not give up, because I was smarter and stronger than all of them. My mother used to give me my food and I used to go to the pasture to graze our animals. There, I organized my peers. Everyday one of them was going to teach me whatever they learned at school. Behiye, Şevket, Satı, Fatma... First, all the letters, then the numbers and then I learned how to read. But this did not last long; all of them complained to their families about me. The parents turned up at our door and my mother struggled with the problem again.

I was the disgrace, the black sheep of the family in every way. But when the topic was money, they were not ashamed at all, especially my brother. He took me to the brick factory with him when I was 10. There, the warnings continued, “Do not talk to anyone. If someone says something tell us and do not beat anyone up.” Because I was tall and strong, they used to give me all kinds of tasks and I completed them all with success. People were not picking on me that much when I was working. I earned everyone’s respect because I was practical. We bought a TV and so I learned to speak Turkish very well. The personnel bus used to stop at the city center for three or four minutes and I used to get off to buy newspapers such as Güneş, Cumhuriyet, Bulvar, whichever I could find. Some people on the bus would laugh at that and some would admire me. All of them knew that I had not gone to school, but the ones who went could not read as well as I did. When my dear brother’s control became less effective, he made more aggressive decisions. He forbade me to buy newspapers. It was no big deal, I bought books. I kept reading everything I found.

This is what I experienced in the village until the age of 12. I hope I will also share the other phases of my life.

Country: Turkey





THEY TOLD MY PARENTS THAT I WAS A BOY THAT NEEDED TO BE “PERFECTED”

I was born in 1981, and when I was three weeks old the doctors noticed that there was something “wrong” with me, since I was not urinating in the right place. I had some tests, and they discovered an intersex “condition”. Apparently they gave my parents the option of performing a surgery, but there would be certain complications either way, however, they didn’t tell them it was an intersex condition. My parents went away and thought about it and when I was three months old I was transferred to another doctor, who told them: “they have to do the surgery,” my parents took me home and at some point on a Friday they were called up and told to bring me in on Sunday. We lived over an hour away from the hospital and my parents had no time at all to prepare themselves or me for the impending physical and emotional trauma. So I suffered my first surgery when I was three months old, which obviously I do not remember, but then I went through nine other surgeries, most of which I do remember.

Basically, until the age of 11 years, I spent my childhood going to the hospital more than every 18 months, undergoing surgeries, with catheters being put in me, tests being done on me. All the time I was poked at and had blood taken from me to check that everything was working “properly”, checking my hormones etc. I couldn’t control my bladder when my catheter was taken out and very often I was in physical pain, the trauma kept me awake at night, and even at 37 years old I still have trouble sleeping.

They told my parents that I was a boy that needed to be “perfected”, this is something my parents accepted, because there was no internet back then, and they were never introduced to any other parents whose children were going through the same thing, they were never told that I didn’t need fixing, that I would grow up to be just fine. So the doctors basically took away my childhood. I could not play with the other children at school because I had been undergoing surgeries in a delicate place and could be damaged, so I could not play sports with all the other boys. My parents decided to enrol me in dance classes, which I liked, and I am very grateful for that, because now I’m a good dancer, but, all these situations somehow gave me the message “you are not really a boy, you are not a girl either. You need to be corrected, you can not socialise with other boys, but you can’t play with the girls either because you’re a boy, you can’t show your body to anyone because you’re different”. I still don’t show my body to people and people take it for conservativeness or shyness. Everything that happened around me in my environment was telling me that I was not normal, that I had no place, that I had to hide this secret, I even had to hide that I danced!

When I was 11 years old, they said that I would not have any more surgeries until I developed at puberty and saw what happened, and although I had these variations in sexual characteristics, all that time I did not have information, I did not even know the name of my condition, my so-called “condition“. Nobody had ever told me I was intersex!

When I was 15 years old, I had a checkup, the first time my father had waited outside. He had always been present while the doctor and often students came to poke me and measure me, telling me how I look or don’t look, whether I’m becoming a real boy or not, checking to see if I was growing feminine characteristics, breasts, if I had body hair or not, to see if my voice was breaking etc etc. The man who had been my surgeon since I was three months old decided to check if I could produce sperm this time. I had no idea that he didn’t need to do this, that a simple test could be done, but this doctor decided to



do it manually. I had no idea that it was inappropriate, or that it was sexually motivated, as an intersex male I was used to having no privacy over the part of my body that everyone calls our “private parts”, they had never been private in my life, at the hospital it was a show for everyone to see, in my daily life it was a secret, my whole body was a shameful secret. How would I have ever known that a doctor shouldn’t be manually doing a sperm test on me?! When he had finished measuring me, in different physical states, had injected me with viagra and taken photos of me, he congratulated me, he told me that I was developing very well, that I was a “normal” boy, that I “wasn’t at the back of the queue when God was designing boys”. What he actually did was masturbate me and when he had his sample he looked under a microscope at my sperm, I felt happy that I could be normal. It happened again when I was 17 years old, he was shocked that I didn’t do those things myself at home, I was asexual, I never even thought about it, he told me that was part of my condition and I should practice, he showed me how to do it, and then he told me he could operate again just to correct those imperfections. I did not really understand, he did not tell me the real reason, that it was just aesthetic, he was trying to make my appearance like a “normal” guy.

After the surgery, and this molestation, for which I had no reference to know that it was molestation, I spent the last years of adolescence, and the beginning of my 20s, confused. I began to realise after I became a sexual person that what the doctor had done to me was sexual abuse. But he had told me it was a medical procedure, and as I was growing up I had become accustomed to being touched and checked, being tested, so I did not know what the limit was.

One day I turned on the television and saw that the doctor had been arrested, he was being tried for sexual abuse of underage patients, and I decided to go to the police and tell them that maybe I could help, to provide evidence, I needed answers and I wanted to know if what happened to me had been for medical reasons or not.

So I think that as an intersex person, I was subjected to this lack of control of my sexuality ... my first sexual experience was in a context in which my body was violated. This violence happens to intersex people a lot... I do not know an intersex person who did not have to go through this.

In fact, I did not meet another intersex person until I was 27 years old, and it happened in the court case. Incidentally the doctor was acquitted in the justice system, we were failed. But we took him to the General Medical Council, which found him guilty, and I have pages and pages of the report made by them that details each of the things we accused him of, and it states that they found him guilty, saying what he did was wholly sexually motivated, it was sexual abuse and he performed unnecessary medical procedures to further his career, his name is Aivar Bracka, he cannot practice anymore. He tried to go to the USA to continue practicing medicine, even knowing that he can not practice in the United Kingdom, but was found out, and the person who tried to hire him was sacked, he is a dangerous person.

I have been in situations where people ask me: "When was your first time?" and once I answered: "Do you mean consensual?" and everyone stares at me like: "do you really have to ask that?" and even I am shocked when I realise that yes, actually yes, I do have to ask that.

I remember when I was 17 or 18, and my mom asked me if I had to tell her something, and the first thing that came to my mind was: "I do not know what my gender is ... I'm not sure... I do not know how to call myself, and I do not know how to express myself." I was always very aware of my behaviour, whether it was masculine or not, sometimes they said things in high school, I do not know why, I never told anyone about my surgeries, I never told anyone that I was going to dance classes. I felt very pressured to behave like a boy, I came from a place where men have to be hyper-masculine, and the differences between men and women were very marked. My mum said everything was fine, but maybe [this pressure] had to do with the surgeries.

I never read my medical file until I was 23 years old, the first time I saw the diagrams I felt overwhelmed, and I still feel that way when I see them, I had things in my body that girls have,

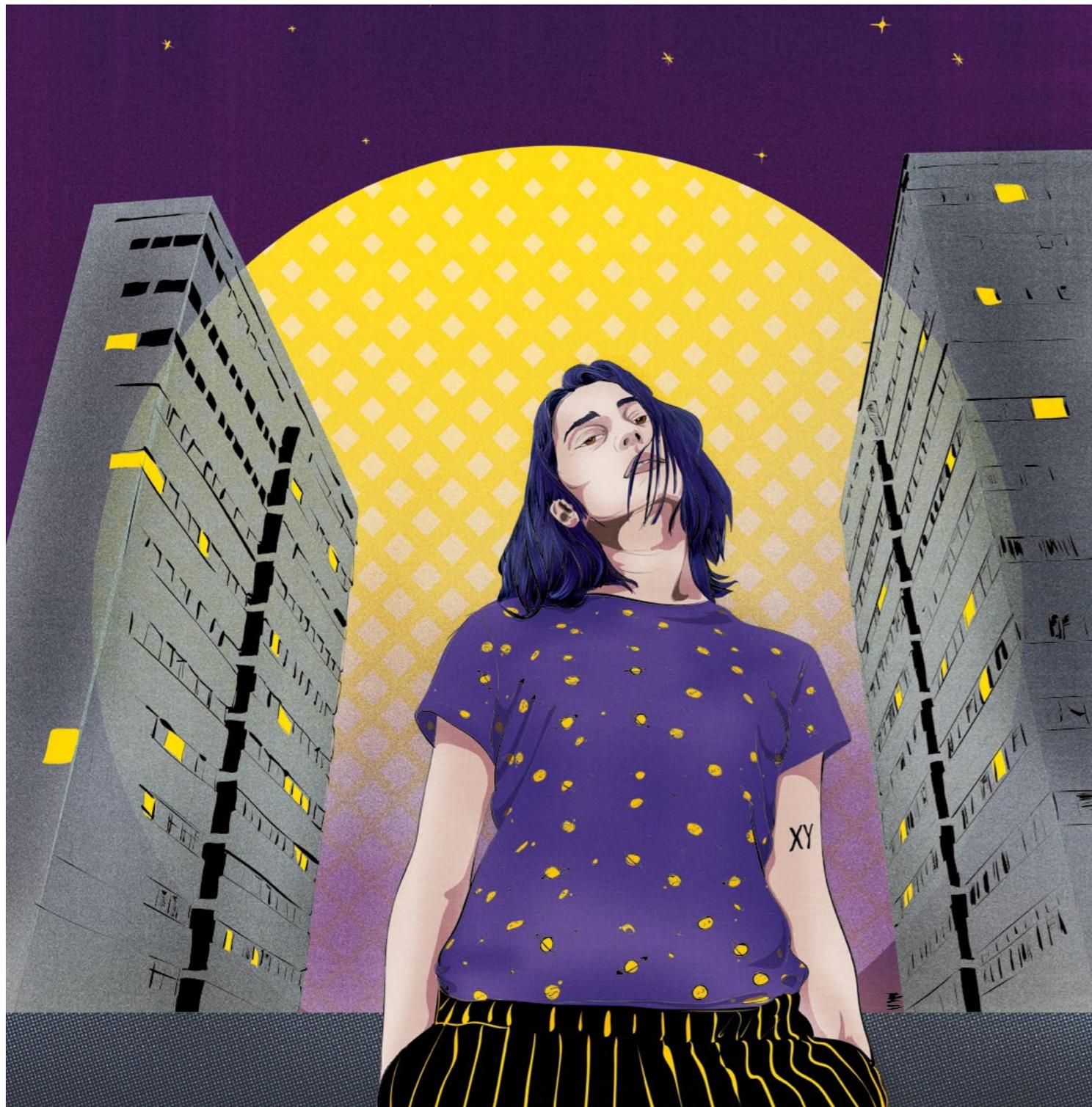
and I'm not supposed to have, and somehow it's scary, because they make us think: "You're a boy so you have a beard, you have to shave, you're a boy, your genitals say you're a boy, and you have to behave this way"... and seeing images of who I was as a baby, seeing that I had things there that boys do not have, and that even the male part of me was different, all this is shocking, because I don't know how I'd look now if I hadn't been changed. They call my condition a "mild intersexual condition" but it is not a condition, it's a difference, I fall within the spectrum that goes from the masculine to the feminine, I'm not in the middle of the spectrum, I look like a man now, but I will never know how I should look if I was left as nature intended.

As an adult, having gone through all those surgeries, the court case, fighting for justice, not giving up and being very aware of the need to monitor my mental health as a result, I do suffer from PTSD and I still question my gender, but I am now proud of who I am, I love myself and I love that I was made different. This makes me understand people who feel their body doesn't match who they are, mine doesn't match who I am, but I also love that about myself, it enables me to understand spirituality, and to not identify only with the physical. I am proud to say I am intersex.

My view of the world has changed a lot since I started learning about myself, loving myself and calling myself what I actually am, an intersex person. But the message is clear, children should not have to suffer because of some backward old-fashioned idea of sex, nature is not binary, we are not only masculine and feminine, and the idea that we can force people into these boxes results in actual physical and emotional violence. Let's start loving people who just don't fit those boxes, because this isn't some "leftie" political ideology, this is the actual human body, your binary gender ideas are the real harmful ideologies. Let's put an end to IGM (intersex genital mutilation)!

Country: UK





EDUCATION IS A DIFFICULT ISSUE

In the UK I know intersex people who are terrified of making even that step, even though they know they need help to cope with their trauma. I know two AIS women who are simply frozen with fear that anyone would discover they are somehow not proper women. It really is desperately sad. The provision for psychological support is woefully underfunded.

I cannot honestly tell you where else in the UK there are specialist clinical psychologists who are familiar with intersex, who will see adults. What few I do know of work in pediatrics, and have quite a different remit.

Education is a difficult issue. I never went to university. I was supposed to but the catastrophic catalogue of events in the summer before (including septicaemia from an infected neo-vaginoplasty) meant I never made it. I was 17 years old at the time. That summer change my life forever. I do know one or two intersex women who have successfully gone to university and secured successful employment – mostly in computer or engineering-related work, funnily enough. Neither of them were out as intersex during those years, and are only out to a very few close and trusted friends, which is how I know. Of the rest its desperately difficult to say because they only rarely contact the group – either on facebook or via the website. Some live quietly productive lives, and others struggle to overcome the effects of what was said and done in their childhood.

On the subject of abuse in the medical environment: AIS-women tell of being repeatedly contacted to attend a pap/smear test. That is a test to check for the possibility of cervical cancer. I have attended appointments for exactly the same only to be told by a nurse that they don't do that for trans people like you – solely on the evidence of the external scarring from the multiple genital surgeries I have endured. It is very wearying to have to repeatedly retell why I have such mutilated genitalia. It is both upsetting, because the look for disbelief is palpable, and I really shouldn't have to keep doing it. The deep scarring also means it is actually very difficult to do the process properly because of the severe introitus and scarring the operations have left me with. Stories of bouts of depression, and PTSD-like trauma feature in people's personal stories. A significant number of intersex adults I know drink quite a lot.

There is the continuing issue of withheld medical records. I made extensive enquiries with Gt Ormond Street: At first they denied ever having heard of me! After we had cleared up that, it turned out, after determined/repeated questioning that my records had been archived in 2011! Yet GOSH seemed unable/unwilling to say where exactly they were now. I still do not have my full paediatric records, only fragments, as I have already said. I do not think this a coincidence. I do believe that as someone who was 'processed' in the 1960/70's I am one of those first generation cohort that dox used as their foundation for what is commonplace today. Dox know they were making it up as they went along: They are simply unwilling to face up to the appalling consequences of using live human beings as whole life experiments, with all that that can mean.

That is all too common. I do not have my complete paediatric records, only fragments.

How much of this has changed in more recent years is open to question. It is very dependent on which doctor you have. A few are very good – like my current endo. Most are dreadful and treat us as pieces of meat, as freaks. None of them will use the word intersex, even if it's



written in the records. The question of the language used is also one worth raising. Clinicians who work in intersex medicine will use the terms intersex/DSD interchangeably. Outside of the rarefied atmosphere of intersex medicine, I never hear the term DSD, and my GP detests the term and will not use it in correspondence.

Intersex people trust me because I am intersex, and I promise to keep their confidences. It is a Catch-22 – they dearly want to see a world in which being intersex is valid and accepted, but they are too afraid to speak themselves. They are the same people who most need the support they are so clearly not getting. That is a direct effect of keeping intersex within a closed, specialist environment rather than training district nurses in local medical clinics to help address the lived experiences of intersex people in day-to-life.

Country: UK



BEING INTERSEX IN RUSSIA

At 14 years old I still hadn't experienced puberty except for some signs of very high testosterone levels. During my first ultrasound my doctors at the time in Ukraine found that both my gonads (or "ovaries" as they perceived them) looked not like they expected, both gonads were missing the follicular apparatus and my right gonad was "in a thick capsule". Despite my gonads not looking like typical ovaries and instead of doing more tests and figuring out what my gonads exactly were, doctors just kept perceiving my gonads as ovaries and said that they would make them work. And of course I never actually had ovaries.

I was sent to these sessions where they would put electrodes on my belly and I would lie there for 30 minutes while the electrodes warmed up my "ovaries" to stimulate them. I have never heard of anybody else undergoing such procedure, it must've been some local "invention". After a couple of months of these session there were no results and still no puberty, but later that year I ended up with appendicitis and had to have surgery for it, and I suspect it was triggered by these sessions.

Since doctors in Ukraine couldn't figure out what was happening to me, I went to doctors in Moscow, who did all the tests but never told me the results, they never talked to me at all. I was always left waiting in the corridor while my father was invited into their office to speak with them. He never told me the truth either, I was given a typical "ovary cancer scare" explanation and told I need to have one or several surgeries.

I had my gonadectomy at the age of 15, while having very little understanding on what surgery I'm getting, nobody told me they would remove my gonads completely. By Russian law a child

has to give full informed consent to any medical intervention since the age of 15. I was 15 and nobody asked for my consent. Now, years since my surgeries I'm still sometimes experiencing pain because of abdominal adhesions caused by my surgeries.

Not knowing the truth about my body and treatment I received impacted me heavily over the years, with me developing lots of shame and self-hatred caused by me feeling "not female enough" and me not understanding why my body's different. I still have to deal with a lot of issues I developed during those years, and I always will.

Over the years I was never given an explanation on why my breasts didn't grow even after years of taking estrogen, the only advice I was given was to "eat more".

Because of my intersex variation I was born with a chest deformity called pectus excavatum. None of the doctors I've visited through the years connected it to my intersex variation, I found out that connection years later by myself on the internet.

My doctors were always very scared that I wouldn't identify as a heterosexual female, for them it was the most important thing. I never understood that fear since I didn't know that I was intersex. When once during a checkup I told my doctors that I felt self-conscious and "not a girl enough" because of lack of breasts growth, and it really scared the doctors, who started interrogating me about my sexual orientation and gender identity, implying that liking boys automatically meant identifying as female. The therapist I was seeing when I was 20 ignored me saying that I was questioning my SOGI (sexual orientation and gender identity), always implying that I'm a girl who eventually will get a boyfriend.

When I finally discovered that my father purposefully kept the truth about my body from me for 7 years, he said that he was following advice given to him by two different child psychologists, who both told him not to tell me the truth.

Discovering the truth about my body was the best thing in my life, the most empowering thing. For the first time in my life I knew I wasn't alone, I finally felt normal, I finally felt confident. But still I'll never be the person that I could've been if I would've known the truth from the very beginning.

Recently my doctor for some reason decided to send me to another doctor, who turned out to be one of the doctors that treated me back when I was 15. When I said that I won't go to them because they ruined my life by keeping everything secret from me, she started defending them and their actions. But now I know my rights and I didn't back down, I kept arguing with her until she had no arguments. Now I would have to find a new doctor myself, and it's not an easy task.

Age: 26

Country: Russia





I AS A PARENT MADE CHOICES THAT SHOULD NOT HAVE BEEN MINE TO MAKE

In 1982 I gave birth to a beautiful healthy baby girl in Landsspítalinn Reykjavík. I took the baby home but few weeks later it was discovered that she had a hernia and an operation was scheduled. I was told that the operation would not take long but after about three hours I started to ask questions but nobody seemed to know anything, the information I got was that she had been sent into surgery at scheduled time and the staff seemed surprised that the operation took so long. When I finally got to see her I asked why the operation took so long, I did not really get any answer.

I had a very strange meeting with the surgeon before we went home, but put it down to bad people skills. The only thing he said was the operation went well, that the stitches would dissolve and I did not need to bring her in for a check up.

The stitches did not dissolve, the wound got infected and I had regular visits to the children's ward. During those visits I started to get strange feeling that something was wrong. Finally one doctor sat me down told me that my baby had a very rare chromosomal disorder, they did not really know much about it but there was a doctor that had been specialising in USA arriving shortly and he would explain everything. I went home and waited.

Finally the doctor came, and as kindly as he could, he explained this so called chromosomal disorder, told me she had undeveloped gonads that would need to be removed due to cancer risk and they advised to do it before the age of 2. He stressed at all times that she was a girl in any respect, she would get a hormonal treatment to help her through puberty and could live a healthy live with a hormonal treatment and the only thing she could not do was give a birth to a child. But he also stressed that I should keep this a secret, not to tell my daughter

till she started her treatment as the information would be too much and she would not be able to keep the secret when she was young. He also stressed that I should not even tell my closest family.

My daughter had a recurring hernia, at three months she had another operation and during that the so-called undeveloped gonads were removed.

2005, years later when we went to a meeting in a support group in the UK, I found out that what was removed were functional testes that would have given her all the hormones to lead a healthy life, and the cancer risk was based on research that was not applicable to her condition. I also found out that the statement of my baby living a healthy life with substitute hormones was not true.

So, the operation that I had allowed in the belief that it would be the only choice to secure a healthy life for my daughter, actually ruined her health. On top of that I had kept this a secret from my daughter, and her trust in me was completely broken when I finally told her. I learned that secrecy is the mother of shame.

I am not saying that the health profession were doing this out of anything but with the best intentions at the time. But 1996 when my niece was born with the same condition, the same procedures started, nothing had changed, operation at the age of a few weeks, no problem they said, artificial hormonal treatment will ensure healthy living.

At that time a change had started in treatment and the advice was to leave the removal of testes or what was always referred to as undeveloped gonads till after puberty. If that had been done then we would have had the knowledge when my niece reached puberty that there is absolutely no reason for this operation.

We as a family had at least learned from my mistake in keeping secrets and my niece knew from a very young age that she was intersex.

We went to an another support group meeting in the UK in 2012, at that meeting we spoke to a doctor from University College London Hospital, and got confirmation that the health problems both my daughter and niece were having were due to early medical intervention and mismanagement of hormonal treatments.

When we started to ask questions and criticize the medical care we hit a brick wall and at that time there was no good intentions or compassion. Finally, we complained to the Directorate of Health, just to get a doctor assigned to my niece as she, at the age of 18, had been diagnosed with osteopenia.

We are still fighting, both for better health care but also for the future intersex children.

I as a parent made choices that should not have been mine to make and most definitely not the doctors to make, I firmly believe that the intersex individual should be the only one allowed to make choices regarding their own body, there must be an end to unnecessary medical treatment and surgery of intersex individuals without their consent. We as parents should not have the right to give this consent.

Country: Iceland





WHY DID THIS HAPPEN TO ME, DAD?

I remember asking this innocent question to my dad, sitting in a wheelchair in the parking lot of the hospital, after my first vaginoplasty. I was 8. My body was still sore from the operation and my mind and soul forever changed. I remember getting ready for an operation, which was barely ever done before. I was a rare case, was I told.

I remember the taste of the gallon of laxative I was forced to drink for my intestine to be clean, the smell of the strawberry balm they put under my nose before anesthesia and I remember the burning pain when I went to the toilet.

The question I have asked my worried father did not need an answer. Missing school on the regular for weekly check-ups and a never-ending burning sensation when I would go to the toilet.

As I was a rare case, I had to see different doctors who wanted to see parts I did not want to show, know things I did not want to tell any grown-up man (or woman for that matter...) and I saw fear and questioning in the loving, sometimes teary, eyes of my parents. I had a malformation in my tummy, was I told.

I grew up believing I was the only one living this and that no one would ever understand... I came to believe I was lucky because my disorder was not visible, no one would ever have to know. It could be worse, I could have had only one leg...

With lots of self-reinforcement, I came to forget what happened and believing these were “just” nightmares. Until the day I met the first intersex person. It was love at first sight. Their words were like mirrors to my soul. We became friends, with high levels of complicity, care and attention.

Yet, at first, it was scary. I was in a vulnerable situation, taking lifelong secrecy and shame away, peel after peel... Like an onion. With the help of the intersex community, I then realized why this happened to me and the force of my question when I was 8. “Why did this happen to me?”.

This happened to me because society wanted it to happen. Bodies that do not conform to societal standards of “normality” have to be corrected, surgically and/or hormonally. In order for this pseudo-normality to stay untouched, we all are rare cases. Keeping us apart, ashamed and in ignorance. Maybe ignorance is not bliss, after all.

It is important to create a movement, today, so that next generations do not have to go through the same “intersex adventure”. For past, present and future generation to express themselves and make our existence as worthy as anyone else’s.

Age: 25

Country: Switzerland





HIDING IN A SMALL SPACE BEHIND MY EYES

I was not detected as intersex at birth but was considered to be a girl and was assigned as such. My childhood was rather happy and uneventful, being an androgynous and tomboyish girl living in the colorful 1970's, until my grandmother, who raised me, developed lung cancer and died when I was 12. With the beginning of my puberty bodily changes began to develop in a masculine way. I began to grow taller than the other girls (I was already over 180cm when 14 years old), my voice dropped, body hair appeared, including beard growth which I tried to hide under my long hair, but eventually began to secretly shave every morning before school. My clitoris grew and could arouse. There was almost no breast development. At first these changes seemed interesting to me until I came to realise that no other girl underwent such changes and was often called or mistaken for a "boy" in public. Also bullying began in school due to looking different from the other youths. I was trying to hide those changes (wearing long sleeves and trousers during summer time to cover up arms and legs, wearing sport clothing underneath to prevent to undress in changing rooms).

I waited for a menstruation that never appeared, then with the age of 17 decided to consult a gynaecologist. The doctor told me that I should have become a boy and that I could never become pregnant due to a missing uterus, and referred me to specialists for further check-up.

At the human-genetic institute I was informed by the specialists with what later in life turned out to be deliberate misleading and false information about “cancerous ovaries” to persuade me to the removal of the gonads (gonadectomy). Without much explanation I was then asked to undress and stand in front of a medical grid for medical photos, arms spread out to the sides, the insides of my hands facing the camera. At this point I felt overwhelmed with the information of being seriously ill and therefore was unable to refuse this request. The shame and helplessness of being naked and photographed forced me to imagine myself out of my body, hiding in a small space behind my eyes.

The evening before the surgery to remove the “inflamed ovaries” the doctor and chief of the department of the hospital examined me on a gynaecologist chair, recommending to also remove the “enlarged” clitoris, which was bothersome to being a woman. I declined. The doctor insisted, so I asked if there was a cancer risk if the clitoris is not removed to which the doctor replied “no”. I declined a second time which then was accepted by the doctor with a mention that this can also be done a later date (at that time I was 18 years old which is the age of majority in Germany).

Hormone replacement therapy (HRT) with oestrogen began after the surgery, it was not clearly explained to me that this would now be required for the rest of my life because of health risks. Due to the HRT my body began to develop more feminine features and I tried to live and pass as a woman. Each time at the yearly check-up with the gynaecologist I was offered to have the clitoris removed or reduced, which I always declined.

Rather by chance I found out about the term intersex and personal testimonials of similar experiences through the internet and began to research what really happened, twelve years after the surgery, now age 29. I ordered copies of my medical records which clearly stated findings

of a 46,XY (“male”) karyotype, of benign and healthy abdominal testes and further medical but also other details, for example in conversation to the transferring doctor the instruction to never tell me the truth about my intersex status in order to protect me from psychological distress.

The same year I stopped my HRT and a few years later switched to the HRT with testosterone to simulate my original hormonal balance. The process to come to terms with the experiences and facts took many years, and when I considered to seek legal measures to sue the hospital and doctors for their mistreatment, the possibility of filing a court case had already expired. In 2015 I requested to have the gender marker of “female” changed to “blank” in my documents.

Because of these traumatic and violating experiences with doctors I am very reluctant to trust medical personal or seek medical assistance, even when needed.

Country: Germany





THIS WAS RAPE!

I was sterilised while I was still relatively young. My parents were told that if they did not consent I would probably get cancer and that the organs were useless tissue anyway. Of course they said yes. What parent would not. If I were in the same situation without any real information I probably would. I only found out when I was older that it was healthy and functional gonadal tissue. That is what my medical records said. They did not need to take them. I have needed to be on hormones since I was a teenager.

The hormones my doctor chose for me meant I needed to come to the hospital regularly to have them administered. One day I came to the hospital and was told my doctor was sick and would be off work for a while. I was already feeling the symptoms of the menopause. No other doctor at the hospital would see me. I started calling every gynaecologist I could find in the phone book. Nobody would see me after I told them why I needed to see them, except one.

I came in and explained why I needed these hormones and he agreed to give me them.

He made me completely undress and lay under a sheet with my legs up in stirrups. My doctor never did that, I could just lay on a bench with my clothes on and expose the area needed. I was confused.

He put his hands on my butt and pulled me further down on the bench. He administered the hormones and they really hurt, a lot. I cried. It had never hurt before. He examined my genitals, his face was very close, I could feel his breathing on my genitals. My doctor never did that, even the one time I had needed a genital examination. I started panicking. I was frozen and could not move, it was hard to breathe and I started seeing black spots. Then he stuck his fingers inside of me and moved them back and forth. He asked me if I felt it, if I liked it... His smile was very creepy. I could not answer. I could not breathe. He stood up and told me to get up and get dressed. Then I had to pay him. It took me many years to realise that this was rape. No one ever talked about rape where I lived except about violent strangers that attacked women and forcibly and violently held them to rape them, rape always involved a penis. It was not until I met feminist groups later in my life that I realised that THIS WAS RAPE and I had paid someone after they raped me.

I still can not talk about it. I might never be able to.

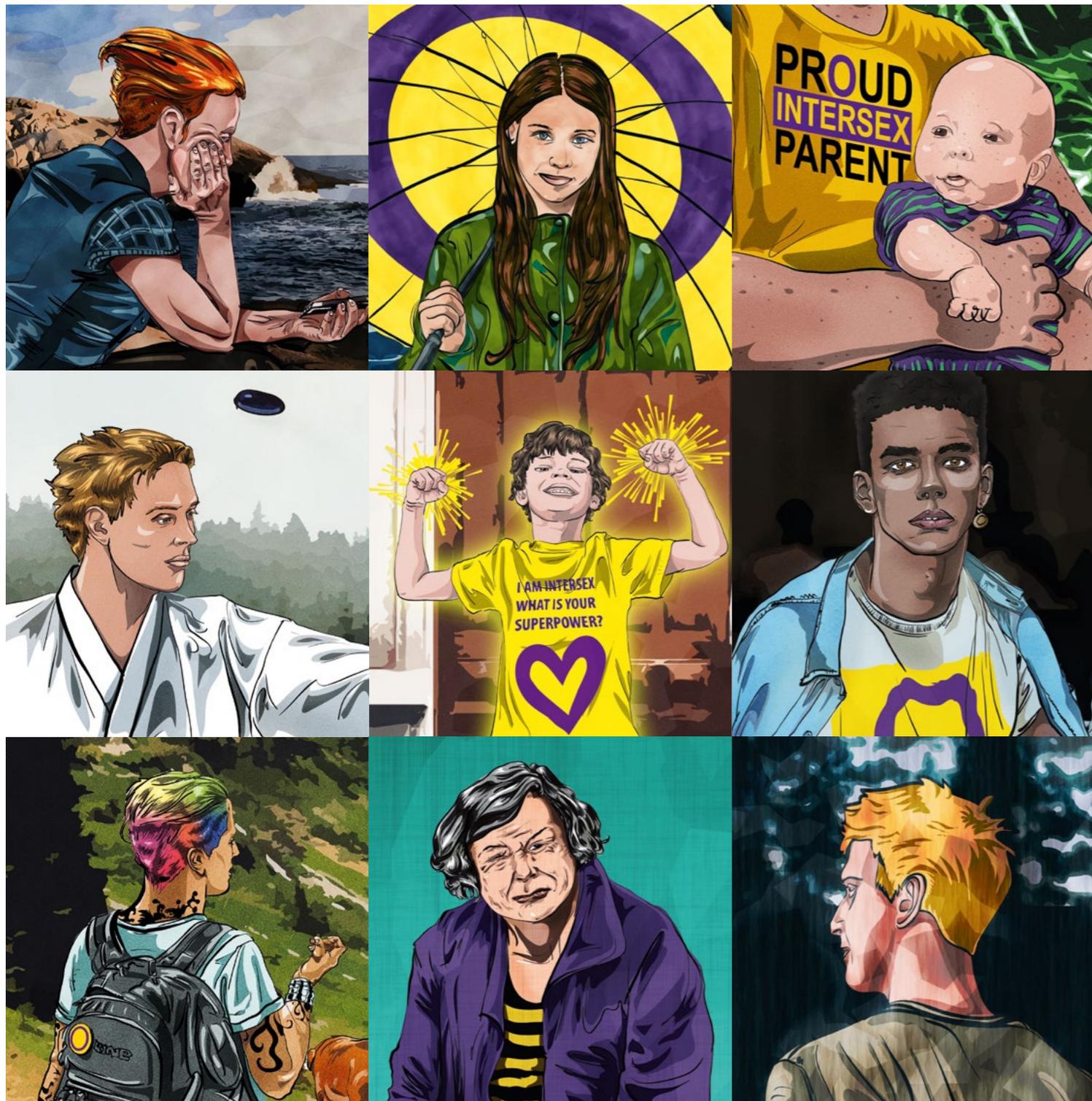




I HAVE A DREAM FOR FUTURE INTERSEX CHILDREN

Text by a parent of an intersex child

- When an intersex child is born it will be welcomed by all.
- The medical profession will stop looking at it as a medical emergency.
- The parents will get a support to be able to understand and support their child.
- The parent will have a chance to meet other parents.
- The child will have a chance to meet other intersex people.
- The people working in the health sector will be educated about intersex.
- Teachers from kindergarten and up will be educated about intersex.
- There will be no unnecessary medical treatment and surgery of intersex individuals without their fully informed consent.



“ON OUR OWN TERMS AND IN OUR OWN WORDS”: THE VALUE OF FIRST PERSON ACCOUNTS OF INTERSEX EXPERIENCE¹

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A long and broad tradition of disrupting status quo narratives

Testimonials or first person accounts have been in use for as long as claims to common human dignity and rights could be made. Its primary initiators have been individuals who have escaped the slave trade or slavery, bearers of experiences and perspectives that remained little known to dominant social groups and exploitative systems, though originating from them³. Ottobah Cuguano, Olaudah Equiano, Mary Prince, Frederick Douglas and others told their inconvenient truths at moments where the very societies who maintained slavery were envisioning themselves as beacons of civilisation driven by humanistic ideals.

¹ Warm thanks to Dan Christian Ghattas and Ins A Kromminga for their very helpful comments on this text.

² Culture du témoignage/Testimonial Cultures has a web address: <http://www.culturesdutemoignage.ca/> The Réseau francophone de recherche sur l'intersexuation (Francophone network of Intersex Research) is a newly founded group that aims at conducting respectful research on intersex experiences.

³ I understand the concept of “domination” in the way the political philosopher Iris Marion Young (2000) defines it, that is, institutional constraints on self-determination: “Persons live within structures of domination if other persons or groups can determine without reciprocation the conditions of their actions, either directly or by virtue of the structural consequences of their actions”. (p. 32). It is not bound to a tyrannical intent, as is often understood. I also follow her definition of oppression, which she defines as institutional constraints on self-development: “Just social institutions provide conditions for all persons to learn and use satisfying and expansive skills in socially recognized settings, and enable them to play and communicate with others or express their feelings and perspectives on social life in contexts where others can listen” (p. 31-32). She posits self-determination and self-development as the two essential principles of social justice.

Furthermore, as Frederick Douglas underscores, those who most benefited from this system had laid claim to the innermost feelings of racialized people toiling under slavery, reporting contentedness and satisfaction where there were none while simultaneously dismissing and cruelly punishing dissenting voices. Telling one's story on one's own terms and with one's own words was a courageous act of defiance that had the potential to chisel away at the denial and justification narratives that were meant to reduce the deep cognitive dissonance at work among the main beneficiaries of slavery in particular, and among their societies in general. Answering A.C.C Thompson's rebuttal of his testimony – a common occurrence Frederick Douglass (1846/1997) and other survivors of slavery had to face –, he says:

You next deny the existence of such cruelty in Maryland as I reveal in my narrative; and ask, with truly marvellous simplicity, 'could it be possible that charitable, feeling men could murder human beings with as little remorse as the narrative of this infamous libeller would make us believe (...)?' 'No you say, it is impossible.' I am not to determine what charitable, feeling men can do; but to show what Maryland slaveholders actually do, their charitable feeling is to be determined by their deeds, and not their deeds by their charitable feelings. The cowskin makes as deep a gash in my flesh, when wielded by a professed saint, as it does when wielded by an open sinner (p. 94-95)

Members of other social groups have also taken to tell their stories and use first person accounts at increasing rates over the last few decades: Survivors of concentration camps or genocide, refugees, women who were subjected to sexual assault, gay, lesbian, bisexual or queer people, trans people, people who have been institutionalized or live with mental health challenges, indigenous people who were forcibly removed from their families and sent to residential schools where they were subjected to violence as part of genocidal practices and policies, people living with hiv/aids, people living with disabilities, children of immigrants, sex workers, parents of gay, lesbian, bisexual, queer or trans people⁴. And lastly but not least, intersex people.

Telling one's story can take many forms. It can be woven into works of fiction or structured around an "I". It can be expressed through literature, theater, performances, film, dance, visual or other media, the most common being written texts or audiovisual recordings. It may

be shared in books, in blogs, in zines, in newspapers, in magazines, in television programs, in audiovisual social media platforms, in documentaries, or at institutional hearings. It can take on many names, like first person accounts, testimonials, testimony, personal stories, personal narratives, telling one's story, etc. We can understand each of them as declensions of a basically similar practice, or as distinct acts. And telling one's story can be shaped into different formats depending on the kind of access one has to media outlets or communication tools, on control over topic and theme selection, as well as on possible length. Content will vary accordingly, as focus, emphasis and depth produced by an author may either remain as it is or be modified by external constraints, preferences or priorities. When modified, it may either be made clearer or less nuanced, it can keep focus on what is important to the person who tells their story, or shift it in such a way that it gives inaccurate impressions. As concrete examples, first-person accounts can be published in books with either little or much editing requests. Journalists, documentarists or researchers can orient content depending on the questions they want to ask or the excerpts they select from testimonials. Some persons may develop their stories unmediated and live in front

of an audience, but still have to decide what to include and exclude in the given time they are allowed.

No matter the diversity of forms, formats and designation, the activity of sharing experiential aspects of one's life generates interest and interrogations. Scholars, legislative actors, the judiciary, the media, practitioners and lay people wonder what worth can be lent them in terms of validity or "truth", and in terms of representativeness. In academia, first person accounts are investigated from a wider set of angles, some exploring the conditions that allowed for their emergence or nurtured them, the role they can play in how one defines oneself and is defined by collective narratives, the evolution of first person accounts respective one's own changing perspectives on past experience, the possibility of inter-intelligibility and the interplay of interpretation filters, the relevance or not, for social actors, to use first person accounts to aim for social change, the many collective reflections and actions surrounding delivery of testimonials. This is bound with much theorizing around the challenges and the meanings of being "out", as going out and sharing one's story, unless done anonymously, implies self-disclosure.

⁴ Examples of testimonial activity and study are: Primo Levi. (1947). *Se questo è un uomo* [If this is a man]. Torino: F. De Silva, coll. "Biblioteca Leone Ginzburg" n. 3, 1 ed.; Truth and Reconciliation Commission of Canada (2015). *The Survivors Speak: A Report of the Truth and Reconciliation Commission of Canada*; Ken Plummer. (1995). *Telling Sexual Stories: Power, Change and Social Worlds*. London: Routledge; Maria Nengeh Mensah (ed). (2017). *Le témoignage sexuel et intime, un levier de changement social?* Québec : Presses de l'Université du Québec; Liz Miller, Michele Luchs and Gracia Dyer Jalea. (2011). *Mapping Memories: participatory media, place-based stories and refugee youth*. Centre for Oral History and Digital Storytelling, Concordia University. Marquis Book Printing Inc. Using the concept of genocide to refer to what indigenous people living in what is now Canada have been subjected to may come as a shock to some readers, but it complies with criteria of the UN Genocide Convention. See: National Inquiry into Missing and Murdered Indigenous Women and Girls. (2019). *A Legal Analysis of Genocide. Supplementary Report of the National Inquiry into Missing and Murdered Indigenous Women and Girls*. URL: https://www.mmiwg-ffada.ca/wp-content/uploads/2019/06/Supplementary-Report_Genocide.pdf

Since the inception of intersex activism, first person accounts are taking center stage⁵. Intersex people must make their existence and the treatment they are subjected to known to a wider audience. Their goal has been to change medical practice and secure the respect of human rights to self-determination of intersex people. While they first tried to reach out to medical practitioners, unsuccessful attempts at changing ways intersex people are treated has led to reaching out to human rights specialists and legislators (Carpenter, 2016). Each have different outlooks on first person accounts and value them differently. Medical practitioners mainly invalidate them as “anecdotal”, human rights specialists considers each instance as relevant when examining human rights violations, and legislators often hesitate between medical authority and human rights obligations⁶.

This text centers on examining the value of intersex first person accounts by looking into what they require to come into being, how they are constituted and evolve through time, what role first person accounts can play in decision making and how one can determine their validity in comparison to mainstream

knowledge production processes, what reactions intersex first person accounts meet when mobilized for medical practice change, and what relevance there is in prioritizing a human rights lens to analyse them.

This text will mainly use “first person accounts”, but also synonyms for the sake of avoiding repetition, even though synonyms do not refer to the very same activity. In all cases, it will refer to this activity where intersex people publicly share, in their own words, the lived experiences of having their bodies invalidated by the medical institution.

First person accounts as personal journeys

Telling one’s story is no simple act. It is part of a personal journey of exiting isolation and succeeding in finding others who underwent similar experiences, of finding or fighting for opportunities to share first impressions, thoughts and questions with these others, of making sense of incongruities and double standards in treatment, of being on a quest for words and meaning that dominant culture does not provide, of finding ways to challenge interiorized stigma, of probing one’s inner

self on the need or not to share one’s story, of weighing potential benefits and risks of this sharing, of readying oneself emotionally for delivering one’s story publicly, of reflecting on how to express it in ways people will comprehend, of anticipating possible reactions, of plunging in and potentially reliving trauma, or witnessing reactions of disbelief, of anger, or empathy and solidarity, of processing these emotions with or without support. And once someone has their first experience of sharing their story, this journey continues as they reflect on how it went, reevaluate commitment to sharing stories, and envision adjustments for future opportunities if they decide to go on.

Doing testimonials thus implies emotional, intellectual, interpersonal, and reflexive labor. A substantial part of emotional and intellectual labor are those many-faceted processes requiring production and imparting of meaning. They originate with sometimes long-lived dissonance between what one actually feels and what one is expected to feel in response to some life experiences or social dynamics, with the failure to be treated by the standards that are cast or implied as central in one’s society, or with the absence of language and explanation frames in which one could set some of one’s lived experiences. The more marginalized and stigmatized people are, the more their lived experiences lay beyond society’s cultural repertoire and reach into the realm of taboo. They are not reflected in the

references and cultural productions they are surrounded with when growing up and going through life. And if their social group is referred to, it is underrepresented and stereotyped. In comparison, members of dominant groups are exposed to, and easily access language, concepts, and cultural productions reflecting, legitimizing, celebrating, and giving meaning to wide dimensions of their lives. But they, too, will be little aware of and scarcely understand marginalized people’s lives, as they will often content themselves with their assumptions. This phenomenon has been conceptualized as hermeneutical injustice by the political philosopher Miranda Fricker (2007), by which she means: “(...) when a gap in collective interpretative resources puts someone at an unfair advantage when it comes to making sense of their social experiences” (p. 1).

This gap is itself the result of socio-economic marginalization, which impairs access to collective social meaning production. Institutions, industries and professions producing collective meaning, like media and journalism, politics, academics, medicine, law, and cultural industries, are disproportionately occupied by members of dominant groups, who disseminate their situated perceptions of the world. They will not fill in the gap and reduce hermeneutical injustice by themselves even when they initiate research on marginalized groups. They will tend to investigate what it is that they consider relevant for themselves within the lives

⁵ The emergence of the intersex movement has witnessed a profusion of first person accounts. Notable examples in the United States, where it first started, are the Intersex Society of North America (ISNA) bulletin *Hermaphrodites with Attitude*, the documentary *Hermaphrodites Speak*, Alice Dreger. (1999). *Intersex in the age of ethics*, Univ Pub Group. In Germany, Elisa Barth, Ben Böttger, Dan Christian Ghattas, Elisa Schneider (ed.). (2013). *Inter: Erfahrungen intergeschlechtlicher Menschen in der Welt der zwei Geschlechter*. Berlin: nono Verlag. In France, the recent work of intersex scholar and activist Loé Petit has collected many testimonials: Loé Petit. (2018). *De l’objet médical au sujet politique: Récits de vie de personnes intersexes*. Université Paris 8. In the Spanish speaking world, Mauro Cabral (Ed.). (2009). *Interdicciones. Escrituras de la intersexualidad en castellano*. Córdoba (Argentina).

⁶ Examples of this hesitation can be observed in the current attempt at protecting intersex people’s bodily integrity with the bill SB201 in California, or in France during the adoption of the new Bioethics law.

of marginalized people, or project their own sensitivities unto marginalized people and make assumptions over what aspects that are crucial to them. Art, literature and movie classics, mass culture, mainstream history, school curricula still reflects and expresses dominant groups' perspectives, although growing inclusivity is nibbling away at overrepresentation. Offsetting hermeneutical injustice requires proportional access of marginalized people and participation to social meaning production, a revision of appreciation standards and correctives to mechanisms of dissemination and cultural products selection.

Fricker (2007) illustrates this point with several examples, among them women's experience of sexual harassment at a time when dominant culture, overwhelmingly produced by men, framed it as "flirting". Before collective consciousness raising between women, hermeneutical marginalization experienced by individual women would cognitively disable them:

(...) the harassee's cognitive disablement is seriously disadvantageous to her. [It] prevents her from understanding (...) a patch of experience which is strongly in her interests to understand, for without that understanding she is left deeply troubled, confused, and isolated, not to mention vulnerable to continued harassment. Her hermeneutical disadvantage renders her unable to make sense of her ongoing mistreatment, and this in turn prevents her from protesting it, let alone securing effective measures to stop it. (Fricker, 2007, p. 151)

With women increasingly accessing institutions, industries and professions where cultural meaning is produced, they could promote the concept of sexual harassment. Though met with resistance, more women could have access to it, better understand upsetting experiences, and mobilize to challenge them. Today, prohibition of sexual harassment as been made into law in many countries.

The struggle to find meaning can be more acute when people are subjected to exceptional and extreme violence and injustice. Carolin Emcke (2015) explores this situation in her book "Weil es sagbar ist [Because we can speak]", where people who have experienced systematized rape, other acts of torture and/or concentration camps, for example, first wrestle with how they can reconcile their previous life of normalcy with an unforeseeable breach of the social contract⁷. They feel overwhelmed, distraught, conflicted, and lost while the formal political and institutional ethics

they grew up among offers them no frame to name, explain or justify their experience. They have to fight for meaning, for words, as much as for connection with the dignity they once had:

⁷ I am much grateful to fellow intersex activist Ev Blaine Matthigack for introducing me to Carolin Emcke's work, which has provided me deeper insights into testimonials.

Beyond seeming impossible to delimit and describe, some experiences do not even seem possible to comprehend. (...) And the experience seems disconnected from everything that ought to happen. It does not fit with one's moral expectations, what ought to exist and who others ought to be. The rupture of civilization that a wrong induces spans over various layers, shatters twofold: the victim's relationship to herself, and their relationship to the world (p. 14-15 [translation by Janik Bastien Charlebois])

Imparting of meaning is a subsequent challenge. As Emcke and Fricker underline, one may fear they will not be understood or believed. Exceptional treatment and lack of words work in conjunction to make the violence experienced unintelligible. People subjected to it anticipate that people who were spared that experience have no frame of reference to understand it, since words seem neither adequate nor strong enough to appropriately convey what was lived:

And the experiences do not seem communicable to others, because they separate those who suffer through them from those who have been spared. Each narrative seems too short in the face of horror, too thin to bear the burden of the whole experience (p. 15 [translation by Ins A Kromminga])

Even non-extreme violence, though by no way equivalent to the violence examined by Emcke, can be hard to describe. This is especially the case with low-key but pervasive and relentless dehumanization and slights conceptualized as micro-aggression (Sue et al., 2007). Many women struggle with how they can adequately portray how subtle sexual harassment gestures can also weigh heavily on their lives, as are requests to

smile or sexual flattery drawing on reciprocity norms to compel responses harassers deem satisfactory. Women are well aware that requests for smiling, even when recurrent and solely directed at them, are not part of the cultural repertoire of what counts as violence, as much as they know that it is hard to go against norms requesting to "be nice" to people who "are nice" to us, or give back to people who present us "gifts", even when this "reciprocity" is imposed and negates consent.

A second substantial part of emotional, intellectual, interpersonal, and reflexive labor of people delivering first person accounts is making oneself vulnerable by opening up on intimate or taboo aspects of their lives which have long been used as levers for discrimination or violence.

Overcoming internalized shame or the idea that one is not "human enough" can be a long battle and steal the courage one needs to go ahead and openly share one's story. This shame is not an abstract concept to be reasoned away, but an occasionally overpowering emotion engulfing oneself without any external prompting. Moreover, one may struggle with anticipated setbacks of sharing traumatic or deeply hurtful dimensions of their lives, as it requires to revisit

them. And finally, one may fear to have their feelings and experiences ignored, disbelieved, judged, minimized, or interpreted around.

A trail of negative experiences, mainly in the media, may inhibit further sharing. If persons nonetheless want to share their stories, they will reflect on what events, feelings, thoughts to tell or not to tell, what should be stressed and what could be considered facultative, what words to select that most successfully promote understanding. They will also attempt to identify and avoid those words that repeat the dominant perspectives and bolster the very system responsible for the discrimination, unjust treatment, or human rights violations which they suffer from. This is work that is most often done collectively, with others who share similar experiences.

As medical professionals acquired complete control over intersex management through the medicalization of birth and judicial deference, intersex people have not only been scarred physically and psychologically, but also deeply impacted by hermeneutical injustice. First, the tangible existence of their intersex variation has totally been absent from their cultural repertoire. Second, most of them have had the characteristics of their birth bodies and the non-consensual interventions they were subjected to kept secret from them. They could only notice scars or odd clues among things

parents would let slip, and puzzle at incongruences between what interventions they were told they were subjected to and the actual changes their body exhibited. They would be struggling with their perception, since they had integrated the notion that medical professionals always tell the truth. Consequently, the very body of birth, medical discussions, written archives, or interpretation frames that could be subject to examination and reflection were inaccessible to the vast majority of them. Other persons with variations of sex development did know that their birth bodies did not conform to medical norms, but were told they were unique and had to keep their difference a secret. They, too, had little they could get a hold on, contextualize, and make sense of. Some succeeded in acquiring their medical documents or came upon their being labeled “(pseudo-)hermaphrodite” or intersex, sending them on a quest for information, perusing medical manuals. They had to make sense of language used to describe their bodies and interventions practiced on them. They had to make sense of contradictions between good intentions and the violence experienced. And they had to fight against feelings of shame that could stamp out the very impetus to look for answers.

Once intersex people find others and exit isolation, the quest for meaning and reducing hermeneutical gaps of understanding can span years. This will be compounded by a long process of shame deconstruction. One has

to struggle against the deep mark medical authority has left on how they perceive their body. This means that one has to develop the cognitive resources and confidence to come to terms with the received notion of medical knowledge superiority. Difficult emotions can be stirred or surface during this closing of the hermeneutical gap, as relationships to parents, to medical practitioners, and the non-intersex world come to be examined as well, some being fraught with realizations of not being adequately protected or unconditionally loved, of being unsafe where one should be kept safe.

Against the backdrop of intersex people who succeeded in learning that their innate sex characteristics do not correspond to medical norms, few have gone out and publicly shared their experience. Even when intersex persons overcome shame and find the confidence to implicitly challenge medical authority, they risk a lot and make themselves vulnerable if they come out. One has to decide what to reveal and what to keep personal, and what words can best convey their experience. One can also feel overexposed and decide to quit first person accounts, at least for some time. This step into visibility benefits from collective intersex reflection and previous testimonial examples.

First person accounts as collective springboards for social change

First person accounts or personal stories sharing from

members of marginalised or oppressed groups are to be seen as part of a long process that goes beyond the decisions and actions of single individuals. Overcoming hermeneutic injustice, that is first making sense of one's experience for oneself, and then aiming at having it understood by others, can only be achieved collectively. Under the iceberg tip of public voices lies previous and regular discussions with others who share common or similar experiences. Incrementally, marginalized people have found others and connected. They eventually came to the realization that despite the absence of cultural references to their lived experiences, these experiences do exist and are no figment of the imagination. Together they set to find language to fill in this void, and then realize that they share some feelings, thoughts and priorities while differing on others. They initiate intra community dialog and deepen their reflections.

Well known examples of this phenomenon are the effects of consciousness raising groups among women in general, racialized women, or among LGBT people, to name but a few. Coming together, women have realized that certain situations they were individually experiencing as distressing and damaging were also felt similarly by others despite mainstream assertions to the contrary. What was once framed or euphemized as “compliments”, “heavy-handed behavior” and “marital duty” by a patriarchal system was better defined as “sexual harassment” and “marital rape”, concepts they had to produce in

order to adequately represent the behaviors they were subjected to. They also noticed the pervasiveness of sexual assault and the damage it causes, steadied if not amplified by mainstream rhetorics minimizing them, explaining them away, or simply turning responsibility upside down. In telling their stories of sexual assaults they were subjected to, they had to break through common misconceptions and dominant paradigms, and underline the validity of their own perceptions.

The same goes with racialized women who experience combinations of racism and sexism, but who first wondered if they were imagining things up when facing daily expression of subtle or blatant discrimination. In the words of the Combahee River Collective:

Black feminists often talk about their feelings of craziness before becoming conscious of the concepts of sexual politics, patriarchal rule, and most importantly, feminism, the political analysis and practice that we women use to struggle against our oppression. The fact that racial politics and indeed racism are pervasive factors in our lives did not allow us, and still does not allow most Black women, to look more deeply into our own experiences and, from that sharing and growing consciousness, to build a politics that will change our lives and inevitably end our oppression (1977)

Gathering and sharing thoughts not only validates impressions, but also paves the way to creating or finding the words and concepts that can shed light on social mechanisms, a necessary step in their examination and transformation. Today, black feminist analyses are one

of the most acute lenses there are, since they are in a position to examine the fine crossings of social structures producing both racism and sexism. Similar things can be said of the evolution of gay, lesbian, queer or trans narratives. Exiting isolation and meeting others has provided opportunities to fill in the cultural voids and produce tapestries of references where one can recognize feelings, interpret experiences, and analyze social dynamics.

When members of marginalized groups first share their stories with members of dominant groups, they do so stumbling in between mainstream narratives that inferiorize who they are and language that strives to secure humanity and dignity. Since giving first person accounts

is no isolated activity and extends to subsequent discussions and reflections with others of the same community, narratives evolve and become more precise, address current political or social contexts, and try to avoid the pitfalls of adopting the frames reproducing inferiority.

Intersex people have known a similar trajectory. At the very beginning of the movement, initial meeting through phone and direct conversations has allowed for the discovery of similar experiences which could be put into words and feelings which could be named

and validated⁸. Written accounts of intersex experience, first relayed through the community-based newsletter Hermaphrodites with Attitude, through the special Intersex Issue of Chrysalis, and through intersex mailing lists and forums did the same. Today, some intersex people exit isolation and connect with others through social media.

Being able to exchange with other intersex people on interventions one has been subjected to helped resolve previous strong dissonance between how medical professionals describe their management and how it was actually experienced. In the same way women in consciousness raising groups provided “sexual harassment” for the ill-fitting “compliments” or “flirting”, intersex people have described their pre-surgical genitals as “intact” in opposition to “deformed”, and their post-surgical genitals as “damaged” instead of “corrected”⁹. Where medical professionals see “early surgery”, intersex individuals see “non-consensual surgery”. And where these same medical professionals refer to “normalization surgeries”, many intersex people find “intersex genital mutilation” to be more adequate.

Community based media and meeting groups have been the springboards from which intersex people

give first person accounts to medical professionals, on television program sets, in social sciences classes. Many testimonials have appeared in books, autobiographies, blogs, documentaries. Over time, words and ways used to describe intersex and intersex management have evolved. For instance, European intersex people mainly prefer intersex variation over intersex condition, which still validates medicalization of intersex. And “patient advocacy” is avoided, as it supports medical professionals’ implicit view that intersex persons are to be patients, either because their difference is something to be “treated” or every aspect of their lives are to be managed by medicine.

Doing first person accounts have prompted reflections on what one experiences throughout, and on the challenges of being intelligible when people who hear or read them have no previous knowledge on intersex and intersex medical management. It also often draws on research done by others into what standards of practice intersex people have been handled with, which allows one to contextualize their experience to an audience. However, the medical policy of secrecy, social marginalization and hermeneutical injustice, as well as file confidentiality have made the production of large scale research arduous for intersex community-based

⁸ Intersex activist and ISNA founder Cheryl Chase relates this in the documentary Intersexion.

⁹ See Suzanne J. Kessler (1997/1998) “Meanings of Gender Variability: Constructs of Sex and Gender”. Chrysalis: The Journal of Transgressive Gender Identities, vol. 2, n.5, p. 33-37.

research. Testimonials have been the intersex community's main medium for counter-discourse, followed by critical analyses of medical texts, discourse, and practices. Intersex testimonials are eminently political.

Reception of first person accounts: From testimonial injustice to enlarged thought

First person accounts from persons who belong to marginalized social groups elicit a variety of responses. They may be met with complete disbelief up to full belief, with varying degrees of empathy, with understanding or confusion and misinterpretation, as well as with varying degrees of solidarity and opposition.

As much as there is fear of not being understood and believed, or of being met with disinterest and hostility, the very act of making first person accounts implies hope of being heard, of stories leaving an impact on people witnessing them, of sowing seeds that could contribute to social change. While some scholars, like Agamben, claim that there is no possibility of making exceptional treatment intelligible, or that interpretation filters deriving from different lived experiences will shape

stories into something different in the witnessing minds, Emcke (2015), Fricker (2007) and Young (2000) are confident that despite serious structural challenges, some understanding is possible and constitutes a lever for social change¹⁰.

In her work on inclusion and democracy, the late political philosopher Iris Marion Young (2000) has stressed how formal inclusion of members of marginalized social groups in decision-making processes still often fails at translating into decisions that take their perspectives into account. She calls our attention to the less theorized dimension of internal exclusion, which she describes as the following:

Though formally included in a forum or process, people may find that their claims are not taken seriously and may believe that they are not treated with equal respect. The dominant mood may find their ideas or modes of expression silly or simple, and not worthy of consideration. They may find that their experiences as relevant to the issues under discussion are so different from others' in the public that their views are discounted. [Conceptually, internal exclusion] concern ways that people lack effective opportunity to influence the thinking of others even when they have access to fora and procedures of decision-making. (p. 55)

Young explains that despite the presence of members of marginalized social groups, internal exclusions happen since there is a lack of "shared understandings"

or "shared experiences" allowing for the development of arguments resting on shared premises. The decision-making process follows the "assumptions, experiences, and values" or paradigms of members of dominant groups who misunderstand, belittle or reinterpret marginalized groups' perspectives. No matter how coherent they are, keeping to arguments alone, Young claims, will not overcome this gap.

This dovetails Fricker's (2007) account of hermeneutical marginalization, which also affects members of dominant groups, albeit not at their disadvantage. She would add to this mechanism that of testimonial injustice, which occurs on an interactive level. As time can hardly be spent fact checking each and every person's claims, credibility attribution follows shortcuts structured around status, notably institutionalized titles. Power dynamics between social groups, however, interfere with appraisal of credibility, so much so that conscious or unconscious prejudice will grant excess credibility to members of dominant groups whereas members of marginalized or oppressed groups will suffer from credibility deficit. Testimonial injustice, then, consists in identity based prejudice which "causes a hearer to give a deflated level of credibility to a speaker's word" (2007, p. 1). As Fricker points out, traditionally inferiorized social groups like working class

people, Black people or women have been attributed traits like "over-emotionality, illogicality, inferior intelligence (...)" (p. 32) seen as impediments to sincerity, truth, factuality or depth of reasoning. Though these attributions have mainly faded away as overt judgments, their deep impact in interactional dynamics and their transmission has given way to diluted and covert prejudice. As a consequence, even people who hold equality principles dear may, unbeknown to them, be influenced by these old prejudices and interactional dynamics when taking unconscious shortcuts to ascribing credibility.

Dismissing person's claims because of their membership in a marginalized group has negative repercussions, some of which can be dire. This is the case, for instance, when Black men are suspected of having committed a crime despite them not being seen doing one. They will not be as readily believed by law enforcers as white men when producing information on their work, their current activity, or their ownership of a given good they have been suspected of stealing, thus subjecting them to unfair treatment and violence¹¹. This is also the case when victims of sexual assault are not believed because people receiving their accounts give more credibility to the alleged perpetrator they appreciate more or identify with, and/or because they

¹⁰ Agamben's position is mentioned in Emcke (2015)

¹¹ One case in point is the arrest of professor Henry Louis Gates jr., suspected of breaking into his own home.

have interiorized the false accusation myth which amplifies real instances of false accusations, drawing on conscious or unconscious prejudice that women and children are prone to lie to “get revenge”. And this is the case when members of marginalized groups attempt to describe discrimination instances in order to initiate social change, but are told they exaggerate, misinterpret disparaging things they were told, or imagine slights where there are supposedly none.

In addition, testimonial injustice is dehumanizing on two levels: “(...) it undermine[s] the [speaker] in a capacity (the capacity for knowledge) that is essential to his value as a human being, [and] it does so on grounds that discriminate against him in respect of some essential figure of him as a social being” (p. 54). This injustice will be more acute the more persons of marginalized groups are “excluded from the community of trusted informants” (p. 132) and treated as “mere sources of information”.

They become observers of the discourses that are produced about them without their participation, which amounts to being treated as objects instead of subjects or persons with valuable insights and sociopolitical objectives of their own. Knowledge production on racialized people, on indigenous people, on women, on poor people, on non-heterosexual people, on trans

people or disabled people has long taken this course, where their own views, perspectives, and analyses of the world they live in have been disregarded or diminished in the final analyses of researchers led by people of dominant social groups. In Fricker’s words, the intrinsic harm of testimonial injustice is “epistemic objectification”, that is: “when a hearer undermines a speaker in her capacity as a giver of knowledge, the speaker is epistemically objectified” (p. 133).

Testimonial injustice and hermeneutical injustice may combine and feed into one another and produce credibility deflation. Given the lack of collective resources – that is previous cultural references, concepts and words – to properly describe the experience of members of marginalized groups, they may come across as rambling incoherently, which adds to the already lowered credibility granted them because of prejudice, and further nurtures it:

If [speakers of marginalized groups] try to articulate a scanty understood experience to an interlocutor, their word already warrants a low prima facie credibility judgment owing to its low intelligibility. But if the speaker is also subject to an identity prejudice, then there will be a further deflation. (p. 159)

Fricker illustrates this by drawing on a situation described by Brownmiller in her memoir. A woman, subjected to sexual harassment on her job at a time when this concept was not used, had to leave her job

because of the physical symptoms the stress from permanent avoidance strategies created. Applying for unemployment insurance, she was at a loss to describe what happened and felt ashamed. The investigator from the insurance company estimated that she did not make sense with what she was trying to say. Even if “she succeeds in saying that she is ‘made uncomfortable’ by his persistent ‘flirtation’” (p. 159), this may not score as a problem to the investigator, who is additionally inclined to grant her less credibility on the basis of her being a woman.

This does not mean that Fricker (2007) considers this epistemic injustice to be inescapable. It could be challenged once people are made conscious of its mechanisms, so as to foster alertness to it. Young (2000) also envisions political

communication modes additional to argumentation that could deepen democracy and address internal exclusion: 1) greeting, or public acknowledgement; 2) affirmative uses of rhetoric, and 3) narrative and situated knowledge.

Like other scholars, Young draws our attention on standards of deliberation and invites us to examine them. Though she agrees with the importance of argumentation or “orderly chains of reasoning from

premises to conclusions” (p. 37), there must be room to explore the premisses themselves, which mainly draw on different values and life experiences. For all their consistency and thoroughness, argumentation chains will not be validated if the premisses are not shared. Furthermore, there should be reconsideration of current speech norms that require to be dispassionate and disembodied. Not only does this favor members of dominant groups who do not have to put up with systemic discrimination, but it also falsely opposes reason and emotion:

[these norms] tend falsely to identify objectivity with calm and the absence of emotional expression. For those suspicious of emotion, expressions of anger, hurt, or passionate concern taint whatever claims and reasons they accompany. Wide gestures, movements of nervousness, or bodily expression of emotion, furthermore, are taken as signs of weakness that cancel out one’s assertions or reveal a person’s lack of objectivity and control. (p. 39)

This standard puts undue weight on members of marginalized groups who not only have to face discrimination and endure regular indignities and slights, but also experience the dehumanizing effects of testimonial injustice, and probably credibility deflation when they attempt to portray their lived experiences and social realities. Members of marginalized groups can indeed be passionate when recounting the discrimination, indignities and violence they have been subjected to for a long time. However, invalidating stories of margin-

alized people or research led by members of marginalized groups on the basis of the emotions they may display when defending their dignity, and preferring research led by members of dominant groups because we presume them “more objective” can only serve episodic objectification and perpetuate marginalization.

This is all the more inadequate, given that inferring that members of dominant groups are more prone to be objective and dispassionate is incorrect. Judgment and passion can still lay behind a calm demeanor and certain chains of reasoning. Language proficiency allows for astute vagueness and the use of words that draw on double entendre, thus protecting demeaning views from accountability. For all their appeal to neutrality driven science, their testing of hypotheses and their use of precise data collection tools, researchers are influenced by cultural lenses and personal values. The social groups and the decision-making involved in defining a given situation as a “social problem”, the objectives set for a research, the hypotheses that are entertained, the indicators that are selected, the way strong correlations are interpreted all draw on assumptions. For a long time, homosexuality was considered a social problem to be solved by eradicating it. This angle was seen as self-evident and was driving investigative goals, notably finding its “causes”. Absent were concerns over how gay and lesbian people experienced their lives, and how they dealt with the social exclusion created.

When members of dominant groups lead research on marginalized groups, the sole interpretative resource they have acquired comes from their cultural repertoire. They lack access to socially marginalized people’s intimate world, the width and depth of their lived experiences, as well as their critical perspectives and analyses. Consequently, it is researchers from dominant groups who will determine what constitutes a problem, frame the questions, and make hypotheses. They will select indicators they deem relevant, direct interactions and data collection with participants, and draw conclusions from data collected that will make sense to the set of assumptions that they entertain, or the paradigm they interpret the world with. Even if they submit data extracted from a large sample of participants and draw conclusions that have high internal coherence, their results will be erroneous. These research processes and their invalid conclusions stem from an incapacity or a reluctance to reflect on how it is that we came to consider a given situation a problem, and who should have a say in this consideration. There can be an unconscious or unavowed interest in leaving the status quo unquestioned, as it provides emotional comfort and preserves deferential treatment, symbolic status, economical advantage, as well as privileged access to decision-making opportunities. These benefits are so ingrained in daily life that they either remain unnoticed or are considered neutral and legitimate. Open challenges to this status quo are often met with

deterministic “just-so theories”, with convoluted claims of acknowledgment that get de facto recanted through additional claims, or with reverse analyses of power, where challengers are depicted as belonging to the dominant group. Interestingly, establishing, maintaining and protecting the status quo is deemed apolitical, objective, or disinterested, whereas those who dare question it are cast as political, subjective and interested.

Erroneous research conclusions are the inevitable effects of ignoring both the complex tapestry of daily life experienced by marginalized groups and epistemological objectification. This has occurred several times when men led research on women, when white people led research on “racial relations”, when researchers from well-off social classes led research on poor people, when settler researchers led research on indigenous people. It is doubtful, under such circumstances, that the attempts at describing how it is that members of marginalized groups fare under the treatment of dominant social groups to whom the researchers belong will be valid. This is especially the case when this treatment has been described by certain marginalized people as highly damaging, if not traumatic, and if the people leading the research had a direct hand in this.

Quantitative methodological tools, enjoying a reputation of scientific rigour for their capacity to provide precision in offering proportions or high correlations

between variables, can be applied thoroughly yet provide little to no enlightenment on the social conditions of these populations. These, in contrast, will frame the problem differently, will have other questions to investigate, other objects to examine and measure, other indicators to look for. They will as well be able to interpret data correlations by drawing on a deeper familiarity with the context they arise from. Examined from the depth of epistemological thought – the discipline that analyses and reflects on how we produce knowledge -, quantitative approaches are poorer than qualitative ones when it comes to identifying what it is that participants consider most important to themselves and provide rich portrayals of their thought processes, beyond the limitations of what researchers presume to be important to them.

Young (2000) states that narrative, storytelling, first person accounts could help solve argumentative dead-ends in political decision-making sensitive to inclusion. Given that research is often drawn upon in these political decision-making processes, and that it can contain irrelevant data when driven by members of dominant groups paying little attention or lending insufficient credibility to what participants consider important for themselves, it is crucial that researchers also open up to this communication mode and reflect on testimonial injustice and hermeneutic injustice dynamics and its effects on knowledge production and

dissemination. According to Young (2000), storytelling can provide, among others :

“Response to the ‘differend’”. Some harms will not be acknowledged as such when they do not fit with the words, the concepts and the repertoire of prevailing normative discourses. In these cases, storytelling “is often an important bridge (...) between the mute experience of being wronged and political arguments about justice. (...) As people tell such stories publicly within and between groups, discursive reflection on them then develops a normative language that names their injustice and can give a general account of why this kind of suffering constitutes an injustice”. (p. 72)

“Understanding the experience of others and countering pre-understandings”. In a context where dominant cultural productions do not provide adequate or valid portrayal – or portrayal at all – of some marginalized social groups, storytelling is the only alternative that allows people from dominant groups to “gain some understanding of experiences, needs, projects, problems, and pleasures of people in the society differently situated from themselves” (p. 74). For members of dominant groups who hold “a stock of empty generalities, false assumptions, or incomplete and biased pictures of the needs, aspirations, and histories of others (...)”, this further gives the opportunity to examine them.

“Aid in constituting the social knowledge that enlarges thought”. Beyond providing accounts of personal lives and experiences, storytelling offers other interpretations of social interactions. It “(...) exhibits the situated knowledge available from various social locations, and the combination of narratives from different perspectives produces a collective social wisdom not available from any one position.” (p. 76).

Single stories or first person accounts may not change interpretation frames, especially with the effect of testimonial injustice or hermeneutical injustice. Their

repetition and dissemination in society, however, will gradually lend them weight and move them from surre-

alness to intelligibility, as new situations, new words or new concepts will be discussed and circulate. Even when initially met with disbelief, stories have enacted change. This has occurred with testimonials of survivors of slavery, survivors of sexual assault, with lgbt people sharing stories of their lives, and with other groups. This process, however, is long, as racism, sexism, sexual assault, heterosexism and cissexism still are present or prevailing.

In the case of people subjected to extreme violence, Emcke still maintains that it remains possible to convey it and raise awareness around it. As a precondition, listeners must learn to adjust to the challenges of these person’s first person accounts, and respect their terms, words and rhythm in opening up. Disbelieving the possibility

of describing violent systems and dynamics “would sacralize them” and have them remain unchallenged. And this would be the greater injustice:

Despair and pain settle like a shell around the affected person and encase them. Thus increases the radius of violence, expanding and inflicting damage. The violence sustained nests in, accumulates, immobilizes, and is enounced through gestures, movements, fragments of words, or silence.

Therein however, in the silence of the victim from extreme injustice and violence, lies the most perfidious capacity of such a crime: to be able to cover up its tracks. When structural and physical violence penetrate its victim, when extreme injustice and violence attack their narrative competence, it remains unnoticed and prospers. (p. 16, [translation from Janik Bastien Charlebois])

Some people who witness stories may rest their reluctance to have first person accounts included in decision-making processes on a lack of representativeness. Stories will certainly not be identical, and some may even contradict, but they provide tension to be rigorously examined. This is when one can also look at the conditions that make first person accounts possible, as well as the structures through which they evolve. As seen before, hermeneutical marginalisation makes it hard for people to develop new concepts where none was offered them. Members of marginalized groups have notoriously tended to interiorize dominant paradigms, or conceptual frames provided to them by persons in positions of authority. Some racialized persons had a hard time developing critical perspectives on the persons who were agents of their oppression and exploitation. This applies as well to women, indigenous people, people with disabilities, non-heterosexual people, or trans people.

It remains that when one listens to first person accounts, one discovers that crucial dimensions are often elsewhere than presumed. And it is through shared stories that sound lines of inquiries can be initiated. In past social movements and other social groups, what was first shared in discussions could subsequently be taken up and further examined with more precise methodological

tools. To date, this intellectual trajectory has produced among the most ground-breaking theoretical and scientific endeavors of today. First person accounts enlarge thought in far-reaching ways.

Reception of intersex first person accounts

Personal stories from intersex people have been met with many different reactions: interest, fascination, dismissal, solidarity, or minimization. Seeing that the medical institution and the exclusionary, heterosexist conception of sexes were responsible for the sufferings they went through, they initially turned to medical professionals and the media. They presumed medical professionals would stop nonconsensual interventions as soon as they would hear of the negative effects they had had. They also addressed major, minor and community (mostly LGBT) media outlets, where they could

make their existence and their realities known to the general public.

They had and still have to deal with both hermeneutic and testimonial injustice, which may generate credibility deflation. This occurs, for instance, when they refer to “intersex genital mutilation”, and bring up current practices or medical resistance to change. In addition, they have to face many instances of their existence becoming an object of fascination, being reduced to the status of mere sources of information or epistemic objects. Media attention focuses out of what intersex people are saying about their realities and demands, and shifts it instead to what their existence could mean for non-intersex people. Astonishment over the existence of sex characteristics not fitting traditional definitions of male and female takes centerplace, so much so that media coverage of intersex has often been caught in a loop of perpetual surprise. Pictures of hermaphrodite statues or babies will often accompany articles, while many intersex people recount frustrating experiences of having casual, standard pictures submitted by themselves be replaced by sensationalistic images.

Media interest flares up when a third gender option is recognized by the State, a measure that is often portrayed as benefiting intersex people regardless of what the community professes on that issue. Direct challenges to medical practice by addressing the courts or leg-

islators, which are a top priority of the movement, does not draw the same coverage. Though media in English and German linguistic spheres have broken up from the cycle of surprise and now cover intersex political dimensions as well, there still seems to be reluctance to lend credence to the depth of the suffering that medical management has caused on intersex people within our “developed societies”. There is reluctance as well to envision the medical institution as being responsible for it and for what amounts to human rights violations, despite intersex people citing human rights convention organs and organisations’ own observations on the matter. Consequently, some media will include excerpts from intersex people’s testimonials, but grant medical professionals the final word. They will be given the opportunity to interpret intersex claims’ and realities as well as state what “really is at stake”. In short, credibility is more readily bestowed to (non-intersex) medical professionals than to intersex people, who thus experience testimonial injustice. Medical claims of interventions having stopped or improved also seem more credible, as they are rarely met with follow-up questions or confronted with human rights perspectives. Many media representatives lack the background information or hermeneutical resources on intersex management, which goes far beyond what they could conceive of. Significant hermeneutical gaps make intersex first person accounts hard to comprehend, while testimonial injustice opens of path of credibility deflation. This may

especially be the case given that the medical institution enjoys not only a highly positive reputation in the realm of ethics, but also in that of knowledge and scientific production quality.

This kind of media coverage extends the experience of epistemic objectification intersex people have been subjected to. There is a long history of medicine using what it once described as “hermaphrodites” or “pseudo-hermaphrodites” for its quest in finding the “true sex” indicator. Intersex people would find themselves depicted naked with bars over their eyes in medical books, and have their bodies qualified in words that are not their own. When intersex people’s recounting of what happened or happens to them and how they felt or feel is not believed; when it is left to medical professionals to describe how intersex people “really feel”, this not only constitutes testimonial injustice and dehumanises, it also casts the harm they were subjected to as unchallengeable and unavoidable – something Emcke underscores as being socially dangerous. Not being believed makes the harm suffered benign or legitimate and to be endured in isolation, without the minimal uplifting force of solidarity and care.

When intersex activists first turned to medical professionals responsible for intersex management as part of their initial efforts, they were shocked to see that they were being met with resistance, denial, minimization, and dismissal. Both in personal interactions at conferences and in the media, their pain could be explained away on factors not related to interventions, and their demands of stopping nonconsensual, irreversible, non crucial for life interventions would be dismissed as irrelevant on the grounds that they did not represent the majority of intersex people or that intervention techniques had improved. Following are four quotes illustrating some of these reactions:

Dr. John Gearhart, a urologist at Johns Hopkins University, dismissed its members [Intersex society of North America] as “zealots” and refused to discuss the organization (Angier, 1996)

But some physicians are indignant that their medical judgment should be called into question regarding the best treatment for patients. Philip Ransley, for instance, dismisses activists against early surgery in the United States as “green-wellied loonies” (Toomey, 2001)

“I never question people’s experiences,” Sandberg said. “What I do question is whether their experiences are generalizable to others. I don’t know who said it, but I’d agree with the quote ‘The plural of anecdote is not data.’” (Ghorayshi, 2017)

Expertise or relevant knowledge from intersex people sharing public first person accounts is either not granted, or considered minimal and secondary to medical expertise on intersex management. Some are also branding the demands for protection of integrity and self-determination as irresponsible and possibly damaging to others. And some again blame intersex people for being too emotive, even when they submit reasoning resting on sound logic, on human rights principles, or on juridical, social sciences, ethical, and medical knowledge. Colette Chiland (2008), for example, used the metaphor “écorchés vifs” as part of her critique of intersex and trans persons blaming medical practice, which in English would approximately translate as both “flayed alive” and “radical”. Yet, those invalidating intersex critique by focusing on tone rarely take up the actual experience and arguments relayed and do not commit to disprove them. This would fit Young’s (2000) observation that we hastily conclude that emotion is necessarily and always incompatible with reason. Not to mention that if non-consensual interventions can cause so much hurt, lack of understanding and validation for the anger felt and expressed betrays lack of sensitivity.

After the adoption of the Consensus Statement introducing adjustments to intersex management in 2006, medical discourse and reception of intersex first person accounts has become polished. More medical profes-

sionals underscore their belief in negative experiences of intersex management and state that they genuinely feel empathy, but they insist that it should not tailor practices or politics. Intersex people have stories, while medical professionals have “science”. Testimonials are but anecdotes with little weight compared to evidence based-research. Implicitly, they are referring to the research they are conducting, given that they benefit from an exclusive access to the confidential files of people whom they diagnosed with variations of sex development. Although there was acknowledgment in the Consensus Statement that follow-up studies were lacking, they maintained the status quo and favoured the risk they created over the unproven risk of respecting an intersex person’s self-determination and having this person potentially be subjected to discrimination: “It is of interest that opponents of early surgery have no evidence that late surgery is better. (...)” (Mouriquand et al., 2014, p. 8-10).

While evidence-based medicine is purported to offer strong data which would be most appropriate to orient practices, reflexivity is next to absent from it. Reflections over where medical professional researchers are coming from, how their views and framing of a problem are affected by general and disciplinary culture are very rare. Medical professionals have had a long tradition of qualifying intersex bodies as failed and inadequate, with rare justification of these judgments: “aberrations”

(Collier, 1948, p. 209), “offending shaft” (Randolph et Hung, 1970, p. 230), “Castration should be performed well before puberty to avoid disturbing virilization” (Saenger, 1984, p. 1), “a boy with this insignificant organ” (Newman et al., 1992, p. 651), “disfiguring effect” (Hughes, 2017, p. 30), to list but a few. When they do attempt to justify this judgment, they do not subject its premise to examination, providing but thin rationale. Teleological thought processes (A exists because A has X purpose), which are present in those cases, go unnoticed and unaddressed. Sex characteristics of intersex variations were not “meant to be”, disqualifying them¹². Definitions are also infrequently used for operational concepts like “function”, despite its being brought up as the rationale for performing non consensual interventions¹³. One has to reflect, though, on what basis non consensual creation of a neovagina or standing up to urinate falls under “function”.

Lack of reflexivity and analytical depth also shows up in the complete absence of reflection on the influence medical professionals exercise on how parents will understand and perceive their child’s intersex variation, and how intersex people themselves will first understand their body and sex characteristics variations.

¹² As food for thought, purposes and goals imply planning, which implies sentience. Yet, as much the existence of God cannot be proven, nor can a “Nature entity”. Whereas focusing on effects instead does not require that leap of faith. I suspect this is the reason why (astro)physicists will describe how gravitation proceeds and explore its effects of gravitation instead of saying that “gravitation’s goal is to produce order among celestial bodies”.

¹³ The Consensus Statement, for instance, uses “function” as a rationale for non consensual interventions, but does not refer to definitions or medical reflections on what it should consist in.

Children are not born with resistance towards medical discourse and authority, but rather are educated into fully trusting medical professionals, despite any discomfort and distress some interventions may cause. As case in point of the potency of medical influence is the situation of gay, lesbian, bisexual or trans people. Those born a few decades ago grew up in a period where scientific and cultural productions overwhelmingly portrayed them as failing, sick, perverted, or mentally disordered. As a result, they would understandably interiorize those perspectives and most of them would agree with medical judgment that they should be “cured” of their disease. Some willingly subjected themselves to treatment that is today considered highly damaging, if not inhumane and degrading. Some would even come to promote the imposition of this treatment on others, or legitimize parents sending their children to therapy. While being isolated and only exposed to pathologizing and negative discourse would insure adhesion to it, slowly getting organized on an autonomous basis would allow – as we saw in the previous section on collective springboards for social change – for the emergence of a critical narrative, one that would be affirmative and gather enough confidence to challenge mainstream scientific and medical “expertise”. Yet, medical profes-

sionals involved in intersex management have not integrated this lesson into their assessment of impact

research results, especially if they

get to be strongly invested in parent-initiated groups who can steer socialization of people with variations of sex development from early on. Moreover, they do not take into consideration how their position and status – even when mediated by research aides representing the medical team – exerts influence over how impact research participants and interviewees will answer them. While interviewer-interviewee dynamics have long been reflected on in other scientific disciplines and proven to generate different data depending on their respective social status, profession, and social group membership, this has not reached medical professionals involved in intersex management yet.

As a result of these many reflexivity failures, when medical professional articles or opinion pieces on intersex management refer to bias, it is solely cast on intersex people who speak publicly of the interventions they were subjected to:

It is the desire of all DSD surgeons to promote this discussion and avoid the biased and counterproductive reports whose lack of evidence does not further our understanding of the issues nor serve the interests of our patients. (Mouriquand et al, 2014, p. 8-10)

If a collection of first person accounts of lived experiences does not, in these medical views, constitute evidence, this suggests either limited analytical capability, or poorly enunciated evaluation criteria. Unless one doubts the veracity of the experience intersex people share, these experiences *are* evidence that non consensual interventions have caused harm. What medical professionals can argue is that their collection cannot produce exact proportions. If “evidence” is understood as the proportion or percentage threshold from which they would acknowledge the need to cease non consensual interventions, then they have to divulge – and justify – a specific threshold as evaluation criteria.

Like Kessler (1998) before them, Machado et al. (2015) noticed an absence of evaluation criteria and indicators tenuously related to dimensions that are important in intersex people’s lives. Both evaluation criteria and indicators are selected by the very medical

professional teams who performed non consensual interventions:

However, one must keep in mind that the representativeness of the case histories on which activists base their critique and suggestion for change is totally undocumented and suspect given the understandable bias implicated in the activist role. (Meyer-Bahlburg et al., 2004, p. 1618)

The articles that proposed to measure sexual satisfaction, when referring to it, were predominantly limited to asking how dilated the vagina was; whether there was the presence of orgasms, lubrication, and pain when ejaculating; capacity to penetrate or to be penetrated; having stable relationships; or the evaluation, by an external observer, of the aesthetic of the genital; and, in fewer cases, how he or she feels concerning the surgery. (...) In most cases, success was defined by the opinion of the team, even when it contradicted the presented data. For example, one emblematic article with “positive results” evaluated, in a prospective follow-up consultation, the surgical results and the sexual satisfaction of 47 patients in an average of 12 years after an intestinal vaginoplasty took place. According to the authors, the result was positive because besides the excellent surgical outcome, 38.3 percent of the sample was sexually active and 8.5 percent was married. Nevertheless, 17 out of 47 patients had complications from the surgery, such as necrosis of part of the genital, abdominal abscess, and vaginal prolapse (...) (Machado et al. 2015, p. 4)

Some medical professionals will claim consultation of intersex people, if not acknowledgment of their expertise. One such instance is the invitation of intersex people to the 2005 Chicago Consortium meeting which would end up with the 2006 Consensus Statement. Also, since the I-DSD 2013 Congress took place in Ghent, medical professionals have taken to refer to intersex people (and their parents) as “patient experts”. A United States wide follow-up research called NIH Translational Research Network has invited social science experts, intersex variation group representatives and intersex scholar Georgiann Davis to participate to

a Advocates Advisory Network. And as a last example, some medical professionals opposing acknowledgement of human rights nonetheless invite intersex people to give testimonials to students.

Including intersex people at the decision making table, however, does not translate into internal inclusion. Of the 45 persons taking part in the Chicago Consortium meeting, only two were intersex. Karkazis (2008) recounts their exclusion from determining the meeting’s objectives, themes to be

discussed, questions to be answered, and committees to be part of. The writing of the Consensus Statement faced similar challenges. Participation at Ghent was minimal and the last word of following reports on the “patient expertise” section was kept by medical professionals. In November of 2015, several social science experts and intersex representatives left the Translational Research Network project over being poorly consulted in research directions¹⁴. And while sharing first person accounts in medical contexts may raise awareness, they will have limited impact if med-

¹⁴ See <https://interactadvocates.org/wp-content/uploads/2018/01/AAN-letter-of-resignation.pdf>

ical professionals oppose intersex children's right to self-determination. Despite Young's (2000) confidence in narration providing understanding of different set of values, there does seem to be hard limits in some social actor's readiness to give them worth and have them influencing their decision-making.

As a consequence of difficulties met in both the media and medical environment, intersex people have grown cautious about the ways their stories can be formatted and left in the hands of external experts to be interpreted. They are filtering media offers more frequently to avoid sensationalism and superficial coverage, share testimonials through their own medium and social media, and have turned to human rights organisations. This approach bore fruit. At least four UN Convention treaty organs (CEDAW, CRC, CAT, CRPD) consider non consensual interventions – or intersex genital mutilations – to fall under human rights violations and describe them as harmful practices. They issued more than twenty final conclusions in revision processes of countries who ratified these treaties, calling for the State to legislate and protect the human rights of intersex children¹⁵. Human rights organisations have also joined their voices, among them Hu-

man Rights Watch and Amnesty International. And in February 2019, the European Parliament has passed a resolution condemning non consensual interventions on intersex children¹⁶. First person accounts of intersex persons' medical experiences have value in those institutions, and have been key in convincing human rights experts of the existence of damaging practices.

When taken to task, State legislators nonetheless hesitate. They are faced with contradictory and competing commitments. One is applying the UN Convention Treaties they ratified by protecting human rights of constituents. The other is leaving the authority of determining what is health and sickness, as well as standards of practice, in the hands of the medical institution. Moreover, recent legislation initiatives in the United States have drawn fierce opposition from medical professionals and associations, who claim that this process interferes with their exercise, is anti-scientific and politically motivated. Lane Palmer, who is president of the Societies for Pediatric Urology, President of the Pediatric Urology Associates, and Chief of Pediatric Urology at the Cohen Children's Medical Center of New York, states:

Such political activism speaks to an agenda designed to interfere with a parent's right, and legal obligation, to make medical decisions on behalf of their child. An issue that should so clearly be considered medical and a private decision has become politically polarized to the point where legislators with no medical background in the field, lacking true knowledge of the issue, have advanced spurious legislation under the pretense of protecting a vulnerable minority without considering the real-life experiences and concerns of those who would be impacted by the legislation (March 13th, 2019¹⁷).

Given that medical professionals express refusal at subjecting their practice to human rights lenses and standards (Ahmed et al., 2013; Baratz et al., 2015; Mouriquand et al., 2014), legislators must choose, on the short term, between approaches grounded on different values and worldviews. In the mid and long term, preventing such competing interests will require an examination of the premises on which each perspective rests. While I would not compromise on basic human dignity and right to self-determination, and while many aspects of medical knowledge are sound and crucial for health preservation, I posit that medical knowledge production and judgment should be desacralized. It cannot provide the best angle on all human and bodily dimensions.

Intersex stories through the lense of human rights standards and values

Human rights, the right to bodily integrity, self-determination and dignity have been acknowledged and fought over by many social groups over the last decades. It implied in part the medical institution. Women have had to fight for bodily autonomy, and still do, as is the case of access to abortion, or access to respectful health care devoid of sexism or obstetric violence¹⁸. Gay, lesbian, bisexual and trans people had to fight for depathologization, and still have to in some States. Pathologization of gay, lesbian, bisexual, trans people by the medical institution has led to the imposition and practice of chemical castration, lobotomy, electroshocks, and aversion therapy. Though medical professionals already professed neutrality and objectivity at the time, it is easy to see today how their practice was driven by value-based re-

¹⁷ To consult the full text of his opinion piece: <https://www.ebar.com/news/news//273442>

¹⁸ Sadler et al. (2016) provide the following translation of the first legal definition of obstetric violence, which was first adopted in Venezuela and is now frequently referred to: "The appropriation of women's body and reproductive processes by health personnel, which is expressed by a dehumanising treatment, an abuse of medicalisation and pathologization of natural processes, resulting in a loss of autonomy and ability to decide freely about their bodies and sexuality, negatively impacting their quality of life." (p. 50). According to the Women's Global Network for Reproductive Rights (WGNRR), obstetric violence occurs through: denial of treatment during childbirth, disregard of a woman's needs and pain, verbal humiliation, forced and coerced medical interventions, dehumanizing or rude treatment, invasive practices. It can occur, for example, when unnecessary episiotomies are performed, when a "husband's stitch" is performed after episiotomy. Further medical violence can also occur when pelvic exams are done on anesthetized women without their consent.

¹⁵ For a list see UN Human Rights Office (2019): *Background Note on Human Rights Violations against Intersex People*, p.37-38, fn. 321-326

¹⁶ For the full text of the European Parliament resolution, see: http://www.europarl.europa.eu/doceo/document/TA-8-2019-0128_EN.html

search, and evidence produced on false premises. They deemed homosexuality unhealthy and had made its management their province. Removal of homosexuality from the Diagnostic and Statistical Manual of Mental Disorders (DSM) and the International Classification of Diseases (ICD) was qualified by many as a politically rather than scientifically motivated process¹⁹.

How people perceive their own bodies, gender identities, gender expressions, and sexualities – which, by and of themselves, do not cause them or other people harm – may conflict with how medical professionals frame them: as pathologies, as frailties, as aberrations, as malformations, as undesirable possibilities, or as possibilities that should not be. These conflicts extend to how people are treated as a result of this framing, or with how people who really suffer from health issues are treated when in the care of health providers: Critiques have accumulated over the years, either stemming from unethical research, from biased management, or from dismissing comments and nonconsensual facultative acts, like those collected in situations of obstetric violence. When conflictual perspectives arise between persons subjected to medical interventions and medical professionals, rigour requires to examine the premises and principles guiding each position before reaching a conclusion, with the

additional condition of reflecting on one's own driving principles as an observer.

People sharing stories introduce new narratives not present in mainstream cultural productions and discourses, but still draw on some shared values for defending their views. They will point to the discrepancy between the profession of these values and how they are applied. Women subjected to obstetric violence will underscore the importance of consent and self-determination, as well as dignity, which are formally shared and more easily accessed by men. The same goes with people who have been institutionalized, subjected to inhumane and degrading treatment and overmedicated for mental health issues or for disobeying social norms. Intersex people as well call for the observation and respect of their human rights and for the exercise of consent in the further treatment of other intersex people. These are human rights to integrity and self-determination promised to all, but not systematically granted.

Additionally, social groups who address critique at the medical institution may point to its presumed commitment to the “First, do no harm” ethical guiding principle, which they find failing when it comes to them. Although the hippocratic oath is not systematically taken, and medical practice may be guided by

contemporaneous bioethics, this reveals an underlying agreement with the idea that medicine must orient its practice in such a way as to avoid causing unjustified harm or prejudice. This further reveals disappointment over its inconsequent application or a disagreement with the interpretation of harm by medical professionals. While it is felt that “First, do no harm” or bioethics should be in step with human rights standards, it is not the case. In fact, neither the “First, do no harm” symbolic principle, nor specific bioethical perspectives are referred to as guiding intervention choices in intersex management, and like other driving concepts as seen above, never defined. It may be considered so self-evident as to not be purposefully mentioned in medical rationales. But given conflicting interpretation over what harm is when people with variations of sex development are concerned, keeping it vague renders accountability impossible.

Human rights are not the principles evoked by medicine when guiding its practices in intersex management. Rather, medical professionals resist them, and resist the evaluations provided by human rights professionals who conclude to human rights violations. They have written letters to human rights commissioners protesting their judgment, mentioned their disapproval in the media, expressed their dismay in peer-reviewed articles and editorials, or refused to include human rights decisions in parental guides.

Instead, they justify non-consensual interventions on the presumption of future negative self-image and impossibility to build a proper gender identity, discrimination from peers, and parental incapacity to bond with their children. They also respond to violation of consent not by strictly providing rationales for breach of consent, but by stressing better surgical techniques, and additional decisional input of colleagues. They blur parental decision-making with the expression of consent from the intersex child himself, herself or themselves. They fear “unintended consequences” of forbidding non-consented interventions, but so far have not proven that leaving to people with intersex traits the decision to modify or not their body will cause them harm. Still, they counter critique of this lack of evidence by saying that intersex people have no evidence to support the idea that stopping non-consensual interventions – or respecting their human rights to integrity and self-determination – will benefit them. Though this portrayal represents a stalemate, these medical professionals do not provide rationales as to why they, and not intersex people, should have the upper hand in decision-making over what practice to adopt. Moreover, they are laying an unequal burden of proof on intersex people in comparison to themselves. No matter how many intersex people who escaped non consensual interventions – or intersex genital mutilation – provide first person accounts of their not experiencing trauma by living with their body of origin, these will only amount to “anecdotes”.

¹⁹ The DSM is a major reference mental illnesses diagnostic guide produced by psychiatrists, while the ICD is the World Health Organisation's physical and mental health guide.

This leaves medically-determined criteria for practice change conspicuously unaddressed. No discussion has been led on what criteria would justify practice revision, and what would not. Or of whether this discussion should be led by medical professionals or not, when physical health is not involved. Proclaimed medical professional objectivity is incongruent with the absence of criteria that would indicate that the option of stopping unconsented interventions is also considered. Like the meta-analysis of Machado et al. (2015) shows, no impact research has submitted criteria that would indicate such an option is considered, let alone have intersex people participate in the determination of said criteria.

It may be tempting to require of intersex human rights activists to submit a similar set of criteria by which they would acquiesce to non-consensual, irreversible, non-crucial for life interventions. However, intersex activists do not base their demands on the same paradigm as the one medical professionals operate within, and thus do not have to show coherence with its professed claims of “neutrality”, “objectivity”, and “scientificity”. A “neutrality”, “objectivity”, and “scientificity” – so it would seem from what medical professionals believe – that would be infringed on by “principles” like human rights. Instead, intersex activists show coherence with human rights standards. It is on these principles that they anchor their data and produce their

analysis. When adhering to a human rights perspective, each and every individual has to have its dignity, its right to bodily integrity and self-determination be protected. The human rights declaration is a continuation of democracy, whose first modern steps expressed refusal at previous human worth distinctions between nobility and commoners. While earlier declarations had general wording, it was narrowly interpreted to only include white men who could pay a poll tax. Through time, other social groups fought for their dignity and for universal principles to be universally applied. The 1948 Human Rights declaration pursues that vein, and holds States responsible for its application. Though States have applied them imperfectly, they can and have been requested to correct failings. It is worth underscoring that the leading principles of human rights declarations were neither founded nor conditional on data gathered through an evidence-based approach. They rather are articles of faith, as declarations such as: “We hold these truths to be self-evident” illustrate. It nonetheless guides legislators and finds common agreement in society. I would take it for granted that neither I, nor any intersex person who shares their lived experience should argue for its relevance.

Through a human-rights lense, denying medical professionals and parents the possibility to impose irreversible and non-crucial for life interventions on their child does not violate their human rights. They are still free

to do whatever they want with their own bodies. And children’s bodies are not an extension or a property of their parent’s. Intersex people want to ensure that each person with variations of sex development has the right to self-determination, which implies the possibility of desiring and initiating bodily modifications. No person with intersex traits has either the option of bodily integrity or change barred from them. While some would argue it would impose on children the suffering of growing up with a body that may impinge on parents’ capability to build attachment, prohibit construction of gender identity, instill feelings of shame and abnormality, and subject them to peer discrimination, these are situations that either are hypothetical, or possible to address through other means than non-consensual body modifications or intersex genital mutilation. A human rights based approach calls for other solutions, which can be provided by other resources than medical ones, like psychosocial support. After all, attempting to preempt discrimination by doing unto someone what it is that bullies would wish – the erasure of their difference from the world – in no way provides protection. It allies up with the bullies’ desire and fulfills it. It accommodates them while it imposes on children with variations of sex development to sacrifice their integrity. Medical authorities have difficulty envisioning people being open to intersex variations because they hold deterministic views about sex, identity, and social dynamics. It would seem that, deep down, they

share the bullies’ discomfort and consider it legitimate. Not unlike school principals and parents who would require of young gay, lesbian, bi or trans youth to hide who they are or subject to conversion therapy instead of demanding of the bullies that they stop intimidating them. Yet the discrimination performed by authorities and the irreversible effects of body modifications cut deeper than most discriminatory scenarios medical professionals and parents would imagine. One does not counter sexism, racism, heterosexism or any kind of discrimination by requiring of the victim to become invisible or to conform to “normality” norms.

Perhaps the strongest disconnect medical professionals have with a human rights perspective is to be found in the implicit expectation of proving the existence of suffering from a *majority* of intersex people. Should suffering from non consensual interventions be proven in 75% of managed intersex people be required to apply human rights to all? Or 50% +1? Or 25% ? Medical professionals could well live with children who would have their human rights be violated if that could translate into what they think would be a better situation to a majority. Yet, in a human rights perspective, one individual suffering from human rights violations suffices to question the practice that produced them. Human rights are not to be quantified.

Every single first person account displaying a situation where human rights have been violated is relevant. A collection of accounts are not mere “anecdotes”, but suffice to require reorientation of practice. Even in a scientific perspective, a collection of cases cannot be dismissed as irrelevant. As sociologist Howard Becker (1998) mentions, an analytic induction approach stresses the importance of understanding specific outcomes by studying them instead of brushing them away as “mere exceptions”. Each situation observed indicates what our social structures and institutions are making possible. Intellectual discipline and boolean logic commands that they not be considered as alien and disconnected phenomena.

And last, but not least. A human rights perspective has greater respect and sensitivity to the unique and often tremendous obstacles people whose human rights have been violated face in finding their voice, and the courage to come forward. It is thus sensitive to the many epistemic challenges intersex people who share their lived experiences publicly have to deal with.

To the initial questionings and turmoils produced by isolation and hermeneutical injustice. To the long and demanding personal journey that precedes first person accounts. To the patient and complex collective work of creating sense where there is none. To finding the courage and confidence to speak one’s mind and share one’s experience when knowing that we risk not being

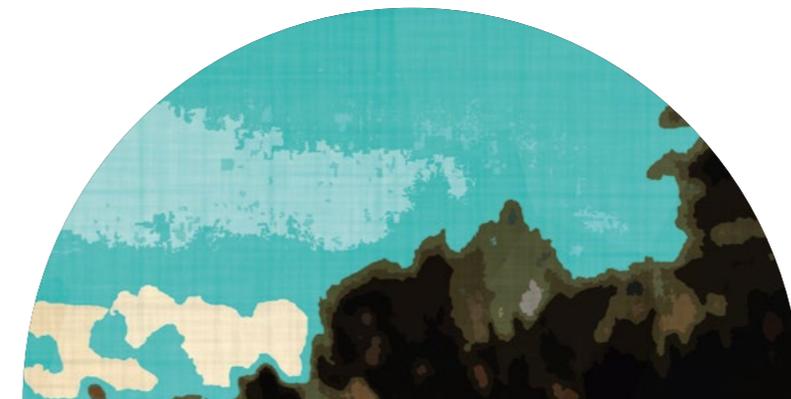
believed and subject to testimonial injustice. To the vulnerability and strength one displays when one is standing “naked” with their intimate stories to share and negative experiences to revive. To the harrowing experiences of having one’s trauma, hurt and human rights violations minimized or disregarded by the highly respected authorities who committed them, and having one’s courageous act cast as extremism or unreasonableness. To having one’s basic human dignity pitted against claims to truth and science from a profession that has shown prejudice without it compromising the excess credibility it benefits from.

Each intersex story is testimony to a path of determination, self-growth, and courage. For want of access to the files and the array of people with intersex variations who would satisfy medical professionals’ requirement of “proof”, intersex people are making use of the sole resources that are left to them: their own lived experiences, their bodies, their analytical capabilities, their dignity. When diminishing those intersex stories to the state of anecdotes, one either compels intersex people to say what one wishes to hear, or prods them to return to a state of “mere object of information”, one that complies with medical research formatting, and medical authority in production of knowledge. In other words, it pushes intersex people back to epistemic objectification. It shows how much there is an underappreciation of the inner turmoils an intersex

person has to live in order to find a public voice, which in return shows an underappreciation of the amount of damage medical erasure and human rights violations have caused. This also indicates that human rights experts are better equipped than medical professionals to measure harmful practices.

Intersex first person accounts are at the forefront of intersex activism, along with intersex-made essays and academic articles. This book embodies this. Fifteen testimonies of intersex people and their families from across Europe share their lived experiences. Their stories are poignant, valuable, precious. They help diminish hermeneutical injustice and provide more readers with frames to comprehend intersex peoples’ lives. They are tools in the fight for dignity of all intersex people. They come with analytical perspectives that can equip readers with situating inter-

sex experiences in a human rights paradigm, and with envisioning other, more respectful, possibilities. We hope they and other testimonials will be appreciated not only for their content, but for the enormous yet mostly invisible personal and collective trajectory that allowed them to come about. Finding their own words and setting their own terms for sharing their story is the end result of much previous work. We thank them all wholeheartedly for their commitment, we admire their courage, we stand in solidarity with them as with all intersex people across partly different, partly similar experiences. We hope that these first person accounts, in providing the tools or hermeneutical resources for understanding intersex experiences and perspectives, will help overcome internal exclusion and ensure intersex people’s right to decide what to do of their own bodies and lives.



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ISBN: 978-3-9821518-1-6

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