

## Who are intersex people?

- a) Individuals who are women or men with a disorder of sex development (DSD)?
- b) Individuals who have a sick body?
- c) Individuals whose chromosomal and/or gonadal and/or anatomical sex does not fit the norms of so-called male and female bodies?
- d) Individuals whose innate sex characteristics are either male and female at the same time or not quite male or female or neither male or female?
- e) Individuals who have a gender identity that is other than male or female?

There are people who think that answer (a) describes them very well. They identify as women or men who have a congenital disorder of sex development. Usually they identify themselves as being disordered due to the information that was given to them or to their parents by medical professionals.

Other intersex people feel consciously or unconsciously that accepting answer (a) also helps them to better fit into societal expectations. Although being diagnosed as disordered still produces a lot of stigma, it might also provide you with some sort of compassion. Being pathologized can be better than being considered a monster or not existing at all – as intersex people are being invisibilized everywhere in society and societal interaction.

It is crucial to realize that answer (b) is false: As male and female bodies intersex bodies are in essence absolutely healthy bodies. Having an intersex body does not mean that the body is not functional. It means that you have a body with sex characteristics and equipment that is configured other than the common so-called female or male body. As with female or male bodies different kinds of intersex bodies can have health risks that are specific to them. Like women have a higher risk of getting breast cancer than men. That is why actually the right answers are (c) and (d): Intersex bodies are not disordered but were born pretty much how they were meant to be (answer (c) and (d)).

If health issues arise from the specific configuration of an intersex body this is perfectly comparable to the fact that so-called female bodies do have specific health issues as well as so-called male bodies – as do the different variations of intersex bodies.

The difference to a body that fits into the norm of male or female is that intersex bodies are considered in need to be “managed” and therefore subjected to cosmetic genital surgeries and cosmetic hormonal treatment at a very early age because *they differ from the norm* – although the bodies are completely healthy and functional. This is like considering the removal of a healthy female breast in order to avoid a possible breast cancer. But whereas with female breast cancer reliable data on the risk does exist, it does not even exist in the case of intersex people. Still hormone producing gonads are removed on the basis of this rationale.

Besides the uneasiness with the *otherness* of intersex bodies there is another reason for the urge of “managing” and “normalizing” intersex bodies: homophobia and transphobia. It is the fear, clearly showing in lots of medical articles that without management intersex people will become gay or will not accept the gender identity assigned to them. Another very heterosexist rationale for interventions is the idea that a healthy body only a fertile body – especially those intersex individuals who are assigned female suffer from that idea at the cost of all other (sexual or other) feelings, interest they might develop or choices they will take later in life.

Do intersex people have a gender identity that is in between, like answer € suggests? No, not necessarily. As everyone else intersex people may have a gender identity as man or woman or a non-binary, non-male/non-female gender identity. And of course, they can also have or develop a gender identity of intersex.

But from which every angle a person with an intersex body that does not fit the norms of female or male bodies will look at the own situation – whether this person will consider themselves as a person with a disorder or as an intersex person with an intersex body: all of us suffer the same pathologization, the same problems with health professionals and the health system and the stigmatization that comes with being diagnosed and/or treated as a person with a disorder of sex development.

I want to draw your attention to the fact that the first question I put on the slide is “*Who* are intersex people?” And not “*what* are they” or “*what* is intersex”. There is a reason for this. Unfortunately intersex people are usually treated as a “what” in our health system: “Good morning Mr. Syndrom, nice to meet you, Mrs. ICD Code. You are coming to get treatment for a cold but may I nevertheless take a look at your genitals? You never know where those little

buggers of bacilli come from.” I am not kidding. Intersex people face this discrimination – today, in Europe.



**Which of the following situations do people with a DSD diagnose/ an intersex body experience on a regular basis?**

- ❖ health professional refusing to give medical care
- ❖ health professionals giving them a disgusted look
- ❖ treatment without personal, free, prior, persistent and fully informed consent
- ❖ being celebrated as a prove of the range and richness of human kind
- ❖ have to pay for themselves to get adequate and respectful medical treatment
- ❖ encounter disbelief about being intersex from medical professionals
- ❖ encounter medical professionals who have zero knowledge about intersex, although they are specialists in their field of expertise (e.g. endocrinologists, gynecologists) but nevertheless think that they can put the blame on the patient for not cooperating physically with the examination they want to perform, due to some psychological trauma

Medical professionals deny treatment because the client wants a prostate examination but is assigned as female. Doctors run out of the room because they are disgusted by the looks of the genitals presented to them during an examination – because those genitals do not match *their* expectations. People who didn't have treatment for DSD do experience those situations.

But – also people who underwent surgery or other normalizing treatment experience exactly the same harassment and discrimination – those people who's genitals and/or bodies were modified according to the current standards of management of people with DSD to fit into societal expectations. Why? Because an intersex body still is an intersex body after such interventions. But it is then a intersex body with scars: physical and psychological scars. Scars that hurt that diminish or erase erotic feelings. Bodies that are transformed by hormonal treatment to look more like female or male bodies but who are still wired in their own specific way and not like a female or male body. Which is completely ok, as long as the person concerned agreed to those interventions.

But very often this is not the case. Intersex bodies and the fact that they differ from the male or female matrix, are treated as a “psycho-social emergency”, as the situation is commonly called in medical articles. In most cases this psycho-social emergency, which is in fact not the emergency experienced by the child or adolescent, but by health professionals, caretakers and

other adults. And mostly it is somehow confused with a physical emergency and thus managed by physical interventions. I want to end by quickly showing you three other slides. If you are not able to understand the treatments listed in this third slide – well, then you are exactly in the same position as most parents who are confronted with a situation they never dreamed of but now are encouraged and often forced to decide on “management” for the so-called best of their child:



**Common treatments that do not manage a physical emergency but a so-called psycho-social emergency**

- ❖ Clitoris Amputation/“Reduction”/“Recession
- ❖ Hypospadias “Repair”, when the person is perfectly able to pee
- ❖ Castrations / “Gonadectomies” / Hysterectomies / (Secondary) Sterilisation
- ❖ “Vaginoplasty”, Construction of Artificial “Neo Vagina”
- ❖ Forced Vaginal Dilation
- ❖ Forced Mastectomy
- ❖ Surgical Transfixation of Undescended Testes
- ❖ Imposition of Hormones
- ❖ Prenatal “Therapy”
- ❖ Selective Abortion, Selective Late Term Abortion
- ❖ Preimplantation Genetic Diagnosis (PGD) to Eliminate Intersex Fetuses
- ❖ Forced Excessive Genital Exams

The next two slides speak for themselves:

## Numbers

**German Study on the life situation of intersex people (2008):** 439 intersex persons of all ages from Germany, Austria and Switzerland. 81% had been subjected to surgeries due to their intersex/DSD diagnose

- ❖ Almost 50% of the participating intersex adults of the study of Lübeck reported psychological problems (Netzwerk Intersexualität 2008, 24) and a variety of problems related to their sex life and sexuality (Netzwerk Intersexualität 2008, 30f.).
- ❖ 2/3 of the adult participants draw a connection between their sexual problems and the medical and surgical treatment they had been subjected to (Netzwerk Intersexualität 2008, 31).
- ❖ Participating children reported significant disturbances, especially within their family life and physical well-being (Netzwerk Intersexualität 2008, 21) – those being the areas that the medical and surgical treatment was supposed to stabilize.

## Numbers

- ❖ 75% of the participating teenagers had no experience with petting and masturbation; although this was a habit for 82% of the girls and 77% of the boys of the same age. (see *Studie der Bundeszentrale für gesundheitliche Aufklärung zum Sexualverhalten von Jugendlichen*, quoted in Netzwerk Intersexualität 2008, 30)

As does the last one:

## Results of biased information management of health professionals

### Research has demonstrated that

- ❖ medical professionals may be quick to propose ‘corrective’ surgeries and treatments aiming to ‘normalise’ the sex of the child even when such surgeries are unnecessary and merely cosmetic.

Charlotte Greenfield (8/7/2014). *Should We ‘Fix’ Intersex Children?*, The Atlantic <http://www.theatlantic.com/health/archive/2014/07/should-we-fix-intersex-children/373536/>

- ❖ parents are often ill-informed and impressionable,
- ❖ without adequate time or options to provide informed consent.

State of Victoria, Department of Health (2013). *Decision-making principles for the care of infants, children and adolescents with intersex conditions*, pp. 2 [http://docs.health.vic.gov.au/docs/doc/0D331CCCA75EE85ACA257B1800707957/\\$FILE/Final%20Intersex%20Conditions%20Resource.doc](http://docs.health.vic.gov.au/docs/doc/0D331CCCA75EE85ACA257B1800707957/$FILE/Final%20Intersex%20Conditions%20Resource.doc)

- ❖ those parents that are provided with medicalised information are almost three times more likely to consent to surgery than those that receive demedicalised information.

Jürg C. Streuli, Effy Veyens, Yvonne Cavichio-Balmer & Johannes Huber (2013). *Shaping parents: impact of contrasting professional counselling on parents' decision making for children with disorders of sex development*, *Journal of Sexual Medicine*, Vol. 8 No. 3, pp. 1933–1960 <http://www.ncbi.nlm.nih.gov/pubmed/23742202>