

**Intersex intervention during the**  
**Public consultation convened by the**  
**UN Independent Expert on protection against violence and discrimination based**  
**on sexual orientation and gender identity**  
**24<sup>th</sup> to 25<sup>th</sup> of January 2017, Geneva**

**Miriam van der Have, Executive Director of NNID, Board Member of ILGA**

Thank you, Professor Muntharborn, for this consultation.

My name is Miriam van der Have, I am Executive Director of the Dutch Intersex organization NNID and board member of ILGA. Today I would like to speak about a publication my colleague Dr. Margriet van Heesch, of the University of Amsterdam, and I are working on. In this publication we discuss what intersex is, and that might be of use for your work.

Over the past two days many states and organizations used the acronym LGBTI. Yet intersex is not a clear part of the mandate of the Independent Expert. International intersex organisations like Organisation Intersex International, are very clear about using the I in LGBTI. They say: don't add the I if you don't include intersex in your policy.

Yet, the work of the UN Independent Expert on SOGI will influence the lives of intersex people as well. As professor Muntarhorn already said, all people have a sexual orientation, and all people have a gender identity. I would like to add to this that all people have sex characteristics.

For being born with a body that does not fit the normative medical definition of male and female, intersex people are treated different from day one on. As soon as we are born we face the violations of human rights, like the violation of our bodily integrity.

One of the goals of the 'normalizing' medical treatment many intersex children undergo, is to assign a gender. From a scientific point of view it is obvious you can't assign a gender. As intersex people are not given the possibility to develop their own gender, because other people decide that for them, there is a link between the discrimination based on gender identity and the discrimination based on sex characteristics.

But that does not mean that what works for the fight against discrimination of LGB and trans people will also work for the fight against the discrimination of intersex people. Though there are similarities between the struggle for equality of these groups, there are also many differences between LGBT and intersex.

To understand that, we need a clear understanding of what intersex is.

If I want to explain to a foreigner what the Dutch word 'stoel' means, I probably will point to a chair and

say, with a certain emphasis, 'chair'. This has two consequences: it gives the meaning of the word we pronounce as 'stoel', and it also gives you a, as linguistics call it, an ostensive definition of a chair. The use of words such as chromosomes, hormones, gonads, etcetera that are used in the current definitions of intersex, is only a step away from an ostensive definition. It does not show the body parts, yet it assumes that the listener understands those concepts. And if that is not the case, you can still identify them in a medical encyclopedia.

The disadvantage of an ostensive definition is that it is limited to what is visible or can be visualised in a drawing or a photo. Notions like stigma, shame or secrecy - key features of intersex - can't be defined with an ostensive definition.

As a result, current definitions tell how we recognize an intersex person, not what intersex is.

But even 'recognition' is not correct for everyone. Because the chromosomes, hormones, gonads, etc. are not visible, for most persons the proposition that someone is an intersex person is only in principle verifiable, but not actual verifiable.

Existing definitions of intersex are operational: they show how to recognize an intersex person. Because they describe the variables that serve as indicators (hormones, chromosomes, gonads, etc.) and the procedures to be followed in measuring or observing these variables (or implicitly: medical procedures), these operational definitions are primarily intended to measure intersex (in other words: to recognize an intersex person).

If we want to know the meaning of intersex, a conceptual definition is needed. A conceptual definition shows how the construct that the definition is, relates to other abstract structures. Without a conceptual definition, it is unknown what is measured with the operational definition.

Dr. Margriet van Heesch, working at the University of Amsterdam, and I have developed a new definition for intersex. This definition reads:

"Intersex is the lived experience of the socio-cultural consequences of being born with a body that does not fit the normative social constructions of male and female."

Our new definition is conceptual and may serve as a framework for a non-medicalized, operational definition of intersex. Most current operational definitions are based on the physical characteristics of intersex and the possibly related psychological problems. As a result, intersex may seem to be only part of the health care domain. In reality, intersex is a multidimensional concept. In a new operational definition it must be clear that intersex is part of many other domains, including the social domain, without assuming beforehand that intersex leads to a reduced quality of life or that intersex is an undesirable outcome of a pregnancy, as is visible in medical technologies such as PGD and NIPT that may lead to the erasure of intersex in society.

## **Dan Christian Ghattas, Co-Chair OII Europe**

Good afternoon, my name is Dan Christian Ghattas, and I would also like to thank the Independent Expert for this consultation. I am Co-Chair of OII Europe, which is the umbrella organisation of European human rights based intersex organisations. By profession I am a researcher. Speaking about research: Despite a frightening lack follow-up studies that would prove the actual benefits of non-life saving, cosmetic genital surgeries and other medical interventions and despite the fact that intersex adults and young adults have pointed and still point today to the human rights violations they faced and face – these medical treatments are still performed on intersex infants and children.

In one of the European Union Member States for the first time worldwide, comprehensive and sound quantitative data on cosmetic genital surgeries performed on children is available: The study published in December 2016, is a retrospective statistical data assessment from the hospital statistics based on case flat rates on feminising and masculinising genital surgeries carried out in that respective country's hospitals between 2005 and 2014.<sup>1</sup> The study focuses on children under the age of 10.

I would like to share some of the key findings with you:

- The development of the relative frequency of so-called feminising genital surgeries showed no significant decline: On average, 99 feminising surgeries *per year* were carried out on infants and children in the period of investigation. In 2012 to 2014 the average number was still 91 procedures per year. Most feminising surgeries were plastic operations on the vulva (including perineum), the other procedures were clitoral surgery and vagina constructions.
- The relative frequency of so-called masculinising surgeries remained almost constant over the period of investigation: The number of plastic surgeries of the scrotum, testicles, and penis, including 'corrections' of hypospadias, that is relocating the urethral opening on the top of the penis were rising in the period under study: from an average of 1601 per year in the period 2005 to 2007 to 1617 in 2012 to 2014.

All in all, the relative *frequency of genital surgeries on infants and children with variations of sex characteristics did not drop between 2005 and 2014*. But in the same period a significant change of underlying diagnoses took place: Whereas the relative frequency of 'classic' intersex DSD-diagnoses such as 'pseudo-hermaphroditism' decreased, the frequency of other diagnoses that make up the spectrum of variations of sex characteristics and which are summed up in the category 'unspecified malformation of the female/male genitalia' remained statistically constant or even increased significantly.

As it can be taken for granted that the biological phenomena *themselves* have not changed.

*The results of the study are worrying, especially in the light of recent statements of medical practitioners who declared that surgeries on intersex children have significantly decreased in the past years: In reality the number of genital operations has not dropped.*

According to the findings of the EU Fundamental Rights Agency focus paper "The fundamental rights situation of intersex people", published in 2015, surgeries on intersex infants and children are still performed in at least 21 member states. A comparative pre-study I published in 2013 about the life

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<sup>1</sup> Ulrike Klöppel: Zur Aktualität kosmetischer Operationen „uneindeutiger“ Genitalien im Kindesalter. Berlin 2016, [https://www.gender.hu-berlin.de/de/publikationen/gender-bulletins/texte-42/kloepfel-2016\\_zur-aktualitaet-kosmetischer-genitaloperationen](https://www.gender.hu-berlin.de/de/publikationen/gender-bulletins/texte-42/kloepfel-2016_zur-aktualitaet-kosmetischer-genitaloperationen) (10.1.2017)

situation of intersex people in 12 different countries from all over the world also showed that intersex people are subjected to unconsented surgery in childhood everywhere in the world. InterACT an intersex organisation based in the US and Human Rights Watch are currently partnering to produce a report on human rights violations against intersex infants in the United States and it is likely that the findings will be similar.

**Betsy Driver, Independent Intersex Expert, Founder of the first internet online community “Bodies Like Ours”**

Good afternoon, my name is Betsy Driver. I am an independent intersex activist in the US. I join my colleagues in thanking the Independent Expert for this consultations.

In 2001, I started to speak publicly about my own experience of growing up with a body that did not fit the medicalized standard definition of male or female, and the medical interventions I was subjected to as a child, including the complete amputation of my clitoris when I was eight months old.

I embarked on this journey by founding an online intersex community that same year. Bodies Like Ours was the first online internet community where those with intersex variations could find kinship with and communicate with others like themselves. I started it for a very simple and selfish reason - it was to find others like myself after a lifetime of being told by my doctors I was the only person out there with a body like mine. This simple action undertaken when the words social media didn't even exist was life-saving for me. A few years later, I came up with the idea of Intersex Awareness Day to help get the word out there that we are not unicorns and that our issues are very real. Both efforts gave rise to many of the intersex advocates you hear from on the global stage today.

Over the past 11 months, I have been interviewing many individuals with intersex characteristics. To date, I have heard the stories of 54 individuals from across the globe.. Most of them are not accustomed to sharing their stories publicly.

Nearly every person has told me the same story - one of shame, and secrecy about their body. It is not their shame, but rather the shame of their parents, and imposed on them by medical professionals with the goal of making their existence as people with queer bodies invisible. I call it the shame heard around the world.

This treatment, and I use that word loosely is rather than calling it torture which I do believe these surgeries are, has been a dark mark on the medical community. It remains a problem in the medical community today. As result of the way many people with intersex variations are treated by the medical community in childhood, they simply stop seeking medical treatment for any health concerns as adults.

As adults, we are a large diverse group. It is approximated that up 1.7 percent of the population has some type of intersex variation. Think about how many redheads you meet - you likely meet the same number of people with intersex characteristics. However, because of the cloud of shame and secrecy that surrounds those of us with intersex characteristics, there is no way to know precisely how many of us exist.

Many of us don't even know ourselves we are intersex, having had that detail kept secret from us.

We are queer, we are straight, we are gay, we are lesbian, we are bisexual. We are trans, we are female, we are male, we are they, we are gender fluid, we are neither.

Our intersectionality is all of this, joined together by our queer bodies.

**Morgan Carpenter, Co-Executive Director OII Australia, Consultant to GATE on intersex issues**

My name is Morgan Carpenter, I'm a consultant to GATE on intersex issues and a co-executive director of intersex organisation OII Australia.

I too welcome the opportunity for participation in this transparent process, and congratulate you, Professor Muntarhorn, on your role. I also thank Betsy and Bodies Like Ours for helping to save my life, after years with no peer support.

Intersex is not widely understood, so I'd like to quickly describe and contextualise some data from the largest sociological study of intersex people yet conducted, an Australian study of 272 people born with atypical sex characteristics. Some of these data show intersectionalities within LGBTI.

You might think that sex characteristics are linked to gender but, for intersex people, biological sex characteristics are loosely related to legal sex assigned at birth.

Initially, 52% of respondents were legally assigned female, 41% were assigned male.

Like everyone else, we have a diverse range of gender identities, and Australia supports a legal non-binary option.

At the time of the survey: 52% of respondents indicated that they were female, 23% indicated that they were male, and 19% selected X or other options.

Like everyone else, people born with atypical sex characteristics have a diverse range of sexual orientations.

48% of respondents stated that they were heterosexual, while 22% selected bisexual, 15% queer. 10% of individuals stated asexual: that's a large figure that may reflect the physical and psychological impact of medical interventions.

And the words we use to describe sex characteristics: overall, 60% of respondents used words including the term intersex; a proportion describe as "having an intersex variation" or "having an intersex condition". The use of diagnostic labels and sex chromosomes is also common. It is particularly notable that only 3% of respondents use the clinical term "disorders of sex development" to describe themselves, while 21% use that term when accessing medical services. From our perspective, this shows a perceived

need to disorder ourselves to access appropriate medical care.

60% received treatments on basis of sex characteristics, half at under 18 years of age. The majority experienced at least one negative impact from treatment. 60% had thought about suicide, 19% had attempted it.

A global and decentralised intersex movement pursues simple core goals: the rights to bodily autonomy and self-determination, and an end to stigmatisation.

The Yogyakarta Principles elaborated an application of international Human Rights Law in relation to Sexual Orientation and Gender Identity. In the decade since then, we have engaged with our local, national and the international human rights system, with a number of wins, including the development of new legal attributes that better capture our experiences: Malta was the first country to protect people from discrimination on grounds of sex characteristics. UN treaty bodies have condemned human rights violations in medical settings as harmful practices.

Major challenges remain to implement those statements. Human rights violations of intersex individuals persist, deeply embedded in a deliberate history of silencing. I was pleased to hear the statement of the Association of LGBT Doctors and Nurses this morning. But I'm also aware that, while other areas of medicine have shifted to become evidence based, the medical treatment of intersex people remains devoid of evidence. Statistical data is scarce, Dan Ghattas has detailed some of it. Evidence of actual practices is often privileged, including in my country, because disclosure of such information discloses human rights violations.

As I wrote in the journal Reproductive Health Matters last year: rhetoric of changes to clinical practices remain unsubstantiated. We still lack credible non-surgical pathways. Policy disjunctions arise in a framing of intersex issues as matters of sexual orientation and gender identity, rather than innate sex characteristics; this has led to a rhetoric of inclusion that is not matched by the reality.

We encourage the mandate holder to engage closely with intersex human rights defenders regarding the role and work of your mandate, and consult with the Special Rapporteurs on Torture and Health, and also with the Office of the High Commissioner on Human Rights about the outcomes of an expert meeting on ending human rights violations against intersex persons.

**Mauro Cabral, GATE, Executive Director of GATE**

Advocacy on depathologization has a really long history, a history full of challenges, as we are struggling to change one of the most powerful institutions in the world, psycho-medical science, and its articulation in legal regulations and bioethical provisions. We have achieved outstanding victories in that struggle, from introducing depathologization as a guiding biopolitical value in the Yogyakarta Principles, including Principle 18 against medical abuses, to statements from regional human rights bodies, to language coming from Special Procedures, such as the Special Rapporteurs on Health and on Torture. We have even achieved what seemed to be impossible just some years ago in terms of

legal reform: depathologizing access to legal recognition and access to gender affirming treatment in Argentina, and protection against normalizing procedures affecting intersex people in Malta.

However if we are talking about depathologization here is because human rights violations based on pathologization are still taking place all around the world.

*Pathologization* is the process by which a physical or mental trait, a habit, a practice, a way of life, an individual, a population or even large groups of persons are arbitrarily defined as *sick* in comparison with other traits, habits, practices, ways of life, individuals, populations and groups of persons arbitrarily defined as *healthy*. *Pathologizing* is not only a very common and pernicious way of stigmatizing and discriminating but also a very usual justification for those two behaviours.

We strongly appreciate the commitment of your Mandate to involve doctors in promoting LGBTBI people's human rights but, in the same sense, we consider really necessary to acknowledge the gross human rights violations against us perpetrated in medical settings by medical practitioners, as well as the way in which psycho-medicine, bioethics and the law are working together in, many countries, to establish, implement, justify and naturalize public policies that clearly violate our human rights, such as sterilization as a legal requirement for gender recognitions.

Your Mandate represents for us not only a historical opportunity of challenging and changing harmful psycho-medical practices by involving psycho-medical practitioners in all dialogs concerning SOGI issues, but also to remind the world that pathologization is not compatible with human rights standards, and that human rights violations perpetrated in medical settings and/or grounded on psycho-medical rationales cannot be justified as matters of ignorance, opinion or preference –as they are what they are: human rights violations.