

Universal Periodic Review for Russia

Written individual submission from Intersex Russia

Intersex Russia

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Intersex Russia was established in March 2017 and is led by two young intersex activists from Moscow.

Our mission is to provide accurate and positive representation of the intersex community in Russia, to raise awareness about the existence of intersex people and the issues that the intersex community faces, to make a strong stance for de-pathologization and de-medicalization of the lives of intersex people throughout all of our activities, and to, over time, create a strong network of intersex support groups across the country. Our motto is intersex people to intersex people for intersex people. Intersex Russia's main constituency is intersex youth in Russia. We are working to eradicate intersex genital mutilation in Russia and to protect intersex human rights.

## Intersex rights in Russia

By the UN definition,<sup>1</sup> intersex people are born with sex characteristics (including genitals, gonads, chromosome patterns and reproductive organs) that do not fit typical binary notions of male or female bodies. Intersex is an umbrella term used to describe a wide range of natural bodily variations, and it covers any congenital sex anatomy (internal and external) that is different from typical male or female. In some cases, intersex traits are visible at birth while in others, they are not apparent until puberty. About 1.7% of the human population is intersex, and the majority of intersex people are physically healthy. Being intersex relates to biological sex characteristics, not sexual orientation or gender identity.

In Russia, intersex people are experiencing violations of their basic human rights, including the right to full informed consent, physical integrity, bodily autonomy and self-determination.<sup>2</sup> Medically unnecessary “normalizing” surgeries and other medical interventions are performed<sup>3 4</sup> on intersex people, often done without their full, free and informed consent, in order to “normalize” their bodies and appearance and to make their bodies conform to social norms of male or female bodies. Selective abortions on intersex fetuses and hormonal interventions on intersex fetuses and small children are being routinely performed.

When performed without informed consent or adequate information, unnecessary surgeries violate intersex people’s right to physical bodily integrity and may have lifelong consequences on their right to health and their sexual and reproductive rights, particularly since they can severely impede people’s fertility (literally being forced sterilization). The specific permanent consequences of IGM often are: loss of sensation, problems with urination, pain, infertility, scarring, need of lifelong hormonal replacement therapy, psychological traumas and lifelong mental suffering. Also, sometimes people are forced into a gender identity they don’t identify with.

These surgeries are often referred to as IGM - Intersex Genital Mutilation. These unnecessary interventions are often done in infancy, and are invasive, irreversible and not emergency-driven. This is a mutilating, harmful practice, inhumane treatment and institutionalized violence that is often referred to as torture. In rare cases intersex people do require medical help - IGM isn’t about that, it’s about surgeries done without any medical necessity.

Both UN Committee on the Rights of the Child (CRC) and the UN Committee against Torture (CAT) have expressed their concern over IGM practices, with CRC calling IGM a harmful practice.<sup>5</sup>

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<sup>1</sup> See English: <https://goo.gl/EDMwZt> Russian: <https://goo.gl/Mq1zJD>

<sup>2</sup> See: <https://goo.gl/kEqjU6>

<sup>3</sup> See: [https://youtu.be/B7hxwjUG3\\_I](https://youtu.be/B7hxwjUG3_I)

<sup>4</sup> See: <https://goo.gl/e42XxJ> (In Russian)

<sup>5</sup> See: (CRC/C/CHE/CO/2-4) <https://goo.gl/VxT5uU> ; (CAT/C/FRA/CO/7) <https://goo.gl/9RmEQc>

These interventions go against principle 18(b) of the Yogyakarta Principles, which calls on the states to “take all necessary legislative, administrative and other measures to ensure that no child’s body is irreversibly altered by medical procedures in an attempt to impose a gender identity without the full, free and informed consent of the child in accordance with the age and maturity of the child and guided by the principle that in all actions concerning children, the best interests of the child shall be a primary consideration”.

These interventions also go against the Russian law N 323-FZ “On the bases of protection of public health in the Russian Federation” which specifically says in the article 20 <sup>6</sup> about full informed consent being a mandatory requirement for any medical intervention.

By article 54 <sup>7</sup> of that law children have to provide full informed consent since the age of 15, but that law is often ignored when it comes to intersex people.<sup>8</sup>

There are no reports of existence of specific support groups for intersex children or their parents, usually they are not provided with any support.

There is no existing legislation protecting the rights of intersex people in any way, and sex characteristics are not mentioned in any policies.

Small sample survey <sup>9</sup> done in September 2016 about life experiences of intersex people in Russia and Post-Soviet Region shows that:

- One third (36%) of participants had surgery without their full informed consent, many of them regret having those surgeries;
- Many participants received no information or false information about their intersex variation (diagnosis) from their doctors and parents. The majority of participants wanted to find out that they’re intersex much earlier in life than they actually did;
- The majority (73%) of participants defined their experience with the medical community related to their intersex variation as negative;
- The majority of participants (64%) had problems obtaining their medical records, with two of those people never getting their medical records in the end;
- Almost all (91%) participants have experienced bullying related to them being intersex at some point in their lives;
- To this day all participants experience negative emotions when visiting a doctor on behalf of their intersex variation;
- Most participants (82%) see intersex representation in the media in Russian language as negative.

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<sup>6</sup> See: <https://goo.gl/FMZQjS> (In Russian)

<sup>7</sup> See: <https://goo.gl/Hmthng> (In Russian)

<sup>8</sup> See: <https://goo.gl/K5QGj7>

<sup>9</sup> See: <https://goo.gl/EdE4YC>

When asked to name the main problems intersex community is facing in Russia, participants of the survey named among others:

- Surgeries done without informed consent and medical necessity; pathologization;
- Doctors providing no choice when it comes to choosing HRT (hormonal replacement therapy) for intersex patients - doctors choices are driven by outdated standards of medical care - gender identities strictly attached to each intersex diagnosis (variation), often ignoring person's own gender identity, medical needs and wishes. For example, people with complete and partial androgen insensitivity syndrome are usually perceived as female and are being prescribed only estrogen; people with Klinefelter syndrome are always perceived as male and are being prescribed only testosterone;
- Bullying; shame, secrecy, stigma;
- Difficulties with getting medical records for intersex people;
- Lack of legal help and proper psycho-social help for intersex people;
- Low quality and high price of medical services;
- Lack of established intersex community and terminology;
- Impossibility to change gender marker for people who are intersex and trans;
- Selective abortions of intersex fetuses.

Intersex variations in Russia are officially considered a disability.<sup>10</sup> This supports the pathologization of intersex people, limits their chances of finding a job, chances of being adopted and possibility to adopt themselves in the future. But, on the other hand, it is useful for some intersex people since it allows them to get disability benefits.

Also, there were cases of trans people denied transitioning and changing their gender marker on the basis of them having intersex variations - even though it's not supported by any laws. This violates the fundamental right to self-determination and of recognition under the law and goes against Article 16 of the ICCPR and Principle 3 of the Yogyakarta Principles.

Unfortunately, there are very few public cases and very little data on human rights violations experienced by intersex people in Russia. Sometimes doctors actually write IGM surgeries down in medical records as some other surgery (hernia repair, etc.) The Russian Ministry of Health does not keep any official specific statistics related to intersex people (in medical settings - people with DSD - Disorder of sex development/НФП - Нарушение формирования пола) and medical interventions performed on them. This impedes advocacy, awareness raising or education on intersex issues; contributes to the lack of recognition of intersex community and intersex human rights; prevents the international community holding the government accountable for human rights violations against intersex people.

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<sup>10</sup> See: <https://goo.gl/D2GoYz> (in Russian)

There were cases of FGM (Female Genital Mutilation) happening in Russia, and that practice was widely condemned by the Russian media. However, IGM (Intersex Genital Mutilation) and violations of intersex human rights are almost never mentioned in the media.

Intersex people are often sensationalized in the Russian media, with very few publications having a depathologizing approach and mentioning human rights violations intersex people are experiencing. Incorrect terminology like “hermaphrodite” is often used, along with incorrect misleading words like “intersexual” or “intersexuals”, which incorrectly makes intersex seem like a sexual orientation.

Non-consensual unnecessary surgeries on intersex infants are actually being mentioned in Russian media in a positive way by journalists, doctors and government officials, and are presented as the right and necessary thing to do. Sometimes they are mentioned as “sex change surgeries”.<sup>11 12</sup>

In May 2017 there were several articles<sup>13 14</sup> in the Russian media about Italian surgeon Roberto de Castro, who performed a non-consensual and medically unnecessary surgery (clitoridectomy and vaginoplasty)<sup>15</sup> on a 3-year-old intersex girl in Syktyvkar, Russia. Even Russian Ministry of Health wrote about it.<sup>16</sup> The surgery was performed in «live-surgery» mode, meaning it was broadcasted to all the visitors of the "Current Problems of Pediatric Surgery" conference. About 50 specialists were present, many of them recorded surgery on video. The video of that genital surgery on a child was openly shared on the internet and in the media.

During the first day of the conference Roberto de Castro performed two surgeries and was planning on performing several more during the conference, saying that: “It's also a great luck that the organizers did a tremendous amount of work and gathered here several patients with this rare disease. Level of surgery's difficulty is different, so the attendees of the conference will see the full spectrum of my method.” Roberto De Castro is an author of his own method in surgically “treating” intersex variation called Congenital adrenal hyperplasia, and he performs demonstrative surgeries in countries all around the world (including Russia), teaching other surgeons his method.

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<sup>11</sup> See: <https://goo.gl/GxWsM5> (In Russian)

<sup>12</sup> See: <https://goo.gl/PLTibN> (In Russian)

<sup>13</sup> See: <https://goo.gl/wmYmX2>

<sup>14</sup> See: <https://goo.gl/AN3p9c>

<sup>15</sup> Clitoridectomy or clitorrectomy is the surgical removal, reduction, or partial removal of the clitoris. Commonly, non-medical removal of the clitoris is performed during female genital mutilation (FGM).

Vaginoplasty is a surgical procedure that results in the construction or reconstruction of the vagina.

<sup>16</sup> See: <https://goo.gl/RG7QjJ> (In Russian)

Talking about that surgery, Minister of Health of Komi Republic Dmitry Berezin said that "This surgery means a lot for the whole Komi Republic. This fact that this surgery was performed says, firstly, about a high level of pediatric surgery in the region. And as pioneers in the sense of receiving unique knowledge, we must meet this level of experience".<sup>17</sup>

We are deeply concerned about Russian government officials speaking out in favor of medically unnecessary surgery on intersex infants.

On 20 September 2017, speaking at a ministerial event during the General Assembly's high-level session the United Nations, High Commissioner for Human Rights Zeid Ra'ad Al Hussein said: "We ask all governments to allow individuals to love whom they choose, to outlaw discrimination, tackle hate crimes and the bullying so frequent in schools, and to protect intersex children from harm – including by banning medically unnecessary surgery on intersex infants. The onus has to be on governments to protect and respect rights – and explain to the public why these measures are needed."<sup>18</sup>

Russia has never received a recommendation on intersex issues in the UPR, only one general recommendation from Norway to Russia about "preventing discrimination on grounds of sexual orientation and protect the rights of LGBTI people", hence the need to have recommendations focusing on intersex issues during Cycle 3.

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<sup>17</sup> See: <https://goo.gl/4W9Fs7> (In Russian)

<sup>18</sup> See: <https://goo.gl/x5WLCg>

Our proposed recommendations are:

1. Ban non-consensual interventions on intersex bodies, made on cosmetic, social, psychosocial, cultural grounds and grounds of ability to have “normal” sexual intercourse, which can be deferred until the person is old enough to provide full, free and informed consent, unless the intervention is absolutely medically necessary (meaning that person’s intersex variation (diagnosis) affects their lifespan and performance of vital bodily functions).
2. Recognize intersex people as a community that has specific and vital needs as well as human rights that need protection.
3. To ensure that human rights violations against intersex people are investigated, all the alleged perpetrators prosecuted, and victims should have access to effective remedy, including redress and compensation.
4. Ensure that intersex people always receive full information about their bodies and diagnoses and that free and informed consent is given by them before all interventions they are receiving. Any treatment performed without the intersex person’s free, personal and fully informed consent, unless life-saving, should be made unlawful.
5. Ban selective abortions, pre-implantation genetic diagnosis (PGD) and prenatal treatment of intersex embryos and fetuses.
6. Install constitutional protection, anti-discrimination and hate crime and hate speech legislation on the grounds of sex characteristics.
7. Depathologize variations in sex characteristics in medical guidelines.
8. Russian Ministry of Health and Russian medical community to be obliged to keep specific official statistics of the number intersex people they are treating and interventions they’re performing on them.
9. To ensure that gender markers can be changed through a simple administrative procedure at the person’s request, no matter if they’re intersex or not.
10. To ensure that medical professionals are getting educated on intersex rights and depathologizing approach to treating intersex variations.
11. To ensure that government would have to consult and get approval from intersex organizations when developing and implementing any training program or policy related to intersex human rights.
12. Recognize that medicalization and stigmatization of intersex people result in significant trauma and mental health problems.
13. To expedite the development and implementation of a rights-based health-care protocol for intersex children and adults that sets the procedures and steps to be followed by health teams in order to ensure that no one is subjected to unnecessary surgery or treatment.
14. To protect the rights of the children to physical and mental integrity, bodily autonomy and self-determination, provide intersex children and their families with adequate counselling and support, including from peers.
15. Increase positive intersex representation in all fields of media, from tv shows and movies to books and magazines.