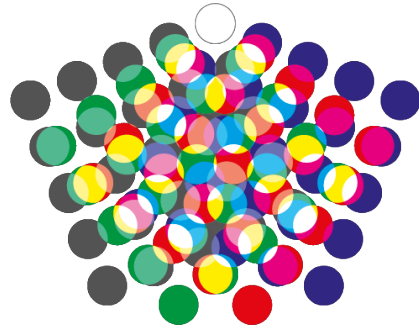


Intersex and medicalized rape



NNID

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Executive Summary

Intersex is highly medicalised. This medicalisation is necessary to hide human rights violations as medical care. While the intentions may not be malicious, when looking at the actions, a different image emerges. It becomes clear that intersex people are regularly and sometimes even routinely subjected to rape and sexual violence. These actions include: grooming behaviour, provoking sexual arousal without consent sometimes even on small children, construction of vagina's on children and teens that require insertion of penis-shaped objects, repeated observing and examining genitals far beyond any level needed to provide care, but rather out of personal interest, and producing photographs and video's of intersex genitals without consent and spreading these images without restrictions. These human rights violations are rarely discussed and even more seldom recognised as human rights violations. Research shows that intersex people are most likely to suffer from a physical or sexual attack out of all LGBTI people. Medicalisation obscures at least a part of these violations. If medicalised rape and sexual violence are recognised, these figures will probably rise. Medicalised rapes on intersex people are not prohibited and therefore not reported. Victims do not have access to justice, and perpetrators are not prosecuted. If the victims would realise that their experiences as children constitute rape, the statute of limitations has generally passed. Lack of recognition has resulted in impunity for the perpetrators and long term sexual abuse for the victims. It is high time that these practices are included in legislation that prohibits rape. States have a responsibility to protect its citizens from these human rights abuses.

Introduction

This report discusses the medicalised rape of intersex people to urge the inclusion in the thematic report to be presented to the UN Human Rights Council in June 2021. This form of rape is rarely discussed and not legally recognised as part of the grave and systematic human rights violation and gender-based violence that intersex people experience. As a result, answers can only be provided for question 25 and 26 of the questionnaire.

As medicalised rapes on intersex people are not recognised, these violations are not officially reported or prosecuted. The impunity for perpetrators of such crimes has regularly resulted in long term sexual abuse as will be shown below. It is high time that these practices are included in legislation that prohibits rape. States have a responsibility to protect its citizens from these human rights abuses.

Additionally, the inclusion of medicalised rape and sexual violence against intersex people is essential for the intersex community. Even if medicalised rape is not immediately recognised in national criminal justice systems, recognition by the special rapporteur and the UN Human rights council will undoubtedly positively affect intersex people and the intersex community. Intersex people experience stigmatisation and have often been forbidden by health workers to speak about being intersex. The combined stigma of being intersex and being a rape survivor coupled with a lack of recognition has resulted in these issues not being discussed. The recognition of intersex genital mutilation as a human rights violation by the UN has allowed intersex people to speak about their experiences, receive support and heal. Recognising that medicalised rape is part of intersex lived experiences will increase the discussion of these issues and allow victims to heal and receive support.

Background and Methodology

NNID Foundation is an intersex-led human rights organization working on the rights, visibility and equality for intersex people. This report is based on peer-reviewed scientific sources, evidence gathered and documented at events and online, and reports made by intersex people to NNID Foundation and other intersex organizations in NNID's network who reported it to NNID.

Intersex

Intersex refers to the lived experiences of people born with a body that does not fit normative societal definitions of male or female. While some intersex people do not identify as men or women, most do. We believe it is crucial to include all intersex people and recognize all intersex people's gender identity. Therefore, the intersex community chooses to use the term intersex people. However, it is important to note that many intersex people are women.

No one can predict the future gender identity of intersex infants. Recent European research showed that five per cent of **all** intersex children change their assigned gender, including those with forms of intersex that are often not recognised at birth. In about 80% of those cases, the shift occurs before puberty¹.

Medicalisation of intersex

Intersex is not a disease. However, intersex people are often treated by society and health workers as if they have a defect to be fixed by surgery and medicine. Throughout the world, intersex children are exposed to non-consensual, unnecessary medical treatment to bring their sex characteristics, both externally and internally in line with society's normative definition of male or female.² These treatments include surgical interventions, to adjust the appearance of external sex characteristics and to remove internal reproductive organs that are not in line with the assigned sex³, hormone treatments, and psychological treatments to enforce and strengthen the assigned sex and gender. Several reasons are mentioned by doctors for these treatments, which are not medically necessary, do not follow from any scientific research or can at least be postponed until free and fully informed consent can be given. These interventions are mostly irreversible, and can lead to intersex children being confronted with a body that does not fit with who they are.

It is necessary to label children and adults who do not experience health issues as intersex, to label intersex as a medical issue, and to label practice that violates human rights as medical care. Otherwise, some medical treatments and studies on intersex children and adults would clearly be

1 Falhammar H, Claahsen-van der Grinten HL, Reisch N, Slowikowska-Hilczer J, Nordenstrom A, Roehle R, et al. Health status in 1040 adults with disorders of sex development (DSD): a European multicenter study. *Endocrine Connections*. 2018. (<https://doi.org/10.1530/ec-18-0031>).

2 ESPU – SPU. Consensus statement 2020: Management of Differences of Sex development (DSD). 2020. <https://www.espu.org/members/documents/383-espu-spu-consensus-statement-2020-management-of-differences-of-sex-development-dsd>.

3 Shnorhavorian M, Fechner PY, Disorders of Sexual Differentiation. In: *Avery's Diseases of the Newborn* (Tenth Edition), 2018

considered sexual abuse⁴. Focusing on the actions rather than on the justification of the actions reveals the true nature of medicalised sexual violence and rape.

Intersex people require health care as all people, however, as a result of these interventions intersex people are often dependent on health workers for the rest of their lives due to complications or a need for medication. Dependency on health workers, usually from a young age, makes intersex particularly vulnerable to medicalised rape and sexual violence. The special position of health workers further contributes to a power imbalance both in knowledge and societal status. Intersex people and their parents or carers are dependent on the knowledge of health workers. Health workers, especially doctors, have a high societal standing. This results in society being positively biased towards health workers. We fully support that many health workers do great work, and intentions may not be malicious. However, it is necessary to understand that even well-intentioned health workers can commit serious human rights violations, especially in the health care of intersex people.

Statistical data on sexual violence against intersex people

Minorities, such as intersex people, have a higher risk to be victims of violence, including sexual violence. Little statistical data on the lives of intersex people is available. Most research on intersex comes from the medical field and focusses on exactly how intersex bodies differ from the norm. It is clear that these violations are common, but not how common. A recent survey from European Union Agency for Fundamental Rights (FRA) showed that 22% of intersex respondents experienced a physical and/or sexual attack for being LGBTI, in the five years before the survey, being the most affected of all LGBTI people. It is unlikely that all respondents were aware that at least some of the treatment they had received from health workers constituted rape. Medicalisation prevents the recognition of these crimes. If medicalised rape and sexual violence are more commonly recognised as human rights violations, these figures will likely rise. We are currently only seeing the tip of the iceberg.

Examples of medicalised rape

Grooming

The practices described below are often started at a young age to prevent intersex children from resisting medicalised rape and sexual violence. A Dutch Urologist told at a conference that she has

4 **Alexander T.** The Medical Management of Intersexed Children: An Analogue for Childhood Sexual Abuse Rohnert Park, CA, USA: Intersex Society of North America; 1997. URL: <http://www.isna.org/articles/analog>.

Dreger AD. Rejecting the Tranquilizing Drug of Gradualism in Intersex Care [Blog]. 2015 [bewerkt 21 november 2015; geraadpleegd 24 november 2015]. URL: http://www.alicedreger.com/DSD_human_rights.

Jones T, Hart B, Carpenter M, Ansara G, Leonard W, Lucke J. Intersex: Stories and Statistics from Australia: Open Book Publishers; 2016. <https://doi.org/10.11647/OBP.0089>.

Knight K, Tamar-Mattis S. "I want to be like nature made me": Medically Unnecessary Surgeries on Intersex Children in the US. New York, NY, USA: Human Rights Watch / interAct, July 2017. Nr. 978-1-6231-35027.

Wiesemann C. Ethical Guidelines for the Clinical Management of Intersex. *Sexual Development*. 2010;4(4-5):300-303. <https://doi.org/10.1159/000316232>.

specifically chosen to start performing genital examinations at a pre-pubescent age because children are more cooperative at that time⁵.

Vaginoplasty and dilation of the vagina

Intersex children who are assumed to be girls, but are born with a vagina that is not deemed deep or wide enough for penetration with a penis according to health workers often receive vaginoplasty surgery or are instructed to dilate. Dilation consists of widening and deepening the vagina with objects shaped like a penis. Dilation must be repeated regularly, also post-surgery, or results will decrease. It is particularly troubling when these practices are started in infancy and childhood. Intersex organisations have received personal reports from parents that they feel they were raping their children, intersex women have reported that they have felt coerced into raping themselves with these practices⁶.

Nath and Munkonge⁷ provide a thorough and explicit description of the practice. In their study the genitals of nine intersex children were surgically altered to fit the norm for female genitalia. Post-operatively the children's mothers were taught how to dilate their child's surgically constructed vagina with fingers and plastic test tubes. Seven of these children received 6-monthly follow up to assess the depth of their vaginas. The authors state: 'The depth is satisfactory when ranging between 2,5 and 3,5 cm and the width when the vagina easily accommodates any of the examiner's fingers'.

In an intersex documentary, *No Box For Me*, two young intersex women from France and Switzerland describe that they received vaginoplasty surgery around eight years old. One of them explained that the surgery was repeated every three to six months as the results were deemed unsatisfactory. The French surgeon who operated on these women when they were girls now argues that these surgeries must be done, but on teens rather than young children⁸. However, personal free and fully informed consent should be required at an age that these children are old enough to make these decisions themselves.

5 **Kortman B.** Genitale chirurgie bij DSD. "Ik kan niet toveren", NVVS Najaarscongres Geslachtsvariatie en Seksualiteit: 'Voorbij het binaire denken', 29 November 2019, Ede, The Netherlands. "I tell them that before they come into puberty, that's when they are often still very open to information and they're not seated across me being irritable. Yes, that is really the time to explain it to them. And to do a physical examination together, because in puberty they find it embarrassing. And if I have seen it before puberty, and I know more or less what it looked like, then I can just talk with them. That physical examination is not nice at all for a lot of people. [They will say:] "Oh then I have to go to that doctor, then I have to take off my underpants again". So, I try to minimize that." (translated from Dutch to English). Audio recording and transcription available through contact information below.

6 **Blair K.** When Doctors Get It Wrong. *Narrative Inquiry in Bioethics*. 2015;5(2):89-92. <https://doi.org/10.1353/nib.2015.0029>.

Frader JE. A Pediatrician's View. *Narrative Inquiry in Bioethics*. 2015;5(2):139-142. <https://doi.org/10.1353/nib.2015.0040>.

Meoded Danon L. Time matters for intersex bodies: Between socio-medical time and somatic time. *Social Science & Medicine*. 2018;208:89-97. <https://doi.org/10.1016/j.socscimed.2018.05.019>.

Monro S, Crocetti D, Yeadon-Lee T, Garland F, Travis M. Intersex, Variations of Sex Characteristics, and DSD: The Need for Change. Huddersfield, UK: University of Huddersfield, October 2017. Nr. 978-1-86218-151-9.

Viloria H. Born both: an intersex life. New York, NY, USA: Hachette Books; 2017.

7 **Nath S, Munkonge L.** Sexual ambiguity and malformation in Zambia: challenges in surgical management. *Central African Journal of Medicine*. 1995;41(5):161-166.

8 *No Box For Me. An Intersex Story.* Floriane Devigne. CFRT. France. 2018.

Clitoral sensory testing and vibratory sensory testing

When the clitoris of an intersex woman is deemed too large by health workers, its size is often reduced. This is a shift away from the complete removal of the clitoris as was the common practice in preceding decades. However, the practice is not fully abandoned.⁹

To check whether the surgically altered clitoris retains some sensitivity clitoral sensory tests and vibratory sensory tests were developed¹⁰. The results of these tests are not compared to results prior to surgical interventions. Tests were performed by applying pressure to the clitoris, by stimulating the inner thigh and genitalia (labia majora, labia minora, vaginal introitus and clitoris) with a cotton tip applicator, and by a device that provided vibratory stimulation to access arousal. The tests in this study were performed on 51 intersex people ranging between 4 months to 24 years old; most (37) were under the age of five years old.

It must be clear that genital stimulation is sexual in nature. While the health care workers may not have derived sexual pleasure from these practices themselves, sexual conduct with a child who cannot provide consent is sexual abuse. Health workers no longer report on these practices. However, it is unlikely to have ceased.

Genital examination to access hormone treatment

As a result of removing gonadal material that produces sex hormones, intersex people regularly require access to hormone treatment provided by health workers. This dependence makes them more likely to be forced into procedures that violate their autonomy, such as submitting to genital examinations, without any medical need.

A non-binary intersex person anonymously reported how a health worker raped them. They submitted to gain access to hormone treatment that they needed. They required estrogen due to being castrated as an infant. However, their physician was unavailable. The replacement doctor refused to prescribe the hormone treatment that they had been using for over two decades without investigating the vagina. They submitted to his demands, as they knew they would feel ill without the medication. The doctor put his face very close to their vulva, inserted his fingers into their vagina, moved the fingers around and asked if they could feel it. Then he asked and if they liked it. They left that doctors office with the needed medication. They closed their statement by revealing that they would likely never be able to speak about the experience personally¹¹.

Repetitive genital examination

While growing up, intersex children in all countries are subjected to regular genital exams. These exams often involve multiple attendees and are often repeated by multiple health workers¹². A British intersex person explained in an interview that he had stopped counting how many doctors

9 Intersex Society of Zambia, NNId Foundation. The Rights of Intersex Children in Zambia. NGO submission for the 86th session of the Pre-Sessional Working Group of Committee on the Rights of the Child. List of Issues Prior to Reporting for Zambia. 1 November 2019.

10 Yang J, Felsen D, Poppas DP. Nerve sparing ventral clitoroplasty: analysis of clitoral sensitivity and viability. *The Journal of urology*. 2007;178(4):1598-1601. <https://doi.org/10.1016/j.juro.2007.05.097>

11 Anonymous, This Was Rape! In: Organisation Intersex International Europe. #MyIntersexStory, Personal accounts by intersex people living in Europe. (2019) pp 69. https://oiieurope.org/wp-content/uploads/2019/11/testimonial_broch_21-21cm_for_web.pdf

12 Tishelman AC, PhD. Shumer, DE, MD MPH. Nahata, L, MD. Disorders of Sex Development: Pediatric Psychology and the Genital Exam, *Journal of Pediatric Psychology*, Volume 42, Issue 5, June 2017, Pages 530–543, <https://doi.org/10.1093/jpepsy/jsw015>. While no research has been done on distress in intersex children, investigations have been done on the distress experienced in examinations by girls where FGM is suspected: Johndotter S. Meaning well while doing harm: compulsory genital examinations in Swedish African girls, *Sexual and Reproductive Health Matters*, 27:2(2019);87-99, DOI: [10.1080/26410397.2019.1586817](https://doi.org/10.1080/26410397.2019.1586817)

and nurses had seen him naked. Over the past few years, it was at least a hundred people¹³. Some examination may be medically necessary. However, it is implausible that the repeated nature and inclusion of multiple attendees are in the best interest of intersex people's medical care.

In a spoken word poem, a Dutch intersex woman describes how she was pressured as a teenager to undergo castration paired with an investigation of her vagina by an unknown number of health workers while she was unconscious. Doctors did this to determine if her vagina would be big enough to have penetrative sex with a man. She was never asked if she had any desire to have sex, and if so, if that would be with a man. The doctors told her that it would be better to undergo this procedure while unconscious, as it would be unpleasant. These investigations of her vagina were repeated multiple times over a period of three years while she was conscious. It was done despite her reporting that she did not experience any difficulties or issues with (consensual) penetrative sex¹⁴.

Furthermore, information regarding a child's sex characteristics can be spread to more people than is necessary for medical care, violating the child's right to privacy. For example, the mother of an intersex child in India described that gossip among medical attendants resulted in the child's genitals becoming a matter of curiosity for hospital staff. Some of the hospital's employees stopped by specifically to look at the child's genitals and laugh¹⁵.

The report from the taskforce on policy, legal, institutional and administrative reforms regarding intersex persons in Kenya described that many intersex people felt that they were used as 'specimens' of curiosity. This resulted from "too much exposure to the doctors, nurses, student interns, who often posed many unnecessary, intrusive and embarrassing questions"¹⁶. These repetitive exams damage children's development, violate autonomy and should be recognised as sexual violence.

Medical photography and videography of intersex children's genitals

Furthermore, photographs and videos are often taken of intersex children's genitals, either during examinations or during surgical interventions to adjust their sex characteristics. These images are regularly shown in medical publications, online and when health workers discuss intersex at conferences. This practice goes far beyond the scope of ensuring health care for the individual child and beyond ensuring that there is teaching material. There is a shocking amount of unrestricted material available online. In some rare cases, the faces of the children are shown in the publications, violating their privacy¹⁷.

13 **McDermott S.** My intersex life: Now I have a new penis, I hope I will find love. BBC News. 26 October 2018. <https://www.bbc.com/news/stories-45979431>

14 **A. Tukker.** Spoken Word at Mama Cash Feminist Festival 8 March 2018. <https://www.facebook.com/nnid.nl/videos/1867630819982852>

15 **Joseph AA, Kulshreshtha B, Shabir I, Marumudi E, George TS, Sagar R, et al.** Gender Issues and Related Social Stigma Affecting Patients with a Disorder of Sex Development in India. Archives of Sexual Behavior. 2018;24(2):361-367.

16 Report of the Taskforce on Policy, Legal, Institutional and Administrative Reforms Regarding the Intersex Persons in Kenya (Nairobi, December 2018)

17 Below are examples from around the world, many more examples can easily be found by typing 'ambiguous genitalia' into google image search or YouTube. Trigger warning: graphic content, including the genitalia of young children. From India, showing the face of a 4-year-old that will be operated on later in the video: **Apollo hospitals Chennai.** Successful surgery saves 4 year-old child from Oman suffering from Hypospadias. Uploaded 5 June 2018. <https://youtu.be/oy0P6YAhJ6Y>. From USA: **Hypospadias Specialty Center Administrator.** Distal-Proximal Hypospadias Repair by Dr. Bush & Snodgrass. Uploaded 4 December 2018. <https://youtu.be/NL-C6XaZKyg>. From Japan: **Kawamura, R., Kato, T., Miyai, S. et al.** A case of a parthenogenetic 46,XX/46,XY chimera presenting ambiguous genitalia. J Hum Genet 65, 705–709 (2020). <https://doi.org/10.1038/s10038-020-0748-4>. From Egypt: **Urology and Nephrology Center Mansuora** – EGYPT. UNC VIDEOS Reduction Clitoplasty UGS Mobilization for

This practice persists, despite research that showed that medical photography of intersex children's genitals is damaging to their development¹⁸. Parents of several intersex children in Poland even reported to a Polish intersex organization that the photographs of their child's genitalia were displayed on top of the child's files at one specialized clinic. This clinic hereby exposes images of these children's genitalia to a large number of people. Parents from a conservative Muslim background in India described how their daughter at age 13 was made to remove her clothes by medical staff. Subsequently, a group of doctors took photographs of her genitals on their mobile phones, while she objected¹⁹. It goes against children's sexual autonomy when images of their genitals are shared without their consent or even the opportunity to object.

Statute of limitations

Many of the abuses described above occur when intersex people are infants and children. Even if these practices were recognised as rape and abuse, access to justice is unlikely due to the statute of limitations. It is also important to remember the experiences of intersex people who are now older. Kosta (pseudonym), 57, from Bulgaria tells: *'When I turned 13, I was brought to a special hospital in the capital city) where I stayed for eight years. I was only allowed to go home for holidays. I spent these years with other kids like me. A few times I heard that we were the subjects of a special experiment program*²⁰. Genital surgery, hormone treatments and regular genital examinations were a part of Kosta's life at the hospital. Statutes of limitation should not start until adulthood and should be long enough to allow victims of these forms of medicalised rape to gain access to justice.

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CAH. Uploaded 8 April 2017. <https://youtu.be/FnT7TZS7clw>. From South Korea: **Videourology 2018**. Asan Medical Center. Feminizing Genitoplasty. Uploaded 13 August 2018. <https://youtu.be/95XtI9zBWco>. From Italy: **Centro Chirurgia Uretrale-genitale**. Ipospadias del neonato e dell'adulto. <https://www.chirurgiauretrale.it/ipospadia/>. From Nigeria: **Osifo OD, Amusan TA**. Female Children with Ambiguous Genitalia in Awareness-Poor Subregion. African Journal of Reproductive Health Vol 13 No 4 December 2009.

¹⁸**Creighton S, Alderson J, Brown S, Minto C**. Medical Photography: Ethics, Consent and the Intersex Patient. BJU international. 2002;89(1):67- . <https://doi.org/10.1046/j.1464-410X.2002.02558.x>

¹⁹**Joseph AA, Kulshreshtha B, Shabir I, Marumudi E, George TS, Sagar R, et al**. Gender Issues and Related Social Stigma Affecting Patients with a Disorder of Sex Development in India. Archives of Sexual Behavior. 2018;24(2):361-367.

²⁰Bilitis Resource Centre Foundation, NNID Foundation. NGO report The Rights of Intersex Women and Girls in Bulgaria - CEDAW CR 75 - Jan 2020.