

# The Rights of Intersex Children in Zambia



NGO submission for the 85<sup>th</sup> session of the Pre-Sessional Working Group of  
Committee on the Rights of the Child

List of Issues Prior to Reporting for Zambia

Joint NGO submission by:

ISSZ - Intersex Society of Zambia

NNID Foundation - Netherlands organisation for sex diversity

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## Executive summary

Harmful practices for intersex children in Zambia include non-necessary medical interventions, and intrusive and irreversible treatments, that can be safely deferred until a later age where these children can provide personal, prior, free, and fully informed consent. These treatments include medical and surgical interventions to 'normalize' the external genitalia of these intersex children. These can have a long-term effect on physical and mental health. Furthermore, long-term hospitalization and bullying impair intersex children's access to education.

Therefore, intersex children in Zambia seek protection under Articles 2, 19, 24, 28, and 29 of the Convention and General Comments no. 13, 15 and 18.

Intersex Society of Zambia and NNID request the Committee to consider these issues for the compilation of the List of Issues Prior to Reporting and suggest the following questions for the Committee to request the government of Zambia to provide information on:

- **What medical treatments are provided to intersex children and clarify whether their free, prior and fully informed consent is ensured?**
- **What measures are taken to eliminate stigma and discrimination of intersex children in education?**

## Introduction

This NGO report is a joint submission by Intersex Society of Zambia (ISSZ), and NNID Foundation to highlight key issues faced by intersex children in Zambia. This submission does not provide information regarding all issues faced by intersex children in Zambia. ISSZ and NNID would greatly appreciate the consideration of these issues by the Committee on the Rights of the Child for the List of Issues Prior to Reporting (LOIPR). The paragraphs give contextual information on topics that specifically affect intersex children, followed by links to the Convention and General Comments, and suggestions for questions which can be used for the preparation of the LOI. Appendix 1 contains statements from two parents of intersex children. Appendix 2 contains background information on intersex and harmful practices.

Intersex Society of Zambia is an intersex led NGO focused on empowering intersex people in Zambia through awareness-raising and advocating for the human rights of intersex people. NNID Foundation is an intersex-led human rights organization working for the equality, rights, and visibility of intersex people, and is based in the Netherlands.

## Intersex in Zambia

Intersex refers to the experiences of people who are born with a body that does not meet the normative definition of male and female.

Out of fear of stigmatization, discrimination, rejection and bullying, most intersex children in Zambia live hidden lives. These children can be exposed to multiple human rights violations.

### Harmful Practices and Health [art. 2, art. 19, art. 24, GC no. 13, 15 & 18]

Harmful practices for intersex children include non-necessary medical interventions, and intrusive and irreversible treatments, that can be safely deferred until a later age when these children can provide personal, prior, free, and fully informed consent. For more general background on intersex and harmful practices, see appendix 2.

Non-necessary medical and surgical interventions on intersex children in Zambia have a history of several decades. In their 1995 research Nath and Munkonge<sup>1</sup> describe cases of nineteen intersex children in Zambia. Nine children were surgically assigned female genitalia. Post-operatively the mothers of the children 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. Reports to Intersex Society of Zambia and the statements from Sherry and Nyambose (appendix 1) show that nowadays these non-necessary procedures still take place without personal, prior, free, and fully informed consent.

These interventions can have a long-term effect on physical and mental health. The statement Nyambose (appendix 1) describes how her child complains of physical discomfort when urinating. The future gender identity of the intersex children undergoing these non-necessary interventions cannot be ascertained when these interventions take place. Recent research has shown that five percent of all intersex children, including those with forms of sex diversity that are usually not recognized at birth, change sex before puberty<sup>2</sup>. Mayo describes (statement 1) that his penis was removed at age 12. However, now at age 28, he knows he is a man, even though most of society believes he is a woman.

*These practices are in violation of Article 24 of the Convention which recognizes the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health. Article 24.2(f), as explicated in General Comment no. 15 article 67 and 68 specifically requires guidance for parents and recognizes parents as the most important source of early diagnosis and primary care for small children.*

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<sup>1</sup> **Nath S, Munkonge L.** Sexual ambiguity and malformation in Zambia: challenges in surgical management. Central African Journal of Medicine. 1995;41(5):161-166.

<sup>2</sup> **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>

*Additionally, these practices fall under the criteria of harmful practices, as described in General Comment no. 18, Articles 15 and 16. GC 18 Art. 15 states: ‘Harmful practices are persistent practices and forms of behavior that are grounded in discrimination on the basis of, among other things, sex.’ GC 18 Art. 16 (d) states: “They are imposed on women and children by family members, community members or society at large, regardless of whether the victim provides, or is able to provide, full, free and informed consent.” The consequences are comparable to the effects of female genital mutilation as described in Joint General Comment no. 18, art. 19, which describes amongst others, severe pain, infections, long-term gynecological problems such as fistula, psychological effects and death. Furthermore, these practices are contrary to Article 2 of the Convention on non-discrimination, Article 16 of the Convention on the right to privacy, and Article 19 of the Convention. Article 19 which requires State parties to take all appropriate legislative, administrative, social and educational measures to protect the child from all forms of physical or mental violence, injury or abuse, neglect or negligent treatment, maltreatment or exploitation.*

**Intersex Society of Zambia and NNID request the Committee to ask the government of Zambia to provide information on what medical treatments are provided to intersex children and clarify whether their free, prior and fully informed consent is ensured.**

#### Education and Bullying [art. 19, art. 28, art. 29, GC 13]

Repeated long term hospitalization of intersex children causes them to miss school. The statement from Sherry (appendix 1) shows that she misses school and spends several months in hospital. She has to study on her own in hopes that she will not fall behind. ISSZ has received reports that intersex children have to lie about hospitalization out of fear of discrimination, and that intersex children are missing school because they are bullied as they are believed to be a curse or a bad omen. Bullying has a negative impact on physical and mental health, personal development, and has links to depression, suicide ideation and suicide.<sup>3</sup> Missing education can have long-term effects on the lives of these intersex children and impede future employment opportunities.

*Bullying that impedes access to education is in clear violation of Articles 28 and 29 of the Convention on the right to education, and of Article 19 of the Convention as explicated in General Comment no 13 art. 21 on mental violence, particularly 21.d which lists “Insults, name-calling, humiliation, belittling, ridiculing and hurting a child’s feelings”.*

**Intersex Society of Zambia and NNID request the Committee to ask the government of Zambia to provide information on what measures are taken to eliminate stigma and discrimination of intersex children in education.**

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<sup>3</sup> See for instance: **Esbensen F-A & Carson D C.** Consequences of Being Bullied. Youth & Society. 2009;41(2):209–233. doi:10.1177/0044118x0935106

## Appendix 1: Statements

### Sherry

Twelve year old Sherry\* had genital surgery to make her sex characteristics look female. Her penis was removed at age two. She says: 'I am always in and out of the hospital, and I am missing out on school. Mum cannot even afford the medicine I take, and I hope someone can help us, so I stop coming to the hospital every now and then.' Her mother tells: 'While Sherry is supposed to be in school, she is in the hospital and has to carry her books with a hope to be studying on her own so as not to miss out much. She has to spend one to two months in the hospital waiting for tests to be done and collecting results of the tests, with a view to see the best way forward.'

### Mayo

Mayo\* penis was removed at age 12, and he was assigned female but no follow up reconstructive surgeries were done. Mayo is now 28 years old and identify as male. 'I wish nothing was done on me. Maybe my life would have been different. I do not even know how my tomorrow will look like for me. I wish I can change my name and sex marker on my document, but I do not have the resources to do that'. Mayo feels male, but society knows him as a woman, and as he is dating a woman, he is often assumed to be a lesbian. 'I feel trapped, and I hope someday this nightmare will come to an end'.

### Nyambose

Nyambose\* is the mother of a 12-year-old intersex person and a single parent. She states: 'I only wanted the penis of my child to be straightened and for my child to be able to pee at the tip of the penis and not at the base of the shaft. I was told that my child was female and not male the way I was identifying him. Before I knew it, they had cut the penis of my child to make him female. The surgery to reconstruct the female sexual organs for my baby have not yet been done. Today I am in and out of the hospital to seek help for my child. My child is on hormone therapy, but I cannot even afford them because they are very expensive, and the tests are also costly. My child always complains of pain when peeing. I wish I had been firm and very observant and avoided what happened to my child. Her appearance and the things she does without a doubt, I was not wrong when I called him my baby boy. When I am in the hospital with my child, her siblings are left alone at home. I pray that she will be fine and will be able to live a normal life.'

## Appendix 2: Intersex and Harmful Practices

In 2013, the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment called on states to repeal any law allowing intrusive and irreversible treatments, including forced genital-normalizing surgery, involuntary sterilization, “reparative therapies” or “conversion therapies”, when enforced or administered without the free and informed consent of the person concerned. He also called on states to outlaw forced or coerced sterilization in all circumstances.<sup>4</sup>

The UN Human Rights Office Background Note on Human Rights Violations against Intersex People states: ‘In recent years, awareness of intersex people, and recognition of the specific human rights abuses that they face, has grown, thanks to the work of intersex human rights defenders. These include risks of forced and coercive medical interventions, harmful practices and other forms of stigmatization due to their physical traits. To date, only a handful of countries have implemented measures to prevent and address such abuses, and the effectiveness of existing measures remains to be fully documented.’<sup>5</sup>

Intersex children are at risk of medically unnecessary, intrusive and irreversible surgery, hormone treatments, other “normalizing” treatments and “normalizing” psychotherapy, without the free and fully informed consent of the child. These interventions may even start before their birth, with experimental medical treatment for which only very limited information is available about the results, while there even are proven negative long-term health consequences.<sup>6</sup>

Medical and surgical treatment of intersex children is based on ‘*predict and control*’: when an intersex child is born, health professionals try to predict the future gender of the child and control the outcome of this prediction by means of medically unnecessary, intrusive and irreversible treatments, that can be safely deferred until a later age where these children can provide personal, prior, free, and fully informed consent.<sup>7</sup>

The ‘*predict and control*’ method is a violation of the right of self-determination, bodily integrity, and the right to the highest attainable standard of physical and mental health. These rights are not guaranteed for intersex children, because they are victims of unnecessary, unproven and unscientific medical treatments.

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<sup>4</sup> Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, Juan E. Medez, Human Rights Council, 1 February 2013 (A/HRC/22/53).

<sup>5</sup> UN Human Rights Office. Background Note on Human Rights Violations against Intersex People. 25 October 2019.

<sup>6</sup> **Dreger A, Feder EK, Tamar-Mattis A.** Prenatal dexamethasone for congenital adrenal hyperplasia. *Journal of bioethical inquiry.* 2012;9(3):277-294.

**Wallensteen L, Zimmermann M, Sandberg MT, Gezelius A, Nordenström A, Tatja J, et al.** Sex-dimorphic effects of prenatal treatment with dexamethasone. *Journal of Clinical Endocrinology & Metabolism.* 2016; 101(10) 3838-3846.

<sup>7</sup> **Wolffenbuttel KP.** Disorders of sex development: méér dan alleen een andere naam. *Tijdschrift voor Urologie.* 2015;5(1):8-12.

**Wolffenbuttel K, Crouch NS.** Timing of feminising surgery in disorders of sex development. *Understanding Differences and Disorders of Sex Development (DSD).* 27: Karger Publishers; 2014. p. 210-221.

Furthermore, a lack of support for intersex people combined with non-necessary, intrusive, involuntary, and irreversible treatments on intersex children can have a severe impact: 45 percent of adult intersex people experience mental health problems, almost 20 percent have suicidal thoughts and almost 7 percent have tried to commit suicide<sup>8</sup> – in general, intersex people suffer from physical and mental health issues throughout their lives.<sup>9</sup>

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<sup>8</sup> **De Vries ALC, Roehle R, Marshall L, Frisé L, van de Grift TC, Kreukels BPC, et al.** Mental Health of a Large Group of Adults With Disorders of Sex Development in Six European Countries. *Psychosomatic Medicine*. 2019;81(7):629-640. DOI: 10.1097/psy.0000000000000718

<sup>9</sup> **Falhammar H, Claahsen-van der Grinten HL, Reisch N, Slowikowska-Hilczler 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>).