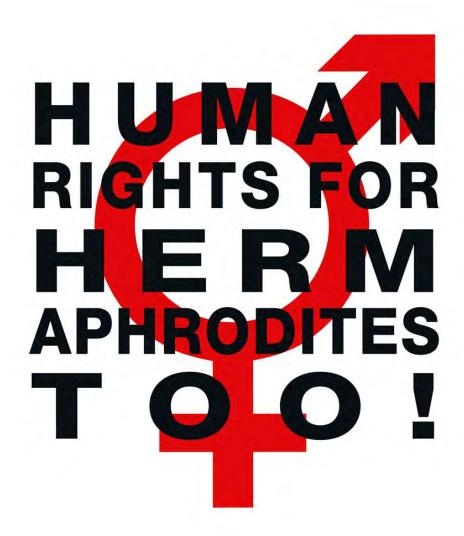
Intersex Genital Mutilation

Human Rights Violations Of Children With Variations Of Reproductive Anatomy



NGO Report (for LOIPR)
to the 7th Report of Norway on the
Convention on the Rights of the Child (CRC)

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February 2023

This NGO Report online:

https://intersex.shadowreport.org/public/2023-CRC-Norway-LOIPR-NGO-Intersex-StopIGM.pdf



Executive Summary

All typical forms of Intersex Genital Mutilation are still practised in Norway, facilitated and paid for by the State party via the public health system. Parents and children are misinformed, kept in the dark, pressured to "consent" to harmful surgery, and denied appropriate support. Despite exemplary first steps and repeatedly stated good intentions by the Government to end harmful practices on intersex children, Norway fails to act.

Norway is thus in breach of its obligations under CRC to (a) take effective legislative, administrative, judicial or other measures to prevent harmful practices on intersex children causing severe mental and physical pain and suffering of the persons concerned, and (b) ensure access to redress and justice, including fair and adequate compensation and as full as possible rehabilitation for victims, as stipulated in CRC art. 24 para. 3 in conjunction with the CRC-CEDAW Joint general comment No. 18/31 "on harmful practices".

This Committee has consistently recognised IGM practices to constitute a harmful practice under the Convention in Concluding Observations.

In total, UN treaty bodies CRC, CEDAW, CAT, CCPR and CRPD have so far issued 77 Concluding Observations recognising IGM as a serious violation of non-derogable human rights, typically obliging State parties to enact legislation to (a) end the practice, (b) ensure redress and compensation and (c) access to free counselling. Also, the UN Special Rapporteurs on Torture (SRT) and on Health (SRH), the UN High Commissioner for Human Rights (UNHCHR), the World Health Organisation (WHO), the Inter-American Commission on Human Rights (IACHR), the African Commission on Human and Peoples' Rights (ACHPR) and the Council of Europe (COE) recognise IGM as a serious violation of non-derogable human rights.

Intersex people are born with **Variations of Reproductive Anatomy**, including atypical genitals, atypical sex hormone producing organs, atypical response to sex hormones, atypical genetic make-up, atypical secondary sex markers. While intersex people may face several problems, in the "developed world" the most pressing are the ongoing **Intersex Genital Mutilations**, which present a distinct and unique issue constituting significant human rights violations.

IGM practices include non-consensual, medically unnecessary, irreversible, cosmetic genital surgeries, and/or other harmful medical procedures that would not be considered for "normal" children, without evidence of benefit for the children concerned. Typical forms of IGM include "masculinising" and "feminising", "corrective" genital surgery, sterilising procedures, imposition of hormones, forced genital exams, vaginal dilations, medical display, involuntary human experimentation and denial of needed health care.

IGM practices cause known **lifelong severe physical and mental pain and suffering**, including loss or impairment of sexual sensation, painful scarring, painful intercourse, incontinence, urethral strictures, impairment or loss of reproductive capabilities, lifelong dependency of artificial hormones, significantly elevated rates of self-harming behaviour and suicidal tendencies, lifelong mental suffering and trauma, increased sexual anxieties, and less sexual activity.

For more than **25 years**, intersex people have denounced IGM as **harmful** and **traumatising**, as western **genital mutilation**, as **child sexual abuse** and **torture**, and called for **remedies**.

This NGO Report has been compiled by StopIGM.org / Zwischengeschlecht.org, an international intersex NGO. It contains Suggested Questions (see p. 14).

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A. Introduction

1. Norway: Intersex, IGM and Human Rights

Despite that the persistence of IGM practices in Norway is a **matter of public record**, same as the **criticism and appeals** by **NGOs**, **experts and allies**, to this day the Norwegian Government fails to **recognise** the serious human rights violations and the severe pain and suffering caused by IGM practices, let alone to "take effective legislative, administrative, judicial or other measures" to protect intersex children from harmful practices.

This Thematic NGO Report demonstrates that the current and ongoing **harmful medical practices on intersex children in Norway** – advocated, facilitated and perpetrated by the state funded **University Hospitals**, as well as **private hospitals**, and **paid for by the State party** via the **public health system** – constitute a **serious breach** of Norway's obligations under the Convention.

2. About the Rapporteurs

This NGO report has been prepared by the international intersex NGO StopIGM.org:

• **StopIGM.org** / **Zwischengeschlecht.org** is an international intersex human rights NGO based in Switzerland, working to end IGM practices and other human rights violations perpetrated on intersex people, according to its motto, "*Human Rights for Hermaphrodites, too!*" ¹ According to its charter, ² StopIGM.org works to support persons concerned seeking redress and justice and regularly reports to relevant UN treaty bodies, often in collaboration with local intersex persons and organisations, ³ substantially contributing to the so far 77 Treaty body Concluding Observations recognising IGM as a serious human rights violation.⁴

3. Methodology

This thematic NGO report is a localised update to the **2022 CRC Spain NGO Report** (for **LOIPR**)⁵ by partly the same Rapporteurs.

^{1 &}lt;u>https://Zwischengeschlecht.org/</u> English homepage: <u>https://StopIGM.org</u>

² https://zwischengeschlecht.org/post/Statuten

³ https://intersex.shadowreport.org

^{4 &}lt;u>https://stopigm.org/post/IAD-2016-Soon-20-UN-Reprimands-for-Intersex-Genital-Mutilations</u>

^{5 &}lt;u>https://intersex.shadowreport.org/public/2021-CRC-Spain-LOIPR-NGO-Intersex-IGM.pdf</u>

B. IGM in Norway: State-sponsored and pervasive, Gov fails to act

1. Overview: Insufficient protections, Government fails to act

In **Norway**, same as in the **neighbouring countries** of *Sweden* (CRC/C/SWE/CO/6-7, para 27(d)+(e)), *Finland* (CCPR/C/FIN/CO/7, paras 20+21(c); CEDAW/C/FIN/CO/8, paras 21(b)+22(b)), and *Denmark* (CRC/C/DNK/CO/5, paras 24+12; CAT/C/DNK/CO/6-7, paras 42-43), and in **many more State parties**, ⁶ there are

- **no legal or other effective protections** in place to **prevent IGM practices** as stipulated in art. 24(3) and the CRC-CEDAW Joint General Comment No. 18/31,
- no legal measures in place to ensure access to redress and justice for IGM survivors,
- no legal measures in place to ensure the accountability of IGM perpetrators,
- no measures in place to ensure data collection and monitoring of IGM practices.

Despite that the persistence of IGM practices in Norway is a matter of public record, same as the criticism and appeals by NGOs, Government agencies, experts and allies (see below, p. 10), and the repeatedly stated good intentions of the Norwegian Government (see below and p. 12-13), to this day, Norway fails to adequately recognise the serious human rights violations and the severe pain and suffering caused by IGM practices, let alone to "take effective legislative, administrative, judicial or other measures" to effectively protect intersex children from harmful practices.

2. Norway's commitment to "protect intersex children from violence and harmful practices", "investigate abuses", "ensure accountability" and "access to remedy"

a) UNHRC45 Statement, 01.10.2020

On occasion of the 45th Session of the Human Rights Council the State party supported a public statement calling to "protect [...] intersex adults and children [...] so that they live free from violence and harmful practices. Governments should investigate human rights violations and abuses against intersex people, ensure accountability, [...] and provide victims with access to remedy."

b) UNHRC48 Statement, 04.10.2021

On occasion of the **48th Session of the Human Rights Council** the **State party** supported a public follow-up statement again calling to end harmful practices and ensure access to justice:

"Intersex persons also need to be protected from violence and States must ensure accountability for these acts. [...]

Furthermore, there is also a need to take measures to protect the **autonomy** of intersex children and adults and their rights to health and to **physical and mental integrity** so that they live **free from violence and harmful practices**. Medically unnecessary surgeries, hormonal treatments and other invasive or irreversible non-vital medical procedures without their free,

⁶ Currently we count **77 UN Treaty body Concluding Observations** explicitly condemning IGM practices as a **serious violation of non-derogable human rights**, see: https://stopigm.org/post/IAD-2016-Soon-20-UN-Reprimands-for-Intersex-Genital-Mutilations

The Statement supported by Norway (and 34 other States) during the 45th Session of the Human Rights Council on 1 October 2020, https://www.dfat.gov.au/international-relations/themes/human-rights/hrc-statements/45th-session-human-rights-council/joint-statement-led-austria-rights-intersex-persons

prior, full and informed consent are harmful to the full enjoyment of the human rights of intersex persons.

We call on all member states to take measures to combat violence and discrimination against intersex persons, develop policies in close consultations with those affected, ensure accountability, reverse discriminatory laws and provide victims with access to remedy." 8

3. IGM practices persist

Despite above calls and repeatedly stated good intentions (see below, p. 12-13), to this day, in Norway all forms of IGM practices remain widespread and ongoing, persistently advocated, prescribed and perpetrated by the state funded University Hospitals, and paid for by the State via the public health system.

In Norway, there are **two regional DSD teams** conducting IGM practices, one at the **Oslo University Hospital** and the other at the **Haukeland University Hospital in Bergen**. ⁹ ¹⁰ ¹¹ In addition, IGM practices are offered in other clinics, including in at least one **private clinic** (see below, p. 9).

What's more, **Norwegian medical bodies** continue to endorse international medical guidelines prescribing all forms of IGM practices:

a) IGM 3 – Sterilising Procedures:

Castration / "Gonadectomy" / Hysterectomy / Removal of "Discordant Reproductive Structures" / (Secondary) Sterilisation Plus arbitrary imposition of hormones 12

The Norwegian Urological Association (Norsk Urologisk Forening (NUF)) still endorses the unchanged, current 2022 Guidelines of the European Association of Urology (EAU), ¹³ which include the current ESPU/EAU "Paediatric Urology" Guidelines 2022¹⁴ of the European Society for Paediatric Urology (ESPU) and the European Association of Urology (EAU) which promote IGM 3: "removal of testes". ¹⁵

⁸ Statement supported by Norway (and 52 other States) during the 48th Session of the Human Rights Council on 4 October 2021, https://www.bmeia.gv.at/oev-genf/speeches/alle/2021/10/united-nations-human-rights-council-48th-session-joint-statement-on-the-human-rights-of-intersex-persons/

Ingrid Egeland Thorsnes (2019), "Sexual Orientation, Gender Identity and Sex Development", in: Children's Rights in Norway. An Implementation Paradox?, p. 387-414, at p. 405, https://www.idunn.no/doi/epdf/10.18261/9788215031415-2019-14

Fae Garland, Nina Lem Samuelsen & Mitchell Travis (2018), "Law and Intersex in Norway; Challenges and Opportunities", University of Leeds, University of Manchester (report commissioned by the Norwegian Directorate for Children, Youth and Family Affairs), p. 41, https://www.bufdir.no/Global/Law%20and%20Intersex%20in%20Norway%20-%20Challenges%20and%20Opportunities%20(2018).pdf (currently not available)

Olve Moldestadt, Anne Wæhre (2017), "Application for project funds from NKSD for 2017. Long-term outcomes in individuals with disorders of sex development: a 15-year follow-up of health, psychosexual outcomes and quality of life.", https://kipdf.com/viewer/web/viewer.html?file=https%3A%2F%2Fkipdf.com%2Fdownload%2Fsknad-om-prosjektmidler-fra-nksd-for-2017_5afe54398ead0ea6158b458c.html%3Freader%3D1

¹² For general information, see 2016 CEDAW NGO Report France, p. 47, http://intersex.shadowreport.org/public/2016-CEDAW-France-NGO-Zwischengeschlecht-Intersex-IGM.pdf

^{13 &}lt;a href="https://uroweb.org/guidelines/endorsement/">https://uroweb.org/guidelines/endorsement/

^{14 &}lt;a href="https://d56bochluxqnz.cloudfront.net/documents/full-guideline/EAU-Guidelines-on-Paediatric-Urology-2022.pdf">https://d56bochluxqnz.cloudfront.net/documents/full-guideline/EAU-Guidelines-on-Paediatric-Urology-2022.pdf

For details and relevant quotes, see 2022 CRC Sweden NGO Report (for Session), p. 2-3,

A 2018 report commissioned by the Norwegian Directorate for Children, Youth and Family Affairs notes: 16

"Another contested treatment procedure, is the removal of gonads. Some intersex conditions have a heightened risk of cancer in the gonads [...] Other variations are as low as 2-3%. Different medical teams are currently dealing with this 'risk' differently. Some parents are given the choice when their child does not have the sufficient age or maturity to decide for themselves. Some young people are given the choice when they are old enough to decide themselves (16 years old as a main rule)."

b) IGM 2 – "Feminising Procedures": Clitoris Amputation/"Reduction", "Vaginoplasty", "Labiaplasty", Dilation 17

The Norwegian Urological Association (Norsk Urologisk Forening (NUF)) still endorses the unchanged, current 2022 Guidelines of the European Association of Urology (EAU), ¹⁸ which include the current ESPU/EAU "Paediatric Urology" Guidelines 2022¹⁹ of the European Society for Paediatric Urology (ESPU) and the European Association of Urology (EAU) which promote IGM 2: partial clitoris amputation on young children based on "social and emotional conditions" and substituted decision-making by "parents and caregivers implicitly act[ing] in the best interest of their children". ²⁰

Accordingly, the **Oslo University Hospital** offers on its homepage under "Congenital adrenal insufficiency (CAH) at the Neonatal Intensive Care Unit, Ullevål" **IGM 2**:²¹

"In girls with labia minora and clitoral enlargement, we may consider surgery. The assessment is done in close collaboration with parents and treating doctors. All treatment and follow-up is adapted individually, and always in collaboration with the patient if age warrants it."

c) IGM 1 – "Masculinising Surgery": Hypospadias "Repair" 22

The Norwegian Urological Association (Norsk Urologisk Forening (NUF)) still endorses the unchanged, current **2022 Guidelines of the European Association of Urology (EAU)**, ²³ which include the current **ESPU/EAU** "*Paediatric Urology*" Guidelines **2022**²⁴ of the European Society for Paediatric Urology (ESPU) and the European Association of Urology (EAU) which promote

https://intersex.shadowreport.org/public/2022-CRC-Sweden-NGO-Intersex-StopIGM.pdf

- Fae Garland, Nina Lem Samuelsen & Mitchell Travis (2018), "Law and Intersex in Norway; Challenges and Opportunities", University of Leeds, University of Manchester (report commissioned by the Norwegian Directorate for Children, Youth and Family Affairs), p. 43-44, https://www.bufdir.no/Global/Law%20and%20Intersex%20in%20Norway%20-%20Challenges%20and%20Opportunities%20(2018).pdf (currently not available)
- 17 For general information, see 2016 CEDAW NGO Report France, p. 48, https://intersex.shadowreport.org/public/2016-CEDAW-France-NGO-Zwischengeschlecht-Intersex-IGM.pdf
- 18 https://uroweb.org/guidelines/endorsement/
- 19 https://d56bochluxqnz.cloudfront.net/documents/full-guideline/EAU-Guidelines-on-Paediatric-Urology-2022.pdf
- 20 For details and relevant quotes, see 2022 CRC Sweden NGO Report (for Session), p. 3-4, https://intersex.shadowreport.org/public/2022-CRC-Sweden-NGO-Intersex-StopIGM.pdf
- 21 https://oslo-universitetssykehus.no/behandlinger/medfodt-binyrebarksvikt-cah?sted=nyfodtintensiv-avdeling-ulleval#gutter-og-menn-med-cah
- For general information, see 2016 CEDAW NGO Report France, p. 48-49, https://intersex.shadowreport.org/public/2016-CEDAW-France-NGO-Zwischengeschlecht-Intersex-IGM.pdf
- 23 https://uroweb.org/guidelines/endorsement/
- 24 https://d56bochluxqnz.cloudfront.net/documents/full-guideline/EAU-Guidelines-on-Paediatric-Urology-2022.pdf

IGM 1: "The age at surgery for primary hypospadias repair is usually 6-18 (24) months." ²⁵

Accordingly, the **Department of Paediatrics, Ullevål** of the **Oslo University Hospital** offers on its homepage under "*Multi-regional treatment service for unclear somatic sex development*": ²⁶

"The service also includes diagnosis and treatment of:

perineal hypospadias

all degrees of hypospadias without both testicles in the scrotum"

And a **2015 publication** out of the **Department of Plastic Surgery** of the **Haukeland University Hospital in Belsen** specifies:²⁷

"The diagnosis is usually made in the maternity ward. After receiving a referral, we assess the boys and have a discussion with the parents at three months of age. Most do not require further investigation and are referred for surgical treatment at around 12 months of age. Oral and written information is given about the procedure and possible complications."

"The aim is for the penis to look as normal as possible, have normal sensitivity with a well-functioning urethra and meatus. The boy should be able to stand and urinate without problems. In adulthood he should function normally sexually."

"However, there are hardly any elective procedures that have more complications than those related to hypospadias."

Also, the **private Cosmo Clinic in Oslo** specialising in plastic surgery states on its homepage under "*Hypospadias*": ²⁸

"There are three main reasons why these children need surgery: So that they can stand and urinate, so that the penis is straight during an erection and so that it is not difficult to urinate.

There are more than 250 different ways to operate on children with hypospadias. Newer methods involve operating on the child in one session at 18 months of age."

Conclusion: This situation is clearly not in line with the Convention, and starkly contradicts the Norwegian's Government repeatedly stated good intentions (see above, p. 6-7 and below, p. 12-13), as well as doctor's claim of allegedly having stopped practicing IGM (see below, p. 11).

For details and relevant quotes, see 2022 CRC Sweden NGO Report (for Session), p. 4, https://intersex.shadowreport.org/public/2022-CRC-Sweden-NGO-Intersex-StopIGM.pdf

^{26 &}lt;a href="https://oslo-universitetssykehus.no/avdelinger/barne-og-ungdomsklinikken/avdeling-for-barnemedisin-ulleval/seksjon-barneernering/flerregional-behandlingstjeneste-for-usikker-somatisk-kjonnsutvikling#omtjenesten">https://oslo-universitetssykehus.no/avdelinger/barne-og-ungdomsklinikken/avdeling-for-barnemedisin-ulleval/seksjon-barneernering/flerregional-behandlingstjeneste-for-usikker-somatisk-kjonnsutvikling#omtjenesten

Paul Egil Gravem, Birgitta Ivarsen (2015), "Hypospadibehandling - også en del av plastikkirurgien" ("Hypospadias treatment - also part of plastic surgery", in: Norsk Kirurgisk Forening (Norwegian Surgical Society) (2015), "Kirurgen. Tema Plastikkirurgi. Medfødte misdannelser og traumer" ("The Surgeon. Theme Plastic surgery. Congenital malformations and trauma"), 4/2015,

 $[\]underline{https://kirurgen.no/fagstoff/plastikkirurgi/hypospadibehandling-\%E2\%80\%93-ogsa-en-del-av-plastikkirurgien/hypospadibehandling-\%E2\%80\%93-ogsa-en-del-av-plastikkirurgi/hypospadibehandling-\%E2\%80\%93-ogsa-en-del-av-plastikkirurgi/hypospadibehandling-\%E2\%80\%93-ogsa-en-del-av-plastikkirurgi/hypospadibehandling-\%E2\%80\%93-ogsa-en-del-av-plastikkirurgi/hypospadibehandling-\%E2\%80\%93-ogsa-en-del-av-plastikkirurgi/hypospadibehandling-\%E2\%80\%93-ogsa-en-del-av-plastikkirurgi/hypospadibehandling-\%E2\%80\%93-ogsa-en-del-av-plastikkirurgi/hypospadibehandling-%E2\%80\%93-ogsa-en-del-av-plastikkirurgi/hypospadibehandling-%E2\%80\%93-ogsa-en-del-av-plastikkirurgi/hypospadibehandling-%E2\%80\%93-ogsa-en-del-av-plastikkirurgi/hypospadibehandling-%E2\%80\%93-ogsa-en-del-av-plastikkirurgi/hypospadibehandling-%E2\%80\%93-ogsa-en-del-av-plastikkirurgi/hypospadibehandling-%E2\%80\%93-ogsa-en-del-av-plastikkirurgi/hypospadibehandling-%E2\%80\%93-ogsa-en-del-av-plastikkirurgi/hypospadibehandling-%E2\%80\%93-ogsa-en-del-av-plastikkirurgi/hypospadibehandling-%E2\%80\%93-ogsa-en-del-av-plastikkirurgi/hypospadibehandling-%E2\%80\%93-ogsa-en-del-av-plastikkirurgi/hypospadibehandling-%E2\%80\%93-ogsa-en-del-av-plastikkirurgi/hypospadibehandling-%E2\%80\%93-ogsa-en-del-av-plastikkirurgi/hypospadibehandling-%E2\%80\%93-ogsa-en-del-av-plastikkirurgi/hypospadibehandling-%E2\%80\%93-ogsa-en-del-av-plastikkirurgi/hypospadibehandling-weight/h$

Plastiskkirurgi.no, Fakta om Plastisk Kirurgi, Hypospadi, https://www.plastiskkirurgi.no/rekonstruktiv-plastikkirurgi/hypospadi

4. Public criticism, medical denials, Government good intentions but no action

a) Public criticism of IGM in Norway

Public criticism of IGM in Norway by NGOs, Government agencies, experts and allies is a **matter of public record**, ²⁹ ³⁰ ³¹ ³² ³³ ³⁴ including criticism by a former CRC chair. ³⁵

In 2016, also the **Directorate of Health** gave a **legal opinion**³⁶ on the situation for intersex children to the **Ministry of Health**. In the opinion, the Directorate found that surgeries often lead to infertility and reduced sexual function, particularly if internal gonads are removed. Furthermore, the Directorate was critical of the National Guidelines for Paediatricians:

"All healthcare offered in Norway should be professionally sound, i.e. of proven utility. According to the guidelines that the service has prepared (Bjeknes 2005), the main aim of the treatment is 'to strengthen the gender role'. Furthermore, Bjerknes writes that 'In this process there are a number of considerations that need to be taken, such as the child having a happy childhood and adolescence, an assured gender identity and the opportunity to have and enjoy sexual relationships.' However, there is no research documenting that the treatment gives such effect. The lack of medical indication and scientific basis for health care may be problematic when viewed against the requirement of sound health care."

- Hedda Fannemel Espeli (2017), "Hanne (28) ble utsatt for operasjoner som ikke var medisinsk nødvendig: Det ble et traume på grunn av det de gjorde" ("Hanne (28) was subjected to operations that were not medically necessary: It became a trauma because of what they did"), Dagbladet, 29.01.2017,
 https://www.dagbladet.no/kjendis/hanne-28-ble-utsatt-for-operasjoner-som-ikke-var-medisinsk-nodvendig---det-ble-et-traume-pa-grunn-av-det-de-gjorde/66908547
- 30 Ingvild Endestad, Pernille Sivertsen, Thale Skybak (2017), "Debatt Interkjønn: Norge bryter med FNs barnekonvensjon" ("Debate Intersex: Norway violates the UN Convention on the Rights of the Child"), Dagbladet, 31.01.2017, https://www.dagbladet.no/kultur/norge-bryter-med-fns-barnekonvensjon/66922729
- Norwegian Directorate of Health (2016), "Spørsmål om atypiske kjønnskarakteristika/forstyrrelser i kjønnsutviklingen (DSD) behandlingspraksis i Norge" ("Questions concerning atypical sex characteristics/disorders of sex development (DSD) treatment practice in Norway"), unpublished, summary and quotes in: Ingrid Egeland Thorsnes (2019), "Sexual Orientation, Gender Identity and Sex Development", in: Children's Rights in Norway. An Implementation Paradox?, p. 387-414, https://www.idunn.no/doi/epdf/10.18261/9788215031415-2019-14
- 32 Fae Garland, Nina Lem Samuelsen & Mitchell Travis (2018), "Law and Intersex in Norway; Challenges and Opportunities", University of Leeds, University of Manchester (report commissioned by the Norwegian Directorate for Children, Youth and Family Affairs), https://www.bufdir.no/Global/Law%20and%20Intersex%20in%20Norway%20-%20Challenges%20and%20Opportunities%20(2018).pdf (currently not available)
- Ingrid Egeland Thorsnes (2019), "Sexual Orientation, Gender Identity and Sex Development", in: Children's Rights in Norway. An Implementation Paradox?, p. 387-414, https://www.idunn.no/doi/epdf/10.18261/9788215031415-2019-14
- 34 Barne-, ungdoms- og familiedirektoratet (Norwegian Directorate of Health, Norwegian Directorate for Children, Youth and Family Affairs) (2016), "OPPSUMMERINGSRAPPORT Symposium om variasjon i kroppslig kjønnsutvikling" ("SUMMARY REPORT Symposium on variation in bodily gender development", https://bibliotek.bufdir.no/BUF/101/Oppsummeringsrapport Symposium om variasjon i kroppslig utvikling.pdf
- Kirsten Sandberg (2015), "The Rights of LGBTI Children under the Convention on the Rights of the Child", in: Nordic Journal of Human Rights, 33:4, 337-352
- Norwegian Directorate of Health (2016), "Spørsmål om atypiske kjønnskarakteristika/forstyrrelser i kjønnsutviklingen (DSD) behandlingspraksis i Norge" ("Questions concerning atypical sex characteristics/disorders of sex development (DSD) treatment practice in Norway"), unpublished, summary and quotes in: Ingrid Egeland Thorsnes (2019), "Sexual Orientation, Gender Identity and Sex Development", in: Children's Rights in Norway. An Implementation Paradox?, p. 387-414, at p. 405 (p. 19 in PDF), https://www.idunn.no/doi/epdf/10.18261/9788215031415-2019-14

b) Medical denials

As a response to the public criticism, **Norwegians doctors** replied by claiming to have entirely stopped IGM practices, for example in a **2016 Joint letter by the two regional multidisciplinary** "**DSD-Teams" in Oslo and Bergen** to the **Ministry of Health**, as documented in a 2018 Government-commissioned study:³⁷

"[T]he teams stated that they do not perform any treatment procedures on intersex children unless there is a so-called 'medical-somatic indication'. Furthermore, they stated that they have not performed any surgeries based on so-called 'psychosocial indications' (term used in the letter) on children between 2013 and 2015."

Such claims of no more IGM in Norway were also **repeated in newspaper articles** written by representatives from the two DSD-teams.³⁸

However, the above-mentioned 2018 government-commissioned study finds that these claims are "not sufficiently reflected in current medical and ethical guidelines within Norway", and further shows that a closer look at doctors' euphonious statements of "no more unnecessary genital surgeries" actually reveals that they are in fact continuing with all but one form of IGM practices: ³⁹

"Additionally, the definition of 'psychosocial' is not clear. In the aforementioned letter, the DSD-teams defined clitoral reductive surgeries to virilised CAH-girls as the only surgical procedure that has a psychosocial indication. Other procedures performed by the teams such as hypospadias-correction and surgical procedures on the vagina are not listed as psychosocial. However, in human rights literature, hypospadias-correction with cosmetic purposes and to enable boys to urinate standing and vaginal surgeries with the aim to create possibilities for penile penetration, are categorized as procedures that are not medically necessary in terms of functionality. The letter from the DSD-teams indicates that all of the treatments were medically necessary. [...] Furthermore, the DSD-teams stated in the letter that they only remove gonads when there is a risk of cancer. This implies that the removal of gonads are not performed to assign or correct the "ambiguous" sex characteristics of intersex people, but to prevent cancer. As previously mentioned, commentators such as the UN question the assessment of the risk of cancer, and claim that the surgeries are performed without adequate proof of a real and immediate risk."

Fae Garland, Nina Lem Samuelsen & Mitchell Travis (2018), "Law and Intersex in Norway; Challenges and Opportunities", University of Leeds, University of Manchester (report commissioned by the Norwegian Directorate for Children, Youth and Family Affairs), p. 43, https://www.bufdir.no/Global/Law%20and%20Intersex%20in%20Norway%20-%20Challenges%20and%20Opportunities%20(2018).pdf (currently not available)

Anne Wæhre, Trond H. Diseth, Hilde Bjørdalen, Agnethe Lund, Helge Ræder (2017), "Debatt: Interkjønn. Behandlingen av modellen Hanne er ikke representativ" ("Debate: Intersex. The treatment of the model Hanne is not representative"), Dagbladet, 18.02.2017, https://www.dagbladet.no/kultur/behandlingen-av-modellen-hanne-er-ikke-representativ/67014633

Fae Garland, Nina Lem Samuelsen & Mitchell Travis (2018), "Law and Intersex in Norway; Challenges and Opportunities", University of Leeds, University of Manchester (report commissioned by the Norwegian Directorate for Children, Youth and Family Affairs), p. 44, https://www.bufdir.no/Global/Law%20and%20Intersex%20in%20Norway%20-%20Challenges%20and%20Opportunities%20(2018).pdf (currently not available)

c) Government states good intentions, but fails to act

Arguably, due to the first CRC Concluding Observations on IGM, starting in 2016, Norwegian government bodies initiated **exemplary first steps** in addressing the topic of intersex children.

In 2016, the **Ministry of Health** contacted the two "DSD Teams" at Oslo University Hospital (the Children's Clinic) and Haukeland University Hospital in Bergen (Department for Child Medicine), requesting details concerning the surgery conducted on intersex children.⁴⁰

In October 2016, the **Norwegian Directorate of Health** and the **Norwegian Directorate for Children, Youth and Family Affairs** co-organized a symposium on the topic, inviting several relevant stakeholders, including doctors, researchers, authorities and civil society. A key issue in the discussions at the symposium and in the relevant correspondence between health services and the authorities, is the distinction between operations due to medical necessity, and operations based on psychosocial indications. However, the definition of what is 'necessary due to medical reasons' remains unclear (see also the conflicting claims by doctors discussed above, p. 11). 41

Subsequently, the Norwegian Government's action plan against discrimination based on sexual orientation, gender identity and gender expression 2017-2020, "Security, diversity, openness" states, "to date the intersex group have remained virtually invisible to the public. It is therefore important to get a better knowledge base about intersex, including the group's need for health care services." One aim outlined in the action plan is to develop research-based knowledge about the situation of persons born with DSD.⁴²

One study resulting from the action plan, a **2022 qualitative medical study**⁴³ out of the **Oslo University Hospital**, found:

"In summary, although a small sample size, and smaller follow-up, this study demonstrated that adolescents assigned females with DSD might have more psychiatric problems and a poorer degree of psychosocial functioning compared to a healthy comparison group." (Note: The male assigned participants were all too young at the time of the baseline study to determine findings via qualitative interviews.)

Ingrid Egeland Thorsnes (2019), "Sexual Orientation, Gender Identity and Sex Development", in: Children's Rights in Norway. An Implementation Paradox?, p. 387-414, at p. 405 (p. 19 in PDF), https://www.idunn.no/doi/epdf/10.18261/9788215031415-2019-14

⁴¹ Ibid., at p. 406 (p. 20 in PDF)

⁴² Quoted from Olve Moldestadt, Anne Wæhre (2017), "Application for project funds from NKSD for 2017. Long-term outcomes in individuals with disorders of sex development: a 15-year follow-up of health, psychosexual outcomes and quality of life.", https://kipdf.com/viewer/web/viewer.html?file=https%3A%2F%2Fkipdf.com%2Fdownload%2Fsknad-om-prosjektmidler-fra-nksd-for-2017_5afe54398ead0ea6158b458c.html%3Freader%3D1

Anne Waehre, Charlotte Heggeli, Kirsten Hald, Anne Grethe Myhre and Trond Diseth (2022), "A 15–20-year follow-up of mental health, psychosocial functioning and quality of life in a single center sample of individuals with differences in sex development", HEALTH PSYCHOLOGY AND BEHAVIORAL MEDICINE 2022, VOL. 10, NO. 1, 837–854, at p. 851, https://www.tandfonline.com/doi/epdf/10.1080/21642850.2022.2116329

This study has to be further commended for noting that, the older the participants, the more severe their problems became:⁴⁴

"One possible explanation is that people with DSD might struggle more with age, getting increasingly aware of their condition, especially when seeking out relationships."

As well as for the following observations:⁴⁵

"Many refused to take part in the follow-up study, which could mean that the mental health and QoL [Quality of Life] of patients are further compromised, since in general the no responders tend to have poorer health, may be depressed or socially isolated."

And the already mentioned **2018 legal report**⁴⁶ commissioned by the **Division for Equality and Inclusion** of the **Norwegian Directorate for Children, Youth and Family Affairs** concluded inter alia (p. 63):

"Evidently, there is a political consciousness within Norway that is striving to improve the lives of intersex people. However, in its current form, Norway's legal and political framework does not offer real, substantive protections for this group of individuals."

Last but not least, the report issued the following **recommendation** (p. 38):

"Recommendation 1: Prohibiting Non-Therapeutic Medical Interventions on Intersex Children Until the Individual Concerned Is Old Enough to Give Informed Consent"

And in **2020** and **2021** Norway supported public **UNHRC** statements committing the State party to "protect intersex children from violence and harmful practices", "investigate abuses", "ensure accountability" and "access to remedy" (see above, p. 6-7).

However, to this day, Norway fails to implement these stated good intentions, recommendations and commitments to effectively protect intersex children from IGM.

⁴⁴ Ibid., at p. 848

⁴⁵ Ibid., at p. 850-851

Fae Garland, Nina Lem Samuelsen & Mitchell Travis (2018), "Law and Intersex in Norway; Challenges and Opportunities", University of Leeds, University of Manchester (report commissioned by the Norwegian Directorate for Children, Youth and Family Affairs), p. 41, https://www.bufdir.no/Global/Law%20and%20Intersex%20in%20Norway%20-%20Challenges%20and%20Opportunities%20(2018).pdf (currently not available)

C. Suggested Questions for the LOIPR

The Rapporteurs respectfully suggest that in the LOIPR the Committee asks the Norwegian Government the following questions with respect to the treatment of intersex children:

Harmful practices: Intersex children (art. 24(3))

- Please provide information on the measures taken to prevent deferrable medical or surgical treatment of intersex children before they can give consent, to provide families with intersex children with adequate counselling and support, and to guarantee access to effective remedies for victims subjected to such treatment during childhood, including the statute of limitations for raising a claim against such treatment.
- Please provide data, disaggregated by type of intervention, age at intervention, and hospital, on the number of intersex children subjected to non-urgent and irreversible surgical and other procedures.