Intersex Genital Mutilation in New Zealand: Update to LOIPR Report

Dear Committee on the Rights of the Child

All typical forms of IGM practices are still practised in New Zealand today, promoted, facilitated and paid for by the State party via the public health system, arguably both domestic under the authority of the Medical Council of New Zealand and overseas under the Special High Cost Treatment Pool, as (partially) admitted by the State Party in the Data Annex to the State Report (reply to 38(b)). While in 2020 the Crimes Act was amended to ensure all types of FGM are illegal, the exception clause for medical surgical procedures "for the benefit of that person's physical or mental health" was retained, thus arguably explicitly legalising IGM practices according to local intersex advocates and human rights institutions. Also, while in 2020 a new clinical guideline "Differences of sex development - Atawhai Taihemahema" aimed at stopping IGM practices was introduced, it excludes the most frequent IGM practice and contains various loopholes, therefore allowing IGM practices to continue. This underlines the urgent need for legislation to explicitly prohibit IGM practices in order to effectively protect intersex children.

Conclusion, despite previous Concluding Observations by this Committee (2016) and CEDAW (2018) denouncing IGM in New Zealand as a harmful practice, to this day the Government fails to act accordingly.

c/o Zwischengeschlecht.org · P.O.Box 1318 · CH-8031 Zurich · Switzerland
info@zwischengeschlecht.org
Mobile +41 76 398 06 50 · https://stopigm.org

1. New Zealand'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."*** [1]

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 reiterating the call 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, 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****."* [2]

2. IGM practices persist, insufficient protections, Government fails to act

Despite above mentioned commitments, **to this day, in New Zealand all forms of IGM practices remain widespread and ongoing**, promoted, facilitated and **paid for by the State party** via the **public health system**, and perpetrated by **New Zealand and/or associated Children's Clinics abroad**:

a) IGM 3 – Sterilising Procedures: Castration / "Gonadectomy" / Hysterectomy / Removal of "Discordant Reproductive Structures" / (Secondary) Sterilisation Plus arbitrary imposition of hormones [3]

The **Urological Society of Australia and New Zealand** still endorses the unchanged, current

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1 Statement supported by New Zealand (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

2 Statement supported by New Zealand (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/

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

2022 Guidelines of the European Association of Urology (EAU),[4] which include the current **ESPU/EAU *"Paediatric Urology"* Guidelines 2022**[5] of the European Society for Paediatric Urology (ESPU) and th European Association of Urology (EAU) which stress:[6]

> *"Individuals with DSD have an increased risk of developing cancers of the germ cell lineage, malignant germ cell tumours or germ cell cancer in comparison with to the general population."*

Further, regarding *"whether and when to pursue gonadal or genital surgery"*,[7] the Guidelines refer to the ***"ESPU/SPU standpoint on the surgical management of Disorders of Sex Development (DSD)"***,[8] which advocates "gonadectomies":

> ***"Testes are** either brought down in boys or **removed** if dysgenetic with tumour risk or **in complete androgen insensitivity syndrome or 5 alpha reductase deficiency.** Testicular prostheses can be inserted at puberty at the patient's request."*

Also, the **"2016 Global Disorders of Sex Development Consensus Statement"**[9] refers to the *"ESPU/SPU standpoint"*, advocates *"gonadectomy"* – even when admitting *"low"* cancer risk for CAIS (and despite explicitly acknowledging CRC/C/CHE/CO/2-4)[10]:

Table 2. GCC risk: clinical management

	Male	Female	Unclear gender
Gonadal dysgenesis (45,X/46,XY and 46,XY)	Undescended testes – Orchiopexy with biopsy – Self-examination – Annual ultrasound (post-puberty) Post-pubertal biopsy – Based on ultrasound and results of first biopsy – If CIS becomes GB → gonadectomy Low threshold for gonadectomy if ambiguous genitalia	Bilateral gonadectomy at diagnosis	Low threshold for gonadectomy if ambiguous genitalia If intact, gonadectomy depends on gender identity
Undervirilization (46,XY: partial AIS, complete AIS, testosterone synthesis disorders	Undescended testes – Orchiopexy with biopsy – Self-examination – Annual ultrasound (post-puberty) Post-pubertal biopsy – Bilateral, CIS → gonadectomy/irradiation Repeat biopsy at 10 years of age – Consider gonadectomy to avoid gynecomastia or if on testosterone supplementation	Partial AIS and testosterone synthesis disorders – Prepubertal gonadectomy Complete AIS – Postpubertal gonadectomy or follow-up – GCC risk low, allow spontaneous puberty	Partial AIS and testosterone synthesis disorders – Bilateral biopsy – Low threshold for gonadectomy Intensive psychological counseling and follow-up

No data are available on the value of cryopreservation or safety if a precursor lesion for GCC is present.

Source: Lee et al., in: Horm Res Paediatr 2016;85:158-180, at 174

4 https://uroweb.org/guidelines/endorsement/
5 https://d56bochluxqnz.cloudfront.net/documents/full-guideline/EAU-Guidelines-on-Paediatric-Urology-2022.pdf
6 Ibid., p. 89
7 Ibid., p. 88
8 P. Mouriquand, A. Caldamone, P. Malone, J.D. Frank, P. Hoebeke, "The ESPU/SPU standpoint on the surgical management of Disorders of Sex Development (DSD)", Journal of Pediatric Urology vol. 10, no. 1 (2014), p. 8-10, http://www.jpurol.com/article/S1477-5131(13)00313-6/pdf
9 Lee et al., "Global Disorders of Sex Development Update since 2006: Perceptions, Approach and Care", Horm Res Paediatr 2016;85:158–180, https://www.karger.com/Article/Pdf/442975
10 Ibid., at 180 (fn 111)

b) IGM 2 – "Feminising Procedures": Clitoris Amputation/"Reduction", "Vaginoplasty", "Labiaplasty", Dilation[11]

The **Urological Society of Australia and New Zealand** still endorses the unchanged, current **2022 Guidelines of the European Association of Urology (EAU)**,[12] which include the current **ESPU/EAU *"Paediatric Urology"* Guidelines 2022**[13] of the European Society for Paediatric Urology (ESPU) and the European Association of Urology (EAU). In **chapter 3.17 *"Disorders of sex development"***,[14] despite admitting that *"Surgery that alters appearance is not urgent"* [15] and that *"adverse outcomes have led to recommendations to delay unnecessary [clitoral] surgery to an age when the patient can give inform consent"*,[16] the ESPU/EAU Guidelines nonetheless explicitly **refuse to postpone non-emergency surgery**, but in contrary **insist to continue with non-emergency genital surgery** (including 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"* and making *"well-informed decisions […] on their behalf"*, and further **explicitly refusing *"prohibition regulations"*** of unnecessary early surgery,[17] referring to the 2018 ESPU Open Letter to the Council of Europe (COE),[18] which further invokes **parents' *"social, and cultural considerations"*** as justifications for early surgery (p. 2).

c) IGM 1 – "Masculinising Surgery": Hypospadias "Repair"[19]

The **Urological Society of Australia and New Zealand** still endorses the unchanged, current **2022 Guidelines of the European Association of Urology (EAU)**,[20] which include the current **ESPU/EAU *"Paediatric Urology"* Guidelines 2022**[21] of the European Society for Paediatric Urology (ESPU) and the European Association of Urology (EAU). In **chapter 3.6 *"Hypospadias"***,[22] the ESPU/EAU Guidelines' **section 3.6.5.3 *"Age at surgery"*** nonetheless explicitly promotes, ***"The age at surgery for primary hypospadias repair is usually 6-18 (24) months."*** [23] – despite admitting to the *"risk of complications"* [24] and *"aesthetic[…]"* and *"cosmetic"* justifications.[25]

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11 For general information, see 2016 CEDAW NGO Report France, p. 48, https://intersex.shadowreport.org/public/2016-CEDAW-France-NGO-Zwischengeschlecht-Intersex-IGM.pdf
12 https://uroweb.org/guidelines/endorsement/
13 https://d56bochluxqnz.cloudfront.net/documents/full-guideline/EAU-Guidelines-on-Paediatric-Urology-2022.pdf
14 Ibid., p. 86
15 Ibid., p. 88
16 Ibid., p. 88
17 Ibid., p. 89
18 https://www.espu.org/images/documents/ESPU_Open_Letter_to_COE_2018-01-26.pdf
19 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
20 https://uroweb.org/guidelines/endorsement/
21 https://d56bochluxqnz.cloudfront.net/documents/full-guideline/EAU-Guidelines-on-Paediatric-Urology-2022.pdf
22 Ibid., p. 26
23 Ibid., p. 27
24 Ibid., p. 27
25 Ibid., p. 27

3. Current Clinical Guidelines advocate IGM practices

Accordingly, current **Clinical Guidelines** including the 2020 guideline **"Differences of sex development - Atawhai Taihemahema"**[26] co-authored by the **National Intersex Clinical Network** (see State Report, para 152) continue to allow or prescribe all forms of IGM practices.

While the **"Differences of sex development - Atawhai Taihemahema"** guideline has to be **commended** for calling to ***"[e]nsure that on-going psychosocial support is included in the multidisciplinary team (MDT)"***, calling for referrals to peer support organisations, and that ***"[d]isclosure to the child about their diagnosis will take place throughout childhood in age-appropriate ways"***, regrettably they **fail** to effectively protect intersex children, but actually **allow or prescribe 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 [27]

While the **"Differences of sex development - Atawhai Taihemahema"** guideline commendably states, *"Surgical management is not a key focus in the early management of DSD"* and *"Surgery will not happen unless there are compelling reasons to do so"*, regrettably it lists as *"compelling reasons"* inter alia ***"Reduction of malignancy risk"***, which, in accordance with the above discussed **ESPU/EAU *"Paediatric Urology"* Guidelines 2022** endorsed by the **Urological Society of Australia and New Zealand**, is often used as a **pretext for justifying IGM 3**.

Unfortunately, the 18 cases of surgery on intersex children mentioned in the State Report are not disaggregated by type of intervention.

b) IGM 2 – "Feminising Procedures": Clitoris Amputation/"Reduction", "Vaginoplasty", "Labiaplasty", Dilation[28]

While the **"Differences of sex development - Atawhai Taihemahema"** guideline commendably states, *"Surgical management is not a key focus in the early management of DSD"* and *"Surgery will not happen unless there are compelling reasons to do so"*, regrettably it lists as *"compelling reasons"* inter alia ***"Management of infection or its risk"***, which is often used as a **pretext for justifying IGM 2**, namely vaginoplasty/"correction of urogenital sinus", by referring an alleged "risk" of infection for which there is no actual evidence.

Unfortunately, the 18 cases of surgery on intersex children mentioned in the State Report are not disaggregated by type of intervention.

What's worse, according to **local intersex advocates and human rights institutions**, when in **2020 the Crimes Act was amended to ensure all types of FGM are illegal**, the exception clause for medical surgical procedures "for the benefit of that person's physical or mental health" was retained, thus arguably **explicitly legalising IGM 2**:[29]

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26 https://starship.org.nz/guidelines/differences-of-sex-development-atawhai-taihemahema/

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

28 For general information, see 2016 CEDAW NGO Report France, p. 48, https://intersex.shadowreport.org/public/2016-CEDAW-France-NGO-Zwischengeschlecht-Intersex-IGM.pdf

29 https://www.renews.co.nz/we-cant-forget-new-zealand-still-discriminates-against-rainbow-communities

"In 2020, the Crimes Act was amended to make Female Genital Mutilation - the cutting of female genitals for no medical reason - illegal. But the Asia Pacific Forum of National Human Rights Institutions says the laws and policies that prohibit female genital mutilation in New Zealand may actually give explicit permission for genital surgeries to 'normalise' the bodies of intersex infants and children. But how?

In the Act, it states that any medical or surgical procedure (including sexual reassignment surgery) can be performed if it is 'for the benefit of that person's physical or mental health.' Influential research from the 1950s on sex assignment argues that having ambiguous genitalia can cause mental distress, so doctors can argue the child is better off being assigned a gender, and they should be operated on when they are young for the best results.

It is difficult to know how many intersex people have had normalising surgeries, as there are no specific records for intersex patients.

[…]

While the MOH states these surgeries on intersex children are no longer the 'accepted' approach, Rogena [Sterling, co-chairperson of Intersex Trust Aotearoa New Zealand] says the way the Crimes Act is written means health professionals can legally still perform these surgeries and justify them as necessary for the child's health and well-being, 'despite evidence indicating many potential physical and psychological harms.'"

c) IGM 1 – "Masculinising Surgery": Hypospadias "Repair"[30]

While hypospadias is mentioned in the **"Differences of sex development - Atawhai Taihemahema"** guideline, in fact most cases of IGM 1, notably the most frequent IGM practice, are **excluded** from this guideline, but are covered in the separate **2019 "Hypospadias" Clinical Guideline**.[31]

In accordance with the above discussed **ESPU/EAU *"Paediatric Urology"* Guidelines 2022** endorsed by the **Urological Society of Australia and New Zealand**, the New Zealand "Hypospadias" guideline prescribes:

"Surgical management

- *Parents should be reassured that hypospadias is a common condition which can be corrected with surgery.*
- *Surgery is performed by the Paediatric Urologists at Starship Children's Hospital.*
- *Surgery is usually undertaken between 6 and 18 months, although timing will depend on the surgeon and other factors. Often more than one procedure is required and it is preferable to complete all stages in early childhood.*

  […]
- *The surgical principles are:*
  - *To reposition the meatus on to the head of the penis (meatoplasty and glanduloplasty)*

30 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

31 https://starship.org.nz/guidelines/hypospadias/

- *To straighten the chordee (othoplasty)*
- *To correct the hooded foreskin (by circumcision)*
- *To achieve all of this with an aesthetically acceptable result"*

Unfortunately, the 18 cases of surgery on intersex children mentioned in the State Report are not disaggregated by type of intervention. However, it's obvious that **hypospadias surgery is not included in those 18 cases**, as a 2021 publication out of the University of Waikato reveals: [32]

> *"The latest **Ministry of Health data** shows that **2017-18**, 265 people aged under 15 were diagnosed with **hypospadias**, with **206 surgical operations** performed – **85%** of those operations performed **on children aged under five.**"*

The publication further notes, *"There is a wide range of variations. **Hypospadias**, where the urethral opening appears on the underside of the penis, is most common. **Although not a health problem, surgery to alter the hypospadic appearance is "routine" in many places, including Aotearoa New Zealand.**"*

And in another 2021 publication, Dr Rogena Sterling, co-chairperson of Intersex Trust Aotearoa New Zealand, states:[33]

> ***"Dr. Rogena Sterling was born with an intersex condition called hypospadias**, where the opening of the urethra doesn't come to the end of the penis. They had their first 'normalising' **surgery when they were just four years old, then another at 15.** Like many surgeries on intersex people, it **was not medically necessary**, meaning the surgery didn't improve physical health, and **Rogena didn't get to chose**.*
>
> ***'The surgery was just so that I could stand up when I peed, like a man,'** says Rogena. 'But I was never given the chance to know about the **physical and psychological impacts of the surgery** and **decide for myself**.'"*

3. Lack of independent data collection and monitoring

The State Party claims in its "Data Annex to State Party Report", regarding intersex children and IGM practices, ***"The number of children who have undergone surgery** or treatment related to their sexual characteristics. = **18**"* (38(b), p. 1)

However, as demonstrated above, for the period **2017-18 the number of children submitted to IGM 1 alone amounts to 206**. Therefore, the figure of 18 proposed by the State Party is obviously **partial at best**. It's also not clear, if this figure includes intersex children **sent overseas** for surgery.

Conclusion, the State Party still refuses to disseminate **comprehensive data on IGM practices**, let alone **disaggregated** by type of intervention, age at intervention, and clinic were the intervention took place.

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32 Claire Breen, Katrina Roen (2021), "Intersex children in New Zealand are routinely undergoing unnecessary surgery – that needs to change", The Conversation, 26.10.2021, https://www.waikato.ac.nz/news-opinion/media/2021/intersex-children-in-new-zealand-are-routinely-undergoing-unnecessary-surgery-that-needs-to-change

33 https://www.renews.co.nz/we-cant-forget-new-zealand-still-discriminates-against-rainbow-communities

5. Suggested Questions for the dialogue

Harmful practices on intersex children: While we welcome the new guidelines "Differences of sex development - Atawhai Taihemahema" aimed at protecting intersex children, we are concerned about reports of persisting unnecessary genital surgery and other procedures on intersex children without their informed consent. These treatments can cause severe physical and psychological suffering, and can be considered as genital mutilation. We are also concerned about the lack of access to justice and redress in such cases.

My questions:

- **Please provide data on irreversible medical or surgical treatment of intersex children, disaggregated by type of intervention and age at intervention, including on hypospadias surgery.**
- **Which criminal or civil remedies are available for intersex people who have undergone involuntary irreversible medical or surgical treatment as children, and are these remedies subject to any statute of limitations?**

6. Suggested Recommendations

The Rapporteurs respectfully suggest that, with respect to the treatment of intersex persons in New Zealand, the Committee includes the following measures in their recommendations to the New Zeland Government (in line with this Committee's previous recommendations on IGM practices).

Harmful practices: Intersex genital mutilation

While the Committee welcome the new guidelines "Differences of sex development - Atawhai Taihemahema" aimed at protecting intersex children, it remains seriously concerned about persisting cases of medically unnecessary and irreversible surgery and other treatment on intersex children without their informed consent, which can cause severe suffering, and the lack of redress and compensation in such cases.

With reference to the joint general recommendation No. 31 of the Committee on the Elimination of Discrimination against Women/general comment No. 18 of the Committee on the Rights of the Child (2019) on harmful practices, and taking note of target 5.3 of the Sustainable Development Goals, the Committee urges the State party to:

- **Ensure that the State party's legislation explicitly prohibits the performance of unnecessary medical or surgical treatment on intersex children where those procedures may be safely deferred until children are able to provide their informed consent, and provide reparations for children who received unnecessary treatment, including by extending the statute of limitations.**
- **Provide families with intersex children with adequate counselling and support.**
- **Systematically collect disaggregated data with a view to understanding the extent of these harmful practices so that children at risk can be more easily identified and their abuse prevented.**

Thank you for your consideration and kind regards,

Daniela Truffer & Markus Bauer (StopIGM.org / Zwischengeschlecht.org)