

## Intersex Genital Mutilation in Ireland: Update to LOIPR Report

Dear Committee on the Rights of the Child

All typical forms of Intersex Genital Mutilation are still practised in Ireland, facilitated and paid for by the State party via the public health system (Health Service Executive (HSE)). Parents and children are misinformed, kept in the dark, sworn to secrecy, kept isolated and denied appropriate support. Despite previous Concluding Observations by this Committee (2016) and CEDAW (2017) denouncing IGM in Ireland as a harmful practice, to this day the Government refuses to take action, upholding the impunity of IGM practitioners, while IGM survivors are denied access to justice and redress. In contrast, Irish intersex advocates are vocal about the need of legislation explicitly prohibiting “*intersex genital mutilation*” and ensuring access to justice.

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### 1. Ireland’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 45<sup>th</sup> 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.*”<sup>1</sup>

<sup>1</sup> Statement supported by Ireland (and 34 other States) during the 45<sup>th</sup> Session of the Human Rights Council on 1 October 2020, <https://www.dfat.gov.au/international-relations/themes/human-rights/hrc-statements/45th->

## b) UNHRC48 Statement, 04.10.2021

On occasion of the 48<sup>th</sup> 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.”<sup>2</sup>*

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

All forms of **IGM practices remain widespread and ongoing**, persistently **advocated, prescribed and perpetrated** by state funded University and public Children’s Hospitals, and **advocated and paid for** by the public Irish Health Service Executive (HSE), including in **National HSE Guidelines** and in **Children’s Health Ireland (CHI) Hospitals** (see our 2020 NGO Report for LOIPR, p. 8-12). Despite previous Concluding Observations by this Committee and CEDAW, the **Government fails to take appropriate action**.

Accordingly, the Irish Society of Urology endorses the current 2022 ESPU/EAU “Paediatric Urology” Guidelines prescribing all forms of IGM:

### a) IGM 3 – Sterilising Procedures:

**Castration / “Gonadectomy” / Hysterectomy /  
Removal of “Discordant Reproductive Structures” / (Secondary) Sterilisation  
Plus arbitrary imposition of hormones<sup>3</sup>**

The **Irish Society of Urology** still endorses the unchanged, current **2022 Guidelines of the European Association of Urology (EAU)**,<sup>4</sup> which include the current **ESPU/EAU “Paediatric Urology” Guidelines 2022<sup>5</sup>** of the European Society for Paediatric Urology (ESPU) and the European Association of Urology (EAU) which stress:<sup>6</sup>

*“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*

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[session-human-rights-council/joint-statement-led-austria-rights-intersex-persons](https://www.unhcr.org/refugees/joint-statement-led-austria-rights-intersex-persons)

2 Statement supported by Ireland (and 52 other States) during the 48<sup>th</sup> 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>

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

population.”

Further, regarding “*whether and when to pursue gonadal or genital surgery*”,<sup>7</sup> the Guidelines refer to the “*ESPU/SPU standpoint on the surgical management of Disorders of Sex Development (DSD)*”,<sup>8</sup> 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**”<sup>9</sup> 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)<sup>10</sup>:

**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 <b>Low threshold for gonadectomy</b> if ambiguous genitalia	<b>Bilateral gonadectomy</b> at diagnosis	<b>Low threshold for gonadectomy</b> 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 <b>gonadectomy</b> to avoid gynecomastia or if on testosterone supplementation	<b>Partial AIS</b> and testosterone synthesis disorders – <b>Prepubertal gonadectomy</b>  <b>Complete AIS – Postpubertal gonadectomy</b> or follow-up – GCC risk low, allow spontaneous puberty	Partial AIS and testosterone synthesis disorders – Bilateral biopsy  – <b>Low threshold for gonadectomy</b> 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

## b) IGM 2 – “Feminising Procedures”: Clitoris Amputation/“Reduction”, “Vaginoplasty”, “Labiaplasty”, Dilation<sup>11</sup>

The **Irish Society of Urology** still endorses the unchanged, current **2022 Guidelines of the European Association of Urology (EAU)**,<sup>12</sup> which include the current **ESPU/EAU “Paediatric Urology” Guidelines 2022**<sup>13</sup> of the European Society for Paediatric Urology (ESPU) and the European Association of Urology (EAU). In **chapter 3.17 “Disorders of sex development”**,<sup>14</sup>

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.jpurology.com/article/S1477-5131\(13\)00313-6/pdf](http://www.jpurology.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)

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://d56bochluzqnz.cloudfront.net/documents/full-guideline/EAU-Guidelines-on-Paediatric-Urology-2022.pdf>

14 Ibid., p. 86

despite admitting that “*Surgery that alters appearance is not urgent*”<sup>15</sup> and that “*adverse outcomes have led to recommendations to delay unnecessary [clitoral] surgery to an age when the patient can give informed consent*”,<sup>16</sup> 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,<sup>17</sup> referring to the 2018 ESPU Open Letter to the Council of Europe (COE),<sup>18</sup> which further invokes **parents’ “social, and cultural considerations”** as justifications for early surgery (p. 2).**

### c) IGM 1 – “Masculinising Surgery”: Hypospadias “Repair”<sup>19</sup>

The **Irish Society of Urology** still endorses the unchanged, current **2022 Guidelines of the European Association of Urology (EAU)**,<sup>20</sup> which include the current **ESPU/EAU “Paediatric Urology” Guidelines 2022**<sup>21</sup> of the European Society for Paediatric Urology (ESPU) and the European Association of Urology (EAU). In **chapter 3.6 “Hypospadias”**,<sup>22</sup> 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.*”<sup>23</sup> – despite admitting to the “*risk of complications*”<sup>24</sup> and “*aesthetic[...]*” and “*cosmetic*” justifications.<sup>25</sup>

### 3. Lack of independent data collection and monitoring

In its State Report and Annex, the Government claims, only “*Two or three children per year are born in Ireland with ambiguous genitalia and are referred to Children’s Health Ireland (CHI)*” (para 166). This is at best a partial number.

While the Government further claims, “*Only medically necessary treatment, which may include surgery, will be performed, and only after a unanimous decision of consultants and parents*” (State Report, para 167), the Government conveniently fails to indicate how many and which “*medically necessary*” surgeries are performed.

Therefore, the State Party should be obliged to provide comprehensive data, disaggregated by type of intervention and age at intervention.

### 4. Public criticism of IGM and calls for a legal prohibition and access to redress

Local NGO Intersex Ireland states on its homepage, “*We are intersex people demanding an end to medically unnecessary, irreversible and damaging surgeries performed on us without our*

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](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

consent.”<sup>26</sup>

The NGO is also vocal about the need of legislation explicitly prohibiting “*intersex genital mutilation*” and ensuring access to justice.<sup>27</sup>

*“Intersex Ireland calls for IGM ban following new legislation in Greece. IGM, or intersex genital mutilation, has been outlawed by the Greek Government, sparking hope for Irish Intersex activists.”*

*“Recently, the HSE informed the UN Human Rights Committee in Geneva that they only operate on the genitals of intersex children when necessary. We at Intersex Ireland are distressed by this response as there is no medical justification for IGM procedures such as those described above.”*

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26 <https://intersexireland.org/>

27 <https://gcn.ie/intersex-ireland-igm-greece/>

## 5. Suggested Questions for the dialogue

**Harmful practices on intersex children:** We are concerned about reports of 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 Ireland, the Committee includes the following measures in their recommendations to the Irish Government (in line with this Committee's previous recommendations on IGM practices).*

### **Harmful practices: Intersex genital mutilation**

The Committee remains seriously concerned about 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)