Intersex Genital Mutilations Human Rights Violations Of Children With Variations Of Reproductive Anatomy



NGO Report (for LOIPR)

to the 8th Report of the United Kingdom on the International Covenant on Civil and Political Rights (CCPR)

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Executive Summary

All typical forms of IGM practices are still widespread in the United Kingdom today, facilitated and paid for by the State party via the National Health Service (NHS), with statistics indicating about 2,900 involuntary, non-urgent interventions practiced annually.

CRC has already considered IGM in the UK as a harmful practice (CRC/C/GBR/CO/5, paras 46-47), CRPD as a violation of the integrity (CRPD/C/GBR/CO/1, paras 10(a)-11(a), 38-41), and CAT as cruel, inhuman or degrading treatment (CAT/C/GBR/CO/6, paras 64-65).

The United Kingdom is thus in breach of its obligations under CCPR to (a) take effective legislative, administrative, judicial or other measures to prevent inhuman treatment and involuntary experimentation on intersex children causing severe mental and physical pain and suffering, and (b) ensure equal access to justice and redress, including fair and adequate compensation and as full as possible rehabilitation for victims, as stipulated in the Covenant in conjunction with the General comment No. 20.

This Committee has repeatedly recognised IGM practices to constitute a serious violation of the Covenant in Concluding Observations, invoking Articles 3, 7, 9, 17, 24 and 26.

In total, UN treaty bodies CRC, CAT, CCPR, CEDAW and CRPD have so far issued 48 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 and (b) ensure redress and compensation, plus (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 treatments** that would not be considered for "normal" children, without evidence of benefit for the children concerned, but justified by societal and cultural norms and beliefs. **Typical forms** of IGM include "masculinising" and "feminising", "corrective" genital surgery, sterilising procedures, imposition of hormones, forced genital exams, vaginal dilations, medical display, 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, less sexual activity, dissatisfaction with functional and aesthetic results.

This **Thematic NGO Report** has been compiled by the international intersex NGO **StopIGM.org**. It contains **Suggested Questions (opposite p. 5).**

Suggested Questions for the LOIPR

The Rapporteurs respectfully suggest that in the LOIPR the Committee asks the UK Government the following questions with respect to the rights of intersex people:

Intersex genital mutilation (arts. 2, 3, 7, 24, 26)

- How many non-urgent, irreversible surgical and other procedures have been undertaken on intersex minors? Please provide detailed statistics on sterilising, feminising, and masculinising procedures, disaggregated by age groups and devolved nations.
- Does the State party plan to stop this practice? If yes, what measures does it plan to implement, and by when?
- Please indicate which criminal or civil remedies are available for intersex people who have undergone involuntary sterilisation or unnecessary and irreversible medical or surgical treatment when they were children, and whether these remedies are subject to any statute of limitations?
- Please indicate which means of rehabilitation are available for intersex people who have undergone involuntary procedures?
- Please indicate which means of psychosocial support, including peer support, are available for intersex children and their families?

A. Introduction

1. Intersex, IGM and Human Rights in the United Kingdom

The United Kingdom has been reviewed by CRC (2016), CRPD (2017) and CAT (2019) with all Committees recognising IGM in the UK as constituting a harmful practice, cruel, inhuman or degrading treatment, and a violation of integrity.

In countries all over the world, UN treaty bodies including CCPR are regularly denouncing IGM as a serious violation of non-derogable human rights. 12

Nonetheless, the UK fails to recognise the serious nature of the violations constituted by IGM practices, and fails to undertake effective measures, including legislation, to protect intersex children from the daily mutilations, amounting to 2,900 incidents annually in England alone. This NGO Report demonstrates that the current harmful medical practice on intersex persons in the UK – advocated, facilitated and paid for by the State party – constitute serious breaches of the UK's obligations under the Convention.

To this day the United Kingdom undeviatingly not only does nothing to prevent this abuse, but continues to directly finance it via the public National Health Service (NHS) and via funding the public university clinics and paediatric hospitals, thus violating its non-derogable duty to prevent inhuman treatment of intersex children, to guarantee access to justice, redress and compensation to IGM survivors, as well as access to adequate counselling and consensual **needed health care** for intersex people and their families.

2. About the Rapporteurs

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

StopIGM.org / Zwischengeschlecht.org, founded in 2007, is an international Human Rights NGO based in Switzerland. It is led by intersex persons, their partners, families and friends, and works to end IGM Practices and other human rights violations perpetrated on intersex people, according to its motto, "Human Rights for Hermaphrodites, too!" ³ According to its charter, StopIGM.org works to support persons concerned seeking redress and justice, and regularly reports to UN treaty bodies on IGM practices. StopIGM.org has been active in the UK since 2011⁵ 6 7 8 9 10 11 12.

Currently there are 48 UN Treaty body Concluding Observations explicitly condemning IGM practices as a serious violation of non-derogable human rights, see: http://stop.genitalmutilation.org/post/IAD-2016-Soon-20-UN-Reprimands-for-Intersex-Genital-Mutilations

² CAT, CRC, CRPD, SPT, SRSG VAC, COE, ACHPR, IACHR (2016), "End violence and harmful medical practices on intersex children and adults, UN and regional experts urge", http://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=20739&LangID=E

http://Zwischengeschlecht.org/, English pages: http://stop.genitalmutilation.org/ 3

http://zwischengeschlecht.org/post/Statuten 4

⁵ http://zwischengeschlecht.org/pages/Open-Letter-ISHID-2011-18-09

Margaret Simmonds, "Girls/women in inverted commas - facing 'reality' as an XY-female", PhD Thesis 6 University of Sussex, p. 208 (PDF p. 214), http://sro.sussex.ac.uk/43431/1/Simmonds, Margaret.pdf

Australian Senate Hearing, 28.03.2013, Testimony G. Ansara, p. 11 (PDF p. 15), http://parlinfo.aph.gov.au/parlInfo/download/committees/commsen/86ba4480-36ef-4e72-b25e-9fa162f9a4ae/toc pdf/Community%20Affairs%20References%20Committee 2013 03 28 1856 Official.pdf;f ileType=application%2Fpdf#search=%22committees/commsen/86ba4480-36ef-4e72-b25e-

In addition, the Rapporteurs would like to acknowledge the work of IntersexUK (iUK)¹³ and The UK Intersex Association (UKIA).¹⁴ And we would like to acknowledge the work of the Androgen Insensitivity Syndrome Support Group UK (AISSG UK)¹⁵ and Margaret Simmonds.¹⁶ We would like to acknowledge the work of Leslie Jaye¹⁷ and of Michel O'Brien.¹⁸ We would like to acknowledge the work of Ellie Magritte¹⁹ and dsdfamilies.org.²⁰ And we would like to acknowledge the work of Daniela Crocetti, Surya Monro and Tray Yeadon-Lee with Fae Garland and Mitch Travis at the University of Huddersfield's Intersex/DSD Human Rights, Citizenship and Democracy [EUICIT] Project.²¹

3. Methodology

This thematic NGO report is in part based on the 2016 CRC UK NGO Report,²² the 2017 CRPD UK PSWG NGO Report,²³ the 2017 CRPD UK NGO Report,²⁴ and the 2019 CAT UK NGO Report²⁵ by *StopIGM.org*, *IntersexUK* and *The UK Intersex Association*.

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- 8 http://stop.genitalmutilation.org/public/Open-Letter I-DSD 2013.pdf
- 9 http://www.ias.surrey.ac.uk/workshops/intersex/papers/Intersex%20programme%20brochure.pdf
- 10 https://research.hud.ac.uk/institutes-centres/ccid/projects/current_projects/intersex-dsd_human_rights/
- 11 http://stop.genitalmutilation.org/public/StopIGM-Concern-Call-for-Evidence-UK-GEO.pdf
- 12 https://cordis.europa.eu/project/id/859869
- 13 https://www.facebook.com/intersexuk/
- 14 http://ukia.co.uk/
- 15 http://www.aissg.org/
- Margaret Simmonds: 'Girls/women in inverted commas facing "reality" as an XY-female', University of Sussex 2012, http://sro.sussex.ac.uk/43431/1/Simmonds, Margaret.pdf
- 17 <u>https://intersexday.org/en/language-truth-jaye/</u>
- 18 http://oiiinternational.com/653/holistic-for-whom/
- 19 http://www.dsdfamilies.org/docs/conf/working together.pdf
- 20 http://www.dsdfamilies.org/
- 21 https://research.hud.ac.uk/institutes-centres/ccid/projects/current_projects/intersex-dsd_human_rights/
- $\underline{\text{http://intersex.shadowreport.org/public/2016-CRC-UK-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf}$
- 23 <u>http://intersex.shadowreport.org/public/2017-CRPD-PSWG-UK-NGO-Coalition-Intersex-IGM.pdf</u>
- 24 http://intersex.shadowreport.org/public/2017-CRPD-UK-NGO-Coalition-Intersex-IGM.pdf
- 25 http://intersex.shadowreport.org/public/2019-CAT-UK-NGO-Coalition-Intersex-IGM.pdf

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

1. Overview: IGM practices in the UK: Pervasive and unchecked

In the **United Kingdom** (see CRC/C/GBR/CO/5, paras 45-46, CRPD/C/GBR/CO/1, paras 10(a)-11(a), 38-41; CAT/C/GBR/CO/6, paras 64-65), same as in *Germany* (CAT/C/DEU/CO/5; para 20; CRPD/C/DEU/CO/1, paras 37-38; CEDAW/C/DEU/CO/7-8, paras 23-24), *France* (CAT/C/FRA/CO/7, paras 32–33; CRC/C/FRA/CO/5, paras 47-48; CEDAW/C/FRA/CO/7-8, paras 17e-f + 18e-f), *Switzerland* (CCPR/C/CHE/CO/4, paras 24-25; CAT/C/CHE/CO/7, para 20; CRC/C/CHE/CO/2-4, paras 42-43; CEDAW/C/CHE/CO/4-5, paras 38-39), and in **many more State parties**, ²⁶ there are

- **no effective legal or other protections** in place to ensure the rights of intersex children to physical and mental integrity, autonomy and self-determination, and **to prevent IGM**
- no measures in place to ensure systematic data collection and monitoring of IGM
- no legal or other measures in place to ensure the accountability of IGM perpetrators
- no legal or other measures in place to ensure access to redress and justice for adult IGM survivors.

To this day, the **UK government fails to recognise the serious human rights violations**²⁷ and the lifelong, severe suffering caused by IGM practices, let alone to "take effective legislative, administrative, judicial or other measures" to protect intersex children.

What's worse, this continues after the State party has already been reprimanded by CRC in 2016, by CRPD in 2017 and by CAT in 2019 for IGM practices, with Committees calling for legislative measures including to ensure access to redress, and to provide adequate support.

UK doctors are very outspoken about their determination to continue with involuntary surgeries etc. on intersex children "[u]ntil such time as there is a change in law" (see p. 10, 18).

To this day, as documented in Annexe 1 (p. 15-21), in the UK 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 National Health Service (NHS).

It should be duly noted that, despite publicly available data on IGM based on NHS England Hospital Episode Statistics (HES) indicating annually up to 2,900 non-urgent genital surgeries on intersex children in England alone, ²⁸ UK Officials and NHS doctors have a long history of ignoring such available data by either completely ignoring questions on IGM (for example answering on FGM instead), ²⁹ or conveniently denying any knowledge of data on IGM, ³⁰ or

²⁶ See http://stop.genitalmutilation.org/post/IAD-2016-Soon-20-UN-Reprimands-for-Intersex-Genital-Mutilations

²⁷ **CAT, CRC, CRPD, SPT, SRT, SRSG VAC, COE, ACHPR, IACHR** (2016), "End violence and harmful medical practices on intersex children and adults, UN and regional experts urge", http://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=20739&LangID=E

See Annexe 1 (p. 15-21), data from a research report of the University of Huddersfield: Monro, Surya, Crocetti, Daniela, Yeadon-Lee, Tray, Garland, Fae and Travis, Mitch (2017), Intersex, Variations of Sex Characteristics, and DSD: The Need for Change. Research Report. University of Huddersfield, http://eprints.hud.ac.uk/id/eprint/33535/

²⁹ See CRPD18 Transcript, http://stop.genitalmutilation.org/post/You-answered-on-female-genital-

severely **downplaying numbers** on IGM practices ("between 20 and 40"). 31

Further, also **intersex children from Ireland**³² **and Malta**³³ are sent to the UK NHS hospitals for IGM: According to the "Irish Examiner"³⁴ paediatricians of the Great Ormond Street Children's Hospital NHS Trust regularly attend "multidisciplinary meetings" at "Our Lady's Crumlin Children's Hospital" in Dublin, **Ireland**, when "difficult decisions" are made regarding IGM surgery on Irish intersex children, and according to Crumlin paediatrician Dr Colm Costigan, "for more complicated rare surgeries, 'we send children abroad'", arguably to Great Ormond Street. Also, **Maltese** intersex children have traditionally been sent to UK NHS Hospitals for IGM surgery which was also indirectly confirmed by a Maltese ERN Board of Member States representative highlighting the special Maltese relationship with England and Great Ormond Street. ³⁵

Last but not least, UK NHS Hospitals play a prominent role in **International IGM Networks**: In 2017, the "European Reference Network" was launched to ensure better treatment for patients with rare diseases within the European Union.³⁶ Unfortunately, **2 of the newly created "ERNs" also specialise in the proliferation and practice of IGM**, namely the "**Network Urogenital Diseases" a.k.a. "eUROGEN"** and the "**Network on Endocrine Conditions" a.k.a. "Endo-ERN"**.³⁷ Like with earlier international networks led by IGM perpetrators, e.g. "I-DSD", ³⁸ "DSDnet" and "DSD-Life", ⁴⁰ UK NHS Hospitals are prominently involved. ⁴¹

2. Insufficient Government Initiatives to Combat IGM Practices

a) NHS Regulation Bodies Ignore Intersex NGOs and Human Rights

NHS "self-regulation" has failed: Not only does the practice continue with impunity, but two newly appointed NHS bodies to address the practice (the "NHS England DSD Surgery Policy Workgroup" led by IGM surgeon Dr Mark Woodward, see fn. 31, and the "NHS England Service Specification Workgroup") so far fail to consult with intersex NGOs in a meaningful way by

mutilation%2C-but-I-was-talking-about-intersex-genital-mutilation-CRPD18

- 30 "The British government has said it is unaware how many intersex children [...] are being subjected to surgeries on the NHS", Buzzfeed News (16.01.2019), https://www.buzzfeed.com/patrickstrudwick/how-many-intersex-children-being-operated-on
- See for example IGM surgeon Dr Mark Woodward publicly claiming: "maybe between 20 and 40 surgical procedures a year in the whole of the UK, so we are talking about relatively small numbers", BBC interview, 14.01.2019, see transcript: http://stop.genitalmutilation.org/post/UK-NHS-Doctor-admits-to-Intersex-Genital-Mutilation
- 32 IGM in **Ireland** has previously been recognised as a serious violation by **CRC** and **CEDAW**: CRC/C/IRL/CO/3-4, paras 39-40; CEDAW/C/IRL/CO/6-7, paras 24-25
- 33 IGM in Malta has previously been recognised as a serious violation by CRC: CRC/C/MLT/CO/3-6, paras 28-29
- 34 Irish Examiner, "What happens when a child is born intersex in Ireland?", 04.11.2016, Cover story, p. 7-9
- 35 See 2019 CRC Intersex NGO Report Malta, p. 10, http://intersex.shadowreport.org/public/2019-CRC-Malta-NGO-Zwischengeschlecht-Intersex-IGM.pdf
- 36 https://ec.europa.eu/health/sites/health/files/ern/docs/2017 brochure en.pdf
- 37 See http://stop.genitalmutilation.org/post/eUROGEN-EU-funded-Intersex-Genital-Mutilators
- 38 See Open Letter to "I-DSD 2013", http://stop.genitalmutilation.org/public/Open-Letter_I-DSD_2013.pdf
- 39 See http://stop.genitalmutilation.org/post/DSDnet-Intersex-Genital-Mutilators-European-Union
- $40 \quad See \ \underline{http://stop.genitalmutilation.org/post/EU-biggest-funder-of-Intersex-Genital-Mutilation-how-much-longer}$
- 41 The "Open Letter of Concern to 6th I-DSD 2017, DSDnet, eUROGEN, Endo-ERN, DSD-Life and Affiliates" lists **14 NHS Clinics involved in current international IGM projects**, see p. 2, http://stop.genitalmutilation.org/public/Open_Letter_I-DSD_Copenhagen_2017.pdf

only consulting with an intersex parents organisation (dsdfamilies.org),⁴² but refusing to consult with intersex NGOs,⁴³ let alone to **consider human rights implications**.

b) GEO "Call for Evidence" Ignores Data and Human Rights

We acknowledge that the 2019 "Call for Evidence on Variations in Sex Characteristics" by the Government Equalities Office (GEO)⁴⁴ and the upcoming Scotland Intersex Enquiry both adequately consulted intersex NGOs, and that the GEO "Technical Paper" ⁴⁵ setting the terms of reference based on a 12-months research exercise by GEO states that the UK Government is now officially "aware of calls from some UK stakeholders to end the practice of what they describe as 'medically unnecessary interventions'". However, we note with great concern that both the "Call for Evidence" itself as well as its "Technical Paper" fail to consider human rights, namely the non-derogable rights to protection from harmful practices, cruel, inhuman or degrading treatment and involuntary scientific or medical experimentation, as well as to justice and redress for victims, despite that these are crucial issues for IGM survivors. ⁴⁶

c) UK NHS Doctors consciously dismissing Intersex Human Rights Concerns

It must be duly noted that **UK paediatric surgeons** are **adamant advocates** of IGM practices, **consciously dismissing to consider any human rights concerns, despite openly admitting to knowledge of relevant criticisms** by human rights and ethics bodies.

For example, the 2013 "ESPU/SPU standpoint on the surgical management of Disorders of Sex Development (DSD)", co-authored by Dr Peter Malone (University College Hospital UCLH, University College London Hospitals NHS Foundation Trust / Royal Berkshire Hospital, Royal Berkshire NHS Foundation Trust) dismissed both the 2013 Report by the Special Rapporteur on Torture and the 2012 Recommendations by the Swiss National Advisory Commission on Biomedical Ethics as "inappropriate and biased statements" and "biased and counterproductive reports", while insisting on continuing with IGM practices.⁴⁷

And paediatric urologist Dr Imran Mushtaq (Great Ormond Street Hospital for Children NHS Foundation Trust / Senior Lecturer Institute of Child Health, London) freely admits **only** "a change in law" would prevent the hospital's "multidisciplinary team (MDT) dedicated to children with DSD" from continuing with IGM practices (see also p. 18):⁴⁸

"Until such time as there is a change in the law, parents will continue to have the right to decide if their child should or should not have genital surgery in infancy or childhood. [...]"

 $\underline{44} \quad \underline{https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/771459/VSC_call_for_evidence_Web_Accessible.pdf}$

http://stop.genitalmutilation.org/post/Letter-of-Concern-Government-Equalities-Office-Intersex-Human-Rights

dsdfamilies.org (2018), submission to Scottish Parliament CTEEA/S5/18/CB/33, p. 5, https://www.parliament.scot/S5 European/Inquiries/CensusBill DSDFamilies CTEEAS518CB33.pdf

⁴³ Personal communication IntersexUK 2019

^{45 &}lt;a href="https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/771468/VSC_Technical_Paper_Web_Accessible.pdf">https://assets.publishing.service.gov.uk/government/uploads/system/uploads/system/uploads/attachment_data/file/771468/VSC_Technical_Paper_Web_Accessible.pdf

⁴⁶ See StopIGM.org (2019), Open Letter of Concern to GEO, http://stop.genitalmutilation.org/public/StopIGM-Concern-Call-for-Evidence-UK-GEO.pdf See also GEO's telling non-answer,

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

⁴⁸ Imran Mushtaq, "Surgery in infants and children with DSD" (2011), http://dsdfamilies.org/docs/mednote/Surgery%20-%20Mushtaq.pdf

This is the more severe, since over a decade of ongoing research published by clinicians from the UCLH Middlesex Clinic caring for adult intersex persons clearly documents the disastrous effects of non-consensual, unnecessary childhood treatments in the UK, so UK paediatric doctors specialising in such treatments are obviously fully aware of the severe pain and suffering caused by their actions, ⁴⁹ as are Government bodies.

Nonetheless, so far Government bodies fail to take appropriate action, but continue to ignore intersex human rights, and allow IGM doctors to continue practicing with impunity.

d) Misrepresentation of Intersex as LGBT issue, Misappropriation of Funding

Intersex persons and their organisations have **spoken out clearly against misrepresenting intersex as an LGBT issue**, and in particular **against instrumentalising intersex** as a means to an end by LGBT groups, and **against pinkwashing of IGM** by State parties trying to deflect from criticism of involuntary intersex treatments, maintaining that IGM practices present a **distinct and unique issue** constituting significant human rights violations, which are different from those faced by the LGBT community, and thus need to be **adequately addressed in a separate section** as **specific intersex issues.** ⁵⁰

A recent UK example of LGBT groups talking for intersex persons and their organisations without consultation or representation is the Scottish Pink Saltire Video "Introducing Intersex" originally also promoted by the Scottish DSD Network, 52 which was financed by the Scottish Lottery Fund, 53 and in which intersex is "introduced" and explained exclusively by non-intersex persons and organisations including Pink Saltire, Equality Network Scotland, and the Scottish DSD Network, while intersex persons and their organisations were neither consulted nor represented.

So far Scotland is the only UK country with a budget for funding **intersex awareness raising** with at least "£135,000 for intersex work", however **paid out exclusively to LGBT organisations**. In total, 2016-2020 a staggering £180,000 will be paid out to LGBT organisations for "intersex work", 55 56 while intersex NGOs continue to receive ZERO.

see e.g. Sarah M. Creighton et al., (2013), Childhood surgery for ambiguous genitalia: glimpses of practice changes or more of the same?, Psychology & Sexuality 5(1):34-43

For a list of older relevant Middlesex publications, see http://www.intersexinitiative.org/articles/minto-creighton.html

For more information and sources, see 2019 CCPR Mexico NGO Report, Annexe 2, p. 37-40, http://intersex.shadowreport.org/public/2019-CCPR-Mexico-NGO-Intersex-Brujula-StopIGM.pdf

Pink Saltire, "Introducing Intersex", video 22.03.2017. **Note:** The Rapporteurs **can NOT endorse this video** as it was made by third party groups without consultation and representation of intersex persons and their organisations. (**Video removed after CRPD18:** https://www.youtube.com/watch?v=onRPZEPDoPs)

⁵² See "Introducing Intersex", http://www.sdsd.scot.nhs.uk/support/ (link removed after CRPD18)

⁵³ See https://pinksaltire.com/2016/10/08/do-you-know-what-the-i-means/

[&]quot;Equality Network funding includes £600,000 for the work of Scottish Trans, representing an increase of 53% on previous funding, and in recognition of the huge increase in demand for trans services, including a Scottish Government gender recognition consultation expected in the Autumn, as well as £135,000 for intersex work.", see Pink Saltire, "Big Four LGBT Charities in Government Funding Windfall", https://pinksaltire.com/2017/06/28/big-four-lgbt-charities-in-government-funding-windfall/

See also £45,000 for "intersex project" paid out to Equality Network in 2016, https://www.gov.scot/publications/equality-funding-2016-2017/

⁵⁶ See also annually £45,000 for "intersex project" paid out to Equality Network in 2017, 2018, 2019.

So unfortunately while the Scottish Government and the Scottish political parties publicly strive to "include[...] intersex as part of our equality approach since 2014",⁵⁷ in fact they only do so regarding issues marginal to most intersex people like e.g. "hate crimes against non-binary or intersex people" ⁵⁸ and "update[ing] the Gender Recognition Act 2004 [...] to alter the law to make better provisions for [...] specifically non-binary and intersex people",⁵⁹ however, regarding the main issue of intersex children being submitted to IGM they steadfastly **keep funding and supporting the doctors and clinics responsible for continuing the practice**.

https://www.gov.scot/publications/equality-national-intermediary-bodies-funding-2017-2020/

^{57 &}lt;a href="https://www.gov.scot/policies/lgbti/">https://www.gov.scot/policies/lgbti/

⁵⁸ https://pinksaltire.com/2017/06/10/scots-lgbt-hate-crime-reaches-new-high/

⁵⁹ https://pinksaltire.com/2016/09/01/nhs-under-strain-as-gender-identity-demand-surges/

C. Conclusion: UK must "take effective measures" to end IGM

For many years, the **UK government has been called upon** to

- undertake **legislation to prohibit** IGM practices (up to **2,900 incidents annually** in **England** alone)
- guarantee access to justice and redress for IGM survivors
- ensure adequate support for intersex children and their families
- systematically collect disaggregated data,

including by UN Treaty bodies CRC, CRPD and CAT, which have expressed concern about

"[c]ases of medically unnecessary surgeries and other procedures on intersex children before they are able to provide their informed consent, which often entail irreversible consequences and can cause severe physical and psychological suffering, and the lack of redress and compensation in such cases",

and have urged the UK, inter alia, to

- "[e]nsure that no one is subjected to unnecessary medical or surgical treatment during infancy or childhood"
- "[provide] protection and care to the child victims and the prosecut[e] those found guilty of perpetrating such acts"
- "[e]stablish measures to ensure equal access to justice"
- "[p]rovide redress to the victims of such treatment"
- "[e]ducate medical and psychological professionals [...] on the consequences of unnecessary interventions for intersex children"

Since then, on the positive side the **last UK Government** has to be commended for being the **very first** to

- publicly **acknowledge the call for legislative measures** to prevent IGM practices (see above p. 10)
- publicly admit that it is wrong to conflate intersex with transgender, 60 61
- undertake a **Call for Evidence on Variations in Sex Characteristics** as a first, however, still grossly insufficient step (see above p. 10)

^{60 &}quot;I draw the committee's attention to a couple of drafting points in relation to the policy memorandum. The first is that it incorrectly includes intersex people under the umbrella term "trans". That was an unfortunate action during drafting in relation to an area that is constantly developing. We recognise that the needs of trans people and of intersex people are different. We will ensure that any future documentation does not include intersex people under the trans umbrella." Fiona Hyslop, Cabinet Secretary for Culture, Tourism and External Affairs, Scottish Government, at the 34th Meeting of the Culture, Tourism, Europe and External Affairs Committee, 20.12.2018, column 28, http://www.parliament.scot/parliamentarybusiness/report.aspx?r=11864&mode=pdf

and hormonal variations. It includes diagnoses such as Congenital Adrenal Hyperplasia (or CAH),
Hypospadias, Androgen Insensitivity Syndrome (AIS), Klinefelter syndrome and Turner syndrome, as well as
many others. This is distinct from being transgender or non-binary, which are to do with a person's gender
identity." Government Equalities Office (2019), Variations in Sex Characteristics. A Call for Evidence, p. 3,
https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/771459/VSC_call_for_evidence_Web_Accessible.pdf

Unfortunately, there are still further serious shortcomings, gaps, concerns and challenges.

To this day, UK doctors, hospitals, the NHS and still far too many Government officials **fail to recognise the serious human rights violations**⁶² and the lifelong, severe suffering caused by IGM practices.

To this day, the United Kingdom is categorically failing to meet its non-derogable obligations under the Convention towards intersex people, and in particular towards intersex children, including to take effective legislative, administrative, judicial or other measures to prevent acts of torture or other forms of cruel, inhuman or degrading treatment, or non-consensual medical or scientific experimentation.

Adult victims of IGM practices unchangedly encounter **severe obstacles** in the pursuit of their right to an **impartial investigation**, and to **redress** and fair and adequate **compensation**, including the means for as **full rehabilitation** as possible.

Also, the United Kingdom's efforts on education and information regarding the prohibition against torture in the training of medical personnel remain grossly insufficient with respect to the treatment of intersex people, as evidenced by the fact that involuntary, non-urgent interventions continue, paid for by the National Health Service (NHS) (see p. 8 and Annexe 1, p. 15-21).

The UK must finally "take effective legislative, administrative, judicial or other measures" to protect intersex children from ill-treatment – in line with its obligations under CCPR, CAT, CRC, and CRPD.

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⁶² CAT, CRC, CRPD, SPT, SRSG VAC, COE, ACHPR, IACHR (2016), "End violence and harmful medical practices on intersex children and adults, UN and regional experts urge", http://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=20739&LangID=E

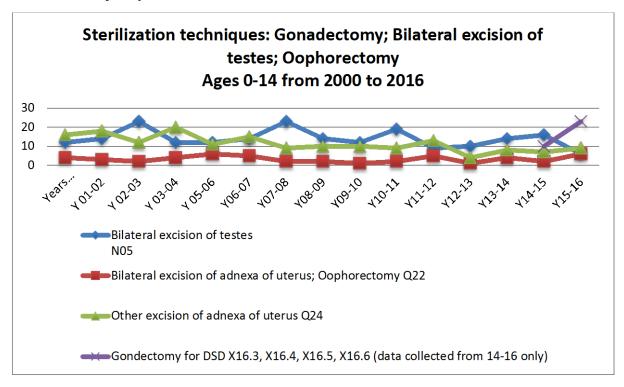
Annexe 1 - IGM in the UK: Current Practice

1. Most common IGM Forms advocated by NHS Doctors and Clinics

While there is no data available on IGM practices in the whole of the UK, statistics based on NHS England Hospital Episode Statistics (HES) and published in a research report of the University of Huddersfield indicate annually up to 2,900 non-urgent genital surgeries on intersex children in England alone.

a) IGM 3 – Sterilising Procedures:

Castration / "Gonadectomy" / Hysterectomy / Removal of "Discordant Reproductive Structures" / (Secondary) Sterilisation Plus arbitrary imposition of hormones ⁶³



Source: Huddersfield UK Intersex Report 2017, p. 13⁶⁴

Removal of testes, as advocated in the 2013 "ESPU/SPU standpoint on the surgical management of Disorders of Sex Development (DSD)", 65 co-authored by Dr Peter Malone (University College Hospital UCLH, University College London Hospitals NHS Foundation Trust / Royal Berkshire Hospital, Royal Berkshire NHS Foundation Trust):

"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."

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

Monro, Surya, Crocetti, Daniela, Yeadon-Lee, Tray, Garland, Fae and Travis, Mitch (2017), Intersex, Variations of Sex Characteristics, and DSD: The Need for Change. Research Report. University of Huddersfield, http://eprints.hud.ac.uk/id/eprint/33535/

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

Similarly, the "2016 Global Disorders of Sex Development Consensus Statement", ⁶⁶ co-authored by Prof S. Faisal Ahmed (Paediatric Endocrinology, School of Medicine, University of Glasgow / Royal Hospital For Children, NHS Greater Glasgow and Clyde) still advocates "gonadectomy" – even when admitting "low" cancer risk for CAIS (and despite explicitly acknowledging CRC/C/CHE/CO/2-4)⁶⁷.

Accordingly, around **450 times annually** the NHS England facilitates and pays for **removal of testes of children 0–14 years, including unnecessary removal in intersex children age 0-14.⁶⁸**

And around **5 times annually** the NHS England regularly facilitates and pays for **unnecessary** removal of "atypical" gonadal tissue of intersex children age 0-14 ("excision of ovotestes"). ⁶⁹

In addition, as the more refined statistics 2014-2015 for "gonadectomies" show, in England often gonadectomies, including excision of ovotestes, still happen very early from 0-4 years, when in any case actual cancer risk is hardly an issue.⁷⁰

b) IGM 2 – "Feminising Procedures": Clitoris Amputation/"Reduction", "Vaginoplasty", "Labiaplasty", Dilation⁷¹

The "Society for Endocrinology UK guidance on the initial evaluation of an infant or an adolescent with a suspected disorder of sex development (Revised 2015)" 72 generally advocates early unnecessary surgeries as legitimate, framing the human rights issues involved as "controversies":

"Some parents may consider early genital surgery as a mechanism that could possibly protect their child from the risk of future stigma. This will require a thorough discussion with several members of the MDT team including the clinical psychologist, surgeons, gynaecologist and nurses so that the parents are fully informed of the controversies around undertaking or withholding early genital surgery."

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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

⁶⁷ ibid, at 180 (fn 111)

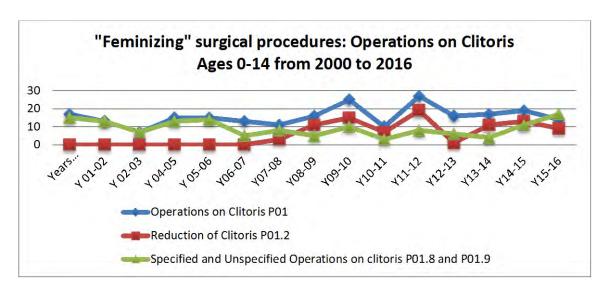
Figure derived from Hospital Episode Statistics (HES) available at https://digital.nhs.uk/data-and-information/publications/statistical/hospital-admitted-patient-care-activity, 2000-2014: "Main procedures and interventions: 4 character", N05.2, N06.3. 2014-15: N05.2, N05.3, N06.6. Note: Numbers also include necessary treatments of non-intersex children.

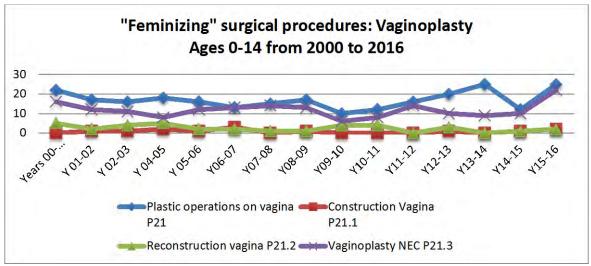
⁶⁹ Figure derived from Hospital Episode Statistics (HES) available at https://digital.nhs.uk/data-and-information/publications/statistical/hospital-admitted-patient-care-activity, 2000-2014: "Main procedures and interventions: 4 character", X15.3. 2014-15: X16.3-6 (see next example).

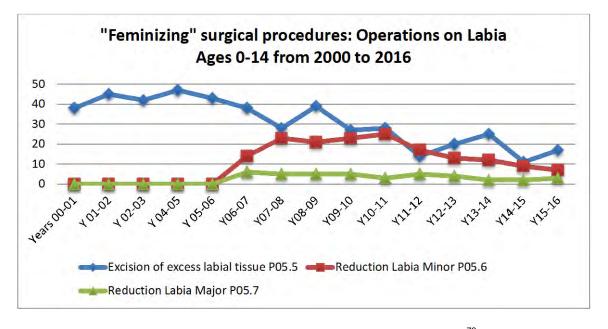
⁷⁰ From Hospital Episode Statistics (HES) available at https://digital.nhs.uk/data-and-information/publications/statistical/hospital-admitted-patient-care-activity, 2014-15: "Total procedures and interventions: 4 character". Note: These procedures may not all constitute unnecessary treatments.

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

⁷² S. Faisal Ahmed et al., "Society for Endocrinology UK guidance on the initial evaluation of an infant or an adolescent with a suspected disorder of sex development (Revised 2015)", Clinical Endocrinology (2016) 84, 771–788, http://onlinelibrary.wiley.com/doi/10.1111/cen.12857/pdf







Source: Huddersfield UK Intersex Report 2017, p. 14⁷³

Monro, Surya, Crocetti, Daniela, Yeadon-Lee, Tray, Garland, Fae and Travis, Mitch (2017), Intersex, Variations of Sex Characteristics, and DSD: The Need for Change. Research Report. University of Huddersfield, http://eprints.hud.ac.uk/id/eprint/33535/

Above UK Endocrinology "guidance" remains remarkably similar to the 2011 "best practice by a multidisciplinary team (MDT) dedicated to children with DSD" as promoted by paediatric urologist Dr Imran Mushtaq (Great Ormond Street Hospital for Children GOSH NHS Foundation Trust / Senior Lecturer Institute of Child Health, London): ⁷⁴

"There is no subject that creates more controversy and debate than that relating to 'feminising' genital surgery in infants and children with DSD. [...]"

"Many parents of children with DSD continue to express deep concerns about the appearance of the genitalia and these concerns need to be taken seriously and managed in an appropriate manner. [...]"

"Clitoral surgery is generally considered when the clitoris is larger than 'normal'. [...]"

"In girls with severe clitoral enlargement we remain happy to undertake clitoral reduction surgery, provided the family are fully informed and cognisant of the potential risks and benefits."

"Until such time as there is a change in the law, parents will continue to have the right to decide if their child should or should not have genital surgery in infancy or childhood. [...]"

Accordingly, the NHS England persistently facilitates and pays for **clitoral surgery on children 0–14 years** around **15 times annually** – despite all ethics and human rights "controversy and debate".⁷⁵

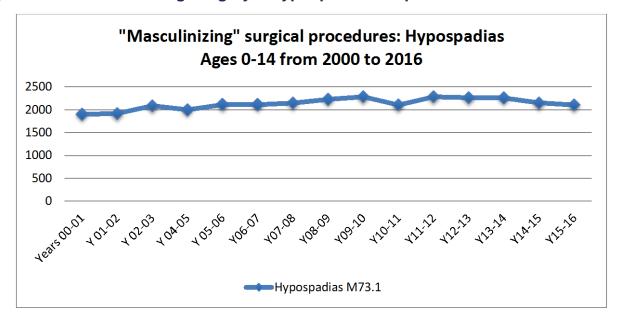
In addition, doctors create **new procedures to avoid clitoral surgery from being included in official statistics:** "Hiding the Clitoris" is a comparatively new surgical method on the rise in Southern England wherein a cut around an "enlarged" clitoris is made and thereafter the clitoral hood is pulled over the clitoris and sewn close in order to "hide" the "enlarged" clitoris. In clinics where this practice is performed, in official statistics it is not listed under clitoral surgery but under "vaginal reconstruction", as doctors argue they would only cut around the clitoris. In fact, in some clinics where doctors distinguish between intersex girls with CAH who had or had not clitoral surgery, all in the group of "no clitoral surgery" still had this new form of "hiding the clitoris" done in infancy. To Despite that such a procedure on a "normal" girl would be considered as FGM and illegal in the UK, on "subhuman intersex girls" this practice is not only deemed acceptable but even declared by doctors as mere "vaginal surgery".

⁷⁴ Imran Mushtaq, "Surgery in infants and children with DSD" (2011), http://dsdfamilies.org/docs/mednote/Surgery%20-%20Mushtaq.pdf

⁷⁵ Figure derived from Hospital Episode Statistics (HES) available at https://digital.nhs.uk/data-and-information/publications/statistical/hospital-admitted-patient-care-activity, 2000-2012: "Total procedures and interventions: 3 character", P01. 2012-15: "All procedures and interventions: 4 character" P01.1, P01.2, P01.8.

⁷⁶ Personal communication by UK doctor, June 2017

c) IGM 1 – "Masculinising Surgery": Hypospadias "Repair" 77



Source: Huddersfield UK Intersex Report 2017, p. 15⁷⁸

Hypospadias "repair", as advocated by the "British Association of Plastic Reconstructive and Aesthetic Surgeons (BAPRAS)" in their online "*Procedure Guide Hypospadias*": ⁷⁹

"There is no urgency to treat this condition, but once recognised you will be referred to a specialist to discuss surgery to correct the problem. [...]"

"What surgery is available, and what techniques are involved?

Surgery is recommended to make the penis look as natural as possible and to enable the child to stand up to pass urine. Corrective surgery for the treatment of hypospadias is often carried out 12 months after birth but can be done earlier or later. [...]."

"Is this surgery available on the NHS?

Surgery to correct hypospadias is widely available on the NHS."

UK NHS medical bodies and children's clinics generally advocate early hypospadias "repair" justified by psychosocial "indications". For example the "Norfolk and Norwich University Hospitals NHS Foundation Trust" and "Ipswich Hospital NHS Trust" in their "Information Leaflet on Hypospadias for Parents": 80

"WHAT AGE WILL MY SON BE?"

"We prefer to perform the operation at about 12 months of age or above."

For general information, see 2016 CEDAW NGO Report France, p. 48-49. http://intersex.shadowreport.org/public/2016-CEDAW-France-NGO-Zwischengeschlecht-Intersex-IGM.pdf

Monro, Surya, Crocetti, Daniela, Yeadon-Lee, Tray, Garland, Fae and Travis, Mitch (2017), Intersex, Variations of Sex Characteristics, and DSD: The Need for Change. Research Report. University of Huddersfield, http://eprints.hud.ac.uk/id/eprint/33535/

⁷⁹ http://www.bapras.org.uk/public/patient-information/surgery-guides/hypospadias

⁸⁰ http://www.nnuh.nhs.uk/publication/download/hypospadias-29-0-14

Or the "University Hospitals Bristol NHS Foundation Trust" in its "Surgery for Hypospadias Family information leaflet": 81

"Surgery usually takes place at 10-18 months of age [...]"

Accordingly, up to **2400 times annually** the NHS England facilitates and pays for **hypospadias** "repair" on intersex children 0–14 years.⁸²

d) "Inferior", "Abnormal", "Deformed": Selective Intersex Abortions in the UK Individual doctors, national and international medical bodies, public and private healthcare providers have traditionally been framing and "treating" intersex variations as a form of disability in need to be "cured" surgically, often with racist, eugenic and suprematist undertones.

Accordingly, also in the UK paediatric doctors frame intersex as "abnormalities", "problems" and "disorders", and by parents as "deformity" and "defect". 87

What's more, the easier an intersex trait can be tested prenatally, **the higher the (selective) abortion rates**, ⁸⁸ arguably also in the UK, ⁸⁹ where in particular most intersex diagnoses are listed as permissible for deselection in State sponsored **Preimplantation Genetic Diagnosis (PGD)** guidelines ⁹⁰, namely:

- 46XY Sex Reversal 6; Status: approved; OMIM number: 613762
- 5 Alpha Reductase Deficiency (5ARD) insofar as that condition affects males, with simultaneous sex determination; Status: approved; OMIM number: 264600
- Androgen Insensitivity Syndrome; Status: approved; OMIM number: 300068

83 201

In the WHO "World Atlas of Birth Defects (2nd Edition)", many intersex diagnoses are listed, including "indeterminate sex" and "hypospadias":

 $\underline{http://web.archive.org/web/20160305152127/http://prenatal.tv/lecturas/world\%20atlas\%20of\%20birth\%20defects.pdf}$

 $^{81 \}quad \underline{\text{http://www.drmark.info/Dr_Mark/Information_leaflets_files/Hypospadias\%20surgery_one\%20 and \%20 two\%20 stage_2012.pdf}$

⁸² Figure derived from Hospital Episode Statistics (HES) available at https://digital.nhs.uk/data-and-information/publications/statistical/hospital-admitted-patient-care-activity, 2000-2012: "Main procedures and interventions: 4 character", M73.1. 2012-15: "All procedures and interventions: 4 character" M73.1.

^{83 2014} CRC NGO Report, p. 52, 69, 84

[&]quot;The Racist Roots of Intersex Genital Mutilations" http://stop.genitalmutilation.org/post/Racist-Roots-of-Intersex-Genital-Mutilations-IGM

For 500 years of "scientific" prejudice in a nutshell, see 2016 CEDAW France NGO Report, p. 7, http://intersex.shadowreport.org/public/2016-CEDAW-France-NGO-Zwischengeschlecht-Intersex-IGM.pdf

⁸⁷ The Guardian, "'We don't know if your baby's a boy or a girl': growing up intersex", 02.07.2016, https://www.theguardian.com/world/2016/jul/02/male-and-female-what-is-it-like-to-be-intersex

For stats and references, see "Selective Intersex Abortions: XXY 74%, Indeterminate Sex 47%, Hypospadias 2%", http://stop.genitalmutilation.org/post/Selective-Intersex-Abortions-Hypospadias-Intersex-XXY

While there are no statistics available on selective intersex abortions in the UK, it's noteworthy that late term abortion is legal in the UK if "E - there is a substantial risk that if the child were born it would suffer from such physical or mental abnormalities as to be seriously handicapped: Section 1(1)(d).", see https://www.gpnotebook.co.uk/simplepage.cfm?ID=1449852947

⁹⁰ For example in the UK, see https://www.hfea.gov.uk/pgd-conditions/
See also 2014 CRC NGO Report, p. 76, https://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf

- Congenital Adrenal Hyperplasia (21 hydroxylase deficiency); Status: approved; OMIM number: 201910
- Gonadal mosaicism; Status: approved; OMIM number: [no number]
- **Hypospadias** (severe); Status: approved; OMIM number: [no number]
- Partial androgen insensitivity syndrome due to defects in the androgen receptor gene; Status: approved; OMIM number: 312300
- Prader Willi Syndrome; Status: approved; OMIM number: 176270
- Smith Lemli Opitz Syndrome (SLO); Status: approved; OMIM number: 270400
- Turner's syndrome (Mosaic); Status: approved; OMIM number: [no number]