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







NGO Report (for PSWG) to the Initial Report of the United Kingdom on the Convention on the Rights of Persons with Disabilities (CRPD)

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A. Suggested Questions for the List of Issues

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

Protecting the integrity of the person (art. 17)

- How many non-urgent, irreversible surgical and other procedures have been undertaken on intersex children before an age at which they are able to provide informed consent? Please provide detailed statistics on sterilising, feminising, masculinising procedures and imposition of hormones, including prenatal procedures.
- Does the State party plan to stop this practice? If yes, what measures does it plan to implement?
- 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?

B. Introduction

1. Intersex and IGM omitted in UK State Report

The United Kingdom of Great Britain and Northern Ireland will be considered for its initial periodic review by the Committee on the Rights of Persons with Disabilities in 2017. In the UK, **doctors in public, university and private clinics** are regularly performing **IGM practices**, i.e. non-consensual, medically unnecessary, irreversible cosmetic genital surgeries, sterilising procedures, and other harmful treatments on intersex children, which have been repeatedly **recognised by this Committee** and other **UN bodies** as constituting **violence**, a **violation of the integrity of the person**, a **harmful practice** and **torture or ill-treatment**.

In 2015, **CRC recognised IGM in the UK** as a serious violation. Unfortunately, the human rights of intersex children and adults weren't broached in the State report. However, this NGO Coalition Report demonstrates that the current **medical treatment of intersex infants and children in the UK** constitutes a serious breach of the UK's obligations also under the Convention on the Rights of Persons with Disabilities.

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 duty** to prevent involuntary harmful medical treatment also on intersex children, and to guarantee access to **adequate counselling and consensual needed health care** for intersex people and their families.

To this day the UK Government **refuses to take appropriate legislative, administrative and other measures** to guarantee the full and effective participation of intersex children in society on an equal basis, and **to remove barriers** preventing intersex people and IGM survivors from the full enjoyment of all human rights, including their rights to physical integrity and selfdetermination, their rights to the best attainable standard of health, and their rights to justice, redress and compensation.

2. About the Rapporteurs

This NGO report has been prepared by the Intersex NGO Coalition UK:

• **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!*" ¹ According to its charter, ² StopIGM.org works to support persons concerned seeking redress and justice, and regularly reports to UN treaty bodies on IGM practices.

¹ <u>http://Zwischengeschlecht.org/</u>, English pages: <u>http://StopIGM.org/</u>

² <u>http://zwischengeschlecht.org/post/Statuten</u>

- IntersexUK (iUK), founded in 2011, is an NGO led by UK intersex persons and survivors of IGM practices working to improve the well-being and human rights of intersex persons, and to raise awareness on intersex issues, including in regional and international media. They deliver educational training in universities and political consultancy to public sector bodies, particularly in England and Scotland.^{3 4}
- The UK Intersex Association (UKIA), founded in 2000, is an NGO led by UK intersex persons and survivors of IGM practices working to improve the well-being and human rights of intersex persons, and to raise awareness on intersex issues.^{5 6}

In addition, the Rapporteurs would like to acknowledge the work of the Androgen Insensitivity Syndrome Support Group UK (AISSG UK)⁷ and Margaret Simmonds.⁸ We would like to acknowledge the work of Michel O'Brien.⁹ And we would like to acknowledge the work of Ellie Magritte¹⁰ and dsdfamilies.org.¹¹

3. Methodology

This thematic NGO report is an abridged, localised and updated **addition to the thematic CRPD** NGO Report for Germany $(2015)^{12}$ and the CRC NGO Report for the UK $(2015)^{13}$ by partly the same rapporteurs.

³ <u>https://www.theguardian.com/world/2016/jul/02/male-and-female-what-is-it-like-to-be-intersex</u> <u>http://www.independent.co.uk/news/uk/home-news/special-report-intersex-women-speak-out-to-protect-the-next-generation-8974892.html</u>

⁴ <u>http://intersexuk.org</u>

⁵ <u>https://www.theguardian.com/world/2016/jul/02/male-and-female-what-is-it-like-to-be-intersex</u> <u>https://www.vice.com/en_uk/read/the-group-campaigning-for-better-intersex-rights</u>

^{6 &}lt;u>http://ukia.co.uk</u>

⁷ <u>http://www.aissg.org/</u>

⁸ Margaret Simmonds: 'Girls/women in inverted commas – facing "reality" as an XY-female', University of Sussex 2012, <u>http://sro.sussex.ac.uk/43431/1/Simmonds, Margaret.pdf</u>

⁹ <u>http://oiiinternational.com/653/holistic-for-whom/</u>

¹⁰ <u>http://www.dsdfamilies.org/docs/conf/working_together.pdf</u>

¹¹ <u>http://www.dsdfamilies.org/</u>

¹² <u>http://intersex.shadowreport.org/public/2015-CRPD-LoI-Germany_NGO-Report_Zwischengeschlecht_Intersex-IGM.doc</u>

¹³ <u>http://intersex.shadowreport.org/public/2016-CRC-UK-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf</u>

C. Background: Intersex, IGM and the CRPD

1. Intersex = Variations of Sex Anatomy

Intersex persons, in the vernacular also known as hermaphrodites, or medically as persons with *"Disorders of Sex Development (DSD),"*¹⁴ are people born with **Variations of Sex Anatomy**, or "atypical" sex anatomies and reproductive organs, including atypical genitals, atypical sex hormone producing organs, atypical response to sex hormones, atypical genetic make-up, atypical secondary sex markers. Many intersex forms are usually detected at **birth** or earlier during **prenatal testing**, others may only become apparent at **puberty** or **later in life**.

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, with **1 to 2 in 1000 newborns** at risk of being submitted to non-consensual "genital correction surgery".

For more information and references on genital development and appearance, please see 2015 CRPD NGO Report (A 1–2, p. 6-7.)¹⁵

2. Intersex is NOT THE SAME as LGBT

Unfortunately, there are several **harmful misconceptions about intersex** still prevailing in public, notably if intersex is counterfactually described as being the same as or a subset of LGBT, e.g. if intersex and/or intersex status are represented as a sexual orientation (like gay or lesbian), and/or as a gender identity, as a subset of transgender, as the same as transsexuality, or as a form of sexual preference.

The underlying reasons for such misconceptions include **lack of awareness**, third party groups **instrumentalising** intersex as a means to an end for their own agenda, and State parties **trying to deflect** from criticism of involuntary intersex treatments.

Intersex persons and their organisations have spoken out clearly against instrumentalising intersex issues,¹⁶ maintaining that Intersex Genital Mutilations 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.

¹⁴ The currently still official medical terminology "Disorders of Sex Development" is strongly refused by persons concerned. See 2014 CRC NGO Report, p. 12 "Terminology", online: http://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM v2.pdf

¹⁵ <u>http://intersex.shadowreport.org/public/2015-CRPD-LoI-Germany_NGO-Report_Zwischengeschlecht_Intersex-IGM.doc</u>

¹⁶ For references, see 2016 CEDAW NGO Report France, p. 40, fn 49. <u>http://intersex.shadowreport.org/public/2016-CEDAW-France-NGO-Zwischengeschlecht-Intersex-IGM.pdf</u>

3. IGM Practices: Involuntary, unnecessary medical interventions based on prejudice

IGM practices include non-consensual, medically unnecessary, irreversible, cosmetic genital surgeries, and/or other similar medical treatments, including imposition of hormones, performed on children with variations of sex anatomy,¹⁷ without evidence of benefit for the children concerned, but justified by "*psychosocial indications [...] shaped by the clinician's own values*", the latter informed by societal and cultural norms and beliefs, enabling clinicians to withhold crucial information from both patients and parents, and to submit healthy intersex children to risky and harmful invasive procedures that would not be considered for "normal" children, "*simply because their bodies did not fit social norms*".¹⁸

Typical forms of IGM include "feminising" or "masculinising", "corrective" genital surgery, sterilising procedures, imposition of hormones (including prenatal "therapy"), forced genital exams, vaginal dilations, medical display, human experimentation, selective (late term) abortions and denial of needed health care, causing lifelong severe physical and mental **pain and suffering**.¹⁹

In a response to international IGM doctors advocating involuntary non-urgent surgeries on intersex children in a 2016 medical publication,²⁰ two bioethicists underlined the **prejudice** informing the current medical practice:

"The implicit logic of [the doctors'] paper reflects what bioethicist George Annas has called a 'monster ethics' [6], which can be summed up this way: babies with atypical sex are not yet fully human, and so not entitled to human rights. Surgeons make them human by making them recognizably male or female, and only then may they be regarded as entitled to the sexual and medical rights and protections guaranteed to everyone else by current ethical guidelines and laws."²¹

4. "Deformities in need to be fixed": Intersex, IGM and the CRPD

It is important to note that Intersex is an **umbrella term** for many diverse variations and "diagnoses", of which only **specific and comparatively rare conditions** represent an **immediate medical situation or impairment,** notably Congenital Adrenal Hyperplasia (CAH) in the salt-losing form which constitutes a vital (metabolical) medical need (i.e. daily substitution of lacking cortisol – *however, this does NOT constitute a need for genital surgeries!*).

Nonetheless, doctors constantly use this specific exception as a justification for imposing unnecessary surgical and other treatments on ALL persons with variations of sex anatomy to

¹⁷ See "What is Intersex?", 2016 CEDAW NGO Report France, p. 39-44. http://intersex.shadowreport.org/public/2016-CEDAW-France-NGO-Zwischengeschlecht-Intersex-IGM.pdf

¹⁸ For references, see "What are Intersex Genital Mutilations (IGM)?", 2016 CEDAW NGO Report France, p. 45. http://intersex.shadowreport.org/public/2016-CEDAW-France-NGO-Zwischengeschlecht-Intersex-IGM.pdf

¹⁹ See "Most Frequent Surgical and Other Harmful Medical Interventions", 2016 CEDAW NGO Report France, p. 47-50. <u>http://intersex.shadowreport.org/public/2016-CEDAW-France-NGO-Zwischengeschlecht-Intersex-IGM.pdf</u>

²⁰ Pierre Mouriquand et al, "Surgery in disorders of sex development (DSD) with a gender issue: If (why), when, and how?", Journal of Pediatric Urology (2016), <u>http://www.jpurol.com/article/S1477-5131(16)30012-2/</u>

Ellen Feder and Alice Dreger, "Still ignoring human rights in intersex care", Journal of Pediatric Urology (2016), <u>http://www.jpurol.com/article/S1477-5131(16)30099-7/</u>

"fix" them,²² and both individual doctors and (state) medical bodies 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.^{23 24 25}

Thus, as a result of having been submitted to IGM practices, most intersex people have actual **physical and psychological impairments and medical needs** (chronic pain, loss of sexual sensibility, lifelong psychological trauma, metabolic problems, and need for daily hormone substitution after castration, etc.). Many can't work anymore, and live in poverty due to **persistent barriers** preventing them from full and effective participation in society on an equal basis as well as from the full enjoyment of all human rights, including their rights to physical integrity and self-determination, their rights to the best attainable standard of health, and their rights to justice, redress and compensation.

On top, both IGM survivors and intersex persons having escaped surgery are facing (fear of) **stigmatisation, ostracism and rejection** by modern society because of their (sometimes) "unusual appearance", compounded by **doctors' constant conjuring up the birth of an intersex child as a "psycho-social emergency"** in need of urgent involuntary "treatment".

In consequence, intersex persons and groups are applying the **social model of disability** to devise strategies in their fight for bodily integrity and recognition as fully human beings, often in collaboration with disability groups. As co-rapporteur *Jay Hayes-Light* of UKIA, an IGM survivor as well as wheelchair user (due to an accident not related with his intersex condition) puts it:²⁶

"Medical practitioners view intersex as something that needs to be fixed. We are regarded as deformed, somehow in deficit anatomically, and therefore the way to fix it is to cobble us together into what they deem to be an acceptable format, instead of allowing us to exist in society."

²² This excuse constitutes also the historic root for imposing systematic unnecessary early surgeries, see 2014 CRC NGO report, p. 54–56

²³ 2014 CRC NGO Report, p. 52, 69, 84

²⁴ In the WHO "World Atlas of Birth Defects (2nd Edition)", many intersex diagnoses are listed, including "*indeterminate sex*" and "*hypospadias*":

http://web.archive.org/web/20160305152127/http://prenatal.tv/lecturas/world%20atlas%20of%20birth%20defects.pdf
 "The Racist Roots of Intersex Genital Mutilations" <u>http://stop.genitalmutilation.org/post/Racist-Roots-of-</u> Intersex-Genital-Mutilations-IGM

²⁶ <u>https://www.theguardian.com/world/2016/jul/02/male-and-female-what-is-it-like-to-be-intersex</u>

D. Intersex Genital Mutilations in the UK as a violation of CRPD

1. IGM practices in the UK: Pervasive and unchallenged

In the **United Kingdom** (see CRC/C/GBR/CO/5, paras 45-46), same as in *Germany* (CRPD/C/DEU/CO/1, paras 37-38; CAT/C/DEU/CO/5, para 20), *Chile* (CRPD/C/CHL/CO/1, para 41-42), *Italy* (CRPD/C/ITA/CO/1, paras 45-46), *Ireland* (CRC/C/IRL/CO/3-4, paras 39-40), *France* (CEDAW/C/FRA/CO/7-8, paras 17e-f + 18e-f; CRC/C/FRA/CO/5, paras 47-48; CAT/C/FRA/CO/7, paras 32–33), *Switzerland* (CEDAW/C/CHE/CO/4-5, paras 38-39; CRC/C/CHE/CO/2-4, paras 42-43; CAT/C/CHE/CO/7, para 20), and in many more State parties,²⁷ there are

- **no 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** non-consensual, medically unnecessary, irreversible surgery and other harmful treatments a.k.a. **IGM practices**
- **no measures** in place to ensure **data collection and monitoring** of IGM practices
- 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** simply refuses to recognise the human rights violations and suffering caused by IGM practices, let alone to *"take effective legislative, administrative, judicial or other measures"* to protect intersex children.

During the recent CRC Review of the UK,²⁸ Flora Taylor Goldhill (Director for Children, Families and Communities, Department of Health) denied the ongoing practice in the UK constituting a human rights violation:

«On intersex children: NHS England are responsible for specialised commissioning which covers this area. [...]

Where babies and children could be described as intersex decisions about when and how to make medical interventions should be taken by clinicians in consultation with the parents of the child, and where possible and the child is older, seeking the views of the child himself or herself or themselves.»

To this day, 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)**, despite that CRC criticised IGM in the UK as a serious human rights violation.

²⁷ See <u>http://stop.genitalmutilation.org/post/IAD-2016-Soon-20-UN-Reprimands-for-Intersex-Genital-Mutilations</u>

²⁸ CRC 72nd Session, 24. May 2016, see transcription: <u>http://stop.genitalmutilation.org/post/UK-Questioned-over-Intersex-Genital-Mutilations-by-UN-Committee-on-the-Rights-of-the-Child</u>

a) IGM 3 – Sterilising Procedures: Castration / "Gonadectomy" / Hysterectomy / Removal of "Discordant Reproductive Structures" / (Secondary) Sterilisation Plus arbitrary imposition of hormones ²⁹

As advocated in the 2013 "ESPU/SPU standpoint on the surgical management of Disorders of Sex Development (DSD)",³⁰ 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."

Similarly, the "2016 Global Disorders of Sex Development Consensus Statement",³¹ coauthored 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)³².

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 0-14.³³

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").³⁴

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.³⁵

²⁹ For general information, see 2016 CEDAW NGO Report France, p. 47. <u>http://intersex.shadowreport.org/public/2016-CEDAW-France-NGO-Zwischengeschlecht-Intersex-IGM.pdf</u>

³⁰ 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, <u>http://www.jpurol.com/article/S1477-5131(13)00313-6/pdf</u>

³¹ Lee et al., "Global Disorders of Sex Development Update since 2006: Perceptions, Approach and Care", Horm Res Paediatr 2016;85:158–180, <u>https://www.karger.com/Article/Pdf/442975</u>

³² ibid, at 180 (fn 111)

 ³³ Figure derived from Hospital Episode Statistics (HES) available at <u>http://www.hscic.gov.uk/searchcatalogue?q=title%3A%22Hospital+Episode+Statistics%2C+Admitted+patient+</u> <u>care+England%22&area=&size=10&sort=Relevance</u>: 2000-2014: "Main procedures and interventions: 4 character", N05.2, N06.3. 2014-15: N05.2, N05.3, N06.3, N06.6. Note: Numbers also include necessary treatments of non-intersex children.

 ³⁴ Figure derived from Hospital Episode Statistics (HES) available at http://www.hscic.gov.uk/searchcatalogue?q=title%3A%22Hospital+Episode+Statistics%2C+Admitted+patient+ care+England%22&area=&size=10&sort=Relevance: 2000-2014: "Main procedures and interventions: 4 character", X15.3. 2014-15: X16.3-6 (see next example).

 ³⁵ From Hospital Episode Statistics (HES) available at http://www.hscic.gov.uk/searchcatalogue?q=title%3A%22Hospital+Episode+Statistics%2C+Admitted+patient+ care+England%22&area=&size=10&sort=Relevance: 2014-15: "Total procedures and interventions: 4 character". Note: These procedures may not all constitute unnecessary treatments.

b) IGM 2 – "Feminising Procedures": Clitoris Amputation/"Reduction", "Vaginoplasty", "Labiaplasty", Dilation³⁶

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)" ³⁷ 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."

Above "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): ³⁸

"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".³⁹

³⁶ For general information, see 2016 CEDAW NGO Report France, p. 48. <u>http://intersex.shadowreport.org/public/2016-CEDAW-France-NGO-Zwischengeschlecht-Intersex-IGM.pdf</u>

³⁷ 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, <u>http://onlinelibrary.wiley.com/doi/10.1111/cen.12857/pdf</u>

³⁸ Imran Mushtaq, "Surgery in infants and children with DSD" (2011), <u>http://dsdfamilies.org/docs/mednote/Surgery%20-%20Mushtaq.pdf</u>

 ³⁹ Figure derived from Hospital Episode Statistics (HES) available at http://www.hscic.gov.uk/searchcatalogue?q=title%3A%22Hospital+Episode+Statistics%2C+Admitted+patient+ care+England%22&area=&size=10&sort=Relevance: 2000-2012: "Total procedures and interventions: 3 character", P01. 2012-15: "All procedures and interventions: 4 character" P01.1, P01.2, P01.8.

c) IGM 1 – "Masculinising Surgery": Hypospadias "Repair"⁴⁰

As advocated by the "British Association of Plastic Reconstructive and Aesthetic Surgeons (BAPRAS)" in their online "*Procedure Guide Hypospadias*": ⁴¹

"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": ⁴²

"WHAT AGE WILL MY SON BE?"

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

Or the "University Hospitals Bristol NHS Foundation Trust" in its "Surgery for Hypospadias Family information leaflet": ⁴³

"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.⁴⁴

2. 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

 ⁴⁰ For general information, see 2016 CEDAW NGO Report France, p. 48-49.
 <u>http://intersex.shadowreport.org/public/2016-CEDAW-France-NGO-Zwischengeschlecht-Intersex-IGM.pdf</u>

⁴¹ <u>http://www.bapras.org.uk/public/patient-information/surgery-guides/hypospadias</u>

⁴² <u>http://www.nnuh.nhs.uk/publication/download/hypospadias-29-0-14</u>

^{43 &}lt;u>http://www.drmark.info/Dr_Mark/Information_leaflets_files/Hypospadias%20surgery_one%20and%20two%20stage_2012.pdf</u>

 ⁴⁴ Figure derived from Hospital Episode Statistics (HES) available at http://www.hscic.gov.uk/searchcatalogue?q=title%3A%22Hospital+Episode+Statistics%2C+Admitted+patient+ care+England%22&area=&size=10&sort=Relevance: 2000-2012: "Main procedures and interventions: 4 character", M73.1. 2012-15: "All procedures and interventions: 4 character" M73.1.

Biomedical Ethics as *"inappropriate and biased statements"* and *"biased and counterproductive reports"*, while insisting on continuing with IGM practices.⁴⁵

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: ⁴⁶

"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. [...]"

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.⁴⁷

3. UK Government, NHS doctors claiming IGM to be a thing of the past

UK government bodies, while admitting to the harm done by the practice, are quick to actively shield IGM perpetrators from human rights criticism by simply **declaring the ongoing practice in the UK a topic of the past:**

"Intersex people are born with ambiguous primary physical sexual characteristics. Until recently they would usually undergo genital surgery at a young age to given them characteristics which are clearly either male or female. Medical professionals are now more likely to advise waiting until the child is older and able to provide informed consent to surgery, because of the implications surgery can have on future health and function."

The above 2016 denial by a **UK Equalities Committee** is remarkably similar to the below 2011 denial issued by the **Great Ormond Street Hospital for Children GOSH**,⁴⁹ once more framing intersex human rights concerns as mere "*different opinions*":

"GOSH are aware of issues you have raised and the personal origins of your concerns. We recognise that in the past such surgeries were carried out and the difficulties this has caused. We would like to reassure you that in advanced centres such as our own your concerns have been heard and influence our decision making process.

⁴⁵ 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, <u>http://www.jpurol.com/article/S1477-5131(13)00313-6/pdf</u>

⁴⁶ Imran Mushtaq, "Surgery in infants and children with DSD" (2011), <u>http://dsdfamilies.org/docs/mednote/Surgery%20-%20Mushtaq.pdf</u>

 ⁴⁷ 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

⁴⁸ House of Commons, Women and Equalities Committee, "*Transgender Equality. First Report of Session* 2015–16", at 5 (fn 3), <u>http://www.publications.parliament.uk/pa/cm201516/cmselect/cmwomeq/390/390.pdf</u>

⁴⁹ Great Ormond Street Hospital (GOSH), reply 19.10.2011 to Open Letter of Concern 18.09.2011, <u>http://Zwischengeschlecht.org/public/Great-Ormond-GOSH NHS Denial-19-10-2011.pdf</u>

Generally families are happy with the treatments now offered but are obviously very keen to protect their children from public attention on this sensitive matter. As with any area of medicine with difficult ethical balances to strike on when and when not to offer treatment, this topic brings out a wide spectrum of opinion and we recognise the right of those with different opinions to express them."