

## **Introduction**

In this article we will be addressing the shift to naming intersex childhood medical treatment as serious human rights abuses (such as harmful cultural practices and/or and cruel, inhuman or degrading treatment). The article presents intersex rights claims, illustrates a brief history of intersex Human Rights strategies as witnessed by the co-authors (co-founders of [Zwischengeschlecht.org/StopIGM.org](http://Zwischengeschlecht.org/StopIGM.org) i.e. StopIGM), outlines specific Human Rights frameworks that have been applied to intersex rights claims by various UN committees, and discusses the implementation gap between Human Rights proclamations and national policies. This article provides unique insight due to the co-authors direct experience lobbying International Human Rights Mechanisms (IHRMs) for intersex rights.

Intersex rights issues have increasingly gained public attention since the 1980s, due to the various forms of activism<sup>1</sup> conducted by those directly effected (not always using the term intersex) as well as historical and social academic research<sup>2</sup>. Activism and advocacy around intersex rights claims have taken many different forms, from public facing actions such as protests and awareness campaigns, to closed groups that offer peer-support and negotiate the role of the ‘patient expert’<sup>3</sup> while demanding better health care<sup>4</sup>. While there might be overlapping membership and strategies, there appear to be continued differences in approaches between associations who push for better medical care (care founded on actual long-term medical data and collective subjective experience), and intersex social activists who no longer believe in medical self-reform and therefore push for criminalization of non-consensual, unnecessary practices. Some patient associations call for a moratorium on early childhood unnecessary surgeries, while others may avoid this approach<sup>5</sup>. This article will focus on Human Rights agendas put forward by StopIGM, while acknowledging that different groups and stakeholders may have different agendas, or reject IHRMs strategies altogether<sup>6</sup>.

We will be primarily using the term ‘intersex’ throughout this article, while other terms such as variations of sex characteristics (VSC), Disorders (or differences) of Sex Development (DSD or dsd), or ‘syndrome’ specific terms are also used by the different stakeholders. Intersex is an umbrella term that entails different definitions and applications that can shift with the context, for the social movement or individuals themselves. Intersex is also the term most commonly used by those that conduct International activism and appeal to IHRMs. Intersex can be defined as being born with bodily sex characteristics that do not conform to standard binary definitions of male or female, often entailing biological material from both ‘sexes’<sup>7</sup>. Biological material has been historically gendered by medicine due to binary expectations regarding the conflation of reproduction and social roles<sup>8</sup>, yet has been shown to be a spectrum containing many different physical components<sup>9</sup>.

In 2006 a new medical term was coined, DSD. The term DSD is contested by many social activists as incorrectly applying the stigmatizing term ‘disorder’ to mere physical variation, but was rapidly adopted by medical teams across the world as well as several patient advocacy associations<sup>10</sup>. This enacts yet another division, creating the illusion that different stakeholders are literally speaking about different things. Medical literature continues to define the acronym ‘DSD’ as ‘*Disorders of Sex Development*’, while many clinicians and patient associations utilize ‘*Differences of Sex Development*’ (dsd). Here the Human Rights framework could prove useful as a uniting thread, as it specifically refers to practices and rights as apposed to categories and definitions.

While IHRMs create soft law that cannot necessarily be directly enforced in national practice, global movements have shown that this strategy can create a ‘boomerang effect’<sup>11</sup> that in turn impacts national law and practice<sup>12</sup>. International Human Rights (IHR) laws and recommendations can lead to hard laws in individual nations<sup>13</sup>. The appeal to IHRMs may have a dual impact of raising public awareness about rights claims, while pushing for actual legislative protection at the same time. After detailing the IHRM frameworks that have been applied to intersex, we will also briefly address the

implementation gaps that remain. Interview data, as well as state responses to IHRMs country reviews<sup>14</sup> shows that the issue of jurisdiction (medical or state) appears problematic in certain national contexts. Here, we would briefly like draw attention to parallels between numerous other rights movements such as mental health, disability, children's rights, survivors of childhood sexual abuse, Trans medicalization and health care for marginalized populations<sup>15</sup>. Also for these movements, the rights claims may address the overlay of social norms (and therefore also prejudice) onto medical practice<sup>16</sup>. We include a short section on tensions around including the 'I' for intersex in the LGBTIQ+ acronym and activism.

While changes can be seen in certain arenas of intersex medical treatment (primarily regarding communication)<sup>17</sup>, key rights concerns such as childhood medical procedures alternately referred to as involuntary, non-consensual, irreversible, unnecessary and/or cosmetic have undoubtedly continued to be practiced across most of the globe<sup>18</sup>. Precisely this continued practice, we would argue, has led intersex activism to appeal directly to IHRMs to denounce Intersex Genital Mutilation (IGM) as a serious violation of non-derogable human rights.

## **Methods**

This article results from collaboration between [Zwischengeschlecht.org/StopIGM.org](http://Zwischengeschlecht.org/StopIGM.org) (International Intersex Human Rights Activists based in Switzerland) and an EU research project on European Intersex, CITizenship and Human Rights (EUICIT)<sup>19</sup>. StopIGM has compiled numerous shadow reports for UN Human Rights bodies<sup>20</sup>, resulting in condemnations of intersex medical practices in numerous countries, and are effectively experts on Human Rights mechanisms as applied to intersex rights claims. These activist-scholars have provided the historical testimony regarding the evolution of intersex Human Rights activism. The academic member performed participant action research<sup>21</sup> (as well as a literature review) as a means of elaborating both action strategies and the knowledge

generated about intersex Human Rights claims. The section Implementation Issues is also informed by analysis of qualitative research in Italy, Switzerland and the UK conducted between February and December 2017<sup>22</sup>.

The project received ethics approval from the EU funding body, the University of Huddersfield and the UK Health Research Agency (HRA)<sup>23</sup>. All of the interview participants were informed of the aims of the research project, given different options regarding anonymity and participating in an open data pilot program, signed informed consent forms, and were given the option to withdraw and review the interview transcripts for three months after the date of the interview. The qualitative data was analysed using NVIVO adopting a thematic analysis approach<sup>24</sup> informed by research on social studies of medicine and science, social health movements, political science, gender and sexuality, citizenship and human rights.

### **Intersex Rights claims**

The rights claims that have been made by social intersex activists and health advocates (who may use DSD, dsd, or ‘syndrome’ specific terms) are numerous and generally concern medical practices in childhood (although there is also concern for the inadequacy of adult care<sup>25</sup>). Combating the practice of surgically modifying the form of intersex children’s genitals without medical indication and the consent of the person concerned was the key focus of initial social activism and continues to be a pressing, but not the only, issue.

IGM, first coined in 1996 by the Intersex Society of North America (ISNA), is used as shorthand for the numerous types of violations of intersex Human Rights. IGM is not intended as a derivative of FGM (Female Genital Mutilation), but rather as a harmful practice in its own right. StopIGM describe the most frequent surgical and other harmful interventions as falling into four primary categories:<sup>26</sup>

- IGM 1 – Masculinising Surgery.
- IGM 2 – Feminising Procedures.
- IGM 3 – Sterilising Procedures.
- IGM 4 – Other Unnecessary and Harmful Medical and Non-Medical Practices.

IHRMs increasingly contend that genital surgery is not necessary for gender assignment, and that atypical genitals are not in themselves a health issue<sup>27</sup>. There are only very few situations where surgery is necessary for medical reasons, such as to create an opening for urine to exit the body<sup>28</sup>. In addition, medical ethical discussions have been raised regarding issues such as informed consent, diagnosis communication, stigmatizing, coercive, and/or deceptive medical communication (such as fictitious cancer risks) and repeat stigmatizing and traumatizing invasive medical exams and photography for the purpose of research instead of treatment. Patient associations have also focused on issues such as the lack of medical research on overall and long-term health, excessive medical attention to gender assignment, as well as stereotypical gendered appearance and behaviour<sup>29</sup>, the lack of medical health services for adults, and the lack of psychological and peer support for parents and families<sup>30</sup>.

### **The evolution of Intersex movements Human Rights strategy and IHRMs statements**

IHRMs' attention to intersex medical treatment is due to extensive lobbying by International networks of intersex activists. As the following brief historical overview illustrates, Human Rights framings were present quite early in the intersex movement, particularly mutilation and torture claims, but it took over 20 years for institutions to replicate these framings. Currently, specific aspects of intersex medical treatment are increasingly being addressed as serious Human Rights abuses, with verdicts from numerous UN Committees<sup>31</sup>, regional Human Rights bodies<sup>32</sup>, UN agencies<sup>33</sup>, the Council of Europe<sup>34</sup>, the Australian parliament<sup>35</sup>, and the Italian, German, and Swiss national ethics committees<sup>36</sup>, the Palm

Center report by three ex-US Surgeon Generals<sup>37</sup>, and the US branch of the organization Human Rights Watch<sup>38</sup>. In addition, in 2017 the Yogyakarta Principles plus 10<sup>39</sup> and in 2015 the Malta Gender Identity, Gender Expression and Sex Characteristics Act<sup>40</sup> specifically include 'sex characteristics' as a protected category.

The first intersex organisations started in the 1980s in the form of Androgen Insensitivity Syndrome Support Groups (in Australia, North America and Europe), some of which were partly initiated by doctors and could still be understood as patient's or health care consumer organisations.

This framing shifted with the birth of the Intersex Society of North America (ISNA), and the introduction of the term IGM. When Bo Laurent a.k.a. Cheryl Case announced the formation of the new group in 1993<sup>41</sup>, the rights requests changed from requesting better medical care to denouncing human rights violations: "Unfortunately the surgery is immensely destructive of sexual sensation and of the sense of bodily integrity,"<sup>42</sup>. ISNA's newsletter "Hermaphrodites with Attitude" spoke of "genital mutilation" and identified the statutes of limitations as the main obstacle in suing IGM perpetrators.<sup>43</sup> ISNA and collaborators further described IGM as Child Sexual Abuse<sup>44</sup> and disability issues.<sup>45</sup>

In 1996 in the U.S. legislation against FGM was partly introduced both on state and federal level. ISNA campaigned to include IGM, but found their concerns mostly ignored by politicians, academics, feminists and anti-FGM groups alike.<sup>46 47 48 49</sup> The leaflet for the historic 1st intersex protest on 26 October 1996 outside of the American Academy of Pediatrics' (AAP) annual meeting in Boston declared "Intersex Genital Mutilation (IGM) is not medicine!", and in 1997 a "STOP Intersex Genital Mutilation" sign was used at protests<sup>50</sup>. IGM terminology was one of the first steps in intersex activist Human Rights strategy. Other strategies have included national lawsuits and registering for disability status<sup>51</sup>. However, it is difficult for adult survivors of childhood IGM practices to bring a civil case before a court, due to statutes of limitations, something that some Human Rights frameworks attempt to address.

The first German activist group "Working Group against Violence in Paediatrics and Gynaecology" AGGPG was founded in 1996 and immediately referred to IGM as torture.<sup>52 53 54</sup> In 1997 the AGGPG and allies started referring to IGM as a form of "genocide", demanding "reparations" for IGM victims and generally "human rights for intersex persons".<sup>55 56</sup>

In 1998 in an amicus brief to the Constitutional court of Colombia, ISNA referred explicitly to the UN Convention on the Rights of the Child (CRC) and the Nuremberg code as being breached by IGM.<sup>57</sup> In 2004-05 the San Francisco Human Rights Commission (SFHRC) hearings were the first documented example of a government body addressing IGM as a human rights violation. However, the Commission did not recommend legislation to end IGM (only addressing gender markers and discrimination).<sup>58</sup> Also in 2004 the South African Human Rights Commission urged to prohibit IGM by law,<sup>59</sup> however only anti-discrimination law resulted. Regulatory attention to gender markers and discrimination without addressing IGM will be further discussed in the implementation section.

In 2004 intersex activists started engaging directly with IHRs bodies, and Mauro Cabral Grinspan was one of the first intersex advocates to raise IGM at a panel on occasion of a UN treaty body session.<sup>60</sup> In 2008 German self-help and advocacy groups Association of Intersex People (IMeV) and XY-Women engaged a human rights mechanism by reporting to the Convention on the Elimination of all Forms of Discrimination Against Women (CEDAW), leading to the first Concluding Observation mentioning intersex, though not yet IGM practices. In 2011 IMeV and XY-Women teamed up with the Humboldt Law Clinic Human Rights to report to the Committee against Torture (CAT), leading to the first UN treaty body Concluding observation recognising IGM as a serious violation of non-derogable human rights, namely as a form of 'Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment', recommending that the German government: "20(b) Undertake investigation of incidents of surgical and other medical treatment of intersex people without effective consent and adopt legal

provisions in order to provide redress to the victims of such treatment, including adequate compensation. [...]".<sup>61</sup>

In 2013, this call was seconded by the UN Special Rapporteur on Torture, and in 2014 by the WHO Interagency Statement on forced sterilization.<sup>62</sup> Also in 2013 the Council of Europe (COE) indicated that: "The Parliamentary Assembly is particularly worried about a category of violation of the physical integrity of children"<sup>63</sup>, including medical interventions on intersex children. However, only further research was recommended.

In the wake of the first CEDAW and CAT recommendations on intersex and IGM, the German associations IMeV and XY-Women and intersex organisations in other countries submitted more reports to various Treaty bodies, as well as to the UN Human Rights Council (UNHRC) for the Universal Periodic Review (UPR)<sup>64</sup>, but in most cases the Committees did not address intersex or IGM in their Concluding Observations. On a strategic level, while NGO reports are important testimonies, it is the Concluding Observations of the IHRMs that raise the issue to the level of public Human Rights concern. Therefore the NGO must engage in numerous strategic lobbying activities to ensure that a committee member brings their concern to the floor in the form of a direct question to the State body under review.

Based on these aforementioned actions, StopIGM began to strategically address Treaty bodies, framing IGM as a harmful practice in their NGO report to the CRC in 2014. Following a CRC committee member suggestion, StopIGM began to collaborate with international intersex advocates and organisations (some of whom conduct parallel IHRM lobbying as well) to write reports for other countries. The NGO reports include detailed evidence of on-going practice, lifelong physical and mental pain and suffering, the inaction and awareness of the State, a Human Rights bibliography and a historical overview.<sup>65</sup>



In 2015 this led the CRC to recognize IGM as constituting a harmful practice like FGM for the first time<sup>66</sup>, referring to the CRC-CEDAW Joint General Comment 18/31 “on harmful practices”. Building on this CRC verdict, in 2015, recommendations were also obtained from CAT, who recognized IGM as constituting ‘Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment’, and recommended that Switzerland take legislative measures, guarantee appropriate services as well as provide protection and redress.<sup>67</sup> In 2015 three CAT recommendations, and a recommendation from the Committee on the Rights of Persons with Disabilities (CRPD) recognized IGM as a violation of the integrity of the person.<sup>68</sup> Also in 2015, for the first time, the UN Human Rights Office (UNHRO) organized a two-day expert meeting to specifically address intersex Human Rights<sup>69</sup>.

International collaborative and strategic approach has enabled the international intersex movement “to produce a relatively high number of strong reports to UN treaty bodies”,<sup>70</sup> resulting in over two dozen UN Treaty body verdicts explicitly recognizing IGM as a serious human rights violation. Following this growing body of recommendations, in 2016 the Joint Statement from UN, COE, ACHPR, IACHR for intersex Awareness Day states:

“States must, as a matter of urgency, prohibit medically unnecessary surgery and procedures on intersex children. They must uphold the autonomy of intersex adults and children and their rights to health, to physical and mental integrity, to live free from violence and harmful practices and to be free from torture and ill-treatment. Intersex children and their parents should be provided with support and counselling, including from peers. [...]”<sup>71</sup>.

In 2017 the Human Rights Committee (HRCttee), recognized IGM inter alia as non-consensual medical or scientific experimentation in violation of art. 7 of the International Covenant on Civil and Political Rights (CCPR), recommending the state take the necessary measures to protect from unnecessary surgeries.

In 2017 the Inter-American Commission on Human Rights (IACHR) press release (No. 189/17) also issued a statement requesting States to intervene with legislation to protect intersex children's bodily integrity and prohibit unnecessary procedures.

“Based on these considerations, the IACHR urges the States to urgently prohibit surgeries and medically unnecessary procedures on intersex children. The Commission further reiterates that States should respect the autonomy of all intersex persons and all dimensions of their right to health, their right to physical and psychological integrity, and their right to live free from all forms of violence and discrimination, and should prevent all inhuman and degrading treatment.”<sup>72</sup>.

Similarly, a 2017 European Parliament resolution,<sup>73</sup> referring to the “serious short- and long-term effects on their physical, psychological, sexual and reproductive health” caused by FGM, recognized “intersex persons subject to genital mutilation also experience effects on their physical, psychological and sexual and reproductive health” and explicitly “Call[ed] on the Member States to prevent, ban and prosecute female genital mutilation and genital mutilation affecting intersex persons, and to provide mental health support, in conjunction with physical care, to victims and to those individuals likely to be targeted”. Among other IHRB proclamations in 2017<sup>74</sup>, Human Rights Watch worked with the US activist group ‘interACT: Advocates for Intersex Youth’ to create the report and campaign “I Want to Be Like Nature Made Me”<sup>75</sup> which includes recommendations for numerous national agencies.

### **Human Rights frameworks that have been applied to IGM**

In order to specifically address IGM, intersex Human Rights lobbying requires strategic study of the existing Human Rights frameworks, which may have different impacts and portray different images of Intersex struggles. In the following sections we outline some of the most significant Human Rights frameworks that have been applied to IGM, and intersex in general, by different IHRMs. International intersex activists that utilize Human Rights tactics adopt this framing in various degrees. While other

Human Rights frameworks may prove useful in the future the following 11 categories have had the most resonance from 2008 to 2017:

1. Harmful practices
2. Prohibition of torture and inhuman or degrading treatment
3. Integrity of the person
4. Access to justice
5. Involuntary medical experimentation
6. Violence against children
7. Right to life
8. Coercive sterilization;
9. Right to health
10. Rights of the Child
11. Anti-discrimination laws that include sex characteristics

While all human rights are indivisible and often interrelated, the strongest protections are offered by non-derogable human rights, in other words, human rights that can not be abrogated by state parties. Within UN Conventions, the Convention against Torture or Cruel, Inhuman or Degrading Treatment (CAT) as a whole is non-derogable (see CAT art. 2). In the International Covenant on Civil and Political Rights (CCPR), protection from non-consensual medical or scientific experimentation and inhuman treatment is enshrined in art. 7. While no further treaties contain explicitly non-derogable

articles, the CAT General comment no. 2 (para 18) protection from (female) genital mutilation and gender-based violence is also a non-derogable right. Non-derogable human rights offer not only the strongest protections, but also stipulate the strongest sanctions (including criminalisation of violations, persecution of perpetrators), as well as access to justice and redress for victims (including the non-applicability of statutes of limitation). All of the listed non-derogable rights have been recognised as applicable to IGM practices by the relevant UN Treaty bodies.

### ***Harmful Practices and Genital Mutilation***

Harmful practices, once also known as Harmful Cultural Practices or Traditional Practices, comprise practices whose harmful nature is hidden in plain view due to cultural consensus.

“Despite their harmful nature and their violation of international human rights laws, such practices persist because they are not questioned and take on an aura of morality in the eyes of those practising them.” OHCHR Fact Sheet No. 23, Harmful Traditional Practices <sup>76</sup>

The best-known example of a Harmful Practice is female genital mutilation (FGM). While Human Rights scholars and mechanisms have addressed FGM in detail<sup>77</sup>, IGM remains an area that requires further attention. Other typical examples of harmful practices include forced marriage and honour killings. While FGM was also the initial point of reference for the framework, it was intentionally not limited to FGM, but meant to include all forms of harmful, violent, and/or invasive traditional or customary practices.<sup>78</sup> CEDAW (1979) Article 5 and CRC (1989/90) Article 24(3) were the first to contain articles on harmful practices.

The CRC-CEDAW Joint General Comment/Recommendation No. 18/31<sup>79</sup> “on harmful practices” (2014) “call[s] upon States parties to explicitly prohibit by law and adequately sanction or criminalize harmful practices, in accordance with the gravity of the offence and harm caused, provide

for means of prevention, protection, recovery, reintegration and redress for victims and combat impunity for harmful practices”<sup>80</sup>.

Other International Human Rights Conventions (IHRCs) have found harmful practices applicable in their Concluding Observations. The CAT determined in its General Comment 2, para 18, that the non-derogable duty of States to protect everybody from torture or cruel, inhuman and degrading treatment also applies to (female) genital mutilation and gender based violence. The Human Rights Committee as the governing body of the International Covenant on Civil and Political Rights (CCPR) regularly finds harmful practices and in particular (female) genital mutilation in violation of the Covenant. Different approaches to FGM and IGM will be briefly addressed in the implementation section.

In 2015, the CRC asserted that non-consensual intersex surgeries violate physical integrity and constitute a harmful practice during its review of Switzerland (CRC/C/CHE/CO/2-4, paras. 42 and 43). CRC further found cases of extreme bullying of intersex children preventing them from attending school to constitute a harmful practice in violation of art. 24(3).

StopIGM (among other international intersex activists) recognizes Harmful Practices as the most effective, well-established and applicable human rights frameworks capable of prohibiting IGM practices.<sup>81</sup> Framing unnecessary intersex medical practices as harmful cultural practices requires policy bodies to address the contentious issue of whether these are practices that parents have the right to consent to. Yet, few nations have applied this framework to their national regulation of intersex medical treatment (notable exceptions are Malta and Colombia<sup>82</sup>).

### ***Prohibition of torture and cruel, inhuman or degrading treatment***

The UN Convention CAT (1984/1987), article 1 lists five requirements for an act to constitute torture: 1. the infliction of severe physical or mental pain or suffering; 2. intention (as opposed to singular mere

negligence); 3. purpose of discrimination (victims must be singled out); 4. consent or acquiescence of a State official); 5. the act does not constitute a lawful sanction. CAT article 16 requires state parties to prevent "other acts of cruel, inhuman or degrading treatment [CIDT] [...] which do not amount to torture as defined in article 1" in any territory under their jurisdiction. As stipulated in CAT General comment No. 3 (on art. 14), the right to access to redress and justice for victims of torture, including to fair and adequate compensation and the means for as full rehabilitation as possible, also applies to CIDT. CAT art. 12 stipulates the obligation of State parties to ensure impartial investigation of cases of torture or CIDT.

In IHRC law, the obligation of the States to "take effective legislative, administrative, judicial or other measures to prevent acts of torture" is non-derogable (CAT art. 2). CAT General comment No. 2 states that these obligations also apply to CIDT, and that the non-derogable obligation of State parties to prevent torture also applies to (female) genital mutilation. CAT General comment No. 3, para 40 indicates *statutes of limitations should not apply* in cases of torture or CIDT.

CRC, CEDAW, CRPD and CCPR also contain articles explicitly prohibiting torture or CIDT, as does the European Convention on Human Rights (ECHR) and the Charter of Fundamental Rights of the European Union.

As noted in the brief historical section above, intersex advocates (particularly in Germany and the US) claimed early on that IGM constitutes a form of torture. The numerous CAT Concluding Observations recognizing IGM as a Human Rights violation was seconded by the UN Special Rapporteur on Torture (SRT) in 2013, and again in 2014 by the WHO Interagency Statement on forced sterilization<sup>83</sup>.

In the US NGO report to the SRT, Anne Tamar-Mattis indicates "how medical treatment of people with intersex conditions fits into the torture and CIDT framework"<sup>84</sup>. In particular, Tamar-

Mattis indicates how mandates against genital cutting for socio-cultural reason and the involuntary sterilisation of children do not include *exceptions* for individuals with atypical sex characteristics.

Many medical professionals (and some patient group advocates) are not comfortable calling the cosmetic aspects of intersex medical treatment ‘torture’ for various reasons. Medical publications that acknowledge the critique and the accusations of torture and/or CIDT add to a situation of mounting tension that begs governmental response.

### ***Integrity of the person***

The ECHR and the Parliamentary Assembly of the COE are among the few IHRMs to *directly* address the Right to Physical and Psychological Integrity. Some conventions address the right to physical and psychological integrity (and the right to refuse invasive medical treatment) as component of the Right to Private Life.

In 2013 the Parliamentary Assembly of the COE in Resolution 1952 directly addressed *Children’s* right to physical integrity and specifically included intersex in its consideration of harmful practices, requesting that State bodies investigate the impact of non-medically justified operations and interventions and regulate accordingly.

In 2015 the European Union Agency for Fundamental Rights (FRA) published the position paper *The fundamental rights situation of intersex people*<sup>85</sup> which also addresses the right to integrity of the person directly (Article 3), indicating the CRC’s statement’s on the child’s right to private life. FRA article 1 protects human dignity and article 7 protects private and family life.

Art 8 of the ECHR, which refers to “private and family life, his home and his correspondence”, also indicates a positive obligation on the part of the state to protect an individual’s right to bodily integrity (not simply prohibiting a State from interfering with rights)<sup>86</sup>.

Obviously the recognition of the child's right to physical integrity *should* change how states address consent for irreversible unnecessary cosmetic interventions. However, most nations give primacy to parent rights.

### *Access to justice*

Statutes of Limitations render redress and access to justice for childhood IGM difficult or impossible in many nations. In 2011, CAT was the first UN body to recognise the lack of adequate laws ensuring redress and investigations for intersex adults, explicitly calling on Germany to “Undertake investigation of incidents of surgical and other medical treatment of intersex people without effective consent and adopt legal provisions in order to provide redress to the victims of such treatment, including adequate compensation.”<sup>87</sup>

In 2015 CAT issued similar recommendations to Switzerland, Austria, Denmark and Hong Kong, repeating its call for “legislative measures to ensure redress” while adding that the state should “undertake legislative, administrative and other necessary measures to ensure the bodily integrity of intersex people, and that no-one is submitted to medical or surgical sex assignment treatments during childhood, which do not constitute a medical emergency”.<sup>88</sup>

Medical allies such as Paediatric Surgeon Blaise Meyrat have also addressed this issue, stating: “Only the fear of the judge will make things change. We need statutes of limitation long enough so that victims may sue as adults.”<sup>89</sup>

In 2015, the WHO Report “Sexual health, human rights and the law” reiterated:

“It has also been recommended [by human rights bodies and ethical and health professional organizations] that investigation should be undertaken into incidents of surgical and other medical treatment of intersex people without informed consent and that legal provisions should be adopted in order to provide remedies and redress to the victims of such treatment, including adequate compensation.”<sup>90</sup>



CEDAW JGR No. 31/18 specifically stipulates the need to ensure that “children subjected to harmful practices have equal access to justice, including by addressing legal and practical barriers to initiating legal proceedings, such as the limitation period” (para 55o), thereby implicitly requiring justice for those subjected to harmful practices.

### ***Involuntary medical experimentation***

CCPR article 7 address the need for *direct* consent in scientifically experimental situations: “In particular, no one shall be subjected without his free consent to medical or scientific experimentation.” Many areas of intersex medical treatment are akin to ongoing experiments due to the lack of scientific follow-up data, and the introduction of questionable procedures and evaluation methods.

After more than 60 years of IGM as standard practice, there are no evidence-based studies that indicate that intersex adults are universally happy that surgeries and therapies were chosen for them. Practitioners indicate that there is actually very little long-term outcome research to back up any claims, one stating “one will have to wait another 15 years to evaluate current procedures.”<sup>91</sup> The European Society of Pediatric Urologists (ESPU) position statement highlights the lack of evidence for timing treatment before consent is possible, claiming that “surgery is technically easier early with *possibly* less psychological impact”<sup>92</sup>. A recent report issued by the Palm Center authored by three former US Surgeon Generals (2017) indicates that “research does not support the practice of cosmetic infant genitoplasty”<sup>93</sup>. There is detailed qualitative evidence that many adults are not happy with the irreversible treatment they received in childhood<sup>94</sup>.

Other areas of experimentation include the untested introduction of prenatal dexamethasone steroid treatment for CAH<sup>95</sup>, condemned by one of the few international groups that has conducted long-term follow-up studies as potentially causing cognitive problems<sup>96</sup>. Problems with consent and research protocol continue in this marginalized population, such as clitoral sensory testing on awake young girls who were subjected to clitoral reduction<sup>97</sup>.

## ***Violence against children***

Activists have denounced IGM practices in general, especially genital surgery, but also castrations, gonadectomies, hysterectomies, secondary sterilisations, human experimentation, forced excessive genital exams, medical display and genital photography, and vaginal dilations as a form of physical and psychological violence, exploitation, and sexual abuse. Intersex children are also at risk of infanticide and abandonment<sup>98</sup>.

The CRC has repeatedly examined IGM practices since 2015, considering IGM to constitute a harmful practice and violence against children according to CRC art. 24.3.<sup>99</sup>

## ***Right to life***

Some intersex variations are correlated to genetic markers, chromosomal variations or can be seen in prenatal ultrasounds. This has led to several intersex variations being subjected to either selective abortion, or being selected out in assisted fertility techniques. For example, the UK Human Fertilisation and Embryology Authority (HFEA) includes numerous intersex variations as “serious” genetic conditions that may be de-selected or used to obtain a late-term abortion.

The 2015 Council of Europe Issue Paper on Human rights and intersex people states:

“Intersex people’s right to life can be violated in discriminatory “sex selection” and “preimplantation genetic diagnosis, other forms of testing, and selection for particular characteristics”. Such de-selection or selective abortions are incompatible with ethics and human rights standards due to the discrimination perpetrated against intersex people on the basis of their sex characteristics.”<sup>100</sup>

The Preamble to the CRC recalls the provision in the United Nations Declaration of the Rights of the Child that “the child [...] needs special safeguards and care, [...] before as well as after birth,” and “[t]he Committee has commented adversely on [...] selective abortions [...]”<sup>101</sup> Therefore prenatal “treatment” to eliminate intersex traits, as well as selective late term abortions and Preimplantation

Genetic Diagnosis (PGD) to eliminate intersex fetuses are at odds with the Right to Life, particularly when framed within the social model of disability. In particular, most individuals receiving prenatal diagnostic information have no personal experience with intersex, and can be strongly influenced by the description of intersex variations as serious genetic illness if a more elaborate description is not provided<sup>102</sup>.

### ***Coercive sterilization***

In 2014, an Interagency Statement on Forced Sterilisation by WHO and 6 UN bodies explicitly criticized IGM practices in general, while also highlighting the impact on reproductive capacities of intersex adults:

“Children who are born with atypical sex characteristics are often subjected to cosmetic and other non-medically indicated surgeries performed on their reproductive organs, without their informed consent or that of their parents, and without taking into consideration the views of the children involved.”<sup>103</sup>

The CESCR General comment No. 22 (2016) on the right to sexual and reproductive health (art. 12) also addressed harmful medical practices on intersex persons, stating:

“59. Violations of the obligation to protect occur when a State fails to take effective steps to prevent third parties from undermining the enjoyment of the right to sexual and reproductive health. This includes the failure to prohibit and take measures to prevent all forms of violence and coercion committed by private individuals and entities, including [...] forced sterilization, [...]; and medically unnecessary, irreversible and involuntary surgery and treatment performed on intersex infants or children.”

German family law 1631c BGB explicitly prohibits caretakers to consent to the sterilization of a child.

The medical practice of removing healthy reproductive organs in intersex children is motivated by the desire to protect the person's gender identity (when the gonads are considered to be of a different gender than genital form) or due to potential cancer *risk*. While the goal of these surgeries is not explicitly sterilization, it is, nonetheless, the end result. In addition, patient groups complain that very little medical effort has gone into research on fertility preservation due to the prioritization of gender presentation<sup>104</sup>.

### ***Right to health***

Article 24 of the CRC indicates:

1. States Parties recognize the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health. [...]
3. States Parties shall take all effective and appropriate measures with a view to abolishing traditional practices prejudicial to the health of children.

These articles can be applied both to IGM harmful practices, as well as the lack of medical attention to intersex people's overall health. This would imply the states responsibility to ensure data collection and statistics, monitoring of medical practice, informed medical practice and follow-up research as well as access to medical records and history. The right to "the highest attainable standard of health" can also be found in Article 12 of the International Covenant on Economic, Social and Cultural Rights (ICESCR) and the Council of Europe's (COE) European Social Charter Articles 11 and 13.

Art 25 of the UN convention on the Rights of Persons with Disabilities (CRPD) also indicates:

States Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. States Parties shall

take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation.

If intersex variations are to be considered disorders, medical attention needs to be free of prejudicial treatment not just regarding gender, but also regarding how the ‘disability’ or ‘disorder’ is itself defined. As previously mentioned, CRC Article 24 para 3 calls on states to abolish harmful “traditional practices prejudicial to the health of children”.

### ***Rights of the Child***

The CRC addresses many issues that are of direct relevance to intersex rights due to the medical practice in childhood. By ratifying the CRC, state parties have committed themselves to ensuring that no child within its jurisdiction is subject to harmful practices, torture, CIDT, or other human rights violations specified in the convention. The CRC addresses many of the aforementioned Human Rights frameworks and discusses them in the context of the child subject who does not have direct juridical status.

In specific, the following CRC principles have all been applied to intersex Human Rights violations: Non-Discrimination (art 2); Best Interest of the Child (art 3); Children’s Right to Life and Maximum Survival and Development (art 6); Preservation of Identity (art 8); Respect for the Views of the Child (art 12); Child’s Right to Privacy (art 16); Child’s Right to Protection from All Forms of Violence (art 19); Rights of Children with Disability (art 23); Right to Health (art 24); Protection from All Forms of Sexual Exploitation of Children (art 34); Protection from Other Forms of Exploitation (art 36); and Protection from Torture or other CIDT (art 37)<sup>105</sup>; as well the CRC/CEDAW Joint General Comment No. 18/31 on harmful practices (2014).

In the concluding observations on Switzerland, the CRC urged the concerned state party to “ensure that no-one is subjected to unnecessary medical or surgical treatment during infancy or

childhood, guarantee bodily integrity, autonomy and self-determination to children concerned, and provide families with intersex children with adequate counselling and support”.<sup>106</sup>

In addition, the Yogyakarta Principles urges states to “establish child *protection mechanisms* whereby no child is at risk of, or subjected to, medical abuse”.

In 2013 the Commonwealth of Australia addressed intersex medical treatment and found it to violate the rights of the child:

“There is frequent reference to “psychosocial” reasons to conduct normalising surgery. To the extent that this refers to facilitating parental acceptance and bonding, the child’s avoidance of harassment or teasing, and the child’s body self-image, there is great danger of this being a circular argument that avoids the central issues. [...] Irreversible medical treatment, particularly surgery, should only be performed on people who are unable to give consent if there is a health-related need to undertake that surgery, and that need cannot be as effectively met later, when that person can consent to surgery”.<sup>107</sup>

### ***Anti-discrimination laws that include sex characteristics***

Many intersex social activists advocate that ‘*sex characteristics*’ best identifies their needs when it comes to protection from social discrimination. Only Malta has directly included sex characteristics as a protected category in a manner that includes unnecessary medical interventions as a form of childhood discrimination. 10 EU Member States (Bulgaria, Estonia, Hungary, Italy, Luxembourg, Poland, Portugal, Romania, Spain and Slovakia) have open (non category specific) discrimination laws. 7 EU Member States implicitly cover categories that can be applied to intersex social discrimination, for instance: gender (in Austria, Denmark, Finland and the Netherlands); gender identity (in Romania and Slovenia); or both gender and gender identity (in Sweden). However, this many contribute to confusion between issues surrounding gender identity and presentation, and instead the right to self-determination and bodily integrity.

In November 2017 *the Yogyakarta Principles plus ten*, the update to the 2006 *Yogyakarta Principles* also specifically included ‘sex characteristics’ in recognition of the distinct violations that affect individuals on these grounds. This document outlines 9 additional principles including principle 32 ‘The Right to Bodily and Mental Integrity’ indicating “No one shall be subjected to invasive or irreversible medical procedures that modify sex characteristics without their free, prior and informed consent, unless necessary to avoid serious, urgent and irreparable harm to the concerned person.”<sup>108</sup>, and details how principle 10 ‘The Right To Freedom From Torture And Cruel, Inhuman Or Degrading Treatment Or Punishment’ applies to sex characteristics<sup>109</sup>. This intersectional application of anti-discrimination laws with other human rights frameworks such as Bodily Integrity and Torture and CIDT specifically addresses rights abuses in medical settings (as opposed to discrimination in the society at large).

### **Implementation issues**

There is currently a gap in legislation regarding intersex Human Rights, with most nation states completely lacking legislation that specifically mentions intersex. Yet many nations have been called on to address intersex Human Rights issues when reviewed by IHRMs, and therefore demonstrate both awareness of the issues and the contention that surrounds them.

In this section we briefly look at policy response and inaction in three national situations, the UK, Italy and Switzerland, who have all received reprimands from IHRBs. The aim here is to highlight the context in which general reoccurring regulatory gaps occur (including confusion with Trans or other LGBT experiences, and/or willingness to regulate only on social destringation), as opposed to provide a detailed analysis of each country.

Since the first drafting of this article the UK Government Equalities Office (GEO) has launched a call for evidence on experiences and needs of people who have variations in sex characteristics<sup>110</sup>. The UK government appears unclear how to move on the issues, previously

indicating intersex as an equalities issue in their periodic reports<sup>111</sup>. UK policy figure responses in 2017 focused largely on equality issues, non-binary identities, and the Gender Recognition Act (one governmental response only addressed Trans issues). Uncertainty was found particularly around *enforcing* Human Rights in arenas where transgressions are permitted by medical best practice statements.

Representatives expressed uncertainty on several levels: “we don’t want to go in too heavy handed, or not strong enough to make the right decisions and have the right outcome for intersex people, but we just don’t know what those are at the moment”<sup>112</sup>. Several representatives indicated that they might like to implement legislation similar to Malta<sup>113</sup>, but one also stated “I’m not aware of any major breaches of Human Rights that cause us significant concerns”<sup>114</sup> and questioned whether something that was following medical best practices could be considered torture. Another used a slippery slope argument for caution in regulating medical treatment:

“Well it could set a precedence, I suppose, you know, how many other surgeries could you say weren’t lifesaving, or just normalising in some ways and would it open the floodgates for lots of redress applications and would that then hamper or hinder the medical profession? We defined the balance in that between what’s helpful, we don’t want to legislate for situations where medical practitioners are going to make their life more difficult and then have a negative impact on those with DSD or intersex variations, its getting the right balance, I think. I think that they (medics) wouldn’t maybe welcome legislation in this area, you know, this is their area of expertise. Its those who are unhappy, who we are engaging with. So it’s a one-sided story at the moment.”<sup>115</sup>

The 2019 UK reply to CEDAW 72<sup>nd</sup> session list of issues states that the “UK Government is aware of some calls from the sector to ban the practice of medical interventions on minor’s sex characteristics”<sup>116</sup>, and indicates the GEO call for evidence.

Italy has responded to IHRB’s reviews by avoiding addressing Human Rights aspects. A bill proposed in 2013 that would have legislated bodily integrity for intersex minors remains undiscussed in



parliament<sup>117</sup>. Policy makers interested in making such changes express difficulty regarding both willingness and comprehension of other governmental members<sup>118</sup>, despite a call for parliamentary discussion by Democratic Party Representative Sergio Lo Guidice in 2016<sup>119</sup>. In CEDAW's 67<sup>th</sup> session in 2017 the Italian assistant Minister of Health simply stated that intersex childhood surgeries were very few per year<sup>120</sup>. The CRC 80<sup>th</sup> session in 2019 includes a specific request for data regarding intersex births and non-urgent interventions. When directly questioned government representatives first responded to birth certificate and gender identity issues. When requested regarding surgical Human Rights issues, the response yet again focused on low frequency<sup>121</sup>. State responses of this nature indicate an unwillingness to address the Human Rights aspects of the issue, which are not determined by the frequency of the violation in any case. Data collection and transparency are certainly important issues in enforcing intersex Human Rights, however, the data provided by the Italian ministry of Health<sup>122</sup> does little to clarify what interventions are being performed with what degree of information provided. The association Certi Diritti has made a formal request that intersex statistics be made available, yet the established timeframe has already expired without official response from the regional health ministries.

In Switzerland, we yet again find a regulatory gap despite the strong statements of the NEK in 2013. To this date, the State has not responded with specific regulations of any type, indicating a willingness to leave the issue to medical regulatory bodies. The Central Ethics Committee (CEC) of the Swiss Academy of Medical Sciences (SAMS) initially (2012) issued a statement indicating they did not feel the issue warranted specific review<sup>123</sup>, while more recently in 2016 they issued a statement indicating that they felt Switzerland was complying with international indications and "that responsibility for this task lay with the professional associations or international expert groups."<sup>124</sup>. Yet again we find an Human Rights implementation impasse where States hesitate to regulate what they deem medical jurisdiction. Swiss interview data shows DSD team medical practitioners that are aware

and concerned about intersex childhood treatment. Most indicated they were in favour of postponing all unnecessary interventions until consent could be obtained directly, yet, at the same time they were not in favour of a moratorium on un-necessary interventions, or in considering certain practices as Human Rights violations.

In all three countries most medical professionals interviewed (with the exception of the NEK representative and one Italian therapist) indicated that they felt IHRM proclamations were conflating issues, and putting too many different realities together (as intersex is an umbrella term), even when they believed that certain procedures (particularly irreversible cosmetic surgery) should not be performed before the child could directly consent. Younger medical practitioners often expressed the opinion that better communication with parents might lead them to decide against early intervention, yet agreed that these procedures remain under parents' legal decisionary jurisdiction.

Implementing intersex Human Rights is also complicated by the lack of clear medical consensus regarding Human Rights concerns. A handful of medical publications, including the 2016 update to the 2006 consensus statement, acknowledge the growing body of IHRM statements in some manner, generally highlighting the unresolved nature of the issue. The *Response to the Council of Europe Human Rights Commissioner's Issue Paper on Human Rights and Intersex People* authored by medical practitioners and health advocates, is perhaps the only published article that replies directly to IHRM claims. In this paper we can see both the impact of IHRM statements, and the contention around intersex childhood medical treatment being framed as Human Rights abuses. This joint paper claims the HRC's paper was: 1. erroneously informed by LGBTIQ activists; 2. was not informed by health advocates or practitioners; 3. misrepresents current practice; and 4. "that the term intersex people is not widely recognised as appropriate among adults and children having atypical sex development".

Ironically, many international intersex activist groups are also wary of intersex issues being appropriated by LGBT activism (thereby risking addressing gender issues instead of bodily integrity),

and also use a variety of terminology to be as inclusive as possible. For instance, after the media coverage of the German legal proposal to either create a third legal gender category, or remove legal gender categories altogether, many intersex activists felt the need to clarify that gender markers are not the primary intersex Human Rights issue<sup>125</sup>. More seriously, however, is that the response paper does not cite any material that would indicate a positive change in practice, or address the actual Human Rights claims in the HRC's paper. For instance, an analysis of UK-NHS data does not support the claim that childhood intersex surgeries have diminished in practice<sup>126</sup>. The lack of short and long term data available makes the various claims on current practice very difficult to evaluate<sup>127</sup>.

Articles such as the *Response to the Council of Europe Human Rights Commissioner's Issue Paper on Human Rights and Intersex People* present intersex activists and patient groups health advocates as having different views and agendas. Our interview data in the UK and Italy paints a less dichotomous picture (unless you include patient associations that are only composed of parents). Some health advocates are certainly wary of 'demonizing' medical practitioners, and appealing the IHRMs that use strong language like torture, CIDT and harmful practices. Yet these groups also tend to share the perspective that early childhood cosmetic treatments are culturally based, and should be avoided. Ironically, one of the most significant reoccurring requests by IHRMs is that States conduct research on national practice, as there appears to be a severe dearth of data collection and long-term satisfaction research. All of our interview participants, medical practitioners, intersex social activists, health advocates and policy makers all indicated a lack of data is a major stumbling block in implementing useful change. In addition, both intersex activists and health advocates often felt that their subjective experience is not given validity as data in formal settings.

There is a clear need for policy makers to understand how to separate categories that have been historically overlapped (the body, gender, identity, sexual orientation, behaviour) in creating a

childhood medical therapy that focuses on cosmetic issues, and respond to the lack of clarity regarding data and patient satisfaction.

### ***Genital Cutting, different state responses to FGM, IGM and male circumcision***

A growing body of scholarship has begun to address differing State responses to the regulation of different types of genital cutting, from FGM to IGM to male circumcision<sup>128</sup>. StopIGM note that until FGM was widely criticised as a fundamental human rights violation, IGM practitioners themselves freely likened FGM to IGM, even defending the latter with the alleged harmlessness of the former.<sup>129</sup> Some IGM practitioners continue to rationalize IGM with the same arguments generally used by medical FGM practitioners.<sup>130</sup> Various authors contend IGMs and FGM stand on similar grounds.<sup>131</sup>

In 2005 legal experts Nancy Ehrenreich and Mark Barr noted that ‘western’ led Human Rights movement that frame FGM as a harmful cultural practice seemed to continue to ignore the ‘western’ practice of intersex childhood genital surgery<sup>132</sup>, indicating a disconnect in western social critiques of ones own institutions of cultural power.

It still stands to be shown if States are willing to consider IGM as a harmful practice akin to FGM and therefore implement some version of regulation in this direction. As stated earlier, the Human Rights framework of harmful practices seems like it could provide a power tool in bridging the existing implementation gap.

### ***Misrepresenting IGM as an LGBT or health care issue***

Further implementation issues include treating intersex Human Rights issues as reducible to LGBTIQ Equality issues, risking merely including intersex (or sex characteristics) as a protected social category, without addressing medical practices in childhood. Social discrimination is a valid fear, seeing as medical research and publication has often overlapped and historically confused the separate categories

of gender identity, gender presentation, gender stereotypes and sexual orientation when investigating variations of sex characteristics, thereby overlaying potential parental fears about gender and homophobia on other fears regarding bodily difference. Yet, more bodily harm to intersex individuals happens in medical settings than in the larger society.

There are no shortage of examples of agencies or State entities that claim either that IGM does not constitute a serious violation of non-derogable rights, or that intersex Human Rights issues should be addressed under LGBT discrimination or health care. This constitutes what StopIGM have referred to as stalling tactics, that is deferring serious Human Rights claims regarding medical treatment and the request to criminalize IGM in favour of anti-discriminatory legislation and/or policies that address gender identity recognition and civil registration. ‘Stalling’ tactics maybe be considered those in which “some” problem is admitted, yet either trivializing language (e.g. “normalizing” or “gender assigning surgery”, instead of mutilation or involuntary, non-urgent genital surgery) is used, non-directive recommendations are made, and 25 years of critical testimony by intersex activists are ignored in favour of ‘further research’. This was aptly described twenty years ago by Tiger Devore as “Endless Calls for ‘More Research’ as Harmful Interventions Continue”.<sup>133</sup>

While many intersex activists indicate that LGBT activism has opened doors for intersex rights concerns to be lifted from invisibility, the risks of appropriation and issue deflection have been clearly demonstrated<sup>134</sup>. At the same time, the few funding bodies that have supported international intersex activism are generally LGBT. Beside the implementation issues we have noted above, some patient advocates are also unhappy for intersex and DSD to be conflated with LGBT, regardless of their stance on Human Rights issues. LGBTI movements embracing the ‘I’ continues to be an area of contention, particularly when there is a lack of direct representation and or deflection of serious Human Rights issues in the medical sphere. Both the conflicts around associating intersex and DSD with LGBT, and the conflation of serious intersex Human Rights issues with discrimination issues is yet another

obstacle to implementation of IHRMs recommendations, yet perhaps one of the areas where there has been the most change in recent years (particularly regarding direct representation).

## **Conclusion**

IHRM's declarations are clearly having both general awareness and specific framing impacts on how intersex is discussed. From early on, intersex activism sought to frame specific aspects of medical treatment as violations of Human Rights, adopting the successful harmful practices framework of FGM to IGM. In this article we have addressed parts of the evolution of intersex movements lobbying of IHRMs, and therefore the evolving strategy to have IGMs recognized as a violation of non-derogable rights. Naming IGM a harmful cultural practice and/or torture has certainly elicited diverse reactions from most of the invested sectors. Not all of the subjects involved have the same perspective on the use of the Human Rights framing, or how it should be implemented in practice.

To this regard we have examined eleven Human Rights frameworks that have been applied to intersex rights claims, contending that harmful practices and CIDT provide some of the most powerful frameworks to date, capable of guaranteeing both legal repercussions for the continued practice as well as redress for those who have been subjected to harm. IHRMs have made strong recommendations and statements to this regard, but States have been slow on the uptake to respond with regulation despite the demonstration that there are clear grounds for defining certain aspects of intersex medical treatment as violations of the eleven human rights frameworks outlined in this paper.

Implementation of IHRMs recommendations remains a significant issue. Most national bodies still seem unclear how to address or implement this growing call to address IGM as a Human Rights violation, yet IHRM declarations have certainly brought the issue to the table. The appeal to IHRMs grew precisely out of frustration with the apparent lack of change in practice, seeking to force governments into considering the issue as in need of legislation. Intersex activists and health advocates

continue to work on many different fronts, not necessarily in agreement regarding the best tactics or framing to effect change. However, it does appear that most are in agreement that parents need support from society, regulation and medical practice to help them celebrate (or not focus negatively on) their child's physical variation, as opposed to medicalize it.

There is greater need for understanding regarding how intersex activist rights claims can be translated into greater changes in medical treatment. IHRM pressure is one of the pieces in the puzzle that will effect this change precisely through its focus on specific practices and non-derogable rights .

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<sup>1</sup> For historical accounts of intersex activism see (among others) Cheryl Chase, "Hermaphradites with attitude: Mapping the emergence of intersex political activism." (1998): 189-211; Sharon E. Preves, "Out of the OR and into the Streets: Exploring the Impact of the Intersex Media Activism." *Cardozo JL & Gender* 12 (2005): 247; Ellen K. Feder, "Imperatives Of Normality From "Intersex" to "Disorders of Sex Development"." *GLQ: a Journal of Lesbian and Gay studies* 15, no. 2 (2009): 225-247; Alice D. Dreger, and April M. Herndon. "Progress and politics in the intersex rights movement feminist theory in action." *GLQ: A Journal of Lesbian and Gay Studies* 15, no. 2 (2009): 199-224; Georgiann Davis, "'DSD is a Perfectly Fine Term': Reasserting Medical Authority through a Shift in Intersex Terminology." In *Sociology of diagnosis*, pp. 155-182. Emerald Group Publishing Limited, 2011; Alice D. Dreger, "Twenty Years of Working toward Intersex Rights". In *Bioethics in Action*, pp. 55–73. Cambridge University Press, 2018.

<sup>2</sup> See (among others) Lorraine J. Daston, and Katharine Park, (1995) *The Hermaphrodite and the Orders of Nature: Sexual Ambiguity in Early Modern France*. *GLQ* I(4).; Alice D. Dreger, *Hermaphrodites and the medical invention of sex*. Harvard University Press, 1998.; Sharon E. Preves, "Sexing the intersexed: An analysis of sociocultural responses to intersexuality." *Signs: Journal of women in Culture and Society* 27, no. 2 (2002): 523-556.; Katrina Karkazis, (2008) *Fixing Sex: Intersex, Medical Authority, and Lived Experience*. Durham: Duke University Press.; Elizabeth Reis, *Bodies in doubt: An American history of intersex*. JHU Press, 2009; Anne Fausto-Sterling, *Sex/gender: Biology in a social world*. Routledge, 2012.; Georgiann Davis, *Contesting intersex: The dubious diagnosis*. NYU Press, 2015.

<sup>3</sup> Regarding the patient expert see also Janneke E. Elberse, J. Francisca Caron-Flinterman, and Jacqueline EW Broerse. "Patient–expert partnerships in research: how to stimulate inclusion of patient perspectives." *Health Expectations* 14, no. 3 (2011): 225-239.

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- <sup>4</sup> On evidenced based health care activism see Vololona Rabeharisoa, Tiago Moreira, and Madeleine Akrich "Evidence-based activism: Patients' organisations, users' and activist's groups in knowledge society." *Biosocieties* 9 (2013).
- <sup>5</sup> For example see the opposing declarations from the US groups AIS-DSD <http://aisdsd.org/wp-content/uploads/2017/09/Human-Rights-Watch-AIS-DSD-letter-to-AMA-August-2017.pdf> and CARES foundation <http://www.caresfoundation.org/wp-content/uploads/2017/02/1CALL-TO-ACTION-Nat-Geo.pdf> regarding the 2017 Human Rights Watch report <https://www.hrw.org/report/2017/07/25/i-want-be-nature-made-me/medically-unnecessary-surgeries-intersex-children-us>.
- <sup>6</sup> StopIGM has collaborated, or worked in parallel with numerous international activists that have provided evidence to International Human Rights Bodies (IHRBs), and would like to acknowledge their essential work in lobbying IHRBs that might not otherwise be highlighted in the description of the their Human Rights framing.
- <sup>7</sup> See also OHCHR. 2015. 'Free & Equal Campaign Fact Sheet: Intersex'. <https://www.unfe.org/wp-content/uploads/2017/05/UNFE-Intersex.pdf>
- <sup>8</sup> See Suzanne J. Kessler, and Wendy McKenna. *Gender: An ethnomethodological approach*. University of Chicago Press, 1978.; Julia E. Rechter. "The Glands of Destiny": A history of popular, medical and scientific views of the sex hormones in 1920s America." (1999).; Nelly Oudshoorn. *Beyond the natural body: An archaeology of sex hormones*. Routledge, 2003.; Chandak Sengoopta. *The most secret quintessence of life: glands, sex, and bodies, 1850-1950*. University of Chicago Press, 2006.; Ingrid Holme. "Genetic Sex: "A Symbolic Struggle Against Reality?" Exploring Genetic And Genomic Knowledge In Sex Discourses." (2007).; Celia Roberts. *Messengers of sex: Hormones, biomedicine and feminism*. Cambridge University Press, 2007; Daniela Crocetti, *L'invisibile intersex: storie di corpi medicalizzati*. ETS, 2013.
- <sup>9</sup> See for instance Julia E. Rechter. "The Glands of Destiny".; Anne Fausto-Sterling. *Sex/gender: Biology in a social world*. Routledge, 2012.; Giorgiann Davis. *Contesting intersex: The dubious diagnosis*. NYU Press, 2015.
- <sup>10</sup> See Ellen K. Feder, and Katrina Karkazis. "What's in a name? The controversy over "disorders of sex development"." *Hastings Center Report* 38, no. 5 (2008): 33-36.; Giorgiann Davis, "'DSD is a Perfectly Fine Term": Reasserting Medical Authority through a Shift in Intersex Terminology." In *Sociology of diagnosis*, pp. 155-182. Emerald Group Publishing Limited, 2011.

In addition, some contest that the ambiguous exclusion of certain variations from intersex (as opposed to DSD) serve to consolidate medical authority in this arena. See Morgan Carpenter, "The "Normalisation" of



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Intersex Bodies and “Othering” of Intersex Identities”. In *The Legal Status of Intersex Persons*, pp. 445–514. Intersentia, 2018.

<sup>11</sup> For example see Kelly Kollman, and Matthew Waites. "The global politics of lesbian, gay, bisexual and transgender human rights: an introduction." *Contemporary Politics* 15, no. 1 (2009): 1-17.

<sup>12</sup> Malta is currently the only example of international intersex Human Rights lobbying being translated into national law which includes sex characteristics as a protected category. See Gender Identity, Gender Expression And Sex Characteristics Act

[https://meae.gov.mt/en/Public\\_Consultations/MSDC/Pages/Consultations/GIGESC.aspx](https://meae.gov.mt/en/Public_Consultations/MSDC/Pages/Consultations/GIGESC.aspx).

IHRB proclamations are currently mostly impacting national debate and soft law as discussed in the Implimentation section.

<sup>13</sup> For instance in the case of FGM see Els Leye, et Al. “An analysis of the implementation of laws with regard to female genital mutilation in Europe." *Crime, law and social change* 47, no. 1 (2007): 1-31.

<sup>14</sup> See <http://intersex.shadowreport.org/>

<sup>15</sup> See also Phil Brown, et Al. "Embodied health movements: new approaches to social movements in health." *Sociology of health & illness* 26, no. 1 (2004): 50-80; Tom Shakespeare. *Disability rights and wrongs revisited*. Routledge, 2013.

<sup>16</sup> See also Henri Wijsbek, "Surgically Shaping Children." *Perspectives in Biology and Medicine* 51, no. 2 (2008): 261-269.

<sup>17</sup> Peter A. Lee, et al., "Global disorders of sex development update since 2006: perceptions, approach and care." *Hormone Research in Paediatrics* 85, no. 3 (2016): 158-180.; Pierre DE Mouriquand, et al., "Surgery in disorders of sex development (DSD) with a gender issue: If (why), when, and how?." *Journal of pediatric urology* 12, no. 3 (2016): 139-149.

<sup>18</sup> For examples see Surya Monro, Daniela Crocetti, Tray Yeadon-Lee, Fae Garland, and Mitch Travis. "Intersex, Variations of Sex Characteristics, and DSD: The Need for Change." Research Report. University of Huddersfield. (2017); <http://intersex.shadowreport.org/>

<sup>19</sup> <https://cordis.europa.eu/project/rcn/202175/factsheet/en>

<sup>20</sup> In collaboration with nation specific intersex activists. See <http://intersex.shadowreport.org/>

<sup>21</sup> Peter Reason and Hilary Bradbury-Huang. "The handbook of action research: Participative inquiry and practice." Sage Press. (2001).

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- <sup>22</sup> UK the interviews were comprised of one NHS DSD healthcare professional, six intersex activists, three patient advocates, one parent member of a family support group, two intersex representatives of LGBT organisations doing work about intersex, four civil servants and one union representative. In Switzerland the interviews were comprised of four DSD healthcare professionals (two with policy roles in the Central Ethics Committee of the Swiss Academy of Medical Sciences, CRC-SAMS, and the Swiss National Advisory Commission on Biomedical Ethics, NEK-CNE, respectively), and two intersex activists. In Italy the interviews were comprised of five NHS DSD healthcare professionals, five intersex activists, two patient advocates, two parent members of a family support group, and one policy advocate.
- <sup>23</sup> Funded by the European Union’s Horizon 2020 Research and Innovation Programme under the Marie Skłodowska-Curie grant agreement number 703352.
- <sup>24</sup> Virginia Braun, et al., “Thematic analysis”. In Poul Rohleder, and Antonia C. Lyons, eds. *Qualitative research in clinical and health psychology*. Palgrave Macmillan, 2014.
- <sup>25</sup> See <https://www.statnews.com/2017/10/26/intersex-medical-care/> By Kimberly Zieselman October 26, 2017
- <sup>26</sup> See: [Zwischengeschlecht.org](http://zwischen-geschlecht.org), [Intersex.ch](http://intersex.ch), Verein SI Selbsthilfe Intersexualität, Intersex Genital Mutilations. Human Rights Violations Of Children With Variations Of Sex Anatomy, NGO Report to the 2nd, 3rd and 4th Periodic Report of Switzerland on the Convention on the Rights of the Child (CRC), [http://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM\\_v2.pdf](http://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf); Daniela Truffer, Markus Bauer, Intersex Genital Mutilations On A Global Scale, CRC Briefing 21.01.2015, [http://intersex.shadowreport.org/public/Zwischengeschlecht\\_2015-CRC-Briefing\\_Intersex-IGM\\_web.pdf](http://intersex.shadowreport.org/public/Zwischengeschlecht_2015-CRC-Briefing_Intersex-IGM_web.pdf); Melinda Jones, Intersex Genital Mutilation – A Western Version of FGM, in: *International Journal of Children's Rights* 25 (2017) p. 396-411
- <sup>27</sup> Anne Tamar-Mattis (2013), Report to the Inter-American Commission on Human Rights: Medical Treatment of People with Intersex Conditions as a Human Rights Violation, at 2, <http://www.aph.gov.au/DocumentStore.ashx?id=432c5135-4336-472e-bb24-59c89eb4a643>
- <sup>28</sup> Jörg Woweries. “Intersexualität: Eine kinderrechtliche Perspektive.” (2011). [http://kastrationsspital.ch/public/fK\\_0310\\_Woweries.pdf](http://kastrationsspital.ch/public/fK_0310_Woweries.pdf)
- <sup>29</sup> See discussions on CAH research in (among others) Anne Fausto-Sterling. “*Sexing the body: Gender politics and the construction of sexuality*”. Basic Books, 2000; Rebecca M. Jordan-Young. *Brain storm*. Harvard University Press, 2010.
- <sup>30</sup> See also Surya Monro, et al. “Intersex, Variations of Sex Characteristics, and DSD: The Need for Change”.

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- <sup>31</sup> See <http://intersex.shadowreport.org/> for NGO reports and concluding statements from various IHR committees.
- <sup>32</sup> For example see the US report Marcus de María Arana, and H.R.C. Staff. "A human rights investigation into the medical "normalization" of intersex people." *A Report of a Public Hearing By the Human Rights Commission* (2005);
- <sup>33</sup> Juan E. Méndez, Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment. (2013). Retrieved from [http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.2.2.53\\_English.pdf](http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.2.2.53_English.pdf); World Health Organization. "Eliminating forced, coercive and otherwise involuntary sterilization: An interagency statement." *Geneva: WHO* (2014): 15-16.
- <sup>34</sup> Silvan Agius, and Council of Europe. Commissioner for Human Rights. *Human Rights and Intersex People: Issue Paper*. Council of Europe, 2015.
- <sup>35</sup> Community Affairs References Committee. "Involuntary or Coerced Sterilisation of Intersex People in Australia". 2013. [http://www.aph.gov.au/Parliamentary\\_Business/Committees/Senate/Community\\_Affairs/Involuntary\\_Sterilisation/Sec\\_Report/index](http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Involuntary_Sterilisation/Sec_Report/index)
- <sup>36</sup> Comitato Nazionale per la Bioetica "I disturbi della differenziazione sessuale nei minori: aspetti bioetici". (2010). [http://bioetica.governo.it/media/170698/p86\\_2010\\_disturbi\\_differenziazione-sessuale-minori\\_it.pdf](http://bioetica.governo.it/media/170698/p86_2010_disturbi_differenziazione-sessuale-minori_it.pdf); German Ethics Council. Intersexuality, Opinion. (2012). Retrieved from: <http://www.ethikrat.org/publications/opinions/intersexuality>; NEK-CNE Swiss National Advisory Commission on Biomedical Ethics. On the management of differences of sex development Opinion No. 20/2012. Ethical issues relating to "intersexuality". Retrieved from: [http://www.nek-cne.ch/fileadmin/nek-cne-dateien/Themen/Stellungnahmen/en/NEK\\_Intersexualitaet\\_En.pdf](http://www.nek-cne.ch/fileadmin/nek-cne-dateien/Themen/Stellungnahmen/en/NEK_Intersexualitaet_En.pdf)
- <sup>37</sup> Joycelyn M. Elders, David Satcher, and Richard Carmona. Re-Thinking Genital Surgeries on Intersex Infants. (2017) The Palm Center.
- <sup>38</sup> <https://www.hrw.org/report/2017/07/25/i-want-be-nature-made-me/medically-unnecessary-surgeries-intersex-children-us>
- <sup>39</sup> <http://yogyakartaprinciples.org/principles-en/official-versions-pdf/>
- <sup>40</sup> <http://justiceservices.gov.mt/DownloadDocument.aspx?app=lp&itemid=26805&l=1>
- <sup>41</sup> For further background see Alice Dreger, "Twenty Years of Working toward Intersex Rights". In *Bioethics in Action*, , pp 55–73. Cambridge University Press.

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- <sup>43</sup> See early legal response letter: J. Barad. "Can you sue your doctors?." *Hermaphrodites with Attitude* Spring (1995). <http://www.isna.org/files/hwa/spring1995.pdf>
- <sup>44</sup> Tamara Alexander. "The Medical Management of Intersexed Children: An Analogue for Childhood Sexual Abuse". (1997). <http://www.isna.org/articles/analog>
- <sup>45</sup> Emi Koyama. "Intersexcritiques: Notes on Intersex, Disability, and Biomedical Ethics". *Confluere* Publications, 2003.
- <sup>46</sup> Cheryl Chase. emails to H-Women list, (1996). <https://networks.h-net.org/node/24029/pages/31357/female-genital-mutilation-us>
- <sup>47</sup> Cheryl Chase. "Hermaphrodites with Attitude, Mapping the Emergence of Intersex Political Activism". *GLQ* 4:2, (1998):189-211.
- <sup>48</sup> Michel Reiter, *Genitale Korrekturen an intersexuellen Menschen*. "It's easier to make a hole than to build a pole", *kassiber* 34 - Februar 98, [https://www.nadir.org/nadir/initiativ/kombo/k\\_34isar.htm](https://www.nadir.org/nadir/initiativ/kombo/k_34isar.htm)
- <sup>49</sup> Cheryl Chase "Cultural Practice or Reconstructive Surgery? US Genital Cutting, the Intersex Movement, and Medical Double Standards". In Stanlie M. James and Claire C. Robertson (eds.), *Genital Cutting and Transnational Sisterhood. Disputing U.S. Polemics*, (2002): 126-151.
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- <sup>52</sup> Michel Reiter, and Heike Bödeker (1996), *Genitalverstümmelungen in Deutschland in der Kinder- und Jugendgynäkologie*, <http://web.archive.org/web/19981203123631/http://home.t-online.de:80/home/AGGPG/tdf.htm>
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<http://blog.zwischengeschlecht.info/pages/%22Vernichtung-intersexueller-Menschen-in-westlichen-Kulturen%22-Flugblatt-AGGPG-%281998%29>
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- <sup>59</sup> Wendell Roelf. Intersex children must be protected from temptation of parents to 'fix' them surgically, Cape Times 01.12.2004,  
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- <sup>60</sup> Mauro Cabral (2004), UN 2004 - NGO Statement: Intersexuality,  
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- <sup>62</sup> A/HRC/22/53. 2013: 18-19.
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- <sup>64</sup> CEDAW France NGO Report. 2016: 36-37. <http://intersex.shadowreport.org/public/2016-CEDAW-France-NGO-Zwischengeschlecht-Intersex-IGM.pdf>
- <sup>65</sup> CRC Switzerland NGO Report. 2014. [http://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM\\_v2.pdf](http://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf)
- <sup>66</sup> CRC/C/CHE/CO/2-4. 2015: paras 42-43.
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<http://stop.genitalmutilation.org/post/IAD-2016-Soon-20-UN-Reprimands-for-Intersex-Genital-Mutilations>
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- <sup>73</sup> European Parliament resolution of 14 February 2017 on promoting gender equality in mental health and clinical research (2016/2096(INI)); <http://www.europarl.europa.eu/sides/getDoc.do?pubRef=-//EP//TEXT+TA+P8-TA-2017-0028+0+DOC+XML+V0//EN>
- <sup>74</sup> Including UN Human Rights Committee recommendations to Australia obligations under the 1966 International Covenant on Civil and Political Rights: ; “The state party should... move to end irreversible medical treatment, especially surgery, of intersex infants and children...” CCPR/C/AUS/CO/6 para 26; and Switzerland “*The State party should: (a) take all necessary measures to ensure that no child undergoes unnecessary surgery...*” CCPR/C/CHE/CO/4 para 25.
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<sup>84</sup> Anne Tamar-Mattis. "Medical treatment of people with intersex conditions as torture and cruel, inhuman, or degrading treatment or punishment." *Torture in healthcare settings: Reflections on the Special Rapporteurs on torture's* (2013): 91-104.

<sup>85</sup> <http://fra.europa.eu/en/publication/2015/fundamental-rights-situation-intersex-people>

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<sup>87</sup> CAT/C/DEU/CO/5. 2011: para 20.

<sup>88</sup> CAT/C/CHE/CO/7. 2015: para 20; see also CAT/C/AUT/CO/6. 2015: paras 44–45; CAT/C/DNK/CO/6-7, 9 December, paras 42–43; CAT/C/CHN-HKG/CO/4-5. 2015: paras 28–29.

<sup>89</sup> Caroline Zuercher. "Les docteurs ne pouvaient pas dire si j'étais un garçon ou une fille". *Tribune de Genève*. 02.08.2015: 5-6. English translation author 2. "A mon sens, seule la peur du juge pourra faire bouger les choses, poursuit-il. Il faut prévoir un délai de prescription suffisant pour que les victimes puissent porter plainte à l'âge adulte."

<sup>90</sup> World Health Organization. *Sexual health, human rights and the law*. World Health Organization, 2015 : 27.

<sup>91</sup> *Ibid*: 9.

<sup>92</sup> Pierre DE Mouriquand, A. Caldamone, P. Malone, J. D. Frank, and Piet Hoebeke. "The ESPU/SPU standpoint on the surgical management of Disorders of Sex Development (DSD)." *Journal of pediatric urology* 10, no. 1 (2014): 10.

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- <sup>99</sup> CRC/C/CHE/CO/2-4: 2015: p. 8; CRC/C/CHE/CO/2-4: 2015: paras 42–43; CRC/C/CHL/CO/4-5. 2015: paras 48–49.
- <sup>100</sup> [https://wcd.coe.int/ViewDoc.jsp?p=&Ref=CommDH/IssuePaper\(2015\)1&Language=lanEnglish&direct=true](https://wcd.coe.int/ViewDoc.jsp?p=&Ref=CommDH/IssuePaper(2015)1&Language=lanEnglish&direct=true)
- <sup>101</sup> Rachel Hodgkin, Peter Newell. "Implementation Handbook for the Convention on the Rights of the Child: Fully Revised Third Edition." UNICEF (2007): 85.
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- <sup>103</sup> World Health Organization. "Eliminating forced, coercive and otherwise involuntary sterilization: An interagency statement." Geneva: WHO (2014): 15-16.
- <sup>104</sup> Gonadectomy and some types of hormone therapy create infertility; see Emilie K. Johnson, and Courtney Finlayson. "Preservation of fertility potential for gender and sex diverse individuals." *Transgender Health* 1, no. 1 (2016): 41-44.
- <sup>105</sup> For more detail on the CRC articles as applied to Intersex see forthcoming Handbook from StopIGM.com
- <sup>106</sup> CRC/C/CHE/CO/2-4. 2015: p. 9.
- <sup>107</sup> Australia, Senate, Community Affairs References Committee. *Involuntary or coerced sterilisation of intersex people in Australia* [Internet]. Canberra: Community Affairs Page 12 of 15 References Committee; 2013: 74.



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- <sup>108</sup> <http://yogyakartaprinciples.org/principles-en/official-versions-pdf/> pg. 10
- <sup>109</sup> <http://yogyakartaprinciples.org/principles-en/official-versions-pdf/> pg. 19
- <sup>110</sup> <https://www.gov.uk/government/consultations/variations-in-sex-characteristics-call-for-evidence>
- <sup>111</sup> The UK was questioned on intersex in the 2016 by the CRC (see CRC/C/GBR/CO/5), in 2017 by the CRPD (see CRPD/C/GBR/CO/1) and in 2019 by CEDAW (see CEDAW/C/GBR/Q/8).
- <sup>112</sup> Representative of Scottish Executive 1.
- <sup>113</sup> The Malta law enforces bodily integrity and autonomy by enshrining sex characteristics as protected characteristics, thereby parents can not choose cosmetic procedures for children.
- <sup>114</sup> Representative of Scottish Executive 2.
- <sup>115</sup> Representative of Scottish Executive 1.
- <sup>116</sup> See CEDAW/C/GBR/Q/8/Add.1 para 46.
- <sup>117</sup> DDL 405 <http://www.senato.it/leg/17/BGT/Schede/FascicoloSchedeDDL/ebook/40335.pdf>
- <sup>118</sup> Members of Certi Diritti Associazione Radicale, association linked to the radical political party (Partito Radicale).
- <sup>119</sup> <http://www.senato.it/japp/bgt/showdoc/frame.jsp?tipodoc=Sindisp&leg=17&id=991855>
- <sup>120</sup> See 2017 CEDAW Italy Thematic Intersex NGO Report;  
<http://intersex.shadowreport.org/post/2017/07/03/2017-CEDAW-Italy-Thematic-Intersex-NGO-Report>
- <sup>121</sup> Links to relevant UN audio: <http://stop.genitalmutilation.org/post/CRC80-Italy-questioned-over-Intersex-Genital-Mutilation-by-UN-Children-Rights-Committee>
- <sup>122</sup> Data annex removed from UN cite  
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can be found here <http://intersex.shadowreport.org/>
- <sup>123</sup> Indicated in Interview with CRC-SAMS representative.
- <sup>124</sup> SAMS, Opinion of the Central Ethics Committee of the SAMS on «differences of sex development» Bern, 16 December 2016.
- <sup>125</sup> For instance see <https://www.facebook.com/intersexuk/posts/874600909364906>
- <sup>126</sup> See Surya Monro, et al. "Intersex, Variations of Sex Characteristics, and DSD: The Need for Change."
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- <sup>129</sup> CRC Switzerland NGO Report. 2014: 57.
- <sup>130</sup> See for example Dr. Kind in CRC Switzerland NGO Report. 2014: 57.
- <sup>131</sup> Hanny Lightfoot-Klein. "Children's Genitals Under the Knife: Social Imperatives, Secrecy, and Shame". BookSurge Publishing, 2007.; Coventry, Martha. "Making The Cut. Every time a baby is born in the United States, doctors decide whether its genitals are "normal" or not." *MS-New York-* 10, no. 6 (2000): 52-60.;
- <sup>132</sup> Nancy Ehrenreich, and Mark Barr. "Intersex surgery, female genital cutting, and the selective condemnation of cultural practices.".; Melinda Jones,. "Intersex Genital Mutilation—A Western Version of fgm." *The International Journal of Children's Rights* 25, no. 2 (2017): 396-411.
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- <sup>134</sup> See Julius Kaggwa "I'm an intersex Ugandan – life has never felt more dangerous". *The Guardian* (September 19, 2016).; Pidgeon Pagonis, "7 Ways Adding 'I' to the LGBTQ+ Acronym Can Miss the Point". *Everyday Feminism* (June 2016) <https://everydayfeminism.com/2016/06/intersex-lgbtq-misses-the-point/>; Tiffany Jones, Bonnie Hart, Morgan Carpenter, Gavi Ansara, William Leonard, and Jayne Lucke. "Intersex: Stories and Statistics from Australia". Open Book Publishers, (2016) pp 43-44.