Statement of OII Europe on Intersex, Disability and the UN Convention on the Rights of People with Disabilities

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Introduction

The Committee on the Rights of Persons with Disabilities is the latest human rights treaty body to address the violations of the rights of the intersex community. The Committee's recommendations to the Federal Republic of Germany recognise the importance of protecting, promoting and fulfilling the rights of intersex individuals.

Content

1 What is OII Europe?

Organisation Intersex International Europe (OII Europe) is Europe's first Umbrella Intersex-NGO and was founded on Human Rights Day, December 10, 2012, during the Second International Intersex Forum in Stockholm, to ensure the further adoption of Human Rights for intersex people all over Europe. OII Europe is an autonomous part of OII World (Organisation Intersex International World) which was founded in 2002 and has operated since then through its national groups in every region of the world.

OII Europe works to end discrimination against intersex people and to ensure the right of bodily integrity and self-determination. OII Europe advocates for the charter of rights formulated by the activists present at the 2nd International Intersex Forum 2012 in Stockholm representing 33 intersex organisations and supportive institutions from all continents that was reaffirmed and extended by 30 intersex organizations at the 3rd International Intersex Forum in Malta, 2013. This charter includes, among others, the following demands: To put an end to mutilating and 'normalising' practices such as genital surgeries, psychological and other medical treatments, including infanticide and selective abortion (on the grounds of intersex). To ensure that the personal, free, prior, and fully informed consent of the intersex individual is a compulsory requirement for all medical practices and protocols. To create and facilitate supportive, safe and celebratory environments for intersex people, their families and surroundings. OII Europe campaigns for the respect of intersex people's human rights on the European and at the national levels and in particular engages with governments, human rights organisations, commissions and the broader LGBTI activist movement. OII Europe also offers information and training to other NGOs and government bodies. *(For the full list of demands please see: http://oiieurope.org/public-statement-by-the-third-international-intersex-forum/)*

2 Human rights treaty bodies and intersex

OII Europe welcomes the CRPD Committee's inclusion of intersex issues in their consideration of the initial State party report from the Federal Republic of Germany[1]. We also highly welcome the CRPD Committee's concluding observations on the Federal Republic of Germany[2] which calls for the State Party to "*take the necessary measures, including of a legislative nature to […] implement all the recommendations of CAT/C/DEU/CO/5, para. 20 relevant to intersex children.*"

Other human rights treaty bodies have made recommendations and statements regarding intersex issues in their examination of State parties namely:

- **The United Nations Committee on the Rights of the Child concluding observations on Switzerland (2015)**[3] called the State Party to ensure

  > "*(b) In line with the recommendations of the National Advisory Commission on Biomedical Ethics on ethical issues relating to intersexuality [ensure] that no one is subjected to unnecessary medical or surgical treatment during infancy or childhood, guarantee bodily integrity, autonomy and self-determination to the children concerned, and provide families with intersex children with adequate counselling and support.*"

- **The United Nations Committee on Torture concluding observations on Germany (2011)**[4] called the State party to:

  > "*(a) Ensure the effective application of legal and medical standards following the best practices of granting informed consent to medical and surgical treatment of intersex people, including full information, orally and in writing, on the suggested treatment, its justification and alternatives;*
  >
  > *(b) Undertake investigation of incidents of surgical and other medical treatments of intersex people without effective consent and adopt legal provisions in order to provide redress to the victims of such treatment, including adequate compensation;*
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  > *(c) Educate and train medical and psychological professionals on the range of sexual, and related biological and physical, diversity; and*

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[1] CRPD/C/DEU/Q/1/Add.1 http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fDEU%2fQ%2f1%2fAdd.1&Lang=en

[2] CRPD/C/DEU/CO/1
http://daccess-dds-ny.un.org/doc/UNDOC/GEN/G15/036/13/PDF/G1503613.pdf?OpenElement

[3] CRC/C/CHE/CO/2-4
http://daccess-dds-ny.un.org/doc/UNDOC/GEN/G15/036/13/PDF/G1503613.pdf?OpenElement

[4] CAT/C/DEU/CO/5 http://www2.ohchr.org/english/bodies/cat/docs/co/CAT.C.DEU.CO.5_en.pdf

> *(d) Properly inform patients and their parents of the consequences of unnecessary surgical and other medical interventions for intersex people."*

Other United Nations bodies and experts have commented on intersex issues, namely:

- **The United Nations High Commissioner for Human Rights (2014)**[5] addressed the "*medically unnecessary and irreversible surgeries and sterilizations [that] continue to be performed on intersex children without their informed consent, causing lifelong harm."*
- **OHCHR, UN Women, UNAIDS, UNDP, UNFPA, UNICEF and WHO, Eliminating forced, coercive and otherwise involuntary sterilization (2014)**[6]: The interagency statement observed that "*Intersex persons may be involuntarily subjected to so-called sex-normalizing or other procedures as infants or during childhood, which, in some cases, may result in the termination of all or some of their reproductive capacity. 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. As a result, such children are being subjected to irreversible interventions that have lifelong consequence for their physical and mental health."*
- **The United Nations Special Rapporteur on Torture (2013)**[7] called upon all States to "*repeal any law allowing intrusive and irreversible treatments, including forced genital-normalizing surgery, involuntary sterilization, unethical experimentation, medical display [...] when enforced or administered without the free and informed consent of the person concerned. He also calls upon them to outlaw forced or coerced sterilization in all circumstances and provide special protection to individuals belonging to marginalized groups."*

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[5] Statement by Navi Pillay United Nations High Commissioner for Human Rights on the occasion of the presentation of the ILGA "LGBTI Friend of the Year" award and 2014 State-Sponsored Homophobia report and the Panel on International Human Rights Law and Sexual Orientation. http://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=14654&LangID=E

[6] OHCHR, UN Women, UNAIDS, UNDP, UNFPA, UNICEF and WHO: Eliminating forced, coercive and otherwise involuntary sterilization. An interagency statement. May 2014, http://apps.who.int/iris/bitstream/10665/112848/1/9789241507325_eng.pdf?ua=1

[7] A /HRC/22/53, p. 23 http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53_English.pdf

Within Europe the following statements have been made on intersex issues:

- **Council of Europe Commissioner of Human Rights Comment, A boy or a girl or a person – intersex people lack recognition in Europe (2014)**[8] points out the violation of intersex people's rights of self-determination and bodily integrity: "*The early "normalising" treatments do not respect intersex persons' rights to self-determination and physical integrity. Intersex babies and younger children are not in a position to give their consent. The proxy consent given by parents may not be free and fully informed and can hardly take into account the best interests of the child in the long-run.*"
- **Council of Europe Resolution 1952/2013, 'Children's right to physical integrity' (2013)**[9] called on member states to "*undertake further research to increase knowledge about the specific situation of intersex people, ensure that no-one is subjected to unnecessary medical or surgical treatment that is cosmetic rather than vital for health during infancy or childhood, guarantee bodily integrity, autonomy and self-determination to persons concerned, and provide families with intersex children with adequate counselling and support*".
- **The Maltese Gender Identity, Gender Expression, and Sex Characteristics Act (2015)**[10] is the first law in the world to make it unlawful "*for medical practitioners or other professionals to conduct any sex assignment treatment and, or surgical intervention on the sex characteristics of a minor which treatment and, or intervention can be deferred until the person to be treated can provide informed consent*".

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[8] Council of Europe Commissioner of Human Rights Comment: A boy or a girl or a person – intersex people lack recognition in Europe. http://www.coe.int/en/web/commissioner/-/a-boy-or-a-girl-or-a-person-intersex-people-lack-recognition-in-euro-1

[9] Council of Europe Parliamentary Assembly: Children's right to physical integrity. Report Doc. 13297, 6 September 2013. C. Explanatory memorandum by Ms Rupprecht, rapporteur. 2013, http://www.assembly.coe.int/nw/xml/XRef/Xref-XML2HTML-en.asp?fileid=20057&lang=en

[10] https://socialdialogue.gov.mt/en/Public_Consultations/MSDC/Documents/GIGESC/70%20-%202014%20-%20GIGESC%20-%20EN.pdf

3 Background: Intersex, the CRPD and Germany

The German Institute for Human Rights noted in their alternative report[11] that being intersex is “neither a disability nor in itself a long-term physical impairment as these are defined in the CRPD” and that being intersex results in stigmatization, non-acceptance by society and often even being denied validation of the fundamental acceptability of one´s existence. Recently (October 2014) the *Conference of the German Ministers for Women and Equalities* affirmed that interventions that modify the sex characteristics of an intersex person constitute human rights violations referenced in Article 2. Abs. 2 Satz 1 GG of the German Constitution. The *Conference of the German Ministers for Women and Equalities* has furthermore equated surgeries with the express aim of modifying the appearance of intersex people’s genitals with Female Genital Mutilation.[12]

OII Germany and the Swiss NGO Zwischengeschlecht.org organised a briefing for the CRPD Committee on disability and intersex before the constructive dialogue with the German delegation on 27 March 2015.[13]

4 Who are intersex individuals?

Intersex people face human rights violations on the basis of their sex characteristics that do not conform to the normative ideology of binary sexes. Consequentially, intersex people are subjected to irreversible medical treatment to align their bodies with the societal expectation in regard to appearance and body function. These procedures include, but are not limited to: genital surgery performed without any pressing medical need, gonadectomies, which lead to a lifelong need for Hormone Replacement Therapy (HRT) and constitute forced or coercive sterilization, hormonal treatment to emphasize the assigned sex and long-term psychological intervention. Those who have endured prenatal, surgical and hormonal treatment without their fully informed, free and prior consent, often face a lifetime of health issues as a result of these violations of their bodily integrity, including physical and psychological impairment. Of especially grave concern is the growing prenatal use of Dexamethasone to pregnant woman aimed at preventing the development of ambiguous genitalia, tomboyism, and lesbianism in intersex individuals with a particular variation (CAH) and XX chromosomes. The growing tendency to include DSD-diagnoses in the list of grounds for termination, pre-implantation diagnostics and abortion is also very disturbing.

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[11] http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=INT%2fCRPD%2fIFL%2fDEU%2f16940&Lang=en

[12] Beschlüsse der 24. Konferenz der Gleichstellungs- und Frauenministerinnen und -minister, -senatorinnen und -senatoren der Länder (GMFK) am 1./2. Oktober 2014 in Wiesbaden, Top 8.1: Rechte intersexueller Menschen wahren und Diskriminierung beenden – insbesondere Schutz der körperlichen Unversehrtheit, p. 52 and 53, http://www.gleichstellungsministerkonferenz.de/documents/2014_10_13_Beschluesse_GESAMT_Extern.pdf

[13] We thank an anonymous donor and GATE for their support and Morgan Carpenter of OII Australia who facilitated the briefing.

In the past years several high-level institutions have addressed the human rights violations that arise from lack of consent, lack of legal provisions, lack of accurate information regarding treatments and alternatives to the current treatment model, lack of psychosocial support and lack of information about the complications that can occur following genital surgery. These are ongoing issues faced by our community. With a lack of independent data collection, the true scale of irreversible sex aligning or sex assigning surgical interventions can at best be considered an educated guess. Estimates are that 0.5 % (1 in 2000) up to 2% (40 in 2000) of children born every year have an intersex variation.[14] With no independent oversight, there are no independent safeguarding measures in place.

5 Key intersex issues in relation to the Convention on the rights of persons with disabilities:

- **Article 3 General Principles (d):** Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity. For intersex individuals, respect for the diversity of everyone is the foundation and key principle for upholding our rights.
- **Article 5: Equality and non-discrimination:** Certain variations of intersex realities are accompanied by specific health needs. With this in mind, it is imperative to note that intersex traits do not constitute physical impairments per se, although all intersex people face severe social impairments due to their physical attributes. Stigmatization on the grounds of non-conforming sex characteristics results in severe impairments being placed on intersex individuals by society. This stigmatization restricts our enjoyment of human rights and readily equates to the societal restrictions faced by those who experience long-term physical impairments. The issue of societal rationale is that surgical interventions and other medical treatment have been claimed to facilitate bonding between parent and child and to lessen stigmatisation, while having no direct medical benefit for the individual in question.
- **Article 7: Children with disabilities:** it is important to note the influence of early trauma, childhood surgeries, and hormone mismanagement on intersex individual's physical and mental health. **Issues of reproductive rights and forced fertility:** Many intersex individuals are denied their right to make decisions in regards to their reproductive organs. In the case of intersex individuals who have received a female assignment, any potential hope for fertility will result in medical interventions at a very young age in order to achieve this fertility. These interventions fail to consider the future intersex adults right to self- determination, the right of one´s identity and the right of bodily integrity. These interventions

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[14] Anne Fausto-Sterling (2000): Sexing the Body: Gender Politics and the Construction of Sexuality. New York: Basic Books.

disregard the child's right to bodily integrity according to the Convention on the Right of the Child, *Article 8, Article 24* and *Article 37*.

- **Article 8: Awareness raising:** Issues of being invisibilized and marginalized means that most intersex individuals or their parents have never heard of the existence of intersex variations before learning that they or their child possesses non-normative sex characteristics. *Article 8* of the Convention, therefore, addresses one of the foundations of intersex activism throughout the previous decades. Many of the human rights abuses taking place are escaping scrutiny because of an enforced code of silence that has dominated the medical field.
- **Article 12: Legal capacity:** As the majority of these non-essential interventions take place during childhood, many during the child´s first years, any indication of consent applies to parental consent only. Parental consent cannot replace the fully informed, free, unwavering, prior consent of the individuals themselves.[15] Many intersex people experience physical and emotional long-term impairments as a result of medical interventions that have been performed on them without their free, prior, personal, persistent and fully informed consent. This is not only applicable to the German context, but is also applicable in Europe and most places globally.
- **Article 13: Access to justice:** Issues of legal recognition and reparative justice means that due to the lack of legal recognition and to statutes of limitations it is impossible for most intersex individuals to seek legal recourse and to enjoy the right to equal recognition before the law and access to justice.
- **Article 15: Freedom from torture or cruel, inhuman or degrading treatment or punishment:** Many of the current medical protocols impair the intersex community on the basis of the ideology of the binary sex model. Few other communities have faced surgical intervention for the sole purpose of normalizing their bodies due to cosmetic and/or functional reasons. The recommendations of the United Nations Special Rapporteur on Torture[16] strongly link the human rights violations intersex people face to *Article 15*. At present, the Maltese *Gender Identity, Gender Expression,*

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[15] Research has indicated that medicalised information, serves to increase greatly, the probability of surgical interventions being chosen by prospective parents. Parents are often emotionally vulnerable and face pressure to collaborate in the medical professionals decision making without any previous psychosocial support (see: Jürg C. Streuli, Effy Vayena, Yvonne Cavicchia-Balmer & Johannes Huber (2013), Shaping parents: impact of contrasting professional counseling on parents' decision making for children with disorders of sex development, Journal of Sexual Medicine, Vol. 8 No. 3, pp. 1953–1960 http://www.ncbi.nlm.nih.gov/pubmed/23742202) and that medical professionals may be quick to propose „corrective" surgeries and treatments aiming to „normalise" the sex of the child even when such surgeries are unnecessary and merely cosmetic (see: Charlotte Greenfield (8/7/2014), Should We 'Fix' Intersex Children?, The Atlantic http://www.theatlantic.com/health/archive/2014/07/should-we-fix- intersex-children/373536/

[16] A /HRC/22/53 http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53_English.pdf

and Sex Characteristics Act[17] is the only law in the world to protect intersex individuals from such treatment.

- **Article 16: Freedom from exploitation, violence and abuse:** Multiple abusive and exploitative practices have characterized the medical treatment of intersex people ever since our population first caught the interest of the medical community. With a treatment model based on complete erasure, the prevalent teaching of secrecy ensured the continuation of the medical communities ability to act without legal and ethical supervision. Due to the intersex communities utter lack of visibility multiple abuses and acts of violence often go entirely unnoticed. In public, physical appearance read by members of the public as gender non-conforming can lead to threats and acts of physical violence. Freedom from exploitation, violence and abuse, as found in *Article 16* of the Convention, would infer upon the intersex community greater freedoms than our community has known up to this day.
- **Article 17: Protecting the integrity of the person:** Protecting the physical and mental integrity of individuals with sex characteristics that do not meet societal expectations of male or female in the sense of *Article 17* of the Convention is key to ensure the enjoyment of all human rights for intersex individuals. Intersex people have surgical genital interventions for cultural reasons which are, in their intentions and consequences, comparable with female genital mutilation (e.g. based on ideas of purity and esthetic appearance), leading to enduring pain due to scar tissue, partial or complete loss of sensation, long-term effects in the urinal system and severe emotional trauma. The aim in both cases is to align the individual's physical appearance to the societal and cultural expectations of how a female body should appear.
- **Article 22: Respect for Privacy:** Members of the intersex community report degrading medical photography and degrading exposure to medical students or staff. Additionally they face inquisitive and degrading questions about their diagnoses or physical features when visiting doctors for health issues not related to having an intersex body. Many intersex individuals have difficulty in obtaining their medical records, and when obtained they are often fragmented or contain derogatory language.
- **Article 25: Health:** Although intersex individuals are routinely subjected to normalizing treatment, including removal of gonads or hormonal therapy with the aim of aligning the physical features to the assigned sex, very little research has been conducted on the actual needs of intact[18] intersex bodies. At the same time intersex individuals who have been subjected to invasive treatment face multiple health issues as a consequence of this treatment that often are not adequately being taken care of by medical professionals. While keeping *Article 25* of the Convention in mind, a great deal of work needs to take place to ensure intersex people's health care is at a level comparable to the general population.

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[17] https://socialdialogue.gov.mt/en/Public_Consultations/MSDC/Documents/GIGESC/70%20-%202014%20-%20GIGESC%20-%20EN.pdf

[18] With intact we mean intersex people that have not been subjected to any sex-altering medical intervention

- **Article 31: Statistics and data collection.** There is very little independent data collection taking place outside the medical paradigm and comprehensive, independent studies are yet to be published. Misrepresentation of research data favoring these early surgical interventions has plagued the intersex community during the last century and has continued into the current century.[19] The collection of appropriate information, as addressed in *Article 31* of the Convention, independent statistical information on medical interventions and data collection on human rights issues is vitally important to our community in order to move towards a humane and ethical treatment paradigm. The German government was not able to provide any information on this topic ahead of their constructive dialogue with the CRPD Committee.

Concerns and recommendations for the way forward

The Convention of the Rights of People with Disabilities addresses many of the human rights violations intersex people face globally. However, we have some concerns, namely:

Interpretation of Article 25, para b: "*Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children and older persons.*"

Medical care today is based on the ideology that sex characteristics that do not comply with a pre-decided "normal" range in and of themselves constitute a health crisis. Intersex people therefore often face health care that focuses on one minute part of one´s physiology, with little care paid to issues of general health. However, if surgery for intersex variation is considered an "appropriate intervention" under *Article 25, para b*, this could prove devastating for intersex people in regards to ending genital surgeries and coercive sterilisation, as well as surgeries aiming to establish possible fertility, without the individual's personal, free and fully informed consent. If physical intersex traits in and of themselves were to be considered a long-term physical impairment, *Article 25, paragraph b* could in practice serve as a justification for the continuation of the current treatment paradigm.

Self-identification of intersex persons as persons with disabilities: In countries where one must apply for the status of disability, intersex people who have impairments due to surgical, hormonal and/or psychological impairments may already have the possibility to apply for and receive disability status. The inclusion of intersex, in general, within a definition of disability could reinforce the current rationale that treats non-normative sex

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[19] Arlene B Baratz, Ellen K. Feder. 2015. Misrepresentation of Evidence Favoring Early Normalizing Surgery for Atypical Sex Anatomies. Springer.com: DOI 10.1007/s10508-015-0529-x

characteristics as an issue that in and of themselves require treatment. Although some intersex bodies do face particular health issues that can require long-term medical attention (e.g. comparable to people with diabetes), the majority of treatments are only performed for cosmetic and societal reasons. Combating attitudinal barriers, discrimination and consequential psychosocial trauma as a result of human rights violations faced by intersex people are the key reasons for addressing intersex issues within the context of the Convention on the Rights of Persons with Disabilities.

However, in countries, where chronic disease is less stigmatized than being disabled, the inclusion of intersex as a disability could lead to even a higher level of marginalisation and stigmatisation. This could increase pressure on intersex individuals and their parents to agree to so called normalizing interventions to prevent the label of disability.

Lack of human rights for persons with disabilities: In countries that have not yet ratified the UN Convention on the Rights of Persons with Disabilities some intersex people who have impairments due to surgical, hormonal and/or psychosocial disabilities may already have the possibility to apply for and receive disability status. However, as the countries have yet to ratify the treaty, the rights of individuals with disabilities may not be upheld. In some countries, for example, identification as a person with a disability can decrease access to health care and essential hormonal medication. Increased stigma can cause adverse effects on an individual's family ties and social standing that in turn can lead to increased isolation and negative psychological impact. All of these are risks already faced by the intersex community but may be further compounded by identifying as a person with a disability.

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Additional Information

Use of the term DSD (Disorder/Differences of Sex Development)
Intersex traits face the classification of "Disorders of Sex Development" (DSD) within the medical community. This terminology originated within the medical community in 2006 and has been condemned by intersex organisations since its original use. The word intersex originated in the field of biology in 1901 and was claimed by intersex people when the medical communities' use of debasing language caused them immense psychological anguish and significantly distorted their self-perception. Many feel that this new medical terminology is no significant improvement and refuse to use or engage with the terminology.

Some use *difference* in sex development or *diverse* sex development. This is an attempt to reclaim the right to self-identify and alter persisting terminology found to compound further, feelings of being in some way inherently wrong or as the terminology states, disordered. In 2012 the Swiss National Bioethics Committee recommended that governments and other organisations use the term "intersex" and not use the term "disorders of sexual development" and encouraged health professionals and health organisations [to] review their use of the term „disorders of sexual development", seeking to confine it to appropriate clinical contexts, and should use the terms „intersex" or "differences of sexual development" where it is intended to encompass genetic or phenotypic variations that do not necessarily require medical intervention in order to prevent harm to physical health.[20]

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[20] Swiss Advisory Commission on Biomedical Ethics (2012): On the management of differences of sex development. Ethical issues relating to "intersexuality". Opinion No. 20/2012. Adopted by the Commission on 31 August 2012. Berne, November 2012.

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