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

HUMAN
RIGHTS FOR
HERMAPHRODITES
TOO!

NGO Report
for List of Issues Prior to Reporting (LoIPR)
for the 4th Periodic Report of Switzerland
on the International Covenant on Civil and Political
Rights (CCPR)
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Annexe: Medical Texts illustrating IGM
Intersex.ch is a Swiss intersex peer support group founded in 2005. The Verein SI Selbsthilfe Intersexualität is a Swiss peer support group for parents of intersex children founded in 2003.

Intersex Genital Mutilations and other human rights violations of persons with variations of sex anatomy are a special and emerging human rights issue, unfortunately still often neglected by human rights bodies concerned, mostly due to lack of access to comprehensive information. However, to assess the current practice at national level, it is crucial to gain some general knowledge of the most pressing human rights violations faced by intersex people in Switzerland as well as all over the “developed world.” Therefore, this NGO report also includes some summarised general information on intersex and IGMs. For further reference, the Rapporteurs would like to refer the Committee to the thematic Supplements “IGM – Historical Overview” and “The 17 Most Common Form of IGMs” included in our 2014 CRC NGO Report.

The Rapporteurs are aware that IGMs are a global issue, which can’t be solved on a national level alone. However, due to its pivotal role in internationally establishing systematic unnecessary intersex surgeries on children, Switzerland would be a most appropriate place to begin with.

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3 http://intersex.ch/
4 http://si-global.ch/
5 Supplement 1: “IGM – Historical Overview”, p. 49–62
   Supplement 2: “The 17 Most Common Forms of IGMs”, p. 48–76
available (for contradicting figures given by Swiss Cantonal, Federal Governments, as well as Clinics and doctors in Zurich, Luzern, Bern, Basel, St. Gallen, see Annexe 2 “Swiss Federal, Cantonal Government Clinics on IGMs (2009–2012)” in our 2014 CRC NGO Report, p. 43–47). Also, the definition of intersex is often arbitrarily changed by doctors and government agencies in order to get favourable (i.e. lower) figures. Therefore, all available numbers are mere estimates and extrapolations. Intersex persons and their organisations have been calling for **independent data collection and monitoring** for some time, however to no avail.

An often quoted number is 1:2000 newborns, however this obviously disregards variations of sex anatomy at risk of “masculinising corrections” (hypospadias). In medical literature, often two different sets of numbers and definitions are given depending on the objective:

a) **1:1000** if it’s about getting access to new patients for paediatric genital surgery, and

b) 1:4500 or less if it’s about countering public concerns regarding human rights violations, often only focusing on “severe cases” while refusing to give total numbers. On the other hand, researchers with an interest in criticising the gender binary often give numbers of up to “as high as 2%”.

However, from a **human rights perspective**, the crucial question remains: How many children are at risk of human rights violations, e.g. by non-consensual, medically unnecessary, irreversible, cosmetic genital surgeries or other similar treatments justified by a psychosocial indication? Here, the best known relevant number is **1:500 – 1:1000 children are submitted to (often repeated) non-consensual “genital corrections”**.

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9 Rainer Finke, Sven-Olaf Höhne (eds.) (2008), Intersexualität bei Kindern, Preface, at 4

10 e.g. “fewer than 2 out of every 10,000 births”, Leonard Sax (2002), How common is intersex? a response to Anne Fausto-Sterling, The Journal of Sex Research 39(3):174-178, at 178


12 Intersex Society of North America (ISNA), How common is intersex?, [http://www.isna.org/faq/frequency](http://www.isna.org/faq/frequency)
Genital surgery is not necessary for gender assignment, and **atypical genitals are not in themselves a health issue**. There are only very few situations where some surgery is necessary for medical reasons, such as to create an opening for urine to exit the body.

In addition to the usual risks of anaesthesia and surgery in infancy, IGMs carry a **large number of known risks of physical and psychological harm**, including loss or impairment of sexual sensation, poorer sexual function, painful scarring, painful intercourse, incontinence, problems with passing urine (e.g. due to urethral stenosis after surgery), increased sexual anxieties, problems with desire, less sexual activity, dissatisfaction with functional and aesthetic results, lifelong trauma and mental suffering, elevated rates of self-harming behaviour and suicidal tendencies comparable to those among women who have experienced physical or (child) sexual abuse, impairment or loss of reproductive capabilities, lifelong dependency on daily doses of artificial hormones.

**2. Most Frequent Surgical and Other Harmful Medical Interventions**

Due to space limitations, the following paragraphs summarise the most frequent and egregious forms only. **The injuries suffered by intersex people have not yet been adequately documented.** For a more comprehensive list and sources, see our 2014 CRC NGO Report, p. 63-76.

**a) Clitoris Amputation/“Reduction”, “Vaginoplasty”, Forced Vaginal Dilatation**

“I can still remember, how it once felt differently between my legs.”

In 19th Century Western Medicine, clitoris amputations a.k.a. **“clitoridectomies”** on girls were prevalent as a “cure” for a) masturbation, b) hysteria, and c) “enlarged clitoris.” While amputations motivated by a) and b) attracted mounting criticism within the medical community and were mostly abandoned between 1900 and 1945, **amputations of “enlarged clitoris” took a sharp rise after 1950**, and in the 1960s became the predominant

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27 ibid., at 3
30 Heinz-Jürgen Voß (2012), Intersexualität – Intersex. Eine Intervention, at 50–65
31 Rare examples of publications documenting and reviewing reports by persons concerned include:
- Katrina Karkazis (2008), Fixing Sex: Intersex, Medical Authority, and Lived Experience
- Kathrin Zehnder (2010), Zwitter beim Namen nennen. Intersexualität zwischen Pathologie, Selbstbestimmung und leiblicher Erfahrung
my such that the penis looks normal." The current AWMF guidelines with Swiss participation explicitly include "aesthetical-psychological reasons".

Hypospadias "repair" is notorious for high complication rates of 50% and more, as well as causing serious medical problems where none had been before (e.g. urethral strictures leading to kidney failure requiring dialysis), and frequent "redo-surgeries". Tellingly, for more than 30 years, surgeons have been officially referring to "hopeless" cases of repeat failed "repair" surgeries as "hypospadias cripples" (i.e. made to a "cripple" by unnecessary surgeries, not by the condition!), while in medical publications on hypospadias, "[d]ocumentation on complication rates has declined in the last 10 years".

For more than 15 years, persons concerned have been criticising impairment or loss of sexual sensitivity (Case No. 1). However, doctors still refuse to even consider these claims, let alone promote appropriate, disinterested long-term outcome studies.

Switzerland was leading in introducing hypospadias surgeries in German language European countries after World War II. Since the "2nd Hypospadias Boom" in the 1990s, hypospadias "repair" is arguably by far the most frequent cosmetic genital surgery done on children with variations of sex anatomy also in Switzerland. In Swiss University Children's Hospitals, systematic hypospadias "repair" within the first 18 months of life is still considered imperative for children concerned and raised as boys (Cases No. 1 and 6).

c) Castrations / "Gonadectomies" / Hysterectomies / (Secondary) Sterilisation

"At 2 1/2 months they castrated me, and threw my healthy testicles in the garbage bin."

Intersex children are frequently subjected to treatments that terminate or permanently reduce their reproductive capacity. While some intersex people are born infertile, and some retain their fertility after medical treatment, many undergo early removal of viable (and hormone producing) gonads (e.g. testes, ovaries, ovotestes) or other reproductive organs (e.g. uterus), leaving them with "permanent, irreversible infertility and severe mental suffering". When unnecessary sterilising procedures are imposed on children e.g. to address a low or hypothetical risk of cancer, the fertility of intersex people is not being valued as highly as that of non-intersex people. What's more, also in Switzerland, persons concerned often have to pay themselves for adequate Replacement Hormones. Even some doctors have been criticising unnecessary intersex gonadectomies for decades, e.g. renowned


E.g. Ernst Bilke, born 1958 in South Germany, was sent to Basel for paediatric hypospadias "repair", because the local German doctors refused to do it, wanting to make him into a girl instead, see Ulla Fröhling (2003), Leben zwischen den Geschlechtern, at 90–105


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e) Other Unnecessary and Harmful Medical Interventions and Treatments

"The assistant called in some colleagues to inspect and to touch my genitals as well." 55

Other harmful treatments include Forced Mastectomy,54 Imposition of Hormones,55 Forced Excessive Genital Exams, Medical Display and (Genital) Photography,56 Human Experimentation,57 Denial of Needed Health Care,58 Prenatal "Therapy",59 Selective (Late Term) Abortion,60 Preimplantation Genetic Diagnosis (PGD) to Eliminate Intersex Fetuses.61

3. How Common are Intersex Genital Mutations?

Same as with intersex births (see above), Swiss Hospitals, Government Agencies and Health Assurances, as well as the Swiss federal invalidity assurance (Invalidenversicherung IV) covering intersex surgeries on children until the age of 20, refuse to disclose statistics and costs, as well as ignoring repeated calls for independent data collection and monitoring.

What’s more, Swiss doctors, government and other institutions involved in IGMs, if questioned about statistics, are notorious for going to extreme lengths following internationally established patterns of a) disclosing only tiniest fractions of actual treatments, often arbitrarily changing definitions of intersex and variations of sex anatomies in order to justify favourable (i.e. lower) figures (Swiss Federal Government, Zurich, Luzern, Basel,62 or b) flatly denying any occurrence or knowledge of IGMs, while at the same time the same doctors and hospitals, including such under the auspices of said departments, are continuing to publicly promote and perform IGM (Bern).63 Or, in the rare cases of studies actually “disclosing” numbers, yet another related tactic involves c) manipulation of statistics, e.g. the world’s largest outcome study on 439 participants, with Swiss participation, the 2008 “Netzwerk DSD” intersex study, in official publications only gave an overall total figure of “almost 81% of all participants had at least once surgery […] most of them before entering school.”64

64 Eva Kleinemeyer, Martina Jürgensen (2008), Erste Ergebnisse der Klinischen Evaluationsstudie
ing doctors publicly admit surgeries taking place. The University Children’s Hospital of Basel (UKBB) claims annually about 22 children born with variations of sex anatomy in the region, while only admitting to 1 genital surgery on intersex children “in the more strict definition” every 5 years. And the Eastern Switzerland Children’s Hospital claims “less than one clitoral reduction plastic surgery annually (using the nerve-sparing method),” again without disclosure of other cosmetic genital surgeries. Conclusion, while all listed parties closely follow the established patterns of non-disclosure and denial, their differing claims don’t add up by far.

What’s more, though for Switzerland officially no current figures are available, internationally the total number of cosmetic genital surgeries performed on intersex children evidently is still rising.

4. Lack of Disinterested Review, Analysis, Outcome Studies and Research

Persons concerned and their organisations have stressed for almost two decades “the unrelatability of research conducted in the setting where the harm was done”, and stressed the imminent need for disinterested research and analysis

Currently, millions of Euros are spent on “intersex research projects” involving Swiss funding and/or participation, as well as Swiss Federal Government representation. “DSD-Life” and “DSDnet”, two current examples, are conducted by the perpetrators themselves, e.g. in “DSDnet” paediatric endocrinologists, and in “DSD-Life” paediatric endocrinologists and paediatric surgeons taking the lead – exactly the professional groups responsible for IGMS in the first place. If other disciplines are included at all in the multi...

73 e.g. “The UK National Health Services Hospital Episode Statistics in fact shows an increase in the number of operations on the clitoris in under-14s since 2006”, Sarah M. Creighton, Lina Michala, Imran Mushtaq, Michal Yaron (2014), Childhood surgery for ambiguous genitalia: glimpses of practice changes or more of the same?, Psychology & Sexuality 5(1):34-43, at 38
74 e.g. Italy: “Boom in Surgeries on Children with ‘Indeterminate’ Sex, in Rome 50% Increase during the Last 5 Years, 25% Increase on National Level”, according to Aldo Morrone, Director General of the Ospedale San Camillo-Forlanini di Roma, quoted in: “Boom di bimbi con sesso ‘incerto’, a Roma un aumento del 50 per cento”, leggo.it 20.06.2013, http://www.leggo.it/NEWS/ITALIA/boom_di_bimbi_con_sesso_quot_incerto_quot_a_roma_aumentano_del_50_per_centо/notizie/294638.shtml
77 e.g. “DSDnet”: Bern, Lausanne, http://www.cost.eu/domains_actions/bmbs/Actions/BM1303management
78 http://www.cost.eu/about_cost/who/%28type%29/5/%28wid%29/1438
79 http://www.cost.eu/domains_actions/bmbs/Actions/BM1303management
80 http://www.dsd-life.eu/the-group/consortium/, for a more accessible graphic overview of the consortium see: http://stop.genitalmutilation.org/post/IGM-Primer-2-The-Global-Cartel
D. The Treatment of Intersex Persons in Switzerland as a Violation of International Law

1. Switzerland's Commitment to the Protection of the Rights of Intersex People

By ratifying the International Covenant on Civil and Political Rights (CCPR), Switzerland has committed itself to ensuring that no child within its jurisdiction is subject to torture and other cruel, inhuman or degrading treatment or punishment (CIDT), nor to other human rights violations specified in the convention. In addition, Switzerland has ratified the Convention against Torture (CAT), and the European Convention on Human Rights (ECHR), which both prohibit CIDT, as well as the Convention on the Rights of the Child (CRC) containing a similar clause prohibiting CIDT, as well as stressing the best interest of the child and the right of children to be heard. Last but not least, the Swiss Federal Constitution (SFC) ensures the right to life and personal freedom, particularly the right to physical and mental integrity, and explicitly prohibits CIDT (Article 10), emphasises the right of special protection of the integrity of children and young people (Art. 11), as well as ensuring the respect for, and the protection of, their dignity (Art. 7), and ensuring equality and non-discrimination (Art. 8).

2. Intersex People denouncing IGMs as Human Rights Violations

"Genital mutilation of intersex children damages genital sensitivity in irreversible ways; it causes postsurgical trauma, and the internalization of brutal prejudices denying or stigmatizing the diversity that in reality human bodies show. [...] The difference in genitalia cannot justify, under any pretext whatsoever, ethical and political hierarchies: cannot justify mutilation, because it never normalizes but does the opposite. For us, mutilation creates a permanent status of human rights violation and inhumanity."

Mauro Cabral, CESC NGO Statement 2004

For 21 years now, intersex people from all over the world, and their organisations have been publicly denouncing IGMs as destructive of sexual sensation, and as a violation of basic human rights, notably the right to physical integrity. For 18 years, they have lobbied for legislation against IGMs to end the impunity of perpetrators due to statutes of limitation. For 17 years, they have been invoking the UN Conventions to fight IGMs, and for 10 years they have been reporting IGM to the UN as a human rights violation.

In Switzerland, like in every intersex community, meanwhile several generations of intersex persons, their partners and families, as well as NGOs and other human rights and bioethics experts, have again and again described IGM as a human rights issue, as harmful and

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84 http://www.admin.ch/ch/e/rs/1/101.en.pdf
While some states, e.g. South Africa\textsuperscript{98} and Australia,\textsuperscript{99} included “intersex status” in anti-discrimination legislation, Switzerland still fails to enact similar legislation to ensure its obligations under the CCPR.

**Article 7: Prohibition of Torture**

The Special Rapporteur on Torture (SRT)\textsuperscript{100} and the Committee against Torture (CAT)\textsuperscript{101} already recognise IGMs as serious human rights violations constituting Cruel, Inhuman or Degrading Treatment (CIDT), or even torture. IGMs clearly violate Article 7 CCPR, as well as General Comment 20 stressing that the purpose of Article 7 is “to protect both the dignity and the physical and mental integrity of the individual”, and noting that this includes mental suffering as well as physical pain, both inflicted by IGMs, and further maintaining that “it is the duty of the State Party to afford everyone protection through legislative and other measures as may be necessary against the acts prohibited by article 7, whether inflicted by people acting in their official capacity, outside their official capacity or in a private capacity.”

**Article 27: Rights of Minorities**

During the Middle Ages and up to 1900, the existence of hermaphrodites in society, and of Intersex as a natural variation, was common knowledge, in humans as well as in (farm) animals, and hermaphrodites were not only quite rightly integrated in the social fabric, but also recognised and protected both by the Canon Law of the Church and Civil Right Codes, that included specific “Hermaphrodite Articles”, granting them the privilege of choosing their legal sex before reaching adulthood (“Sex Oath”), possibly overthrowing the earlier decision granted to their parents. Thus, unlike today, the intersex people were allowed to decide themselves whether to live (and to be able to marry) as males or females.\textsuperscript{102} Only after abolishing these “Hermaphrodite Articles” during the Modern Age due to the medical takeover of their right to self determination by the emerging modern medicine,\textsuperscript{103} and followed by systematic early “genital corrections” of all intersex newborns after 1950,\textsuperscript{104} intersex people as a distinct biological and social minority group all but vanished from western societies. Thus, IGMs also represent a violation of the commitment to protection of minorities according to Article 27 CCPR.

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2006: UN WHO, Genomic resource centre, Gender and Genetics: Genetic Components of Sex and Gender (online)

Gender Assignment of Intersex Infants and Children

Intersex is defined as a congenital anomaly of the reproductive and sexual system. An estimate about the birth prevalence of intersex is difficult to make because there are no concrete parameters to the definition of intersex. The Intersex Initiative, a North-American based organization, estimates that one in 2,000 children, or five children per day in the United States, are born visibly intersex. (36) This estimate sits within range; from genital anomalies, such as hypospadias, with a birth prevalence of around 1:300 to complex genital anomalies in which sex assignment is difficult, with a birth prevalence of about 1:4500. (37) Many intersex children have undergone medical intervention for health reasons as well as for sociological and ideological reasons. An important consideration with respect to sex assignment is the ethics of surgically altering the genitalia of intersex children to “normalize” them.

Clitoral surgery for intersex conditions was promoted by Hugh Hampton Young in the United States in the late 1930s. Subsequently, a standardized intersex management strategy was developed by psychologists at Johns Hopkins University (USA) based on the idea that infants are gender neutral at birth. (38) Minto et al. note that “the theory of psychosexual neutrality at birth has now been replaced by a model of complex interaction between prenatal and postnatal factors that lead to the development of gender and, later, sexual identity”. (39) However, currently in the United States and many Western European countries, the most likely clinical recommendation to the parents of intersex infants is to raise them as females, often involving surgery to feminize the appearance of the genitalia. (40)

Minto et al. conducted a study aiming to assess the effects of feminizing intersex surgery on adult sexual function in individuals with ambiguous genitalia. As part of this study, they noted a number of ethical issues in relation to this surgery, including that:

• there is no evidence that feminizing genital surgery leads to improved psychosocial outcomes;

• feminizing genital surgery cannot guarantee that adult gender identity will develop as female; and that

• adult sexual function might be altered by removal of clitoral or phallic tissue. (41)

2009: UN CEDAW, CEDAW/C/DEU/CO/6, 10 February 2009, para 61–62:
http://www2.ohchr.org/english/bodies/cedaw/docs/CO/CEDAW-C-DEU-CO6.pdf

Cooperation with non-governmental organizations

61. [...] The Committee regrets, however, that the call for dialogue by non-governmental organizations of intersexual [...] people has not been favourably entertained by the State party.

62. The Committee requests the State party to enter into dialogue with non-governmental organizations of intersexual [...] people in order to better understand their claims and to take effective action to protect their human rights.

Follow-up to concluding observations

67. The Committee requests the State party to provide, within two years, written information on the steps undertaken to implement the recommendations contained in paragraphs 40 and 62.

2011: UNHCHR, A/HRC/19/41, 17 November 2011, para 57:

“In addition, intersex children, who are born with atypical sex characteristics, are often subjected to discrimination and medically unnecessary surgery, performed without their informed consent, or that of their parents, in an attempt to fix their sex.”

2011: UN CAT, CAT/C/DEU/CO/5, 12 December 2011, para 20:
http://www2.ohchr.org/english/bodies/cat/docs/CO/CAT.C. DEU.CO.5_en.pdf

Intersex people

20. The Committee takes note of the information received during the dialogue that the Ethical Council has undertaken to review the reported practices of routine surgical alterations in children born with sexual organs that are not read-
7.2. initiate focused awareness-raising measures for each of these categories of violation of the physical integrity of children, to be carried out in the specific contexts where information may best be conveyed to families, such as the medical sector (hospitals and individual practitioners), schools, religious communities or service providers; [...] 
7.4. initiate a public debate, including intercultural and interreligious dialogue, aimed at reaching a large consensus on the rights of children to protection against violations of their physical integrity according to human rights standards; 
7.5. take the following measures with regard to specific categories of violation of children’s physical integrity: [...] 
7.5.3. 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; [...] 
7.7. raise awareness about the need to ensure the participation of children in decisions concerning their physical integrity wherever appropriate and possible, and to adopt specific legal provisions to ensure that certain operations and practices will not be carried out before a child is old enough to be consulted.

2014: UN CRPD, CRPD/C/DEU/Q/1, 17 April 2014, paras 12–13:
http://tbinternet.ohchr.org/Treaties/CRPD/Shared%20Documents/DEU/CRPD_C.DEU_Q_1_17084_E.doc

Freedom from exploitation, violence and abuse (art. 16)

12. How many irreversible surgical procedures have been undertaken on intersexual children before an age at which they are able to provide informed consent? Does the State party plan to stop this practice? 
13. Please provide up to date statistics on forced sterilizations of persons, i.e. without their free and informed consent.

2014: OHCHR, UN Women, UNAIDS, UNDP, UNFPA, UNICEF and WHO, Eliminating forced, coercive and otherwise involuntary sterilization. An interagency statement, May 2014, paras 2, 6, 7: 
http://www.who.int/iris/bitstream/10665/112848/1/9789241507325_english.pdf?ua=1

Background

Some groups, such as [...] intersex persons, also have a long history of discrimination and abuse related to sterilization, which continues to this day. [...] Intersex persons, in particular, have been subjected to cosmetic and other non-medically necessary surgery in infancy, leading to sterility, without informed consent of either the person in question or their parents or guardians. Such practices have also been recognized as human rights violations by international human rights bodies and national courts (15, 64).

[...] Intersex persons

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 (64, 147, para 57, 148, 149). As a result, such children are being subjected to irreversible interventions that have lifelong consequence for their physical and mental health (64, 150, para 20, 151).

Medical procedures that might result in sterility may sometimes be justified because of benefits to health, including the reduction of cancer risk (152). Such treatments may be recommended for [...] intersex persons; however, they may be proposed on the basis of weak evidence, without discussing alternative solutions that would retain the ability to procreate (151, 153–157). Parents often consent to surgery on behalf of their intersex children, including in circumstances where full information is lacking (151, 156, 159).

It has been recommended by human rights bodies, professional organizations and ethical bodies that full, free and informed consent should be ensured in connection with medical and surgical treatments for intersex persons (64, 150) and, if possible, irreversible invasive medical interventions should be postponed until a child is sufficiently mature to make an informed decision, so that they can participate in decision-making and give full, free and informed consent (15, 149). It has also been recommended that health-care professionals should be educated and trained about bodily diversity as well
4. NGO, NHRI Reports on Human Rights Violations of Intersex Children

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2008: CEDAW Germany, Intersexuelle Menschen e.V./XY-Frauen

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2013: UPR Germany, German Institute for Human Rights (GIHR), para 23
- German CRPD ALLIANCE, para 15
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- National Coalition for the Implementation of the UN Convention on the Rights of the Child in Germany (NC), para 4
http://lib.ohchr.org/HRBodies/UPR/Documents/Session16/DE/js5_upr_deu_s16_2013_jointsubmission5_e.pdf
- Forum Menschenrechte, paras 38, 39, 58
http://lib.ohchr.org/HRBodies/UPR/Documents/Session16/DE/js6_upr_deu_s16_2013_jointsubmission6_e.pdf

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