HEINRICH BÖLL STIFTUNG
DEMOCRACY

VOLUME 34

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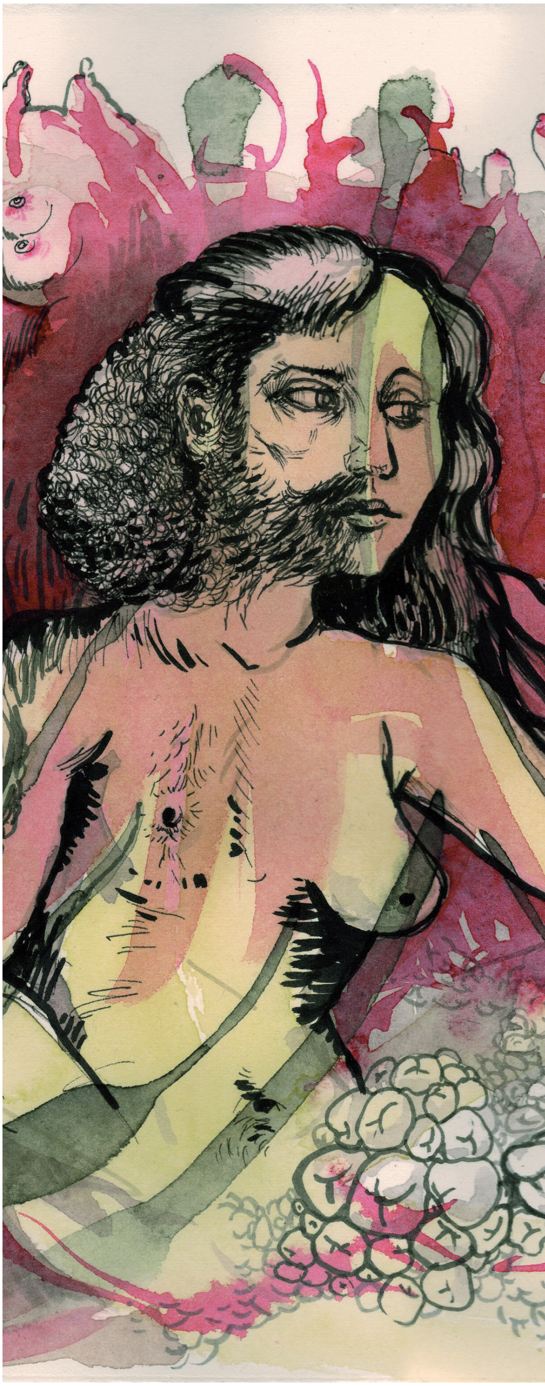
A preliminary study on the life situations of inter* individuals

By **Dan Christian Ghattas**



HUMAN RIGHTS BETWEEN THE SEXES

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By Dan Christian Ghattas

Edited by the Heinrich Böll Foundation

About the Author

Dr. Dan Christian Ghattas works as a university lecturer and cultural scientist. He is an expert on the issues trans and intersex, inter alia, for the «Expert Round Table on Gender Mainstreaming» (2010), the «Training for ILGA-Europe and ILGA World Staff and Board on Inter*» (2011), the «First, Second, Third International Intersex Forum» (2011, 2012, 2013) and the «Seminar on Trans and Intersex Issues – Challenges for EU Law» (a hearing before the European Parliament, 2012). He compiled the first empirical study on the life situations of transsexual individuals in Germany called «Studie zur Lebenssituation von Transsexuellen in Nordrhein-Westfalen» (2012), in collaboration with Wiebke Fuchs, Deborah Reinert and Charlotte Widmann). He is co-editor of the book «Inter*: Erfahrungen intergeschlechtlicher Menschen in der Welt der zwei Geschlechter» that was published by NoNo-Verlag in 2013.

Human Rights between the Sexes
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By Dan Christian Ghattas
Edited by the Heinrich Böll Foundation
Volume 34 of the Publication Series on Democracy
Translation: Adrian de Silva
Title photo: Ins A Kromminga (painting detail; © Ins A Kromminga)

Design: feinkost Designnetzwerk, Sebastian Langer (predesigned by blotto design)
Printing: Lokay, Reinheim
ISBN 978-3-86928-107-0

This publication can be ordered from: Heinrich-Böll-Stiftung, Schumannstr. 8, 10117 Berlin
T +49 30 28534-0 **F** +49 30 28534-109 **E** buchversand@boell.de **W** www.boell.de

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PREFACE

Intersex individuals are people who cannot be classified according to the medical norms of so-called male and female bodies with regard to their chromosomal, gonadal or anatomical sex. Inter* individuals are still pathologised and classified as «sick» or «abnormal». As early as in infancy, by means of surgical interventions, they are frequently assigned to the male or female sex/gender in the Western world. However, there is no medical necessity to do so, since intersex individuals are, for the most part, absolutely healthy. Medical treatment mostly takes place without the consent of inter* individuals, especially when it is carried out in the early years of their lives. Frequently, they seriously suffer from the psychic and physical effects of medical interventions. They are, for the most part, denied the development of a gender identity of their own, which may be located between the socially dominant bipolar sex/gender model of male or female.

Inter* individuals encounter legal obstacles in many countries when registering their sex/gender for a critically important birth certificate, which needs to be acquired a few weeks after birth. In Germany, it is only with a birth certificate that, for example, parental pay can be applied for, health insurance coverage can be granted, separate fatherhood can be recognised and a childcare place can be reserved. The pressure on parents to have their child surgically assigned to an «unambiguous» sex at an early age is high.

Inter* individuals are socially barely visible worldwide, since intersex is still a strong taboo. For fear of stigmatisation and social exclusion, many inter* individuals do not come out. If it becomes known, in rare cases, they are not only exposed to verbal and structural discrimination, but also experience physical violence and life-threatening situations. In Uganda, for instance, intersex infants are severely jeopardised, since the mother risks being excluded from the community upon discovery of having given birth to an intersex infant. There is strong evidence that mothers kill their intersex babies in order not to be cast out.

With the present study on the state of discrimination of inter* individuals in 12 selected countries, the Heinrich Böll Foundation wishes to call attention to these violations of human rights against intersex individuals. Over the past years, awareness of human rights protection for individuals with a non-compliant sexual orientation and gender identity has increased significantly internationally and has, from time to time, led to actual improvement. Lesbians, gay men and, in part, trans* individuals have benefited from this development. Discrimination against inter* individuals has to this day mostly remained invisible.

Current human rights instruments and programmes directed towards lesbian, gay, bisexual, trans* and inter* (LGBTI) individuals aim to use the term «gender identity» inclusively. However, the actual conceptual realisation in, for example, concrete projects varies. For the most part, trans* and inter* individuals are only rhetorically included into the concept of sexual orientation and gender identity (SOGI) without their circumstances being substantially reflected upon or addressed. And if gender identity is defined conceptually, it is mainly trans* issues that can be found. The concerns as well as physical and gender diversity of inter* individuals are marginalised, if not invisible, even in the concept of gender identity – a conceptual void that is also mirrored in the absence of funding.

With this study, the Heinrich Böll Foundation would like to counteract this gap. It names the largely invisible discrimination against intersex individuals and, in doing so, brings it to light. We offer a first overview of the life situations of intersex individuals from 12 selected countries in various regions of the world. The study provides points of departure for strategies to improve the human rights situation of intersex individuals and recommends to actors how to develop measures in this area in order to render visible gender diversity as a means of enhancing human rights protection.

Our stated aim was – and is – that inter* individuals may describe their situations and their needs themselves. The challenges that we had to deal with when collecting the data presented here once more confirmed how hidden, risky and precarious inter* individuals are, in part, forced to live and how few come out as intersex. Therefore, we most sincerely thank Dr Dan Christian Ghattas for his persevering commitment when collecting the data and drafting the study. Moreover, we would particularly like to thank all inter* activists involved who shared their experiences with us and, as a result, render the study so valuable. We truly hope that international actors working on human rights, LGBTI rights, health, education and other issues will pick up on the findings. In collaboration with inter* individuals, they are intended to prompt an improvement in their situations. We consider the present publication a preliminary study. Its scope can be broadened by using concrete contextual analyses of individual countries. However, it can already assist with the exploration of practical projects at this point, without any further research being needed.

Berlin, September 2013

Barbara Unmüßig	Jana Mittag
President	*Head of Democracy Promotion and Human Rights*
Heinrich Böll Foundation	*Heinrich Böll Foundation*

ACKNOWLEDGEMENTS

I would like to express my gratitude to the Heinrich Böll Foundation for being willing to address the life situations of inter* individuals and the human rights breaches they are subjected to worldwide in a study. I would particularly like to thank Jana Mittag for excellent collaboration and her dedicated support when I encountered difficulties with the data collection, given the invisibility of inter* individuals.

The study would not have been possible without the unconditional support of the responding NGOs and activists. I would like to thank them for investing their scarce time to complete the questionnaire and for readily providing information when I approached them for further enquiries. Some of the activists work in countries where they are at great risk due to their commitment to the human rights of LGBTI. All of these activists gave me their contact data and provided internal information about their organisations, and I am very grateful for this confidence. I thank the NGOs and activists who do not work on inter* issues themselves for supporting the research.

I would like to express my sincere thanks to Dr Ulrike Klöppel for counterchecking the questionnaire and the study as well as for very useful comments.

Dan Christian Ghattas

0. Definition of inter*, intersex

Intersex individuals are persons who cannot be classified according to the medical norms of so-called male and female bodies with regard to their chromosomal, gonadal or anatomical sex. The latter becomes evident, for example, in secondary sex characteristics such as muscle mass, hair distribution and stature, or primary sex characteristics such as the inner and outer genitalia and/or the chromosomal and hormonal structure.

The current medical term Disorders of Sex Development (DSD), which was established as an umbrella term for several «syndromes» in 2006,[1] suggests that some variations of human bodies are more «normal» and desirable than others. From this perspective, bodies that do not comply with these norms are considered «atypical» or «disordered». Based on this assumption, allegedly wrongly developed genitalia are surgically «corrected» as early as in infancy and babyhood, depending on the supposed «deficiency» that was discovered, and changed using hormone therapy later on. The indication for surgical and hormonal «rectification» is not based on a medical necessity due to a life-threatening situation. Rather, it is an attempted «preventive psycho-sexual normalisation».[2] From the point of view of intersex activists, such an approach does not comply with human rights.[3] Further problem areas arise from the legal situation of intersex individuals. Their gender is legally and administratively non-existent due to the worldwide dominance of the gender binary. This codified invisibility is supplemented by invisibility in everyday life, the taboo on intersex and the experience of discrimination and violence.

The term *inter** is an umbrella term that was developed in the German intersex community. As an emancipatory and identitarian umbrella term, it denotes the diversity of intersex realities and bodies. It is used in the title of the study and in the questionnaire in order to approximate different international (self-) designations and the scope of experiences and cultural backgrounds with a preferably broad term. Meanwhile, inter* has become known in international intersex human rights activism and is, in part, used as a term. The term is prevalent in intersex human rights discourse outside Europe.

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[1] Cf. P. A. Lee et al., «Consensus Statement on Management of Disorders», Pediatrics 118:2 (2006): e488500. http://pediatrics.aappublications.org/cgi/reprint/118/2/e488 (accessed June 30, 2013).

[2] Cf. Ulrike Klöppel, *XX0XY ungelöst. Hermaphroditismus, Sex und Gender in der deutschen Medizin. Eine historische Studie zur Sexualität* (Bielefeld: 2010), transcript, p. 110.

[3] Cf., for instance, the press release of the Second International Intersex Forum (Stockholm, December 911, 2012); cf. the English version: http://www.ilga-europe.org/home/news/for_media/media_releases/_forum_2012_media_release (accessed June 30, 2012); cf. the German translation: http://www.ualite.de/index.php/2-internationales--forum-stockholm/ (accessed on June 30, 2013).

1. The aim and time frame of the preliminary study

While human rights protection for individuals with non-compliant sexual orientations and gender identities (SOGI) has gained more attention internationally over the past years, which has led to actual improvements, discrimination against intersex individuals has mostly remained invisible to this day.

1.1 The aim of the preliminary study

The aim of the study is to specify – and shed light upon – the largely invisible discrimination against intersex individuals. To this end, a survey with questionnaires was conducted that aimed at gaining an initial overview of life situations of intersex individuals in selected countries and regions of the world. The survey focussed on medical interventions, health care, legal and social (in)visibility, and experiences of discrimination in social life.

The results offer initial indications for strategies to improve the human rights situation of intersex individuals as well as initial recommendations for developing strategies and measures for the Heinrich Böll Foundation and other actors. Moreover, initial knowledge was gained on the specific conditions that the responding activists are exposed to when performing their work, and contact with potential local co-operation partners working on intersex from a depathologising human rights-oriented perspective were made.

1.2 The time frame of the study

The study was conducted from August 1, 2012, to December 31, 2012. The by far largest part of this time period was spent collecting data (September-December, cf. section 2.3, Problems with the data collection); the evaluation was carried out in parallel.

2. Methodology

Methodologically, the study followed an approach that gives the subjects control, that is, an approach that aims at letting the subjects – whose experiences are the subject matter of the examination – participate in the conceptualisation, realisation, evaluation and publication, thereby allowing their specific knowledge-flow into the research, following the principle that research must be useful or meaningful to them.

2.1 The target group of the questionnaire and the response rate

One hundred and three organisations and individuals were contacted in 24 countries of the global South and East as well as Europe.[4] Personal contacts, non-governmental organisations (NGOs) and offices of the Heinrich Böll Foundation were contacted, and they were all asked for further contacts relating to intersex activists, intersex organisations and NGOs with potentially relevant contacts.

NGOs that were not known to be working on the issue of intersex were also contacted if they were working on discrimination on the basis of gender, sexual identity and physical condition. Among these were, for example, lesbian, gay, bisexual and trans* (LGBT) organisations and NGOs in the areas of women's rights and HIV prevention/care.[5]

Apart from organisations from countries in the global South and East (including Eastern Europe), several Inter* NGOs from Western European and other so-called Western countries were approached. The reason for this was that the situation of intersex individuals by no means complies with human rights. Western actors need to consider this at all times when collaborating in an international context.

Sixteen questionnaires were returned from 12 countries (Australia, Belgium, Germany, France, New Zealand, Serbia, South Africa, Taiwan, Turkey, Uganda, Ukraine and Uruguay). The feedback of the responding NGOs and activists on the realisation of the study and its methodical approach was extremely positive. All of them agreed to further collaboration under such circumstances.

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[4] Uganda, Namibia, South Africa, Kyrgyzstan, Croatia, Poland, Russia, Serbia, Ukraine, Hungary, Turkey, Lebanon, Taiwan, India, Argentina, Chile, Paraguay, Uruguay, Australia, New Zealand, Sweden, Germany, Belgium, France.

[5] In particular LGBT organisations have become sensitised to human rights concerns of intersex individuals due to their work in the past years. Notably in Eastern Europe and in part in South America, too, it is especially LGBT organisations that have campaigned intensively for the rights of trans* individuals, support intersex individuals and enquire with human rights-based inter* organisations in order to elaborate on corresponding work programmes.

2.2 The questionnaire and the evaluation

General remarks

The questionnaire consists of two parts. The first one enquires into medical practices and procedures, the legal situation and everyday life. The second part examines the working conditions and organisational structure of the NGOs and activists, their financial resources and, in particular, their fields of work, projects and needs. When ambiguities arose, the questionnaires were supplemented by e-mail and Skype interviews as well as face-to-face interviews, for example during the Second International Intersex Forum (Dec. 9-11, 2012, Stockholm) and the ILGA World Conference (Dec. 12-16, 2012, Stockholm).

Previous information led to the conclusion that activism in the area of intersex predominantly takes place voluntarily worldwide or is performed in rather precarious funding relationships. Therefore, the questionnaire was brief in order to increase chances of a response. Since the questionnaire was designed as a qualitative survey, it provided an opportunity to comment extensively, especially on all questions related to the respective life situations. Hence, the interviewees were able to explain country-specific circumstances and, if necessary, mark as unsuitable questions that did not apply to their context.

The first part of the questionnaire: Life situations of intersex individuals

- Medical practices and procedures:
  The respondents were asked whether, to their knowledge, the most common medical interventions (cosmetic genital surgery, removal of the gonads, hormone therapy) occur in the respective country in cases where DSD is diagnosed, and if so, at which age.[6] Moreover, it was asked whether health insurances pay for these interventions, how many individuals are covered by a sickness insurance scheme

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[6] The questionnaire differentiated between «babies», «children», «teens» and «adults». In everyday use and lexically, these terms cover slightly different periods in different cultures. In English everyday use, the term «baby» covers the period from the time of birth to increasing independence at age two to maximum three years. Since operations are frequently performed within the first postnatal weeks, for reasons of clarity I decided to use the term «infant/baby». The term «teen», too, frequently refers to a more accentuated period in English everyday use (as a rule to a time between 13 and 19 years of age). I mean (and conveyed to the NGOs) the period between the beginning of puberty and the legal and social breaking away from the close family community or the parents. The other two terms («children», «adults») cover the remaining periods. Finer gradations would not have made sense in the light of lacking statistics.

and whether individuals pay for these interventions themselves.[7] The follow-up treatment of intersex individuals after medical interventions and their general medical care is frequently insecure. This issue was enquired into as well as if there are protests against medical interventions without the intersex individual's personal, free, prior and informed consent and to which extent there is public feedback on these protests, for example by means of media reports. A further set of questions aimed at the surroundings in which children in rural and urban areas are born. The study reveals where births generally take place (at home, in a birth centre, in a hospital) and who is generally present (midwife, medical doctor, elders, the family). The assumption was that the external circumstances of the birth offer different starting positions for the way intersex children are received in the human community.

- The legal situation:
  This section focussed on the civil status. The enquiry aimed at the entries of sex/gender that are permitted in the respective country, time limits for registering the civil status and possibly special regulations for intersex newborns (whose existence would, in the event of special regulations, at least be legally recognised). The question of whether and how civil status can be changed is also important for intersex children, adolescents and adults. Since a person's gender identity cannot be predicted, the civil status registered at birth might deviate from the actual gender identity or the civil status the intersex person desires (based on pragmatic reasons, too, such as, e.g. the outer appearance). Therefore, it was interesting to know whether, and under which conditions, intersex individuals are able to change their civil status.
- The social situation:
  This section focussed on issues related to the social visibility of – and the respective cultural knowledge of – intersex; the taboo on intersex and intersex individuals and procedures with regard to intersex; and the way intersex is dealt with beyond the pathologising discourse of Western medicine. Furthermore, this section enquired into established terms for intersex individuals (e.g. neutral, self-designation, etc.). Finally, data were collected to answer the question of whether it is possible to be out as intersex without being verbally or structurally discrimi-

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[7] The working hypothesis was that in countries in which the population is provided with a comprehensive statutory health insurance system that covers the costs of medical interventions, medical interventions on infants/babies take place more frequently, since the respective families do not have to bear the costs themselves. This has definitely proven to be the case in the selected Western European countries. However, the data compiled also reveals that in countries with a similar health system, such as Australia, most of the interventions are performed on adolescents. In South Africa, on the other hand, interventions are even-handedly performed on infants/babies, children and adolescents, despite a comparatively low number of beneficiaries (approximately 20 per cent are covered by a sickness insurance scheme). However, this says nothing about the number of interventions. This result raises further questions about details of health financing as well as specific medical practices. Due to time pressures and the specific communication difficulties (e.g. overwork of the few activists that work on this topic, cf. 2.3 Problems with the data collection), these issues could only be clarified selectively.

nated against or violently attacked or killed in the respective country. This issue requires considering that naming structural and verbal discrimination depends on the concept of discrimination the interviewees applied. An emotion-centred definition of discrimination, for instance, includes all situations according to which a person can be offended, disadvantaged or excluded, based on a particular feature. It is irrelevant whether the feature actually applies to the respective person (or e.g. in the case of structural discrimination, whether it is intended). Homophobic insults serve as an example. In most cases they are directed towards non-compliant gender behaviour or a non-stereotypical gender appearance, whereas the discriminating person is mostly unaware of the actual sexual preferences of the other person. This last set of questions, which does not distinguish between structural discrimination and discrimination in non-institutional everyday life for reasons of scope, clearly reveals the limits of the preliminary study. A more comprehensive study would definitely need to go into more detail here and would, using guided interviews, need to consider the different experiences that come along with different physical traits and social life circumstances.

2.3 Problems with the data collection

Relatively few questionnaires were returned, which was not surprising, given the information already available at the time. Out of eight countries (Australia, Belgium, New Zealand, Serbia, Taiwan, Turkey, Ukraine, Uruguay), only one questionnaire was returned, and two questionnaires each were returned from four countries (Germany, France, South Africa, Uganda). The answers from the four countries with two questionnaires each assessed the situation similarly in their respective country. Differences mainly arose from different fields of work (e.g. urban and rural areas in the case of the two organisations from South Africa).

The reasons for the relatively few returns were identified as the following:

- *The invisibility of inter*:* Treating the existence of intersex as a taboo and the resulting invisibility of intersex individuals prevents community-building among intersex individuals. In addition, intersex individuals frequently experience massive psychological and physical problems due to medical interventions and discrimination in everyday life. These aspects prevent or impede intersex self-organisation and activist work.
- *Difficult access to data:* There is a striking lack of independent quantitative and qualitative research worldwide. As a rule, the medical apparatus is non-transparent, for instance with regard to the number of operations performed on intersex individuals per annum. Intersex individuals are even denied access to their own medical records, frequently for inadequate reasons (e.g. fire, water damage, etc.). The amount of data available on individual countries for this preliminary study depends on the efforts of NGOs to collect cases and identify the number of cases. The latter is directly related to the financial and human resources of the NGOs and the legal possibilities in the respective country.

- *The small number of NGOs that work on inter* human rights:* Depathologising, human rights-based inter* activism is relatively recent in most of the countries. Even if the number of NGOs operating, or wanting to operate, from this perspective has increased since the beginning of the 2000s, their total number is extremely small on an international scale.
- *The resources of the NGOs and activists:* The size of these NGOs range from one person functioning as a contact person for a multitude of other intersex individuals by means of a mailing list and performing international political work at the same time (e.g. Taiwan) to NGOs with a few active members (the majority) to the rare exception of organisations, such as SIPD in Uganda, that have seven full-time positions (however, these individuals mainly work on site within families and rural communities and barely have time for office work). Most of the NGOs that returned a questionnaire almost entirely serve in an honorary capacity and oftentimes to breaking point.
- *The language barrier:* This preliminary study abstains from a translation of the English questionnaire into the respective regional or national language. Therefore, activists who are unable to speak English could not be reached.

The scope of the questionnaire entails a further – however, deliberately chosen – methodical limitation. The questionnaire, for example, abstains from predetermined answers that are too detailed, such as with regard to country-specific health systems or experiences of discrimination. Instead, it relied on the willingness to comment on issues as a means to avoid too heavy a bias towards structural causal connections that exist in Central Europe, but may be irrelevant to the respective country of the global South or East.

The questionnaire does not enquire into medical diagnoses and classifications of syndromes, either. The latter are generally irrelevant from a human rights perspective. Nevertheless, practical work needs to consider that different diagnoses may lead to different forms of discrimination and medical and/or legal incapacitation of intersex individuals. The examination of such causal relationships – provided they are visible and relevant in the respective countries of the global South and East – could not be dealt with within the scope of this preliminary study.

3. Summary of findings

In the following, I will initially describe aspects of medical practice, legal proceedings and social life that particularly influence the life situations of intersex individuals. The study abstains from a detailed comparison, since it focusses on country-specific situations. The second part provides an overview of the fields of work and needs of the participating NGOs.

3.1 The life situations of intersex individuals

3.1.1 Medical practices

Intersex individuals are considered individuals with a «disorder» in all areas in which Western medicine prevails. They are more or less obviously treated as sick or «abnormal», depending on the respective society. As a rule, Western medicine aims to allocate intersex individuals to one of the two sexes/genders as quickly as possible and to apparently «normalise», that is, conceal the intersex body, using surgical and other medical means.

The interventions are rarely life-sustaining measures in a narrow sense, since intersex individuals generally have completely healthy bodies.[8] These measures solely serve to socially adapt the intersex individual to the socially dominant corset of two sexes/genders.[9] It is barely possible to develop an identity as a person (e.g. inter*,

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[8] An exception is the obstruction of passing urine, which requires a life-sustaining operation and hormone substitution, which is vital in the case of the salt-losing syndrome CAH, cf. Jörg Woweries, «Antworten auf die Fragestellung des Deutschen Bundestages, Ausschuss für Familie, Senioren, Frauen und Jugend», Öffentliche Anhörung zum Thema Intersexualität am Montag, den 25. Juni 2012, Deutscher Bundestag: Ausschussdrucksache 17 (13) 181c, p. 6, http://www.bundestag.de/bundestag/ausschuesse17/a13/anhoerungen/archiv/2012/ualitaet/Stellungnahmen/17_13_181c_Dr_Woweries.pdf (accessed June 30, 2012). Moreover, intersex individuals may theoretically belong to different risk groups, depending on their different physical constitutions, just as women and men do with regard to the risk of developing breast cancer. Other than with so-called male and female bodies, where certain risks are well-known and have been researched with large sample sizes, risk estimates with intersex individuals are for the most part based on small sample sizes, in part because of preventive surgery in the past. Hence, the AWMF guidelines on DSD (2007/2010), for instance, conclude that: «The bibliographical references on the definite risk of developing gonadal tumors are meagre», cf. Woweries (2012), p. 7. Nevertheless, physicians still recommend to parents and intersex individuals to have hormone-producing gonadal tissue removed preventively, which in turn requires a lifelong hormone replacement therapy.

[9] The notion that the human species consists of two dichotomous sexes only is no longer tenable, even in the light of recent bio-medical research. Studies of the past 20 years clearly reveal the gaps in classical genetic models, also with regard to sex determination, cf. Heinz-Jürgen Voß, *Making Sex Revisited. Dekonstruktion des Geschlechts aus biologisch-medizinischer Perspektive* (Bielefeld 2011): transcript, p. 314.

woman or man etc.) with an intersex body that has a right to remain unmodified, even if the respective individual so wishes.

However, intersex is considered a threat to the social order outside Western medicine, too. The birth of an intersex child is considered to be a punishment for previous misdoings, for example of the mother, in predominantly rural areas of, for instance, Uganda or parts of South Africa. NGOs in Uganda and South Africa report that intersex newborns are killed. Mothers retain their place in society, which is essential for survival, by killing the children. In such a situation, it can be life-saving to explain intersex using biological factors and the Western term «disorder». Nevertheless, here too intersex individuals whose relatives are able to pay for the operations that are recommended by individuals trained in Western medicine report severe physical and psychological damage in the aftermath of medical interventions, sometimes to the point of life-threatening organ damage.

Neither appropriate medical post-operative treatment based on a diagnosis of DSD, nor funding of medication is guaranteed in most of the countries. This applies to hormone replacement therapy, too, which is obligatory in order to maintain physical health after the hormone-producing gonads have been removed. In addition, it can be extremely difficult to obtain medication that, according to the doctrine of Western medicine, is not indicated for a particular DSD syndrome, regardless of whether the respective individual tolerates it better and therefore wants it. This means that even in countries in which health insurances finance the so-called medically indicated support, individuals become self-payers. A further problem concerning medical care arises with regard to those physical aspects that do not match the assigned gender. In nearly all countries examined, NGOs primarily working on inter* report significant problems, including situations whereby individuals are unable to obtain the necessary medical care. France is an exception. There are no data for Taiwan on this issue.

Genital surgeries are especially performed on:

▣ babies/infants
☐ children
≡ adolescents
Ⅲ adults
⁙ unknown

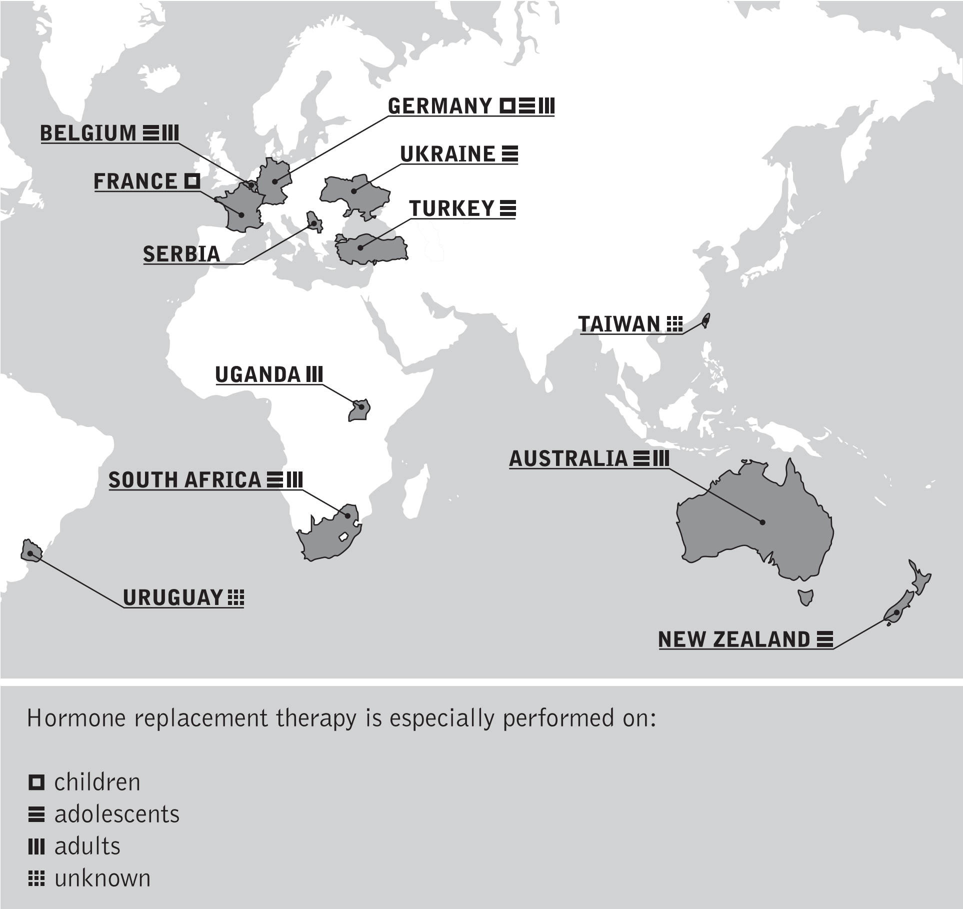
World map 1: Genital surgery

Nearly all over the world, intersex bodies are considered to be barely, or not at all, capable of being integrated into the social order. Therefore, genital surgery is performed from infancy to adolescence and adulthood in all examined countries. In a minority of cases are we dealing with medical emergencies in a narrow sense, because intersex individuals generally have perfectly healthy bodies (cf. footnote 8). With exception of Australia and Turkey, babies/infants are most heavily affected. Western European countries and South Africa have a tendency towards a distribution up to adolescence. However, it needs to be considered that operations in early childhood usually require follow-up measures. Australia is an exception and indicates a certain reservation with regard to genital surgery in early childhood. No details could be provided on Taiwan.

The removal of the gonads is especially performed on:

□ children
≡ adolescents
⦀ adults
⁙ unknown

World map 2: Removal of the gonads
There is a clear tendency in nearly all of the examined countries to remove hormone-producing gonadal tissue (gonads) as early as in childhood, and at latest in adolescence, if it does not correspond with the assigned sex/gender. This step is justified with an allegedly very high risk of tissue degeneration, without any scientific proof however (cf. footnote 8). In Germany surgical removal is continued into adulthood. In Australia there is a tendency to do without early removal in favour of an operation in adolescence and adulthood. No details could be provided on Taiwan.



World map 3: Hormone replacement therapy

Intersex individuals are mostly assigned to one of two sexes, «female» or «male». At the latest from the beginning of puberty, an intersex body can undermine this by producing hormones that provoke physical changes towards the non-assigned gender. Accordingly, hormones are administered especially to adolescents in all countries examined. Germany and France are known to administer hormones to children. In cases in which hormone-producing gonadal tissue is surgically removed, the ensuing hormone deficiency needs to be compensated in order to avoid physical damage (e.g. bone atrophy). Missing adult groups for a number of countries in which gonads were removed in childhood and adolescence (cf. world map 2) reveal that hormone replacement therapy is not guaranteed. No details could be provided on Uruguay and Taiwan.

Aftercare of surgically treated individuals resulting from a DSD diagnosis:

☐ yes
■ no
▦ unknown

World map 4: Aftercare

An appropriate post-operative treatment based on a diagnosis of DSD is barely ensured in any country. There is a positive tendency in Germany and Turkey only. No details could be provided on Taiwan.

Can inter* individuals obtain medical care that does not match the assigned sex/gender?

- □ yes
- ▣ mostly
- ☰ problematic
- Ⅲ very difficult
- ■ nearly impossible
- ▦ unknown

World map 5: Medical care
It is mostly difficult, if not impossible, to obtain medical care with regard to physical aspects that do not correspond with the assigned gender. There are no significant differences between the so-called Western countries and the countries of the global South and East, either. No details could be provided on Uruguay and Taiwan.

3.1.2 The legal situation

In nearly all of the countries examined, a child's sex/gender needs to be officially registered within less than a week up to a maximum of four weeks after it is born. It is only possible to choose the sexes/genders «female» or «male» for the birth certificate. In some countries, there are special regulations for intersex children that extend the deadline. However, the regulations are still enforced.

The coercion to register either «male» or «female» cements the notion that there are only «men» and «women» top-down, which increases the pressure not only to render the child legally «unambiguous», but physically, too. A German mother, for instance, explains that, «[…] the pressure exerted by the registry office to […] slot one's child into one of the two genders [builds] up an unreasonable pressure that is only surpassed when the attending physicians demand to consent to allegedly pressing operations at the same time. […] The option to leave the sex/gender entry vacant for years would have let me know from the legal side that it is absolutely appropriate to wait in this situation.»[10]

Until January 31, 2013, it was possible in two countries to either leave the entry vacant (Germany[11]) or to register the child's sex/gender as «intermediate» (New Zealand). This entry is, however, only temporary in the latter case.

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[10] Julia Marie Kriegler, «Stellungnahme aus Elternsicht von Julia Marie Kriegler, Vertreterin aus der Elterngruppe der xy-Frauen. Deutscher Bundestag, Ausschuss für Familie, Senioren, Frauen und Jugend», Öffentliche Anhörung zum Thema Intersexualität am Montag, dem 25. Juni 2012, Deutscher Bundestag: Ausschussdrucksache 17 (13) 181f, pp. 23, http://www.bundestag.de/bundestag/ausschuesse17/a13/anhoerungen/archiv/2012/intersexualitaet/Stellungnahmen/17_13_181f_Kriegler.pdf (accessed June 30, 2012).

[11] See section 5.1.3.

How quickly does a child's gender have to be registered?

⊟ No entry required / The entry needs to be left open
□ temporary entry
▣ within three years
≡ within three months
⦀ within four weeks
■ within one to two weeks
⁜ within less than a week
⠿ unknown

World map 6: Entry of sex/gender

The coercion to quickly register the sex/gender in the birth register greatly increases the pressure on parents. In Germany, until January 31, 2013, it was possible to leave vacant the child's sex/gender. However, this led to significant bureaucratic problems. Since January 31, 2013, the sex/gender entry has to be left vacant after DSD has been diagnosed. The child is outed as intersex everywhere. NGOs fear that the pressure on parents to have their child surgically aligned to a sex will continue to increase. New Zealand provides the option of leaving the sex/gender entry vacant. However, this is only accepted as a temporary state. All of the other countries clearly limit the period of time provided to register a child's sex/gender, even in the case of an intersex child. While France seems to give parents time to decide by means of a deadline of three years for an entry in the case of intersex, NGOs report that, in practice, parents nevertheless mostly have their child assigned to one or the other sex/gender as quickly as possible. In all of the other countries, the deadline ranges from three months in the case of Belgium to less than a week in the case of Uganda. No details could be provided on Taiwan.

3.1.3 The social situation

In all of the countries examined, intersex is treated as a taboo, and intersex individuals encounter prejudices. With the exception of Australia and Uruguay, the interviewees stated that it was not common knowledge that intersex individuals exist.[12] At the same time, intersex individuals are more or less heavily discriminated against in the majority of the countries examined. The experiences range from structural and verbal discrimination to physical violence and life-threatening situations.

In many cases we are dealing with discrimination based on non-gender-conforming behaviour and appearance. There is a clear overlap with homophobic discrimination. The extent to which discrimination is experienced and reported always depends on whether the respective social environment insists on stereotypical modes of behaviour, the extent gender-transgressive behaviour is tolerated and how the individuals concerned overcome their experiences (e.g. by means of confrontation, repression, resignation, etc.). This question requires particular consideration of a large number of unreported cases that accompany the recorded ones. A more extensive study would have to include the different experiences that go along with different physical traits and circumstances in social life, which indirectly influence what is perceived, categorised and reported as discrimination.[13]

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[12] In addition, intersex individuals from various countries report that they were repeatedly told that there were no other individuals who felt the way they did whenever they, for example, asked medical staff to help them contact individuals with the same experiences.

[13] For instance, nobody ticked off verbal/structural discrimination for Belgium, although the intersex child's gender needs to be registered within three months of birth and cannot be changed thereafter.

Individuals who out as inter* risk:

□ discrimination (verbal and/or structural)
≡ bodily harm
■ life-threatening situations
▦ unknown

World map 7: Discrimination

Intersex is mostly treated as a taboo, and prejudices against intersex are common. If intersex individuals do not conform to a gender in behaviour and appearance, they frequently experience discrimination and violence. Except for France, Belgium, New Zealand and South Africa, all countries stated structural or verbal discrimination. With exception of Turkey, discrimination is followed by experiences of physical violence. Being out or evidently intersex in Ukraine, Uganda, South Africa and Australia was declared potentially life-threatening. No details could be given for Uruguay on all three aspects and none for Taiwan on the question of life-threatening situations. When looking at this overview, however, it needs to be considered that it is frequently difficult to answer the question clearly on discrimination or danger based on being out and evidently intersex. For instance, Turkey treats intersex as a strict taboo and is known for instances of physical violence and murders[14] based on non-gender-conforming appearance and behaviour.

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[14] Cf. the data provided by the Trans Murder Monitoring Project, http://www.transrespect-transphobia.org/en_US/tvt-project/tmm-results.htm (accessed June 30, 2013).

3.2 The fields of work and the needs of the NGOs

Human rights-based inter* activism is comparatively recent in most of the countries, and the number of NGOs working on this issue is extremely small from a global perspective. The organisations that returned the questionnaire can be divided into Inter* NGOs that only work on the issue of intersex (10 NGOs), Trans* and Inter*NGOs, which carry out trans* and inter* activism alike (2 NGOs), and LGBT NGOs, which work on human rights in general, beyond issues pertaining to those affecting the LGBT community (4 NGOs). The latter revealed a strong interest in working on – or extending their work to – the human rights of intersex individuals. In order to avoid an appropriation of the topic and mistakes in political advocacy, they are explicitly looking for active collaboration with, and instructions by, intersex activists.

All of the interviewed NGOs work on different issues, such as, for example, health or education. Most of them direct their work towards the local as well as the national, continental and international levels. This particularly goes for the Inter* and Trans* NGOs, which, with two exceptions, organise local self-help and, in part, provide psycho-social care. They carry out local and national awareness training at schools and universities, for future medical professionals, for government agencies and in the media. They advocate politically on the national, continental and international levels. Their work includes the strategic conduct of cases on the national level. In contrast, LGBT NGOs limit their work on intersex geographically and, with regard to the contents, to the local and, in part, national areas. Their core areas are education on intersex in selected areas and – with regard to Eastern Europe particularly – political advocacy.

The work is predominantly volunteer-based. In part the NGOs are staffed with a few part-time or full-time positions. The Central European NGOs and the Asian Inter* NGO operate on an entirely honorary basis. The Eastern European, South African and South American (Inter* / Inter*-Trans* / LGBT) NGOs are in the middle range with regard to full-time and part-time positions, of which Eastern European NGOs have two and South African NGOs have three full-time positions. The NGOs in Uganda spearhead the list with up to seven full-time positions. The number of positions does not correlate with the geographical diversity and the diversity with regard to the contents of the work. NGOs with few or no positions at all cover vast or even all areas of the main fields of action mentioned above.

The NGOs finance their work with a series of sources. Among these are the activists' private budgets, membership fees, private donations and supportive events organised in the wider community, such as, for example, benefit parties. In addition, nine NGOs (Australia, Belgium, Germany, New Zealand, South Africa, Uganda, Ukraine and Uruguay) receive municipal and/or national partial funding and are subsidised by larger NGOs and/or foundations, for instance, by means of project-linked funds. However, these funds do not nearly cover the total needs. All of the interviewed NGOs stated that they need more money for their work. The Inter* and Inter*-Trans* NGOs as well as nearly all of the LGBT NGOs need more money for psycho-social aid and self-help. It was also important to all of the NGOs to have more financial resources for awareness-training on inter*, for instance, in order to intensify the work outside the metropolitan areas or to be able to print educational materials. The activists also mentioned the financing of travel expenses and attendance fees for conferences and conventions. On the one hand, this need refers to conferences where activists working on human rights network internationally. On the other hand, it refers to international academic conferences that generally deal with intersex without the professional expertise of academics who are intersex activists themselves. Some organisations need networking technology, such as computers and access to the internet. Most of the NGOs wanted to develop skills needed for applying for international funding or for a coach to support them in this process.

With the exception of two NGOs, none of the organisations required basic training on building up an NGO. This can be explained by the fact that even though they were in part officially founded or registered only recently, all of the active members of the NGOs were able to draw upon an extensive treasure trove of experiences in human rights-based activism. The need for basic training in political advocacy is relatively small, too. However, one needs to bear in mind that it is especially the Inter* NGOs that provide for a large number of intersex individuals, who, due to the problems outlined in section 2.3, Problems with the data collection, are unable to organise themselves and to represent their interests. Financing best practice workshops that are carried out by experienced NGOs in the area of inter* activism might be supportive. NGOs in Eastern Europe that have so far mainly been working on LGB and trans* issues would explicitly like to have this kind of support.

About half of the NGOs are well-positioned and do not voice any further needs with regard to linking up with political decision makers. Even in the area of dealing with the media and social networks, only half of the NGOs formulated a need. Slightly more than half of the NGOs would be interested in training in the strategic conduct of cases. NGOs from non-English-speaking countries or countries with several national languages would appreciate assistance with translating their own and national (e.g. legal) documents on the situation of inter* into English as well as articles and documents that are in English into the national language(s).

I did not enquire into the reasons for the individual requirements. If, for example, the need for training on the strategic conduct of cases was not voiced, this can mean that the NGO does not have the time or human resources, or that this route does not appear promising to the respective NGO. Studies focussing on the reasons are urgently needed in order to better understand the country-specific situations.

4. Recommendations for action for international actors

The following recommendations for action can only be fragmentary. Generally, the contact to the respective NGOs is strongly recommended for on-site assistance. Basic needs of the NGOs as well as their current fields of work are listed in section 3.2, Fields of work and the needs of the NGOs.

In order to improve the human rights situation, the Heinrich Böll Foundation and other interested actors in a global context should work towards:

- widely spreading knowledge on *the existence of intersex individuals* and providing partner organisations in the respective countries with information on the issue of intersex and the problem areas linked to it;
- *increasing the visibility of intersex individuals and expanding knowledge of their life situations in different countries,* for example by means of a qualitative and quantitative study that documents the life situations of intersex individuals in the different countries of the global South and East on a larger scale and in collaboration with partner organisations and individuals on site. In conjunction with a web site that is running in parallel and continuously documenting the findings, such a study could, for the first time, provide qualitative and quantitative data on the life situations of intersex individuals and, in doing so, make reliable material available to on-site NGOs for their political work. On the other hand, the visibility of intersex individuals would increase significantly, and hence the study would empower intersex individuals. For several years, the study Transrespect versus Transphobia in the area of trans* has revealed the political and social power that a procedure with an international approach controlled by individuals concerned can develop;
- *encouraging intersex individuals to voice their needs and organise themselves,* for example by means of assuming travel expenses for national, continental or international conferences that serve human rights work on the issue of inter* or where activists can engage in education;
- *intensifying the collaboration with, and support of, NGOs that work on – or wish to work on – human rights breaches against intersex individuals* and render possible relevant capacity-building, for example by means of best practice workshops;
- *taking into consideration inter* and intersex individuals in all areas of project work as a cross-sectoral topic,* be it in work on health issues, education, gender democracy, labour, migration, sex work, etc. and to examine project proposals as to whether they include and let inter* individuals participate.

5. A description of countries

The description is structured according to regions (Western/Central Europe; Eastern Europe/the Balkans; Africa; South America; Oceania; Asia) and alphabetically within the regions. There is a tabular overview in the annex.

5.1 Western/Central Europe

5.1.1 Belgium

Medical practice

Belgium has a statutory health insurance system that covers approx. 95 per cent of the population. In the case of a diagnosis of DSD, health insurance companies pay for cosmetic genital surgery, the removal of gonads and hormone therapy. At the same time, there are individuals who pay for medical measures out of pocket.

Most of the births in rural and urban areas take place in hospitals and in the presence of a physician and a midwife. Cosmetic genital surgery is mostly performed on infants/babies, children and adolescents. Gonads are in most instances removed in adolescence. Adolescents and adults receive hormone therapy. There is no adequate follow-up care in the subsequent years. Generally, it is very difficult for intersex individuals to receive care that is not indicated, from a medical perspective, for the registered sex/gender (e.g. preventive medical checkups for cancer of the gonads, if the individual has a female civil status or if the person is considered to be female).

There are protests in Belgium against medical interventions performed on intersex individuals that take place without their personal, free, prior and informed consent. However, there is no public feedback (for instance in the media).

The legal situation

Belgium only allows for a sex/gender entry as «male» or «female». The child's sex/gender needs to be registered within one week. There is a maximum deadline of three months for intersex newborns. The intersex individual cannot change the assigned gender thereafter.

The social situation

It is not common knowledge in Belgium that there are intersex individuals. Western medicine constitutes the dominant medical approach to intersex. There are reports of prejudices against intersex individuals, for example when seeking employment. The interviewees, however, denied that they experienced structural and verbal discrimination, physical violence or life-threatening situations as a result of being out or evidently living as an intersex individual. It is unclear whether there is a specific taboo on intersex.

Intersex individuals use the neutral term inter* for themselves.

5.1.2 France

Medical practice

France has a statutory health insurance system that covers 99 to 100 per cent of the population. In the case of a diagnosis of DSD, health insurance companies pay for cosmetic genital surgery, the removal of gonads and hormone therapy. The interviewees disagree about whether there are individuals who pay for medical measures out of pocket.

Most of the births take place in hospitals in rural as well as in urban areas and in the presence of a physician and a midwife. Just as with the question on self-paying patients, the respondents are at variance with each other on the question of cosmetic genital surgery. While some report that genital operations are mainly performed on babies/infants and children, and that they are uncertain about the question of the removal of gonads and hormone therapy, others suggest an even age distribution. According to the latter, cosmetic operations are performed on babies/infants, children, adolescents and adults: Gonads are mostly removed in childhood, while children, adolescents and adults are treated with hormones. There is little to no aftercare in the years after the intervention. With regard to the care of intersex individuals in the case of medical problems that are, according to medical opinion, not typical of the registered sex/gender (e.g. preventive medical checkups for cancer of the gonads, if the individual has a female civil status or if the person is considered to be female), some are unaware of any problems, whereas others cannot impart any information on this issue.

There are protests in France against medical interventions performed on intersex individuals that take place without their personal, free, prior and informed consent. However, there is no public feedback (for instance in the media).

The legal situation

France only allows for a sex/gender entry as «male» or «female». The child's sex/gender needs to be registered within three days. There is a maximum deadline of three years for intersex children. The sex/gender entry can be left open during this period of time. The interviewees emphasise that this occurs rather seldom, since most of the parents wish to register their child as male or female as quickly as possible. The assigned gender can be changed to the opposite gender later on. A medical report and judicial authorisation serve as prerequisites. Intersex individuals can file a suit if the desire to change their respective gender is denied.

The social situation

It is not generally known in France that intersex individuals exist, and Western medicine dominates the way intersex individuals are dealt with in society as a whole.

The interviewees disagree about whether intersex is treated as a taboo in France. However, both NGOs affirm that intersex individuals experience structural discrimination in the areas of health, employment and housing. The notion that intersex individuals have a complete set of so-called male and female genitalia is a popular prejudice. Some people consider intersex individuals monstrosities. Others believe intersex individuals do not exist. The medical apparatus is said to be based on the discriminatory prejudice that assigning medical interventions in early childhood are a problem-solving strategy.

Verbal discrimination occurs, too, in France. Experiences diverge on the question of whether physical violence or life-threatening situations arise as a result of being out or evidently living as an intersex individual. The interviewees give an account of cases that involve physical as well as life-threatening situations. They suggest that it is possible to live openly as inter* but that it is difficult. Whether an individual experiences discrimination or not very much depends on the geographical and social environment the person lives in.

Discrimination against intersex individuals and their invisibility lead to comparatively little exchange among each other. Therefore, it is difficult to obtain secured information on the current situation of intersex individuals in France.

Intersex individuals use the neutral term «intersexué» or «intersexe» to describe themselves. The term «hermaphrodit» may serve as a self-designation as well as an insult. Non-intersex individuals use the term because they are unaware of any other. In a medical context, the term «DSD (Disorder of Sex Development)» is used.

5.1.3 Germany

Medical practice

Germany's statutory health insurance system covers approximately 99 per cent of the population. In the case of a diagnosis of DSD, health insurance companies pay for cosmetic genital surgery, the removal of gonads and hormone therapy. At the same time, there are individuals who pay for medical measures themselves, for example if they wish to take hormones that – from a medical point of view – do not match the registered sex/gender, such as testosterone in the case of an intersex individual bearing a female civil status. In this case we are dealing with off-label use, that is, the prescription of a drug outside the terms of marketing authorisation. Health insurance companies frequently do not pay for the costs.

Most of the births in rural and urban areas take place in hospitals and in the presence of a physician and a midwife. Cosmetic genital surgery is mostly performed on infants/babies, children and adolescents. Gonads are largely removed in childhood, adolescence and adulthood. Children, adolescents and adults also receive hormone therapy. Medical aftercare is provided in the subsequent years. Generally, it is very difficult for intersex individuals to receive care that is not indicated, from a medical perspective, for the registered sex/gender, for example, preventive medical checkups for cancer of the gonads, if the individual has a female civil status or if the person is considered to be female.

There are protests in Germany against medical interventions performed on intersex individuals that take place without their personal, free, prior and informed consent, and in the meantime there has been quite significant feedback in the media. In particular, since the German Ethics Council published its statement, which the two German Inter* NGOs criticise some points of,[15] there has been a growing public interest in – and public awareness of – the existence of intersex, for instance with social partners, political associations, anti-discrimination offices, human rights organisations, LGBT communities, and social science and cultural studies departments in universities. OII Germany, TransInterQueer e.V. and the Association of Intersex Individuals e.V. (Intersexuelle Menschen e.V.) have since then repeatedly been requested for interviews and approached for training programmes. The situation of a comparatively great visibility of inter* is currently unique in Europe (and most probably worldwide, too).

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[15] The NGOs especially criticise the inconsistency of the statement. While the Ethics Council notes that all interventions have more or less dramatic effects on the core area of personal identity and bodily integrity (cf. Deutscher Ethikrat, 2012, pp. 5559), it nevertheless refrains from an unambiguous recommendation to abandon non-life-sustaining operations (cf. footnote 8) on individuals with so-called CAH, that is, for a group that is most severely affected by cosmetic operations in infancy and as babies (cf. Alfons Bora, *Zur Situation intersexueller Menschen*, Bericht über die Online-Umfrage des Deutschen Ethikrats, 2012, edited by the Deutsche Ethikrat, pp. 14-15, http://www.ethikrat.org/dateien/pdf/bora-zur-situation-intersexueller-menschen.pdf (accessed June 30, 2013). The German Ethics Council justifies this attitude in accordance with medical doctrine that this group predominantly identifies as female and therefore benefits from feminising treatment (cf. Deutscher Ethikrat, 2012, p. 174). Apart from the fact that the consent of the person concerned regarding the irreversible bodily interventions addressed here is indispensable from a human rights perspective, the assessment of the German Ethics Council contradicts the findings of its own online study. After all, 20 per cent of the adult individuals with so-called CAH who participated in this study clearly argued against operations on individuals who, due to their age, are incapable of giving their informed consent (cf. Bora, 2012, p. 28) and 14 per cent stated that they neither had a female nor a male gender identity (ibid., p. 32). However, the statement goes on that a medical measure should only be carried out on «individuals concerned who are not yet able to decide on their own behalf» if «this is necessary for irrefutable reasons pertaining to the child's best interests after extensive consideration of all of the advantages and disadvantages of the intervention and its long-term effects» (Deutscher Ethikrat, 2012, p. 174). The child should be involved in the decision wherever possible, and its wishes should be heard (ibid., pp. 174-175), a suggestion that will presumably not have much weight, considering the age at which these interventions are undertaken. De facto, the statement once more endows those in the concerned individual's environment with the authority to make a decision. Cf. Deutscher Ethikrat (2012): *Intersexualität*, Stellungnahme, Berlin; cf. Alfons Bora, *Zur Situation intersexueller Menschen*, Bericht über die Online-Umfrage des Deutschen Ethikrats, 2012, edited by the Deutsche Ethikrat, http://www.ethikrat.org/dateien/pdf/bora-zur-situation-intersexueller-menschen.pdf (accessed June 30, 2013). On the critique of the NGOs, cf. «Statement der 1. Vorsitzenden des Vereins Intersexuelle Menschen e.V. anlässlich der Übergabe der Stellungnahme des Deutschen Ethikrates» (Feb. 23, 2012), http://www.ethikrat.org/presse/dateien/pdf/pk-23-02-2012-veith.pdf (accessed June 30, 2013); «Presseerklärung OII Deutschland zur Stellungnahme ‹Intersexualität› des Deutschen Ethikrats vom 23.02.2012», http://www.intersexualite.de/index.php/presseerklarung-zur-stellungnahme-intersexualitat-des-deutschen-ethikrats-vom-23-02-2012/ (accessed June 30, 2013); Ulrike Klöppel, «Geschlechtergrenzen geöffnet?», in: *Gen-ethischer Informationsdienst*, 211 (2012), pp. 3537.

The legal situation

Until Jan. 31, 2013, Germany only allowed for a sex/gender entry as «male» or «female». The deadline for registration is one week.

According to the Civil Status Regulation (PStV s.7) and from 2009 until the beginning of 2013, the sex/gender entry of an intersex newborn baby could be left open until the sex/gender was resolved. However, a birth certificate was not issued for this period of time. Instead, the parents obtained a certificate on the entry of an announced birth. However, this does not suffice to carry out legal transactions on behalf of the child.[16] The birth certificate is imperative, for example, to apply for health insurance coverage, maternity and parental benefits, or the separate recognition of paternity to open up a savings book; for a child's ID; statements on inheritance; the registration for childcare centres; to take out life insurance, occupational disablement insurance or private health insurance; or to register for pension insurance. This constitutes a direct discrimination on the basis of gender.

On Jan. 31, 2013, the German Bundestag passed a new act on changing regulations on civil status, which, with regard to intersex individuals, includes a new passage in s.22 «Missing information»: «(3) If the child can be assigned to neither the ‹male› nor the ‹female› sex/gender, the civil status case is to be registered in the birth register without such a detail.»[17] This might appear as progress at first glance. To the contrary, however, it exacerbates the situation of the parents and children.

While the Civil Status Regulation (PStV) rendered it possible not to register the sex/gender for a potentially indefinite time, the amendment of the Civil Status Act means that the information is legally no longer an option but an obligation, all the while the deadline for the entry remains the same. For parents this means that they hold the birth certificate in their hands directly after the child is born. However, it also means that the child is outed as intersex in all legal transactions, since the practice of leaving open the entry is for intersex individuals only.

The NGOs in the German-speaking areas point out that this new regulation rather increases the danger of stigmatisation and «might encourage (potential) parents and physicians even more to avoid an ‹ambiguous› child at any cost (by means of abortion, prenatal ‹treatment› or so-called ‹normalising› surgical and/or hormonal interventions).» At the same time, they criticise that the gatekeeper function of medicine is reinforced, since its diagnosis decides upon the child's sex/gender. It would be a real improvement of the existing situation if the gender entry was left open for all children

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16 Cf. the Civil Status Regulation (Personenstandsverordnung; PStV) of Nov. 22, 2008, p. 35. The Civil Status Regulation regulates the practical application of the Civil Status Act (Personenstandsgesetz; PStG).

17 An Act to Amend Civil Status Act (Personenstandsrechts-Änderungsgesetz; PStRÄndG) bill, http://dip21.bundestag.de/dip21/btd/17/104/1710489.pdf (accessed Feb. 27, 2013) with changes according to Drucksache 17/12058, p. 4 of the electronic preliminary version, http://dipbt.bundestag.de/dip21/btd/17/121/1712192.pdf (accessed June 30, 2013); commencement of the Act: November 1, 2013.

until they have reached a uniformly agreed upon age when they are capable of making decisions.[18]

Theoretically, the assigned gender can be changed later on. In practice, however, this way is fraught with many obstacles. Section 47 of the Civil Status Act can be applied. This particular section rules that an incorrect sex/gender entry may be revised upon application. The applicant is required to supply relevant evidence in the form of a medical report. Initially, this section was not meant to be for intersex individuals. It can be used for a change of the sex/gender entry when civil proceedings are applied for. The obstacle lies in the medical diagnosis, which, as a rule, determines the (alleged) sex/gender on the basis of the chromosomal configuration.

The second and most frequently used route is the proceeding according to the Transsexual Act (Transsexuellengesetz; TSG). Since the Federal Constitutional Court declared sex-reassigning measures (including sterilisation) as preconditions for a change of civil status unconstitutional in 2011, the civil proceeding remains the only condition for which two psychological reports need to be produced. These expert reports are meant to certify that the applicant has «due to his transsexual imprinting no longer [..] a sense of belonging to the sex/gender specified in the birth entry, but to the opposite sex/gender and has since at least three years felt compelled to live according to his idea» (s.1 TSG). Since transsexuality (ICD 10, F64.0) excludes intersexuality (DSD), from a diagnostic perspective, the applicant is forced to use false pretences and to conceal being intersex.

The social situation

It is not common knowledge in Germany that intersex individuals exist. However, awareness thereof has increased in the past years. Intersex individuals have created self-help structures and increasingly working on successfully breaking the taboo of intersex. Nevertheless, Western medicine continues to dominate the way intersex individuals are dealt with.

With regard to structural discrimination, the federal government's reply to the parliamentary question put forward by the Bündnis 90/Die Grünen on Dec. 12, 2012, reveals that the federal government does not consider any specific need for policy action, despite the recommendations of the Ethics Council and the demands that

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[18] Cf. press release by OII Germany on Feb. 2, 2013, quotation ibid., http://www.intersexualite.de/index.php/pm-mogelpackung-fur-inter-offener-geschlechtseintrag-keine-option/ (accessed June 30, 2013); web page of Zwischengeschlecht.org, http://blog.zwischengeschlecht.info/post/2013/02/03/-Offenlassen-Geschlechtseintrag-seit-2009-Genitalverstummelungen-zunehmend (accessed June 30, 2013).

German NGOs have been formulating repeatedly for years.[19] This attitude has not changed in 2013 either. In the aftermath of the statement by the Ethics Council, several opposition parties introduced various motions into the parliament to protect intersex individuals that exceeded the recommendations in essential points. The recommendations were in part clearly orientated towards the demands of Inter* NGOs. The joint consultative committees recommended rejecting all of the motions in June 2013.[20]

The NGOs answered the question on experiences of discrimination in the affirmative. Popular prejudices against intersex individuals are based on the notion that they are sick or defective with regard to their (physical) development. Examples of structural discrimination are, for instance, the problem with birth certificates, the incapacitation of intersex individuals within the medical system and also the attitude of the federal government. Intersex individuals experience increased verbal discrimination and physical violence in instances in which they either disclose their intersex status or if their behaviour and/or outer appearance do not match stereotypical notions of male and female norms. Just like in other countries – and depending on whether the social environment tolerates gender-transgressive behaviour and appearance or not –

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[19] Cf. Deutscher Bundestag, Drucksache 17/11855. 17. Wahlperiode. Dec. 12, 2012, http://dipbt.bundestag.de/dip21/btd/17/118/1711855.pdf (accessed June 30, 2012). This applies to the improvement of the medical care of intersex individuals (p. 3 and p. 6), increased training in medical training (p. 3), the establishment of interdisciplinary centres of excellence in which psychologists and peers counsel intersex individuals and their parents (p. 2f.), funding of self-help groups and intersex individuals› organisations (p. 7f.) and the extended obligation to preserve the patients› records (p. 6). In all these cases the federal government passed on the responsibility, for example, to the Association of Statutory Health Insurance Physicians (Kassenärztliche Vereinigung) and the Medical Advisory Service of the German Association of Statutory Health Insurance Funds (Medizinischer Dienst der Krankenkassen), the Länder, medical expert centres and the National Action Alliance for People with Rare Diseases or, in the case of the obligation to preserve records, to the intersex individuals themselves. In other points, for instance the establishment of a compensation fund, the government declared that it was in the process of examining the issue (p. 7) and responded to the question of how the independence of consent could be adequately ensured in the case of intersex individuals who are not yet able to speak up for themselves and that the medical debate on intersexuality is continuously developed and that the legal debate has only just started (p. 4f.).

[20] The Committee for Family, Seniors, Women and Youth as well as all of the committees that were involved in the consultations (the Committee of Home Affairs, the Committee on Legal Affairs, the Committee on Health, the Committee on Human Rights and Humanitarian Aid, the Committee on Education, Research and Technological Impact Assessment) recommended on June 12, 2013, together with the votes of the government factions and against the abstentions of the opposition parties, to reject all of the motions put forth. On the motions, cf. Deutscher Bundestag, Drucksache 17/12859. 17. Wahlperiode, March 20, 2013., http://dip21.bundestag.de/dip21/btd/17/128/1712859.pdf (accessed June 6, 2013); Deutscher Bundestag, Drucksache 17/12851. 17. Wahlperiode, March 20, 2013, http://dip21.bundestag.de/dip21/btd/17/128/1712851.pdf (accessed June 30, 2013); Deutscher Bundestag, Drucksache 17/13253. 17. Wahlperiode, April 24, 2013, http://dip21.bundestag.de/dip21/btd/17/132/1713253.pdf (accessed June 30, 2013). On the decision recommendation, cf. Beschlussempfehlung und Bericht des Ausschusses für Familie, Senioren, Frauen und Jugend (13. Ausschuss), Drucksache 17/14014 17. Wahlperiode, June 14, 2013, http://dip21.bundestag.de/dip21/btd/17/140/1714014.pdf (electronic preliminary version, accessed June 30, 2013).

physical violence and life-threatening situations may occur. Depending on the degree of personal traumatisation, for instance as an effect of medical interventions, intersex individuals are, in addition, at an increased risk of committing suicide.

Intersex individuals use the neutral term «inter*» or «intergeschlechtliche Menschen» for themselves. Both terms are rooted in human rights-oriented activism, and although not all intersex individuals use these terms to describe themselves, the majority do, and they are gradually becoming accepted as politically correct terms. «Zwitter» and «Herm» (derived from «hermaphrodite») are further self-designations. The latter are only welcome as a pugnacious self-designation of activists within the peer group. Non-intersex individuals ought to avoid them, since they originally used to be pejorative terms.

The terms «girl/boy/man/woman with a DSD» originate from a medical context. The majority of intersex individuals reject this term, especially those who do not consider themselves sick or as having a disorder.

5.2 Eastern Europe/The Balkans

5.2.1 Serbia

Medical practice

Serbia has a statutory health insurance system. However, only individuals employed in the civil service are fully insured. Individuals in the private sector to whom a full salary is transferred are insured. Very often, however, employees receive a part of their salary in cash and are therefore not insured.

Statutory health insurance companies do not generally pay for cosmetic genital operations, the removal of gonads and hormone therapy in adolescence and adulthood. Whether private health insurance companies assume a part of the costs is unclear. Babies/Infants and children are an exception. If the latter feature any physical «anomalies», they are referred to a hospital in Belgrade that is specialised on such cases. The «normalising» interventions are performed there. Statutory health insurance companies pay for the costs, regardless of the parent's insurance status. Whether there are individuals who pay for these surgical interventions out of pocket is unclear.

Most of the births take place in hospitals in rural as well as in urban areas and in the presence of a physician and a midwife. Cosmetic genital operations are mostly performed on babies/infants and children. The gonads are largely removed from children. There is no information on hormone therapies. It is also unclear according to which diagnoses interventions are performed. After an intervention, there is no follow-up care in the subsequent years. It is generally very difficult for intersex individuals to receive medical care that is not indicated, from a medical perspective, for the registered sex/gender (e.g. preventive medical checkups for cancer of the gonads, if the individual has a female civil status or if the person is considered to be female).

There are no protests in Serbia against medical interventions performed on intersex individuals that take place without their personal, free, prior and informed consent, nor is there any public feedback (for instance in the media).

The legal situation

Serbia only allows for a sex/gender entry as «male» or «female». It is obligatory to register a child's sex/gender. The time frame is uncertain. The interviewees assume that a period of two to three weeks applies. No information was given on special provisions for intersex newborns. It is also unclear whether intersex individuals are allowed to change the gender they were assigned to later on.

The social situation

It is not common knowledge in Serbia that intersex individuals exist. Intersex is subject to a strong taboo. It is unclear whether there are other ways of dealing with intersex than Western medicine does. There are reports on prejudices against intersex individuals. The interviewees answered in the affirmative the question on structural and verbal discrimination as a result of being out or evidently living as an intersex individual. However, they suggested that life-threatening situations do not occur.

The interviewees did not specify how intersex individuals call themselves or how they are referred to.

5.2.2 Turkey

Medical practice

Turkey has a statutory health insurance system that covers 97 per cent of the population. In the case of a diagnosis of DSD, health insurance companies pay for cosmetic genital surgery, the removal of gonads and hormone therapy. Nobody pays for these measures themselves.

Most of the births take place at home in rural areas and in the presence of a midwife and in urban areas in a hospital in the presence of a physician. Cosmetic genital surgery is mostly performed on adolescents. The same applies to the removal of gonads and hormone therapy. After an intervention, medical aftercare is provided in the subsequent years. Intersex individuals are able to receive care that is not indicated, from a medical perspective, for the registered sex/gender (e.g. preventive medical checkups for cancer of the gonads, if the individual has a female civil status or if the person is considered to be female). However, access to this particular treatment may be difficult for intersex individuals.

So far, there has been only one public protest against medical interventions performed on intersex individuals that take place without their personal, free, prior and informed consent, namely during the Christopher Street Day Parade in 2012 (LGBT Pride March). The media reported on the parade.

The legal situation

Turkey only allows for a sex/gender entry as «male» or «female». The child's sex/gender needs to be registered within a period of one month. There are no special provisions for intersex newborns.

Intersex individuals are allowed to change the gender they were assigned to later on. A medical report that states that the applicant has the «correct» genitalia with regard to the desired sex/gender entry is a prerequisite for such an undertaking. The regulations correspond with those for transgender individuals. Hence, if e.g. an intersex individual who was assigned to the female sex/gender and whose outer genitalia and appearance are not (completely) stereotypically «male» wishes to change his civil status, he has to commence hormone replacement therapy with testosterone and undergo sex reassignment surgery, including a mastectomy, phalloplasty and scrotoplasty.

The social situation

It is not common knowledge in Turkey that intersex individuals exist. Intersex is subject to a strong taboo. Western medicine constitutes the only approach.

Common prejudices against intersex individuals, for instance, include the notion that the latter have a penis as well as a vagina, and that they are gigantic. Some individuals mistake intersex individuals for transgender sex workers. If an intersex individual was legally assigned to a civil status as female and appears as what is generally considered to be masculine, this person is mostly considered lesbian, regardless of her actual sexual orientation. Moreover, there is a series of further prejudices that affect gay men, lesbians, bisexuals, transgender and intersex individuals likewise.

Intersex individuals experience structural and verbal discrimination if they are out or evidently live as an intersex individual. However, the interviewees suggest that being out or evidently living as an intersex individual does not result in physical violence and life-threatening situations. Nevertheless, this does not preclude that intersex individuals do not experience violence and life-threatening situations due to the prejudices mentioned above in a way that is especially common for transgender individuals in Turkey.

Intersex individuals use the neutral term «Interseks» for themselves.

5.2.3 Ukraine

Medical practice

Ukraine does not have a statutory health insurance system, and only 4 to 5 per cent of the population are covered by a sickness insurance scheme. In the case of a diagnosis of DSD, health insurance companies neither pay for cosmetic genital surgery nor for removing the gonads or hormone therapy. There are individuals who pay for these medical measures out of pocket.

Most of the births take place in a birthing centre in rural as well as in urban areas and in the presence of a physician and a midwife. Cosmetic genital surgery is mostly performed on babies/infants. Gonads are largely removed in childhood and adolescence. Adolescents mostly receive hormone therapy. After an intervention, there is no follow-up care in the subsequent years. It is unclear whether it is difficult for intersex individuals to receive medical care that is not indicated, from a medical perspective, for the registered sex/gender (e.g. preventive medical checkups for cancer of the gonads, if the individual has a female civil status or if the person is considered to be female).

There are no protests in Ukraine against medical interventions performed on intersex individuals that take place without their personal, free, prior and informed consent.

The legal situation

Ukraine only allows for a sex/gender entry as «male» or «female». The child's sex/gender needs to be registered within one month. There are special provisions for intersex newborns. However, it is unclear what they look like. Once a sex/gender has been assigned, it cannot be changed anymore.

The social situation

It is not common knowledge in Ukraine that intersex individuals exist. Western medicine constitutes the only approach.

Intersex is subject to a strong taboo. As a result, NGOs have difficulties obtaining information. Intersex individuals are not visible, and organisations that make efforts to contact them can barely reach them. It is not possible to be out as an intersex individual without encountering structural and verbal discrimination, physical violence or life-threatening situations.

It is unclear whether there are any specific prejudices against intersex individuals beyond the prejudices against individuals with non-gender-conforming behaviour and appearance. It is known that intersex individuals are contemptuously called «abnormal men» or «abnormal women».

5.3 Africa

5.3.1 South Africa

Preliminary note

The NGOs that responded work in different environments: some in urban areas and predominantly with the white part of the population, others mainly in rural areas with a large proportion of black individuals. In the following, I will distinguish between NGO-UA (for NGO urban area) and NGO-RA (for NGO rural area).

Since intersex is heavily stigmatised in South Africa, it is difficult for intersex individuals to come out, organise and speak up on their own behalf. This applies especially – but not exclusively – to the black part of the population in rural areas, because everything that is included in LGBTI is generally considered to be a disease imported by the West that «by nature» does not exist among black individuals. According to the NGO-RA, this rejection and taboo is initiated and promoted by political and religious leaders. The population mostly knows that intersex exists, even if it does not have an expression for it, and it is frequently prepared to learn more about it.[21]

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[21] Contribution to the discussion by TIA on Dec. 11, 2012 during the 2nd International Intersex Forum, Stockholm.

Medical practice

South Africa does not have a statutory health insurance system, and only about 16 to 20 per cent of the population is covered by a sickness insurance scheme. In the case of a diagnosis of DSD, health insurance companies (probably) pay for removing the gonads and, according to the NRO-UA, most probably not for cosmetic genital surgery and hormone therapy, whereas the NGO-RA affirms the assumption of costs for both measures. According to the NGO-UA, there are a few individuals who can and do pay for these medical measures themselves (e.g. hormone replacement therapy after the removal of the gonads).

Most of the births in rural areas take place in the presence of a midwife and, according to the NGO-RA, at home and, according to the NGO-UA, in a birthing centre. In urban areas, most of the mothers give birth to their children in a hospital and in the presence of a physician and a midwife. According to the NGO-UA, cosmetic genital surgery is mostly performed on babies/infants, children and adolescents. Gonads are mostly removed in adolescence. No information was available on the age distribution with regard to hormone therapy.

To the knowledge of the NGO-RA, cosmetic genital surgery is mainly performed on babies/infants and adolescents. Gonads are mostly removed in adolescence, and hormone treatment mostly occurs in adolescence and adulthood. The organisations agree on the issue that there is no follow-up care in the subsequent years. The NGO-UA reports about occasionally life-threatening consequences of this underprovision. In contrast, the NGO-UA notes that the greater poverty of the black population in rural areas on the one hand aggravates the underprovision. On the other hand, it also means that intersex children from these areas are more likely to escape cosmetic operations.

The difference between the urban and largely white area of work of the NGO-UA and the rural and largely black area of operation of the NGO-RA is also mirrored in the answers to the question whether it is difficult for intersex individuals to receive care that is not indicated, from a medical perspective, for the registered sex/gender (e.g. preventive medical checkups for cancer of the gonads, if the individual has a female civil status or if the person is considered to be female). According to the NGO-UA, this can be difficult, whereas the NGO-RA states that it is very difficult.

In rural areas, infanticide may occur. Cases have become known about midwives who killed children directly after they were born, because an intersex child is considered as a curse for the whole community. The mother was informed that her child was stillborn. According to the NGO-RA, it is generally very difficult to obtain reliable information about this issue.

The only protests against medical interventions performed on intersex individuals that take place without their personal, free, prior and informed consent in South Africa emanate from the NGO-UA. These protests, however, do not have any public feedback (for instance in the media).

The legal situation

South Africa only allows for a sex/gender entry as «male» or «female». It is obligatory to register a child's sex/gender. Mothers are advised to do so immediately after birth and before they leave the hospital. Otherwise, it is suggested that it be done within a month, but this, too, is only a recommendation. There are no special provisions for intersex newborns.

The sex/gender assigned to the child can be changed later on («Alteration of Sex Description Act»). However, in practice this is difficult. The applicant has to attach a birth certificate to the application and a doctor's note that states that the applicant is intersex. Moreover, a psychologist‹s or social worker's report needs to document that the applicant has lived continuously, stably and convincingly for at least two years according to the gender role that corresponds with the gender the person wishes to have registered.

The social situation

It is not common knowledge in South Africa that intersex individuals exist.[22] The respondents report that there are strong taboos and prejudices. Whereas institutional discrimination based on gender and sexual orientation, that is, based on sexual identity, is comparatively low according to the NGOs, the situation is different with regard to verbal discrimination and physical violence, which sometimes escalates to the point of life-threatening situations. Although the NGO-UA states that it is possible to live openly as an intersex person without being verbally or physically attacked for this reason, it emphasises that it is very difficult and largely depends on the individual life situation and strength.

The NGO-RA has some information on intersex children who were forced to undress publicly to be discredited as «monstrosities». Cases are known in which children dropped out of school due to the verbal and physical violence they were subjected to by the teaching staff and schoolmates. Androgynous intersex individuals are heavily stigmatised and frequently insulted in public. Intersex women live in fear of being raped if they come out as intersex. Due to the increasing number of homophobic hate crimes, there is a growing danger of being raped or murdered, and this applies to closeted, androgynous intersex women, too, since they are usually taken for lesbians.

Apart from the NGO-UA, the NGO-RA and LGBTI organisations, there are no support structures for intersex individuals and their parents in South Africa. The NGO-RA emphasises that it is especially children who are completely isolated and do not know how to come to terms with the situations they are confronted with.

The NGOs interviewed are unaware of any neutral or positive terms for intersex in the languages of their country. Intersex individuals use the neutral term «intersex» for themselves. The term «hermaphrodite» is only used derogatively. «Stabane»

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[22] Of course, many South Africans are aware of the case of the 18-year-old athlete Caster Semenya, who won gold in 2009 and was then suspected of being intersex. According to the NGOs, there can be no question of a comprehensive awareness of the existence of intersex individuals in their own neighbourhood.

is a further derogatory term. Due to a lack of knowledge about intersex, intersex individuals are still referred to as «homosexual» («gay») or derogatively as «trassie» («transvestite»/«tranny»).

5.3.2 Uganda

Preliminary note

Other than in the other countries examined in this study, the Western medical approach to intersex is not predominant in largely rural Uganda, but rather the traditional magical perspective. In association with the typical circumstances of giving birth in the rural areas of Uganda, this generally leads to grave threats to the lives of intersex babies.

Medical practice

Uganda does not have a statutory health insurance system, and only about 4 per cent of the population is covered by a sickness insurance scheme. In the case of a diagnosis of DSD, health insurance companies do not assume the costs for medical measures. Some people pay for cosmetic genital surgery, the removal of the gonads or hormone therapy for themselves or for relatives.

In rural areas, most of the births take place at home or in a birthing centre. A traditional midwife and an experienced elder are present for most births. Every birth is traditionally a feast, and it is celebrated in the presence of the entire village community. Soon after the birth, every single member of the community welcomes, hugs, bathes, etc., the child. Hence, it is generally impossible to conceal the newborn's intersex appearance if it is noticeable as early as at the time of birth.

If an intersex (or sick) child is born in rural areas of Uganda, it is considered to be a punishment for an offence the mother committed either in the present life or an earlier life. The child and the mother are expelled from the community, which is essential for survival. Therefore, many mothers kill their newborn baby, hoping that the child's intersex remains undetected at the funeral.[23] The NGOs suggest that it is easier for the mothers to mourn their child than to live with it. If the child is not killed immediately after having been born, the mother mostly turns to a traditional healer and tries to resolve the curse, for example through ritual prayers. Even then the child's survival is not secured. Rather, it remains dependent on the mother's strength to cope with the exclusion from the community. Babies and infants who have access to Western medicine due to rich relatives in the city are usually operated on immediately. However, the cosmetic and functional results are generally disastrous, and the operations are life-threatening and accompanied by organ damage, regardless of the age of the patient and the type of intervention.

Therefore, the strategy of the NGOs is, first and foremost, pragmatically geared towards saving lives. They try to educate traditional midwives, representatives of the

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[23] Other members of the community rarely touch the dead body during the funeral.

village community and, if available, experts trained in Western medicine[24] on intersex. In these instances, the term DSD (Disorder of Sex Development) is used, that is, the concept of «disorder» anchored in Western medicine, since pathologisation offers a trustworthy counterbalance to the magical perspective.

The concepts of human rights and self-determination are essential to the work of the interviewed NGOs. However, since these terms have, according to the NGOs, barely any meaning in the perception of everyday life, and since change is primarily initiated bottom-up, the long-term goal in Uganda, Burundi and Rwanda[25] is to encourage mothers via education to speak out and demand better conditions.

Children are born at home or in a hospital and in the presence of a physician and a midwife in urban areas.

The interviewees' responses diverged on information about the frequency and the age at which medical interventions occur. Cosmetic genital surgery is mostly performed on babies/infants in families from rural areas. However, this only happens if the family has wealthy relatives in the city who pay for the intervention. Gonads are not removed, nor are hormone therapies performed.

Due to the work done in the context of health and HIV prevention for the more urban LGBTI community, the respondents are well aware that cosmetic genital surgery, the removal of the gonads and hormone therapies are mainly performed on adults. The organisations agree that there is no follow-up care in the subsequent years. Both of them consider it virtually impossible that intersex individuals would receive medical care that is not indicated, from a medical perspective, for the registered sex/gender (e.g. preventive medical checkups for cancer of the gonads when the individual has a female civil status or if the person is considered to be female).

There are no protests in Uganda against medical interventions performed on intersex individuals that take place without their personal, free, prior and informed consent.

The legal situation

Uganda only allows for a sex/gender entry as «male» or «female» (both organisations initially had ticked off the box that there was no sex/gender entry in official documents, which suggests that documents pertaining to a person's civil status only play a marginal role in everyday life). The organisations› responses diverge on the issue of a requirement to register a newborn child's sex/gender. Some are unaware of such a requirement. Other statements suggest that a person's sex/gender needs to be registered immediately after birth. There are no special provisions for intersex children. Whether the assigned sex/gender can be legally changed later on is currently unclear. However, there is lobbying to this effect.

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[24] According to the interviewees, experts trained in Western medicine are often aware of infanticide. However, they remain silent.

[25] So far, SIPD operates in 25 regions of the three countries mentioned.

The social situation

It is not common knowledge in Uganda that intersex individuals exist. Due to activism, knowledge on intersex has increased, especially in rural areas. There are strong taboos on, and prejudices against, intersex individuals. If they survive infancy, they are frequently expelled from the community or hidden by their parents. Adult intersex individuals are denied the right to reproduce. They experience structural discrimination as well as verbal and physical violence, which sometimes escalates to the point of life-threatening situations. The respondents noted that although adult intersex individuals are not necessarily killed, social stigmatisation leads many of them to commit suicide.

The responding NGOs are unaware of a neutral or positive term for intersex in the respective languages of the country. Intersex individuals use the term «intersex» for themselves. They also mentioned the term «dormedef», which is generally used as an insult.

5.4 South America

5.4.1 Uruguay

Preliminary note

Although the existence of intersex is common knowledge in Uruguay, intersex individuals are barely visible. Most of the intersex individuals are subject to «normalising» medical measures. They are usually not informed about their status as intersex later on. This renders self-organisation impossible. Therefore, there are no intersex organisations in Uruguay.

LGBT groups address the subject on behalf of intersex individuals and stand up for their right to make decisions about their lives and their bodies. Due to the social taboo on intersex, the interviewees are unaware of any out intersex individuals, even within the LGBT community. In general, it is difficult to obtain any information on medical measures and procedures. Repeated enquiries with, for instance, medical faculties always lead to the same response: Intersex is not a part of medical training, neither for future physicians, nor for nurses.

Medical practice

Uruguay has a state-financed health care system that covers 100 per cent of the population and 100 per cent of the medical treatment. In addition, it is possible to turn to private medical service providers at one's own expense. It is known that the health care system pays for removing the gonads and hormone therapies if DSD is diagnosed. It is unclear whether this applies to cosmetic genital surgery, too. The respondents are unaware of any individuals who pay for these measures out of pocket.

Most of the births take place in a hospital in rural as well as in urban areas and in the presence of a physician and the family. Cosmetic genital surgery is mostly performed on babies/infants. Gonads are removed in childhood. Information on hormone therapies is not available. There is no follow-up care after an intervention in the subsequent years. It is not clear whether it is difficult for intersex individuals to receive medical care that is not indicated, from a medical perspective, for the registered sex/gender (e.g. preventive medical checkups for cancer of the gonads, if the individual has a female civil status or if the person is considered to be female).

Although there are protests in Uruguay against medical interventions performed on intersex individuals that take place without their personal, free, prior and informed consent, there is no public feedback (for instance in the media). The protesters are generally members of the LGBT community and LGBT groups/NGOs.

The legal situation

Uruguay only allows for a sex/gender entry as «male» or «female». The child's sex/gender needs to be registered within a period of 10 days. There is no special provision for intersex newborns. It is possible to alter the assigned sex/gender later on. The same applies to the name.

For this purpose, however, the intersex individual is required to revert to the procedure provided for transgender individuals. Civil proceedings are applied for at the family court. The following documents are required: a report by a multidisciplinary team from the Directorate-General of the public authority, who is responsible for recording the civil status (Dirección Nacional de Identificación Civil); witness statements by neighbours or friends who state that the applicant has lived according to their chosen gender (as opposed to their assigned gender) throughout a period of at least two years and that the applicant's chosen identity is accepted within their personal environment; reports issued by physicians and psychologists that confirm that the gender identity deviates from the assigned gender. The witnesses are heard in a court hearing prior to a court decision. If the decision happens to turn out in favour of the applicant, the latter obtains all the rights of the chosen gender, except for the right to marry. The individuals who are (really) entitled to make an application are transgender individuals who have undergone a sex-reassignment operation; transgender individuals aged 18 or older who have been living according to the chosen gender identity for at least two years (without any further measures); and transgender individuals under 18 years of age with parental consent, or who are supported by a legal representative and a youth worker if the parents do not consent to the procedure.

The social situation

Although it is common knowledge in Uruguay that intersex individuals exist, they are not visible. Whether there are taboos with regard to intersex is unknown. It is also unknown whether there are other ways of approaching intersex other than the way Western medicine does. It is unclear whether intersex individuals are subjected to prejudices and, if so, what kind of prejudices. The question on structural and verbal discrimination and physical violence could not be answered due to the invisibility of intersex individuals.

The LGBTI community uses the neutral term «intersex» for intersex individuals. «Hermaphrodite» is the prevalent term in society.

5.5 Oceania

5.5.1 Australia

Medical practice

Australia has a statutory health insurance system that covers 97 per cent of the population. In the case of a diagnosis of DSD, health insurance companies pay for cosmetic genital surgery, the removal of gonads and hormone therapy. Nobody pays for these measures themselves.

Most of the births in rural and urban areas take place in hospitals and in the presence of a physician and a midwife and the family. Cosmetic surgical operations are mostly performed in adolescence and adulthood. The same applies to the removal of the gonads and hormone therapy. There is barely any medical and psychological follow-up care after a surgical intervention in the subsequent years. Generally, it is very difficult for intersex individuals to receive care that is not indicated, from a medical perspective, for the registered sex/gender (e.g. preventive medical checkups for cancer of the gonads, if the individual has a female civil status or if the person is considered to be female).

There are protests in Australia against medical interventions performed on intersex individuals that take place without their personal, free, prior and informed consent. However, there is no public feedback (for instance in the media). Non-intersex individuals who become aware of the extent and the consequences of such interventions mostly disapprove of them thereafter.

The legal situation

Australia only allows for the categories «male» and «female» in the birth certificate and all nationally relevant documents that contain a sex/gender entry. Since 2011, all intersex (and transgender) individuals who locate themselves between or outside of the two sexes/genders «male» and «female» are allowed to choose X as an entry. The most important prerequisite is a medical letter stating that the applicant is living as «a person of indeterminate, unknown or non-specified gender».[26]

The child's sex/gender needs to be registered within 30 days after the birth. There is no special regulation for intersex newborns. However, there is an option to change the assigned gender in national documents later on. Three Australian states require a medical report stating that a person is intersex. It is only possible to switch between the categories «male» and «female». The state of Victoria provides the additional option of not specifying sex/gender instead of having to choose M/F. In the rest of the Australian states, intersex individuals need to be diagnosed as transgender and are required to fulfil the respective conditions for a gender reassignment in order to have their sex/gender entry changed.

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[26] Cf. OII Australia, Dec. 9, 2011: «On Australian Passports and ‹X› for Sex», http://oiiaustralia.com/14763/on-x-passports/ (accessed June 30, 2013).

The social situation

It is common knowledge in Australia that intersex individuals exist. Reportedly, there are taboos with regard to intersex and prejudices against intersex individuals as well as structural and verbal discrimination, physical violence or life-threatening situations if an individual is out or lives as an intersex individual. In all of these cases, we are generally dealing with discrimination due to non-compliant gender behaviour and appearance. The extent of the discrimination also depends on how strongly those in the respective environment insist on stereotypical behaviour and to what extent gender-transgressive behaviour is tolerated. There is significant overlap with homophobic discrimination here.

This kind of discrimination is common in the indigenous Australian culture, too. Since homophobia is particularly pronounced, the pressure to be normal is, according to the interviewees, equally high. It remains unclear whether we are dealing with an attitude that was adopted from Western religious groups or whether these prejudices existed before the white population settled the country.

Intersex individuals use the neutral term «intersex» for themselves.

5.5.2 New Zealand

Medical practice

New Zealand does not have a statutory health insurance system. Approximately 30 per cent of the population is covered by a sickness insurance scheme.[27] Health insurance companies do not pay for cosmetic genital surgery, the removal of gonads or hormone therapy. Instead, the state assumes the costs of the respective interventions up to the age of 16. To the interviewees' knowledge, nobody pays out of pocket.

Most of the births take place in hospitals in rural as well as in urban areas and in the presence of a physician and a midwife. Cosmetic genital surgery is mostly performed on babies/infants. Gonads are largely removed in adolescence, and adolescents receive hormone therapy. After an intervention, there is no follow-up care in the subsequent years. It is generally very difficult for intersex individuals to receive medical care that is not indicated, from a medical perspective, for the registered sex/gender (e.g. preventive medical checkups for cancer of the gonads, if the individual has a female civil status or if the person is considered to be female).

There are only very few protests in New Zealand against medical interventions performed on intersex individuals that take place without their personal, free, prior and informed consent. However, the media reported extensively about the two roundtables conducted by the New Zealand Human Rights Commission in 2010 and 2011. The roundtables were attended by intersex individuals, their families, health care representatives, scholars and politicians.

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[27] Calculated on the basis of the population of New Zealand (4,451,017) on Jan. 1, 2013, cf. http://www.stats.govt.nz/tools_and_services/tools/population_clock.aspx (accessed Jan. 1, 2013) and the statistics provided by the New Zealand health insurance companies of March 2012, cf. http://www.healthfunds.org.nz/pdf/2012MarHealthInsuranceStatistics.pdf (accessed June 1, 2013).

The legal situation

New Zealand only allows for the categories «male» and «female» in the birth certificate and all nationally relevant documents that contain a sex/gender entry. Since December 2012, as in Australia, intersex and transgender individuals are allowed to have an X entered in their passports. The respective individual is required to produce a declaration on oath as a precondition.

The child's sex/gender is supposed to be registered «as quickly as possible». A time limit of two months is considered to be typical. Intersex newborns can be registered as «indeterminate». However, this entry is temporary only. The sex/gender assignment can be changed later on before a family court. However, the binary options «male» and «female» are the only options.

The social situation

It is not common knowledge in New Zealand that intersex individuals exist. Western medicine determines the way intersex is dealt with.

Reportedly, there is a large range of prejudices against intersex individuals. The extent of prejudices varies greatly, depending on whether a person is known to be intersex or whether this person looks «different», that is, does not match the stereotypical appearance of the assigned sex/gender. The interviewees suggested that no structural and verbal discrimination, physical violence or life-threatening situations result from being out or living as an intersex individual. The respondents added, however, that intersex individuals whose appearance does not conform to the stereotypical image of a man or a woman are more at risk than other parts of the population in many large cities of New Zealand.

Intersex individuals use a multiplicity of terms for themselves, among others, the neutral term «intersex».

5.6 Asia

5.6.1 Taiwan

Medical practice

Taiwan has a statutory health insurance system. However, it remains unclear what portion of the population is covered. Whether health insurance companies pay for cosmetic genital surgery, the removal of the gonads or hormone therapy in the case of a diagnosis of DSD is uncertain, too. It is known that there are individuals who pay for these medical measures themselves.

Most of the births take place in hospitals in rural as well as in urban areas. No information was imparted on who is generally present. It is virtually impossible to obtain information on medical procedures in Taiwan. Even the enquiry on the frequency, age distribution and the kind of medical interventions with a doctor friend who works with intersex individuals himself remained inconclusive. Therefore, there is no information available on the age distribution with regard to cosmetic genital surgery, the removal of the gonads and hormone therapies. However, the interviewees know that there is no follow-up care in the subsequent years. It is not clear whether it is difficult for intersex individuals to receive medical care that is not indicated, from a medical perspective, for the registered sex/gender (e.g. preventive medical checkups for cancer of the gonads, if the individual has a female civil status or if the person is considered to be female).

While there are protests in Taiwan against medical interventions performed on intersex individuals that take place without their personal, free, prior and informed consent, there is, however, no public feedback (for instance in the media). Media feedback is limited to being interested in the «intersex phenomenon», which is exoticised on the one hand, and debated thoughtfully and with sympathy at the same time.

The legal situation

Taiwan only allows for a sex/gender entry as «male» or «female». It is obligatory to register a child's sex/gender. No information was given on the period of time. It is not clear whether there are special regulations for intersex newborns and whether an intersex individual can change the assigned sex/gender later on.

The social situation

It is not common knowledge in Taiwan that intersex individuals exist, and the perception of intersex in society as a whole is the same as that of Western medicine. Intersex is treated as a taboo. Intersex individuals are threatened by prejudices and subjected to structural discrimination (e.g. when job-seeking because of an unambiguous outer appearance that is not typical of a gender stereotype) and experience verbal and physical violence. Whether the latter situations assume life-threatening dimensions, too, is not clear. However, there is no doubt that the experiences are highly dependent on the environment and that not every intersex individual can afford to be out.

The respondents did not provide any information on the terms intersex individuals use for themselves or the ones that others use for them.

6. Annex

6.1. Tabular overview of the answers

Legend: --- (no entry), 1;2 (differing answers from countries with two questionnaires), DK (don't know)

	Belgium	France (2)	Germany (2)	Serbia	Ukraine	
MEDICAL PRACTICE and PROTOCOLS						
Do you have a statutory health insurance system in your country?						
	Yes	Yes	Yes	Yes	No	
How many people are covered by a sickness insurance scheme in your country?						
	+/- 95 %	99-100 %	99 %	(see 5.2.1)	3-5 %	
In case of a diagnosis of DSD, do health insurance companies pay for						
HRT	Yes	Yes	Yes	No	No	
Genital Surgery	Yes	Yes	Yes	No	No	
Removal of Gonads	Yes	Yes	Yes	No	No	
Do people pay for such surgery and/or HRT out of pocket?						
	Yes	No; Yes	Yes	---	Yes	
Genital surgery is mostly performed on						
Babies	Yes	Yes	Yes	Yes	Yes	
Children	Yes	Yes	Yes	Yes	---	
Adolescents	Yes	Yes; ---	Yes	---	---	
Adults	---	---	---	---	---	
The removal of gonads is mostly performed on						
Babies						
Children	---	Yes; DK	Yes	Yes	Yes	
Adolescents	Yes	---; DK	Yes	---	Yes	
Adults	---	---; DK	Yes	---	---	

	Turkey	Uganda (2)	South Africa (2)	Uruguay	New Zealand	Australia	Taiwan
	Yes	No	No	(see 5.4.1)	No	Yes	Yes
	97.29 %	4 %; 0 %	+/- 20 %	100 %	+/- 30 %	100 %	---
	Yes	No	No; Yes	Yes	No	Yes	---
	Yes	No	Yes	(see 5.4.1)	No	Yes	---
	Yes	No	No (probably); --	Yes	No	Yes	---
	No	Yes	Yes (few can afford it); No	No	No	No	Yes
	---	---; Yes	Yes	Yes	Yes	---	DK
	---	---	Yes; ---	---	---	---	DK
	Yes	---	Yes	---	---	Yes	DK
	---	Yes; ---	---	---	---	Yes	DK
	---	---	Yes;---	Yes	Yes	---	DK
	Yes	---	Yes	---	---	Yes	DK
	---	Yes; ---	---	---	---	Yes	DK

	Belgium	France (2)	Germany (2)	Serbia	Ukraine	
HRT is mostly performed on						
Babies						
Children	---	Yes; DK	Yes	---	---	
Adolescents	Yes	---; DK	Yes	---	Yes	
Adults	Yes	---; DK	Yes	---	---	
Is there any follow-up (aftercare) in the years following surgery that was based on a diagnosis of DSD?						
	No	No	Yes	No	No	
Is it difficult for an inter*person to obtain medical care that is not related to the assigned gender?						
No problem	---	Yes; DK	---	---	---	
Usually no problem	---	---; DK	---	---	---	
Can be difficult	---	---; DK	---	---	---	
Very difficult	Yes	---; DK	Yes	Yes	---	
Almost impossible	---	---; DK	---	---	---	
Rural Areas: Where do people mostly give birth						
At home	---	---	---	---	---	
Birth house	---	---	---	---	Yes	
Hospital	Yes	Yes	Yes	Yes	---	
Rural Areas: Who is usually present?						
Midwife	Yes	Yes	Yes	Yes	Yes	
Doctor	Yes	Yes	Yes	Yes	Yes	
Elders	---	---	---	---	---	
Family	---	---	---	---	---	
Cities: Where do people mostly give birth?						
At home	---	---	---	---	---	
Birth house	---	---	---	---	Yes	
Hospital	Yes	Yes	Yes	Yes	---	
Cities: Who is usually present?						
Midwife	Yes	Yes	Yes	Yes	Yes	
Doctor	Yes	Yes	Yes	Yes	Yes	
Elders	---	---	---	---	---	
Family	---	---	---	---	---	

	Turkey	Uganda (2)	South Africa (2)	Uruguay	New Zealand	Australia	Taiwan
	---	---	DK; ---	DK	---	---	DK
	Yes	---	DK; Yes	DK	Yes	Yes	DK
	---	Yes; ---	DK; Yes	DK	---	Yes	DK
	Yes	No	No	No	No	No	No
	---	---	---	DK	---	---	DK
	---	---	---	DK	---	---	DK
	Yes	---	Yes; ---	DK	---	---	DK
	---	---	---; Yes	DK	Yes	Yes	DK
	---	Yes	---	DK	---	---	DK
	Yes	Yes	---; Yes	---	---	---	---
	---	---; Yes	Yes; ---	---	---	---	---
	---	---	---	Yes	Yes	Yes	Yes
	Yes	---	Yes	---	Yes	Yes	DK
	---	---	---	Yes	Yes	Yes	DK
	---	---; Yes	---	---	---	---	DK
	---	Yes; ---	---	Yes	---	Yes	DK
	---	---; Yes	--	---	---	---	---
	---	---	---	---	---	---	---
	Yes	---; Yes	Yes	Yes	Yes	Yes	Yes
	---	---; Yes	Yes; ---	---	Yes	Yes	DK
	Yes	---; Yes	Yes	Yes	Yes	Yes	DK
	---	---	---	---	---	---	DK
	---	---	---	Yes	---	Yes	DK

	Belgium	France (2)	Germany (2)	Serbia	Ukraine	
Do people protest against medical practices and protocols that are performed without the personal, free, prior and fully informed consent of the inter* individual?						
	Yes	Yes	Yes	No	No	
If yes, is there any public feedback to such protests (e.g. media coverage)?						
	No	No	Yes	No	No	
LEGAL SITUATION						
Do you have gender markers in your official documents (e.g. driving licence, identity card)?						
None	---	---	---	---	---	
Male/Female	Yes	Yes	Yes	Yes	Yes	
Male/Female/Other	---	---	---	---	---	
Do you have gender markers in your passports?						
None	---	---	---	---	---	
Male/Female	Yes	Yes	Yes	Yes	Yes	
Male/Female/Other	---	---	---	---	---	
Is it legally required to register the sex/gender of a newborn (baby) in your country? If so, how quickly do you have to register the sex/gender of a baby (weeks)?						
	Yes/ 1 week	Yes/ 3 days	Yes/ 1 week	Yes/ 2-3 weeks, not sure	Yes/ 4 weeks	
Are there any special legal regulations for inter*individuals when the baby's sex/gender is registered?						
	Yes/max. 3 months	Yes/3 years	Yes/theoretically no limit, but see 5.1.3	DK	Yes/---	
Are inter* individuals allowed to change the gender marker assigned at birth? If so, what are the prerequisites?						
	No	Yes/ see 5.3	Yes/ see 5.1.3	DK	No	
SOCIAL LIFE						
Is the existence of inter* common knowledge in your country?						
	No	No	No	No	No	

	Turkey	Uganda (2)	South Africa (2)	Uruguay	New Zealand	Australia	Taiwan
	No	No	Yes+No; No	Yes	No	Yes	Yes
	Yes	No	No; ---	Yes	Yes	Yes	No
	---	[Yes]; ---	---	---	---	---	---
	Yes	---; Yes	Yes	Yes	Yes	Yes	Yes
	---	---	---	---	---	---	---
	---	[Yes]; ---	---	---	---	---	---
	Yes	---; Yes	Yes	Yes	---	---	Yes
	---	---	---	---	Yes/ male female and X	Yes/ male female and X	---
	Yes/ 4 weeks	No; Yes/ at birth	Yes/ after birth up to 4 weeks (recommended)	Yes/ 10 days	Yes/ ---	Yes/ 30 days	Yes/ DK
	No	No	No	No	Yes/ temporary reg. as «indeterminate»	No	DK
	Yes/see 5.2.2	[No]/see 5.3.2	Yes/see 5.3.1	DK/see 5.4.1	Yes/see 5.5.2	Yes/see 5.5.1	DK
	No	No	No	Yes	No	Yes	No

	Belgium	France (2)	Germany (2)	Serbia	Ukraine	
How are inter*individuals called? / How do they call themselves in your country? (Please specify whether the term is derogatory, neutral, a self-designation, etc.)						
	Inter* (neutral)	Intersexué, intersexe (neutral) hermaphrodite (self-designation) hermaphrodite (derogatory or used by people who DK another term) DSD (medical practicioners)	Inter*, Intergeschlechtlich (neutral, self-designation, is in the process of becoming accepted as pc terms) Zwitter, Herm (as a self-designation only, otherwise offensive) girl/ boy/ man/ woman with DSD (pathologising, is only used by a small fraction of intersex individuals)	---	Abnormal men, abnormal woman (derogatory)	
Are there taboos concerning inter* in your country?						
	DK	No; Yes	Yes	Yes	Yes	
Are there other social/medical ways of dealing with inter* and persons who are inter* than the ways Western me						
	No	No; DK	No; [Yes] (see 5.1.3)	DK	No	
Are you aware of any prejudices against persons who are inter*?						
	Yes	Yes	Yes	Yes	DK	
Is it possible to be out as an inter* person?						
without being discriminated (verbally, on a structural level)	Yes	Yes; DK	No	No	No	
without being harassed (physically)	Yes	Yes	No (see 5.1.3)	No	No	
without mortal danger (e.g. being killed)	Yes	Yes	Yes (see 5.1.3)	DK	No	

	Turkey	Uganda (2)	South Africa (2)	Uruguay	New Zealand	Australia	Taiwan
	Interseks (neutral)	Dormedef (---); no specific name	Intersex (neutral, self-designation) Stabane (derogatory) hermaphrodite (derogatory) gay, trassie (derogatory)	Intersex (used by LGBT community) Hermaphrodite (common designation)	Wide variety	Intersex (neutral, self-designation)	---
	Yes	---; Yes	Yes	DK	Yes	Yes	Yes
dicine deal with them in your country?							
	No	Yes (see 5.3.2)	Yes (see 5.3.1)	DK	Yes (see 5.5.2)	No	No
	Yes	Yes	Yes	DK	Yes	Yes	Yes
	No	No	Yes	DK	Yes	No	No
	Yes	No	Yes; No	DK	Yes	No	No
	Yes	No; Yes (see 5.3.2)	Yes; No	DK	Yes	No	DK

Intersex individuals are people who cannot be classified according to the medical norms of so-called male and female bodies. Inter* individuals are still pathologised and classified as "sick" or "abnormal", they also experience physical violence and life-threatening situations. This study by Dan Christian Ghattas names the largely invisible discrimination against these individuals and offers a first overview of their life situations from 12 selected countries in various regions of the world. The study provides points of departure for strategies to improve the human rights situation of intersex individuals and recommends to actors how to develop measures in this area in order to render visible gender diversity as a means of enhancing human rights protection.

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ISBN 978-3-86928-107-0