

AMC16-12: Position Paper on Intersex DRAFT

Draft submitted to IGLYO's Board – 2 August

Draft submitted to MOs, 2nd mailing – 23 August

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Government of the Netherlands

IGLYO is funded by the European Union, the Council of Europe European Youth Foundation and the Government of the Netherlands.
IGLYO aisbl is a registered charity in Belgium (No d'entreprise: 808808665) IGLYO Rue de l'Industrie 10, Brussels 1000, Belgium

21 Chapter 1 - What Is Intersex?

22 *Basic Concepts*23 **a. Intersex**

24 Intersex is an umbrella term describing people who are born with sex characteristics (gonads,
25 hormones, chromosomes, genitals and/or secondary sex characteristics) that do not strictly fit
26 into the dominant binary “male” and “female” categories. These biological sex characteristics
27 are naturally occurring and can be present at birth or become apparent later in life.

28
29 **b. Sex vs. Gender**

30 Many people assume sex and gender are the same thing, but they are actually very different.
31 Sex describes a person’s sex characteristics or biological aspects of their sex. Gender
32 describes a person’s identity, or how they feel on the inside. The majority of people have a
33 gender identity that matches the sex they were assigned at birth. However, some people
34 identify with a gender that is different from the sex they were assigned at birth. This describes
35 somebody who is transgender. Gender exists on a spectrum, with people identifying with a
36 variety of gender identities, including but not limited to: genderqueer, genderfluid, agender,
37 non-binary, neutrois, etc. It should be recognized that all ideas around sex and gender are
38 socially constructed. Sex characteristics by themselves do not inherently fit within our socially
39 constructed ideas of sex and gender (i.e. a penis is not technically “male,” we have just
40 constructed that idea within our society).

41
42 **c. Sex s on a spectrum**

43 As more awareness is raised around intersex issues, a greater number of people are coming
44 to realise and accept that sex is also on a spectrum. Intersex people fit somewhere on that
45 spectrum, based on their sex characteristics. Some intersex people’s sex characteristics will
46 align more with the constructed binary categories: male or female, and many intersex people
47 have sex characteristics that are a combination of the two.

48 IGLYO recognises that the spectrums of gender and sex are not linear. Male and female are
49 not categories that lie at either end of a continuum of possibilities, with all other potential
50 permutations falling somewhere in between. Rather, sex and gender exist within a spectrum
51 that is three-dimensional, with all variances existing at once. Male and female are commonly
52 portrayed as the sole or dominant possibilities but they are just two of many.

53
54 **d. Transgender**55
56 **i. Trans vs. Intersex**

57 Many people frequently conflate transgender and intersex. However, they are not the same
58 thing. As previously stated, intersex describes a person’s biological sex, while transgender
59 describes somebody whose gender identity does not align with the sex they were assigned
60 at birth. A person can be both transgender and intersex, such as when they don’t identify



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61 with the gender they were assigned at birth. Yet, some people who are both transgender and
62 intersex will choose not to identify as transgender because their transition was solely related
63 to their intersex experience.

64 ii. Surgeries

65 The biggest difference between transgender and intersex people is that transgender people
66 often have a difficult time accessing the transition related health information and care that
67 they may require while intersex people are constantly fighting against the performance of
68 unnecessary and unwanted medical procedures and treatment that they didn't ask for or
69 need.

70 iii. Cisgender

71 Cisgender is a term to describe a person who is not transgender. Unfortunately, this term
72 was created without taking intersex people into consideration. Because of this, many
73 intersex people don't identify as cisgender because their experiences were vastly different
74 from those of typical cisgender people. However, they also don't want to appropriate trans
75 identities either. Therefore, regrettably, because society lacks the proper understanding and
76 inclusive language, intersex people are regrettably erased from conversations about sex and
77 gender, and related human rights, that affect and concern them.

78

79 e. **Sexual Orientation and Identity**

80 Being intersex does not mean somebody will identify with a particular sexual orientation. Just
81 like non-intersex people, intersex people can have a variety of sexual orientations. They can
82 also have a variety of gender identities. Being intersex does not mean that someone will
83 necessarily identify as being both 'male' and 'female', though some intersex people do. Many
84 intersex people also identify as either 'male' or 'female' with many identifying as the gender
85 they were assigned at birth.

86

87 f. **Identity**

88 While intersex is first and foremost about sex characteristics, many people choose to use
89 intersex as an identity as well. However, intersex is not an identity on its own, and somebody
90 who was not born with intersex traits may not adopt that identity for themselves. Additionally,
91 intersex people choose not to identify as "intersex," preferring to use a different label for
92 themselves. All intersex people have the right to define themselves. People should not be told
93 or pushed into identifying a certain way.

94

95 *Terminology*

96 a. **Intersex**

97 i. Intersexed, intersexual

98 When people are unfamiliar with discussing intersex issues, they will often use words like
99 "intersexed," "intersexual" or "an intersex." All of these are incorrect. Just like you wouldn't call
100 someone "maled" or "femaled," "intersexed" is not correct, either. And while there's nothing
101 inherently wrong with "intersexual" or "intersexuality," those often imply a sexuality, like



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102 “homosexual” or heterosexual.” This will often confuse those who are unfamiliar with intersex
103 people.

104 **b. Disorders of Sex Development (DSD)**

106 i. History of DSD

107 In 2006, a group of American doctors came together and created a “consensus statement”
108 about intersex medical treatment. In this Consensus, the term “Disorders of Sex Development”
109 was introduced to replace “intersex.” This is incredibly controversial, as it names all intersex
110 variations as disordered, implying that intersex people need to be “fixed” or “healed.” This kind
111 of language should not be used unless specifically chosen by the intersex person themselves.

112 ii. Diagnosis

113 There are many medicalised intersex variations that doctors classify intersex people under,
114 though many people do not fit neatly under these classifications. Often, people are
115 misdiagnosed under the medical framework being utilised and get poor medical care because
116 of this.

117 These medicalized variations are highly disputed, because doctors often classify intersex
118 people as “disordered.” This kind of medicalized thinking tends to cause harm to intersex
119 people and it will be discussed later in this paper.

120 iii. Differences of Sex Development

121 Some people and organizations will use “Differences of Sex Development” as a way to work
122 with the medical establishment. This is a slightly more accepted term over “Disorders”, though
123 many intersex people do not use this term.

124

125 **c. Hermaphrodite**

126 This term has historically been used to describe intersex people, based on the Greek
127 mythological character Hermaphroditus, who had both ‘male’ and ‘female’ sex characteristics.
128 Unfortunately, this term is misleading and stigmatizing, and is now considered outdated by
129 most. Some intersex people have chosen to reclaim hermaphrodite, using it proudly to
130 describe themselves. However, that’s something that is strictly for them to do. Non-intersex
131 people should not use this term to describe people.

132 Some non-english speaking countries don’t have a word for intersex, but instead have a word
133 closer to “hermaphrodite”, which is considered acceptable in those particular cultures.

134

135 **d. Dyadic**

136 This term is used to describe non-intersex people, as it is simpler than saying “non-intersex.”
137 Some intersex people prefer to use it. Some intersex people prefer not to, because it can
138 enforce existing binaries.

139

140 **e. Proper Terminology**

141 Whenever discussing about intersex people, either “intersex person,” “intersex people,”
142 “intersex traits,” or “intersex realities” should be used.



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143 As with any label, when talking to an intersex person, ask them the terminology they prefer
144 you to use.
145

146 *Statistics*

147 It's difficult to give a precise number on how many people are intersex because so many
148 intersex people across the world still experience high levels of shame and stigma, which
149 doesn't allow them to be open about their experiences. Additionally, many intersex people still
150 use medicalized terminology to describe themselves, and therefore won't identify as intersex
151 when given the chance. It also happens that many people don't even know they're intersex,
152 or won't find out until later in life. Intersex traits frequently become apparent at puberty or later
153 on in life. Through collected data, some estimates put intersex people at 1 in 1500 or 1 in
154 2000. It is believed among intersex activists that this figure falls far short and may only account
155 for those intersex people who have visible intersex traits at birth and who are thus subjected
156 to surgical interventions to align or normalise their sex characteristics. The most current
157 research by the Netherlands Institute for Sociological Research¹ puts intersex people at about
158 1 in 200. This figure would put the number of Intersex people at well over 3.5 million in Europe
159 alone.
160

161 Chapter 2 - Human Rights Violations

162

163 *Main human rights violations faced by intersex youth*

164 a. **Inequalities in health care**

165

166 i. Pathologizing terminology - treated as disordered

167 Intersex people are rarely told they are intersex by the medical establishment. Rather, doctors
168 have historically medicalized intersex people: classifying them as disordered, and categorising
169 them into pathologizing conditions.

170 The goal of the entire medical establishment is to fix things, or to make them "better" and this
171 causes a plethora of issues for intersex people, who do not need to be "fixed." Intersex is not
172 something that can be cured, nor should it need to be. Because of this thinking, doctors
173 continue to see intersex people as broken and disordered, intervening in their medical care,
174 when in fact, most of the times, no or limited medical intervention is necessary.

175 ii. Surgeries

176 The worst consequence of this pathologizing treatment is unnecessary, nonconsensual
177 surgeries on intersex youth, children, and babies. When an intersex child is born, doctors

¹ https://www.scp.nl/english/Publications/Publications_by_year/Publications_2014/Living_with_intersex_DSD,
accessed in July 2016



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178 frequently feel the need to surgically alter the child, to “fix” them so that their bodies conform
179 more to their idea of what gender the child is and how they should look. In essence these
180 are non-essential, unnecessary cosmetic surgeries that may have far reaching and long term
181 consequences for the child involved. Many times the doctors run tests to try and guess the
182 gender of the child, but that gender is never certain. Some intersex children grow up not
183 identifying with the gender they were assigned. Unfortunately, if a doctor has performed
184 surgery in order to align the child’s sex with the presumed gender, it can be incredibly
185 problematic for the child. Almost always, these surgeries are irreversible, removing healthy,
186 functioning tissue, for no medical reason whatsoever. Parents are counselled that these
187 surgeries are in the best interest of the child leading to an extremely high rate of parents
188 consenting to surgeries on behalf of their children. Research points to the fact that the
189 information parents are presented with can greatly affect parents’ decision making, with
190 medicalised information increasing the rate at which surgery is chosen and de-medicalised
191 information decreasing the rate of parents choosing surgeries.²

192 iii. Physical Integrity

193 Frequently, these interventions take place in the child’s first years, before the child has
194 reached an age when they can express what they want and how they feel about themselves.
195 Therefore, these procedures take place without the full, informed consent of the child. As the
196 vast majority of these interventions are not medically necessary, their basis is only cosmetic
197 and societal. Many intersex children grow up to regret the interventions performed on them
198 and would have liked to have choices about what, if any, medical intervention took place on
199 their body.

200 This complete lack of bodily integrity can lead to inordinate amounts of shame and stigma, as
201 well as internalised feelings of lack of worth or validity.

202 iv. Access to documents (or information about oneself)

203 These surgeries not only happen without the consent of the intersex person in question, but
204 they can also occur without the fully informed consent of the parents or guardians, or even
205 without their consent at all. In many countries, there have been instances of parents not
206 knowing a surgery was performed on their child. This secrecy is a terrible violation of children’s
207 rights. It can then be incredibly difficult for children to access their medical records, with no
208 way to discover information about what happened to their bodies.

209 v. Right to privacy

210 The right to privacy, as protection from external and public intrusion on the personal life of the
211 individual, is continuously violated. Intersex people’s privacy is repeatedly broken, from a
212 wrong assignment of gender at birth, intrusive and unnecessary cosmetic surgeries performed
213 without their consent, abuse by medical professionals, to questions and harassment in their
214 daily lives. Some intersex people constantly have to give explanation about their documents
215 that present a name and a gender marker which do not correspond to how people perceive
216 their physical appearance.

217 vi. Misinformed medical establishment

² <http://www.ncbi.nlm.nih.gov/pubmed/23742202>, accessed in July 2016

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218 Many medical professionals believe that what they are doing is in the best interest of the child
219 because these procedures have become enshrined as medical tradition. These interventions
220 are taking place without strong evidence that they will have a positive effect on the lives of
221 these children or without any long term follow up studies to back them up and should as such
222 be considered experimental. The lack of research on the lives of intersex people and the
223 medical communities continued disregard of the testimony of intersex adults leads to the
224 tradition of sex “assigning”, “aligning” or “normalising” surgeries continuing.

225
226

227 **b. Inequalities in societal treatment**

228
229

i. Bullying

230 Intersex children are frequently mistreated by their peers, if they perceive differences and
231 some even are subjected to hate crimes, hate speech, and bullying. This bullying can be
232 damaging to the child and leads to more stigma and negative mental health outcomes.

233

ii. Lack of education

234 There is a severe lack of education about intersex people starting with primary school, and
235 continuing throughout all levels of education. The general public is taught in school that there
236 are only two sexes: male and female. This two-sex myth is perpetuated throughout all areas
237 of education: biology classes, health classes, even in gym class. Students are not taught about
238 intersex realities, and when intersex people discover that they are intersex, many of them have
239 no idea what that even means. Similarly, non-intersex children don't have any idea what it
240 means to be intersex and if they perceive differences they often treat intersex children poorly
241 because of this lack of knowledge.

242

iii. Employment discrimination

243 Intersex people can be victim of discrimination and harassment in the workplace or when
244 entering the labour market because of their physical appearance and gender expression. They
245 can have gaps in education and professional experience because of the ongoing treatments
246 and traumas.

247 Intersex people can have difficulties finding jobs because of their intersex traits and because
248 of their documents which could present names and gender markers that do not correspond to
249 how people perceive their physical appearance.

250

iv. Access to support

251 Intersex support groups are few and far between throughout the world. Intersex people do
252 not have a proper support system, as most people are not educated about intersex realities,
253 and, therefore, do not have the skills or motivation to become a support system to intersex
254 people when the time comes.

255 Intersex people are often not told about the existing support groups when they discover that
256 they are intersex. They are not directed to other intersex people like them, and, in all actuality,
257 intersex people are instead sometimes told that there is nobody else like them, or that they
258 will never meet another person like themselves.

259

v. Right to found a family



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260 Many intersex people are born without the ability to have children. This infertility can be very
261 damaging for intersex people who don't live in a place where founding a family through
262 adoption or otherwise is a possibility. Many employers and governments don't offer assistance
263 when founding a family. Paternal leave and other benefits are available for non-intersex
264 people, but are not always available for intersex individuals. Assistance should be provided
265 by governments to help intersex people in starting a family of their own.

266 vi. Self-determination and development of self, right to change names and gender
267 markers

268 There are only a few countries in Europe where those intersex people that need to have the
269 option to change their gender marker or name on public records can do so. This is a basic
270 right that intersex people should have access to, as their gender identity does not often align
271 with the sex that they are assigned at birth. This ability to change a gender marker and name
272 is a basic right to self-determination that all intersex people should have access to.
273

274 *Intersex rights protection and violations covered in human rights*
275 *documents:*

276 A full list of references was compiled by OII International and can be consulted here:
277 [http://oiieurope.org/wp-content/uploads/2016/03/International-intersex-human-rights-](http://oiieurope.org/wp-content/uploads/2016/03/International-intersex-human-rights-movement_Links-to-human-rights-documents-adressing-intersex-and-important-events.pdf)
278 [movement_Links-to-human-rights-documents-adressing-intersex-and-important-events.pdf](http://oiieurope.org/wp-content/uploads/2016/03/International-intersex-human-rights-movement_Links-to-human-rights-documents-adressing-intersex-and-important-events.pdf)
279

280 a. **Yogyakarta Principles** - were created in 2006 [full name: Yogyakarta Principles on
281 the Application of International Human Rights Law in relation to Sexual Orientation and
282 Gender Identity] and consist of a set of principles relating to SOGI; it intends to lay out how
283 current international human rights law standards apply to address the abuse of the human
284 rights of lesbian, gay, bisexual and transgender (LGBT) people. Principle 18 has been stated
285 to also apply to intersex people. "B. *Take all necessary legislative, administrative and other*
286 *measures to ensure that no child's body is irreversibly altered by medical procedures in an*
287 *attempt to impose a gender identity without the full, free and informed consent of the child in*
288 *accordance with the age and maturity of the child and guided by the principle that in all actions*
289 *concerning children, the best interests of the child shall be a primary consideration;*
290 *C. Establish child protection mechanisms whereby no child is at risk of, or subjected to,*
291 *medical abuse;"*

292
293 b. **UN Special Rapporteur on torture and other cruel, inhuman or degrading**
294 **treatment or punishment**, issued in 2013 a statement condemning non-consensual surgical
295 intervention on intersex people. The report says:

296
297 "76. *There is an abundance of accounts and testimonies of persons being denied medical*
298 *treatment, subjected to verbal abuse and public humiliation, psychiatric evaluation, a variety*
299 *of forced procedures such as sterilization, State-sponsored forcible ... hormone therapy and*
300 *genital-normalizing surgeries under the guise of so called "reparative therapies". These*



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301 *procedures are rarely medically necessary, can cause scarring, loss of sexual sensation, pain,*
302 *incontinence and lifelong depression and have also been criticized as being unscientific,*
303 *potentially harmful and contributing to stigma. (A/HRC/14/20, para. 23).*
304

305 *77. Children who are born with atypical sex characteristics are often subject to irreversible sex*
306 *assignment, involuntary sterilization, involuntary genital normalizing surgery, performed*
307 *without their informed consent, or that of their parents, "in an attempt to fix their sex", leaving*
308 *them with permanent, irreversible infertility and causing severe mental suffering...*
309

310 *78. The mandate has noted that "members of sexual minorities are disproportionately*
311 *subjected to torture and other forms of ill-treatment because they fail to conform to socially*
312 *constructed gender expectations."*
313

314 c. **Resolution issued by Council of Europe in 2013**

315 Council of Europe adopted Resolution 1952 on "Children's Right to Physical Integrity". The
316 resolution calls on member states to: undertake further research to increase knowledge about
317 the specific situation of intersex people, ensure that no-one is subjected to unnecessary
318 medical or surgical treatment that is cosmetic rather than vital for health during infancy or
319 childhood, guarantee bodily integrity, autonomy and self-determination to persons concerned,
320 and provide families with intersex children with adequate counselling and support.
321

322 d. **WHO and UN Interagency Report, 2014**

323 The document "Eliminating Forced, Coercive and Otherwise Involuntary Sterilization, An
324 Interagency Statement" was issued in May 2014 by the OHCHR, UN Women, UNAIDS,
325 UNDP, UNFPA and UNICEF. It says:
326

327 *"Like any other contraceptive method, sterilization should only be provided with the full, free*
328 *and informed consent of the individual. However, in some countries, people belonging to*
329 *certain population groups, including people living with HIV, persons with disabilities,*
330 *indigenous peoples and ethnic minorities, and transgender and intersex persons, continue to*
331 *be sterilized without their full, free and informed consent."*
332

333 e. **Council of Europe Issue Paper, 2015**

334 The Council of Europe issued in May 2015 a paper entitled "Human Rights and Intersex
335 People". The document highlighted a historic lack of attention to intersex human rights, stating
336 that current social and biomedical understandings of sex and gender make intersex people
337 "especially vulnerable" to human rights breaches. The Commissioner for Human Rights made
338 eight recommendations. For the first time, these recognized a right to not undergo normalising
339 treatment.
340

341 f. **UN Office of the High Commissioner for Human Rights report, 2015**



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342 Human rights violations against intersex people were also described in the report issued by
343 the OHCHR.

344
345 *“53. Many intersex children, born with atypical sex characteristics, are subjected to medically*
346 *unnecessary surgery and treatment in an attempt to force their physical appearance to align*
347 *with binary sex stereotypes. Such procedures are typically irreversible and can cause severe,*
348 *long-term physical and psychological suffering.”*

349
350 It called on UN member states to protect intersex persons from discrimination, and address
351 violence by: banning conversion therapy, involuntary treatment, forced sterilization and forced
352 genital and anal examinations, prohibiting medically unnecessary procedures on intersex
353 children.

354
355 g. **FRA: “The Fundamental Rights: Situation of Intersex People”, 2015**
356 The European Agency for Fundamental Rights published “The Fundamental Rights Situation
357 of Intersex People” in 2015, confirming the violations expressed by the Intersex movement
358 and highlighting that 21 Member States in the EU still practice unnecessary and “normalising
359 surgeries” and in 8 Member states it is for the legal representative to decide if surgeries are
360 performed.

361
362 h. **The United Nations Joint Statement on ending violence and discrimination**
363 **against LGBTI people, 2015.**

364
365 *“ They may also face abuse in medical settings, including unethical and harmful so-called*
366 *“therapies” to change sexual orientation, forced or coercive sterilization, forced genital and*
367 *anal examinations, and unnecessary surgery and treatment on intersex children without their*
368 *consent. “*

369
370 i. **The United Nations Committee on the Rights of the Child, 2015-2016**

371 The United Nations Committee on the Rights of the Child has made concluding statements on
372 Switzerland, France and Ireland.

373
374 On Switzerland, 2015, they say:

375
376 *“42. While welcoming the adoption of a new provision of criminal law prohibiting genital*
377 *mutilation, the Committee is deeply concerned at:*

378 *(b) Cases of medically unnecessary surgical and other procedures on intersex children,*
379 *without their informed consent, which often entail irreversible consequences and can cause*
380 *severe physical and psychological suffering, and the lack of redress and compensation in such*
381 *cases*

382
383 *43. The Committee draws the attention of the State party to the joint recommendation/general*
384 *comment No. 31 of the Committee on the Elimination of Discrimination against Women and*
385 *No. 18 of the Committee on the Rights of the Child on harmful practices (2014), and urges the*
386 *State party to:*



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

392
393 On France, 2016, they say:

394
395 “47. While noting with appreciation the progress made by the State party in eradicating female
396 genital mutilation, the Committee is nevertheless concerned by the many young girls still at
397 risk and the possible resurgence of the phenomenon. The Committee is also concerned that
398 medically unnecessary and irreversible surgery and other treatment are routinely performed
399 on intersex children.

400
401 48. Recalling the joint general recommendation/general comment No. 31 of the Committee on
402 the Elimination of Discrimination against Women and No. 18 of the Committee on the Rights
403 of the Child on harmful practices, the Committee recommends that the State party gather data
404 with a view to understanding the extent of these harmful practices so that children at risk can
405 be more easily identified and their abuse prevented. It recommends that the State party:

406 (b) Develop and implement a rights-based health-care protocol for intersex children, ensuring
407 that children and their parents are appropriately informed of all options; that children are
408 involved, to the greatest extent possible, in decision-making about their treatment and care;
409 and that no child is subjected to unnecessary surgery or treatment.”

410
411 On Ireland, 2016, they say:

412
413 “39. The Committee notes as positive the adoption of the Gender Recognition Act 2015 by the
414 State party. It remains concerned, however, about cases of medically unnecessary surgeries
415 and other procedures on intersex children before they are able to provide their informed
416 consent, which often entail irreversible consequences and can cause severe physical and
417 psychological suffering, and the lack of redress and compensation in such cases.

418
419 40. The Committee recommends that the State party:

420 (a) Ensure that no one is subjected to unnecessary medical or surgical treatment during
421 infancy or childhood, guarantee bodily integrity, autonomy and self-determination to children
422 concerned, and provide families with intersex children with adequate counselling and support;
423 (b) Undertake investigation of incidents of surgical and other medical treatment of intersex
424 children without informed consent and adopt legal provisions in order to provide redress to the
425 victims of such treatment, including adequate compensation;
426 (c) Educate and train medical and psychological professionals on the range of sexual, and
427 related biological and physical, diversity and on the consequences of unnecessary surgical
428 and other medical interventions for intersex children. “”

429
430
431 h. **Good practices: Malta**

432 In 2015 Malta adopted a ground-breaking piece of legislation referring to trans and intersex
433 people and rights. In the bill known as the Gender Identity, Gender Expression and Sex
434 Characteristic Act, there is recognition of the right of each person to their gender identity and



435 their free development. The bill introduces a procedure before a notary which requires a
436 simple declaration based on a person's self-determination and prohibits requests for medical
437 information. The entire process lasts a maximum of 30 days. It thus delivers a key task of
438 gender recognition, that is to quickly enable the individual to pursue their life without further
439 interference. The bill stipulates that parents or legal guardians may decide to postpone the
440 inclusion of a gender marker on the birth certificate until the child's gender identity is
441 determined.
442

443 Chapter 3 - Challenges in Society: what societal challenges the 444 intersex community faces.

445 1. Challenges

446 a. Lack of knowledge

- 447 i. There is little to no information about intersex people in school, college,
448 university or informal education. Educational curricula should be
449 organised to inform and train both students, staff and support workers
450 on intersex realities.
- 451 ii. An educational curriculum should be created to teach both the medical
452 establishment and government institutions about intersex realities.
453 Teaching these establishments about the circumstances and
454 experiences that intersex people face can, hopefully in time, help to
455 reduce discrimination against intersex people in all systems.
- 456 iii. Information is really difficult to disseminate across language barriers to
457 places in Europe where English is not the first language. Information
458 should be made more accessible through translating content that has
459 already been produced. New up to date content should be produced
460 and distributed. This content should be distributed physically through
461 leaflets, posters, infographics and informative sessions. This content
462 should also be distributed on the internet. By using websites and social
463 media channels, visibility can be increased to teach the general public
464 about intersex issues.

465 b. (in)Visibility

- 466 i. Positive media coverage, making information much more accessible
467 through personal narratives and fiction stories (recorded and written,
468 animations), organizing street actions (performances, flash mobs,
469 drama pieces).

470 c. Educational needs go largely unmet, increased focus is needed on the 471 following areas:

- 472 i. Educating parents
- 473 ii. Educating healthcare professionals; in particular, it is important to



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- 476 educate professionals connected to ante-natal health care and the
477 delivery of the child
- 478 iii. Educating professionals in the education system, teachers, school
479 counselors and other school staff
 - 480 iv. Making more space for expression in the public sphere, for example, by
481 increased media coverage focused on educating the general public
 - 482 v. Educating legislators and policy makers on intersex realities and needs
 - 483 vi. Conducting research on the needs of intersex people and what barriers
484 they face in the full enjoyment of their human rights
 - 485 vii. Educating at all levels on appropriate, human rights-affirming
486 terminology

d. NO SECTION TITLE HERE

- 490 i. The serious lack of knowledge about intersex issues and the historical
491 and still largely prevalent practice of secrecy have serious
492 consequences for today's intersex youth, such as:
 - 493 1. Lack of support, in particular peer support, which leads to
494 feelings of isolation
 - 495 2. Research on the need for psychological support for intersex
496 shows that this need largely goes unmet; in one study 52.3% of
497 parents report receiving no psychological support and 35%
498 report receiving this only partly
 - 499 3. Shame and stigma: through the continued practice of secrecy,
500 shame and stigma are perpetuated
 - 501 4. Lack of positive role models: often role models are only covered
502 in relation to their intersex traits in, for example, coverage of
503 sporting sex testing, which is generally highly derogatory in
504 nature.
 - 505 5. Media and popular media coverage of intersex people is often
506 sensationalised and portrayed in a manner that does not affirm
507 the intersex person's right to dignity. Derogatory and
508 problematic vocabulary still persists. All stakeholders should
509 aim to use human rights affirming language such as: intersex
510 people, intersex traits, sex characteristics, and avoid
511 stigmatising and pathologizing language such as
512 hermaphrodites, disorders or disordered or language that
513 serves to sensationalise or exoticize should be avoided.

Comment [t1]: Needs citation

2. Basis:

a. Heteronormativity, cisnormativity and gender norms

514 The norms around sexuality and gender have a big impact on how we portray people and their



518 identities. Heteronormativity, cisnormativity and gender norms all assume that there are two
519 distinct categories of people who are polar opposites. It assigns certain behavior, expectations
520 and expression upon people based on these categories and people who fall somewhere in
521 between or out of these categories are made invisible. It is therefore important that these
522 norms are challenged and that different identities and bodies are talked about and celebrated
523 as well.

524 **b. Two-sex myth**

526 Through school we are taught that there are two distinct sexes. This can pose various
527 problems for intersex students. This can lead to the mistaken belief that intersex bodies
528 somehow constitute a distinct third sex category, ignoring the fact that having non-normative
529 sex characteristics does not automatically exclude you from being a man or a woman. They
530 can also lead to feelings of exclusion for intersex students. Absolutes in teaching about human
531 biology should be avoided. Statements that include all woman or all men tend to be
532 exclusionary to parts of the student population. Statements like these can easily be modified
533 to most or many while still utilising the same teaching materials.

534 **c. Stereotypes**

536 It is too often assumed that all intersex people must come under the LGB or T umbrellas when,
537 in fact, they also have their own umbrella of variations. Intersex people can identify as
538 transgender or LGB but many do not. Some mistakenly believe that measures that serve the
539 LGBTQ communities well also serve the intersex community. Intersex people also need their
540 own community because issues that pertain to living with intersex traits are their own issue
541 and need to be addressed as such.
542 There is a stereotype that all intersex people are sterilised or infertile, however, some manage
543 to avoid sterilisation surgeries.

544 **d. Misinformation (general public, medical establishments)**

- 546 i. Misinformation about intersex issues are prevalent throughout society.
547 They are too often portrayed as broken, disordered or in some way
548 abnormal. Various ideas based on outdated and highly medicalised
549 views of intersex traits still persist. The idea that intersex people are
550 both sexes or hermaphrodites still holds a lot of public sway.
- 551 ii. Ideas that intersex people need to be fixed in some way are still
552 common and are reigning within the medical establishment. Sex
553 assigning, sex aligning and sex normalising treatments are still seen as
554 a way to hide the child's differences without consideration that society
555 is shifting and has shifted considerably in acceptance of non-normative
556 bodies since these practices originated.
557 Many current medical treatments originate in ideas that are considered
558 outdated. In some cases parents used to be told that certain cosmetic
559 procedures would decrease the likelihood of lesbianism and



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560 tomboyism. While the originating reasoning is not as widely used,
561 surgical practises based on this reasoning persist.

562 iii. Paternalistic views that are still too commonly found within the
563 healthcare establishments often lead to a lack of consideration for the
564 intersex persons lived experiences and consider they previous
565 teachings and practices as absolute truths. Worryingly many intersex
566 people share instances of wrong information being provided by their
567 medical professional.

568 iv. In research on the need of psychological support for parents, a worrying
569 40.9 % of parents reported not fully understanding the information
570 provided about their child's biology. Despite indications that many
571 parents do not understand fully the information being provided to them,
572 they are still asked to consent to proposed medical treatments. Consent
573 of this nature cannot be considered fully informed consent.

Comment [t2]: Needs citation

e. Lack of positive role models

576
577 There is a lack of positive role models due to stigma and invisibility of intersex people. Unlike
578 any other identities, intersex people are not presented in mainstream media. In produced
579 media, intersex people are rarely portrayed in a positive way, but rather as curiosities. This
580 leads to intersex youth rarely seeing positive portrayals of themselves in any of the media they
581 consume.

582 If there were more intersex people positively portrayed by the media, other intersex people
583 will be more likely to come forward and feel less isolated.

Comment [t3]: Chapter 3 is still being worked on.

586 Chapter 4 - The I of LGBTQI+: including intersex in the queer 587 community, in activism and in campaigning

588
589 The LGBTQI+ community is an ever expanding umbrella related to gender identity, gender,
590 sexual orientation, sex characteristics and sexuality in general. It has expanded from its initial
591 focus on gay and lesbian identities only and has been growing in many places across the
592 world as a community of a wide range of identities related to sexual orientation or gender
593 identity. The newest addition to the umbrella in many countries is intersex. When a new
594 identity or experience becomes a part of a community it is very important to wonder how they
595 can be included and accepted within the community in an acceptable manner. Adding a letter
596 to the acronym might seem like a reasonable step, but it is important that organizations and
597 communities realize that, in order to be able to add another letter in good faith, they need to
598 show that they have the capacity, will and level of inclusion needed. They need to be able to
599 consult with intersex people about their own inclusion in these organizations and they need to



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600 actively reach out and show that they are fighting for the rights of intersex people as well. They
601 need to show that the community and/or the organization is willing to do what it takes to make
602 sure intersex people have their rights protected and that they are included in society. This
603 chapter will provide some practical examples and ideas on how to effectively include intersex
604 in your work and community.
605

606 *Inclusion: The importance of intersectionality*

607 Including intersex persons and topics in LGBTQI community activities and discussions is
608 essential for intersectional, **norm critical activism**. Coherently addressing all dominant binaries,
609 regarding sex, gender, sex characteristics, race, class, dis/ability, etc, is crucial for creating
610 non dichotomous social systems, which strive to divide power more equally, while enabling
611 more fair distribution of access to goods and services to all. It is the omnipresent structural
612 binary system that divides powers and denies access, legitimacy and agency to social
613 minorities and it can only be tackled when addressed systematically and **intersectionally**.
614

615 Without including all persons and social groups who experience social and systemic
616 discrimination and erasure based on sexual orientation, gender identity, gender expression
617 and/or sex characteristics, they cannot become a unified movement. Intersex persons may
618 identify with one or more identities which belong under the LGBTQI umbrella and it is thus
619 very important that all their personal circumstances are acknowledged and respected. On this
620 note, however, it is important to note that not all intersex persons feel or wish to feel a sense
621 of belonging to LGBTQI communities and spaces, and it should not be expected from them to
622 necessarily want to engage in these movements. Another thing that must be done before and
623 also always during including intersex persons and topics in LGBTQ events, spaces,
624 communities, legislation, fundraising and movements is to self/critically think about how to
625 include them, to avoid tokenism and appropriation. Dyadic (non/intersex) persons should aim
626 to be constantly aware of their privilege for not being intersex. If an initiative or organisation
627 includes intersex persons or topics, they should do so in a manner that always considers
628 needs and specificities of intersex persons as narrated and experienced by intersex persons.
629 If there are no intersex persons included in local LGBTQ communities, activists and sources
630 from other countries should be sought out. The best interest of intersex persons should always
631 be a priority and they should never be included or mentioned solely to appear more inclusive,
632 timely and popular, or to secure funding more easily, etc. Whenever possible, LGBTQI
633 organizations should facilitate empowerment of intersex persons to become voices regarding
634 their human rights. This can be done in various ways, i.e. offering spaces for meetings, offering
635 use of materials and other facilities, supporting in fundraising processes, etc. LGBTQI activism
636 generally fights for the rights of people who fall outside the heteronormative and cisnormative
637 gender binary. Intersex people can have similar or related types of oppression with the
638 LGBTQI community, such as medicalization, inclusion (both socially and legally), norms and
639 values and more.
640



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641 There are numerous ways in which LGBTQI organizations and movements can include
642 intersex persons or topics in activism and campaigning, and here are a few examples:

643

644 • Organizing intersex themed events (good opportunities are specific intersex holidays,
645 i.e. October 26th: Intersex Awareness Day and November 8th: Intersex Day of
646 Remembrance and Intersex Solidarity Day),

647 • Providing intersex persons, activists and groups with facilities and resources (space,
648 materials, funding, etc.),

649 • Producing educational materials and events fore-fronting narratives of intersex
650 persons (leaflets, stickers, badges, conferences, study sessions, celebratory events),

651 • Changing organizations' names, logos and public image to include and accommodate
652 needs of intersex persons,

653 • Educating LGBTQI activists and communities regarding the specificities of human
654 rights of intersex persons,

655 • Organizing social media campaigns (photo campaigns and exhibitions, videos and
656 movies, fact sheets, hashtags, etc.)

657 • Implementing public awareness and visibility raising actions (poster distribution,
658 flashmobs, theatre productions, animations, performances, human libraries etc.)

659 • Organising and participating in demonstrations and protests, including both intersex
660 specific topics but also other LGBTQ topics and broader intersectional issues (sex
661 work, disability, reproductive rights, anti-racism, anti-xenophobia, etc.),

662 • Enabling and empowering intersex inclusive and respectful media representations,

663 • Implementing usage, translation and distribution of already existing materials made by
664 and for intersex persons for further education, awareness and visibility raising.

665

666

667

