

## **"THIS IS A SEGMENT OF SOCIETY OF WHICH WE DO NOT KNOW ANYTHING"**

NATIONAL SITUATIONAL ANALYSIS REPORT, HUNGARY





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## CONTENTS

I.1. The status of intersex people in Hungary	5
I.2. National legal framework	11
I.2.1. Hate crime legislation and definition in Hungary	11
I.2.2. Anti-discrimination legislation	13
I.2.3. Legislation on health	15
I.2.4. Legal gender recognition	18
I.3. National central policies and good practices	19
Háttér Society (LGBTQI organization)	21
Transvanilla Transgender Association	21
The Office of the Commissioner for Fundamental Rights	21
II. Field research: interviews with experts, stakeholders,	
policy and decision makers	23
II.1. Background and profile of interviewees	23
II.2. Basic Knowledge (of terminology and legal framework)	23
II.3. Status and support of intersex people in the country	24
II. 4. Recommendations	28
III. Field research: interviews with intersex people	30
III.1. Background and profile of interviewees	30
III.2. Personal experiences and needs	30
III.3. General views – the status of intersex people in the country	31
IV. General conclusions and recommendations	34
IV.1. Conclusions	34
IV.2. Recommendations	36



#### Foreword

The overall objective of the "BRING-In" project is to prevent and combat discrimination on the grounds of sex characteristics, by building the capacity of social and health care professionals in order to better meet the needs of intersex people and provide them with high quality support services and avoid abusing and discriminatory practices. Háttér Society has been working to promote social inclusion and positive visibility for intersex people, that is, people who "are born with physical, hormonal or genetic features that are neither wholly female nor wholly male; or a combination of female and male; or neither female nor male" (IGLYO, OII Europe & EPA, 2018:31), and was happy to join the project coordinated by the Panteion University of Social and Political Sciences and the NGO Symplexis in Greece, bringing together experts from Greece, Bulgaria, Cyprus and the UK as well as Hungary.

A crucial task of Háttér Society in the "BRING-In" project was to obtain information on the status of intersex people, one of the most invisible social groups in Hungary. (As one of the interviewees in the project, a psychologist insightfully explained: "These are people who are very much closeted. It must be really difficult to be excluded, not being part of the binary system, and to be fully alone, as they do not have a community even within the LGBT group. Support by one's chosen family is a great resilience factor in the lives of many LGBT people, but I assume it is much more difficult for intersex people to have access to this resource.") To gain information, Háttér conducted a combination of desk and field research on the basis of the research protocol prepared by Panteion University. The field research included semi-structured personal interviews with relevant stakeholders and experts, as well as intersex people themselves and/or close family members of them.

The results of this research are included in the present publication. Because of the COVID-19 pandemic and the implementation of protective measures, the interviews were conducted via video meeting / conference applications or telephone. Excerpts from the interviews are quoted throughout the relevant parts of the report.

3



Part I reports on the desk research results, while Parts II and III analyze the field research results. Part IV summarizes the main findings of both the desk and the field research, and contains recommendations for future work.



#### I. Desk research results

#### I.1. The status of intersex people in Hungary

When working on our report on the situation of intersex people in Hungary, we relied on desk research (interview transcripts with intersex people, parents and health professionals conducted in 2012 by Háttér Society;<sup>1</sup> news articles published on the subject;<sup>2</sup> and a report written by Hungarian CSOs in 2018<sup>3</sup>) as well as interviews conducted as part of the Bring-In project with various stakeholders, with intersex people and the parent of an intersex child.

Both earlier and recently made interviews show that many intersex people think they are alone and cannot connect with others or learn about experiences similar to theirs. Their right to health and bodily integrity are often violated, "normalizing" operations have been and are performed without their informed consent. Parents of intersex people often do not have the chance to get proper and comprehensible information on the health status of their children, and therefore they frequently rely on doctors' opinions, even though there is now a growing body of outcomes data from other countries showing that early surgery can lead to physical and psychological harm for intersex people.

Surgeries on intersex people are performed in Hungary. In an article published in Gyermekgyógyászat (Pediatrics) in 2008, surgeons at Semmelweis University summarise their experience with such surgeries, and provide statistics:

<sup>&</sup>lt;sup>1</sup> Interviews conducted as part of the "Monitoring Implementation of the Committee of Ministers' Recommendation" project, supported by ILGA-Europe, 2012

<sup>&</sup>lt;sup>2</sup> A recent article on intersex children, which also contains an interview with a geneticist, published in a popular lifestyle web magazine (Divany.hu): "Egyszerűbb volna, ha csak kislányok és kifiúk születnének – de ez nincs így" ("It would be simpler if only girls and boys were born – but this is not the case"), 26 January 2021, <u>https://divany.hu/szuloseg/2021/01/11/interszex-gyerek/;</u> an interview with an intersex woman: "Az orvosnál csak azt mondogattam magamban, hogy én nő vagyok, nem lehetnek heréim" ("At the doctor's, I kept telling myself: I am a woman, I cannot have testicles"), 26 April 2020, <u>https://24.hu/elet-stilus/2020/04/26/interszex-interju-baba-dorottya-Imbtq/</u>

<sup>&</sup>lt;sup>3</sup> Report about the Implementation of the Council of Europe Recommendation to member states on measures to combat discrimination on grounds of sexual orientation or gender identity (CM/Rec(2010)5) in Hungary, prepared by Háttér Society, Hungarian LGBT Alliance, Transvanilla Transgender Association, 2018.



between 1984 and 2008 92 feminisation and 35 masculinisation surgeries were performed on intersex patients. The National Health Insurance Fund reported<sup>4</sup> that their records show 22 genital reconstruction surgeries performed on minors in the period 2010-2013.

In theory, the provision in Hungarian legislation that requires that consent given by the parents "cannot have a detrimental effect on the health of the patient" (cf. the chapter on National legal framework), that is, that consent can only be given to treatments medically required, provides protection against surgeries that are not medically required. The question on what treatment is "medically required" for intersex people, however, is not clearly settled. In an interview conducted as part of the Bring-In project, a surgeon claimed that there have been no "routine corrective surgeries for the past 15 years; if there is an operation at all, it is fundamental that fertility and neural areas are kept; no, there are no destructive surgeries, only fully reversible ones." However, he also added that he is the only surgeon with a special training background to do these surgeries, that there are other clinics in Hungary where intersex babies are operated, and that only "one third of parents accept the suggestion that no surgery should be made at a very early age, we should wait for a few years."

Based on other articles published on the subject,<sup>5</sup> it seems to be the case that most Hungarian medical professionals share the view that early interventions are needed to "save" children from the negative impact of gender ambiguity. One article, for example, clearly states that the aim of the intervention should be to create functioning heterosexuals out of intersex people.<sup>6</sup> In a recently published interview in a popular lifestyle web magazine, a geneticist also implicitly suggests that

<sup>&</sup>lt;sup>4</sup> Hungary, National Health Insurance Fund (2014), Letter No. 1021/41-3/2014 in response to an information request by the Hungarian Helsinki Committee, 3 March 2014.

<sup>&</sup>lt;sup>5</sup> In order to assess the medical communities' opinion, a search was conducted in the Hungarian Medical Bibliography (Magyar Orvosi Bibliográfia), for a list of results see: <u>https://mob.aeek.hu/itmsbydict.jsp?DCTID=207430&DCTDESC=HERMAPHRODITISMUS,</u> <u>https://mob.aeek.hu/simplesearch.jsp?WHAT=-1&TOSRCH=interszex</u>

<sup>&</sup>lt;sup>6</sup> László Ságodi (2006), 'Interszexuális betegek ellátása, az átmeneti külső genitalék sebészeti kezelése', Gyermekgyógyászat, 57:5, 543-552.



"corrective" operations are performed when he states: "People are born who seem to have two genitals. In reality, they only have one, which is not properly developed. They are the ones called intersex people. In their case, it is the paediatric surgeon who (based on the examination of internal and external sex organs) decides upon what type of genitals should be formed for the child, by surgery."<sup>7</sup>

Recent legislative changes only make the situation of intersex persons worse in Hungary. From summer 2020, an individual's birth sex, once recorded, cannot be amended. The prohibition of legal gender recognition clearly violates international human rights norms, and the consistent case law of the European Court of Human Rights. It also has a very negative impact on parents' and doctors' willingness to postpone surgical procedures: while until 2020, doctors could argue that a child's legal gender can be changed at any point if the child is intersex, now "birth sex" is put in the registry before a baby is 6 weeks old and it cannot be changed. This will possibly entail much more unnecessary / not medically required treatments and surgical interventions compared to the previous years.

Interviewees in Háttér Society's 2012 and present research also talked about discrimination in the health system: mainly lack of information on medical treatment and their situation and possible future developments, insensitive communication by health professionals, and being objectified.

Although there are groups and even organizations that support people and parents of children with different intersex conditions (e.g. a group for people living with Turner syndrome<sup>8</sup> or a foundation for children with CAH (Congenitalis Adrenalis Hyperplasia)<sup>9</sup> or a private Facebook group of people living with Klinefelter syndrome<sup>10</sup>, etc.), these groups are based on identification related to certain physical syndromes and not a common intersex identity. We know of plans to create groups

<sup>&</sup>lt;sup>7</sup> <u>https://divany.hu/szuloseg/2021/01/11/interszex-gyerek/</u>

<sup>&</sup>lt;sup>8</sup> <u>http://www.turnerszindroma.hu/</u>

<sup>&</sup>lt;sup>9</sup> Endoped Foundation, <u>http://endoped.shp.hu</u>

<sup>&</sup>lt;sup>10</sup> <u>https://www.facebook.com/groups/syndroma</u>



from an interview with an intersex woman published by an internet news portal<sup>11</sup> and from the interview we made within the framework of the Bring-In project with the mother of an intersex child (who mentioned that a trans organization wanted to set up a self-help group for intersex people and parents of intersex chilren), but none of these function at this point. As one of our interviewees, an expert working in an LGBTQI organization, said: the stigmatization of LGBT people, which has been getting stronger in Hungary during the past 5-10 years, does not help. Intersex people feel stygmatized enough, an in a social environment where all sexuality-related minority groups are stigmatized (and described as representatives of a demonized "gender ideology", attacking "natural sexes" and "families"), they are most probably wary of being "grouped together" with LGBT+ people and organizations. Thus their self-organization is hindered, and their voice remains unheard.

A basic problem is that – like in many other countries – individuals' "birth sex" is registered very early in Hungary, and it is based on a binary sex / gender system. This puts a huge pressure on parents, who have often felt uninformed by health professionals even before 2020, but since registered "birth sex" cannot be modified any more from summer 2020, doctors might be even more in the position of decision-makers than previously. Even if they know that "corrective surgeries" performed at a very early age are unacceptable from a human rights perspective (e.g. the Parliamentary Assembly of the Council of Europe called on member states to "prohibit medically unnecessary sex-"normalising" surgery, sterilisation and other treatments practised on intersex children without their informed consent"<sup>12</sup>), they may feel entrapped by the unchangeability of "birth sex" in Hungarian registration.

As for the lived experience of intersex people in Hungary, data collected by the European Union's Fundamental Rights Agency (FRA) between May and July

<sup>&</sup>lt;sup>11</sup> "Az orvosnál csak azt mondogattam magamban, hogy én nő vagyok, nem lehetnek heréim" ("At the doctor's, I kept telling myself: I am a woman, I cannot have testicles"), 26 April 2020, <u>https://24.hu/elet-stilus/2020/04/26/interszex-interju-baba-dorottya-Imbtq/</u>

<sup>&</sup>lt;sup>12</sup> Resolution 2191 (2017) Promoting the human rights of and eliminating discrimination against intersex people, <u>https://pace.coe.int/en/files/24232/html</u>



2019<sup>13</sup> also show that Hungarian intersex respondents face more discrimination than LGBT respondents. When asked about personal experiences of discrimination in the preceding 12 months in 8 areas of life (when looking for work, at work, when looking for housing, when using healthcare or social services, in educational institutions, in public spaces like cafés, restaurants or shops, or when showing an ID/official document), 83% of intersex respondents marked "yes" (the highest proportion among EU member states), compared to 49% of all LGBTI respondents. 72% of intersex respondents had felt discriminated against due to being LGBTI by healthcare or social services personnel (e.g. a receptionist, nurse or doctor, a social worker) in the 12 months preceding the research (compared to 22% of all LGBTI respondents). (It should be remarked that results based on a small number of responses are statistically less reliable, and FRA flagged the results pertaining to intersex respondents in Hungary as based on 20 to 49 unweighted observations.)

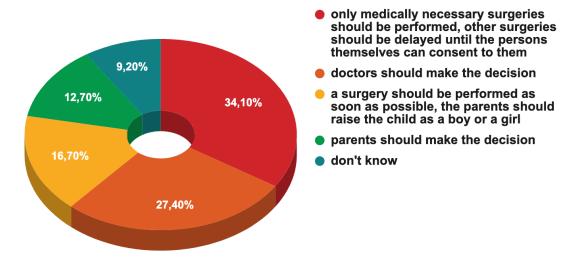
Recent data is also available about societal attitudes towards intersex babies. A representative survey research commissioned by the Hungarian LGBT Alliance, and carried out by Medián Polling Agency in September 2019 shows that while 17% of Hungarians think that intersex babies should be operated on as soon as possible, and be raised clearly as a girl or a boy, 9% of respondents are undecided, 34% (the largest segment of respondents) think that only medically necessary surgeries should be performed, and all other interventions should be delayed until the persons themselves can consent to them; 27% would relegate such decisions to doctors and 13% to parents.<sup>14</sup>

<sup>&</sup>lt;sup>13</sup> Data from: <u>https://fra.europa.eu/en/data-and-maps/2020/lgbti-survey-data-explorer</u>

<sup>&</sup>lt;sup>14</sup> Hungarian LGBT Alliance: Social attitudes towards LGBT+ issues in Hungary. September 2019. http://lmbtszovetseg.hu/sites/default/files/mezo/file/lmbtszov\_research2019sept\_en.pdf p. 15.



If a child is born with ambiguous genitalia based on which it is impossible to decide if the child is a boy or a girl, what should doctors do?



At the same time, we also have to add that the European Commission's Special Eurobarometer 493 Survey (May 2019)<sup>15</sup> shows that more than three quarters (77%) of Hungarians do not support the idea that someone's ID / official documents contain another option beside "male" and "female" if they do not identify as male or female. To the question "Do you believe that official documents, like passports and birth certificates, should have a third option, such as X or O (Other) beside male (M) and female (F) for those persons who do not identify as female or male?", 77% of Hungarian respondents said "no" (as opposed to the 42% EU average), and only 13% said "yes" (as opposed to the 46% EU average).

#### I.2. National legal framework

#### I.2.1. Hate crime legislation and definition in Hungary

Hungarian law does not refer to "hate crimes" or "hate speech" *per se*. The Criminal Code, however, defines and punishes bias-motivated criminal acts. There are two

<sup>&</sup>lt;sup>15</sup> European Commission: Special Eurobarometer 493, Discrimination in the European Union, May 2019

<sup>&</sup>lt;u>https://ec.europa.eu/commfrontoffice/publicopinion/index.cfm/survey/getsurveydetail/instruments/spec</u> <u>ial/surveyky/2251</u> (Factsheets in English and national languages)



groups of relevant criminal acts: *sui generis* acts, where the description of a criminal act explicitly refers to bias when defining the motive and the aim of the criminal act; and other criminal acts that do not contain an explicit reference to bias motive, but their qualifying circumstances<sup>16</sup> refer to "malicious motive," which includes bias motive based on someone's belonging to a social group. The following criminal acts defined by the Criminal Code<sup>17</sup> can be regarded as LGBTI relevant hate crime provisions:

- as *sui generis* acts that explicitly refer to sexual orientation and gender identity:
  - violence against a member of a community (CC Article 216);
  - incitement against a community (CC Article 332);
- indirectly, listing malicious motive as a qualifying circumstance:
  - homicide (CC Article 160), assault (CC Article 164), illegal restraint (CC Article 194), defamation (CC Article 226), unlawful detention (CC Article 304), offending a subordinate (CC Article 449).

Both sexual orientation and gender identity are explicitly mentioned in Article 216 and 330. Sex characteristics (intersexuality) *per se* is not mentioned in the law, but since the list of protected characteristics is an open ended one, such bias motive is also implicitly covered both in the case of violence against a member of a community and inciting to hatred against a community.

Violence against a member of a community (CC Article 216) is a crime committed by someone who

(1) displays an apparently anti-social behavior against others for being part, whether in fact or under presumption, of a national, ethnic, racial or religious group, or of a certain societal group, in particular on the grounds of disability, gender identity or sexual orientation, aiming to cause panic or to frighten others; this felony is punishable by up to three years of imprisonment;

(2) assaults another person for being part, whether in fact or under presumption, of a national, ethnic, racial or religious group, or of a certain societal group, in particular

<sup>&</sup>lt;sup>16</sup> A *qualifying circumstance* is a feature of a criminal act specifically included in the definition of the crime in the CC that imposes a higher sanction for the act.

<sup>&</sup>lt;sup>17</sup> Act no. C of 2012 on the Criminal Code, hereafter also referred to as Criminal Code or CC.



on the grounds of disability, gender identity or sexual orientation, or compels him by applying coercion or duress to do, not to do, or to endure something; this felony is punishable by one to five years imprisonment.

The Criminal Code also lists qualifying circumstances that result in higher penalties in case of violence against a member of a community. Punishment is two to eight years imprisonment if violence against a member of a community is committed by carrying a deadly weapon, by causing a significant injury of interest, by tormenting the victim, in a group of 3 or more persons and / or in criminal association with accomplices (CC Article 216(3)).

Preparation for this criminal act is also a misdemeanor punishable by up to two years imprisonment (CC Article 216(4)). Preparation means providing the means necessary for or facilitating the committing of a criminal offense; inviting, volunteering or agreeing to commit a crime (CC Article 11(1)).

Incitement against a community (CC Article 332) is a felony committed by "any person who before the public at large incites hatred or violence against the Hungarian nation, any national, ethnic, racial or religious group, or certain societal groups, in particular on the grounds of disability, gender identity or sexual orientation." The perpetrator is punishable by up to three years of imprisonment. However, as the Working Group Against Hate Crimes in Hungary warns, the Hungarian authorities very rarely launch investigations into incitement, "even though in recent years there have been a number of hateful public speeches against minority groups in connection with which the proceedings would have been justified."

#### I.2.2. Anti-discrimination legislation

There is no specific legislation or case law on how to deal with discrimination based on sex characteristics. It could be dealt with either as sex discrimination, or discrimination based on gender identity, but also as discrimination based on health status or discrimination based on "other ground", as these latter two are also

<sup>&</sup>lt;sup>18</sup> Cf. <u>https://gyuloletellen.hu/aktualitasok/hatosagoknak-tenyleges-uszitasok-ellen-kellene-fellepniuk</u>



specifically included as protected grounds in the comprehensive equal treatment legislation (ETA).<sup>19</sup> This legislation prohibits direct and indirect discrimination, harassment, unlawful segregation and retribution on multiple grounds, including sex, state of health, sexual / gender identity and "other status, attribute or characteristic." (The Act on Equal Treatment prohibits discrimination on the basis of protected characteristics. Protected characteristics are as follows: gender, ethnic origin, race, skin colour , age, mother tongue, disability, state of health, parenthood (including pregnancy), family status, sexual orientation, gender identity, social origin, financial status, religious or ideological conviction, political or other opinion, part-time status or fixed-term of employment relationship, membership in an interest representation organization and any other status.)

A procedure may be initiated by natural persons who suffered disadvantage, representatives of legal persons, or organizations with a clear interest submitting a complaint as *actio popularis*. Complaints may be submitted against state and local government organizations; organizations exercising official powers; the Hungarian Army and law enforcement bodies; organizations performing public utility services, educational, social, child protection and cultural institutions as well as health service providers; voluntary and private insurance funds; and parties and all other budgetary agencies. Proceedings may also be started in certain relations of the private sector: if complaints are launched against an employer, an entrepreneur or legal person getting state subsidy, anyone who offers goods or services to the public, and anyone who bids contracts or invites contractors to tender. If the violation of the principle of equal treatment is found, sanctions include: ordering that the state of infringement be terminated; forbidding the continuation of the violation; ordering that the decision declaring the infringement be made public; and the imposition of a fine.

From its establishment in 2005 until 2020, the Equal Treatment Authority, an independent and autonomous administrative body, was responsible for monitoring the implementation of the principle of equal treatment and investigating complaints

<sup>&</sup>lt;sup>19</sup> Act No. CXXV of 2003 on equal treatment and the promotion of equal opportunities (2003. évi CXXV. törvény az egyenlő bánásmódról és az esélyegyenlőség előmozdításáról), Art. 8 point a), n), t) respectively, available in Hungarian at: <u>http://njt.hu/cgi\_bin/njt\_doc.cgi?docid=76310.256015</u>.



and reports filed concerning cases involving alleged discrimination. From January 1 2021, however, the functions of the Equal Treatment Authority are taken over by the Commissioner for Fundamental Rights of Hungary, and thus the Ombudsman acts in administrative proceedings in cases concerning the promotion of equal treatment and equal opportunities, theoretically in accordance with the relevant rules of procedure. However, a shadow report compiled by the Hungarian Helsinki Committee elucidates how the Commissioner for Fundamental Rights of Hungary failed to protect the rights of LGBTQI people (and other vulnerable groups) between 1 October 2019 and 18 February 2021, for example by not stepping up against the prohibition of legal gender recognition in 2020,<sup>20</sup> so it remains to be seen how the Equal Treatment Act is applied in the future.

#### I.2.3. Legislation on health

Intersexuality is not referred to in any legislation or policy, except for the provision on public health coverage for gender reassignment treatments: the legislation provides that "treatment to alter external sexual characteristics" are only partially covered by the public health insurance, unless "the aim of the treatment is to construct external sexual characteristics in line with the genetically defined sex following a developmental disorder."<sup>21</sup> By literal interpretation of the legislation, this means that those intersex people who have a clear genetic sex and would like their body to correspond to that sex get their gender reassignment treatments free of charge, while transgender people, those intersex people who have no clear genetic sex, or do, but have a different gender identity would not be fully funded by the public health insurance. There is no information available on whether this literal translation holds true, or whether the exception rule is liberally interpreted as covering all intersex

<sup>&</sup>lt;sup>20</sup> Hungarian Helsinki Committee: Shadow Report to the Global Alliance of National Human Rights Institutions (GANHRI) Sub-Committee on Accreditation on the Activities and Independence of the Commissioner for Fundamental Rights of Hungary in Light of the Requirements Set for National Human Rights Institutions. 18 February 2021.

https://www.helsinki.hu/wp-content/uploads/Assessment\_NHRI\_Hungary\_18022021\_HHC.pdf

<sup>&</sup>lt;sup>21</sup> Act No. LXXXIII of 1997 on mandatory health insurance (1997. évi LXXXIII. törvény a kötelező egészségbiztosítás ellátásairól), Art. 23 k), available in Hungarian at: <u>http://njt.hu/cgi\_bin/njt\_doc.cgi?docid=30386.255766</u>.



people. Some fear that this legislation cannot be applied since May 2020, when the Act on Registry Procedures (Act I of 2010) was amended (see in Chapter I.2.4.).

Intersex children cannot remain without a gender marker/identification on their birth certificates. Article 69/B (1) b) be) of the Act on registry procedures clearly states that the "birth sex" of the child is a compulsory part of the registry of personal identification data, and Article 10 d) of the Governmental decree on the tasks related to registries contains that "birth sex" is a compulsory element of the birth registry. The Ministry of Public Administration and Justice confirmed in 2014<sup>22</sup> that there are no exceptions for intersex children either, they have to be registered as male or female. The Act on Registry Procedures states that any birth shall be reported to the registrar on the first working day following birth (by the head of the hospital, if the birth happened at an institution; or by the parent if it took place outside of an institution).<sup>23</sup>

The Ministry of Human Resources reported in 2014 that there are no specific regulations on surgical and medical interventions performed on intersex people, the general rules of healthcare provision apply.<sup>24</sup> The Ministry cited Article 15 (2) of the Healthcare Act on consent as the key provision.<sup>25</sup> Interviewees who are health care professionals reinforced that no new protocols on treatments for intersex babies and children have been accepted in recent years.

Consent to medical interventions are governed by The Health Care Act.<sup>26</sup> Article 15 contains the general principle that patients have the right to self-determination, Article 15 (2) more specifically says: "*As part of patients' right of* 

<sup>&</sup>lt;sup>22</sup> Hungary, Ministry of Public Administration and Justice (2014), Letter No. XVII/102/3/(2014) in response to an information request by the Hungarian Helsinki Committee, 25 February 2014.

<sup>&</sup>lt;sup>23</sup> Hungary, Law Decree No. 17 of 1982 on registries, marriage procedure and bearing names (1982. évi 17. törvényerejű rendelet az anyakönyvekről, a házasságkötési eljárásról és a névviselésről), Art. 10 (1), available in Hungarian at: <u>http://njt.hu/cgi\_bin/njt\_doc.cgi?docid=5276.242620</u>.

<sup>&</sup>lt;sup>24</sup> Hungary, Ministry of Human Resources (2014), Letter no. 12460-7/2014/NEUF in response to an information request by the Hungarian Helsinki Committee, 12 March 2014.

<sup>&</sup>lt;sup>25</sup> Hungary, Act No. CLIV of 1997 on health care (1997. évi CLIV. törvény - az egészségügyről), available in Hungarian at: <u>http://njt.hu/cgi\_bin/njt\_doc.cgi?docid=30903.255769</u>.

<sup>&</sup>lt;sup>26</sup> Hungary, Act No. CLIV of 1997 on health care (1997. évi CLIV. törvény - az egészségügyről), available in Hungarian at: <u>http://njt.hu/cgi\_bin/njt\_doc.cgi?docid=30903.255769</u>.



self-determination, patients are free to decide whether to make use of medical services, and when doing so, which treatments they agree to and which one they reject." Consent to invasive treatments shall be provided in writing, or in case acquiring such a consent is impossible, verbally in the presence of two witnesses.<sup>27</sup> For persons without legal capacity (such as those of minor age) consent shall be given by the legal guardian, but the opinion of the patient shall be taken into account to the extent professionally possible.

(2) If a patient has no or limited legal capacity, and there is no person entitled to make a statement on the basis of Paragraph a) Subsection (1), the following persons, in the order indicated below, shall be entitled to exercise the right of consent and refusal within the limits set out in Subsection (4), subject to the provisions of Paragraph b) of Subsection (1):

a) the patient's legal representative, in the absence thereof,

*b)* the following individuals with full disposing capacity and sharing household with the patient:

ba) the patient's spouse or common-law spouse, in the absence thereof,

bb) the patient's child, in the absence thereof,

bc) the patient's parent, in the absence thereof

(...)

(4) The declarations of persons listed under paragraph (2) can only extend to invasive interventions suggested by the doctor, and only after being fully informed according to Article 13. Except for the case covered under Article 20:3, such a declaration cannot have a detrimental effect on the health of the patient – except for the risks involved in the intervention –, and in particular cannot lead to severe or permanent damage to health. The patient shall be informed about the decision as soon as possible after he (re)gains legal capacity.

(5) In making decisions on the health care to be provided, the opinion of a patient with no or limited legal capacity shall be taken into account to the extent professionally possible also in cases where the right of consent and refusal is exercised by the person defined in Subsection (2).

A further important provision is that minors above the age of 16 can name a person of major age other than their parents to practice the right of consent until they reach majority.<sup>28</sup>

<sup>&</sup>lt;sup>27</sup> Hungary, Act No. CLIV of 1997 on health care (1997. évi CLIV. törvény - az egészségügyről), Art. 15 (5), available in Hungarian at: <u>http://njt.hu/cgi\_bin/njt\_doc.cgi?docid=30903.255769</u>.

<sup>&</sup>lt;sup>28</sup> Hungary, Act No. CLIV of 1997 on health care (1997. évi CLIV. törvény az egészségügyről), Art.16 (6), available in Hungarian at: <u>http://njt.hu/cgi\_bin/njt\_doc.cgi?docid=30903.255769</u>.



There is no guidance available on what "to the extent professionally possible" means in case of intersex minors, but in the interviews Háttér conducted with a surgeon in 2012 and in 2020 as part of the Bring-In project, the doctor claimed that adolescents are always consulted, and that for minors above the age of 14 they request all the papers to be signed by the patients themselves besides their parents (even though it is legally not required).

In 2014 the Ministry of Human Resources emphasized the provision in the legislation that requires that consent given by the parents "cannot have a detrimental effect on the health of the patient", i.e. that consent can only be given to treatments medically required.<sup>29</sup> The question on what treatment is "medically required" for intersex people, however, is not clearly settled. In the interviews mentioned above, the surgeon doctor claimed that destructive surgeries are no longer performed on minors (unless medically indicated), only fully reversible ones. However, in the 2020 interview he also admitted that not all surgeries are performed by himself, only approximately 90% of surgeries in Hungary.

Based on medical professional articles published on the subject,<sup>30</sup> it seems to be the case that most Hungarian health professionals share the view that early interventions are needed to "save" children from the negative impact of gender ambiguity. One article, for example, clearly states that the aim of the intervention should be to create functioning heterosexuals out of intersex people.<sup>31</sup> A recently published interview also claims as completely self-evident that in the case of intersex children, "it is the paediatric surgeon who (...) decides upon what type of genitals should be formed for the child, by surgery."<sup>32</sup>

<sup>&</sup>lt;sup>29</sup> Hungary, Ministry of Human Resources (2014), Letter no. 12460-7/2014/NEUF in response to an information request by the Hungarian Helsinki Committee, 12 March 2014.

<sup>&</sup>lt;sup>30</sup> In order to assess the medical communities' opinion, a search was conducted in the Hungarian Medical Bibliography (Magyar Orvosi Bibliográfia), for a list of results see: http://mob.gvemszi.hu/itmsbydict.jsp?DCTID=207430&DCTDESC=HERMAPHRODITISMUS

<sup>&</sup>lt;sup>31</sup> László Ságodi (2006), 'Interszexuális betegek ellátása, az átmeneti külső genitalék sebészeti kezelése', Gyermekgyógyászat, 57:5, 543-552.

<sup>&</sup>lt;sup>32</sup> Fenyvesi Zsófi: "Egyszerűbb lenne, ha csak kislányok és kisfiúk születnének – de ez nincs így." An interview with dr. Norbert Varga, a clinical geneticist.

https://divany.hu/szuloseg/2021/01/11/interszex-gyerek/



#### I.2.4. Legal gender recognition

Recent legal changes that were adopted and came into earlier this year made the situation of intersex persons much worse in Hungary. In May 2020, a law banning legal gender recognition was voted by the governing majority. It amends the Registry Act and replaces the word "sex" with the expression "birth sex". Birth sex is defined in the legislation as "biological sex based on primary sex characteristics and chromosomes." According to the bill, birth sex, once recorded, cannot be amended. This most probably has a very negative impact on parents' and doctors' willingness to postpone surgical procedures: while until 2020, doctors could argue that a child's legal gender can be changed at any point if the child is intersex, now "birth sex" (put in the registry before a baby is 6 weeks old) cannot be changed. This will probably entail more unnecessary / not medically required treatments and surgical interventions compared to the previous years.

Another legislative change adopted in 2020, an amendment to the Constitution<sup>33</sup>, sets trans- and interphobia – by its rigid and cemented attachment to "birth sex" as well as what the government regards as Christian religion and culture – in a constitutional frame. The addition to Article XVI (1) says: "Hungary protects children's right to their identity in line with their birth sex, and their right to education according to our country's constitutional identity and system of values based on Christian culture."

#### I.3. National central policies and good practices

We can only give account of a very few good practices:

• In May 2015, the Commissioner for Fundamental Rights in Hungary organized a thematic workshop and discussion on the situation of intersex children. The event took place with the participation of various stakeholders: child and

<sup>&</sup>lt;sup>33</sup> 9th amendment to the Fundamental Law, in force from 23rd December 2020.



health rights experts, health and mental health professionals as well as trans and LGBTQI civil society organizations.

- The Commission for Fundamental Rights in Hungary has also been supporting projects implemented by Háttér Society that include or focus on intersex people's human rights. However, the mandate of the previous Commissioner for Fundamental Rights expired in autumn 2019, and the present Commissioner for Fundamental Rights has as yet proved to be completely inactive when requested to respond to any violation of fundamental rights regarding LGBTI+ people in Hungary.
- The surgeon who has been performing most surgical interventions on intersex babies and children in Hungary, and was interviewed by Háttér in both 2012 and 2020 (as part of the Bring-In project), told that there have been no *"routine* corrective surgeries for the past 15 years, if there is an operation at all, it is fundamental that fertility and neural areas are kept", and "there are no maiming surgeries, only fully reversible ones." He explained that his own approach to the subject changed after he had attended training events and conferences abroad. He also added that until 2020, there had been more and more parents who agreed to not wanting early surgery: "one third of parents accept the suggestion that no surgery should be made at a very early age, we should wait for a few years."
- There have been efforts by a trans civil society organization and by an openly intersex activist to set up groups / organize meetings for intersex people and / or the parents of intersex children. These groups and efforts did not last long, thus there is no intersex informal or registered organization in Hungary yet, but from what we know about the history of LGBTI+ organizing, these first seeds are necessary predecessors to future organizing.
- Háttér Society has been working on challenging the 2020 ban on legal gender recognition since spring 2020. Its Legal Aid Service is helping dozens of affected persons (among them one intersex person) to challenge rejection of



legal gender recognition in court, and also represents petitioners in front of the Commissioner for Fundamental Rights and the Constitutional Court.

- Háttér Society and the Hungarian LGBT Association (of which Háttér is a member) has been conducting research and training and has published information material that (at least partially) focus on the situation of intersex people in Hungary. A few examples:
  - Reports about the Implementation of the Council of Europe Recommendation to member states on measures to combat discrimination on grounds of sexual orientation or gender identity (CM/Rec(2010)5) in Hungary in 2013 and 2018<sup>34</sup>;
  - Research report by the Hungarian LGBT Association on a representative survey on social attitudes towards LGBT+ issues in Hungary, September 2019<sup>35</sup>;
  - Háttér's translation of OII's guide for parents of intersex children on how to support their child<sup>36</sup>;
  - the Hungarian LGBT Alliance's translation of OII's guide on how to be an intersex ally;<sup>37</sup>
  - Háttér's participation in the Bring-In project as well as a workplace equality project called Inclusion4All (2020-2022) focusing on the workplace equality of trans, intersex and nonbinary persons.

<sup>&</sup>lt;sup>34</sup> <u>https://hatter.hu/kiadvanyaink/jelentes-europa-tanacs</u> (prepared by Háttér Society); <u>https://hatter.hu/kiadvanyaink/jelentes-europa-tanacs-2018</u> (prepared by Háttér Society, the Hungarian LGBT Association, and Transvanilla Transgender Association)

<sup>&</sup>lt;sup>35</sup> http://lmbtszovetseg.hu/sites/default/files/mezo/file/lmbtszov\_research2019sept\_en.pdf

<sup>&</sup>lt;sup>36</sup> Translation of <u>https://oiieurope.org/supporting-your-intersex-child-a-parents-toolkit/</u>, in Hungarian: <u>https://hatter.hu/kiadvanyaink/interszex-utmutato-szuloknek</u>

<sup>&</sup>lt;sup>37</sup> Translation of <u>https://oiieurope.org/tag/allies-toolkit/</u>. In Hungarian: <u>http://lmbtszovetseg.hu/eroforrasok/az-interszex-emberek-jogainak-vedelme-hogyan-segithetsz-te</u>



#### I.4. Useful contacts

#### Háttér Society (LGBTQI organization)

Email: hatter@hatter.hu Webpage: https://hatter.hu/

### Transvanilla Transgender Association

Email: szervezet@transvanilla.hu Webpage: http://transvanilla.hu

#### The Office of the Commissioner for Fundamental Rights

Email: hungarian.ombudsman@ajbh.hu Webpage: <u>https://www.ajbh.hu/en/web/ajbh-en/</u>

## ENDOPED Foundation (for children living with CAH – Congenitalis Adrenalis

Hyperplasia) Email: info@endoped.hu Webpage: www.endoped.shp.hu

#### Turner Syndrome Group

Email: http://www.turnerszindroma.hu/contact-form/index.php Webpage: <u>www.turnerszindroma.hu</u>

#### **RIROSZ National Association of People Living with Rare and Congenital Disorders**

Email: <u>https://www.rirosz.hu/kapcsolat/</u> Webpage: <u>https://www.rirosz.hu/</u>



# II. Field research: interviews with experts, stakeholders, policy and decision makers

#### II.1. Background and profile of interviewees

Altogether eleven interviews were conducted with various stakeholders as part of the Bring-In project, and a health visitor (public nurse) asked other health visitors in a social media forum and sent information on their responses in an email. The interviews were conducted over the phone or via videoconferencing software between October 2020 and February 2021. The interviews lasted 30 to 90 minutes. Interviewees included:

- health professionals (4 people): a surgeon who was also interviewed in Háttér's 2012 research on the situation of intersex people in Hungary, a gyneacologist, an endocrinologist and a health visitor (public nurse);
- psychologists (3 people);
- professionals working in service providing CSOs (3 people): a staff member of the Legal Program and the Director of the Mental Health program of an LGBTQI organization, the organizer of a trans and intersex group;
- other professionals (2 people): a teacher and a school social worker.

#### II.2. Basic Knowledge (of terminology and legal framework)

Some of the interviewees were among the very few people in Hungary who have a hands-on knowledge and experience with intersex people. Some were keen to talk about the subject, but as they had no direct experience with intersex people, resorted to talking about LGBTI people, the role of education and sensitization in general – this was the case with interviewees working in schools. Several interview requests were turned down because the social workers, psychologists and health professionals (that is, health visitors / public nurses who meet each and every newborn and their parents / guardians / family members) claimed they had not been in contact or worked with intersex people or parents of intersex children. Some of them were confused about the basic terminology: they thought we were asking them



about trans people, and when they found out what the term intersex means, told us they could be of no help because of lack of experience. Eventually only those stakeholders were willing to talk on the issue who were (at least relatively) knowledgeable of the terminology and the legal framework as well as fundamental rights issues pertaining to intersex people, so the interviews are not representative of the whole healthcare and social services sector.

Only the staff of civil society organizations as well as doctors had a clear knowledge and understanding of what the ban on legal gender recognition means for intersex children (see chapter I.2.4). Doctors who work with intersex babies and children and professionals working on LGBTI+ advocacy were completely aware of how harmful this legislation is for intersex children. As the surgeon interviewed explained:

Chromosomes must be examined. And if these are not 46 XX or XY, then it's a mozaik. Perhaps the baby looks more like a boy, but within one year, the estimated 90 - 10% might become 50 - 50%. And results are also different if the sample is taken from someone's blood or someone's marrow. This cannot be decided within 6 weeks. (...) There are countries where a 3rd sex is registered. There are rational countries where there are no immediate surgeries. But what happened here in the spring is dramatically different, really. The Parliament adopted this and they clearly did not ask a single health professional. (...) We simply stepped back 50 years. No one consulted doctors, no one at all. (Surgeon interviewed as part of the Bring-In project, December 2020)

#### II.3. Status and support of intersex people in the country

The medical professionals interviewed all shared the experience that being intersex or having an intersex child is stigmatized in Hungary. They talked about how many parents require cooperation and secrecy, so that no one in their immediate social environment (family, childcare institutions, etc.) can find out the intersex status of their child. These parents want surgery immediately, when the baby is only a few days old, so that no one knows. However, even though the surgeon interviewed said that they encourage parents to wait for years and see what is best for their child, he admitted that at least two thirds of the parents ask for an active intervention as soon as possible. And, even though he was critical of Hungarian society, he also seemed



to assume that his success was measured by his ability to "create" "sexually functioning" heterosexual people.

I can see the material of 30 years. And well, we operated on approximately 150 patients, making them into girls. There are only two of them who have girlfriends. And they were raised in state custody, not by their parents, one of them lived with 5 or 6 foster parents, and they have an interest in their being ill, being medical patients. Anyway, they know that they are ill but they are not unhappy. (Surgeon interviewed as part of the Bring-In project, December 2020)

Another doctor interviewed, an endocrinologist, told that she would not be able to really support a decision that would question the binary gender system:

Doctors cannot be fully objective. Or I should talk about myself: my own opinion will definitely be there. Until the last decade, the concept of a delayed decision had not even existed. No one was thinking of making a decision at puberty. I myself cannot imagine raising someone gender-neutrally. I cannot imagine this. (...) Children have their own world, a gendered word, one has to decide what kind of toys they get and what colors they should wear. (Endocrinologist interviewed as part of the Bring-In project, February 2021)

Both health professionals and professionals working at CSOs talked about the lack and importance of clear policies, medical protocols as well as information for parents. According to CSO experts, health professionals should be sensitized and trained to think outside the framework of "normalizing surgeries," and besides parents, school teachers as well as day-care providers and kindergarten teachers should also have access to more information.

The director of the Mental Health Program of an LGBTQI organization explained that according to research, professionals working in the health and social sphere do not even know about the existence of intersex people. Many doctors do not know the meaning of the word "intersex," even though "disorders of sexual development" are detailed in their university textbooks. Social workers often use the word "hermaphroditism". She also talked about how in her own work experince a social worker who dealt with young people who had grown up in state care had shared the information on a young person's intersex status as a sensation with



everyone, completely disregarding the person's right to privacy. Other problems she mentioned were:

- late diagnosis and protracted examinations during childhood and puberty,
- the lack of protocols on diagnosis, treatment and communication with patients and parents,
- lack of information for parents so that they can relate to intersex status "naturally", without treating it as a secret, stigma, traumatizing their children.

A legal expert working at an LGBTQI civiil society organization told that even though no one turned to the organization's Legal Aid Service explicitly because of being discriminated against on the basis of their intersex status, they have had a few clients who realized that they were intersex while transitioning and / or applying for legal gender recognition as trans persons. Their experience was that their intersex status was completely ignored by the relevant authorities.

He also talked about Háttér's research on the social, legal and health-related situation of intersex people in 2012-2013. (Háttér also shared the transcripts of these interviews made with both intersex people and professionals for the purposes of the present research.) He emphasized how professionals described the unprepared nature of health institutions and service providers. In 2012, most intersex interviewees talked about being treated as a "rarity."

Another problem he outlined was that intersex people are still quite invisible in Hungarian society and within the civil society, too. There are groups and organizations for people who live with (rare) syndromes, e.g. a group for people who have Turner syndrome, but homo- and transphobia already makes the situation of intersex people difficult, as people in Hungary tend to react with growingly homoand transphobic arguments to anything that questions the binary gender system, and they may not want to make it even more explicit by joining an LGBT focused organization. (This was reinforceed by what an intersex interviewee also stated.) Many of them are wary of "confusing" the different groups, and feel that discussing intersex issues in the framework of LGBTI makes their situation more difficult due to widespread homophobia and transphobia. Besides, those who attend these groups,

25



do not necessarily apply the umbrella term "intersex" for themselves. They identify with the status / syndrome they live with, but not with this general category or label. This seems to be slowly changing. In recent years, there have been a few people who talked about themselves as intersex, even publicly, whether they found out about the intersex status while transitioning as trans persons or otherwise. He added that the first time the expression gained real publicity in the media was after the 2018 decision of the German Constitutional Court to include the category "diverse" as a third gender option beside male and female in registries. This really boosted the use of the word intersex.

He also talked about how information materials for parents and patients should be made available through health institutions, and then perhaps intersex people would find Háttér Society or other LGBTI or trans and intersex organizations. At this point, it is only Háttér as an LGBTQI, and Transvanilla as a transgender civil society organization that explicitly welcomes intersex people and works on these issues in a focused way. There might also be special organizations of people living with rare symptoms, but these focus on specific health states and not intersex people as such. However, stigmatization is present even at an early age. If for example there is an article on a child living with cancer, they would not be stigmatized. If, however, an intersex child was portrayed, people would ask why they need to talk about this issue, just because it is about gender, or a "third sex."

The LGBTQI organization's legal expert interviewed also talked about parental consent as a "fiction". Parents do not get adequate and transparent information. (This was reinforced by our interview with the mother of a 7-year-old intersex child.) Most parents are only told by the doctors that there is a "small problem" that can be solved by surgery. However, they are not informed about possible outcomes, and future treatments and surgeries. This cannot be called an "informed consent." As a psychologist explained:

I think that doctors have this completely pathologizing attitude. They communicate about this to parents as an illness, a syndrome, an anomaly. They say that the baby was born with such and such deformity, but we are going to solve this. I think that this is how they deal with an intersex body: like when someone is born with six fingers instead of five. I think the communication is the same, sensitivity, attitudes are the



same... They do not deal with an intersex person as a more complex construct than a *limb or a finger.* (Psychologist interviewed as part of the Bring-In project, February 2021)

Unfortunately, what this psychologist assumed was reinforced by what intersex people told in earlier and newer interviews made in 2012 and in 2020-21. The endocrinologist interviewee also described how people in general, or in this case, parents deal with social stigma: choosing complete silence:

I had a patient whose sex was changed at the age of 3. As the parents completely disappeared, I myself called them once to find out if they were dissatisfied, or chose another doctor... But they told me that was not the case. They were completely satisfied, but did not want to contact me ever again, as I was someone who knew about their past. This was how they were coping with it. (Endocrinologist interviewed as part of the Bring-In project, February 2021)

#### II. 4. Recommendations

From the views of the stakeholders interviewed, the following recommendations can be drawn:

- The legal framework should be improved to make it possible for intersex children and grown-ups to proceed to the legal recognition of their gender identitty.
- Registration of sex should not be compulsory at least until a certain age.
- A professional body should create and adopt a medical protocol on treating intersex babies and children, the advantages and disadvantages of treatments and surgical interventions, risks, informing parents, clarifying questions related to the ability of understanding, when surgical intervention is necessary, etc.
- Legislation prohibiting discrimination should be amended to explicitly include intersex status, as this would help people understand what it means.
- Support services for intersex children, grown-ups and parents of intersex children should be set up and operated, but these should not be maintained by health institutions or healthcare professionals.



- Publications for parents of intersex children should be written by civil actors and health professionals together. These should be distributed in healthcare institutions. Some should only contain very basic, easy-to-understand information.
- Health professionals, especially obstetricians, neonatologists, birth attendants and public nurses should be trained.
- Statistics should collected, which is of course not simple, given that the very definition of intersex status is quite complex.
- Education professionals working with children (kindergarten teachers, daycare personnel and school teachers) should be trained.



#### **III. Field research: interviews with intersex people**

#### III.1. Background and profile of interviewees

Two interviews were conducted as part of the Bring-In project with adult intersex people (both between 40 and 45). They both work in factories. One of them (henceforth referred to as A.) was diagnosed with Klinefelter syndrome as an adult. She later realized that although she was registered at birth as male, she would like to be legally recognized as female. She applied for a gender and name change, however, her request was dealt with in the same way as any other request by a trans person: it was not processed for several months and then rejected after the legislation banning legal gender recognition entered into force. Our other interviewee (henceforth referred to as B.) identified first as a trans person, and it was during her transition that compulsory examinations revealed her intersex status. She managed to get her gender legally recognized in 2018.

As Háttér Society also made interviews with intersex people in 2012, we could also draw information from these. The interviews that a young intersex woman gave to magazines in 2020<sup>38</sup> are also a good source of information, her experience resonating with those of our interviewees.

#### **III.2.** Personal experiences and needs

A. was born in a larger city, but not the capital. She introduced herself as a person living with Klinefelter syndrome. She explained that her documents contained a male name and gender marker, but she lives as a woman. She was 18 when she found out she was intersex: "my organization did not take testoterone," as she explained. However, she did not care about this at the time. When she talked about her childhood, it turned out that she had been excluded and tormented by her classmates. "Especially during physical education classes," she added. "And now my papers cannot be changed. That's a shame. People see me as a woman." She

<sup>&</sup>lt;sup>38</sup> E.g. the one she gave to 24.hu:

https://24.hu/elet-stilus/2020/04/26/interszex-interju-baba-dorottya-Imbtq/



talked about how her family never accepted her status, and how health professionals "were staring" when she went to see the doctor. When talking about her work experience, she said she once had an inclusive employer, where she could use women's changing rooms. However, at other places she has to use the men's changing room. At the time of the interview, she was just starting to work at a new place, where she was hired with a male name. "It would be so much easier to live with a woman's name," she said.

Unlike A., B. was already almost 40 when she found out about her intersex status. She suspected that her mother had always known about this (e.g. they got a higher family allowance when she was child, which means she was registered as having an illness), but they never talked about this. She said that it was probably the suggestion of doctors to simply not talk about this, so that she would not be an outcast in the society of children. However, she was abused as a child by her schoolmates. (At that time she was registered as a boy and they mocked her because of being feminine.) She managed to get her name and official documents changed in 2018 when she was 40 years old. She had a traumatic childhood, and got no help at all. As she explained:

I really do not know why they looked at me as gay in school, I actually did not feel any kind of sexual attraction for a very long time. But as I was battered there, I did not want to go to school. So I was absent a lot and began to loaf about. Then I was sent to a corrective institution. It was very bad there, too. They treated it as if it had been my fault, as if I had been bad and had just wanted to avoid school, when in fact I could not go there because of the battering. (Intersex interviewee B.)

#### III.3. General views – the status of intersex people in the country

B. talked about how she had a basically non-consensual surgery as part of her gender reassignment surgery at the age of 39:

They found out that I had a small vagina during the surgery. But they made another one, a bigger one. I actually did not think it was that important for me, but anyway, I had the surgery and from then on I can live as a woman.

She also talked about severe stigmatization and the difficulty of intersex organizing:

Nagyon kevesen vagyunk, rejtőzködnek. Ez az LMBT-be bevonás se jó, nem megy, teljesen más, hogy szexuális orientáció vagy egy biológiai állapot. Így szexuális aberrációnak tekintik! (...) However, I usually say I am trans, as people at least



understand that. If I say intersex, well, they simply do not know what that is. There was this intersex activist who gave interviews, but could not organize a group, because intersex people do not want publicity. They want to pass. Of course we should be visible, but then we might be attacked... But we do need an intersex organization, and inform society.

Interviewees in 2012 also talked about similar problems and needs to what B. listed:

 the mother of an intersex child told they had been urged to make a decision as the child had to be registered within 6 weeks after birth, and examinations took some time;

When you are in a situation like that, you do not care about registration during those first few weeks, it does not matter for the baby either. There are things that cannot be speeded up just because you are urged to decide and name the baby. A bad decision might ruin someone's life. It was not like when a parent cannot decide whether her baby should be named Julie or Luisa. It was not me who could not choose among names. We had a really hard time deciding what would be the best for the baby, what the registry should contain: a boy or a girl.

• they also met prejudiced kindergarten teachers:

It is really not kids who cause problems but grown-ups with their prejudices. My daughter was 5 when they told the children in the kindergarten that they could bring in Valentine gifts for one another. Just whoever they wanted to. So my daughter gave a bar of chocolate to another girl. And the way they reacted... It was hysterical. We soon left the kindergarten and found a much better place. The kindergarten teacher accepted and loved my daughter there, and all problems disappeared.

• an interviewee talked about the way doctors communicated with her when she

found out about her Turner syndrome at the age of 17:

Well, I did not at all like the way they treated me and this situation. They did not properly inform me. They did not treat me as someone they could talk to.

• yet another interviewee talked about how insensitively she had been informed about the impossibility of her conceiving a child when she was 16:

I would have needed psychological help, but this was never even mentioned. There was this medication on which I read the warning that it should not be taken by pregnant women. So I just asked this. What would happen if I am pregnant and cannot take this. And then the doctor told it, just like that, while handing over the prescription: "Well, you cannot have a child." And then goodbye, see you in three months.



All interviewees talked about the lack of information, self-help / discussion groups, psychological counseling and prejudicial attitudes in society as well as the defects of health services and service providers.



#### **IV. General conclusions and recommendations**

#### **IV.1. Conclusions**

Our interview and desk research conducted in the Bring-In project show that a major hindrance to the equality of intersex people is a **lack of knowledge on variations of sex characteristics and the diversity of human sexes** even among health professionals, but also among educators, and the general society. Political messages have also strengthened the **social exclusion of** several social groups, including **sexual and gender minorities** during the last decade in Hungary. This tendency shows clearly in **legislative changes** introduced in 2020, mainly the complete **ban on legal gender recognition**, which implies that **birth sex, once recorded, cannot be amended**.

Both earlier and recent interviews show that **many intersex people experience that their right to health and bodily integrity are violated**, "normalizing" operations have been and are performed without their (or their parents') informed consent. Parents of intersex people **do not have the chance to get proper and comprehensible information** on the health status of their children, and therefore they often rely on doctors' opinions, even though there is now a growing body of outcomes data from other countries showing that early surgery can lead to physical and psychological harm for intersex people.

In theory, the provision in Hungarian legislation that requires that consent given by the parents "cannot have a detrimental effect on the health of the patient" (cf. the chapter on National legal framework), that is, that consent can only be given to treatments medically required, provides protection against surgeries that are not medically required. The question on what treatment is "medically required" for intersex people, however, is not clearly settled, and it is clear from both medical literature and popular articles published in magazines that **both professionals and "lay people" assume that "normalizing surgeries" are necessary** to fit the body of "intersex" babies to the binary social norms.

33



What all parents and intersex people as well as health professionals interviewed in 2012 and as part of the Bring-In project experienced was the **lack of medical protocols and professional guidelines** on treatments for intersex babies and children, the **highly deficient communication** with and information for patients and parents, and the **lack of psycho-social services** for intersex people and their families. As our psychologist interviewee highlighted problem areas:

People do not know anything about intersex existence, intersex realities, so we cannot even talk about it being rejected. But this is even worse from a certain angle. It is worse to be non-existent than to exist and be in danger. If I exist and am in danger, I can try and defend myself... Of course if we told people that this was a more correct and adequate name for what they call hermaphroditism, their prejudices would immediately come up and overrule. (...) At the moment we make clear that we are talking about non-cis, non-heteronormative bodies / identities, all the hatred is switched on that is usually directed against all non-heterosexual and non-cis lives.

Training and research is needed. It is bizarre that we do not know what is going on in hospitals. That there are no medical protocols, numbers, statistical data. We need data to design a functional healthcare system. We should understand what doctors think, what they resist. And what parents know, what they are told. This is a segment of society we do not know anything of. These are difficult lives, and people and their families are left alone in this. (...) We should have access to knowledge on intersex bodies and being intresex outside the LGBTI umbrella, too. As this is a part of the cultural reality in Hungary: that many people are utterly homophobic. But this should not be an impediment to have access to knowledge can only be accessed within the LGBTI community. I also think that intersex people, like everyone who is not heterosexual and cisgender, belong to the LGBTI community, but perhaps not everyone agrees with that, and people should have access to knowledge even if they do not agree with that. (Psychologist interviewed as part of the Bring-In project, February 2021)

All problems are rooted in **strict binary sex and gender norms**, which cause that intersex people are treated as a taboo, and leads to **silencing their existence and experience**. Our research and activities in the Bring-In project strive to break this vicious cycle and start to give voice and solutions to the needs of all stakeholders and affected people.



#### **IV.2.** Recommendations

- 1. Intersex people's rights to bodily integrity and self-determination should be ensured. Any non-vital, medically unnecessary surgeries or other interventions performed to "normalise" intersex children's sex characteristics without the child's informed consent should be prohibited. With the exception of situations where a child's health is at immediate risk, no interventions aiming to modify sex characteristics should be performed until the child is capable of making an informed and independent decision on the matter.
- Healthcare for intersex people should be provided by multidisciplinary teams including medical professionals, psychologists as well as experts with proficiency in ethical and human rights issues.
- 3. A professional body should create and adopt a medical professional protocol on treatments for intersex babies and children, the advantages and disadvantages of treatments and surgical interventions, risks, informing parents, clarifying questions related to children's ability of understanding, when surgical intervention is necessary, etc. The professional protocol should take full account of the child's best interests and rights to participate in making decisions concerning their treatment in accordance with their age and maturity, in keeping with the obligations of the Convention on the Rights of the Child. It should also cater for ethical and human rights considerations. The protocol should be developed in multidisciplinary cooperation between professionals from different fields and representatives of intersex people.
- 4. Intersex people and parents of intersex children must be guaranteed access to appropriate information regarding variations of sex characteristics and the diversity of human sexes. Publications for parents of intersex children should be written by civil actors and health professionals together, and should be distributed in healthcare institutions. Basic, easy-to-understand information should also be included in the information package containing relevant publications for parents.



- Intersex people and their parents should be guaranteed access to psychosocial support and peer support. Adequate resources should be secured for organisations providing such support.
- 6. Intersex people should be guaranteed **access to the healthcare services** that they require and the right to check records on their own treatment.
- 7. Healthcare professionals, especially obstetricians, neonatologists, birth attendants and public nurses, as well as psychologists, should be provided with training on variations of sex characteristics and the diversity of human sexes. Their awareness of the potential effects of intersex-related medical interventions on children's health and wellbeing should be raised.
- 8. Legislation prohibiting discrimination should be amended to explicitly include intersex status to help people (professionals among them) understand what it means.
- 9. Discrimination against intersex people should be prevented purposefully and systematically. The National Human Rights Institution and other human rights and equality bodies should communicate and act for the legal and social equality and against the discrimination of intersex people.
- 10. Efforts should be made to increase awareness and information measures concerning variations of sex characteristics and the diversity of human sexes among all professionals working with children (daycare, education, leisure and sport activities, healthcare), as well as at educational institutions, in workplaces and in society at large.
- 11. Both **medical and social research should be conducted into the topic** and information on being intersex and the diversity of human sexes should be communicated appropriately.
- 12. Legislation should make it possible for intersex children and grown-ups to change their sex registered at birth. Registration should not be compulsory at least until a certain age. Legislation governing legal gender recognition should be shaped such that the legal gender recognition procedure will be a



quick and transparent administrative process based on the right to self-determination.

13. Resources should be allocated to the activities of intersex people's organisations aiming to dismantle the stigma and silence associated with being intersex.