

**Diskriminerings
ombudsmannen**

Report 2022:4

Living conditions for persons with intersex variation

Knowledge from a discrimination perspective

Living conditions for persons with intersex variation

Knowledge from a discrimination perspective

The Equality Ombudsman (DO)

© DO

R21 2022 ENG PDF

ISBN 978-91-88175-32-8

Illustration: Stina Wirsén. Layout: Kollijox AB.

This PDF is accessible. Other alternative formats such as Daisy, easy to read or Braille can be ordered when needed. To do so, please contact DO at order@do.se.

Contents

Introduction	4
Increased awareness	5
Various names and terms	7
Protection offered by the Discrimination Act	9
Vulnerability and risks of discrimination	11
A heterogeneous group	11
A strong gender binary norm	12
Shame and vulnerability	12
Vulnerability and risks of discrimination in the healthcare system	12
Vulnerability and risks of discrimination in education and working life	15
Vulnerability and risks of discrimination in other areas of society	17
Proposed measures	19
The protection from discrimination should be clarified	19
Insufficient knowledge and attitudes need to be addressed	19
More research and knowledge are required	20
References	21

Introduction

The purpose of this publication is to contribute knowledge about the living conditions of persons with intersex variation – also known as persons with variations in sex characteristics – from a discrimination perspective. The text is based on a knowledge base that DO developed in response to an assignment from the Swedish Government, and on which a final report was submitted in March 2022.¹

Variations in sex characteristics can manifest in many different ways. For some the variation is visible in the external sexual organs. For others, examinations and tests are required in order to establish whether there is a variation in sex characteristics. In some cases the condition is discovered in the newborn child, in others it becomes evident during puberty. It may also be discovered during adulthood.

This publication is largely based on information obtained through a number of dialogue meetings with civil society organisations. The meetings took place in the autumn of 2021 and the purpose was to learn from their knowledge and experience of what the situation is like for persons with intersex variation. The dialogue involved the following organisations: the Swedish Federation for Lesbian, Gay, Bisexual, Transgender, Queer and Intersex Rights (RFSL), RFSL Youth, the Swedish Association for Sexuality Education (RFSU), Intersex Sverige/OII Sverige, Svenska Klinefelter nätverket [the Swedish Klinefelter Network], Riksföreningen CAH [National CAH Association], Svenska Turnerföreningen [the Swedish Turner Association] and the Ågrenska Foundation, which is the National Centre of Competence for Rare Diseases.

In addition, the text is based on information from reports, memos, articles and other writings. The selection is based on DO's inventory of existing knowledge and it primarily involves material from the Council of Europe and institutions within the EU and UN. In addition to this, we have identified and used relevant reports from civil society organisations such as Amnesty and Organisation Intersex International Europe (OII). We have also received information about relevant material from experts and researchers within the field.

We have also obtained evidence from central government authorities that have knowledge of the conditions for persons with intersex variation. The public sector bodies DO has engaged in dialogue with are the Ombudsman for Children, the Public Health Agency of Sweden, the Swedish Agency for Youth and Civil Society and the National Board of Health and Welfare. We have also spoken to representatives from the healthcare system who are involved in caring for persons with intersex variation (the DSD team at Karolinska University Hospital in Stockholm and Centrum för sällsynta diagnoser [Rare Disease Centre]).

1 Ministry of Employment (2021a) Appropriation directions for budget year 2021 in respect of the Equality Ombudsman. The final report that DO submitted to the Government is titled *Livsvillkor för personer med intersexvariation ur ett diskrimineringsperspektiv* [Living conditions for persons with intersex variation from a discrimination perspective] (LED 2021/77).

Based on the evidence obtained, DO is able to conclude that the living situation of persons with intersex variation varies. Persons with intersex variation have various diagnoses as well as different life experiences and outlooks on their identities. There are people within the group who identify as “a person with intersex variation” or “an intersex person”. Others do not and choose instead to talk about their variation in sex characteristics on the basis of their specific medical diagnosis. This is also reflected in how civil society is organised, with some organisations being patient associations, while others are special-interest organisations with a more distinct focus on identity.

There is no consensus about the number of persons with intersex variation but a common estimate is that the proportion of persons with intersex variation in the world is 0.05–1.7 per cent, which equates at present to 4–130 million people globally.² For Sweden this would equate to 5,000–175,000 persons with congenital variations in sex characteristics.

Increased awareness

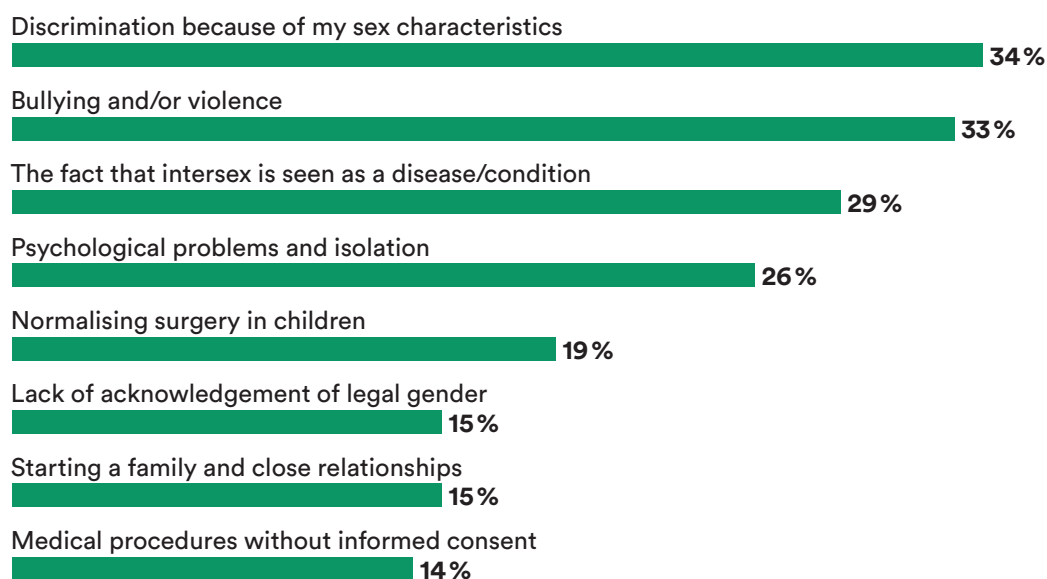
Living conditions for persons with intersex variation is a matter that has only been given attention relatively recently – the last thirty years – in Sweden and internationally. Over this period, intersex has gone from being treated as an exclusively medical issue to now also encompassing the individual’s living situation from a broader perspective. In addition to the medical issues³, this also includes issues relating to visibility in society, identity, human rights and discrimination.⁴

An international perspective shows that the most important rights issues linked to the living conditions for persons with variations in sex characteristics relate to bodily integrity, self-determination and various issues related to the healthcare system. In addition to this, discrimination and harassment have been brought into focus, as has mental illness and the fact that many people fear being open with others about their variation in sex characteristics.

-
- 2 United Nations Office of the High Commissioner for Human Rights (2015). There are other estimates which claim that the proportion is between 1.7 and 4 per cent. See Aranda & Zeeman (2020).
 - 3 For a broad review of care and treatment of persons with intersex variation, DO refers to the National Board of Health and Welfare’s reports *Vård och behandling av personer med intersexuella tillstånd* [Care and treatment of persons with intersex variation] (2017) and *Vård och behandling vid tillstånd som påverkar könsutvecklingen* [Care and treatment in conditions that affect disorders of sex development] (2020). For an international review, see Aranda and Zeeman (2020).
 - 4 Monro et al. (2021). Also see Pikramenou (2019) and Carpenter (2016) as well as the Swedish Agency for Youth and Civil Society’s report (2022) on young LGBTIQ people’s living conditions, which also studies the situation for young persons with intersex variation.

In 2019, the European Union Agency for Fundamental Rights (FRA) conducted a large survey in Europe about LGBTI people’s living conditions from a human rights perspective.⁵ Those who responded to the survey included just over 1,500 persons with intersex variation. The responses consistently indicate that people in this group experience more mental and physical illness and a greater degree of discrimination than other LGBTI groups and the European population as a whole.⁶ FRA’s study also contained certain questions that were only posed to persons with intersex variation. In one of these, the respondents were encouraged to rank the biggest problems for persons with intersex variation in the country in which they live.

Figure 1. What do intersex people experience to be the biggest problem today?



Source: EU-LGBTI II survey 2019. The question asked in the survey was: “What are the biggest problems that intersex people come across in [COUNTRY]? Please select up to three options that are the most important to you.” The number of respondents to the question was 1,519 people who self-identified as intersex people in the questionnaire.

For further reading regarding the human rights situation for persons with intersex variation in an international perspective, DO refers readers to the reports published by the UN, the Council of Europe, the European Commission and other organisations in recent years.⁷

5 The study as a whole is entitled EU-LGBTI II and the summary is called A Long Way to Go for LGBTI Equality.

6 The majority of persons with intersex variation (62 per cent) had felt discriminated against in the past 12 months, compared to 42 per cent in the LGBTI group as a whole. The proportion who had experienced harassment, physical violence and sexual violence was higher among persons with intersex variation than among other LGBTI people who participated in the study.

7 A brief introduction has been published by the United Nations High Commissioner for Human Rights. Background Note on Human Rights Violations against Intersex People (2019). For further reading, see also Commissioner for Human Rights Council of Europe (2015), Amnesty International (2017), Dunne and van den Brink (2018), Ghattas (2019), European Union Agency for Fundamental Rights (2020), Ministry for Foreign Affairs of Finland (2020) and Fütty, Höhne and Lloveria Caselles (2020).

Various names and terms

In this document we primarily use the term “persons with intersex variation” when we talk about the individuals in question. Interchangeably, we also use the synonym “persons with variations in sex characteristics”. The choice of terminology is based partly on discussions we have had with civil society organisations and partly on the wording of other authorities.⁸

In the assignment DO received from the Government, the term intersex person was used.⁹ However, DO has established that many representatives of different civil society organisations that we have met do not use this term themselves – or feel comfortable with it.

In particular, patient associations for persons with intersex variation often use other terminology such as disorders of sex development (DSD) or the specific diagnoses in question.

DO has chosen not to use terms such as “intersexuality”, “intersexual” and “intersexual conditions” as they may suggest that congenital variations in sex characteristics are linked to sexuality or sexual orientation.¹⁰

The term DSD (disorders of sex development) is used in the Swedish healthcare system as a collective term for the congenital conditions where sex development in terms of chromosomes, sex glands or sexual organs is not unambiguous in relation to biological sex.

The DSD terminology has been criticised by some researchers and activists as derogatory as it can be interpreted as meaning that persons with variations in sex characteristics are “divergent” in a negative sense. For this reason, organisations have also proposed that differences in sex development should be used instead of disorders of sex development.¹¹ DSD is also used within the WHO cooperation.

8 For example, compare this with the Ombudsman for Children’s report *Erfarenheter från unga transpersoner samt från barn och unga med intersexvariationer* [Experiences from young transgender people and young people with intersex variations] (2021) and the Ministry of Employment (2021b).

9 Ministry of Employment (2021a) Appropriation directions for budget year 2021 in respect of the Equality Ombudsman.

10 Another term that other authorities use to refer to variations in sex characteristics is “congenital abnormalities in sex development”. This terminology is used in texts such as the Act (1972:119) concerning recognition of legal gender in certain cases.

11 For a discussion relating to the term DSD, see the National Board of Health and Welfare (2017) p. 12.

Growing up with a variation in sex characteristics – a life story

Ellinor was born in autumn 2005.¹² As early as her birth, it is obvious that there is something special about this child: the external sexual organs do not look as expected. The midwife becomes so shocked that she starts crying. The early part of Ellinor's life becomes tumultuous for their parents: What is it about our child that is not right – what is this?

After a few days the doctors are able to give them an answer: Due to a congenital enzyme deficiency, Ellinor has been subjected to large amounts of male sex hormone in the womb. This has resulted in the external sex organs developing in a male direction. The doctors say that Ellinor has the rare syndrome congenital adrenal hypoplasia (CAH) and recommends starting treatment with cortisone immediately.

The doctors also recommend that cosmetic surgery is performed in order for Ellinor's body to develop in a more female direction.

Ellinor grows up in a rural area in western Sweden together with Ellinor's mother, father and brother. From an early age, both the family and people close to them perceive Ellinor to be more traditionally boyish in terms of both behaviour and interests. Sometimes neighbours and friends refer to the siblings as "the two boys".

Ellinor starts playing football when she is around ten – and loves it. She spends all her time on the grass pitch in the little village and she is keenly supported by her dad, who is the coach of the village's junior team. When the football season starts, however, parents from the opposing teams sometimes raise their eyebrows when they see Ellinor play and soon there are angry shouts from the sideline: Take him off for God's sake! You can't have a boy in the girls' team! Ellinor's parents have to get used to explaining to the opposing team who Ellinor is ahead of games.

At the senior level, life becomes tougher for Ellinor, not least in school. She has difficulties concentrating, feels harassed, stared at and bullied. In the middle of eighth grade, she does not want to go to school anymore and starts isolating herself at home. She shaves her hair off. One day she confronts her parents: Why did you let them perform surgery on me? You made the wrong choice for me!



¹² The story comes from one of the dialogue meetings DO held in the autumn of 2021 and is published with the consent of the person in question. The name of the person in the story has been changed to protect their anonymity.

Protection offered by the Discrimination Act

The Discrimination Act refers to seven different grounds of discrimination. The legal definitions of the grounds of discrimination do not explicitly state that discrimination associated with a variation in sex characteristics is encompassed by any of the grounds.

However, the preparatory works do state that the legislator intended for discrimination associated with intersex variations to be included under the ground transgender identity or expression. The definition of transgender identity or expression in the Act is that someone does not identify as a woman or a man or expresses by their manner of dressing or in some other way that they belong to another sex. The preparatory works to the Discrimination Act contain the following explanation for why persons with intersex variation are protected as persons with transgender identity or expression.

Out of necessity, the scope of each of the grounds of discrimination does not have any strict boundaries. The intention is for those who identify or express as, for example, a transvestite or intersex to be able to cite the prohibitions against discrimination. However, this statement of categories is not to be seen as an exhaustive list of who falls under the grounds of discrimination, rather as examples.¹³

The preparatory works define persons with intersex variation in the following manner:

Intersex individuals may, for example, be born with atypical sexual organs. The intersex individual's sex may therefore be uncertain.¹⁴

Even if the preparatory works of the act do mention persons with intersex variation, it has been questioned whether this really provides complete protection. According to its critics, the prerequisite "identity or expression" entails a risk of persons with variations in sex characteristics not being able to cite the Discrimination Act in practice.¹⁵ There are persons with variations in sex characteristics who neither see intersex as an identity nor express their variation in sex characteristics.

To date there have been no complaints to DO in which people have reported discrimination associated with intersex variation.¹⁶ Nor are there – as far as DO is aware – any cases in a Swedish court where discrimination or other violation of dignity involving persons with intersex variation have been subject to scrutiny.

¹³ Govt Bill 2007/08:95, p. 116.

¹⁴ Govt Bill 2007/08:95, p. 115.

¹⁵ Garland (2018).

¹⁶ DO has no specific registration for intersex variations and is therefore unable to perform a search for such cases in the register, but as far as we are aware, the authority has not received any complaints regarding discrimination from a person where intersex or variations in sex characteristics has been stated as a ground. We have reviewed all complaints regarding transgender identity or expression in the period 2009–2021 without finding anything regarding intersex variation.

The European Commission has, in collaboration with legal experts from all over Europe, charted the protection against discrimination that persons with intersex variation have in Europe. The overall assessment of the experts is that the protection is considered unclear in most countries. Only a few countries (Malta, Finland, Norway and Iceland) have included sex characteristics as an explicit protected ground.¹⁷

Both the Council of Europe and the European Parliament recommend that member states introduce more distinct protection for persons with intersex variation in their discrimination legislation. They are of the opinion that it would be desirable for member states to introduce sex characteristics as an explicit protected ground.¹⁸

¹⁷ Dunne and van den Brink (2018).

¹⁸ European Parliament resolution on the rights of intersex people (2019) point 10 and Resolution 2191 of the Council of Europe Parliamentary Assembly (2017) point 7.4.

Vulnerability and risks of discrimination

Before we get into the different areas of society where persons with intersex variation experience vulnerability, we would like to highlight some general aspects that affect the risk of discrimination against persons with intersex variation. These observations are important for understanding that the individuals in this group can have different living conditions and that not all of them perceive themselves to be subject to discrimination associated with their variation in sex characteristics.

These observations also provide us with the knowledge that persons with intersex variation may be in a vulnerable situation even if they are not subjected to discrimination in accordance with the Discrimination Act.

A heterogeneous group

Firstly, it is important to point out the fact that persons with intersex variation do not constitute a homogeneous group. Based on the dialogues DO has had with representatives of civil society organisations, we come to the conclusion that far from all persons with variations in sex characteristics perceive discrimination to be a major issue or something that leads to other problems in their lives.

At the same time, there are areas where people risk being subjected to discrimination associated with intersex variation or where they do not get access to equal rights and opportunities. This primarily applies to the healthcare system but also to education, working life and certain other areas of society.

As mentioned previously, the variation within the group can also be seen in the names used. Sometimes “intersex people” or “persons with intersex variation” is used. However, not everyone identifies with the term intersex – some choose to talk about their variation in sex characteristics on the basis of their specific diagnosis. The degree to which persons with variations in sex characteristics feel an affiliation with the LGBTIQ movement also varies. Some consider their condition as solely a physical matter, while others see similarities with, for example, transgender persons’ vulnerability.

A strong gender binary norm

In Sweden and in many other societies in the world there is a widespread perception that gender identity is a matter of “either or”. According to this outlook, a human being belongs to either the male group or the female group. It is not possible to belong to both groups, something in between, or something beyond that.

This perception results in expectations about how human bodies are supposed to look and function. Those whose bodies diverge from these ingrained expectations, for example persons with intersex variation, are often met with negative reactions from other people such as suspicion, dislike and dissociation.¹⁹ They may also be subjected to more well-meaning yet demeaning reactions such as paternalism, excessive curiosity and fascination.

Shame and vulnerability

Several civil society organisations have highlighted the fact that variations in sex characteristics can entail social stigma and feelings of shame, for several different reasons. One explanation could be that it involves an unknown and relatively small group. Another explanation is that, historically speaking, it has been considered a divergent physical condition that has to be “corrected” by the healthcare system. This can also be linked to the aforementioned perception that people must have one of two genders and that there are no variations in sex characteristics. Added to this is the fact that variations in sex characteristics have often – for example in popular culture and science – been the object of fascination and various types of exoticisation.²⁰

The consequences, which several organisations testify to, are that a sort of culture of silence has emerged, and that many people choose not to tell others that they have a congenital variation in sex characteristics. In some cases, this may in turn lead to people experiencing isolation and loneliness.

Vulnerability and risks of discrimination in the healthcare system

Based on the dialogues and the evidence-gathering conducted by DO with civil society organisations, we are able to establish that issues relating to vulnerability in the healthcare system are central. Representatives of both civil society and public authorities have highlighted how persons with intersex variation are at risk of being subjected to negative treatment, harassment and a lack of equivalent care. They also testify to there being inadequate information in contact with the healthcare system. In addition to this, access to rights for minors with intersex variation is a particularly complex area. We will return to this issue under the heading “Children’s rights”.

19 Ghattas (2019) pp. 13–14, Commissioner for Human Rights Council of Europe (2015) pp. 13–14, Agius and Tobler (2012).

20 Dreger (1998) and Holmes (2008).

The discrimination legislation (Chapter 2, Section 13 of the Discrimination Act) applies within the healthcare system and encompasses six different forms of discrimination: direct discrimination, indirect discrimination, inadequate accessibility, harassment, sexual harassment and instructions to discriminate. The act applies to “decision-making, all formal and informal processing of cases, such things as information, guidance and outreach activities, and also failing to act or unjustified delays to decisions”. It also includes the actual actions of and reception by healthcare personnel. Furthermore, the act encompasses “the right to access care, treatment and other interventions, the scope and content of these interventions and, where applicable, payment of charges”.²¹

The prohibition against discrimination does not encompass “assessments of care needs that are based on best practice and established treatment methods, nor does it encompass incorrect medical assessments”. It also states the following: “If there is a lack of effective care or treatment methods, medicinal products etcetera for a certain disease, that is also not a question of discrimination”.²²

DO has established in an earlier report that the Swedish healthcare is generally of a high standard but it is not entirely equal and there are problems with discrimination.²³ There are also groups that have a significantly harder time than others gaining access to the correct care. Some groups of patients also feel that they are given a poorer reception than other people.²⁴ This has consequences for someone’s inclination to seek care. There are vulnerable groups that do not make contact with the healthcare system due to their own bad experiences or those of others. For example, it happens that that homosexual, bisexual and transgender people avoid seeking care.²⁵

Adults’ contact with the healthcare system

At present, seeking healthcare as an adult with variations in sex characteristics can be associated with difficulties. Something pointed out by both representatives of civil society organisations and healthcare personnel is that there is a general lack of knowledge within healthcare – especially primary care – about what variations in sex characteristics are and how they affect the health of the individual. There is a risk of this leading to individuals with intersex variation being disadvantaged and having worse opportunities than others to gain access to adequate healthcare.

This lack of knowledge seems to apply particularly to healthcare for adults, where, according to several sources, there is a lack of resources and combined expertise. Many people feel that they have to act as experts about their own situation or diagnosis. In the long run, this may also lead to persons with intersex variation refraining from seeking care. DO notes that persons with intersex variation share this set of problems with others who have rare diagnoses.

21 Govt Bill 2007/08:95, p. 522.

22 Govt Bill 2007/08:95, p. 522.

23 Equality Ombudsman (2012) p. 9.

24 Equality Ombudsman (2012) p. 9.

25 Equality Ombudsman (2012) p. 21.

Furthermore, it emerges that persons with intersex variation may have experiences of negative encounters and situations that they find offensive in the healthcare system. For example, they have to endure questions that violate their integrity and/or unjustified examinations. This has emerged from our dialogue meetings and the reports that exist in this area.²⁶ We make the assessment that such situations may to some extent be due to a lack of knowledge, but healthcare personnel may also be shaped by the gender norms that exist in society as a whole.

In addition, healthcare personnel are not always aware of the shame and stigmatisation that persons with intersex variation describe themselves as bearing, which may also contribute to negative experiences of the healthcare system.

Children's rights

Care and treatment of minors with variations in sex characteristics is another complex area that is subject to debate. This primarily relates to what treatment and/or surgery the healthcare system should have the opportunity to provide to children in consultation with the legal guardians.

Some civil society organisations and international political bodies want to prohibit medical interventions that are intended to change a child's sex characteristics, while other organisations and healthcare representatives argue that prohibition is not the right path to take.

DO notes that the healthcare system has become increasingly restrictive with regard to surgery and treatment of young children with intersex variation. One important reason for this is the knowledge-based guidance containing national recommendations published by the National Board of Health and Welfare in 2020. This has also led to a more uniform treatment within Swedish specialist care. However, this does not mean that treatment has been stopped completely. Nor are there any proposals for new rules or legislation in order to further protect minors with variations in sex characteristics.

There has been criticism from a legal standpoint that points to the fact that all healthcare in Sweden has to comply with the requirements in the Patient Safety Act that healthcare personnel provide "expert and conscientious healthcare" that is consistent with the evidence base and proven experience.²⁷ These critics argue that surgery performed on young children with variations in sex characteristics does not comply with these requirements. These critics argue that if these minors with variations in sex characteristics were encompassed by the Discrimination Act, surgery and other treatment of minors could be challenged under Section 13 of the Discrimination Act.²⁸

26 National Board of Health and Welfare (2017) pp. 69–70. Ombudsman for Children (2020) p. 67.

27 Patient Safety Act (2010:659), Chapter 6, Section 1.

28 Garland (2016) pp. 269–273 & 467 and Garland (2018).

Lack of access to information from the healthcare system

Lack of information from the healthcare system is another problem area. People who underwent various treatments as children have not always been given information about this. Persons with variations in sex characteristics also testify to the lack of information having contributed to stigmatisation and feelings of shame and, in the worst cases, mental and physical illness.

The international research highlights how difficult it is for persons with intersex variation to gain access to their own medical history, and this is seen as a serious rights problem.²⁹ It is also pointed out that persons with intersex variation often ask for support and help to interpret the language and medical terminology in their medical records.

In its review, the National Board of Health and Welfare concludes that the healthcare system is still unable to guarantee that all patients are given relevant information during their childhood and adolescence. The board says that this is primarily due to many parents finding the subject difficult to bring up. It can also be due to parents being unwilling or unable to take in the information.³⁰

Vulnerability and risks of discrimination in education and working life

Reports also indicate that there is discrimination associated with intersex variation in the field of education and in working life. Both of these areas of society are covered by the Discrimination Act.³¹

Persons with intersex variation and discrimination in education

The vulnerability that may be experienced by persons with intersex variation in school can, as has been highlighted in reports and by civil society organisations, take various forms.³² One example is harassment, which is a form of discrimination. There is currently limited knowledge about the group young persons with intersex variation in Sweden but experience from other countries indicates that discrimination associated with intersex variation takes place in school. The situation for people with an appearance that is perceived as abnormal by others is particularly vulnerable.

29 Pikramenou (2019) pp. 57–58.

30 National Board of Health and Welfare (2017) pp. 74–75.

31 The prohibitive provisions in respect of working life are in Chapter 2, Sections 1–4 of the Discrimination Act and those in respect of education are in Chapter 2, Sections 5–8 of the Discrimination Act.

32 Fütty, Höhne and Llaveria Caselles (2020), p. 27. See also Ghattas (2019) p. 27 and Jones (2016).

It is worth mentioning in this context that people who identify (or may be perceived by others) as transgender are at higher risk than others of being subjected to violations of dignity in school. Violations of dignity that are often grounded in negative attitudes towards people who are perceived to challenge the two-gender norm. As persons with intersex variation can also be perceived as challenging the two-gender norm, there is a risk of them also being subjected to similar violations of dignity.

One environment in schools where persons with intersex variation may be particularly vulnerable is changing rooms and showers – spaces where their bodies are often extra visible to other pupils and staff.

In addition to intentional violations of dignity, our dialogues with civil society organisations indicate that school staff, out of ignorance, may respond to children with intersex variations in an uncertain and/or insensitive manner. For example, this might involve groups being divided on the basis of gender and staff using personal pronouns such as she and he.

Persons with intersex variation and discrimination in working life

The problems described above can also present in working life. In the major European investigation by the European Union Agency for Fundamental Rights (FRA) from 2019 it emerged that a significant proportion (38 per cent) of persons with intersex variation had experienced discrimination in working life in the past 12 months in Europe.³³ The figures for Sweden are not available; there is too little data with which to publish statistics.

DO has not received any complaints concerning discrimination associated with intersex variation in working life (or in any other area of society). Nor have there been any cases in Swedish courts in which discrimination associated with intersex variation has been subject to scrutiny. In light of this, DO takes the view that it is important to develop knowledge about the situation for persons with intersex variation in working life. It would also be valuable if DO received and was able to investigate complaints concerning discrimination associated with intersex variation. This could contribute to the development of case law in discrimination cases linked to persons with intersex variation. It would also give individuals who have been subjected to discrimination associated with intersex variation an opportunity to obtain redress. This applies to both working life and other areas.

³³ FRA is an abbreviation for the European Union Agency for Fundamental Rights. The investigation in question is EU LGBTI II, the results of which are summarised in the report A Long Way to LGBTI Equality.

In the dialogue meetings DO conducted in autumn 2021, it emerged that there is demand among representatives of civil society organisations for more knowledge and greater understanding among employers of what it means to live with intersex variation.

For example, it is not uncommon for persons with intersex variation to go through hormone treatment that may cause their working capacity to be reduced for periods of time. Certain persons with intersex variation also have a diagnosis that makes it difficult for them to handle loud work environments and/or certain types of stress.

Vulnerability and risks of discrimination in other areas of society

In addition to healthcare, education and working life, there are other areas where people are at risk of being subjected to discrimination associated with intersex variation and where there may be obstacles to equal rights for persons with intersex variation.

Persons with intersex variation within sport

One area that is subject to international debate is the situation for persons with intersex variation within sport. This issue has been especially topical in the world of athletics, where, for the past few years, testosterone testing has been carried out in some events on women who are suspected of gaining an advantage thanks to a congenital variation in sex characteristics.

How this issue develops is also of interest to athletes in Sweden with variations in sex characteristics. Even if the issue of testosterone levels and intersex does not seem to be pertinent here at present, it is highly probable that issues relating to intersex variation and sport may become so at a later stage.

In this context, DO notes that sport is typically treated as a part of the voluntary sector. That means that situations within sport generally fall outside of the scope of the protection offered by the Discrimination Act. Sportspeople being disadvantaged within the scope of working life, education or healthcare is however encompassed by the Discrimination Act.

In addition to the gender categorisation itself, and rules around this, potentially being a challenge, DO would also like to point to other factors that may affect the participation of persons with intersex variation in a sporting context. Insecurity experienced in changing rooms and showers may be of significance here. Surveys have also shown that homophobia and transphobia are often expressed in the world of sport, which likely has a negative effect on opportunities for persons with intersex variation to participate.³⁴

34 Menzel, Braumüller and Hartmann-Tews (2019).

Allocation of legal gender

There is no specific regulation on the allocation of a legal gender when a child is born with an intersex variation. The applicable rules are the general provisions of the Population Registration Act.³⁵

In cases where the child's biological sex is not unambiguously male or female, the decision concerning legal gender shall be made in consultation with the legal guardians who must also give their explicit consent to the decision. For a child who is being investigated by a DSD team, a report is made by the healthcare service once the investigation is concluded.

Representatives of both international and Swedish civil society organisations are of the opinion that the introduction of a voluntary third option could also make a positive contribution to the group's visibility and provide recognition for those persons with intersex variation who do not want to register as either a man or a woman. Furthermore, civil society organisations recommend that changing legal gender should be a simple administrative procedure without medical questions.

³⁵ The basic principle is that child who is born is registered with the Swedish Tax Agency by the hospital and is then allocated a personal identity number consisting of ten digits. The Population Registration Act stipulates that the date of birth is given with two digits for the year, two for the month and two for the day – a total of six digits. This is followed by the “identity digits” consisting of three digits, the third of which is odd for men and even for women. The final digit is a control digit.

Proposed measures

In the previous section DO has highlighted some areas where we see there being vulnerability for persons with intersex variation that also risk leading to discrimination and may be an obstacle to equal rights and opportunities. In this concluding section we would like to point to some measures we assess as having the potential to counteract these risks.

The protection from discrimination should be clarified

As described above, discrimination associated with intersex variation is currently encompassed by the Discrimination Act by virtue of statements in the preparatory works. The robustness of this protection has been criticised on the basis that it is unclear whether this also applies to persons who are not transgender in terms of their identity or expression. We also know that there are as yet no complaints concerning and no case law regarding discrimination associated with intersex variation.

DO makes the assessment that there may be a need to clarify that discrimination associated with intersex variation is encompassed by it being mentioned explicitly in the wording of the act – not simply through statements in the preparatory works.

DO is therefore of the opinion that the act as it is currently worded should be reviewed in order to make discrimination associated with intersex variation visible and ensure there is legal protection against it. Such an inquiry should also consider whether there is a need to introduce a separate ground of discrimination or explicit wording about discrimination associated with intersex variation into the act.

Insufficient knowledge and attitudes need to be addressed

DO is able to conclude that awareness and knowledge of variations in sex characteristics need to increase in society as a whole. It is especially important that knowledge is increased among those who work in healthcare and education, but also in other institutions that come into contact with children and adolescents and their parents. Legal guardians and other relatives play a very important role in supporting persons with intersex variation and breaking the culture of silence and shame that surrounds the subject of variations in sex characteristics.

Insufficient knowledge is a factor that may lead to a risk of discrimination against intersex persons. DO is of the opinion that other factors that may lead to risks of discrimination and other violations of dignity against persons with intersex variation are, for example, social and cultural perceptions about gender identity that we have discussed in this report.³⁶ Countering these attitudes is a long-term, important and complicated process.

Another way to increase awareness and contribute to long-term change would be to revise the sex and human relationships teaching in schools so that issues relating to variations in sex characteristics are addressed in that context as well. DO notes that revised course and subject syllabuses for this subject will be introduced in 2022.³⁷

More research and knowledge are required

DO makes the assessment that the state of research and knowledge regarding discrimination against persons with intersex variation needs to be enhanced. There is a need to follow up living conditions for persons with intersex variation in general, not least on the basis of issues related to the situation within the healthcare system. In this respect, DO's view is that authorities such as the National Board of Health and Welfare, the Public Health Agency of Sweden and the Health and Social Care Inspectorate should, in future, have a potential to contribute important knowledge. DO could also make more of a contribution, for example by investigating the situation in schools and in working life more closely. Efforts to increase the inclination to make complaints about discrimination associated with intersex variation is an important factor in this. There is also a need for continuous dialogue with civil society organisations, as well as research and knowledge from other authorities.

³⁶ See SMER (2017) and Council of Europe Parliamentary Assembly resolution 2191 (2017) points 7.4, 7.6 and point 8.

³⁷ The field that has previously been called "sex and human relationships" is changing its name to "sexuality, consent and relationships" in 2022. Changes in the curriculum applying from 1 July 2022 in all schools at the compulsory and upper secondary levels. For more information on this, see skolverket.se.

References

Agius, Silvan. & Christa Tobler (2012). Trans and intersex people: discrimination on the grounds of sex, gender identity and gender expression. Luxembourg: Office for Official Publications of the European Union.

Amnesty International (2017). First, Do No Harm. Ensuring The Rights Of Children With Variations Of Sex Characteristics In Denmark and Germany. London: Amnesty International.

Ministry of Employment (2021a). Regleringsbrev för budgetåret 2021 avseende Diskrimineringsombudsmannen [Appropriation directions for budget year 2021 in respect of the Equality Ombudsman].

Ministry of Employment (2021b). Handlingsplan för hbtqi-personers lika rättigheter och möjligheter [Action plan for the equal rights and opportunities of LGBTIQ people]. Stockholm: Ministry of Employment.

Aranda, Kay and Laetitia Zeeman (2020). A Systematic Review of the Health and Healthcare Inequalities for People with Intersex Variance. *International Journal of Environmental Research and Public Health*, vol 17 (18).

Ombudsman for Children (BO) (2020). Erfarenheter från unga transpersoner samt från barn och unga med intersexvariationer [Experiences of young transpersons and from children and young people with intersex variation]. Stockholm: Ombudsman for Children.

Carpenter, Morgan (2016). The human rights of intersex people: addressing harmful practices and rhetoric of change. *Reproductive health matters*, vol. 24, pp. 74–84.

Commissioner for Human Rights Council of Europe (2015). Human rights and intersex people. Strasbourg: Council of Europe.

Council of Europe Parliamentary Assembly resolution 2191 (2017). Promoting the human rights of and eliminating discrimination against intersex people. Strasbourg: Council of Europe.

Council of Europe Parliamentary Assembly resolution 1952 (2013). Children's right to physical integrity. Strasbourg: Council of Europe.

Equality Ombudsman (DO) (2012). Rätten till sjukvård på lika villkor [The right to healthcare on equal terms]. Stockholm: Equality Ombudsman.

Dreger, Alice Domurat (1998). Hermaphrodites and the medical invention of sex. Cambridge: Harvard University Press.

Dunne, Peter and Marjolein van den Brink (2018). Trans and Intersex Equality Rights in Europe: A Comparative Analysis. Publications Office of the European Union.

- European Parliament (2019). [Resolution on the rights of intersex people \(europarl.europa.eu\)](#) [Downloaded 17/01/2022]
- European Union Agency for Fundamental Rights (2020). A Long Way to Go for LGBTI Equality. Luxembourg: Publications Office of the European Union.
- Füty, Tamás Jules, Marek Sancho Höhne, Eric Llaveria Caselles (2020). Gender Diversity in Employment and Occupation. Employers' needs and options to implement anti-discrimination policies. Berlin: Federal Anti-Discrimination Agency.
- Garland, Jameson (2018). "The Legal Status of Intersex Persons in Sweden". The Legal Status of Intersex Persons. Cambridge: Intersentia.
- Garland, Jameson (2016). On science, law, and medicine: the case of gender-“normalizing” interventions on children who are diagnosed as different in sex development. Uppsala: Uppsala University.
- Ghattas, Dan Christian (2019). Protecting Intersex People in Europe: A toolkit for law and policymakers. Brussels: ILGA/OII Europe.
- Jones, Tiffany (2016). The needs of students with intersex variations. *Sex Education*, vol. 16:6, pp. 602–618.
- Govt Bill 2007/08:95. Ett starkare skydd mot diskriminering [Stronger protection against discrimination]. Stockholm: Ministry of Culture.
- Menzel, Tobias, Birgit Braumüller and Ilse Hartmann-Tews (2019). The relevance of sexual orientation and gender identity in sport in Europe. Findings from the Outsport Survey.
- Ministry for Foreign Affairs of Finland (2020). No information or options. Study on the Rights and Experiences of Intersex People in Finland. Helsinki: Ministry of Justice.
- Monro, Surya, Morgan Carpenter, Daniela Crocetti, Georgiann Davis, Fae Garland, David Griffiths, Peter Hegarty, Mitchell Travis, Mauro Cabral Grinspan & Peter Aggleton (2021). "Intersex: cultural and social perspectives". *Culture, Health & Sexuality*, vol. 23:4, pp. 431-440.
- Swedish Agency for Youth and Civil Society (2022). Jag är inte ensam, det finns andra som jag [I am not alone, there are others like me]. Växjö: Swedish Agency for Youth and Civil Society.
- Pikramenou, Nikoletta (2019). *Intersex Rights*. Switzerland: Springer.
- National Board of Health and Welfare (2017). Vård och behandling av personer med intersexuella tillstånd: kartläggning av det tidiga omhändertagandet [Care and treatment of persons with intersex variation: survey of early care intervention]. Stockholm: National Board of Health and Welfare.
- National Board of Health and Welfare (2020). Vård och behandling vid tillstånd som påverkar könsutvecklingen ("DSD") Kunskapsstöd med nationella rekommendationer [Care and treatment in conditions that affect disorders of sex development ("DSD")]

Knowledge support with national recommendations]. Stockholm: National Board of Health and Welfare.

Swedish National Council on Medical Ethics (Smer) (2017). Vården av intersexuella barn – etiska aspekter på tidiga kirurgiska ingrepp [The care of intersex children – ethical aspects of early surgery] (Smer comments 2017:2, published 27/03/2017).

United Nations Office of the High Commissioner for Human Rights (2015). Fact Sheet Intersex. Switzerland: United Nations Office of the High Commissioner for Human Rights.

United Nations Human Rights Council (2013). [Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment - Report 53 of the 22nd session of the Human Rights Council \(ohchr.org\) \[Downloaded 18/01/2022\]](#)

DO

www.do.se

Box 4057

169 04 Solna

Telephone 08-120 20 700

facebook.com/Diskrimineringsombudsmannen

