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National situational analysis report: United Kingdom

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Contents

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National situational analysis report United Kingdom

1. INTRODUCTION

This report draws on secondary sources and our own qualitative fieldwork to explore the current situation in the UK affecting intersex people and people with variations of sex characteristics, specifically relating to medical interventions, issues of equality and discrimination, national legal protections, and effective policies and practices to promote social inclusion and equality.

The terms 'intersex' and 'variations of sex characteristics' refers to people born with sex characteristics such as chromosomes, genitals, and/or hormonal structures that differ from typical definitions of male or female. It means an individual's sex development or reproductive anatomy is different to most other people. A child may have sex chromosomes usually associated with being female or usually associated with being male, but reproductive organs and genitals that may look different from usual. The vast majority of variations do not require any medical care other than understanding the infant's development and knowing what to expect as they grow older. The terms 'Disorders of Sex Development', and more recently, 'Differences of Sex Development' (DSD) are often used in healthcare settings. However, such terminology is perceived by some as pathologizing and stigmatizing[1]. Among our research contributors, there were mixed views on the most appropriate terminology. In attempt to be as inclusive as possible we have chosen to borrow Surya Monro and colleagues' (2017) term 'Intersex and Variation of Sex Characteristics (IVSC)'. Notwithstanding this, we understand that some readers may prefer to use other terms such as 'Variations of Sexual Development', 'Diverse Sex Development', or specific variations.

2. PART A: DESK RESEARCH RESULTS.

2.1 THE STATUS OF IVSC PEOPLE IN THE UK

Identifying the population of IVSC people is problematic. Variations in sex characteristics may not be apparent until later in life, some IVSC people choose not to disclose information about their sex characteristics, and there is no consistent definition or approach to gathering data on IVSC. As a result population estimates vary dramatically. A 2017 United Nations report, estimates that between 0.05% and 1.7% of infants are born with intersex traits (UN, 2017). Similarly wide estimates appear in the UK Government Equalities Office's (GEO) 2019

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[1] [1] For an extensive review of the history and politics of IVSC terminology see Georgiann Davis' (2015) Contesting Intersex.

call for evidence for Variations in Sex Characteristics.[2] The British charity DSD Families estimates that in the UK around 140 babies born each year require investigations before their sex is assigned (DSDfamilies, 2019).

There is very little data on the socio-economic status of IVSC people in the UK. Research from other countries provides a mixed picture. A large scale Australian survey by Jones et al (2016) found that IVSC people were likely to experience higher rates of poverty. Conversely a Danish study reported that income for females with intersex variance was higher compared to the general population where they performed well in the labour market (Zeeman and Aranda, 2020).

It is acknowledged by many academics, intersex rights organizations and national and international government bodies, that IVSC people experience stigmatization, discrimination, bullying and other harmful behaviours on the basis of their sex characteristics, in many aspects of their daily lives (Astraea Lesbian Foundation for Justice, 2016; Carpenter, 2019a; Council of Europe, 2017; European Union Agency for Fundamental Rights, 2020). By far the greatest area of concern in relation to discrimination and unfair treatment, in the UK and elsewhere, is the non-consensual, harmful and medically unnecessary surgical interventions routinely faced by many people born with variations in sex characteristics. While certain variations can be associated with life-threatening problems, such as salt-wasting in congenital adrenal hyperplasia (CAH), and do require immediate medical intervention, the vast majority of variations are not life-threatening (Garland and Travis, 2020a).[3] Most surgeries are carried out in order to make intersex bodies appear more typically male or female (Carpenter, 2018; Garland and Travis, 2020a). Such deferrable procedures frequently result in pain (Ehrenreich and Barr, 2005), loss of sexual function and sensitivity (Minto et al., 2001; Minto et al., 2003), need for further medical treatment (Creighton et al., 2001), and experiences of violation and sexual assault (Carpenter, 2019b). This is in spite of recent evidence that demonstrates good psychological and physical outcomes for children and their families that chose not to have surgery (Bougneres et al., 2017).

In January 2016, the House of Commons' Women and Equalities Committee (2016) published a report on transgender equality, which referenced IVSC, claiming that problematic medical interventions on ISVC infants were no longer commonplace in the UK. Analysis of NHS statistics by Monro et al (2017) suggests otherwise. According to their analysis, an average of over 2,500 such procedures took place on patients aged between 0 and 14 each year between 2000-2016.[4] A year after the publication of the 2016, House of Commons' Women and Equalities Committee' s report, the GEO launched a consultation on reform of the Gender Recognition Act 2004 (GRA), in which IVSC issues were also discussed (Minister for Women and Equalities, 2018). Contradictory

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[2] A 2015 study cited in the summary report states that "the birth prevalence of atypical genitalia may be as high as 1 in 300 births, but the birth prevalence of a condition that may lead to true genital ambiguity on expert examination may be as low as 1 in 5000 births" (Ahmed et al., 2015).

[3] For more detailed discussion on disentangling immediate and deferrable interventions see Monro et al (2017) and Garland and Slokenberga (2018).

[4] The authors (Monro, et al., 2017) state that these data are indicative and should not be treated as conclusive as it is not possible to ascertain whether each individual procedure took place at an age where a child could give meaningful consent, and some of the procedures are likely to be treatment for separate conditions such as penile cancer.

to the 2016 report on transgender equality, this consultation discussion did acknowledge, albeit briefly, the harms of the 'gender-normalizing' medical interventions on IVSC, and crucially that they are still occurring.

In 2019 the European Union Agency for Fundamental Rights (FRA) conducted a 'Lesbian Gay Bisexual Transgender and Intersex' (LGBTI) survey to identify the level of discrimination against and victimisation of LGBTI groups across the EU member states and the UK. This was the first time that the FRA surveyed IVSC (FRA, 2020). In total 1,519 people from across the EU identifying as 'intersex' were surveyed with 121 respondents in the UK. Findings from across the EU showed that a significant majority (59%) of IVSC respondents report experiencing discrimination at school, when looking for housing, accessing healthcare or social services, and in shops, cafés, restaurants, bars or nightclubs. The survey also reveals that experiencing physical or sexual attacks is more common for IVSC respondents, with 22 % experiencing such incidents in the five years before the survey, compared with the average for all respondents of 11 %. One in five IVSC respondents faced hurdles when registering their civil status or gender in a public document, including denials of service or mockery by staff. This survey shows that IVSC people face considerable discrimination in a range of different areas. Moreover, anecdotal evidence from a number of different European countries also suggests that IVSC people are victims of biased violence including on the streets, in some family settings and other environments (Karsay, 2018).

As for public perceptions toward IVSC people among the general public, a 2019 Special Eurobarometer on discrimination that included a variety of questions on perceptions of IVSC, showed that overall perceptions towards IVSC in the UK are generally more positive than the European average (European Commission, 2019). 79% of UK respondents were comfortable with the highest elected official being intersex, compared with 54% across the EU as a whole. 89% stated they would feel comfortable with a work colleague being intersex as opposed to 66% EU average. 69% would feel comfortable with their child having a romantic relationship with an intersex person. While these figures are more favourable than those in the other European countries surveyed, it would seem that there are still prejudicial views toward IVSC among some sections of the British public. However, these survey findings must be interpreted with caution; when we consider the lack of awareness of IVSC among the wider public, which is elaborated in the next sections of the report, it is likely that some of the 1,022 respondents may not have had a true understanding of what IVSC is and may have conflated it with other groups (e.g., transgender, non-binary).

Further research from non-UK contexts also suggests that in education IVSC students are more likely to leave school early without any qualifications due to bullying and the impact of repeated follow up medical appointments (Jones et al., 2016). This study also revealed poorer mental health outcomes, including higher rates of suicide, when compared the average population. There is also some evidence that early exposure to general anaesthsia is associated with developmental delays (Schneuer et al., 2018).

2.2 NATIONAL LEGAL FRAMEWORK

IVSC status is not a protected characteristic in UK anti-discrimination law. Consequently, IVSC people are not protected from discrimination in the work place or in education settings. Hate crime is defined in the UK as "any crime that is motivated by hostility on the grounds of race, religion, sexual orientation, disability or transgender identity" (Home Office, 2016: 12). This fails to include crimes motivated by hostility on the grounds of sex characteristics and therefore excludes IVSC people, leaving them vulnerable to hate crime incidents.

Despite this it is sometimes incorrectly assumed that anti-discrimination protections on the ground of 'gender identity' cover IVSC (Astraea Lesbian Foundation for Justice, 2016). While having variations of sex characteristics may inform a person's gender identity, what defines IVSC is the presence of atypical sex characteristics that do not meet typical expectations for men and women, not how a person identifies.

Scotland has its own legal traditions and a distinct legal system, including hate crime legislation, which does explicitly reference protections to IVSC status (Offences (Aggravated by Prejudice) (Scotland) Act 2009). While it is progressive in that it does include IVSC status, it is incorrectly placed as a subcategory of transgender identity as opposed to a separate characteristic. The fact that the Scottish government has made this conflation between transgender and IVSC speaks volumes about the lack of broader understanding among policy makers. The Scottish government has recently held a consultation with stakeholders to inform the amendment of the current legislation, including rephrasing protections to IVSC .

While inclusion of IVSC seems like a step in the right direction, such reforms alone can prove ineffectual. As can be seen in Australia, where in 2013 IVSC was included as a protected characteristic within anti-discrimination law. Despite this, in 2016 the Family Court of Australia ruled that parents can consent to gender-normalizing interventions on their children without seeking the Court's approval (Garland and Travis, 2020a).

Regarding legal registration at birth, there is no 'third marker' or 'x marker' in the UK, only male and female sex categories. 'Unknown sex' upon birth registration is allowed and a short delay in registering new births is permitted to enable the 'medical identification' of a 'preponderant' sex (European Union Agency for Fundamental Rights FRA, 2015).

IVSC people are not permitted to change sex classification except by declaring themselves transgender, providing a diagnosis of gender dysphoria, and following related medical protocols (gov.uk, n.d). While some IVSC people may also be transgender, the vast majority do not have gender dysphoria and so this does not apply to them. It is worth noting that findings from our fieldwork suggested that the majority of IVSC people do not wish to change their sex classification. However, while of secondary importance to the problems associated with medical treatment, there should be legal processes for IVSC people who do wish to change their legal sex classification from the one assigned at birth, without pretending to be transgender.

Despite considerable evidence on its harms, there are no laws to protect IVSC infants from undergoing unnecessary surgery in the UK. Nor do any existing anti-discrimination laws cover discrimination that can arise when healthcare professionals lack adequate training or knowledge to give appropriate care and respect the autonomy and rights of IVSC people.

It could also be presumed that intersex people legally fall under the disability umbrella, but this is problematic as it further pathologizes IVSC.

2.3 NATIONAL CENTRAL POLICIES AND GOOD PRACTICES

Following the 2006 Consensus Statement on the Management of Intersex Disorders, a raft of changes to improve treatment of IVSC people were made, including more collaborative care and encouraging psychological and counselling support over surgical approaches (Houghes et al., 2006). A 2016 update to the consensus statement reiterated the importance of these recommendations and encouraged delaying surgeries until patients can provide informed consent and therefore participate in decision making (Lee et al., 2016).

Despite these recommendations, access to psychosocial services varies massively across the UK (Ernst et al., 2018), and non-consensual medical interventions continue (Bauer and Truffer, 2020; Monro et al., 2017).

It must be acknowledged, as our research contributors did, that there are many medical professionals who endeavor to deliver on these recommendations, providing a patient centered model of care that moves away from the surgical approach. A 2015 editorial in the BMJ noted the importance of the European Union Agency for Fundamental Rights 2015 recommendation for EU member states to avoid non-consensual medical treatments on IVSC individuals (Liao et al., 2015). However, it seems that the necessary systemic change is yet to take place.

In addition to the previously mentioned 2017 GRA consultation, which acknowledged a range of issues facing IVSC people, in 2019 the UK Government Equalities Office launched a call for evidence on IVSC issues in England and Wales. This was comprehensive and demonstrated an acknowledgement and appreciation for the need to engage and understand more about the experiences of IVSC in the UK. While it is definitely a positive step to see the government seeking to strengthen their evidence base with a view to inform future policy interventions, there remains little intimation of any specific plans for concrete policy changes.

There is a much positive work being done by a number of IVSC activist and advocacy organizations and support groups (see list of organizations at end of chapter), both in directly supporting individuals and their families as well as campaigning for policy reform, including improvements to medical treatment and wider issues of discrimination and equality. As observed by a number of pertinent medical professionals, 'Intersex advocacy groups are driving increased accountability of teams serving patients with a DSD to provide effective psychosocial services that go beyond tokenistic "hand holding" to pacify patients and families in emotional crises' Ernst et al (2018: 3). They also state that the work of patient advocates has

improved care, by encouraging openness with patients and families about the childrens' variations and its implications, and promoting shared decision-making. However, considerable limitations remain on the ability of such groups to conduct support services and effectively campaign due to severe lack of funding directed towards IVSC work.

When compared to other groups also fighting for greater equality and human rights protections, it seems that IVSC is rather lower down on the UK governments' agenda. As shown with the 2016 House of Commons' Women and Equalities Committee report on transgender equality, which gave a number of recommendations that were considered helpful by various transgender groups (Griffiths, 2018). While IVSC organizations and individuals provided substantial evidence to the committee, IVSC was only mentioned briefly, with the recommendation that the government needs to assess how best to meet the needs of IVSC children and adults in the future (ibid).

2.4 USEFUL CONTACTS

IVSC NGOs, Support Groups and LGBT organisations working on IVSC issues

- The UK Intersex Association

  http://www.ukia.co.uk/

- Intersex UK

Info@intersexUK.org

http://intersexuk.org/

- Genital Autonomy

  https://www.genitalautonomy.org/

- Klinefelter’s Syndrome Association UK

  http://www.ksa-uk.net/

- Living with CAH

  http://www.livingwithcah.com/

- Androgen Insensitivity Syndrome Support Group (AISSG)

  http://www.aissg.org/

- Hypospadias UK Trust

  http://www.hypospadiasuk.co.uk/

- OII-UK – Intersex in the UK

  http://oiiuk.org/

- dsdfamilies (international)

  http://www.dsdfamilies.org/

- StopIGM

  https://www.stopigm.org/contact/

- Astrea Lesbian Foundation for Justice

  info@astraeafoundation.org

National Equality Bodies

- UK Equality Advisory & Support Service

  https://www.equalityadvisoryservice.com/app/ask

- Government Equalities Office (GEO)

  https://www.gov.uk/government/organisations/government-equalities-office

- Equality and Human Rights Commission (EHRC)

  https://www.equalityhumanrights.com/en

- Scottish Human Rights Commission (SHRC)

  https://www.scottishhumanrights.com/

- Northern Ireland Human Rights Commission (NIHRC)

  https://www.nihrc.org/

3. PART B: FIELD RESEARCH – INTERVIEWS WITH EXPERTS, STAKEHOLDERS, POLICY AND DECISION MAKERS.

3.1 Background and profile of interviewees

Between July and October 2020 we conducted 11 interviews with key stakeholders, experts, and policy makers, including IVSC advocate and activist organizations, academics and researchers specializing in IVSC issues, as well as a psychotherapist and counsellor with experience in IVSC, and a member of the House of Lords who is the Lord's LGBT spokesperson. We tried to reach out to more health and social care professionals working in specialisms pertinent to IVSC but were unsuccessful in our attempts. We assume that the current Covid-19 pandemic was partially responsible for limiting our access to more health and social care professionals. Existing literature also suggests that medical teams may be reluctant to speak to projects such as ours on due to perceived criticism. Where the names of the contributor's and/or their organizations appear alongside quotes consent was obtained.

3.2 Basic Knowledge (of terminology and legal framework)

Our contributors all stressed the importance of understanding the internal biological nature of IVSC. Their definitions centred on congenital variations of sex characteristics that differ from traditional categories of male or female, or fit into both or neither. Several made reference to the 2018 Government Equalities Office (2018) 'National LGBT survey' in which many respondents identified as 'intersex', seemingly using the terms 'intersex' and 'non-binary' interchangeably, and describing themselves as IVSC in terms that were outside of biological definitions. This is seen as problematic as it potentially masks some of the structural systematic health issues that intersex people actually face.

There was also frequent reference made to the politically contested nature of the terminology used to refer to IVSC. DSD is often seen as pathologizing and therefore inappropriate, but also continues to be used by some IVSC people. Many people with variations of sex characteristics do not see themselves as being 'an intersex person', but simply as a person with a specific variation. At the same time, the use of 'intersex' as an umbrella term is seen as empowering and providing a sense of community to many. It is also acknowledged that 'intersex' is the term that most non-IVSC people would be most familiar with. This contestation also extends to decisions on what variations are considered to be IVSC.

As mentioned in the previous section, IVSC is not a protected characteristic in the UK national legal framework other than in the Offences (Aggravation By Prejudice) (Scotland) Act 2009, which as previously stated, incorrectly files 'intersexuality' under transgender identity. One contributor did point out that under EU law ISVC could be seen as falling under the category of sex because sex is very general category, therefore sex discrimination might apply to IVSC. However, there is no precedent for such an application.

As for patients' rights concerning the medical treatment of IVSC, under the Human Rights Act the National Health Service (NHS) is a public body and as such is required to ascribe to the European Court of Human Rights. However, there is no specific reference to IVSC patients' rights in relation to the key areas of human rights concerns (e.g., bodily integrity, self-determination).

In the UK IVSC is also identified with the language of disability, which is very problematic on human rights grounds. The Human Fertilization and Embryology Act 2008 indicates the types of embryos that can be screened for to find variations that can be terminated. Variations of sex characteristics are within this and under the Abortion Act 1967 foetuses healthy foetuses with such trats can be terminated.

3.3 Status and support of IVSC people in the UK

According to our key stakeholder, expert, and policy maker research contributors the biggest challenges faced by IVSC people in the UK relate to their medical treatment and the impact this has on their human rights. In line with findings from the desk research, our contributors described the trauma and harm caused by the medicalization of IVSC bodies:

> *"I sat one afternoon while a number of people from different government departments sat and listened to intersex people of different ages and backgrounds tell their stories and I thought that I knew quite a lot about the issues intersex people face in their lives, and I knew some, but I have to say it was one of the most harrowing meetings I have ever been in. Peoples' experiences of the health service were just so frightening, so traumatizing. When they describe it as torture I don't think that they exaggerate. I don't believe for a moment that that is what people in the medical profession believe, but that is what is the end experience" (Baroness Barker, House of Lords LGBT Spokesperson).*

> *People with intersex variations are discriminated against in hospitals as they are operated on, to make their bodies fit in with binary ideas of biology. The surgeries are non-consensual*

because this is surgery on babies. That's a human rights abuse and obviously discriminatory as well but discriminatory isn't quite strong enough" (Private Psychotherapist and Counsellor).

As highlighted by the United Nations (Mendez, 2013; Office for the High Commissioner for Human Rights et al., 2016), European Union (2015), Council of Europe (2015) such surgeries are increasingly seen as violations of the right to physical integrity, bodily autonomy, and self-determination.[5] The perception of such treatment as 'torture', and 'abuse', and the language of human rights violations, is likely to be extremely challenging both for medical professionals working in the field, and to the parents of IVSC children who give consent for surgical procedures. However, it must be acknowledged that this is how some experience the psychological and physical effects of non-consensual procedures.

Our contributors also stated that voices from the UK medical profession often claim that continuous technical improvements have meant that modern medical practices no longer cause harm. This is not supported by the most recent empirical evidence (Creighton et al., 2014).

Forms of discrimination such as workplace discrimination and incidents of hate crime and hate speech are considered to be less of a serious threat than the harms associated with structural healthcare problems and lack of legal protections in this area. This is not to downplay such forms of discrimination which were mentioned to varying degrees by a number of our contributors and within the wider literature.

It [discrimination] is an issue but it is a marginal issue as far as we understand it for intersex people. Most of the intersex people we know they are not getting attacked or harassed on the street. The main issue is IGM [Intersex Genital Mutilation] surgeries. What we experience is often its being talked about discrimination and hate speech and you see this also in the UK in Scotland for example but the elephant in the room is kept out (Markus Bauer, StopIGM.org).

Contributors also raised concerns over a general lack of awareness and knowledge about IVSC among medical professionals, including those in senior positions. This included the conflation of IVSC with transgender, and even the lack of understanding of the existence of IVSC. Of course, this raises major concerns as to how IVSC people's needs can be met if they are not understood, or even known, by senior medics.

I talked to clinicians who've asked me what intersex is, and these are doctors who work in the BMA and work in quite high up levels … If you're in charge of shaping the profession and you're practicing and you don't know what intersex conditions are then how can you say your practice is protecting them … failing to acknowledge the identity of people that in itself breaches human rights let alone whatever treatment you give them- not being suitable for them (Bioethics researcher, Centre for Social Ethics and Policy).

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[5] For a comprehensive summary of United Nations and other international organisations statements on IVSC surgeries, see Baur and Truffer (2020)

> *I'm just thinking about my own profession and there aren't that many people that know about intersex, so they might confuse it with transgender and they might have certain ideas about what it means to be intersex which may make them treat intersex people as lesser (Private Psychotherapist and Counsellor).*

> *I know quite a lot of intersex people who have been mistaken for trans people either when they have been admitted into hospital, or they are going through other hospital procedures, and of course that is just deeply frustrating because it doesn't really talk to their medical needs (Academic, Centre for Law and Social Justice).*

Attention was also drawn to the lack of good psychological care which is seen as crucial for supporting IVSC people. The contributor from the Centre for Law and Social Justice discussed cases of IVSC teenagers who had managed to access psychological support being assessed for gender dysphoria and discharged after a single appointment after being assessed as not having gender dysphoria. This is because the training for clinical psychologists is coming through the gender identity disorder services. Clearly, this is incredibly problematic as IVSC people are not receiving adequate care recommended by the Consensus statements and IVSC organizations.

It is important to note that all of our contributors acknowledged that there are a number of individual medical professionals doing very good work in this field, some of whom they had collaborated with.

There are huge levels of societal ignorance and many misconceptions about IVSC. Contributors expressed concerns over the ubiquitous conflation between IVSC and transgender among the public. Although both groups face significant structural problems, they should be understood separately from one another. IVSC people have distinct needs and human rights concerns. Conflating the two denies their individual experiences and limits service providers abilities to meet their specific needs. This is not to say that IVSC people cannot also be transgender.

> *There is just an absolute conflation with trans people so even when I am speaking to academics who research sex and gender and I am talking about intersex people they can immediately conflate it with trans issues so that is problematic in terms of general societal perceptions but it also really problematic in terms of healthcare provision (Academic, Centre for Law and Social Justice).*

Many contributors state that this lack of awareness is related to the small IVSC population, the fact that intersex variations are not visible, existing cultural taboos on talking about genitals, and the 'culture of medical secrecy and medical erasure'. The later point refers to the once widespread practice of doctors telling parents of IVSC children to lie to their children about their variations, and in some cases being lied to themselves. It is acknowledged in recent years there has been a greater emphasis on truth telling and patient centered care. With that being said many contributors reported that some families still feel that they are being forced to make decisions over surgery before their child is old enough to make an informed decision themselves.

This lack of awareness and understanding links with the wider lack of visibility of IVSC that many contributors reported. This extends to the lack of voice in public debate and discourse, lack of a legal recognition and protection, and appreciation of the different needs and rights of IVSC people. Indeed, IVSC people are often ignored or forgotten.

In recent years, there has been a tendency to include 'Intersex' within the LGBT banner (Monro et al., 2017), with many civil society groups affixing an 'I' on to the LGBT acronym, to stand for intersex. It is also important to remember that the problems that confront IVSC people and LGBT people are very

different. The biggest difference being that non-IVSC LGBT people do not have to experience the effects of unnecessary medical interventions that many IVSC people have to live with. And, as previously mentioned, IVSC people do not experience hate crime and hate speech discrimination to the same extent as other non-IVSC LGBT groups. As one of our contributors points out:

> *We don't have to forget that the majority of intersex people have been mutilated in childhood and treated with hormones like me. I know a lot of people who have had the same experience and the majority have never had these problems of discrimination like LGBT people but we are often added to LGBT and to discrimination campaigns but they don't reflect that the majority of intersex don't have these problems. I have never been bullied in the streets I have never been discriminated in the work place except for when I was in the media campaign fighting against IGM (Daniela Traufer, StopIGM.org). LGBT spokesperson).*

There is distrust from some over LGBT organizations that are perceived to 'add on the "I"', and proceed to secure funding for 'intersex' work, without actually doing anything to benefit IVSC communities. Several contributors also raised concerns that when IVSC issues are presented to governments as LGBT issues it might make it easy for governments to bring in limited LGBT-specific measures, which do nothing for IVSC rights, framing this as benefiting IVCS people and therefore avoiding delivering on any meaningful reforms. With that being said many contributors made the case that LGBT groups are 'natural allies' of IVSC people and as long as their differences are respected their allyship should be a positive force.

> *I don't see lots of other people queuing up to be allies for change unless they happen to be parents or families or friends or whatever so if we recognize their differences, you know, I think it's great that intersex organizations now turn up on pride in London (Baroness Barker, House of Lords).*

3.4 Recommendations

A range of recommendations to improve the lives and experiences of IVSC people were put forward. These included changes to medical treatment, including enacting legal protections to prevent unnecessary and non-consensual surgeries, increased funding for IVSC organizations and support groups, implementation of wider legal protections, and increased public awareness raising efforts.

Our contributors agreed that the legal prohibition of unnecessary medical intervention on infants and children too young to give consent is the most important change required. Identifying the correct definition of what is and what is not 'medically necessary' (e.g., necessary to stop threat to life) will be crucial here, to ensure that the truly medical necessary procedures can continue and to avoid a situation where any cosmetic 'gender-normalising' practices continue. Procedures which are not medically necessary should be deferred until the individual is old enough to provide informed consent and decide for themselves if they need the intervention.

Many pointed to the case of Malta as an example of how this could be achieved through criminal law, with the threat of fines and imprisonment for carrying out the practice.[6][7]

It is argued that a robust patient and family cantered approach with an emphasis on psychosocial care must take the place of surgical pathways.

> *Growing up different is not easy, not easy for the parents not easy for the children, there needs to be appropriate support to help with this. But right now there is money for surgery but not for psychosocial support (Markus Bauer, StopIGM.org).*

Currently, access to psychosocial care is inadequate for patients and families affected by IVSC (Ernst et al, 2018). Contributors put this down to large disparities in funding for such specialist services across different regions in the UK. There must be adequate funding to allow for this specialist psychosocial support.

Other recommendations in relation to healthcare included specialized education and training for health and social care professionals, including those who do not specialize in areas pertinent to IVSC, as all specialisms are likely to come into contact with IVSC individuals. The NHS should also introduce a patient advisor system which would allow parents the opportunity to meet IVSC adults in order to allay any concerns that their children would grow up to be abnormal. Again, these measures would require additional funding.

Alongside improvements in medical care and the emphasis on bodily integrity and personal autonomy, wider legal protections should be enacted to protect IVSC from discrimination such as hate crime, hate speech and employment discrimination. To this end, variations of sex characteristics should be made a protected characteristic under the Equality Act.

Contributors supported moves to facilitate IVSC people changing their legal sex in cases where individuals are assigned a sex on their birth certificate but do not identify as when growing up, to avoid the current situation which, under the Gender Recognition Act 2004 requires evidence of gender dysphoria.

There were mixed views on the introduction of a third gender marker. On the one hand some felt that this would provide wider recognition of the existence of IVSC. Others believed it could be very detrimental to IVSC children due to 'othering' and bullying at school. It is suggested that this would only be appropriate when IVSC people have capacity to decide for themselves. For example, when they reach a certain age (e.g., 16 or 18) or through a competence test, such as the Gillick competency described in footnote 8.

Currently, IVSC organizations and support groups are relatively small and poorly funded, which consequently impacts on their ability to organize and expand the impact of their work. To allow these groups to increase the

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[6] There is some debate as to whether this should be achieved through criminalisation or updating medical guidelines. Medics have had at least 20 years of knowing about the significant proportion of IVSC activists and advocates who disagree with current practice, giving ample time to create adequate medical guidelines, and they have not done so. It would seem that some compulsion is required.

[7] In Malta, children over 16 'sufficient maturity and understanding' can consent to medical treatment. Alternatively, a competency test such as the Gillick competency, already in use in the UK, could be used as opposed to a fixed age limit, but safeguards would be needed to protect IVSC children from family pressures that could influence their decision (Garland and Travis, 2020b).

impact of the important work they carry out our contributors called for greater funding. State-level funding is recommended to remedy the funding inequality between different groups working in this area.

> *I think it would be good to put more resources into the groups that specialize in these areas, Intersex UK is very under-funded and I think it would be good if more money could be put into them and so far I don't think they have been very successful in raising funds (Bernard Reed, Gender Identity Research and Education Society).*

Together with these medical and legal changes it is recommended that continued efforts be made to raise public awareness to ensure societal appreciation for the existence of, and challenges faced, by IVSC people. This is seen as a way of overcoming stigma and secrecy. Specific IVSC content could be included in school education, for example in Personal, Social, Health and Economic education (PHSE) lessons, and in employment training. Some also believed that a more aware and informed public, especially around the problems associated with early medical interventions, would put greater pressure on policy makers to enact reforms. All public awareness raising activities must be done respectfully with IVSC communities at their centre.

4 PART C: FIELD RESEARCH – INTERVIEWS WITH EXPERTS, STAKEHOLDERS, POLICY AND DECISION MAKERS.

4.1 Background and profile of interviewees

We conducted interviews with six IVSC people. Their ages ranged from 25 to 47. All contributors either had graduate or postgraduate qualifications and all but one were employed at the time of interview. They worked in a variety of different sectors, including medicine, psychotherapy, arts, education, and information technology. When asked what their gender identity was, two identified as male, one as femme non-binary/female, one as an intersex women, one questioned whether they had a gender identity (but stated her sex was female) and another stated that they did not believe in the concept of gender identity, but had no choice to live and be recognized as a women.

4.2 Personal experiences and needs

Most of these medical interventions are based on the premise that IVSC bodies need to be made normal. During consultations with medics, surgery is commonly presented as the primary 'solution' to 'fix' patients' non-standard genitalia. This can reinforce families' unrealistic and unhelpful expectations:

> *I think my mum, because, she just listened to the doctors and I think they told her, "that once all this was done, she'd be completely fixed and normal". So I think she was just very much focusing on that. But obviously that didn't happen because it's so much more complex than that (C4).*

> *Families can then go into that "there has to be a simple solution where we can fix it, we can surgically fix it and then pretend it hasn't happened". I think the one thing that is most important that that just isn't possible and most of the early surgeries have significant risks and risk of repeat surgeries needed later on and often bodies are better being left alone unless there is a real medical need (C1).*

Indeed, early medical interventions, which are very rarely necessary for physical functioning (Travis and Garland, 2020) often lead to repeated surgeries later in life, and other serious complications including pain (Ehrenreich and Barr, 2005), and loss of sexual function and sensitivity (Minto et al., 2001; Minto et al., 2003), as experienced by some of the research contributors:

> *But then what ended up happening was I needed lots of reconstructive surgery in the same area because it didn't fully work out so up until the age of five I had repeated surgeries and I don't actually know how many of them there were (C2).*

> *There were actually some very serious complications during these further operations which resulted in some further scarring and most particularly some chronic nerve damage. So in the process of dissecting the tissue that goes missing, there was, they basically engineer the nerves so what that meant was that I came out of that operation with no urethra, and no feeling at all there (C5).*

The construction of variations of sex characteristics as an emergency, immediately 'fixable' through medical intervention, as experienced by many of our contributors, ignores the lifelong nature of IVSC (Travis and Garland, 2020a) and individuals ongoing psychosocial care needs. If there was any follow up treatment, it was almost exclusively surgically repair oriented, as with the above examples. Furthermore, findings from our contributors showed that medical treatment was centred around surgeons, urologists, gynaecologists and endocrinologists with little or no psychological support.[8]

> *There was no counselling, like I say we were literally, it was a gynaecologist who told us they just told me I didn't have a cervix and that my uterus hadn't developed and then he just sent painkillers, and that's it there was no follow up (C3).*

> *Yeah so there was no psychological or sociological support and it was kind of just it felt like invasions (C2).*

Fears of discrimination and bullying have often been cited by parents and doctors as a reason and justification for performing surgical interventions on IVSC children (Kennedy, 2016). Rather than making intersex bodies appear more 'normal', gender-normalizing surgeries often have the converse effect of making people feel more abnormal, as described by one of our contributors:

> *I was actually getting comments in the changing room because of the scars created by in surgery rather than by the my kind of natural appearance. Yeah, so to speak and in my writing on the topic, this is really one of my key things that I always emphasize is that the surgery just makes bodies more strange (C5).*

One of our contributors who did not go through with surgery raised the point that feelings of abnormality can arise wthout having actually had any surgical interventions. Outside of the direct physical consequences of surgery the broader medicalization of IVSC bodies can also lead people to feel abnormal:

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[8] International research into the availability of psychological care found that only 53% of centres offered face-to-face psychological support (Kyriakou et al., 2016).

> *There varying interventions that are meant to make us feel normal cause so much physical consequence in terms of where it always goes wrong and complications but also in terms of feeling different and I would say you know being older in comparison when I was given this label and having the autonomy to say actually I don't want this surgery but still you know how profound it makes you feel about yourself and maybe how you're gonna be seen and relationships to say you need this surgery to be normal (C6).*

Related to the feeling of abnormality is a sense of isolation and anomalousness described by many. It is true that the population of IVSC people is small. However, these feelings were often more closely related to miscommunication from medical professionals which gave our contributors and their families the impression that they were alone in being affected by IVSC, rather than being part of a relatively small population. In some cases there was incomplete disclosure of medical information, and outright mistruths told about the lack of a wider IVSC communities and support groups.

> *I wasn't being told that I was in the right place even though when I looked at my records now I can see that my consultant was actually a paediatric urologist at the time I didn't know he was I just thought he was a normal pediatrician, and that no one knew what was going on so I thought I was some kind of anomaly (C2).*

> *At the hospitals and stuff, they were like "Can we speak to other people [other families of IVSC people]" and they [hospital staff] were like, "yeah, there wouldn't be enough people in the UK to make a support group". So just like, like outright lying. Yeah outright just being so misinformed. So for my mom she was just like, oh my God, like my daughter's a freak (C4).*

> *Like simple things they could've done like psychological support or let me understand that I'm not the only person who's dealing with this would have been really helpful at that stage (C1).*

Effective peer support for children and families affected by IVSC is perceived as essential for combatting isolation. Such support, provided by IVSC NGOs, both national and international, and variation specific support groups, allowed contributors to not feel as if they were alone and gave a sense of community. They also served to provide important practical information. The US based international NGO, 'InterACT', was referenced by several IVSC contributors for their useful resources for IVSC people. Other UK based organisations that were mentioned, included Intersex UK, DSD Families, the UK Intersex Association, and the AIS support group. It should be noted that while each of these was mentioned favourably by some, they were also spoke of in un-favourable terms by others.

Miscommunication and a lack of adequate information provided by doctors to patients and families, and the effect this has on parents ability to adequately communicate with their children, was a major theme throughout all interviews. This included medical staff not taking the time to thoroughly explain children's variations and their implications as well as failing to listen to the concerns of patients. One particularly poignant example came from an IVSC person whose parents spoke English as second language.

> *Because my parents couldn't even pronounce the word hypospadias, which you know is a difficult word to pronounce anyway, if you're not in a medical practice, she asked a nurse*

once what it meant and the nurse just laughed at her pronunciation and said it doesn't matter you don't need to worry about it and at that point my mum stopped taking me to the doctor's and it was my dad who started taking me instead and my dad speaks much less English than she does so I kind of had to navigate the system on my own (C1).

It is self-evident that when parents find out about that their child's variation in sex characteristics, which is for most families, an incredibly confusing, and for some distressing experience, they should be provided with comprehensive information on their child's variation and the impact of potential procedures. Without effective communication and honest information, it is not possible for children to learn about their own bodies or for parents to understand their children's needs. This is especially true when the decisions that parents have to make can have such serious consequences for their children:

They're the decision makers um so helping them to understand their child's body and what might need to be fixed and what can be left alone, because I know like I understand that sometimes there are gonna be medical procedures that need to be done … as a parent you're overwhelmed by everything that's being thrown at you, trying to then pick through what has to be done what can wait and it's such a pressure isn't it because are you making the right decision and you can't undo that decision once you've made it so I think for me that's where I would rather see it happen so that people are confident in the decisions they make as well and they feel empowered to make decisions (C3).

There was a lot of resentment from me towards them [parents] growing up because I felt like they weren't interested enough but what I didn't account for was actually the impact it had on them, having to make these decisions thinking they're doing the right thing, not being able to speak to other parents who've had a similar situation, not being explained what the actual conditions were and then having their child grow up and blame them for potentially making them sterile and things like that cause that's what's happening. I can't have children now and I don't know if I had been able to before. Doctors can't tell me if I would have been able to before because my body hadn't developed yet and I have other friends who have literally had their gonads removed and they have to spend the rest of their life on hormone replacement therapy and we end up having very difficult relationships because our parents weren't given the information but they don't want to told or be treated like the did the wrong thing because they just trusted the doctors obviously (C2).

Problems of miscommunication and misinformation form part of a wider culture of secrecy surrounding variations of sex characteristics. These are deeply connected with feelings of shame and stigma, which limit people's ability to talk openly about their variations.

I've met loads of people who've said apart from my parents no one knows and I know people who say just have surgery and then your husband doesn't need to know and I'm like what kind of relationship is that gonna be? But fine, you know so I think the shame and stigma that stops people from even telling anyone (C6).

This often has very damaging effects on people's mental health and wellbeing. As with one contributor who attempted to take their own life at the age of 14. He spoke about this in relation to not being able to talk about his experiences of being IVSC:

At that point I thought it was something which I should keep to myself so I couldn't have gotten the support. Whereas if I was 10 and going to the paediatrician's office and they had sat me down with someone and put me through therapy and said everyone's bodies are a bit different and this is what yours means that would have negated a lot of that I wouldn't have felt so alone about it (C2).

As discussed in the previous section, since the 2006 consensus statement there has been a new emphasis on more open and patient centred care. While all of our IVSC contributors were themselves born before the 2006 changes, many of them continued to receive ongoing medical treatment well after 2006, and some were also in touch with other younger individuals, or their families members, who had experienced initial medical treatment in infancy post-2006. Most of our contributors echoed findings in the literature that the consensus statement recommendations have not been fully implemented, and that harmful practices continue.

4.3 General views – the status of IVSC people in the UK

Our research contributors' perspectives on the status of IVSC people in the UK, presented nuanced understandings of discrimination. None of the IVSC contributors believed that they had experienced discrimination in the form of hate crime or hate speech on the basis of their sex characteristics. However, there was a sense that the threat of such incidents could be of greater concern to IVSC individuals who appear more visibly different. There were many references made to the more subtle ways in which IVSC people can experience discrimination. For example, having to use accessible toilets in public places when one does not look visibly disabled drawing strange looks from and the anxiety surrounding having to ask to use the accessible toilets.

Several spoke of medical treatment being a form of discrimination. One contributor expressed this in terms of 'medical violence' – in reference to surgical procedures.

In many ways the medical treatment is discrimination, right because it's not normal to do these kinds of surgeries particularly given the lack of clarity over what their purpose or effect actually is. I mean, so let suppose it's, I suppose it depends how you frame the question because if you see surgery as a kind of violence, then obviously that's ubiquitous and kind of you know banal in how often it happens and how normalized it is. If you don't see surgery in that way then I think on a if we think about other kinds of discrimination or violence you might face. I think the answer is probably not very (C5).

Others questioned whether the more general un-comfortability associated with attending a routine doctor's consultation could qualified as discrimination. They mentioned the unfairness of having to detail their variations in situations in which they were clinically irrelevant and having to lie about themselves for fear of being made to have additional tests etc. For some there was also a general sense of anxiety and fear associated with interacting with medics.

As for discrimination in the workplace, school and education settings, none of our contributors reported experiencing bullying or unfair treatment as a result of their sex characteristics. Again this was caveated with the understanding that IVSC people who appeared more visibly different might have experienced such treatment. The only incident that was mentioned was comments about scars as a result of surgery, as mentioned in the previous section. According to one contributor, rather than problems in school associated with bullying and teasing, it was the repeated absences from school as a result of surgery, and the resulting social isolation, that characterized problems at school.

I would actually probably turn the question around and say what it did do of course was take me out of school to have the surgeries … is actually it's around the social isolation. More so than people kind of pointing and staring (C5).

The way in which issues of IVSC have been debated by different groups to advance their own agendas was also mentioned in reference to discrimination. A few contributors described how IVSC is discussed and used, particularly on social media by certain groups (e.g., trans activists and feminist activists) for their own political reasons, and the damaging effect this has by limiting IVSC peoples' ability to represent themselves. For many this marginalization in public discourse and debate feeds into the wider sense of invisibility.

And so you're either described as some sort of circus curiosity, sex spectrum, 3rd, 4th, 5th sex, or your people try to force you into just like a very narrow box. And I think that doesn't give much space for people to define themselves or have think about how they want to describe themselves (C1).

I don't know particularly towards the hate speech but the, there's a lot of people with an interest in intersex and in controlling how people talk about it and the language that we can use and I find that the most difficult that I'm always upset (C3).

If anything intersex people are kind of used as a scapegoat to try and prove either side of the argument, some people will say intersex people or just male and just female and try and work their way around using that narrative and other people will say the complete opposite and say intersex breaks the line (C2).

There was consensus among our contributors that wider public perceptions on issues of IVSC are generally speaking very misinformed, with many suggesting that the majority of people in the UK are unaware of the existence of IVSC. In addition, IVSC is frequently falsely conflated with transgender. Of course some IVSC people can also be transgender, but these are two different characteristics which intersect but should not be treated as one and the same. Such a conflation was perceived as unhelpful by all of our contributors. For some the lack of understanding and awareness is related to broader societal discomfort with sex variances, and views on what it means to a boy or girl. Indeed, IVSC's questioning of the 'the binary system' was raised by a number of our contributors'. Others made the point that people's ignorance of variations in sex characteristics is due to the fact that talking about anything to do with genitalia is a taboo topic.

There were very mixed views on the recent alignment of IVSC with LGBT groups. Some believed that there was a natural affinity between IVSC and LGBT groups due to shared experiences of oppression marginalization, and othering:

You know 'I' belongs in the LGBTI continuum and again some people feel, and that's cool I accept that, but feel they don't want to be associated with that but the association of saying we're oppressed by the same stuff that makes sense to me and I think since I've made that connection (C6).

> *It's a lot more closely aligned to being othered, which is why people are finding so much solace within the LGBT community, which is probably why I have as well. Whoo. Yeah, I again I think it just comes down to the breadth of difference even within the intersex community (C4).*

Others felt that such an alignment was problematic due to the potential framing of IVSC as an issue of identity. Which then diverted attention away from medical treatment:

> *Often what people want to move away from is they don't want it to do with gender they want to do to be to do with you know ensuring that we get honest information about our bodies, ensure that we have access to good medical and psychological support if needed, that we get honest information and that we can move away from the stigma and shame that many of us experience (C1).*

> *Sometimes it comes from people who like represent LGBT orgs as well. I think they think they know about intersex and um, they don't quite often. Like there's the whole thing about you know um, it's just a harmless variation kind of thing which really, when you've had to like go through the diagnosis process and come to terms with it, it's really minimised but you're not supposed to feel negative about it (C3).*

4.4 Recommendations

Our contributors key recommendations focused on improving medical treatment for IVSC people. Most importantly, medically unnecessary surgeries on infants too young to give informed consent should be stopped, and a more holistic and systemic non-surgical care pathway should be created, including improved support for families of IVSC people. This non-surgical pathway should involve ongoing counselling and psychological care both for ISVC children and their families, and ISVC adults later in life. Peer-led services and support provided by IVSC NGO's and support groups are key here. Increased funding is required for these groups and for specialist psychological care across the UK, as such specialist care is currently unequitable.

Effectively communicating with patients and families and providing families with the information and support needed to communicate with their children is an essential part of a non-surgical pathway.

> *They [families] just don't have any language to be able to discuss these issues and they just want to keep this hidden because they feel so ashamed and they don't know how to talk about it and these families need that psychological and family support so they are able to be the best advocated for their children so they are able to advocate in their very best interest rather than go down the route of we must do something to fix (C1).*

One contributor suggested that having variation specific timelines for recommendations of when to talk and how to share information in an age appropriate way would ensure IVSC children and families are equipped with adequate knowledge about their bodies and would help prevent feelings of shame. Wider training for health and social care workers on how to better meet the needs of IVSC issues is also recommended.

Several contributors supported a legal ban on non-consensual infant surgeries, while one believed that a ban would be too much of a 'blunt tool', preferring additional guidance. Another contributor believed that there would be great difficulty in distinguishing between medically necessary and cosmetic surgeries, and that a complete ban on all medical interventions on infants would be required to ensure that no unnecessary surgeries take place - missing the small number of medically necessary surgeries would be worth the full de-medicalization.

Other recommendations which were focused on the wider societal level included greater public awareness raising efforts in order to de-stigmatize IVSC. It was suggested by some that positive representation would limit parental demand for surgeries.

> *Unless there's greater awareness that this exists and actually it's not a terrible thing doesn't mean you have a doomed life then probably just stopping the surgeries in itself is not gonna be enough because these kids are still gonna have to grow up you know in a binary world but not fitting in (C6).*

As for the need to update gender markers, which has been called for by some groups, this was generally viewed as somewhat of a distraction from the most important issues surrounding medical treatment. There were also concerns over the potential othering effect of a third marker. This also brought up the issue of perceiving IVSC as a matter of identity, which many were opposed to.

Some of our contributors felt very strongly that education on IVSC issues should be included in the school curriculum under PHSE education, on the grounds that this would promote better awareness among the public. However, others were less convinced, referencing the small IVSC population and that the attention should really be focused on IVSC children's medical treatment.

5 PART D: GENERAL CONCLUSIONS

Our research findings show that IVSC people living in the UK still face numerous problems in a variety of areas, but none more serious than within medical treatment. This situation is summarized well by one of IVSC contributors as 'over-medicalized and under-cared'.

The often severe and harmful effects of medical interventions on IVSC infants and children reported by our research contributors must be acknowledged and addressed. Practically speaking, this demands reform to medical practice to ensure a genuine shift towards non-surgical clinical pathways, which must include access to ongoing emotional and psychological support for IVSC children and their families, as well as IVSC adults. As highlighted by our contributors, IVSC NGOs and support groups should be involved with providing this holistic care, and should receive adequate state level funding in order to do so. There must be a clear distinction made between medically necessary (i.e., life-saving) treatments needed by some IVSC infants and children, and other cosmetic surgeries which should be delayed until the patient is able to provide informed consent and decide for themselves. There must also be wider training for medics on issues of sex variation.

Of course, it must be acknowledged that there have been some improvements in recent years and that many medical professionals working in this field are endeavouring to improve practice. However, our findings suggest that recommendations agreed in the 2006 consensus statement and 2016 update are yet to be implemented fully. Indeed, current UK practice contravenes various international legal directives.

Primary legislation is required to prevent medically unnecessary surgeries on infants too young to give informed consent, and to prevent discrimination on the basis of variations in sex characteristics. It is crucial that anti-discrimination measures must take place in conjunction with, not instead of, projections to bodily integrity, as was a concern of some of our contributors. Legislative change should also look to address concerns over the termination of healthy IVSC foetuses. However, it is acknowledged that any moves to amend the abortion act must be handled extremely carefully to ensure women's wider rights to reproductive health are not weakened. The UK should look to other national examples, such as Malta's 2015 Gender Identity, Gender Expression and Sex Characteristics Act, as a template on which to develop such legislation.

The fact that there has never been a longitudinal study on the effects of gender-normalising surgeries in infancy and early childhood – a point that many contributors observed – shows how little is actually known about this area. More research is needed here, especially if medical practices are said to have improved.

Ultimately, any changes must be led by IVSC people and policy makers must ensure they are listening to a full range of people with variations in sex characteristics. Where LGBT organisations seek to include 'Intersex' in their work, IVSC people must be consulted and acknowledged to overcome any concerns relating to the uniquely different experiences of IVSC people.

Along with the field research carried out with various health care and social work professionals in the training and capacity building phase of the BRING-In project, these research findings will be used to devise a training platform to equip health and social care workers with adequate tools and knowledge to better meet the needs of IVSC.

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