

JUSTICE COMMITTEE

HATE CRIME AND PUBLIC ORDER (SCOTLAND) BILL

SUBMISSION FROM KLINEFELTER'S SYNDROME ASSOCIATION

We support a group of people from all over the British Isles, including Scotland, who have distinct variations of sex characteristics, as a result of atypical sex chromosomes, resulting in bodies that do not fit typical descriptions of what is usually meant by the terms 'male and female' This is in line with the United Nations statement on Intersex people.

Those who are members of our Support Group are comfortable with a wide range of terminology including Klinefelter's Syndrome, XXY, Intersex and Variations of Sex Characteristics. Our members are men, women and non-binary people.

We have contributed to the co-authored Appendix A attached because our members have experienced negative behaviour and stigmatising language from others, including persons providing professional services and there is, as yet, no clear protection anywhere in UK or Scottish Law for I/VSC people when such protections do exist for our LGBT allies.

As a result we petition the Committee to consider the evidence presented in Appendix A with a view to including I/VSC as a distinct category within Hate Crime Legislation in Scotland; thereby enacting the first distinct protection for I/VSC people in these islands.

Klinefelter's Syndrome Association

23 July 2020

Appendix A

Contextualisation of the inclusion of I/VSC as a Distinct Category within Scottish Hate Crime legislation - Hate Crime and Public Order (Scotland) Bill (2020) - Stage One Written Evidence

Co-authored by Dr Rebecca Crowther (Equality Network)¹,
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Professor Peter Hegarty (The University of Surrey)⁵.

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- 1) Visibility and empowerment

¹ Rebecca is the Policy Coordinator at Equality Network.

² Magda Rakita is co-founder of iCon UK (InterConnected UK) an I/VSC advocacy charity. Magda also works in I/VSC support in Europe and is a noted intersex activist in both the UK and Poland. Magda has lived experience of I/VSC.

³ Kaz Williams is an adult support group co-ordinator with The Adult CAH Support Group (Living with CAH). The CAH Support Group is run by people who live with CAH. They provide support to people living with CAH as well as raise awareness of this VSC. Kaz has lived experience of I/VSC. Her views are her own and of those she works with.

⁴ Paul Dutton works with Klinefelters Syndrome Association UK. The Klinefelter’s Syndrome Association (KSA) offers support and information to all affected by, or having an interest in, Klinefelter’s Syndrome (KS) and XXY. Paul has lived experience of I/VSC.

⁵ Peter Hegarty is Professor of Psychology at the University of Surrey where he leads the research group on Social Emotion and Equality in Relations (www.surrey.ac.uk/seer).

2) Stakeholders on why I/VSC should be included as a distinct category within hate crime legislation

V) Regarding the separation and distinct inclusion of I/VSC as a characteristic within Hate Crime Legislation in Scotland. *p20*

I) Introduction: The importance of considering the lived experience of individuals with a variation in biological sex characteristics

It is important to note the socio-cultural context in which the proposed hate crime legislation would sit when considering people who live in Scotland with an I/VSC and how hate crime may influence their social life and interactions with others.

It is imperative to listen to the voices of those who live within Scotland and have a variation in sex characteristics or who are intersex.

'Currently, Scotland, and the UK in general, is not a very intersex friendly place. We need to have our own voice.'

- Equality Network I/VSC survey respondent (2020)

We believe that there is an essential need for engagement between people with a variation in sex characteristics, or who are intersex, and government policy makers, equality organisations, service providers, and researchers to improve policies and practices affecting the lives of people with I/VSC.

We acknowledge the policy work and academic research that is being done in this area in the UK. It is worth noting that there are scholars working in partnership with people with a variation in sex characteristics to ensure that their voices are represented within any research about the lives of people with variations of sex characteristics or who are intersex. We would highlight here the work of Surya Monro at Huddersfield University, Charlotte Jones at The University of Exeter, Peter Hegarty of The University of Surrey (co-author to this evidence), and Lih-Mei Lao from University College London Hospitals. These academics understand that the voices of those who have lived experience of I/VSC are essential. Similarly, the Equality Network (as a strategic intermediary to the Scottish Government) works closely with people I/VSC and facilitates and supports these people to engage with policy that affects them. Our further co-authors, Magda Rakita, Kaz Williams and Paul Dutton are individuals who have an I/VSC and who advocate for and support others with a VSC.

We welcome Lord Bracadale's review and acknowledgment that intersex is not a sub-category of trans/transgender and welcome his recommendation that a separate category should be created within Scotland's hate crime legislation that encompasses those who have a variation in biological sex characteristics. As research evidence has shown, there is a risk that the general public may confuse I/VSC (variation in physical biological sex characteristics) and trans status (relating to ones gender identity as different to that which was assigned at birth). Making a clear distinction within hate crime legislation is important. We will expand on this study below.

II) Regarding language and terminology used within the bill:

- It is widely agreed that I/VSC is the most inclusive and helpful terminology across the stakeholders and individuals with whom we work and/or have consulted.

1) Research and international best practice in relation to terminology.

- Surveys in several countries have shown that most people who are, or could be identified as having a 'DSD' diagnosis prefer diagnosis specific terms (e.g., Congenital Adrenal Hyperplasia or Androgen Insensitivity Syndrome) over the term 'DSD'.⁶
- This inclusive and non-pathologising terminology is often used by variation specific support groups with whom we work in partnership.
- It is widely agreed that the acronym DSD and the term 'Disorders of Sex Development' is pathologising. This is clearly evidenced as not only expert opinion and agreed by many with an I/VSC but as an opinion held by the wider general public.⁷
- The term DSD as an umbrella term was used within the Chicago Census Statement (a new medical consensus) in 2006 in favour of intersex. 'DSD' was then rapidly adopted by healthcare professionals and biomedical researchers following this consensus statement.⁸ However,

'a ten year update to the Chicago Consensus Statements shows considerable disagreement among experts as to the appropriateness of the term, and the meanings that it communicates. A persistent concern in these discussions is that the use of an acronym including the term 'disorder' can enhance the form of stigma that medical intervention is supposed to alleviate.'⁹

⁶ For example SEE: Bennecke, E., Köhler, B., Röhle, R., Thyen, U., Gehrman, K. & Wiesemann, C. (2020). Disorders or differences of sex development? Views of affected individuals on DSD terminology. *Journal of Sex Research*. DOI: 10.1080/00224499.2019.1703130; Davis, G. (2014). The power in a name: Diagnostic terminology and diverse experiences. *Psychology & Sexuality*, 5, 15–27; Lundberg, T., Hegarty, P., & Roen, K. (2018). Making sense of 'intersex' and 'DSD': How laypeople with varying experience of intersex/DSD understand and use terminology. *Psychology & Sexuality*, 9, 161-173.; Simmonds, M. (2012). Girls/women in inverted commas – facing 'reality' as an XY-female. Unpublished PhD thesis: University of Sussex, UK; See also Delimata, N., Simmonds, M., O'Brien, M., Davis, G., Auchus, R., & Lin-Su, K. (2018). Evaluating the term 'Disorders of Sex Development': A multidisciplinary debate. *Social Medicine*, 12, 98-107.

⁷ Peter Hegarty, Lois Donnelly, Paul Francis Dutton, Sara Gillingham, Valentino Vecchietti, Kaz Williams (2020 – unpublished – in press) Understanding of Intersex: The Meanings of Umbrella Terms and Opinions about Medical and Social Responses among Lay People in the USA and UK. *Psychology of Sexual Orientation and Gender Diversity*: 08.

⁸ Pasterski, V., Prentice, P., & Hughes, I. A. (2010). Consequences of the Chicago consensus on disorders of sex development (DSD): *Current practices in Europe*. *Archives of Childhood Diseases*, 95, 618-623.

⁹ Delimata, Simmonds, O'Brien, Davis, Auchus, & Lin-Su, 2018 – *ibid*:07

- 62% of participants sampled by Davis (2015) disliked 'DSD'.¹⁰
- Within the national survey of Australians born with an I/VSC the term 'Intersex' was preferred by 60% and 'DSD' by only 3% of participants.
- A study surveying attitudes towards terminology among support group members in the USA stated that only 24% used 'DSD' to describe their child or themselves.¹¹ 'These participants preferred 'Intersex', 'differences' or 'variations' of sex development over 'DSD'.¹²
- 'In a report from the UK, none of the participating advocacy or support groups surveyed supported the term 'DSD' and most participants used 'Intersex'.¹³

Additionally,

- 'Social scientists¹⁴ have repeatedly pointed out how language use in medical contexts implies the pathology of intersex variations, and creates a conceptual framework within which medical interventions appear urgently necessary and singularly benevolent. A consequence of this framing is that other understandings of intersex variations are made less available.¹⁵

¹⁰ Davis, G. (2015). *Contesting Intersex: The Dubious Diagnosis*. New York, NY: New York University Press.

¹¹ Johnson, E. K., Rosoklija, I., Finlayson, C., Chen, D., Yerkes, E. B., Madonna, M. B., Cheng, E. Y. (2017). Attitudes towards "disorders of sex development" nomenclature among affected individuals. *Journal of Pediatric Urology*, Advance online access. doi:10.1016/j.jpuro.2017.03.035

¹² Tove Lundberg, Peter Hegarty & Katrina Roen (2018) Making sense of 'Intersex' and 'DSD': how laypeople understand and use terminology, *Psychology & Sexuality*, 9:2, 161-173, DOI: 10.1080/19419899.2018.1453862: 163

¹³ Monro, S., Crocetti, D., Yeadon-Lee, T., Garland, F., & Travis, M. (2017). Intersex, variations of sex characteristics, and DSD: The need for change. Retrieved from <http://eprints.hud.ac.uk/id/eprint/33535/> in Tove Lindberg et al (2018)

¹⁴ SEE: 'Gough, Weyman, Alderson, Butler, & Stoner, (2006). 'They did not have a word': The parental quest to locate a 'true sex' for their intersex children. *Psychology & Health*, 23, 493-507.; Karkazis, (2008). *Fixing Sex: Intersex, Medical Authority, and Lived Experience*. Durham, NC: Duke University Press.; Kessler, (1990). The medical construction of gender: Case management of intersexed infants. *Signs: Journal of Women in Culture and Society*, 16, 3-26.; Liao, L.-M., Hegarty, P., Creighton, S., Lundberg, T., & Roen, K. (2019). Clitoral surgery on minors: An interview study with clinical experts of differences of sex development. *BJM Open*, 9, e025821. doi:10.1136/bmjopen-2018-025821; Roen, K., & Hegarty, P. (2018). Shaping parents, shaping penises: How medical teams frame parents' decisions in response to hypospadias. *British Journal of Health Psychology*, 23, 967-981.; Roen, K., Liao, L.-M., Hegarty, P., Lundberg, T., & Creighton, S. (2019). Clitoral surgery on minors: Interview study with clinical experts of differences of sex development. *BJM Open*, 9, e025821. doi:10.1136/bmjopen-2018-025821; see Roen, 2019 for a recent review' - Roen, K. (2019). Intersex or diverse sex development: Critical review of psychosocial health care research and indications for practice. *Journal of Sex Research*. DOI: 10.1080/00224499.2019.1578331.

¹⁵Roen, K. (2019). Intersex or diverse sex development: Critical review of psychosocial health care research and indications for practice. *Journal of Sex Research*. DOI: 10.1080/00224499.2019.1578331.

- There are empirical studies that include UK health professionals working within 'DSD' teams in the NHS that focus on practitioners' discourses with regards to interventions related to I/VSC.¹⁶
- 'Social scientists and humanities scholars have pointed out that medical terminology has negative unintended effects in communicating larger contestable pathologising frameworks'.¹⁷
- In a recent large study of the United Kingdom's LGBT population, 1,980 people, or 2% of the sample, identified as 'intersex' (Government Equalities Office, 2018).
- Klinefelters Syndrome Association UK (KSA UK) have stated to the British Society for Endocrinology and others recently, that they regard the term 'DSD' as stigmatising language that members would not wish to be associated with. Paul Dutton of KSA UK states:

The fact that many doctors use the term DSD in our presence does not mean that it is acceptable to us and we would wish Medical Schools to encourage the use of our preferred terminology when their students are actually with patients.

Whilst the vast majority of us would describe ourselves as 'having KS' or 'being xxy' in preference to anything else, there are some who are accepting of 'Intersex or Variations of Sex Characteristics' and the expression i/VSC is helpful here.

- The term intersex is used within international human rights legislation and is recognised terminology around the world.

The term intersex is used by/within:

- The United Nation's Special Rapporteur on Torture¹⁸
- The Council of Europe (2015) *Issue Paper on Human rights and intersex people*¹⁹

¹⁶ Studies are about (1) the clitoris: Liao, L.-M., Hegarty, P., Creighton, S., Lundberg, T., & Roen, K. (2019). Clitoral surgery on minors: An interview study with clinical experts of differences of sex development. *BJM Open*, 9, e025821. doi:10.1136/bmjopen-2018-025821; (2) the vagina; Roen, K., Creighton, S.M., & Hegarty, P., & Liao, L.-M. (2018). Vaginal construction and treatment providers' experiences: A qualitative analysis. *Journal of Pediatric & Adolescent Gynecology*, 31, 247-251, and (3) the penis; Roen, K., & Hegarty, P. (2018). Shaping parents, shaping penises: How medical teams frame parents' decisions in response to hypospadias. *British Journal of Health Psychology*, 23, 967-981.

¹⁷ Davis, 2015; Holmes, 2011; Topp, 2013 in Tove Lundberg, Peter Hegarty & Katrina Roen (2018) Making sense of 'Intersex' and 'DSD': how laypeople understand and use terminology, *Psychology & Sexuality*, 9:2, 161-173, DOI: 10.1080/19419899.2018.1453862: 161

SEE also: Roen, K. (2019). Intersex or diverse sex development: critical review of psychosocial health care research and indications for practice. *Journal of Sex Research*, 56, 511-528.

¹⁸ UN Special Rapporteur on torture and other cruel, inhuman, or degrading treatment or punishment.

¹⁹ Council of Europe; Commissioner for Human Rights (April 2015), Human rights and intersex people, Issue Paper

- The European Union Agency for Fundamental Rights (2015) *The Fundamental Rights Situation of Intersex people*²⁰
- UN General Assembly – uses ‘intersex’ when discussing the intersection of race and gender discrimination in sport²¹
- Joint statement on the International Classification of Diseases 11²²
- European Parliament resolution of 14 February 2019 on the rights of intersex people²³

2) Equality Network I/VSC Survey Results concerning terminology

Between November 2019 and July 2020 the Equality Network gathered 28 responses to a survey they released asking people with an I/VSC to share their experiences of living in Scotland. This survey is still currently open.²⁴

Survey respondents to the Equality Network I/VSC survey (n²⁵28) stated that their specific variations included: MRKH, MRKH type 2, Turner Syndrome, Congenital Adrenal Hyperplasia (CAH), Non-classical CAH, Complete Androgen Insensitivity Syndrome (CAIS), Klinefelters (KS) and 47XXY KS.

There are findings within the initial survey analysis of the Equality Network I/VSC Survey, done for the purpose of providing evidence to the Hate Crime Bill Stage One evidence gathering exercise, that are important to highlight here. One area of enquiry was in to the terminology preferred by respondents who had an I/VSC²⁶.

Concerning terminology, 87% (n22) of survey respondents to the Equality Network I/VSC survey were familiar with the term ‘intersex’ with only 4.5% stating that this survey was the first occasion when they had heard the term in reference to themselves.

- 55% (n22) of survey respondents to the equality Network I/VSC survey used the term intersex in reference to their own body as opposed to any other term.
- It is worth noting that from this group (n22) 64% of people did not consider themselves to be an ‘intersex activist.’

²⁰ The European Union Agency for Fundamental Rights (2015) *The fundamental Rights Situation of Intersex people*. Available at <https://fra.europa.eu/sites/default/files/fra-2015-focus-04-intersex.pdf> Accessed on 15th July 2020.

²¹ Report of the United Nations High Commissioner for Human Rights* - Human Rights Council Forty-fourth session 15 June–3 July 2020 Agenda items 2 and 3 <file:///C:/Users/rebecca/Downloads/intersex%20discrimination%20in%20sports.pdf>

²² A statement signed by over 60 I/VSC organisations and activists <https://ihra.org.au/35299/joint-statement-icd-11/> Morgan Carpenter on 23 May 2019

²³ European Parliament (2019) https://www.europarl.europa.eu/doceo/document/TA-8-2019-0128_EN.pdf

²⁴ Respondents were between the ages of 18 and 74 years. They resided in various location across rural, suburban and urban Scotland. 67% of respondents identified as heterosexual, 7% as bisexual, 7% as lesbian and 20% identified as ‘other’ when asked about their sexual orientation.

Survey available at: <https://www.surveymonkey.co.uk/r/IVSC>

²⁵ Where ‘n’ refers to the number of people who answered the question.

²⁶ Within the poster and social media posts that called for participation in this survey the terms VSC, Variation in Sex Characteristics, Intersex and Differences of Sex Development were used. In previous flyers produced by the Equality Network, specific variations have been listed.

- We note from our stakeholder engagement that many prefer that people use specific diagnostic terms or the umbrella term VSC.
- One respondent to the Equality Network I/VSC survey stated:

'The term DSD is traumatic and degrading for me, please refrain from EVER using this.'

In addition, another stated:

'I love the term intersex, I consider any other term to describe my body as offensive, hurtful and traumatic.'

- It is worth noting that, 'different framings of stigma appear to be encoded in different 'umbrella terms,' none of which seems to perfectly meet the needs of all affected individuals, families and communities.²⁷

3) Stakeholders on language used within the bill

We asked stakeholders, with whom we work, who have a Variation of Sex Characteristics, or who were intersex, to comment on three areas of the proposed Bill. They were: Language and what they would hope for in terms of terminology usage within legislation; Whether they had lived experience of a hate crime/discrimination and prejudice based on being intersex or having a VSC²⁸, and to comment on why they felt it was necessary that I/VSC be an included characteristic within Hate Crime Legislation. The later two will be detailed throughout.

In relation to terminology, they told us that:

- In relation to language and terminology used, all stakeholders that we consulted with prior to this submission were comfortable with the term VSC or Variation in Sex Characteristics.
- All but one stakeholder used the term intersex in reference to themselves and were happy with the term.
- Some also liked the phrasing 'intersex variations.'
- Many with an I/VSC prefer the umbrella term VSC or I/VSC or reference to their specific variation, for example, Congenital Adrenal Hyperplasia, Klinefelters Syndrome, or Androgen Insensitivity syndrome.

²⁷ Peter Hegarty, Lois Donnelly, Paul Francis Dutton, Sara Gillingham, Valentino Vecchiotti, Kaz Williams (2020 – unpublished – in press) Understanding of Intersex: The Meanings of Umbrella Terms and Opinions about Medical and Social Responses among Lay People in the USA and UK. Psychology of Sexual Orientation and Gender Diversity:06

²⁸ This was to include any time they may have been bullied, persecuted, denied services, experienced institutional bullying or prejudice etc. Additionally we stated that this could be any time that they felt fear, alarm or distress due to the actions of others based on their (or perception of them having) a VSC or being intersex.

One stakeholder told us that:

'Use of language is crucial as it is important to be able to define who we are instead of having others come-up with labels for us, often objectifying us. [...] "DSD- Disorders of Sexual Development" is truly offensive and a medically created term. [This term] arose from the widely felt oppressive language of 'disorder' but does not reflect how I see my condition.

I am happy to have a descriptor of my condition however, I prefer the term I/VSC as this is inclusive of people with a wide range of conditions and variations. It is also neutral and from my experience widely accepted and now used.

This term does not trigger trauma as the medical DSD does and nor is it seen as too 'political' which the use of Intersex can be perceived to be which detracts from inclusive work for change.'

Another told us that:

'I do not like being called Intersex as this doesn't describe me. I don't like being called 'disordered' so don't like DSD. I am happy to be called by the name of my condition however, if working with others I [feel] that VSC is good as this is what I have and names me correctly.'

4) Concluding comments and recommendations concerning terminology used within the Bill.

For these reasons, we recommend that the terminology used within Scottish Hate Crime Legislation should reflect both international practice and the preferred terminology of those with a variation in sex characteristics living in Scotland and the rest of the UK. Therefore, we recommend the abbreviation 'I/VSC', the use of 'Variations of/ in Sex Characteristics' (VSC) and the use of 'intersex' as terminology within legislation.

Additionally,

- Particularly as the term 'intersex' is associated with transgender and non-binary for the general public, we also suggest that it is made clear that this umbrella term refers to a multitude of biological variations in sex characteristics and where possible some of these specific variations should be exemplified.²⁹
- Having a biological variation in sex characteristics is entirely different from identifying with a gender other than the one assigned at birth.
- It should also be made clear that I/VSC is not necessarily expressed as a social identity but is always a physical variation in biological sex characteristics.

²⁹ Hegarty et al (in press)

- It is clear that people may need (and prefer) to use different umbrella terms in different contexts
- It is vital that the terminology used within this legislation is to be acceptable to and inclusive of the widest possible of those affected by an I/VSC:
 - It must also be inclusive enough to ensure that not only are people protected (clearly covered) under the legislation but also that a perpetrator of a hate crime based on the perception of someone having an I/VSC would be brought to justice, and a victim would not fall prey to a gap in the legislation.
 - It is not necessary that this terminology align with a laypersons understanding but instead must be clear to the persons who will enforce this legislation. For this reason language must be wholly inclusive of all with I/VSC as ensuring those with an I/VSC are comfortable with the language is crucial in ensuring they are comfortable reporting hate crimes they face.

III) Lived experience of hate crime, prejudice, and discrimination perpetrated based on the perception of difference due to having an I/VSC

1) Necessity to understand hate crime as experienced by individuals living with a variation in sex characteristics.

- Anecdotally we know that individuals are subject to discrimination, prejudice, and bullying including such that has caused fear and alarm due to being perceived as 'different' due to having an I/VSC.
- I/VSC prejudice and discrimination can cause extreme internal distress and can take many forms in public life, including but not limited to in school, in the streets, and in the workplace. This can and does affect other social issues such as unemployment and poverty.
- Indeed, medical interventions have long been based on the rationale that social stigma causes unbearable distress, such that medical intervention is the only viable option:

*'The ultimate goal of medical and psychological interventions in this area is to avoid and to alleviate the impact of stigma on psychological well-being, and those risks are understood to be located within social reactions to intersex traits.'*³⁰

- Hate Crime statistics detailing the number of people who have an I/VSC who have suffered a hate crime or incident based on the perception of

³⁰ UK Government Equalities Office (2018) LGBT Survey Research Report. Ibid: 26

having an I/VSC, are not currently available. This is due to the fact that I/VSC has not previously been its own distinct characteristic within hate crime legislation.

- The lack of a specific I/VSC category might be, at least partially, responsible for the lack of reporting.
- Associated stigma and taboo felt may also have had an effect on whether or not an individual would report such an incident.³¹
- The inclusion of I/VSC within this legislation will significantly improve this situation by increasing visibility and awareness that a hate crime perpetrated on this basis is wrong and should be reported.
- Additionally, this visibility provides a basis for educating those in front line services, emergency services, in social services, and the police force etc. about I/VSC.

2) Living in Scotland with an I/VSC

Again, there are findings within the initial survey analysis of the Equality Network I/VSC Survey, done for the purpose of providing evidence to the Hate Crime Bill Stage One evidence gathering exercise, that are important to highlight here. These provide an important intra-personal and social context in which to frame the inclusion of I/VSC within Hate Crime legislation in Scotland.

It is worth considering these statistics and this qualitative data in relation to areas of social life as they may have a direct impact on both experience of and perpetration of hate crimes and prejudice based on a person having an I/VSC. They serve to begin to highlight why it is essential that this be an included characteristic within hate crime legislation.

- 82% (n17³²) of our survey respondents stated that they had difficulties with mental ill health.
- Twenty-five per cent (n1920) of I/VSC respondents to the UK GEO LGBT Survey had accessed mental health services in the 12 months preceding

³¹ According to the UK GEO's LGBT Survey Research Report (2018) 'Empirical studies of stigma and public understanding [of I/VSC] are lacking³¹' (ibid.02) and there has been a call from intersex advocate and experienced clinical psychologist, Dr Lih-Mei Liao, for studies of public understanding and stigma dating back to 2014. (Liao, L. M., & Simmonds, M. (2014). A values-driven and evidence-based health care psychology for diverse sex development. *Psychology & Sexuality*, 5, 83–101.) Very few studies of the general public have examined stigma or understandings about intersex and variations of sex characteristics, but those studies have shown that intersex traits can be framed in either medical or psychosocial terms. We believe it is important to examine the perception of I/VSC within the general public.

³² Where 'n' is the number of respondents who answered this question.

the survey. A further 13%, however, had tried to access mental health services but had been unsuccessful.³³

- 'Intersex respondents were more likely than non-intersex respondents to have found accessing mental health services difficult. 37% stated that accessing mental health services had not been at all easy, compared to 28% of non-intersex respondents.'³⁴

Additionally, we point to the GEO's finding that:

- 'Intersex respondents were more likely to report that their GP had not been supportive (19%) than non-intersex respondents (16%), and also more likely to say that their GP had not known where to refer them (13%) than non-intersex respondents (11%)'³⁵

Respondents to the Equality Network Survey stated that:

'I felt very lost and alone when discharged at 17 I felt different. My plans to have 4 kids was up in smoke. When I met my first boyfriend, he wanted kids so dumped me when he found out. When I eventually married, I was very depressed about infertility. I went to see about IVF as my sister had said she would surrogate. My husband refused to get his sperm tested. He refused to foster or adopt. I got more depressed. Eventually I divorced him. MRKH affects you throughout your whole life. I have been ill and [I] am now single again, and [I] am back dilating. It's depressing at times.'

'[Having a VSC] messes up with your head and you feel like you can't talk to anyone, that's why I don't mind talking about it.'

'My depression has always been associated with my feelings of being damaged goods.'

'I have found having MRKH to be upsetting and stressful, at times. I think finding out that your body is not the one you thought, and some of your life plans will not be happening, is quite a lot to take on board in your teens. This has definitely had an impact on my confidence and my understanding of myself. I know that depression is quite high among infertile people. I think that is probably applicable.'

'It affects who you trust [and] how you live your life [as well as] who you tell...most of all people's total lack of knowledge. I have been asked 'if I am like a doll down below'...total ignorance.'

'Depression started shortly after diagnosis.'

³³ UK Government Equalities Office (2018) National LGBT Survey Research Report: 243

³⁴ Ibid: 243

³⁵ Ibid: 244

'The Scottish Government should be aware of the harassment and abuse people with DSDs can experience, as this is obviously detrimental to people's mental health.'

As a result of harassment and abuse people with an I/VSC may suffer from minority stress, a factor in poor mental health, and a potential to withdraw from aspects of social life. The 10-year medical consensus update on the Chicago Consensus acknowledged the possibility of minority stress; heightened stress experienced, and fear experienced by members of stigmatised minority groups that impacts mental health³⁶. That 10-year medical update called for studies on minority stress among IVSC populations and called for studies on minority stress among I/VSC populations.³⁷

- 86% (n14) of our survey respondents stated that they had suffered trauma in relation to their I/VSC status.
- 94% (n16) of our survey respondents stated that they had low body confidence and 75% said that they felt shame about their body.
- 36% (n14) of our survey respondents felt uncomfortable due to other people's lack of knowledge or understanding regarding I/VSC.
- 60% (n15) of our survey respondents said that having an I/VSC affected their social relationships.
- 20% (n15) of our survey respondents did not enjoy school, with only 73% sometimes enjoying school.

Many of our respondents had been bullied at school due to perceived difference. They told us that:

'Primary School from age 4 to 11 was on the most part good. Secondary School from age 11 to 16 was hellish for the most part due to being so different, being bullied was a multiple times per day occurrence.'

'I got bullied, called names. Asked if was a boy or a girl'

³⁶ Clark, R., Anderson, N.B., Clark, V.R., & Williams, D.R. (1999). Racism as a stressor for African Americans: A biopsychosocial model. *American Psychologist*, 54, 805-816;
Meyer, I.H. (2003). Prejudice, social stress and mental health in lesbian, gay, and bisexual populations: Conceptual issues and research evidence. *Psychological Bulletin*, 129, 674-697;
Frost, D. (2019). Hostile and harmful: Structural stigma and minority stress explain increased anxiety among migrants living in the United Kingdom after the Brexit referendum. *Journal of Consulting and Clinical Psychology*, 88, 75-81.

³⁷Lee P.A.a · Nordenström A.b · Houk C.P.c · Ahmed S.F.d · Auchus R.e · Baratz A.f · Baratz Dalke K.g · Liao L.-M.h · Lin-Su K.i · Looijenga 3rd L.H.J.j · Mazur T.k · Meyer-Bahlburg H.F.L.l · Mouriquand P.m · Quigley C.A.f, n · Sandberg D.E.o · Vilain E.p · Witchel S.q · and the Global DSD Update Consortium (2015) Global Disorders of Sex Development Update since 2006: Perceptions, Approach and Care. *Hormone Research in Paediatrics* 2016;85:158–180 DOI: 10.1159/000442975 Available at <https://www.karger.com/Article/Pdf/442975>

'I was bullied and socially excluded but academically gifted and loved learning.'

'[I was] bullied by classmates and teachers. Teachers did not see a struggling child but just assumed I was badly behaved, e.g. humiliated most days by teacher for needing to go to the toilet frequently, which often goes with Turner Syndrome. Humiliated by teacher for becoming lost in familiar surroundings, also a common feature of Turner Syndrome. Humiliated by teacher for always being clumsy and dropping things- Turner Syndrome again. Lots of other examples. Other pupils saw teacher's behaviour and took their example from it.'

One stakeholder shared her experience of school for the purpose of providing this evidence document, she said:

I remember being the first girl to wear a bra and the other girls laughing at me when they could see it through my PE T-shirt.

I remember having to get changed separately (an agreement my mum made with the teacher) to avoid the other kids commenting on my early puberty. It worked but I often faced many questions.

The teacher did discuss moving me up into the year above so that I would fit in better, being so tall and developing so early, but my mum didn't want to split me up from my friends.

I remember comments about having hairy arms, and legs, and a "moustache". But I think I avoided too many comments by either removing the hair as often as possible or covering up all the time. At age 16, I had laser hair removal which helped to stop any further comments.'

It is worth noting that this kind of school bullying is one rationale given for infant genital surgery, particularly on the most "visible" genitalia (the clitoris, the penis). If surgery is performed with the intention of avoiding social bullying or prejudice and hate crime, it is vital that this be addressed within hate crime legislation itself perhaps negating the need for this intervention. Bioethicists described surgeries as being performed to avoid bullying but at the risks to social function. Addressing prejudice through legal means such as hate crime law, reduces the need for surgeries that are at the centre of global human rights debates.³⁸

A finding in the Hegarty et al³⁹. (2020) study is that lay people are much more in favour of medicalising I/VSC (and less supportive of a variety of social responses, including the kind of legislative inclusion proposed within the Hate Crime Bill, if they had

³⁸ SEE: Weisemann, C., Ude-Koedler, S., Sinnecker, G.H.G., & Thyen, U. (2010). Ethical principles and recommendations for the medical management of differences of sex development (DSD)/intersex in children and adolescents. *European Journal of Paediatrics*, 169, 671-679.

³⁹ Peter Hegarty, Lois Donnelly, Paul Francis Dutton, Sara Gillingham, Valentino Vecchiotti, Kaz Williams (2020 – unpublished – in press) Understanding of Intersex: The Meanings of Umbrella Terms and Opinions about Medical and Social Responses among Lay People in the USA and UK. *Psychology of Sexual Orientation and Gender Diversity*.

measurably stronger “gender binary beliefs” (a belief that there are only two genders, male and female). In other words, people opposed the kind of inclusive legislation the Scottish Government is aiming for here if they thought that (1) there are only two genders and (2) gender is always aligned with genital anatomy. Therefore, this data outlined here makes the important points that although having an I/VSC is not the same as being trans, but both groups of people suffer prejudice and harassment (and in other areas are neglected and silenced) by the same normative binary system of gender.⁴⁰

With regards to the workplace;

- 47% (n15) of our survey respondents were open at work with an employer or human resource department about their I/VSC status. 33% were open with their colleagues. 21% said that their privacy had not been respected concerning their I/VSC at work.

In relation to bullying and discrimination at work, respondents told us that:

‘I was asked if I was a man or a woman, they drew derogatory images on my name badge and hung it up in the break room.’

‘I was groped and talked about to determine if I had a penis or not.’

A stakeholder also told us that;

At work, people [have found] out about my condition and thereafter treat[ed] me differently, as an ‘other’.

From the Equality Network Survey, related to prejudice, discrimination and hate crime as a person with an I/VSC

- 40% (n15) of our survey respondents stated that they and experienced prejudice, bullying and negative comments at work due to having an I/VSC.
- 50% (n10) of our survey respondents had experienced a hate crime on the basis of having a I/VSC.
- 43% (n14) of our survey respondents had experienced difficulties or issues within public bodies such as schools, hospitals or with the police due to having an I/VSC.

⁴⁰ A nationally representative sampled study showing a relationship between belief in binary gender and transphobia is:
A.T.Norton & G.M. Herek (2009). Heterosexuals’ attitudes toward transgender people: Findings from a national probability sample of US adults. *Sex Roles*, 68, 738-753

3) Stakeholders on their experiences of hate crime due to having I/VSC:

In relation to experiences of prejudice and / or hate crime or hate incident we have gathered some qualitative data that is important to share in light of this call for evidence regarding the inclusion of I/VSC in Hate Crime legislation in Scotland:

One stakeholder told us:

'I have been subject to bullying on social media by members of the public, when they have read my story. I received a couple of calls for me to be killed over social media in February 2020.'

'[At] Easter [time in] 2020 I had eggs thrown by a neighbour at my car. This was reported to the police.'

'In the street when I was wearing a t-shirt with 'intersex' printed on the front, a man screamed at me that I was "possessed by Satan along with paedophiles & rapists" backed by a group of friends.'

'I had rumours spread about me amongst dozens of Church goers at social/family events, after writing about my lived experience, that I was "really a man and had bad intentions".'

'I have had people sit beside me and start praying uninvited that I be healed.'

'I have asked for specific safeguarding measures to be put in place by Church, but they have been denied until such time as the whole Church has a debate on the I/VSC ([this has] been ongoing for five years).'

[I have] had various discussions about my 'variations' happen in the workplace, whilst I was not present. Also, experienced some bullying.

Another told us that:

'[I have experienced] bullying due to delayed puberty and atypical secondary sex characteristics. I am also familiar with other people's experiences, which are similar to mine, including bullying and inappropriate comments by teachers.'

'Also, I have experienced prejudice and inappropriate comments in the health care system, during a visit in regards to an unrelated issue.'

'I am also aware of instances of violence and threats of violence, including sexual violence, against some of my intersex friends who have non-typical secondary sex characteristics.'

Finally, another stakeholder with an I/VSC told us that:

Experiences at the hands of medical professionals as a child/young person and continuing into adulthood include unnecessary examinations, intrusive questioning, and being made to feel as if I was an object of curiosity.

As a child then young person I was endlessly and persistently bullied at school by peers and teachers for the way I looked. Comments about my body hair, body shape, strength and generally what was perceived as 'difference'. This included verbal and physical abuse and being deliberately left out.

I was forced to stop sport, even though I was very good, on a false basis and physically restrained to prevent me competing on more than one occasion. Others refused to take sport with me as I was 'weird' and 'not like a girl'.

[I suffered] public shaming in shops and on the streets including verbal abuse and people commenting on [my] appearance.

[A] GP described me as 'not normal' and denied [me] medication as 'too expensive' and put on cheaper version without myself or my consultants permission.

[I have experienced] rejection in social situations, people questioning who and 'what' I was.

[I] have self-excluded from certain professions due to anxiety about bullying and being seen as too 'different' based on experiences.

[I have felt the] impact of internalised feelings of shame, difference, and having to hide who I am due to knowing how people would react. [I have] protect[ed] myself.

At times [I have not received] the right medical treatment as not seen or helped like others, as due to my variation [I was] told not to expect a 'normal life'. [I] have to fight for medical treatment and to be treated with level of respect [rather than] just as a curiosity.

This stakeholder's experiences touch on prejudice within school, within medical establishments, within sport, in social situations, at work and in one's career. The previous two stakeholders touch upon experiences of prejudice within the church, at work, and in public places, by neighbours and on social media, as well as experiences of threats of violence and sexual violence. These individuals have experienced prejudice, hate incident, and hate crime because they have an I/VSC. We feel that this is a clear case for the inclusion of I/VSC as a category within Hate Crime legislation in Scotland.

IV) Regarding the inclusion of I/VSC as a distinct category within Hate Crime legislation in Scotland:

1) Visibility and empowerment

- The inclusion of I/VSC within this legislation will acknowledge that a hate crime based on I/VSC is unacceptable, thus empowering those affected. For the first time UK legislation would acknowledge the problem thus making a positive step towards improving social life and life outcomes for a person with an I/VSC.
- We are aware that many people born with an I/VSC are told from a young age never to discuss their variation in sex characteristics with others. For that reason, it is very important that I/VSC be included within this legislation to ensure that people are able to speak out about potential hate crime, to report it, and to know that they are right to do so.
- There is considerable evidence that both parents and young people themselves maintain secrecy regarding their I/VSC, many due to a fear of stigma.⁴¹
- Removal of I/VSC from this legislation strengthens the norm against speaking about one's Variation in Sex Characteristics when it may be necessary or useful to tell others about it.
- Visibility of I/VSC within legislation will empower people to report hate crime perpetrated on the basis of perception of an individual having an I/VSC.
- In the absence of I/VSC specific law that people with I/VSC will face a double bind between (1) not reporting hate crime vs (2) reporting it as anti-LGBT hate crime (which in most cases won't fit with their definitions of who they are.)

2) Stakeholders on why I/VSC should be included as a distinct category within hate crime legislation

Stakeholders with an I/VSC provided us with detail on why they felt it necessary that I/VSC should be included as a distinct category within hate crime legislation. They told us that:

'[This inclusion] will enable safeguards to be put in place in the workplace (and Church, if not exempted). Occupational Health tended to rely on protections for people with 'disabilities' to support me, as I/VSC was not a protected characteristic.

⁴¹ Roen, K. (2019). Intersex or diverse sex development: Critical review of psychosocial health care research and indications for practice. *Journal of Sex Research*. DOI: 10.1080/00224499.2019.1578331.

The Police have also been very supportive, but it is a 'grey' area which needs to be clarified.'

Another informed us that:

'It is a necessary step to make sure people like me have an option of looking for help and remedy should we experience hate speech, bullying or violence again. It would be the right signal to send to potential perpetrators. It would also be a signal to police as currently many of us do not have the confidence to report any incidents as the awareness of intersex issues and challenges we face is very limited.'

In addition, another told us that:

As the situation stands crimes against us are often hidden as those who take reports have nowhere to record those specific incidents against us. It is in part due to the so long invisible struggles we have faced, not being able to name what is happening to us, and feeling above all such a deep sense of shame.

To have it stated in law that what we experience is a hate crime would have powerful psychological impact

For too long these experiences have been internalised, we feel it is our 'fault', we are 'freaks' and it is up to us to change our lives so we are not out there in public or make every effort to alter ourselves.

This legislation would give confidence to people to know they do not have to take this treatment, that we do have rights and a voice and are entitled to be who we are without fear.

Finally, another stakeholder informed us that:

We need to know that what we go through because of our conditions is not right and not our fault.

If teachers at school, college and work as well as family knew we were protected from this bullying and discrimination then maybe things would have been different.

As an adult, I could have been protected and not felt so ashamed of who I am and what I look like.

My life could have been different if this legislation was in place in the choices I have made and my confidence and also work opportunities.

Again, we feel that the lived experiences of people with I/VSC speaks for itself. It is imperative, for the wellbeing of those with I/VSC that this be included as a category

within Scottish Hate Crime Legislation and we welcome the bill, which as proposed, would do so.

V) Regarding the separation of I/VSC from trans identity and the distinct inclusion of I/VSC as a characteristic within hate crime legislation in Scotland:

We welcome the fact that this legislation proposes to separate and distinguish I/VSC from trans. Having a biological variation in sex characteristics is entirely different from identifying with a gender other than the one assigned at birth.⁴²

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⁴² Scientists are increasingly understanding the complexity of these issues and that the “gender built on sex” model is not enough: Van Anders, S. (2015). Beyond sexual orientation: Integrating gender/sex and diverse sexualities via sexual configurations theory. *Archives of Sexual Behavior*, 44, 1177-1213.