

JUSTICE COMMITTEE

HATE CRIME AND PUBLIC ORDER (SCOTLAND) BILL

SUBMISSION FROM DSD FAMILIES

We welcome this opportunity to respond to the Scottish Government's Draft Hate Crime and Public Order (Scotland) Bill. We are restricting our comments to the inclusion of 'variations of sex characteristics' (sic) as a protected characteristic both as a statutory aggravator and under the proposed new offence of stirring up hatred.

About us

dsdfamilies is the only UK based charity promoting the rights and wellbeing of children with a difference of sex development. We offer a positive, can-do approach to raising children and advocate placing the interest of the child at the heart of care.

We have been registered as a charity in Scotland since 2018 and in England and Wales since 2016. We have received funding from BBC Children in Need, Big Lottery, Glasgow Children's Hospital Charity and Edinburgh Children's Hospital Charity. Our income for 2019/2020 totals £18,500. We do not receive funding from the Scottish Government.

dsdfamilies has a track record of **producing accessible and evidence-based resources**. For example, our brochure '*When your baby is born with genitals that look different*' has been translated into 12 different languages from French and German to Turkish, Polish, Urdu and Arabic. Another resource '*Top Tips for (vaginal) Dilation*' is disseminated by the British, European and International Professional Societies for Paediatric and Adolescent Gynaecology. Our most popular resource is '*Top Tips for Talking – to children about Differences of Sex Development*', launched in September 2018. All resources can be accessed via our [website](#).

Working directly with young adults and an expert psychologist, we co-produced a website for young people www.dsdteens.org which talks about puberty, friends and school, sex and relationships.

In March 2019 we published our '**Listen to Us**' report, the largest ever consultation with families, children and young people ever held in the UK.

Summary

dsdfamilies opposes the inclusion of a protected characteristic of 'variations of sex characteristics' under hate crime legislation. Singling out a biological condition in this way reinforces stigma rather than working towards understanding and societal acceptance.

Our work with families, children, teens and adults demonstrates that what those with DSD and their families want is increased psychological support, better understanding of DSD amongst the medical community, investment in accessible patient resources and peer support, and positive and accurate public engagement.

In general, we are concerned at the Scottish Government's approach to children, young people and adults living with different sex development in Scotland. DSD are not an identity characteristic and policy responses should be framed primarily within a healthcare context.

Terminology

The terminology we use to refer to the set of conditions that affect the development of the reproductive organs and genitals is '**differences of sex development**' or **DSD**. DSD is clearly defined and we know and understand who the population is that are born with and live with different sex development.

Intersex is a term that was previously used by healthcare professionals before DSD and for them it has the same meaning. Most healthcare professionals see it as an out-dated term. For some adults, intersex or intersex traits is the term they choose for the way their bodies have developed.

Some adults and organisations define and use 'intersex' in a very broad sense, including conditions one would not think of as DSD (e.g. Late Onset CAH).

The information dsdfamilies produces is written for parents and children who are learning about their bodies and it builds on what doctors have told them. Therefore, we start with DSD (differences of sex development) and the specific words used as a diagnosis. We are meeting people who are mostly new to their child's/their condition and who have usually not developed a sense of themselves in relation to 'intersex'.

Many others simply don't like the label intersex for themselves or their child or have no idea it could apply to them. This means that to focus on 'Intersex' might bypass the people we want to reach at this early stage.

We do not favour the term 'variations of sex characteristics' (VSC) because there is no 'clear understanding of the meaning and scope of the term and to whom it applies' (dsdfamilies 2019; 4).¹

The term is unknown outside a small group of policymakers, LGBT groups and academics and is not recognised by those living with DSD (or those using intersex) as 'related to them'.

¹ dsdfamilies (2019) [Consultation on Scottish Hate Crime legislation](#)

What are DSD?

Differences of sex development is an umbrella name for some 40 different conditions that affect the development of the reproductive organs and of the genitals in boys and girls.

These biological conditions become apparent, due either to genital appearance or different development at the time of puberty.

DSD conditions are understood in terms of specific health diagnoses involving chromosomes, hormones, the development of the reproductive organs and puberty, for example:

- Large clitoris in girls due to excess androgen production in the adrenal gland (e.g. Congenital Adrenal Hypoplasia – this is a life-threatening condition);
- Small penis with the opening at the base not at the tip and a bifid scrotum (appearance of labia) due to partially developed testes and reduced production of testosterone (Peno-scrotal Hypospadias)
- Testes in a girl who is insensitive to androgen so follows a female development in puberty but without a womb (Androgen Insensitivity Syndrome).

For more information please refer to the FAQ on our website www.dsdfamilies.org, our website for young people www.dssteens.org, and our leaflet 'When your baby is born with genitals that look different'

The incidence of DSD

Some reporting² has referred to a statistic of 1.7% (1/60) of the total population being 'intersex' or 'as common as red hair'.

This broad tally includes a wide range of sex developmental endocrine/ gynaecological/ urological conditions where there is no ambiguity regarding the person's sex e.g. an XX girl with functioning ovaries but without a womb or an XY boy with a meatus (hole) in the shaft of his penis. It also includes a condition called Late-Onset CAH representing 1.5% of the 1.7%. People with such development are recorded straightforwardly as male or female at birth. We are concerned how this inflated number is dismissive of the challenges people born with DSD conditions face.

We are also concerned how it reinforces the category-error around 'intersex'.

² For info and discussion <https://ihra.org.au/16601/intersex-numbers/> - <https://www.ncbi.nlm.nih.gov/pubmed/12476264>

0.02% of newborn presentations to health professionals require specialist DSD input to understand why a baby is born with genitals that look different. These represent **ca 0.02% of the total population (1/5500 or 1/4500)**³ This statistic includes a small number of adolescent girls who are diagnosed in puberty (e.g. when a girl doesn't have periods towards the end of puberty; or a girl who at puberty has an unexpected androgen response).

It is also not clear at all whether a whole range of other conditions that affect sex characteristics but have nothing to do with DSD are included and have been consulted (e.g.: PCOS – hirsutism; Poland Syndrome – affecting breast development in girls; Kallman Syndrome – delayed or absent puberty).

The Policy Memorandum for the draft Bill states that VSC is “used in the Bill as this is the term most commonly used by stakeholders”. These ‘stakeholders’ are not named and we question the degree to which they represent or have widely consulted with those with DSD with regard to preferred terminology.

In the UK this translates to approx. **130 babies needing specialist input every year at birth**. This may include assignment of legal sex based on the investigation of the person's biology. Such investigation will include blood tests, hormonal responses, karyotype and physical external (and sometimes internal) assessment to inform sex assignment.

For most babies with a DSD diagnosis sex assignment will be clear. In about 7 or 8 babies annually this is not the case.

0.0001%? – There is no systematic data on whether, and how many, people with DSD seek to change the sex marker on their birth certificate at a later date.

Estimates are one per two years in the UK equating to **1 out of approx. 200 babies born with physical ambiguity or 0.0001% of the total population.**

The characterisation of those with DSD

We welcome the fact that the Scottish Government now recognises that the conflation of 'intersex' (sic) conditions and those with transgender identities in the 2009 Act was mistaken and entirely inappropriate. This represents a welcome shift from the Scottish Government's position in the Census

³ <https://www.karger.com/Article/FullText/442975> - Global Update DSD 2016

(Amendment) (Scotland) Bill, which sought to include ‘intersex’ under the ‘trans’ category (Scottish Government, 2018 para. 18).⁴

However, the Policy Memorandum accompanying the draft Bill still makes references to “differences between intersex and transgender *identities*”. Also, we should like to reiterate that the terms ‘variations of sex characteristics’ and ‘intersex’ remain a contested category, with no ‘clear understanding of the meaning and scope of the term and to whom it applies’ (dsdfamilies 2019; 4).⁵

The evidence base for including those with DSD as a protected group

Neither the Bracadale Review nor the Scottish Government’s 2019 consultation document provide objective evidence to support the introduction of a hate crime category for those with DSD.

In line with Lord Bracadale’s recommendations, the Bill establishes a new category for ‘variations in sex characteristics’, separate to transgender identity, and defines VSCs in the following terms:

A person is a member of a group defined by reference to variations in sex characteristics if the person is born with physical and biological sex characteristics which, taken as a whole, are neither—

- a. those typically associated with males, nor*
- b. those typically associated with females.*

The Scottish Government’s response to a recent parliamentary question confirms that the Government’s evidence base for the new protected characteristics proposed in the draft bill does not extend beyond that cited in the Bracadale Review and its own recent consultation on reform of hate crime legislation.

The Bracadale Review cites only the Equality Network, whose view on hate crime is that ‘intersex should be seen as a separate characteristic rather than as a sub- category of transgender identity’ (2018 3.31)⁶. **The Review does not consider whether VSCs *should* be legislated for, or acknowledge the lack of clarity or at times, politicisation associated with its definition.**

The Scottish Government does not explain why it has chosen to legislate for people with VSCs, other than with reference to the views of the Equality

⁴ Scottish Government (2018) [Census \(Amendment\) \(Scotland\) Bill Policy Memorandum](#)

⁵ dsdfamilies (2019) [Consultation on Scottish Hate Crime legislation](#)

⁶ Lord Bracadale (2018) [Independent Review of Hate Crime Legislation in Scotland. Final Report](#)

Network, which acknowledges on its website that ‘we are very aware that we are not the experts in the remit of lived experience of being intersex’⁷. The Bill EQIA states:

‘Some respondents, including dsdfamilies, argued that the creation of a separate intersex/ variations in sex characteristics category was neither appropriate nor helpful when wider consideration of intersex issues was needed. However, the Equality Network welcome the inclusion of intersex/ variations in sex characteristics as a separate category within hate crime legislation. They believe that ‘intersex’ people, or people perceived to be intersex, can face ‘intersex-phobic hate crime.’ (Scottish Government, 2020: 36)¹⁹

The ‘intersex-phobic hate crime’ cited in the EQIA refers to research undertaken by the Equality Network which ‘found that 29% of intersex respondents had experienced hate crime based on being intersex (although noting the small number of respondents)’ (Scottish Government 2020; 36)⁸. Breaking this figure down further shows that 17 respondents who identified as intersex answered the question on whether they had experienced hate crime based on being intersex, and of these, 29% said they had (five individuals).

The Equality Network report also cautions that the ‘intersex-specific quantitative information is indicative rather than statistically significant’ and notes that the sample is ‘self-selecting, and largely consists of people connected in some way to our LGBTI networks’ (2017: 30, 14, 15)⁹.

As acknowledged in the EQIA, the Bill does not reflect the views of dsdfamilies. We were, to the best of our knowledge, the only stakeholder respondent whose advocacy is dedicated exclusively to children and families affected by DSD. In our submission to the Scottish Government consultation, we recommended that ‘intersex’ should be omitted from the legislation, and stated that other hate crime provisions, including disability, provided protection for those with DSD.

We note that this argument is not acknowledged in the analysis of responses.

⁷ Equality Network (online) [The variations of sex characteristics and intersex project](#) [accessed 29 June 2020]

⁸ Scottish Government (2020) [Hate Crime and Public Order \(Scotland\) Bill Equality Impact Assessment](#)

⁹ Equality Network (2017) [Scottish LGBTI Hate Crime Report](#)

Whilst it is clearly erroneous to have 'intersex' included in the trans umbrella (and it should be investigated why it was ever so), the remedy is not to have a separate category. Instead intersex should be omitted altogether from this legislation until there is a clear understanding of the meaning and scope of the term to whom it applies...

There is no evidence to suggest that those targeted as 'intersex' in the proposed legislation welcome being considered vulnerable to hate crime. We need investment in psychological support, health information, peer support, and accurate and public engagement. The needs of this group are covered elsewhere. Disability legislation protects from instances of work discrimination due to health needs. All have a legal sex, so sex discrimination protections apply. Protections on grounds of sexuality also exist. (dsdfamilies, 2019: 4)¹⁰

In a written Parliamentary Question asking the Scottish Government what analysis it had undertaken to establish the need to include 'variations of sex characteristics' as an aggravating factor, the Justice Minister stated that *'The majority of organisations who responded agreed with Lord Bracadale's recommendation to include "intersex" as a separate category from transgender identity within hate crime legislation'*¹¹. This does not address the question as to whether VSCs *should* be included as a hate crime characteristic.

Both Stonewall Scotland¹² and I Am Me Scotland¹³ recommended that 'intersex' people and groups are consulted on whether 'intersex' is recognised as a separate aggravated offence. The Bill Policy Memorandum also states that *'the views of equalities organisations were particularly valuable in informing the detail of the Bill provisions given that these organisations reflect, and are representative of the needs of those who have experienced hate crime, or have one or more of the characteristics included within the Bill'*.

The reclassification of 'intersex' and change in terminology in the Bill is motivated by the recognition that VSCs are a physical condition and should not be conflated with gender identity. This represents a welcome shift from the Scottish Government position in the Census (Amendment) (Scotland) Bill, which sought to include 'intersex' under the 'trans' category (Scottish

¹⁰ dsdfamilies (2019) [Consultation on Scottish Hate Crime legislation](#)

¹¹ Scottish Parliament [Parliamentary Question S5W-29138: Liam Kerr](#)

¹² Stonewall Scotland (2018) [Response to Independent Review of Hate Crime Legislation](#)

¹³ I Am Me Scotland (2018) [Response to Independent Review of Hate Crime Legislation](#)

Government, 2018 para.18)¹⁴. Nonetheless, it should be noted that VSCs or 'intersex' remains a contested category, with no 'clear understanding of the meaning and scope of the term and to whom it applies' (dsdfamilies 2019; 4)¹⁵.

The main tension lies between those advocating for improved healthcare and support for those with VSCs, and those advocating for 'intersex' as category under the LGBTI umbrella (where 'I' represents 'intersex'). Within the latter group, 'intersex' tends to be politicised, and often used by activists to support the argument that sex is not binary but exists on a spectrum. This position is reflected in the '*Statement of the European Intersex Meeting*' (Riga, 2014), where the first objective is: '*To challenge the definition of sex as consisting of only male and female and promote the knowledge that sex is a continuum, as is gender*'¹⁶. This objective was also, until recently, adopted by Scottish Government funded LGBTI charity Equality Network, which changed its charitable remit in December 2014 to include intersex equality and human rights, alongside lesbian, gay, bisexual and transgender equality and human rights¹⁷¹⁸.

The needs of those with DSD

dsdfamilies shares concerns - with the Scottish Government, with adult and family groups - about the need for improvements in services including consent to all interventions and focus on the **entire support and care infrastructure** for people with DSD conditions. We work in tandem with the NHS and DSD healthcare professionals, including the Scottish Differences of Sex Development Clinical Network (<http://www.sdsd.scot.nhs.uk/>).¹⁹²⁰

A challenge that families often face in Scotland and elsewhere is that many doctors and healthcare professionals encountering these rare conditions are

¹⁴ Scottish Government (2018) [Census \(Amendment\) \(Scotland\) Bill Policy Memorandum](#)

¹⁵ dsdfamilies (2019) [Consultation on Scottish Hate Crime legislation](#)

¹⁶ Organisation Intersex International Europe (2014) [Statement of the European Intersex Meeting in Riga, 2014](#)

¹⁷ Equality Network (2014) [Intersex equality](#)

¹⁸ In 2019, following a [Parliamentary Question S5W-23930](#), the Equality Network amended its website, and stated that it had not yet taken a policy position on intersex/VSCs issues.

¹⁹ Scotland is one of the only places worldwide where there is a Registry of babies born with DSD/intersex conditions. 81 new-borns in Scotland have required specialist DSD input in the last 5 years (1 in every 3,378 births in Scotland). This number is slightly higher than the statistics previously quoted because it refers to 'any full term infant who is born with atypical genitalia requiring specialist input in the first 4 weeks' and it includes circumstances such as babies with undescended testes.

²⁰ We also work closely with another Scottish (and English/Welsh) charity, the CAH Support Group (www.livingwithCAH.org). CAH happens to both boys and girls. There is an overlap between different sex development and girls with CAH. The Chair of the CAH Support Group is a trustee of dsdfamilies.

not well enough informed to ensure high standards of advice and care. This is a particular concern since these conditions are by definition intimate and sensitive and require support carefully attuned to those sensitivities. Children, young people and their families need to deal with challenging, intimate anatomical issues which cannot be fully addressed until those with the conditions can make what can be complex decisions.

Some of the main issues pursued by dsdfamilies include:

- **Need for urgent investment in building resilience, psycho-social support, information and communication/skill development for children, young people, adults and their families:** a need to promote understanding and acceptance as soon as baby is born, help families understand their child's development, support openness within families to share information with a child from early on, support families, children and young people in building a peer community and social network, help young people talk about their health to peers and friends, provide psycho-sexual support to young people, provide psychological and peer support to adults who often never received support to learn to talk about their condition and who often live in isolation.
- **Develop a child's capacity to be involved in their own care and to feel good about their body.** Move away from a medical approach to a child-centred approach. This includes a need to develop non-surgical pathways and long-term **support to enable a child become the decision-maker about their body.** Invest in the support needed to raise confident and resilient young people able to make informed decisions about their body
- **Other key issues for children, young people and adults living with DSD are:** General health and wellbeing; long term endocrine care; reproductive possibilities; living with atypical biology; cognitive and emotional wellbeing; managing involvement with health services, access/transition to adult care/availability of adult care; social context – privacy vs openness; positive public awareness.

dsdfamilies is concerned that the Scottish Government's policy responses to those with DSD are muddled and inconsistent.

DSD are *primarily* a healthcare issue, yet in our dealings with the Scottish Government, we are frequently directed towards civil servants working on equalities issues. Nor is there evidence of much coordination between officials working across different policy areas, e.g. law, education, health.

As a matter of urgency, the Scottish Government must develop a clearer understanding of the needs of children and young adults growing up with DSD and the needs of adults living with DSD in Scotland²¹. It is our strong view that that work should be led by officials working on health policy.

dsdfamillies
24 July 2020

²¹ 'Listen to Us' - Consultations with children, young people and families living with different sex development <https://www.dsdfamilies.org/application/files/8015/5447/3715/reportdsdf-2019.pdf>