

CULTURE, TOURISM, EUROPE AND EXTERNAL AFFAIRS COMMITTEE

CENSUS (AMENDMENT) (SCOTLAND) BILL

SUBMISSION FROM DSDFAMILIES

We are grateful to the CTEEA Committee of the Scottish Parliament for the opportunity to comment on the Census (Amendment) (Scotland) Bill.

Our submission seeks:

1. To inform the Committee on what 'intersex' (also known as Differences of Sex Development – DSD) is and what the needs are of children, young people and adults with a DSD
2. To point out that the inclusion of DSD/intersex as a trans identity in Article 18 of the Policy Memorandum accompanying the Bill incorrectly groups biological DSD/intersex states with sexual and gender *identities*.

What is DSD/intersex?

DSD (or intersex) is an umbrella name for some 40 different conditions that affect the development of the reproductive organs and of the genitals.

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 whom 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.dsdteens.org , and our leaflet 'When your baby is born with genitals that look different'

(<https://www.dsdfamilies.org/application/files/1615/4236/8548/firstdays-dsdfamilies.pdf> - which is available in 12 different languages on our Resources page).

The instance of DSD/intersex?

Some reporting has referred to a statistic of 1.7% (1/60) of the total population being 'intersex' or 'as common as red hair'. This 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. People with such development are recorded straightforwardly as male or female at birth.

0.02% of DSD 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)**¹ 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).

In the UK this translates to approx. **130 babies needing specialist input every year at birth** (for Scotland approx. 12 babies). 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 conditions find that the sex assigned at birth does not align with their gender identity *and wish to act to revise their sex assignment*. Estimates are one per 2 years in the UK equating to **1 out of approx. 260 babies born with physical ambiguity or 0.0001% of the total population**.

A Community?

In other words DSD/intersex for most people refers to **a person's biological characteristics**; and for many is not a sexual or gender identity unlike L, G, B, T, non binary, gender-fluid or Queer.

There is a sub group of people with diagnosable conditions that will refer to themselves as having an intersex identity and may refer to an intersex community. However, most children and most young people, parents and adults affected by DSD rarely see themselves as intersex, nor do they embrace belonging to an intersex (or DSD) community. Individual people and their families will talk about having Congenital Adrenal Hypoplasia, Androgen Insensitivity Syndrome, or Peno-scrotal Hypospadias or will describe what some of the characteristics are for their particular condition (e.g. 'I was born without a womb').

Working for Better Healthcare

¹ <https://www.karger.com/Article/FullText/442975> - Global Update DSD 2016

A number of organisations work to secure better care and support for people with DSD/intersex conditions. Organisations such as UK Intersex Association, Intersex UK and the Swiss StopIGM.org campaign against the use of surgical interventions at infancy and in childhood to ‘correct’ physical characteristics associated with DSDs. Such surgeries often have problematic later consequences and, by definition, are not subject to the informed consent of the child concerned. These organisations campaign to use human rights provisions to secure a legal ban on such surgeries.²

dsdfamilies shares concerns 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/>).³

A challenge that families often face in Scotland and elsewhere is that many doctors and healthcare professionals encountering these rare conditions are 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 psychological support, building resilience, 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;

² See also Travis Mitchell, 2018.

³ 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.

managing involvement with health services, access/transition to adult care/ availability of adult care; social context – privacy vs openness; positive public awareness.

Census 2021 – observations

We will be taking up this issue separately with the Scottish Government but note a confusion regarding DSD/intersex in the Policy Memorandum accompanying the Census 2021 Bill. In section 18 it states:

“The umbrella term ‘trans’ can include trans women, trans men, non-binary gender people, people who cross-dress and intersex people.”

We have in the meantime received written confirmation from the National Records of Scotland⁴ that the inclusion of intersex under the trans umbrella is ‘an error’.

But the fact that this was written illustrates why we are rightly concerned about further conflation between physical characteristics and sexual/gender identity and the inappropriate use of ‘intersex’ in the debate surrounding Census 2021.

DSD/ intersex is not a ‘third’ biological sex, it is a series of different biological pathways which produce different anatomical characteristics among people who are female or male. A very small number of babies (estimated 7/8 per year in the UK – possibly one every other year in Scotland) have the biology that means they could be raised either male or female and a legal sex assignment is made.

Ways forward

In conclusion, we urge the committee to support children, young people and adults with DSD/intersex conditions by helping discussion to focus on the lived experience of the majority people with those conditions. **We suggest to the Committee that including ‘intersex’ as a census category would capture only a small group of people with DSD for whom intersex is a social identity.**

⁴ Correspondence from National Records of Scotland to dsdfamilies, 23 November 2018

Note on dsdfamilies

- dsdfamilies is an information and support charity that was established in 2011 by two parents **to promote the rights and wellbeing of children with a difference in sex development.**
- Charity in England and Wales since Oct 2016, Charity in Scotland since summer 2018. Funded by BBC Children in Need, Big Lottery and Glasgow Children's Hospital Charity.
- We offer a **positive, can-do approach to raising children and advocate placing the interest of the child at the heart of care.**
- 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 in 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 latest resources '*Top Tips for Talking – to children about Differences of Sex Development*' was launched in September 2018. All resources can be accessed via our website www.dsdfamilies.org
- We also co-produced with young adults and an expert psychologist a website for young people www.dsdteens.org which talks about puberty, friends and school, sex and relationships.
- dsdfamilies is the only family-led/patient group sitting on both the newly launched NHS England Service Specification Workgroup and the NHS England DSD Surgery Policy Workgroup. In Scotland we liaise regularly with the Scottish DSD Clinical Network.
- **Consultation with families, children and young people:** in January 2019 dsdfamilies will be publishing its report on the consultation process with families, children and young people. This report ('what families, children and young people are saying they need') will inform our 2019-2021 work programme.
- Civil servants from both the Scottish Government and the UK Government have requested access to this unique data to inform their own work. It has been financed solely with modest resources from BBC Children in Need and Big Lottery grant (£29K).
- dsdfamilies has informed the work of civil servants in the Scottish Family Law department since March 2017; we are informing the forthcoming Call for Evidence by the Government Equality Office (Westminster) and provided input to the Office of National Statistics re Census 2021 in England/Wales/NI.