

DIFFERENCES
OF SEX DEVELOPMENT
(DSD)
Information for schools



DIFFERENCES OF SEX DEVELOPMENT (DSD)

Information for schools, produced by UK Charity dsdfamilies

This information has been produced to inform school management and teachers about what DSD is, and how they might support children growing up with these conditions.

We urge teachers to carefully consider the impact different sex development can have on a growing child.

Please recognised that many children and teens and their families will not have had any psychological support. Often they will not have had an opportunity to meet other kids with similar conditions.

If you wish to raise awareness around DSD we urge you to read our report 'Listen to Us' to fully appreciate what children, young people and their families, growing up in the UK, say they need and want.

Introduction

'Differences of Sex Development (DSD) is an umbrella term that brings together a range of approx. 40 biological conditions which affect sex-linked chromosomes, sex-linked hormones (i.e.: testosterone/oestrogen) and/or the development of the genitals and the reproductive organs.

DSD relates to biological sex and is not to be confused with sexual orientation or gender identity.

Prevalence (i.e. how often DSD happens) varies widely between conditions. It also depends on how DSD is defined.

In the UK, once every three days, a midwife will spot that a baby might have a DSD because they cannot observe without further specialist input whether the genitals of a new-born are those of a little girl or a little boy. Perhaps the clitoris might be swollen or larger than usual or the penis might be smaller than usual. This relates to just under 0.02% of the population.

In other DSD conditions the external genitals have a typical appearance and only the internal organs or the chromosomes may not be as expected.

Some DSD conditions are not diagnosed until puberty or may never be diagnosed. This includes conditions such as: MRKH, Klinefelter's Syndrome and Turner Syndrome which are much more common and relate to approx. 0.2% of the population

Sometimes people talk about 'Intersex' and also use a much broader definition that relates to lived experience. When including Late-Onset CAH (which some describe as similar to Polycystic Ovarian Syndrome) to the above conditions this affects up to 1.7% of the population.

Many people dislike the terms Intersex and DSD or are totally unfamiliar with them. Most will only use the specific name of the condition they or their child has.

DSD in media coverage

Some educational practitioners and pupils will come across coverage of the South African Athlete Caster Semenya. Ms Semenya is a female athlete with 46 XY, DSD.

Whilst in the womb she was unable to produce testosterone (T) because the 5-ARD gene was not 'switched on', in puberty her body found atypical, exceptional ways to produce more T than is usual for female athletes. There is a big controversy about whether her unusual ability to produce T is similar to e.g. the legs of Usain Bolt or the large feet of swimmer, Adam Peaty OR if the fact she produces and can use the T means she has an unfair advantage on her fellow female athletes.

DSD in schools

Differences of sex development will impact on school life in many different ways depending on what the underlying condition is or how old the young person is.

Primary school

- Some parents chose not to say anything to school unless the child needs regular medication or requires an emergency kit in school. You can find more information on the [Living with Cah website](#).
- Some children will need help or more time to use the toilet. Young children thrive when they know there are clean (!) toilets for their age

group nearby and an informed and supportive teacher who doesn't mind regular voiding.

- Some children may dislike having to use communal changing rooms. This needs to be handled with sensitivity.
- Some parents have simply let school know that their child is well but has medical check-ups and will need time out for appointments.

When an underlying condition can contribute to how a child learns and socialises, it might help teachers to know more about their condition. You can visit the [Turner Syndrome Support Society](#) and [Klinefelter's Syndrome Association](#) for more information.

Primary – sex education

Children with different sex development may not experience a typical puberty and are often unable to have biological children.

Across sex education classes, use inclusive language and talk about how many girls will have periods, that many boys will develop this way, that there are many different ways to build a family...(rather than using language that is limiting: all boys... all girls...)

Secondary school

Information related to different sex development can be relevant in biology classes when discussing human chromosomes.

Most boys have 46,XY chromosomes and most girls have 46,XX chromosomes. Keep open the existence of variation by including different combinations of chromosomes (E.g.: sex chromosomes DSD including Klinefelter's Syndrome 47,XXY, Turner Syndrome 45,X0, or Mixed Gonadal Dysgenesis 45,X0/46,XY; also: some girls will grow up with 46,XY DSD and some boys with 46, XX+SRY DSD.)

The British charity dsdfamilies¹ hosted a focus group for teens with different sex development.

They noted how some variations need close medical management whereas others do not. Some of those not needing regular medicines or emergency treatment felt their variation was 'private business'. Other teens were unclear about whether schools knew or not.

Most concerns of young people were related to their healthcare, the lack of peer support, and the way 'DSD/Intersex' is reported in the media.

¹ <http://dsdfamilies.org/application/files/8015/5447/3715/reportdsdf-2019.pdf>

A focus group discussed their school experiences and young people were clear that they:

- Did not want to be removed from sex education classes (in the rare circumstances that a teacher knew they live with DSD);
- Want to be treated like everyone else;
- Want their differences of sex development to be part of the curriculum, but not as a 'special' topic, just acknowledged; and,
- Want teachers not to generalise – everyone is a unique individual, not everyone will have periods or will be able to have their own children and all bodies are different.

Ensuring children and young people have a route to support groups was highlighted as a key resource for everyone. To help with this, links to some of the main organisations is noted below. Where possible, links are to the support networks.

- dsdfamilies (Differences of Sex Development) – www.dsdfamilies.org or www.dsdteens.org
- CAH (Congenital Adrenal Hyperplasia) – www.livingwithcah.com
- Klinefelter Syndrome Association (KSA) – www.ksa-uk.net
- Turner Syndrome Support Society – www.tss.org.uk

Produced by dsdfamilies, January 2020

For info and suggestions please contact us on info@dsdfamilies.org