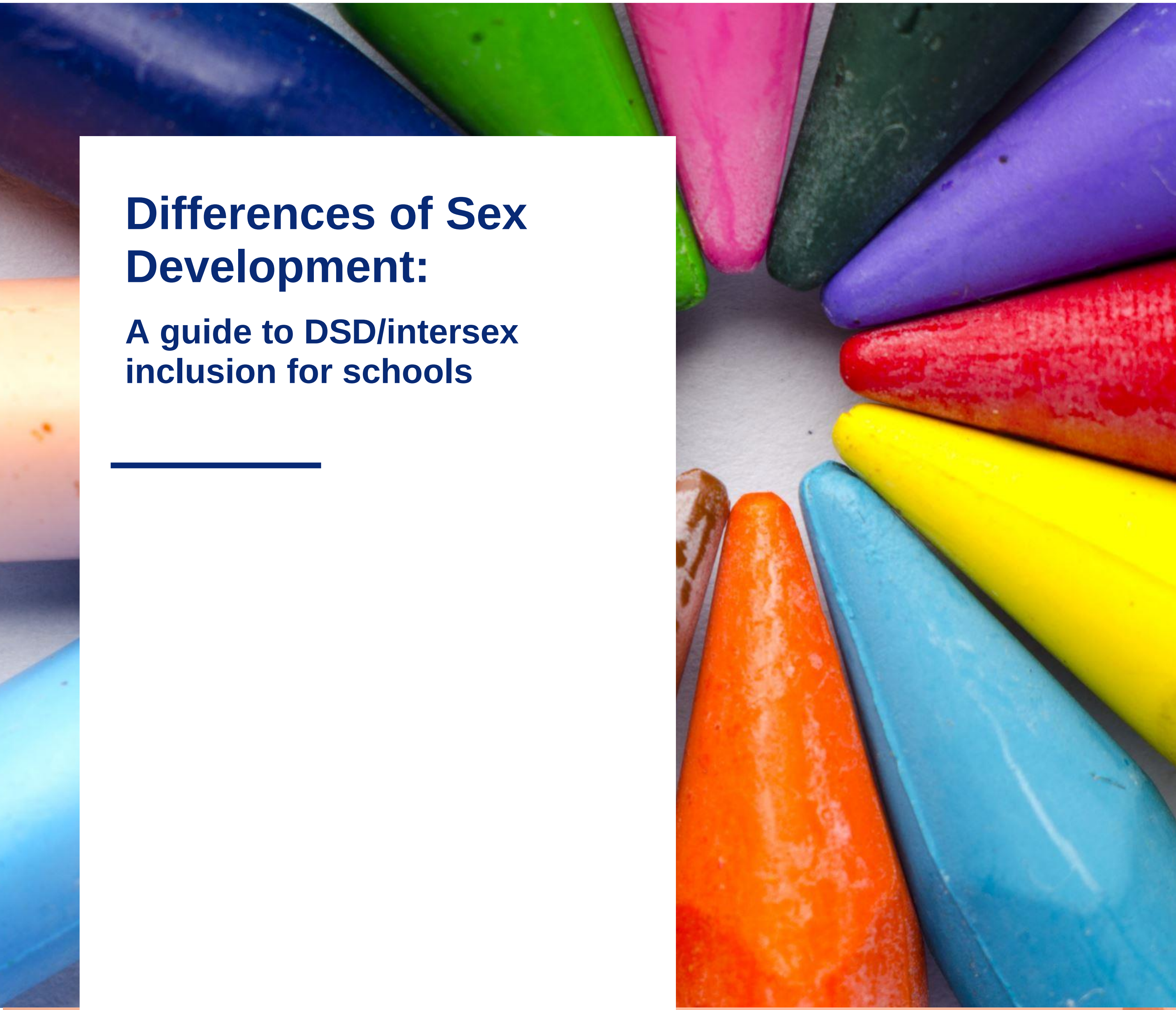
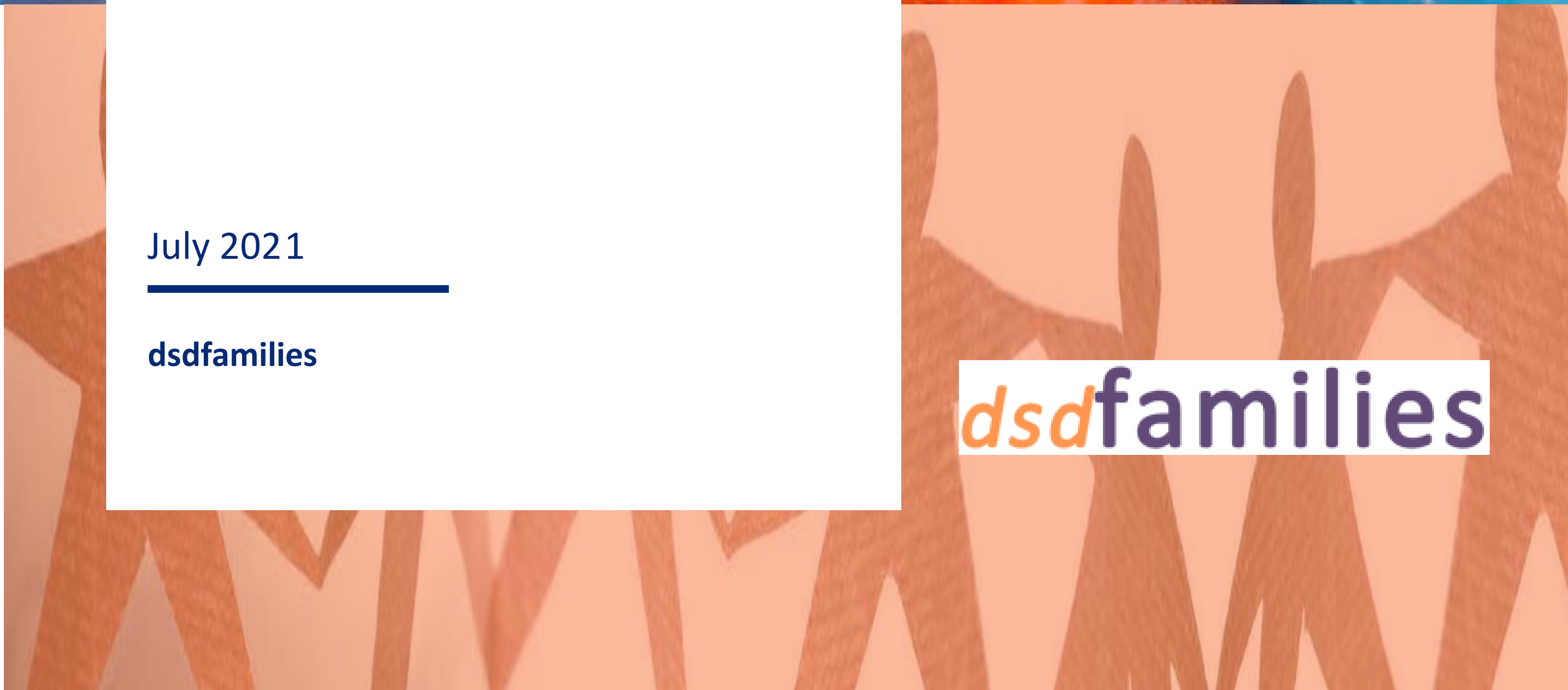


Differences of Sex Development:

A guide to DSD/intersex inclusion for schools

July 2021

dsdfamilies



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About this guide

This guide is about school's responsibilities to pupils with Variations of Sex Development and the broader issue of "intersex" inclusion in the school curriculum.

This is not a guide about LGBT+ issues, as Differences of Sex Development/Intersex Variations are not a form of sexuality or gender identity; they are about physical differences in a person's reproductive development and sometimes genital development.

Who is this guide for?

This guide is for:

- Teachers, school leadership teams and governors in both state and private schools
- Parents and young people with Variations of Sex Development who would like to understand their rights
- Local education authorities producing their own guidance
- Anyone who has an interest in promoting the wellbeing and academic attainment of children and young people with variations of sex development

Who are we?

Every year in the UK, approximately 150 children are diagnosed with differences of sex development (DSD) – and that means there are approximately 2,300 children living with DSD conditions in the UK. dsdfamilies is the only UK charity that specifically supports all children and young people, and their families, living with DSDs in the UK. We work together with families and their children, teens and young adults, and healthcare providers in the UK, to raise happy, confident, and well-informed young people who can speak up for the support they need.

Throughout this guide you will also see quotes from our Youth Ambassadors, a focus group of young people living with DSD in the UK, who help to advise dsdfamilies on the focus and direction of our work.

Key aims:

- To understand that Variations of Sex development is an umbrella term, encompassing around 40+ different medical conditions
- To introduce some of the issues faced by children and young people with DSD and schools' legal responsibilities towards them
- To empower teachers and school leaders with the skills and knowledge to evaluate so called "intersex inclusive" resources and advice from outside agencies being presented to schools
- To explore ways that lessons can be inclusive of DSD without othering pupils

Relevant Statutory guidance for schools

- Supporting pupils at school with medical conditions
- Special educational needs and disability code of practice: 0 to 25 years
- Working together to safeguard children
- Relationships Education, Relationships and Sex Education (RSE) and Health Education

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Foreword

Schools can play an important role in helping children with Variations of Sex Development to become confident and happy adults. Their role is particularly key as some students with DSD may only discover they have a DSD during the school years, especially at important times for sex development, such as puberty.

Relationship and Sex Education classes and some science lessons offer a variety of opportunities for inclusive talk about people with differences in their sex development, but these need to be handled thoughtfully and sensitively.

In recent years education has had a focus on inclusion. This has been heightened by the introduction of the RSE curriculum in September 2020. At dsdfamilies we have received many emails from concerned parents and teachers about materials going into school which claim to be "intersex inclusive".

Many of these materials, while well meaning, are not written by people with any expertise in supporting children and young people with DSD. This means a lot of the materials contain misleading or outdated information and are not representative of the experiences of children and young people with DSD.

Schools have a statutory responsibility to properly support children with medical conditions under Section 100 of the Children and Families Act 2014.[1] As schools may not be aware of pupils with DSD in school, it is important that teachers are particularly mindful in discussions around this issue and the "talk about it as though someone in the room is living it" rule should be a guiding principle.

Golden rule: Talk about it as though someone in the room is living with it.

This guide aims to provide teachers and other education providers with an overview of Variations of Sex Development, the needs and experiences of children and young people with DSD, and an understanding of schools' responsibilities, both in terms of curriculum content and day to day support of pupils with DSD.

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[1] https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/803956/supporting-pupils-at-school-with-medical-conditions.pdf

DSD/intersex inclusion – a quick summary for busy teachers

- DSD (sometimes also known as DSDs or intersex variations) is an umbrella term for 40+ congenital medical conditions that affect the development of sex characteristics and sometimes the genitals.
- Schools have a statutory responsibility to properly support children with medical conditions under Section 100 of the Children and Families Act 2014. As schools may not be aware of pupils with DSD in school, it is important that teachers are particularly mindful in discussions around this issue.
- Young people with DSD will have a variety of experiences and needs, depending on their specific diagnosis, sex and age, etc.
- Language is a complicated issue, schools should be mindful of how young people may use language to describe themselves and avoid imposing terms like "intersex", which may alienate or further stigmatise pupils.
- When talking about puberty, sex development and reproduction, try to avoid phrases like "all girls…", "all boys". Use "most/some" language and acknowledge that for some pupils this may be different.
- Acknowledge different types of families and different ways people build families. This is especially important for children with DSD who have fertility issues, as well as being inclusive of children in families where a parent may have a DSD.
- If a child requires separate toilet or changing facilities, try to accommodate this.
- Respect the privacy of pupils and staff with DSD.
- Avoid resources and external agencies that use "intersex" in a tokenistic or inaccurate way – if you're not sure, it would be best to leave intersex/DSD out of lesson plans. This is especially important if schools are planning on covering LGBT+ issues.
- Remember the golden rule; **Talk about it as though someone in the room is living with it.**

Background

An important note about inclusive language

Language is a complex issue in the area of Differences of Sex Development/Intersex variations. **This is especially true for children and young people, many of whom may not even know the word "intersex" or may not like it**.[2] Some young people can find the word particularly stigmatising and difficult. dsdfamilies have heard of children with DSD having panic attacks when finding out that they may be labelled as intersex.

"I wouldn't say intersex has any connotation with it, but it does kind of have the notion of an 'otherness' which can be quite difficult to tell children about." **(dsdfamilies youth ambassador)**

This guide will sometimes refer to the term "intersex", as this is often the term schools have met in other training materials. It is important to remember that few who are diagnosed with a DSD uses this term themselves.

This guide will also refer to the umbrella term DSD (Difference of Sex Development). This is the term used by the NHS[3], although not everyone likes it because of its association with an earlier term "Disorders of Sex Development". Most young people will use diagnostic specific labels, e.g., CAIS, PAIS, CAH, MRKH, Klinefelter's, Turner Syndrome, gonadal dysgenesis, and penoscrotal hypospadias.[4]

However, we note that many of our young people also prefer the term Variation of Sex Development. We would encourage schools to be guided by young people living with DSD, and meet them where they are at, by using either DSD or VSD. The most important thing is not to impose any terms that may make young people feel uncomfortable or excluded.

"…there is, not a stigma, but a sense of otherness, and some people don't really like it. So, I think it is good to keep with DSD or variations of sex development. Those terms seem more clinical and easy for a child to understand." **(dsdfamilies youth ambassador)**

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[2] https://www.tandfonline.com/doi/10.1080/19419899.2018.1453862 **14% of the young people spontaneously said they had never heard the term intersex before, only three identified as Intersex, and slightly more than a third liked 'Intersex' or did not mind it. 50% of young people and their parents found the term to be problematic**

[3] https://www.nhs.uk/conditions/differences-in-sex-development/

[4] **The DSD listed in this guide are some of the most common that schools may come across. The dsdfamilies website has a more detailed list, with explanations about each DSD, available here** https://dsdfamilies.org/parents/what-dsd/brief-overview

What are Variations of Sex Development?

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

The prevalence of DSD varies widely between conditions. It also depends on how DSD is defined.[5]

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. 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.

Sometimes people talk about 'Intersex' and use a much broader definition that relates to lived experience. This can sometimes be misunderstood to mean that "intersex" is about identity or gender. It is important for schools to understand that these are unrelated issues, and to not let the needs of children be overlooked by this confusion.

> ***"Going to school after he was bullied for having a small penis and talking about his biological development but also the psychological impact on us as a family was awful in one way, but on the other hand it was almost like a release, with the headteacher kindly saying 'wow, and you managed to carry all that just on your own' .The fact she then went on to talk about gender dysphoria and 'intersex' wasn't helpful, and again, I wish I was better prepared to explain that these variations aren't about identity."*** **(dsdfamilies parent)**

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[5] https://www.bbc.co.uk/sounds/play/m000222z **This interview for BBC Radio 4's More or Less with endocrinologist Dr Bernard Khoo discusses why the 1.7% figure is probably too high and highlights the importance of specific diagnostic language rather than seeing "intersex" as a homogenous group**

Listening to children and young people with DSD

Over an 18-month period, dsdfamilies consulted with 194 children, young people and adults living with different sex development.[6]

Young people 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.

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

- **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.**

"One thing I liked about this discussion… I just liked… these issues are unspoken. No one really asks anyone like 'are you comfortable with the term intersex? Are you comfortable with comparing yourself to LGBT?' and I like that, you are asked, and it is important that we have our own say."
(dsdfamilies youth ambassador)

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[6] https://dsdfamilies.org/application/files/6715/5403/9993/dsdfreport-2019.pdf

DSD inclusion in schools

DSD in RSE and science lessons – guidance for inclusive talk

The DfE's statutory guidance, 'Supporting pupils at school with medical conditions', advises schools to not make assumptions that all children with a particular medical condition need the same treatment. This is an especially easy trap for teachers to fall into if "intersex" is treated as a homogenous group. These tips should help teachers to see when inclusive talk is possible, to acknowledge difference, without singling out pupils with DSD or treating them as a monolith.

As schools, especially primary schools, are encouraged to plan Sex Education according to the needs of their pupils, the advice has not been sorted into particular key stages.

Try to avoid blanket statements like "all girls have XX chromosomes", or "all boys have XY chromosomes". Most girls do, but some girls with DSD may not. For example, girls with CAIS have XY chromosomes, girls with Turner Syndrome have X0 chromosomes.[7] Similarly, some boys with DSD may have XXY chromosomes. Some children may have a mosaic, XY/X0, karyotype.

Be mindful when teaching about puberty that some children (whether they have a DSD or not) will experience atypical puberties. For example, when talking about periods, it is useful acknowledge that this may not happen for some girls (this could be for a number of reasons, not just due to DSD), or when talking about development in boys, acknowledge that sometimes a penis might not grow without hormone therapy. This will not only help to include children who already know they have a DSD, but also prepare children who may go onto discover their diagnosis later.

***"[The teacher] said 'every girl has periods', but I know I won't…they told us to draw a 'normal boy and a normal girl'… I felt really angry and got upset"* (dsdfamilies youth ambassador)**

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[7] **When delivering lessons on sex determination for KS4 science, teachers should be clear that what they are teaching is a simplified version, which happens in most cases, but that, like all things in nature, variations do occur.**

When talking about genitalia, acknowledge that all genitals look a bit different. Some girls might have a slightly larger clitoris, some boys might have the urethral opening on the underside of their penis, for example.[8]

Avoid resources that refer to "intersex" as a third sex category. This is inaccurate and stigmatising and could be very distressing for children with DSD. It is also not inline with schools' responsibility to teach UK equality law accurately to pupils.[9]

If a child is worried about their puberty or genitalia, and thinks they may have a DSD, the school should encourage them to speak to their parent or carer. If this is causing a significant issue, they will need to make an appointment to see their GP. They will then consider whether a referral to an endocrinologist and/or gynaecologist may be required. Parents can also be signposted to dsdfamilies for support and information.

Recognise different ways people can build families. Some people with DSD will have fertility issues, talking about adoption and fostering will help children to think about what their family may look like in the future as well as building understanding of families where parents may have a DSD.

Be aware of other medical issues that children with DSD may be facing. Many resources talk about "intersex" as a "harmless variation". For children who may need to take lifesaving medication or may have related disabilities (see also our 'Practical tips' section for more information about this), this approach could seem exclusionary and dismissive of their needs.

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[8] **The Bare Reality series by photographer Laura Dodsworth may provide schools with some excellent resources for exploring how bodies, in particular our genitals, may all look a bit different. Some of her work includes people with VSD. https://www.lauradodsworth.com/bare-reality-photography**

[9] **The Equality Act 2010 defines sex as "a reference to a person who has a particular protected characteristic is a reference to a man or to a woman". All children with VSD are given a sex of either male or female, in the UK. https://www.legislation.gov.uk/ukpga/2010/15/section/11**

Avoid conflating DSD with LGBT and identity issues. Although this approach may seem common, most intersex and DSD orgs and consensus statements agree that it is unhelpful and does little to highlight and address actual issues faced by people with DSD (see also the Resources and External Agencies section of this booklet). Schools should also be mindful of this if other students give talks about LGBT+ issues in school.

"I think it is different in the sense that, well at least when I describe it to people, you get confused very easily with trans people when you describe intersex as something that is within the LGBT acronym which I think… it feels like… it can sort of be like your struggle is overshadowed almost… by something that you are not affected by at all… that you are conflated with." **(dsdfamilies youth ambassador)**

Do not pressure children and young people into talking about their DSD. DSD can be very personal, and the young person should feel comfortable and in control of who they choose to tell and when. **Remember, we are often talking about genitals, as well as intimate medical issues, and we encourage other children to understand that these are private.** Children with DSD may be especially vulnerable in this area and usual safeguarding procedures should apply.

Be mindful of family members of people with DSD, who may be in class. Siblings especially may be worried about issues surrounding sex or puberty. Children and young people should also not be put in the position of talking about someone else's DSD.

Resources and External Agencies

Schools have a responsibility to ensure all resources are age appropriate, meet the outcome of the relevant part of the curriculum, and are in line with your school's legal duties in relation to impartiality.

When deciding if a resource is suitable, you should consider if it:

- aligns to the teaching requirements set out in the statutory guidance.
- would support pupils in applying their knowledge in different contexts and settings.
- is age-appropriate - think about the age, developmental stage, and background of your pupils.
- is evidence-based and contains robust facts and statistics.
- fits into your curriculum plan.
- is from a credible source[10]

This is particularly important when assessing resources that mention "intersex". **If in doubt about the accuracy of information in materials, when it comes to DSD, schools would be best to err on the side of caution and not use them.**

Teachers also must ensure external agencies are appropriate and their content is in line with schools' legal responsibilities. Schools should be particularly aware of this if inviting LGBT+ speakers into school. Many of these organisations tack 'intersex' onto their training, despite having very little expertise in the area.[11][12]

Schools should ask external agencies if they plan to include "intersex" in their materials. If so, they should work with them to ensure content meets with the advice in this guide. If this cannot be done, the speaker should be asked to leave "intersex" out of their materials, or schools should find a different agency to work with.

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[10] **https://www.gov.uk/guidance/plan-your-relationships-sex-and-health-curriculum#using-external-agencies**

[11] **https://pubmed.ncbi.nlm.nih.gov/27210458/ This letter to the Council of Europe explains some of the issues with LGBT+ "intersex inclusion", and how this often ignore the needs and experiences of children and young people living with DSD**

[12] **This essay, by intersex activist Emi Koyama, explores some of the potential benefits and the pitfalls of including the I in LGBT http://www.intersexinitiative.org/articles/lgbti.html**

Practical tips for supporting children and young people with DSD in school

Schools should already have a policy in place for supporting pupils at school with medical conditions, which, along with their SEND policy, should address most of the needs of pupils with DSD.[13]

The experiences of dsdfamilies have shown that **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 does not mind regular voiding.

> ***"You have to trust the school. If you don't, it is the wrong school. You should talk to the headteacher and tell them that your child is really self-conscious about going to the toilet when other people are there. You don't have to tell them about the condition. Explain that the child doesn't like to admit it and that the teacher should watch out for him. His class teacher should know about it. And if the teacher is watching out then, but not making a big deal out of it, then everything should be fine."*** **(dsdfamilies youth ambassador)**

Some children may dislike having to use communal changing rooms. This needs to be handled with sensitivity.

Some parents may 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.

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[13] https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/803956/supporting-pupils-at-school-with-medical-conditions.pdf

Supporting Teachers with DSD

The DfE’s guidance on planning the RSE curriculum reminds school leaders that they also have a responsibility to protect the wellbeing of teachers, especially when subjects might trigger “feelings or thoughts, including of historic, recent or current trauma.” School leaders should be aware of the difficult feelings that might arise in staff members with DSD, especially when covering RSE content.

It is also important that staff with DSD do not feel pressured to share this information about themselves. Information about DSD should not be collected for equality and diversity monitoring purposes, unless it is relevant to the role, as this would not be compliant with schools’ duties under the GDPR.

Useful Resources

Further support

Ensuring children, young people and adults have a route to support groups is key 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) – https://www.livingwithcah.com/
- Klinefelter's Syndrome Association (KSA) – www.ksa-uk.net
- Turner Syndrome Support Society – www.tss.org.uk
- MRKH Connect https://mrkhconnect.co.uk/

Suggestions for further reading

Knowing me, knowing you – a blog post about a family's experience with education and how adaptable children with DSD can be

Top Tips for Talking About Differences of Sex Development – this booklet was made for parents, but may give some useful ideas for inclusive talk in the classroom

The Story of Sex Development – a really useful resource for explaining sex development in a DSD inclusive way

Listen to Us – a unique report, produced by dsdfamilies, capturing the voices of children, young people and adults with DSD in the UK

dsdfamilies resource page – Lots of links to further resources, including our EYFS/nursery guide and examples of inclusive children's books that celebrate diversity