

Born and raised

Children born intersex or with differences of sex development are an often misunderstood subject. **Caroline Vollans** explores the issue and reveals how settings can offer support



We live in a world where issues involving the body, sex, sexuality and gender have an increasingly high profile. There is, however, one issue of bodily development that is rarely mentioned – that of intersex.

Babies all over the world are born with genital differences – that is, they do not have a typical male or female anatomy. This is an issue that should be of concern to all those involved in education who, indeed, could encounter these children and their families.

Good early years practice needs to consider how to be proactive in breaking the taboo of ignorance and stigmatisation of children with differences of sexual development.

In the NHS, intersex is generally

referred to as ‘disorders of sex development’. The term ‘disorder’ is, understandably, not favoured by many and the preferred term is differences of sex development (DSD). This emphasises that sex development is a complex process, and many variations can result. Alternatively, rather than using any of these umbrella terms, the specific diagnosis is used.

Terminology is often a matter of subjective preference and some find the term ‘intersex’ a useful way of describing themselves. Here, I will use the terms differences of sex development and intersex. As this topic becomes more spoken about, no doubt the terminology debate will continue.

DEFINITION

Basically, a person with intersex or DSD has a mix of female and male

Babies born intersex or with DSD have a mixture of male and female characteristics

sex characteristics. In some way or other, their biological sex make-up is not classified as what is traditionally thought of as either female or male. They may be chromosomally female (XX) or male (XY), though not in every case, but their reproductive anatomy will not match in the expected way. DSD or intersex can take various forms.

MAIN TYPES OF DSD

Girls are born with XX chromosomes, a womb and ovaries but have genitals that are not usual in females – this is often an enlarged clitoris that sometimes resembles a penis. The most common cause for this is congenital adrenal hyperplasia (CAH).

If a child has CAH (the name for this diagnosis), they are lacking the enzyme that is needed to ▶

produce the hormones cortisol and aldosterone. Without these, their body produces more male sex hormones (androgens) and this results in the genitals appearing more male. CAH involves kidney problems, sometimes ones that are life-threatening and requiring immediate medical treatment.

Girls are born with an underdeveloped or absent womb, cervix and upper vagina. This may go undetected for some time as their ovaries and external genitalia are present and they will develop breasts and pubic hair. One of the first signs of their condition is that they don't start having periods. This is known as Rokitansky syndrome or Mayer-Rokitansky-Küster-Hauser (MRKH).

Boys can be born with XY chromosomes, but have a smaller penis, usually as a result of underdeveloped testes. Sometimes they have parts of a womb and fallopian tubes. There are many reasons for this, often genetic or relating to proteins and enzymes. Peno-scrotal hypospadias is quite rare, but it is part of the hypospadias family, which is actually relatively common, occurring in one in 300 male births.

Babies are born chromosomally XX though have both ovarian and testicular tissue; for example, one ovary and one testicle. Their genitals may appear female, male or a mixture of both. It is not clear why this occurs though some cases show that genetic material usually found on the Y chromosome is found on the X chromosome.

Babies are born with a Y chromosome but are insensitive to or unable to produce androgens, resulting in female sex development. The most common condition here is androgen insensitivity syndrome (AIS).

WHERE CONFUSION CAN ARISE

Intersex or DSD can be confused or conflated with sexual identity, gender identity and transgender issues. This is categorically wrong – difference in sex development is exclusively a physical matter about biological sexual characteristics and nothing at all to do with sexual or gender identity.

It is important to make this clear – there is as varied a range of gender and sexual identities within the DSD population as with the

non-DSD population. It is highly offensive to those with DSD to associate their anatomical difference with identity issues.

Medical intervention

There may be implicit medical concerns arising from being intersex that need treatment (such as the adrenal problems associated with CAH), but this is not to say that being born with different sex development per se implies or requires medical intervention.

In the past, often genital surgery would be on offer to 'align the genitals with the chromosomal appearance'. This is a hotly debated issue. Surgery should always be decided on an individual basis – what is the right choice for one is not for another.

The main problems for families are generally not of a medical nature but are related to a need for knowledge and understanding:

- how and why their babies developed this way
- what it means for the baby's and child's future development
- how to raise a resilient and confident child
- how to talk to them.

Often it is early intervention psychological support that is required, not medical.

The terms intersex and DSD are not applicable to individuals who have intentionally altered their own anatomical characteristics.

Case study

In the *Beyond Today* broadcast, Megan Mohan, the BBC's global gender and identity correspondent, met six-year-old Rosie who was born with CAH. This adrenal kidney condition means Rosie's clitoris is enlarged and looks like a penis. Rosie's parents chose to bring her up as a girl because she is genetically female (she has XX chromosomes).

Rosie's parents made the decision to raise her openly as what Mohan, using Rosie's family's preferred terminology, refers to as 'intersex-bodied'. Later in life, Rosie can choose what gender she would like to be. Though often mistaken for being a boy, Rosie seems to be able to handle it very well.

Mohan says, 'She is raised in a family that has allowed her to embrace who she is, and this acceptance seems to enable Rosie to weather tricky moments.



Early psychological support is often required more than medical intervention

Embracing and accepting DSD, however the family choose to do this, seem key if ignorance and stigmatisation are going to be challenged effectively. This does not mean that all families should be like Rosie's and want to speak out about their child's difference – many families see their child's body as private to them. As with most aspects of child-rearing, finding the right support for the child is a unique process for which there is no right or single way.

IMPLICATIONS FOR EARLY YEARS PRACTICE

There are three main underlying principles to guide our work in the early years:

- Offering reassurance.
- Reducing anxiety.
- Promoting openness.

Put DSD on the agenda

Families of children with different sex development are often isolated because genital development is rarely discussed. In contrast to this, other parts of the child's body and their development are discussed pretty feely without any of the awkwardness experienced when describing the sexual organs. Perhaps an initial and helpful step could be to establish a vocabulary that would make this more straightforward and matter of fact.

Many young girls, for instance, never use the word 'vagina', and

often don't even have a euphemism for it – this whole area of the girl's anatomy is known as her 'bottom'. Similarly, 'penis' is not a common word of reference for young boys, though there is an array of euphemisms used from the start of their lives – it is not incorporated into 'bottom', so at least they know they have one!

Early childhood is a time when children are exploring aspects of their bodies and appearances, and they tend to be quite open to this. It would help if adults supported children in asking questions and saying their opinions, rather than making the whole thing seem off-limits. This is an approach that could support settings and children in dealing with all sorts of sensitive matters about appearance and identity, as well as this one.

Another tricky aspect can be finding a forum in which to speak – where is a good place to bring up these delicate, clandestine conversations? Other areas of child development can be heard spoken about loquaciously in many social groupings – cafés, when dropping the children off, in the street. This is not the case, however, with the sexual anatomy, both among children and adults – it is as if it is not part of everyday life.

Settings need to do whatever it takes to recognise that DSD exists and must not be hidden or ignored. Currently, the terms DSD or intersex

do not jump out of a setting's documentation. This will not be helpful to families who are already isolated and possibly feeling shame or embarrassment. They may, however, be helped and encouraged knowing that if their child has a DSD, it is just one of many diversity or special needs issues the setting is aware of and is keen to support the child and their family.

Ellie Magritte, a trustee at the advice and support group dsdfamilies, makes clear the importance of peer support. 'As a charity', she explains, 'one of our main objectives for the next years is to ensure all families and children have access to peer support – the opportunity of meeting with other children with similar needs and developmental challenges. It is really important that we help a family feel comfortable about different sex development and help them talk about it with their child, with other families, and with good friends.'

Offer support and build a strong key person relationship

Lisa, a parent from dsdfamilies and also an early years practitioner, thinks the key person role is critical in providing the kind of support that the child and their family want and need.

'It is so important that the child's key person has a positive relationship both with the child and with the parents/carers should they wish to discuss anything about DSD,' she says. 'I feel there is no need to sugarcoat anything. At the end of the day, these children are no different from any other child within that setting.'

Her experiences with her own son in nursery have been positive. 'In my experience with my son, he hit every milestone, followed the EYFS development stages perfectly



→ **SUPPORT GROUPS**
These groups can offer information, advice and support to children and their families, adults and practitioners. They can also link up people living with DSD:

- dsdfamilies, www.dsdfamilies.org
- MRKH UK, www.mrkh.org.uk
- Congenital Adrenal Hyperplasia Support Group, www.livingwithcah.com
- NHS website, www.nhs.uk/conditions/disorders-sex-development

While some families are keen to discuss the matter publicly, others will want to keep it private

and is now one of the highest academic achievers in the school,' she explains. 'This doesn't mean it hasn't been difficult at times, and families do need a lot more support in helping their kids grow up healthy and happy. I want my son to have that support too.'

'I think a practitioner should support the wishes of the family when any special requests are made, just as they would make special arrangements re allergies, and so on. The parents may, for example, wish to toilet-train their child differently, as we did with my son – a child may need to be cleaned differently when having a nappy change.'

Respect the child's and family's privacy

Sometimes parents might be concerned about the privacy of their child. All early years settings will have a confidentiality policy and under no circumstances should any practitioners discuss a child with anyone outside of the setting.

Contact support groups

Finally, with DSD being a marginalised and, some might say, maligned subject, it is not surprising that many settings do not have anything in place for DSD families. What is problematic, however, is if nothing is done about it. The aim of this article is to give enough information and guidance in order to prompt settings to make a start to getting this aspect of development on the early years agenda. This is essential if we are to offer all children equality of opportunity.

Accepting differences of sex development and being open to the child is key. However, in common with other minority issues, it is a delicate one. We must be careful not to use children when attempting to raise awareness of DSD, along with the implicit ignorance and stigmatisation. Raising awareness has to respect the fact that some children and families will choose to remain private, others will not.

I'll end with Ms Magritte's words of inspiration and encouragement: 'If you're feeling a bit lonely and isolated, knowing someone is there keeping an eye out for your precious little one is priceless.'

Surely, it is this quality of support that we must aspire to and aim for in our early years practice? ■