

Difference of sex development: parent information

What Information does this factsheet cover?

Babies and children will sometimes have male or female sex organs which develop differently. This is sometimes called 'intersex variation'.

The factsheet contains general information about intersex variation. Please talk to your doctor or other health professionals for individual advice on your child.

What is DSD?

Differences of Sex Development (DSD), formerly also known as Disorders of Sex Development, describes a wide range of conditions which a child may present with from birth. The internal or external features of male or female sex development may be different from what's usually expected. These conditions are most often diagnosed at birth or at puberty (for endocrinology). Some may never be diagnosed.

These conditions may be:

- genetically female with some male features
- genetically male with some female features
- a mix of male and female features often associated with gene disorders, including genitalia which is not clearly male or female.

Genitals may appear different due to a range of factors. Genetic factors may influence their appearance. Genitals may develop differently in utero. In some cases, general health may also be affected.

Between 0.5 and 1 % of babies are born with genitals that look different in some way. In the NT, this means up to 30 babies each year. Children who have these types of conditions usually grow up to be happy, healthy, and live normal lives. They may or may not need any medical treatment.

What are the next steps and treatment options?

If a baby's gender is not clear when they are born it can be unsettling and stressful for parents and families. Families need a specialised and experienced health team to work with them to accurately diagnose the condition. Medical treatment may need to start straight away, or there may not be a medical problem at all.

To help make a diagnosis, as parents you may be asked information about your family's history and the pregnancy. Blood tests may be helpful. Doctors may look at the structure of genitalia and do an ultrasound to look at internal structures. The team of health professionals will work with parents to determine the sex of the baby if necessary.

Is surgical treatment necessary?

In some conditions, surgery may be considered to avoid risks to the child, such as not having a free-flowing urinary opening. This will be discussed in depth with parents.

In the vast majority of cases, babies and children do not need any surgery or medical treatment. If they do need it, treatment often can wait until they are of an age where the young person is able to make their own choice, with the help of good health information.

Sharing baby news and raising your child

Diversity is natural and variations in body parts are normal. Openness and honesty are the best way to share information both with your child and others. When announcing your baby to family and friends, you may choose not to refer to the sex of the baby or the diagnosis until you are ready. You may prefer to wait until the health team has had time to investigate and decide with you on the best way forward. One option is to announce a healthy baby arrival and use a nickname until the sex of your baby is determined.

You can choose a gender-neutral name – used for both boys and girls. You don't have to rush to register the birth. You have 60 days to register a birth and name your baby. In the Northern Territory there is an option for gender to be unspecified on birth certificates, which can be changed in the future. You choose what information to share with relatives and other people.

As your child grows up, teaching them in a 'matter-of-fact' way, free of shame, about 'girl parts' and 'boy parts' and the differences they may have, is important. The information that you will discuss with them will change over time as they grow. Your health team will support you in how and when to do this.

Other information and support

- [Intersex Human Rights Australia \(IHRA\)](#)
- [DSD Families \(UK\)](#)
- [The Gender Centre \(NSW\)](#)
- [Gender help for Parents Australia](#)

References

- [Monash Children's Hospital 'Information Sheet: Disorders of sexual development'](#)
- Organisation Intersex International Australia (OII Australia) 2014 'Your beautiful Child: Information for parents of intersex kids'
- [Society for Endocrinology Patient factsheet: UK guidance on disorders of sex development in children](#)
- [Victorian Government 'Parents Factsheet Ambiguous genitalia in neonates'](#)