



Has your child been diagnosed with a variation of sex characteristic?

The information and recommendations provided in this eBrief are based on findings of the research projects developed in the framework of the INIA: Intersex – New Interdisciplinary Approaches Innovative Training Network.

You may be feeling:

- Isolated, lost, or anxious.
- Worried about the future of your child.
- You may be taken care of by a medical team that suggests surgeries or hormonal treatments, and you may be unsure about what decision to take.
- You may need more information.

Will my child be ok?

- Understanding, family and peer support will help your child not to feel isolated.
- Medical treatments can be a source of distress for your child in the long term. Often, they have a negative impact on their mental and physical health.
- Bullying is often presented as a major risk for your child, but keep in mind that society is changing.
- There is nothing shameful about having an intersex variation. Intersex people have always existed, it is part of natural human bodily variation.
- Since the 1990s, there is increasing work to ensure the human rights of intersex people.
- The visibility and acceptance of intersex variations have improved across the world.

Basic Information:

According to the United Nations background note *'Human Rights Violations Against Intersex People'* up to 1.7 % of the population has an intersex variation. This means they have a body that does not conform to traditional understandings of male and female bodies.

People with intersex variations may be subjected to medical interventions, which can be experienced as traumatic.

Language in this space is very contested. Within medical circles, intersex variations have many diagnostic labels but are collectively known as *'Disorders of Sex Development (DSD)'* or *'differences of sex development (dsd).'* Some people prefer to use terms like *'intersex'*. In this brief, we use the term *'intersex variations'* to be inclusive of all perspectives.

Are all medical interventions necessary?

- Intersex variations, also called variations of sex characteristics, disorders of sex development (DSD) or differences of sex development (dsd), can be discovered at any age, sometimes before birth, sometimes at birth, and sometimes at a later point.
- Intersex variations encompass more than 40 different types of variations. Only few of them require some care, e.g. mineralocorticoids in the case of CAH with salt wasting, or if the child cannot urinate.
- Most variations do not need medical intervention. So, there is no urgency and you can wait.
- International and European bodies have taken a stand against these treatments and surgeries. Also, several European countries (Germany, Iceland, Malta, Portugal, and Spain) have prohibited surgeries on children with intersex variations where they themselves cannot consent to it.
- Once you operate, there is no coming back. You and your child might regret medical interventions in the future, and you may prefer to wait until your child can decide.
- It may help you to seek information from people who have been subjected to these types of treatments. In almost every country in Europe, there are intersex groups that offer support for parents of children with an intersex variation.
- You have the right to ask for more information and to say no to medical professionals.

Things you could do:

- Look for diverse sources of information. For instance, you can visit: <https://www.intersexnew.co.uk/>.
- Reach out to intersex organisations and peer-support groups.
 - Talk openly to your child about their body and variation to help them generate a positive body image, if they are old enough to understand.
 - If you want, talk about your concerns and worries with trusted family members or other people, as it is neither harmful nor shameful.
 - It is good to talk with your other children, if you have any, about the intersex variation of your child.
 - Look for books and other resources to learn more about intersex variations and how to discuss this topic with your child.

About the INIA project:

The INIA Innovative Training Network is supported by a grant from the European Commission's Marie Skłodowska -Curie Actions program project number 859869.

For more information, please check

<https://www.intersexnew.co.uk/>

*We acknowledge that there are differences of opinion amongst INIA Consortium members and more widely amongst people with intersex variations.

**This brief reflects only the views of the authors, and the agency is not responsible for any use that may be made of the information it contains.

2023