



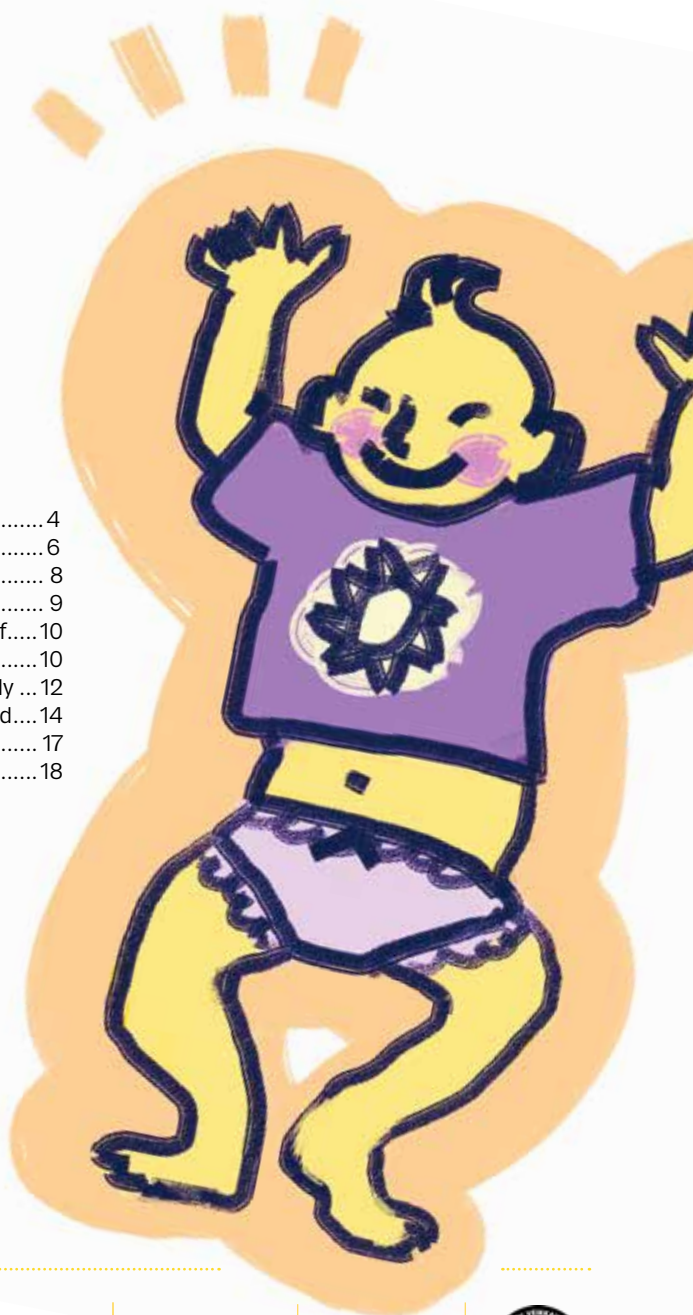
GUIDE

for families and relatives

of an intersex child

SISÄLLYS

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GUIDE

for families and relatives of an intersex child

This guide is meant for families with an intersex child. The guide discusses matters that most likely affect all parents and educators. How to support a child's feeling of safety, a positive image of themselves and their body, give them the peace to grow and help them set their own boundaries? In addition, this guide includes basic information about having an intersex body and raises themes that may affect families of intersex children, in particular. How can a parent or an educator support the child in receiving information about their intersex body, how to discuss with your child and from where can you look for information and support for yourself and your child?

The abovementioned themes have been raised when we have talked with parents of intersex children. And we have also experienced that the parents and families of intersex children need more support than currently is available. As having an intersex body is becoming a more common subject in society, discussing it and finding information and support will probably become easier, too. Most probably, also children and adolescents will ask more questions.

The guide also offers examples of how you can talk about different themes with a child. The purpose of this guide is to support both you as a parent or educator and the intersex child.

*Best regards, Jaana Pirskanen and Juha Kilpiä
Tukea intersukupuolisille, keinoja ammattilaisille
("Support for intersex people, methods for professionals") project*

*"An intersex body is valuable,
lovely, natural, ordinary,
beautiful, cool!"*

– Intersukupuolisuus.fi-network



Intersex

The concept of intersex refers to bodily diversity that includes different bodily variations in which chromosomes, genitalia, hormones or other gendered bodily characteristics are not exclusively male or female-typical. Being intersex makes it visible that humans cannot be biologically classified into two exclusive sexes.

Currently, at most approximately forty different diagnoses are connected with being intersex. The most common diagnoses according to the most extensive definition include congenital adrenal hyperplasia (CAH), complete androgen insensitivity syndrome/androgen insensitivity syndrome (CAIS/AIS), Klinefelter syndrome, Turner syndrome, Müllerian agenesis and 5 α -Reductase deficiency. There are several different sex chromosome combinations, including 45,X and 47,XXY. Sex chromosomes can resemble a mosaic: one might have the chromosomes 46,XX in some cells and the chromosomes 46,XY in others. There are also plenty of other options. For an individual, being intersex

intersects life in many different ways. This is something diagnoses can never reach.

Depending on the definition, 0.02–1.7% of humans are intersex. Many live their entire lives without knowing that they are intersex. Some people find out that they are intersex in their youth if their period doesn't start or as an adult if having children proves to be difficult, for instance. Only a small fraction of intersex people are diagnosed right after birth. This is one reason that affects the estimates on how common being intersex is.

When an intersex child is born, a doctor defines the child to be one of the two legal sexes. However, gender can never be unequivocally determined based on bodily characteristics. The majority of children express their gender and determine it to be the same sex as assigned at birth. Some children identify with some gender other than the one assigned at birth. You can only know a child's gender when they tell you themselves. Being intersex cannot lead to conclusions about the gender identity a person will develop.

Your child is unique

Being intersex is part of bodily diversity that is part of natural individual variations. Some intersex variations may include situations requiring medical care, but in themselves, being intersex or the unique characteristics of a child's body are not a disease or disorder. An intersex child is unique and good as they are.

The child doesn't need cosmetic surgery or other treatments in order to be registered as male or female. Many intersex people have stated that cosmetic genital surgery and hormone treatments may be traumatising and harmful for children. Organisations promoting the rights of intersex people, such as the Organization Intersex International (OII), recommend that the child's bodily integrity be honoured. This means refraining from cosmetic genital surgery and hormone

treatments until the child is old enough to make their own decisions. It's good to discuss what being intersex means with the child and tell that their body is unique and good. For a parent, it's good to know that your child being intersex doesn't mean that you are in a hurry to make decisions for your child. If the child has, for instance, salt-wasting congenital adrenal hyperplasia or a closed urethra, which means that urea cannot leave the body, they need urgent care. As opposed to that, cosmetic genital surgery or taking hormones aligning the child's body with a specific gender are not urgent or necessary for the child's health. A parent should take their time and gather information from organisations promoting the rights of intersex people and the health care and talk with intersex people and their families, for instance.





A safe and loving environment

Every child wants to feel loved in the eyes of the parent. Every child needs to be seen and heard by their parent and for the parent to be interested in who the child is. All children also need space to become their own persons. However, a child also needs a parent to verbalise the world, other people and themselves. By being present in everyday life, talking and setting an example, the parent helps the child to construct an understanding of the world as a safe place where actions can be anticipated as well as an understanding of themselves as a good and capable being. The peace to grow also means that children can be children without responsibilities that are too great for them to bear. It's good for the parent to express to the child that everything is all right and that the parent is the one who has the responsibility for running daily life and errands, finding information and transmitting it to the child.

“It’s important that you can say to the child that I don’t know but I know how to find out so you will not be left alone with this. This is extremely important in the matter of being intersex.”

–Intersukupuolisuus.fi -network



Talk with your child

It's important to talk to your child honestly and in an age-appropriate manner about things that affect them. The child has the right to know important things about themselves and their own medical history. The child selects the topics; the adult selects the way in which they are discussed. Staying silent may cause feelings of confusion and shame.

“My life and story about being intersex is about keeping it a secret. It has been from the beginning and, in some way, I’m still acting it out continuously. It can’t be seen by looking at me but it’s there, somewhere, as a topic that might be good to talk about in certain situations but I don’t talk about it.” – K

“Above all, not having information is the worst. If I had had information about why certain things happen, it would have helped me create some sort of a cohesive experience of knowing what is going on. Everything happening in secret is a bad thing.” – T

The child can be afraid that they are left alone if they express things that concern them to their parents. By discussing different things in life and actively giving the child space and opportunities to talk, the adult communicates that talking about things that feel difficult, too, is allowed.

Own words about your own body

This child's experience of themselves and their gender may change and be different at different times. This applies to all people. It's good if the child has the space to verbalise themselves, their gender and experiences and also use playing to try out different roles and names.

Giving the child the peace to grow is also about giving space for the child's experiences and self-determination.

A key thing is that our experience of ourselves may change over time. We don't have to have definitive answers or know exactly who we are. The child can define themselves and decide the words they want to use about themselves. The child can find their own gender identity. A parent cannot modify the child's gender by raising them in a certain way. Many intersex people identify as men or women as adults. However, for some, being intersex, non-binary or trans is an important part of their identity.

"I want for the child to know that we have never thought that there is anything wrong with them."

–Anneli, parent of a nursery-aged child



For more information, please check: Seta's website

Names for body parts


It's important for the child to have words for different body parts. It's important to know that talking about different body parts is allowed and nothing to be ashamed of. Sometimes children come up with their own funny words to describe their bodies. It's good for the child to get experiences of all bodies existing and being equally good.







Positive talk about the child's body



The adult can tell the child that all humans have unique bodies and that the child's body is beautiful, capable, strong, and healthy. The adult can also talk about all the miraculous things the child's body can do, such as heal itself, fall asleep, wake up and grow. It's also important for the child to be seen by the adult in an admiring and loving way.

The adult can prepare the child for the changes puberty will bring and tell how their development might be. If the child is concerned about developing at a different time than others or about the special characteristics of their body, the adult can support them. The child or adolescent can decide upon the treatments that affect the shape of

their body. Female or male-typical characteristics or androgyny may be reinforced through medical methods in puberty or adulthood, respecting the pace of the child or adolescent, if the child so wishes.

For instance, if a girl doesn't have a vagina, she can decide if she wants one and if she wants to have the procedure in adolescence or adulthood. Turning to multidisciplinary support may be a good idea, for instance, a sexual therapist could be the right person to talk about the wishes and concerns of an adolescent when it comes to sexuality and treatment options. Professional support can also provide a counter-balance for social peer pressure and comparing to peers.





The right to stand up for your child

The parent of an intersex child may face situations in which health care, educational or teaching professionals don't have sufficient information about being intersex or their perspective is very different from the perspective of the parents of an intersex child. The parent may have to supervise the child's interests and negotiate for the best interest of the child in a daycare centre, school or health care.

“I’ve noticed that I have a high threshold for taking the child to the health care centre if the situation requires showing genitals because I cannot trust that the doctor or nurse knows what being intersex means. I don’t want that my child has to hear people talk about being intersex in ways I don’t want to process it.”

—Anneli, parent of a nursery-aged child

In a health care context, the parent should...

1 Tell the child that their body is being inspected because it is different in some ways and that's why it must be treated. Being inspected doesn't mean that the child is damaged or somehow wrong.

2 Before the treatment, find out what happens in the situation and go through this with the child in an age-appropriate way. It's good if the child can ask questions and talk about their concerns and how everything feels. This way, you can also look for ways to make the situation safe for the child together.

3 Think what to do in case the child isn't respected and their boundaries are broken: how to intervene in the situation, how to leave the situation, how to say to express to the child that the situation wasn't in any way caused by them.

4 Finally, help the child to debrief the situation, for instance, by talking, playing or drawing. It's important for the child to have the space to verbalise their experience.

– *rephrasing from Intersukupolisuus.fi network*

Every child needs a parent who will support and stand up for them. It's possible that the child is not seen as who they are. Standing up for the child means demanding sensitive encounters and verbalising things for the child.



You can tell the child that an adult's cup of worries is greater than the cup of a child. All of the child's worries can easily fit into the adult's cup of worries. If necessary, the adult can pour some worries from their cup into some other adult's cup.

Support for the parent

The parent processing their emotions benefits the child because, this way, the parent can better support the child. It's ok to be confused and look for information as an adult. When finding and learning new things, the parent's own world view might change. Parents need space for their own exploration. Carrying the thing alone can be hard. For many, it's good to have someone with whom they can share the experiences of parenthood.

Parents can talk about how they feel. Fear and confusion are normal feelings, as are joy and relief.

Sources of information

- www.seta.fi
- www.intersukupuolisuus.fi (in Finnish)
- OII Europe: www.oiiurope.org/
- Supporting your intersex child guide: www.iglyo.com/wp-content/uploads/2018/10/Supporting-Your-Intersex-Child.pdf

Where to look for support?

- *Gender Diversity & Intersex Centre of Expertise*: www.seta.fi
- Perhesuhdekeskus (Centre for LGBTI family relations): www.perhesuhdekeskus.fi
- Child guidance and family counselling centres

“I’m thinking about if our child will have space to grow and be who they are. Do they have to fit a mould? Can they be openly intersex and a manly man, if that is what they are? Our child being intersex isn’t really visible in our everyday life in any way. Except that it affects everything because now we live a normal life. If we had done what the doctors suggested, our child would be in and out of surgery, again and again. Now we don’t have to be afraid. Everything is principally good. Our child is not defective, but healthy.”

–Anneli, parent of a nursery-aged child

Exercises



How to support a child in setting their boundaries?

You can model positive speech to the child by talking in a respectful and beautiful manner to the child about your own body, the child's body and the bodies of others. You can also talk with the child about the private parts in the body that you don't have to show anyone if you don't feel like it. It's good to tell the child that they can trust their own feeling of what feels good. For instance, what kind of a touch feels nice and who can touch them. You can also tell the child that they can get to know their own body and be happy about their own touch.

NAMING BODY PARTS

Information the child needs

- Tell the child about all different parts of the human body.
- Teach the child the words used to describe different body parts.
- Together with the child, get to know the human body in different ways: look at photos, draw and play.
- The child knows that all body parts can be talked about with adults and other children.

Competences the child needs

- The child knows how to talk about their body.
- The child knows how to use suitable and appropriate names for body parts.





The child's attitude towards their body

- All parts of the human body are equally good.
- It's important to respect and take care of your body.
- All bodies are equally important.
- It's good to have different kinds of bodies.

Drawing, painting or taking a photograph of yourself can strengthen a positive body image.

Identifying and verbalising emotions

- Where in the body do you feel joy? Where in the body do you feel sadness?

For more information, check the website of Mental Health Finland, emotional map.

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