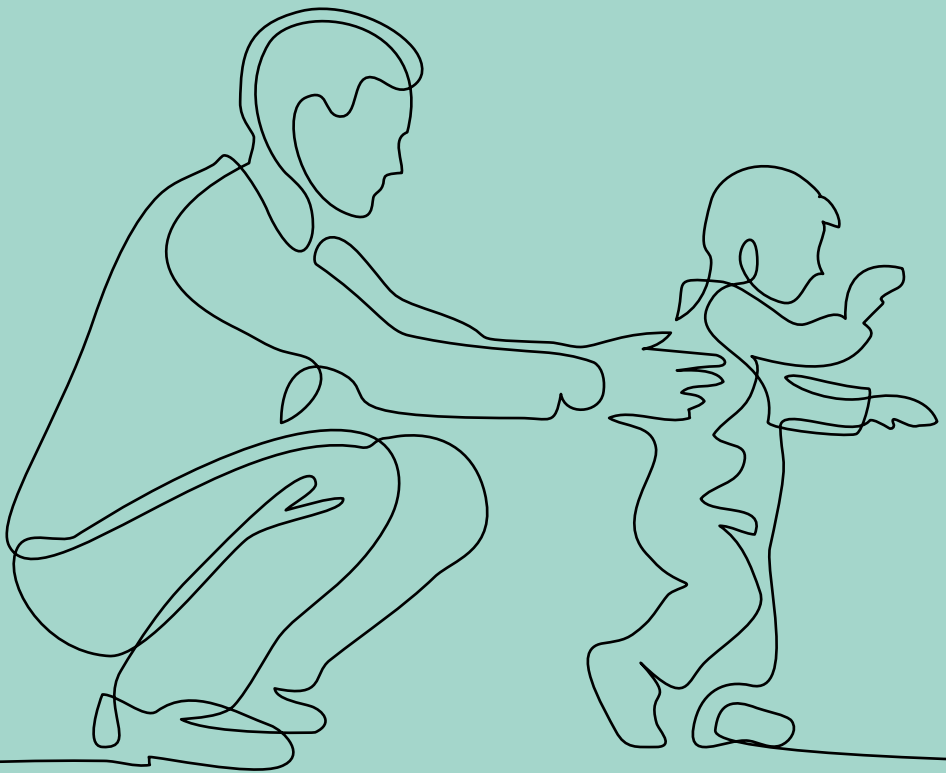


Supporting your intersex child

Created by IGLYO, OII Europe & EPA





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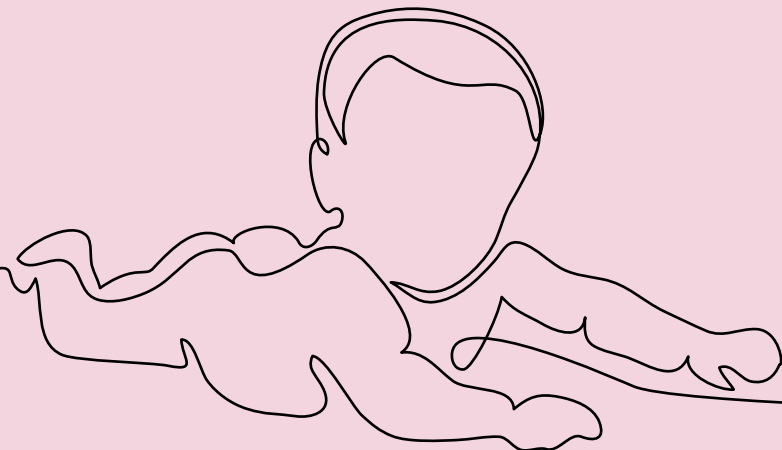
Introduction

What is intersex?

Is it a boy or a girl? This is the question that is asked the world over when someone gives birth. Many parents will answer that question without much thought. But for a significant number the answer will be more complex.

Intersex is an umbrella term used to describe a wide range of natural bodily variations. Intersex individuals are born with sex characteristics (*for definitions, see Glossary, P30*) that are either female and male at the same time, not quite female nor male, or neither female nor male. Intersex people's sex characteristics and bodies are healthy variations of the human sexes.

For some intersex people, their intersex body becomes visible at birth, for some during childhood and with others their body shows itself to be intersex during adolescence or even adulthood. For some, the differences will be so small they may never realise they are intersex at all.



There are many ways in which variations of sex characteristics can appear. A child may be born with a larger clitoris or smaller or differently shaped penis. Sometimes a child is born looking typically female, but is discovered to have internal testes, and sometimes a typically male looking child is found to have a uterus or ovaries. In some cases, a girl will not start to menstruate or a boy will start to menstruate. Other children may have a hormonal setup that is different than what is expected for a "girl" or a "boy".

These kinds of variations are natural and more common than you might think. It is estimated that at least 1 in 200 people are intersex and some sources state that up to 1.7% of people have some variation in their sex characteristics.

Sex characteristics can be divided into primary sex characteristics and secondary sex characteristics.

Primary sex characteristics are all the characteristics that are present at birth. These include the person's chromosomes, genitals, reproductive systems, gonads and hormone sensitivity and production.

Secondary sex characteristics are all the sex characteristics that become visible during puberty and include breast growth, hair growth, menstruation, Adams apple, stature, muscle mass and fat distribution.

This guide has been created by IGLYO, OII Europe and EPA. It aims to introduce the topic, give advice on how to best support your intersex child, and where to get further information. In the following text, we will use 'they' (rather than he or she) as the neutral pronoun for everybody, fully acknowledging that a diversity of genders exists.

Advice for Parents

Finding out that your child is intersex may come as a surprise to you. You may feel and think many things as a result of the news.

You might simply feel utter joy that your child is born or you may start worrying about your child's or adolescent's wellbeing. You may be told that your child is not healthy. As with male and female children and adolescents, intersex children and adolescents may face health issues, but this does not define who they are. They are, first of all, your child, who will need your love and attention, will laugh with you and make you angry sometimes. When they grow older they will make their own choices in life as who they are: another proof of nature's diversity.

Here are some tips to help process the information and prepare you to provide the support your child, like any other child, will need.

There is nothing wrong with your child

For the vast majority of intersex people, there is nothing physically wrong with them and there is no need for any medical interventions. If your doctor tells you that medical treatment is necessary, ask about the health implications and risks both of carrying it out and of doing nothing. Then take time to make an informed decision. Always get a second opinion and carry out your own research.



It's not your fault

When parents find out there is something different about their child, one of the first thoughts is often, *'Did I do something wrong?'* or *'Could I have prevented this?'* Having an intersex child is completely natural and is not the result of anything you have done. There is nothing to feel ashamed of.

It's ok to feel confused or upset

When we have certain expectations, especially around something as major as having a baby, it is understandable that we experience many different emotions when something unexpected happens. Finding out your child is intersex might make you feel scared, angry, upset, worried, ashamed, guilty or a mixture of some or all of the above. Many of these feelings are caused by the unknown and will lessen as you learn more about intersex and talk to others about it. Try not to suppress feelings, even if they are challenging. Find people you can talk to and can provide you with the support you need. Ask the hospital or your medical practitioner about the options to get psychological support. Reach out to organisations to get more information and advice. Speak with family or friends, if possible. You need to look after yourself, otherwise you won't be in a good position to look after your child.

You are not alone

It's easy to feel like you are the only person in the world going through this and that no-one else will understand. The truth is there are an increasing number of intersex organisations that can provide information, signpost to support groups (physical and online), connect you with intersex peer councillors and connect you with other parents of intersex children. Talking to other people who have intersex children can provide you with information, advice and support. Talking to others is an important step in 'coming out' as an intersex parent. Don't feel it's a secret you need to keep, as this is not good for you or your child. If you live in a country where you feel coming out would not be safe for you and your child we encourage you to connect with OII Europe, who can help you to find parents who are in a similar situation with whom you can talk.

You don't need to know all the answers

Over time, as you tell your child and others around you, you will be faced with a lot of questions. This can be overwhelming and create a sense of having to become an expert in the subject overnight. It's ok not to know all the answers straight away. At the same time don't shy away from the subject. The more you learn about it and discuss it with others, the better placed you'll be to support your child when they start asking questions too.

Common Questions

How will I find out if my child is intersex?

You might find out when your child is born, during puberty, or during adolescence. There are different ways to find out, depending on the specific variation. Sometimes a child is visibly intersex from birth. This however is not always the case and your child may well be discovered to be intersex after birth or later in life through various means, including:

- Blood tests shortly after birth
- Routine medical examinations such as sonograms on your child's abdomen
- Routine operations in childhood such as hernia repair and appendectomy
- Puberty may be different than for the child's peers.
- Occasionally a parent will know as early as pregnancy due to pre-natal screening
- People find out they are intersex at all ages

My child is intersex. What now?

Variations occur everywhere in nature. Being intersex is one of them and it is nothing to be afraid of. One of the most important things is to be open with your child (in an age appropriate manner) and to listen to what your child tells you about their needs. There will be some challenges on the way, of course. One will be that most people still don't know a lot about the existence of intersex people, so you might need to find ways to introduce the subject and educate people on the specific needs and situation of your child. For example, to support/advise school staff in preventing your child from being teased at nursery or school.



Parents who are open about their child being intersex report that, most often, the people they tell are interested to learn more and willing to support the child. As parents, you basically set the tone for how others will treat your child. For you (and your partner), it may take some time to get used to the idea and to learn what having an intersex child means. Give yourself this time. In the process, you might be asked to take some difficult decisions, such as being asked to give consent to irreversible surgeries or other medical procedures, but remember that unless your child needs medical attention as a matter of urgency (which is rarely the case), you should get advice from more than one source and take time before reaching any definite course of action.

Do I need to consent to surgery before registering my child as male or female?

Before, when, or after you register the sex of your child, you might be advised by medical professionals, family or friends to consent to medical treatment that changes your child's body towards a more female or male appearance. These 'normalising' surgeries, however, can be highly traumatic for those involved and often lead to ongoing medical problems throughout their lives. Some common arguments in support of such interventions include:

- Not operating will increase the risk of cancer
- It is better to operate on the child at a very early age, so that the child will not remember the interventions
- Early intervention is less risky/more successful
- Interventions will reduce social pressures and help the child 'fit in' better

Before you consent to any surgeries or medical interventions, it is important to know that no scientific evidence to support these arguments currently exist. This means that no one has carried out research to prove that such surgeries have had a positive impact on the children and young people who have undergone them compared to intersex people who did not.

Ask yourself: would you have wanted your parents to make a decision in regard to your body that is irreversible, that could have been deferred and that you might not be happy with as an adult, or would you rather they waited to seek help and allow you to grow up and take your time to understand how you feel about your body?

My new born is intersex. What is likely to happen at the hospital?

If your child is discovered to be intersex at birth, your post-delivery experience is likely to be different than most parents:

- Your child may possibly be removed from you immediately or shortly after birth for varying lengths of time. Always ask where your child is being taken, why they are being removed, and when they will be returned to you. Ask to go with them if possible.
- Instead of routine check-ups by doctors, and interactions with nurses or midwives, you will likely meet some specialists. These can include for example a paediatric endocrinologist, a paediatric surgeon or other specialists. You may meet them one at a time, or you may meet them as a group. There will likely also be nurses and other hospital staff present.
- It is likely that you will either receive a lot of new information that is hard to understand or receive requests for allowing your child to have various tests. Much of the information you receive will be in complex medical language. If there is anything you don't understand, ask for clearer explanations and ask if any tests are necessary before consenting.
- The medical team at your hospital may suggest a variety of medical treatments, surgical and other means. These include gonadectomies (the removal of ovarian or testicular tissue) and various genital surgeries. Postpone all surgeries that are not life-saving and seek secondary advice.



There are many experimental treatments taking place at different hospitals. Some of these have already been found to have worrying long-term side effects on mental health and cognition. These include pre-natal drug administration as well as hormone manipulation of young children through hormone treatments administered via injections or gels.

- If your baby has for some reason been removed from you ask that they be returned immediately.
- Ask for any testing to take place in your presence and ask about the reasons for the tests before giving consent. (If, for some reason, a blood test is needed, it will be much easier for your baby for this to take place with you present, ready to soothe them).
- If possible, call a loved one or a trusted person and ask them to join you. This is a strenuous time for all new parents and you will have more to keep track of than most. Having someone to help by taking notes and giving a helping hand can be very beneficial. Ask if discussions can be postponed until this person arrives.
- Write down or record as much information as you can. Recording your conversations means you don't have to worry so much about taking notes and most phones today come with built-in voice recorders or have applications you can download. In the case you are alone after the birth of your child, recordings can provide a valuable alternative to a second person when later recalling information.
- Ask questions, ask for explanations, and ask for clarifications. Take your time. You cannot make decisions without understanding. It sometimes takes us a longer time to grasp new concepts and terminology and you have an absolute right to understand what is going on.
- Ask about when you can go home. A home environment is a much better environment than a hospital ward for bonding with your new-born. In most cases, you should be able to go home in a similar time frame as other parents. If for some reason, this is not the case, ask why. If the reason is that they are waiting for test results to come in, then ask if you can still go home and come in for a visit when they come in. Press for an answer as to why you cannot go home.

Doctors are pushing me to make a very fast decision.

What should we do?

Immediately after birth you (and your partner) are likely to be filled with conflicting emotions. Furthermore, childbirth itself causes significant changes in hormone levels, affecting how we feel. These two factors alone mean it's not an ideal time to be taking big decisions, let alone decisions that can greatly affect your child's future. In some cases, however, doctors will offer immediate treatment or surgery. Occasionally there is a need for immediate treatment, these will be discussed further in the next chapter. While some medical treatments are necessary for your child to maintain health (*See Making decisions in relation to medical interventions p14*), the majority of treatments cannot be rationalised solely based on medical need but are rather based on social and cosmetic factors. These include surgeries to change the appearance of your child's outer genitals because they do not look like most people's genitals, or so your child can perform a gendered social function, like standing up to urinate if they have been assigned male. These also include surgeries to create vaginas in infants assigned female so that they can fulfil certain social roles. These are elective treatments and your child has a right to choose these for themselves when they are old enough to make that decision. In the meantime, seek support and reach out to intersex organisations, as they may be able to connect you with other parents that have similar experiences. Remember, your child is an autonomous being relying on you for protection, support and most of all love. Shower your child with affection and enjoy getting to know them.

I hear different opinions about what I should do with my child.

How do I know what's best?

Every situation is different. You always need to put the wellbeing and the health of your child first. Also, don't forget the wellbeing of yourself and your family. Talk with experienced people, including intersex adults, and explore options. Be critical of advice which focusses only on changing your child physically. Don't let people push you into a quick decision. Most decisions can be deferred until your child is mature enough to be included in the decision making processes. Take time to research, reach out to intersex advocates for support and concentrate on getting to know your beautiful new child.

Wouldn't it be easier for everyone to operate while my child is still a baby?

Whilst having surgery or other medical procedures when your child is still a baby might be presented to you as the best option, it's important to know what the longer-term consequences could be. First, it's important to be aware that any full anaesthetic surgery is a life-threatening action. Especially, but not limited to, surgeries that are performed on infants and young children. Second, there is the possibility that your perfectly healthy intersex child will lose the functionality of the operated body part, such as their urethra during a non-life saving normalising surgery. No long-term studies exist yet on the actual preservation of everyday and future erotic function of genitals that have been operated on at an early age. To the contrary, many intersex people that have been subjected to surgeries in childhood have reported numbness and pain (due to scar-tissue) and a lack of or limited erotic sensation as adults. Third, medical interventions often lead to further interventions being necessary and sometimes result in lifelong dependency on doctors. Furthermore, psychological research has shown that the pain memory is already developed in infants, and intersex people who were operated on as babies often report that they felt that something had been done to them even though they could not point to it until much later. Finally, normalising interventions do not change an intersex body to become a 'male' or 'female' body, they simply alter the appearance to make them look/function as such to varying degrees of success.

If we decide not to allow any medical interventions or surgery, will my child's body be fully functional?

Many intersex people who have *not had any* surgery or medical interventions have perfectly healthy bodies. According to the few studies that exist, most intersex people who have undergone normalising surgery have a whole range of health issues related to these treatments. Unless there are serious health risks, it is highly recommended to wait until your child is old enough to be involved in the decision-making process.

How should I register my child's gender on their birth certificate?

The fact that we live in a society that, for the most part, still does not legally acknowledge the diversity of human sexes will put you under pressure to register the child as either male or female in most countries. Different countries have different regulations regarding if and when a sex marker must be entered into official registries and this can vary from a few days to weeks or even months. You should not feel pressured to enter a marker before this period ends. In countries where only male or female options are available, intersex organisations recommend that parents assign the sex which feels most appropriate, but understand as the child grows up this may need to be changed to fit with their gender identity.

In which gender should I raise my child?

Intersex organisations recommend that you raise your child as male or female, as currently this is how our societies are structured. At the same time, you should keep in mind that your child might develop a gender that is not in accordance with the sex and gender you chose. There is nothing wrong with this - it is simply your child telling you who they are when they are old enough to express their individual personality.



Is it a disability?

Being intersex is a form of body diversity. Being intersex is neither a disability nor a long-term physical impairment. Intersex people who have been subjected to surgery and other medical interventions, however, often do have health issues because of these interventions that qualify as disabilities.

Should I tell my child that they are intersex?

Yes. Intersex individuals who are now adults and were raised in shame and secrecy have spoken very clearly about how these experiences negatively impacted their personal life, their family life, and their relationships with their parent(s) or carer(s). On the other hand, families who have established a culture of speaking openly with their children about their bodily diversity report how positively this openness has impacted on their family life and the self-confidence of their child and adolescent. You can choose age-appropriate explanations. The most important thing is to let your child know that you love them exactly the way they are.

Should I tell others?

The decision to tell others is a personal choice, but you should also think about how it could affect your child later in life. Keeping it a secret from everyone and not talking about it at all, however, is unlikely to be good for you or your child. Like any other personal information, think about who you trust and who it might be beneficial to tell. In fact, when it comes to your child going to nursery, kindergarten or school you will need to disclose this information up to a certain degree to make sure that your child can be open about being intersex with others. This can be challenging, so we encourage you to seek support to take care of your own wellbeing. Many parents that have chosen to disclose this information, however, have reported a significant positive impact, which helped them to raise their child in a safe and empowering environment. Remember, you don't have to answer all questions, especially those which are too private.

Making decisions in relation to medical interventions

The first question you should ask yourself is: Why do I think that my child needs medical interventions?

Is it because my child is suffering from a physical condition that actually threatens their life? Below are some examples of conditions where immediate treatment or surgery may be necessary, followed by conditions where immediate intervention is not proven to be necessary.

1. When immediate intervention may be necessary

Salt Wasting

Salt wasting can occur with a bodily variation that is called Congenital Adrenal Hyperplasia (CAH) by medical professionals. Both children who are assigned as girls and boys can suffer from salt wasting. Immediate medical intervention is needed to substitute the lacking minerals within the child, but afterwards they will usually be out of danger within 24 hours. Monitoring and medication to prevent future incidents may also be necessary.

Closed Urethra

If your child is born with a closed urethra, urine cannot leave the body. In such cases, immediate surgery might be needed to prevent your child's body from poisoning.



2. When immediate intervention is unlikely to be necessary

Removal of Gonadal Tissue

Sometimes doctors tell parents that gonadal tissue (the tissue of which the testis and ovaries are made). should be removed to prevent potential cancer. The percentage of intersex people, however, who have developed gonadal cancer has never been properly verified, as gonadal surgery for intersex people has been performed as standard for decades. In other words, there are not enough intersex people who have not had gonadal surgery to prove such a risk. To make a comparison, the risk of developing breast cancer does not mean that doctors recommend all women to undergo mastectomies as standard, but rather that routine screenings take place to monitor for any signs of cancer. Removing your child's ovarian or testicular tissue will also remove their ability to go through a natural puberty. Furthermore, if a child's gonads are removed they will have to undergo hormone replacement therapy to induce puberty. This means regular visits to a doctor all through your child's adolescence. For various reasons, some young people do not adhere to their hormone treatments, which can cause further complications. Hormones are vital to bone health and not taking hormones after a gonadectomy has a high risk of leading to osteopenia or osteoporosis – conditions where a person's bones become brittle. Many intersex adults, including some adolescents, report cases of osteopenia and osteoporosis.

Genital Surgeries

We all have certain expectations of how female or male genitals look, but rarely have opportunities to see the wide range of variations that exist. In most of our societies, we are taught that genitals should be hidden, so our impressions are limited to what we seen in biology textbooks or in different media. The genitals of intersex babies and children are operated on and cosmetically altered in a high number of cases. Reasons given for such surgeries include the desire to enable the future adult to:

- Fit better with society and grow up as male or female
- Have a healthy sexual life by having genitals that function more in line with societal expectations
- Reproduce and have a family

Some intersex people are subjected to surgical and other medical interventions that aim to guarantee them the possibility of becoming pregnant or to procreate. Many who were subjected to these measures as children grow up to report that, mentally and physically, they felt like violations of their body, even up to the degree of being comparable with sexual abuse. They also report that this treatment destroyed any wish to have sexual relations in adulthood. Some medical practitioners have raised their voice against early intervention from a purely medical perspective arguing that the physical results will be much better when the body is grown up more and when the patient is pursuing the treatment by their own will.

Conclusions

In a very small number of cases surgeries may be essential and non-deferrable, but many non-essential surgeries may be presented to you as otherwise. Make sure you have as much information as possible and some time to reach a decision before agreeing to any medical procedure. Most intersex activists and organisations strongly recommend that no non-essential or normalising surgeries or interventions are carried out before the individual is old enough to make an informed decision themselves. Once your child is old enough, they may decide to go ahead with some medical procedures, but this is very different to learning that interventions were carried out on you as a baby or young child without your consent.

Doctors have often told parents that not performing normalising surgeries or not strictly defining their child's gender will lead to psychological problems. There is virtually no evidence, however, that this is the case. An increasing number of intersex people who have not had medical interventions are speaking out to show that surgery is not necessary and that they are living healthy and happy lives. Sadly, the psychological damage of having intrusive and often painful interventions at a young age is also widely documented from intersex people who have undergone such interventions.

If a doctor tells you that surgery or another type of medical intervention is necessary, ask them to:

- Explain in detail what needs to happen and why
- Outline the risks of both taking action and of doing nothing at this stage
- Tell you where you can get more information

After an appointment with a doctor who recommends medical interventions:

- Reach out to an intersex organisation or a parent's group for advice, information and support.
- Get help finding a doctor who can give a second opinion.
- Do your own research, review your notes, and make sure you fully understand everything that was said during the appointment.

If your child or you decide that medical intervention is necessary:

- Ask the doctor to explain what will happen in detail
- Ask the doctor to tell you if further interventions will be needed and the risks associated with them
- Ask the doctor what psychological or other support is available for your child (and you) if necessary
- Seek advice, information and support from an intersex organisation

A family, who had migrated to Europe from Latin America, reported the following situation. When their child was born, their child's penis was not as long as usually expected for a boy. The medical practitioner took the father aside and delivered the – in his opinion – bad news. He also told the father that his child might suffer from a disorder of sex development and that a more detailed diagnose would follow. Assuming that the father would be most desperate about the manhood part of the issue, he also tried to provide a comforting solution by telling the father that if they wished the genital could be reduced further and the child could be raised as a girl. The reaction of the father was quite different than expected though. He started yelling at the doctor, forbidding him to go any further and pointing out that all men in his family have had this penis size for generations and all had grown up to live happy married lives.

Talking to your child about being intersex

Although it's important to not make your child feel different in a negative way or for them to worry about being intersex, not talking about it at all can be equally problematic.

How and when to talk with your child

Although it might seem 'safer' to not mention it until they are older, hiding things from your child as they grow up may lead to a bigger shock when they eventually do find out.

- Try to answer all questions that arise in an age-appropriate manner, so that your child will be prepared for everything new that they'll learn.
- You don't have to explain biological terms to your child from a very young age, but you can start gradually introducing ideas of difference by telling them things like not all girls are the same
- Prepare your child for challenges and difficulties along the way, but assure them that you will be there for them and that you're in this together
- Also remind them during difficult times, that everyone faces challenges and upsets when growing up
- Keep in mind that your child will grow up to be completely autonomous one day, and they need to know all the facts from early on, to be able to make their own decisions later in life.
- Also, keep in mind that honesty will help you to have a healthy relationship even throughout and after the most challenging teenage years. Your child realising that you were dishonest with them may damage your relationship and cause serious difficulties within your family. For many intersex young people, finding out that those closest to them lied is a traumatic experience and can lead to longer term issue with trust. Children have a right to and deserve to know the truth about themselves.

Minimising and dealing with shame

- Although you might want to plan how you and your child tell other people about them being intersex (see *Talking to others about your child being intersex*, p22), be careful not to turn it into a secret. If your child thinks it's something that needs to be hidden from others, it can lead to them feeling that there is something wrong or shameful about them.
- Let your child know all the facts about their bodies in a positive way, explaining that everybody is different, and that people can be healthy and happy without having to fit into strict categories.
- Try not to emphasise that being intersex is rare or uncommon, as this can lead to feelings of isolation.
- Think about experiences or situations which may be different for your child and think about how to discuss them in a supporting way.
- If your child decides to be open about being intersex, support them. If they do not feel like it, let them know that you support this decision too.
- Don't assume your child's identity or tell them what it will be. Like all children, their gender identity and or sexual orientation may be different to what you expect.
- Many people are not aware of the diversity that exists within our societies, let alone the existence of intersex people. You might want to prepare your child for that situation and there are many tools available to help. The most important thing is to build self-confidence and make your child feel comfortable with- and even be somewhat proud of- their body. It is also important that your child knows they have parents who love them exactly the way there are and who will always support them.

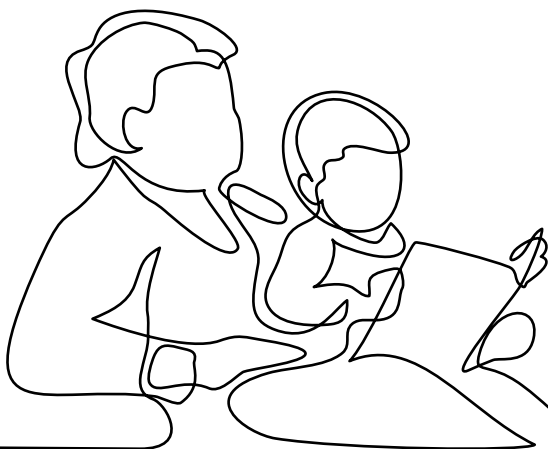
Decision-making

- Although it might feel like making decisions and taking action early on will be better for your child in the long run, the experience of many intersex people shows that the opposite is true. Waiting until your child is at an age that they can make their own decisions or be involved in the process is more likely to have a positive outcome. Children start to express their own opinions around two years, so you should involve your child in decision making as soon as they are able.
- Make sure that doctors do not overwhelm you or your child. This might simply happen due to medical terminology they use, a sense that they are the experts in this situation, or not knowing enough information. Where possible, bring a friend or family member with you that you and your child trust to help you discuss the possibilities and reach decisions.
- Discuss all the possibilities with your child, leaving surgery as the last option (unless there are immediate health implications).
- Share all the information about risks and possible outcomes in an age appropriate manner.
- Give them access to their own medical records/history. They have the right to know.
- Answer all their questions. Research the subject and empower them to do their own research too. Teach yourself and them how to do good research – how to identify valid information and avoid being misinformed.
- Reassure your child that they're the one who knows best how they feel about their lives and their bodies, but that there is help and support available if they need it.
- Involve your child in conversations with the doctors. Encourage them to ask questions and to critically review advice and information.
- Empower your child to be in control of any medical examinations or interventions, and that their consent needs to be given at every stage. Research and teach them their patient rights.
- When it comes to medical examinations make sure the medical professionals involved know that your child is intersex.

- Unless your child is older and requests otherwise, you should always be present during all medical examinations your child may need.
- Give your child time and space to prepare for and deal with things like medical examinations that can be daunting.
- Overall, trust your child – they are more capable of responsible decision-making than you might think.

Support

- Remember that you are not alone and that you and your child may need some additional support from others at various stages.
- Let your child know that there are various support options available to them, including intersex groups, counselling and therapy, and that getting help when you need it is not a sign of weakness, but a positive step in looking after yourself.
- Encourage your child to find and join support groups, if they want to. Let them know that sharing experiences and life stories with other intersex people is one of the best ways to help them realise the possible outcomes of their decisions, and find a safe place to explore what being intersex means. Young people who use social media can be directed to online support groups. Before your child joins a support group, however, do your research to ensure that they are approved by an intersex organisation.
- As a parent or carer, there will be times when you need additional support too. Although there might not be a specific group for parents of intersex children in your area, look for other relevant parents' groups or join an online group.



Talking to others about your child being intersex

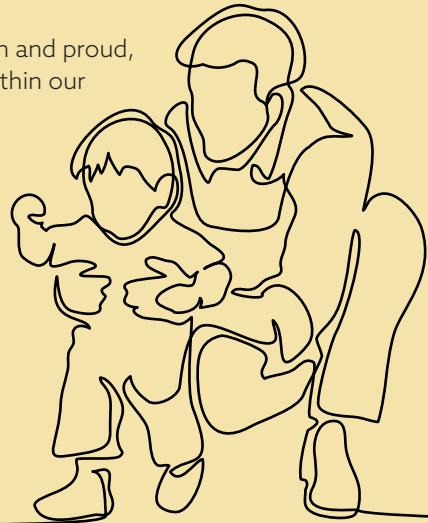
Consent

Children start to express their own opinions around two years, so you should involve your child in decision making as soon as they are able. Ask them how they feel about talking to other people about them being intersex. Remind them that there is nothing to be ashamed of, but you want to make sure that, when they feel ready to tell others, they understand what kind of reactions they might get and how they will deal with them. It's also important to agree who else can tell people, who they can tell and how this is done. Any personal information about a child or young person should be managed carefully, with them always feeling in control of who knows and when. It's also useful to discuss terms and language to agree on what words are used and how it is explained to others. Please keep also in mind that your child might think differently about the subject during different stages of their life and that this conversation should be revisited at all significant milestones (starting a new school, moving to a new neighbourhood/city, joining a new group/club).

Be proud

When talking to others about your intersex child, don't talk about it as if it's a secret or something to be ashamed of. Although you might receive negative or awkward reactions from others, the more you are able to show that there is nothing wrong, the more people will realise that the only problem is their preconceptions or lack of knowledge on the subject.

The more that parents of intersex children are open and proud, the more awareness and understanding there is within our societies, which is beneficial for all.



Be patient

For other people, the topic of intersex might be new and they might not understand at first. Take your time to explain what it means to be intersex. Explain that it is common and completely natural. Be prepared for awkward or inappropriate reactions and questions and try to respond calmly and positively. Most people will not mean any harm, but are just unsure how to respond due to lack of awareness. Use simple terms and language that's easy to understand. At the same time, it is not your sole responsibility to educate others. If someone is asking too many questions, tell them that you too are still learning, but can signpost them to resources if they are still interested.

Talking to other family members

If you have other children, it's important to talk to them about what it means to be intersex. Through general conversations around difference and diversity you can gradually introduce what it means to be intersex. As well as teaching your intersex child how to positively respond to bullying or teasing it is also important to teach siblings to do the same, as they might also experience it through association. When it comes to older family members don't assume that they will be necessarily more difficult to talk to. For example, values such as treating everyone with respect or accepting what life presents us with can be used to appeal to individuals with more traditional beliefs. Even if you experience reluctance from a family member to accept or discuss your intersex child, give the person time and ask other family members who have been accepting to help you speak with them. Encourage them to learn more about being intersex through articles, documentaries or personal accounts. The more they know about the subject, the more likely they are to become accepting and supportive.

Be an ally

If your child is comfortable with you doing so, try to raise awareness about intersex people wherever you can. Find opportunities to bring up the topic of intersex with different groups of people or post relevant articles or personal accounts on your social media channels. If people say something inaccurate or offensive about intersex people, try to correct them in a polite and friendly, but firm way. Another possibility is to join or support an intersex organisation to help increase visibility in society and progress intersex rights.

Questions others may ask

Is your baby/child a boy or a girl?

How you answer this will depend on how you are raising your child. If you are raising them as a girl or a boy, you can simply say so. If you know the person well or feel comfortable doing so, you can answer that they are intersex and you are raising them as a boy or a girl. If you are raising them without defining their gender at this point, you can say that you are raising them in a gender-neutral way.

Did something go wrong?

No, it is perfectly natural. It happens to at least 1 in 200 children with some sources stating that up to 1.7% of children can have some variation of sex characteristics. It is just not widely spoken about in society.

Does that mean your baby is a hermaphrodite?

No. Hermaphrodites have full sets of both male and female organs, and that's impossible in humans. They just have variations in their sex characteristics which do not meet medical norms of male and female bodies.



Is it a type of disability/disorder?

Intersex is just another diversity found in humans, no different to variations in hair colour or height. It only becomes a disability if you treat intersex people differently and don't give them the same chances as you would with non-intersex people.

What does your baby/child's genitals look like?

Suggestion for strangers: Don't you think this is a strange question? It is not so common to ask how someone's genitalia look. Even the youngest children have the right to privacy.

Suggestion for family members: They look absolutely fine.

How will it affect them growing up?

Many intersex children will grow up without needing any medical interventions or any specialist support as long as they are surrounded by people who love and accept them for who they are. Being different in any way tends to lead to higher incidences of bullying or discrimination, so the main issue is ensuring that there is greater understanding and acceptance of intersex people in all areas of your child's life.

Will it affect who they are attracted to?

There's no link between sex characteristics and sexual orientation, so intersex people can be lesbian, gay, straight, bisexual or any other sexual orientation.

Intersex people and gender identity

Many intersex people identify as women or men and often also agree with the gender marker they were assigned at birth. Sometimes intersex people who have been assigned a gender at birth, may realise that this is wrong for them as they grow up. This means they will probably want to change their name and how they present themselves to fit better with their gender identity. Others may not identify as a woman or a man (non-binary gender) and express both or neither aspect of what is considered traditionally masculine and feminine. Two intersex people who share the same sex characteristics may have different gender identities.

Talking to teachers, doctors and other professionals about your child being intersex

At various points in your child's life, you will have to make decisions about which professionals will need to know that your child is intersex and how you approach this with them.

It is important to involve your child in the decision-making process as soon as possible. Very young children can voice preferences and opinions, if they are asked in the right way. While your child will not be able to handle all aspects of decision making at a very young age, it is important that they start handling the aspects they can as soon as they are able. This will empower them and give them a stronger feeling of control over their own life. In this chapter, you will find some pointers for planning and having discussions with teachers, doctors and other professionals/adults who will come into contact with your child.

1. Doctors and medical staff

The first professionals you and your child will be involved with are most likely to be doctors and medical staff. Making decisions about medical interventions has already been covered (see *p14*), so the following will focus on regular check-ups and other appointments.

- When choosing a doctor for your child, check if they are informed about intersex people or at least open to learning. Make sure you feel comfortable with them before taking your child to register with and meet them. If your child is older, encourage them to be part of the screening/selection process, letting them decide if it's the right doctor for them
- Make a list of questions in advance of the meeting and take notes during the meeting as a reminder. You might also want to record the conversation, with the permission of your doctor, so you can come back and listen to the conversation again for clarification of points you did not quite catch during the appointment. If this is not possible then ask the doctor to write down any words, terms or phrases you do not fully understand

- Always consult your child if they want you to be with them in the doctor's office or not. Generally, parents are present unless asked explicitly by the child not to be. Make it clear that this is the child's choice.
- Ask the doctors where you can find more information about your child's particular biology. Provide the doctor with resources you have already found.
- Make sure to make copies of your child's medical records: documents and results of medical tests.
- Be there with your child and do your best to prevent any unnecessary tests or visitations from doctors who don't really need to examine your child.

If a medical professional recommends any type of surgery, then ask them to explain if it is important for the child's physical health or if it is 'cosmetic' in nature. Do not settle for vague answers such as "it's going to be better this way", always ask for clear information. Record the information or take notes. Always seek a second opinion, try to reach out to intersex organisations or parents of intersex children.

2. Teachers and school staff

Younger Children

There may be no need to discuss anything with school staff at all. This depends on your child and your personal situation. If your child is open to talking about being intersex and is likely to mention it in school, then it is best to speak with their teacher and the head of the kindergarten, nursery or school in advance. You should check what they know about being intersex (or more likely be ready to signpost them to information about it), discuss the possible scenarios that are likely to arise and agree on how they should be handled. If your child rarely gives being intersex a second thought and therefore seldom or never mentions it, there may be no need to inform school staff at this point.

If your child needs to take medication or needs any specific facilities for changing/using the bathroom, then plans to deal with this should be agreed with the necessary staff. Remind school staff that your child has a right to privacy and that any information disclosed should be treated confidentially, only being shared with those who need to know. Inform yourself on regulations and guidelines that are in place in your area.

Older Children

Before starting high school or college, have a talk with your child about how they would like the situation to be managed. Encourage them to think about the pros and cons of different approaches and what some of the consequences may be, so they can make an informed decision. If they decide that a meeting with the school or institution before they start is the best plan, encourage them to be involved in the meeting and support them to take a lead in the discussions by planning what they want to say and preparing for any questions that are likely to be asked.

It's good to ask the school if they have a bullying policy and to discuss how they deal with incidents. It's also worth asking about pupil support and what services or groups are available to learners that might be helpful.

If your child wants to be open about being intersex, discuss different ways of raising the subject with staff and agree on how they can support your child to do this in a way that feels positive and safe. Think about ways that you and the staff can check in with your child in a non-intrusive way to ensure they aren't experiencing any negative consequences of being openly intersex. If your child doesn't want to disclose they are intersex or chooses only to do so to a few trusted individuals, talk through how to manage this and how they would deal with someone finding out accidentally.

3. Other professionals

Other professionals who might be involved in your child's life could include social workers, youth workers, sports trainers, religious leaders or psychologists. Disclosure of your child being intersex generally follows similar guidelines as disclosure to teachers. Take into consideration how much time your child spends with the person in question and in what context. There is generally no need to discuss your child being intersex with many of the above professionals unless your child is likely to instigate the discussion or wants to tell them. Apart from this, the only other reason it may need to be discussed is if there are any specific requirements for your child, such as a private changing facility.

If your child needs to see a psychologist or other mental health professional, then it is advisable to discuss this with them and your child before their first appointment. Not all mental health professionals will have knowledge on being intersex, so may require some information or guidance around dealing with the topic. When discussing it, watch the person's reaction. Most professionals will be happy to learn something new, but if the person reacts in a way that makes you feel uncertain, you can either discuss this with them to get reassurance or seek an alternative practitioner. Also, listen closely to your child's feelings about all professionals they come into contact with. Children are usually able to voice an opinion on if they want to see someone or not from a very young age.

If your child attends a place of worship, you may want to discuss it with relevant individuals. Again, this will depend on your personal situation and how you engage with your faith. You may personally want to seek out support from a leader within your congregation, or your child may have a trusted individual they want to inform.

4. Conclusions

Depending on the age and maturity of your child, you should aim to include your child in all of these conversations. Very young children may not be at the stage of participating fully in the conversations, but it is good to involve them from the beginning to give them the choice as to how much they want to contribute. If they are not interested in being part of the discussions or find it awkward or embarrassing, let them know what you will say and check if they are happy with how you plan to represent them. Also, don't assume that because they didn't want to be involved in one discussion that this won't change over time. Always give them the option to participate without putting any pressure on them to do so.

Glossary

Chromosomes

A thread-like structure of nucleic acids and protein found in the nucleus of most living cells, carrying genetic information in the form of genes.

Disclosure

To reveal something personal about yourself to another, such as being intersex

DSD – Disorders of Sex Development (or *Differences of Sex Development*)

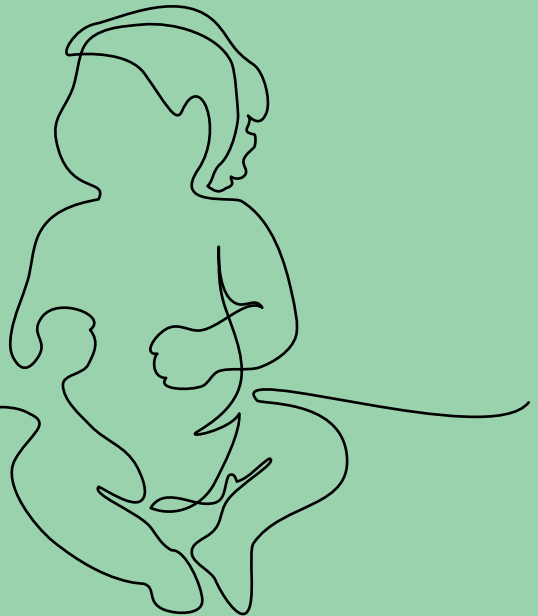
The term DSD was introduced in 2006 and has since then been used by medical professionals to refer to intersex bodies. Some intersex people use these terms when referring to themselves. A growing number of intersex people consider DSD terminology to be stigmatizing and prefer to use the term intersex.

Dyadic

Consisting of two parts or two elements, a binary.

Gender

Refers to a social construct which places cultural and social expectations on individuals based on their assigned sex.



Gender expression

Refers to people's manifestation of their gender identity to others, by for instance, dress, speech and mannerisms. People's gender expression may or may not match their gender identity/identities, or the gender they were assigned at birth.

Gender identity

Refers to each person's deeply felt internal and individual experience of gender, which may or may not correspond with the sex assigned at birth, including the personal sense of the body (which may involve, if freely chosen, modification of bodily appearance or function by medical, surgical or other means) and other expressions of gender, including dress, speech and mannerisms.

Some people's gender identity falls outside the gender binary, and related norms

Genitalia

A person's sexual organs

Gonads

A testis, ovary or ovo-testes

Hermaphrodite

An out of date term often used to describe intersex people. Today it is generally considered derogatory.

Intersex

A term that relates to a range of physical traits or variations that lie between stereotypical ideals of male and female. Intersex people are born with physical, hormonal or genetic features that are neither wholly female nor wholly male; or a combination of female and male; or neither female nor male. Many forms of intersex exist; it is a spectrum or umbrella term, rather than a single category.

That is why intersex activists frequently prefer to use the term sex characteristics (for example, when talking about grounds that can be protected against discrimination). There is not one static state called 'intersex status', so using the term sex characteristics reflects the fact that being intersex is a bodily experience and only one part of a person's identity.

LGBTQI

An acronym for Lesbian, Gay, Bisexual, Transgender, Queer and Intersex.

Non-binary

A term used to describe people whose gender identity falls outside or in between the traditional categories of male and female.

Sex

The combination of a person's bodily characteristics including: chromosomes, hormones, internal and external reproductive organs, and secondary sex characteristics. In most countries this is still limited to the binary of female and male, which can exclude intersex people

Sex characteristics/Variations of sex characteristics

Sex Characteristics is a term that refers to a person's primary sex characteristics such as: chromosomes, anatomy, hormonal structure and reproductive organs or a person's secondary sex characteristics which become apparent at puberty such as: breasts, facial and pubic hair, Adam's apple, muscle mass, stature and fat distribution.

The term 'variations of sex characteristics', therefore, is seen by many activists as a more accurate term than 'intersex status', as it refers to a spectrum of possible characteristics instead of a single homogenous status or experience of being intersex.

Sexual orientation

Refers to each person's capacity for profound affection, emotional and sexual attraction to, and intimate and sexual relations with, individuals of a different gender or the same gender or more than one gender.

Trans

Is an inclusive umbrella term referring to people whose gender identity and/or gender expression differ from the sex/gender they were assigned at birth.

It may include, but is not limited to: people who identify as transsexual, transgender, transvestite/cross-dressing, androgyne, polygender, genderqueer, agender, gender variant, gender non-conforming, or with any other gender identity and/or expression which does not meet the societal and cultural expectations placed on gender identity.

Intersex people may or may not identify as trans, when rejecting the sex that was assigned to them at birth.

Many of the above definitions have been kindly supplied from ILGA Europe's online glossary.



Useful links and resources

European Intersex Organisations

OII Europe

www.oii-europe.org
www.intervisibility.eu

Young & Intersex

www.facebook.com/Youngandintersex

European LGBTQI Organisations

IGLYO

www.iglyo.com

ILGA Europe

www.ilga-europe.org

Transgender Europe (TGEU)

www.tgeu.org

European Parents' Organisations

EPA

www.euparents.eu

European Association for Children in Hospital

www.each-for-sick-children.org

Useful Resources & Articles

Standing Up for the Human Rights of Intersex People

www.goo.gl/NQmPSa

www.goo.gl/fs3pXU

Promoting the human rights of an eliminating discrimination against intersex people, resolution of the Parliamentary assembly of the Council of Europe

www.goo.gl/wZHFgW

Council of Europe report: Promoting the human rights of and eliminating discrimination against intersex people

www.goo.gl/eHjPsx

Council of Europe Paper: Human Rights and Intersex People

www.goo.gl/gc6QdN

Council of Europe: Resolution on Children's Rights to Physical Integrity

www.goo.gl/XDjjxs

United Nations Convention on the Rights of the Child

www.goo.gl/SAAouz

Universal Declaration of Human Rights

www.goo.gl/zwnieT

EACH Charter

www.goo.gl/QJ4SGe



About

IGLYO

www.iglyo.com

IGLYO – The International Lesbian, Gay, Bisexual, Transgender, Queer & Intersex (LGBTQI) Youth & Student Organisation is the largest LGBTQI youth and student network in the world with over 90 member organisations in 40+ European countries.

IGLYO's objectives are to:

- build young activists
- increase the visibility and highlight the diversity of LGBTQI youth identities
- make education safe and inclusive for all
- develop and sustain an engaged and connected network of member organisations

IGLYO achieves these objectives through an extensive programme of international trainings and events, online capacity building, youth representation and participation, digital storytelling and campaigning, and our LGBTQI inclusive education project.

IGLYO aisbl is registered as a non-governmental organisation in Belgium (No. d'entreprise: 808808665).

OII Europe

www.oii europe.org

OII Europe (Organisation Intersex International Europe) is the umbrella organisation of European human rights based intersex organisations with member organisations in all Council of Europe regions. OII Europe was founded on Human Rights Day, 10 December, during the Second Intersex Forum at Stockholm in 2012.

OII Europe is an autonomous affiliate of OII (Organisation Internationale des Intersexués), a decentralised global network of intersex organisations, which was founded in 2003 and has operated since then through its national groups in every region of the world.

Oll Europe's goals are:

- full implementation of human rights, bodily integrity & self-determination for intersex people
- legal prohibition of non-consensual medical & psychological treatment; medical practitioners or other professionals should not conduct any treatment to the purpose of modifying sex characteristics which can be deferred until the person to be treated can provide informed consent
- promotion of self-awareness, visibility and recognition of intersex people
- full protection against discrimination & the adoption of sex characteristics as a protective ground
- education of society on intersex issues from a human rights perspective

EPA

www.euparents.eu

EPA gathers the parents associations in Europe which together represent more than 150 million parents. EPA works in partnership both to represent and give to parents a powerful voice in the development of education policies and decisions at European level. In the field of education, EPA aims to promote the active participation of parents and the recognition of their central place as the primary responsible of the education of their children.

- EPA supports the participation and collaboration of parents in many educational respects by:
- Gathering and disseminating information by means of EPA publications including, newsletters, seminar reports, EPA website, discussion forums.
- Highlighting innovation in educational partnership and spreading information about interesting and innovative educational practices.
- Promoting parents' ongoing support and training.
- Supporting research in all fields relating to the participation of parents in the educational environment.
- Collaboration with various partners in the broad field of education.



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