



# Better Lives

*Improving outcomes for babies born  
with variations of sex characteristics*

A partnership between:



"Intersex is an umbrella term used to describe a wide range of innate bodily variations in sex characteristics. Intersex people are born with sex characteristics that do not fit typical definitions for male or female bodies, including sexual anatomy, reproductive organs, hormonal patterns, and/or chromosome patterns."

*Office of the High Commissioner for Human Rights. 2019.*

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# Body Diversity is Natural

Congratulations on the birth of your new baby. The purpose of this resource is to support you with the news that your baby has (may have?) an intersex variation. You likely have a lot of questions so the information below and extra resources at the back is a good place to start.

Body diversity is normal and natural. All sorts of variations occur within the human body, such as different sized toes and hair colour. Variations to sex characteristics are as normal. Our chromosomes, hormones, internal reproductive organs, and external genitalia exist on a continuum.

**typical male**

**atypical**

**typical female**



The UN charter for the rights of the child recommends that you do no harm, this includes surgical and hormonal "normalising or cosmetic" treatments – this is different from life saving treatments.

Many studies and research have noted these normalising treatments reinforce stigma and shame. There is no clear evidence of benefit from these interventions. There is evidence that harm comes from normalising treatments, including damaging consequences for intimacy and sexual function in later life, damage to nerve tissue, repeat surgeries, developmental delays with exposure to general anaesthetic and many others. Like any child, intersex kids may grow up to identify in ways that are not expected and early surgeries reduce their ability to claim an identity that is rightfully theirs.



## **The most important thing to do in the first few days is to bond with your baby. It is a time to:**

- Get to know your baby.
- Have quality cuddling.
- Start daily routines.
- Learn your baby's needs.
- Recover from the birth.

A baby born with intersex variations, that is variations to their sex characteristics, can be the focus of a lot of medical attention. This can feel overwhelming for parents. Many parents may feel they don't know what to do or have a choice. You do.

The following suggestions may help you...

### **You are your baby's main carer**

Your baby needs you to feel safe, loved and nurtured. As a parent you are your baby's greatest advocate. To be able to make decisions you need to be informed, and have time to understand.

### **Keep your baby with you**

If anyone wants to take your baby for a test, you can:

- Go with them.
- Ask for the test to be done at your bedside.
- Ask if the test is needed. Ask for evidence.

### **Record and document requests**

- A lot happens and it is hard to keep track or remember everything.
- A mobile phone is a useful tool to record information or discussion. You can listen again or share if needed.

## Say no to unwanted attention

Healthcare professionals may be keen to 'learn' from your baby's variation. You have the right to say no. You do not have to agree to them looking, taking photographs or showing others.

## Hospital stay

- If you feel uncomfortable staying at hospital, go home with your baby. Any further tests or follow up can be done as an outpatient or with home visits.
- Contact a support organisation who can help provide information and support. (See resources section).
- Introduce your baby by their name not gender. When you are ready you will decide what gender to raise your child. Some children with intersex variations do choose a different gender when they are old enough to decide who they are.



## Announcing a Birth

Often, the first thing people ask is if your baby is a boy or girl. If you don't have a clear idea, it's okay to delay telling people or making an announcement until you are ready.

A solution to the "which" sex question may be to just share the most likely sex as advised by clinicians. In this case it isn't necessary to tell any more personal information than that, unless the assigned sex changes – which it could with more information further down the track.

One strategy you can choose is a gender-neutral name – a name used for both boys and girls.

Your child (like any children) might grow up to understand themselves and their gender differently. Bear in mind that sex assignment does not actually require surgical or hormonal treatment.

Importantly, don't feel pressured to make fast decisions. Gather information then chat with a support organisation (contact details in Resources).



There is a difference between life saving surgery and life changing surgery. Life changing surgery (cosmetic/normalising) can occur later when your child is old enough to give their informed consent.

## Life-saving surgery

There are instances where immediate interventions are necessary:

- **Salt wasting** – this is a medical emergency; the treatment is simple and effective.
- **Closed urethra** – (absence of an exit for urine) this is a medical emergency – surgery is required.
- **Anorectal atresia** – (absence of an anus) this is a medical emergency – surgery is required.
- **Other body system abnormalities** – not related to the genital area and connected organs i.e. heart valve defect – surgery is required.

## Life-changing surgery

Surgeries to modify (change) the sex characteristics of infants that can be irreversible and invasive. They can be deferred until your child can be part of the decision-making. These surgeries also have human rights implications. You should never be put in a position where you are asked by clinicians to consent to such practices on behalf of your child.

## Unnecessary interventions

You may be asked to give permission for interventions that are not necessary:

- **Removal of Gonadal tissue** – If gonadal tissue is removed your child will need further medical interventions during puberty. International guidelines suggest a 'wait and see' approach with regular ultrasounds to check for changes.
- **Genital surgeries for cosmetic or social cultural reasons** – is a decision for your child. This is called bodily autonomy, a United Nation right of every person.



## Diagnoses

There are different diagnosis that come under the intersex umbrella. These include:

5-alpha-reductase deficiency,	Fraser syndrome, gonadal dysgenesis,	micropenis
androgen insensitivity syndrome(AIS),	hyperandrogenism,	mosaicism involving sex chromosomes,
bladder exstrophy,	hypospadias,	mullerian (duct) aplasia,
clitoromegaly,	Kallmann syndrome,	ovotestes,
congenital adrenal hyperplasia (CAH),	Klinefelter syndrome/ XXY,	progesterin induced virilisation,
cryptorchidism,	leydig cell hypoplasia,	Swyer syndrome
De la Chapelle (XX male) syndrome,	Mayer-Rokitansky-Küster-Hauser syndrome (MRKH, mullerian agenesis, vaginal agenesis)	Turner's syndrome/ Xo (TS)
epispadias,		Triple-X syndrome (XXX).

Some of these diagnoses are found at different stages of the lifespan.

As in all diagnoses, there can be other health implications that may need short or long term management.

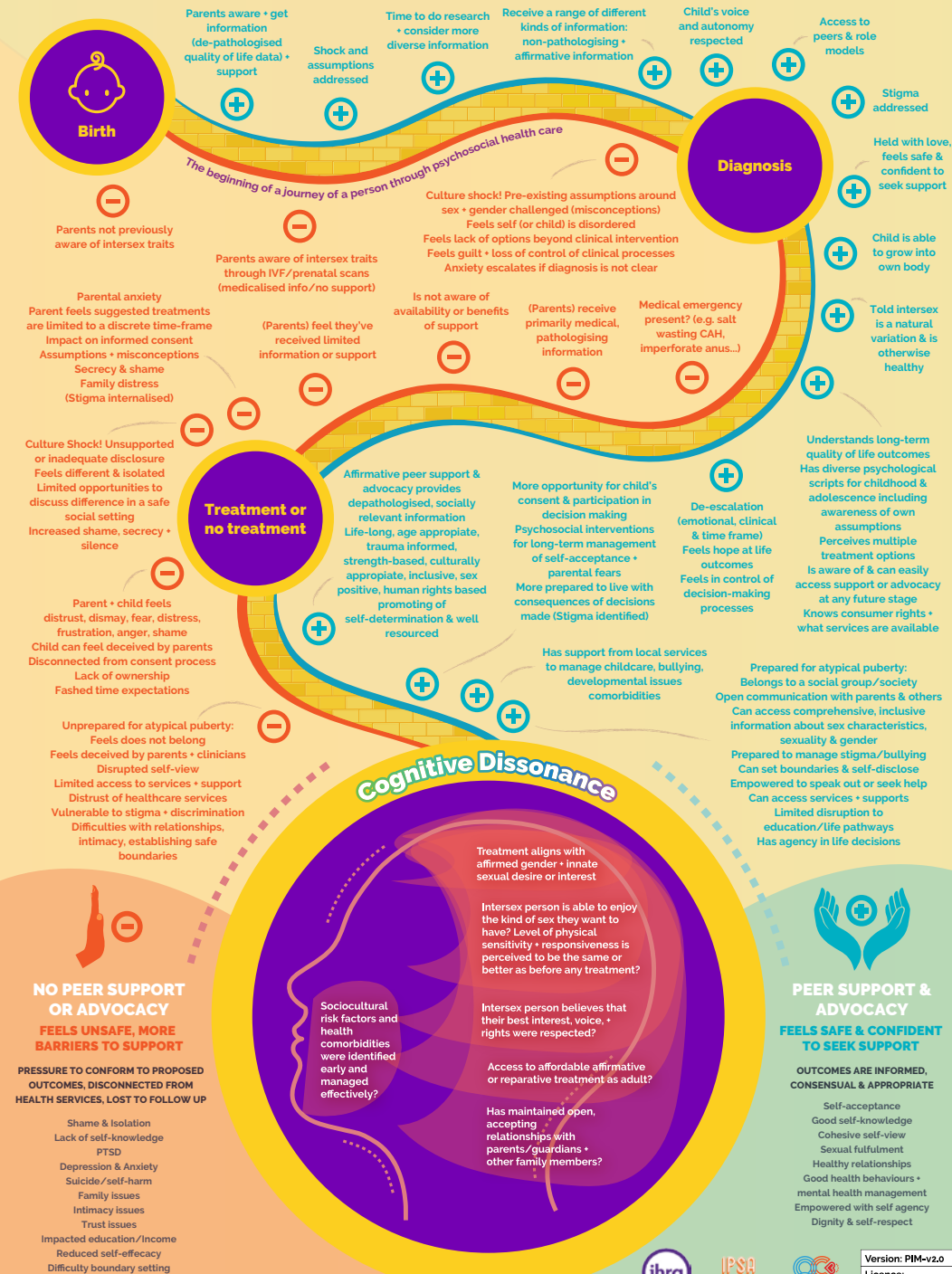
# Future Pathways:

## Intersex Health + Wellbeing

Persons born with variations in sex characteristics  
Psychosocial Impact Map

- + = Psychosocial approach - wait + watch, stigma addressed, socially normalised
- = Biomedical approach - intervene early, stigma remains, medically normalised

We acknowledge the traditional owners of the land on which we live, work and play, and pay respect to elders past, present and emerging. We recognise the important role Aboriginal and Torres Strait Islander people continue to play in forming work for our diverse communities.



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## Common Questions

### Q. How will I find out if my child is intersex?

A. Sometimes a child is visibly intersex from birth. It is not always the case and may well be discovered after birth or later in life through various means, including:

- Blood tests.
- Medical examinations such as ultrasound.
- Childhood operations such as hernia repair and appendectomy.
- Puberty may be different than for the child's peers.
- A parent may know in early pregnancy due to ante-natal screening.
- People find out they are intersex at all ages.

### Q. My child is Intersex. What now?

A. One of the most important things is to be open with your child (in an age-appropriate way) and to listen to what your child tells you about their needs. Variations occur everywhere in nature. Being intersex is one of them and it is nothing to be afraid of.

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

A. Your intersex child does not need surgery for you to register them. However, you still might be advised by medical professionals to agree to medical treatment that changes your child's body towards a more female or male appearance, *you do not have to consent to these treatments.* Some common *inaccurate*, 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.

It is important to know that there is no good scientific evidence to support these arguments that currently exists.

**Q. Doctors are pushing me to make a very fast decision. What should I do?**

**A.** Take the time you need to understand the best options for your child and seek the support of appropriate agencies/organisations.

Don't make decision based on social and cosmetic factors:

- Surgeries to change the appearance of your child's outer genitals.
- Surgeries so your child can perform a gendered social function, like standing up to urinate.
- Surgeries to create vaginas in infants assigned female so that they can fulfil expected 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 support organisations. You can also connect may with other parents who have had 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.

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

**A.** Your child's gender is not yet certain. We live in a society that struggles to legally acknowledge the diversity of human sex and gender, in most cases it is best to register the child's sex as either male or female (there is an option for a nongendered approach), following medical advise and your intuition, recognising that this might change once you come to know your child better.

**Q. I hear different opinions about what I should do with my child. How do I know what's best?**

**A.** Every situation is different. Put the wellbeing and the health of your child first, but don't forget the wellbeing of yourself and your family.

Take time to research, reach out to intersex advocates and support organisations. Find the information you need to understand the options.

Listen, talk, explore and check you understand what is offered and why. Be critical of advice which focusses only on changing your child physically. Don't be pushed into a quick decision. Most decisions can wait until your child is mature enough to be part of the decision-making processes.

**Q. If we decide not to allow any medical interventions or surgery (cosmetic), will my child's body be fully functional?**

**A.** Many intersex people who have not had any surgery or medical interventions, generally have perfectly healthy bodies. According to the few studies that exist, most intersex people who have undergone normalising (cosmetic) 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.

**Q. Is it easier to operate when my child is a baby?**

**A.** Whilst having surgery/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.

- Any full anaesthetic surgery is a life-threatening action. Especially, but not limited to, surgeries that are performed on infants and young children.
- The surgery may affect the functionality of the operated body part, such as their urethra or penis.
- Whilst no long-term studies have been done on the impact of genital surgery, many intersex people have reported a lack of, or limited erotic sensation as adults. They also report numbness and pain due to scar tissue.
- Medical interventions often lead to further interventions being necessary, and sometimes result in lifelong dependency on doctors.
- 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.
- 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.

**Q. Which gender should I raise my child?**

**A.** Intersex organisations (contact details in Resources) recommend that you raise your child as male/female or gender neutral, 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.

**Q. Is it a disability?**

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

*Taken with permission from "Supporting your intersex child" IGLYO, Oll Europe and EPA (2018) CC (BY-NC-ND 4.0) Oll Europe.*

# Glossary

- **Chromosomes** – a threadlike structure of nucleic acids and protein found in the nucleus of most living cells, carrying genetic information in the form of genes.
- **Disclosure** – the action of making new or secret information known.
- **DSD** – Disorders of Sex Development (or Differences in Sex Development) – conditions of incomplete or disordered genital or gonadal development leading to discordances between genetic sex, gonadal sex and phenotypic sex.
- **Endosex** – people without a variation to their sex characteristics.
- **Gender** - either of the two sexes (male and female), especially when considered with reference to social and cultural differences rather than biological ones. The term is also used more broadly to denote a range of identities that do not correspond to established ideas of male and female.
- **Gender expression** - the way in which a person expresses their gender identity, typically through their appearance, dress, and behaviour.
- **Gender identity** - an individual's personal sense of having a particular gender.
- **Genitalia** – the male or female reproductive organs.
- **Gonads** – an organ that produces gametes; a testis or ovary.
- **Hermaphrodite** - denoting a person, animal, or plant having both male and female sex organs or other sexual characteristics.
- **Intersex** - intersex people are individuals born with any of several sex characteristics including chromosome patterns, gonads, or genitals that, according to the Office of the United Nations High Commissioner for Human Rights, "do not fit typical binary notions of male or female bodies".
- **LGBTIQ+** - is an acronym for Lesbian, Gay, Bisexual, Transgender, Intersex, Queer and more.
- **Non-binary** - nonbinary gender identity is just one term used to describe individuals who may experience a gender identity that is neither exclusively woman or man or is in between or beyond both genders.
- **Sex** - sex is a trait that determines an individual's reproductive function, male or female, in animals and plants that propagate their species through sexual reproduction. The type of gametes produced by an organism define its sex.
- **Sex characteristics/ Variations to sex characteristics** - sex characteristics/Variations to sex characteristics - Sexual characteristics are physical or behavioral traits of an organism which are indicative of its biological sex. These can include sex organs used for reproduction and secondary sex characteristics which distinguish the sexes of a species, but which are not directly part of the reproductive system.
- **Sexual orientation** - sexual orientation is an enduring pattern of romantic or sexual attraction to persons of the opposite sex or gender, the same sex or gender, or to both sexes or more than one gender.
- **Transgender** - denoting or relating to a transgender person, especially one whose bodily characteristics have been altered through surgery or hormone treatment to bring them into alignment with their gender identity.

Personal stories by parents on raising their child:

- ***Raising Rosie: Our Story of Parenting an Intersex Child*** by Eric and Stephani Lohman. 2018. London: Jessica Kingsley Publishers.
- ***Raising an intersex child: 'This is your body... There's nothing to be ashamed of'*** – Stephani and Eric Lohman talk with CNN ([edition.cnn.com/2019/04/13/health/intersex-child-parenting-eprise/index.html](http://edition.cnn.com/2019/04/13/health/intersex-child-parenting-eprise/index.html))
- ***'You can't undo surgery': More parents of intersex babies are rejecting operations*** – Ori and Kristina Turneer talk with NBC News ([www.nbcnews.com/feature/nbc-out/you-can-t-undo-surgery-more-parents-intersex-babies-are-n923271](http://www.nbcnews.com/feature/nbc-out/you-can-t-undo-surgery-more-parents-intersex-babies-are-n923271))

Resources about parenting intersex children:

- ***Supporting an intersex teenager***, a resource by ReachOut Parents published in October 2019
- ***United Nations for Intersex Awareness***
- ***Supporting your intersex child***, a toolkit by OII Europe
- ***What we wish our parents knew*** a guide by interACT Youth (USA)
- ***Letter to parents of children with congenital adrenal hyperplasia and "ambiguous genitalia"*** in English by Brújula Intersexual (Intersex Compass)

We also recommend the UN site ***United Nations for Intersex Awareness***.

## Organisations

**IPSA** – Intersex Peer Support Australia: [isupport.org.au](http://isupport.org.au)

Intersex Peer Support Australia is an intersex peer support, information and advocacy group for people born with variations in sex characteristics and their families.

**IHRA** – Intersex Human Rights Australia: [ihra.org.au](http://ihra.org.au)

Intersex Human Rights Australia Ltd (formerly Organisation Intersex International Australia or OII Australia) is a national body by and for people with intersex variations.

**WIO** – Working it Out: [workingitout.org.au](http://workingitout.org.au)

Working It Out is Tasmania's sexuality, gender and intersex status support and education service. Working It Out provides support and advocacy services for lesbian, gay, bisexual, transgender, intersex and queer (LGBTIQ+) Tasmanians and education and training programmes to schools, workplaces, government and non-government organisations.

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