

# OII - International Intersex Organisation

## Handbook for Parents

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Parents,*  
by OII.  
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des Intersexués  
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# Introduction:

**T**here are no words to explain how it feels when a parent first learns that their child is born with a difference, be it an illness, or a physical or mental difference.

When parents are informed of their child's difference, they often feel an enormous emptiness verging on despair.

For many years now, children have been born with what doctors call a "Disorder of Sex Development", but the words most often used in a medical context are still: ambiguous genitalia and hermaphroditism.

These words keep coming back to you like an echo, incomprehensible and frightening.

What do the doctors mean and how does this affect my child's health?

- **Ambiguity** is the property of being ambiguous, where a word, term, notation, sign, symbol, phrase, sentence, or any other form used for communication, is called ambiguous if it can be interpreted in more than one way.

- **Hermaphrodite**, to many of us, is a god from Greek mythology and is used in a general sense to refer to an organism having both male and female reproductive organs. Who can have both? Impossible. Inconceivable. How can anyone say that our children are born with both sex

organs or that they are both sexes? Difficult to understand.

How are we mortals supposed to understand what all these words mean?

State of shock.

Confusion.

When the doctors do finally start giving explanations, we, the parents, are not able to come to terms with the words being used to describe our child.

We are completely overwhelmed by the way this announcement is made to us.

The words still used by the medical experts to inform parents that their child was born with a variation which affects the reproductive system are distressing, even painful to hear.

Words such as "ambiguity" give the impression that the sex of our child will be a mystery.

"Hermaphrodite" makes us think that our child is both sexes; "intersexuality" conveys the idea that the child is in between two sexes.

"Disorder" gives us the impression that the sex of our child is a disease which will have to be treated or cured. ❀

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# Chapter 1: The Shock of the Announcement

**A**fter giving birth, parents are ecstatic and wish this moment would last forever. And while experiencing one of the most marvelous moments in your life, you sense that something is wrong. You see it on the doctor's faces but no one will say anything to you. When someone finally speaks to you, it is to tell you that your child has a problem.

The words used are violent, incomprehensible, shocking, because there are no real words to explain it.

No matter what the doctors say, you can't follow it.

There is something sinister in the atmosphere and it feels so painful.

There are too many contradictory emotions all pulling you in different directions: confusion, sadness, pain, guilt and hate.

Each parent has to work through several difficult stages and the people involved are vital for the parents' and the child's well-being.

Doctors and psychologists must help the parents and the child make it through this long, painful process.

Everything concerning genital development and sex identity are rather taboo or unfamiliar to most people but these issues are not as rare and we are led to think.

It is important that parents of children who are born intersexed not feel all alone.

They need to talk to others, share their doubts, ask questions, express their fears, their joys and not feel as if they are the only ones in the world dealing with this.

Communication is essential because our own sense of not being alone is very important for our children and their future.

It will take time to understand this topic.

It is extremely important that parents have access to psychologists and therapists to help them deal with the shock.

Their psychological well-being is what is most important for the child's future development.

The parents need help understanding their child's difference, help in dealing with the unknown and how to understand the real health needs of their child. ❁

# Chapter 2: Learning About Intersex

**P**erhaps the most distressing stage is learning about intersex and understanding what it is: learning about this variation, the consequences, trying to understand your child, your child's life and health.

But understanding this is so complicated because it seems like a totally unknown world.

And this is why parents must not feel alone and isolated when confronted with doubts and more questions.

The more information they get to help them, the easier it is for them to understand and accept their child.

Information is necessary. It is necessary to explain clearly to the parents that their child was born with a physical difference, and not fixate on the sex of the child.

What is important is the health of the child.

It is important that the parents understand that there are sometimes health issues which are more prevalent with certain intersex variations.

At this stage, what is most important is that the parents be well informed and given the help necessary to ensure the well-being of their child. ❁

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# Chapter 3: Acceptance

**A** cceptance is a very difficult stage for the parents. If the parents are not given the support they need, there are serious risks which could have repercussions on the health of the child and be detrimental to the child's development.

This is a very long stage in the process and you will probably feel alone and lost, in uncharted territory.

Despite the explanations given by the experts, you often are unable to find the words or images that express your own feelings.

You want to find out why this happened, why your child was born this way, why your family was affected, but sometimes there are no answers to these questions.

Some variations have no genetic explanations and some variations have no current explanation at all, genetic or otherwise. We would give our lives for our children.

So, it is crucial that we accept them.

Accept that they are different, accept that their bodies are different, but most importantly, accept them just as they are. ❁

# Chapter 4: Love is Not Ambiguous

**N**ever forget, whether your child is intersexed or not, that s/he is first of all your child. S/he will need you, your help, and your support.

To help your child in the future, it is necessary to understand that intersexuality will not prevent “them” from living a productive life.

Never forget that it is your child who will know who s/he really is.

Although you must make a choice, this choice may possibly not be theirs.

Nobody will be able to choose for your child.

Only s/he will know “their” body.

Only s/he will be able to say what sex s/he is.

It is important to understand that this physical difference will not prevent your child from being a “man” or a “woman” and from living a happy and healthy life.

If parents understand this, that is the most important stage in the process because it will instill confidence in the child and the child will understand that “their” parents accept their difference.

In spite of the fact that the others mistakenly believe that the sex of our child is not clear, we know that, given time, the child will communicate clearly what is best for “them”.

We have to help the child develop “their” own sex identity and our love which is not ambiguous will permit us to see as clearly as our child that “their” sex is not ambiguous and is not a disorder.

The Organisation Intersex International has a support group for parents of intersexed children: <http://parentsinx.org/>. ❁

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# Chapter 5: Choice – Developing an Identity

**W**hen a child is born, the first thing we do is identify the sex. But when it is not easy to identify the child as a boy or a girl, the doctors and surgeons do everything possible to make the sex of the child correspond to the binary logic which has caused us to conclude mistakenly that everyone is either male or female.

The medical experts do everything possible to conceal intersex issues and how problematic sex assignments are from the public.

It is easy to believe that intersex is a mistake of nature but the mistake is our own blindness.

We refuse to look at the natural world and all the possible sex variations which overlap one another in various gradations on a spectrum with male at one end and female at the other.

As a result, modern medicine continues to impede the progress and social integration of many children, not just the intersexed.

Intersexuality is not just about the body of the child but also the child's own sense of self and how s/he feels inside.

An individual's sex identity is a crucial part of one's overall identity.

Focusing exclusively on the body as the main factor for determining a person's identity reduces the individual to a limited number of body parts and completely dismisses the perception that the individual has of their own body and the person living in that body.

As a parent, it is important to understand that, even though we are required to choose a sex for our child, the one chosen may not be that of our child.

This responsibility cannot be the sole responsibility of the parents.

Do we as parents have the right to own and assume complete control over the bodies of our children?

Are surgeries which supposedly can change the sex of our children and which are often irreversible really necessary?

Questions and more questions, but this is all an integral part of being the parent of an intersex child.

This is why it is necessary to take time to understand intersexuality before making any decisions. Intersex is not an illness.

However, one must not forget that there can be some serious health issues involved as with any child and certain treatments and operations may be necessary.

To try to change the child's sex does not respect the child's own choice.

The doctor's choice is what becomes more important when surgical sex assignments are considered but they know that no one can predict the sex identity of the child.

We all have "ambiguities" and differences but we are still able to see what we have in common – our humanity.

Doctors know that all people are not male or female.

It is our humanity which should count most.

Human affection, our capacity to love others despite our differences, is the greatest contribution that we as parents can offer the world.

Our love for our children is a gift which will help humanity accept diversity and social changes which encourage a more just and tolerant world.

If you want to give your child a chance for being happy, then surgery is not automatically the solution.

Doctors must be honest with parents. It will be the parents who have to decide.

So, first of all, it is the duty of the medical community to inform the parents of the consequences of surgery – all of them.

Not choosing surgery does not mean that parents are not raising their child as a boy or a girl.

Every child needs a sex identity in order to be integrated into society.

You can help your child develop an identity without surgery or other interventions that are not necessary for the child's health.

At first you will have to go on your own instinct; what you feel deep down in your own heart is the best.

But the child will need to develop an identity that works best for the child.

This is true of all of us.

The purpose of OII is to work in favor of human rights for the intersexed by helping people to understand that there are not just two preexisting sexes.

There is an infinite combination of possibilities on the spectrum of sex and gender.

OII campaigns against all nonconsensual normalization treatments of infants that are not medically necessary and favours the right of all intersexed children to determine their own sex identity once they are capable of communicating it to us.

Furthermore, OII advises parents to respect the sex identity of their children and to do all that is necessary so that their children can live according to their choice. ❁

# Chapter 6: Child Rearing

## How is a parent supposed to raise an intersexed child? Like any other child.

Don't stress what makes the child different.

Help the child accept the difference and stress how the child is like other children because all children are different.

There are many different kinds of boys and girls.

The parents need to understand their child's body and leave as many options as possible for the child's future development.

It is important to accept behaviour that is not considered typical for the assigned sex but it is still necessary to help them develop sexually.

Everyone has a social identity – a social role.

It is not possible at this time to raise a child as simply intersex in the sense of an intersex identity.

The fact that the child develops a social role as a boy or a girl in accordance with what seems most appropriate to the child will not prevent the child from developing an intersex identity once they are adults.

The parents need to understand the issues.

The child will develop an identity as a result of their upbringing.

There are many facets to one's identity.

Every child presently needs a social identity as a boy or a girl and the parent can help them develop a social identity by being honest and listening to the child.

Parents should not feel they are responsible for determining the child's choice.

Every human being is different in the way they think about themselves and develop an identity.

We cannot control our child's brain.

No matter how much we are involved in their upbringing, we must understand that the child may come to an opposite conclusion concerning their identity. ❁

# Chapter 7: How to Tell Your Child

**I**t is important for the child to understand intersex too in order to help the child grow up and make a life independent from us in the future.

Don't conceal intersexuality from your child.

Your child will sense there is something different and will want to understand.

Don't make this a family secret.

Your child might not ask questions or may not have the words to express what they want to know.

What is important is to find out if the child has doubts about their body and if so respond to those doubts in a way that the child will understand.

Sometimes you will need to help the child feel comfortable to ask questions without giving them more information than they are ready to deal with.

Keep it simple and only answer the questions as honestly as possible as the child tries to understand their own body and/or identity.

You can ask specialists about how to answer certain questions or what to expect at certain stages in a child's development but do not get a mental block against any possible question the child might ask. All children ask unexpected questions.

There are times that parents will not know the answer to the child's question and it is best to tell the child you simply don't know but that you will try to find out from people who may have the answer.

Use very simple words when possible and let the child know that "they" also are free to ask a specialist if "they" would like to.

This manual was written for parents of intersex children to help them better understand how to deal with what is most likely an unknown world for them – intersex.

It was written by parents who hope to help other parents understand their child's difference and accept their child. ❁

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