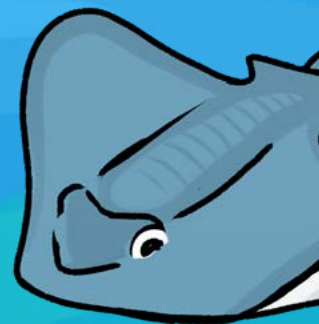


Variations in Sex Characteristics/ Ira Tangata



Navigating Healthcare Decision Making

A guide for parents and
caregivers in Aotearoa





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Kia ora, nau mai, Haere mai

Welcome to this guide for navigating healthcare decision making for children born with an innate variation in sex characteristics (VSC)¹ in Aotearoa/New Zealand.

This guide is for anyone who is a parent or caregiver of a child/tamaiti with a VSC in Aotearoa and for the healthcare professionals working with you.



Ngā mihi

E hara taku toa i te toa Takitahi, engari he toa Takitini.

We give our sincere thanks to those who took part in the research that made this guide possible, and to honouring us with further feedback to improve the guide.

Ngā mihi aroha ki a koutou





Intentions of this guide

Whenever you have to navigate the health care needs of your child/tamaiti it can throw up challenges, especially when it comes to making complex decisions that will have long-lasting impacts on your child's/tamaiti's future.

You already have the skills to be a wonderful parent and provide love and support to your child/tamaiti.

This guide is designed to give you the information to build on and strengthen your skills to support your child/tamaiti now and for their future. It aims to assist with the conversations you can have with your healthcare team.

Who developed the guide?

All the information in this guide is based upon the findings from a joint venture project done in collaboration with the Intersex Trust Aotearoa New Zealand (ITANZ), Wellington Hospital Department of Paediatric and Child health (WHDPCH) and University of Otago.

The research project involved interviews with parents, health professionals and young people (aged 14-26) here in Aotearoa. The participants shared their lived experience of what it is like to have a VSC and the way that the health care system works for parents, caregivers, whānau, young people, and health professionals.¹

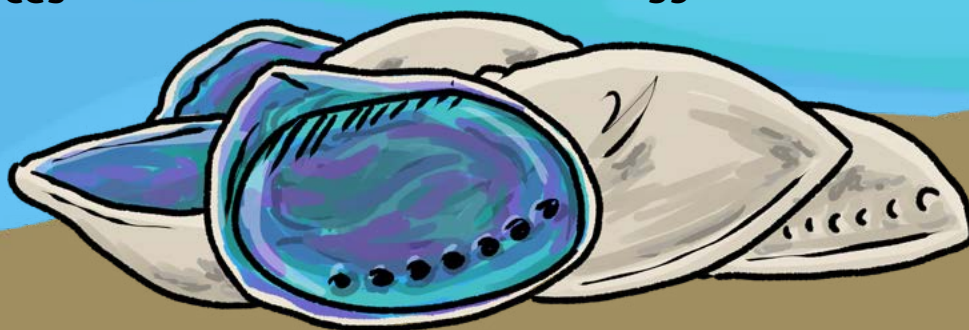
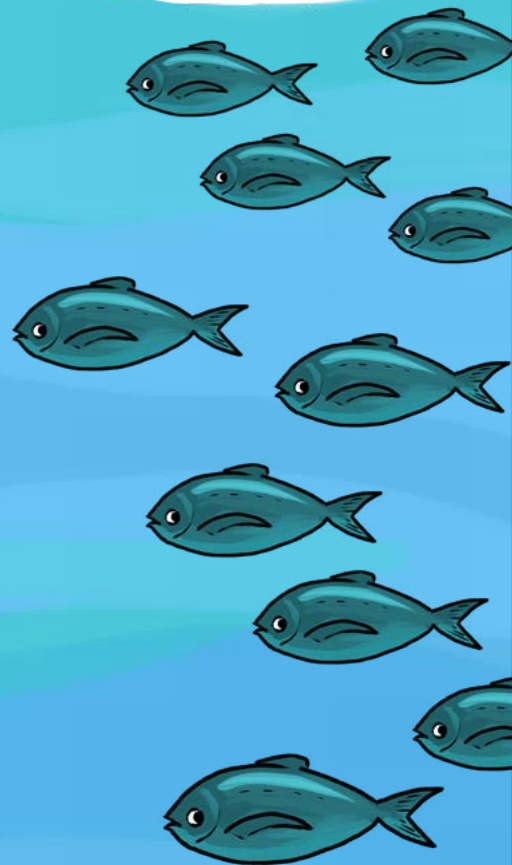
Terminology

Throughout this guide we have chosen to use the umbrella term VSC as this is seen as a more inclusive term. Our aim is to be as inclusive as possible and we acknowledge that this term may not suit everyone.

In this guide we will provide anonymous quotes from our participants in the research.

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Tikanga Matua

Core Principles

Collaboration

This guide is intended to encourage collaboration between health professionals, VSC advocates, VSC peer support and parents/caregivers with a view to achieving the best possible healthcare options together.

Diversity

There is a great deal of diversity among people with a VSC. While there will be aspects of commonality among this group, there will be a wide range of lived experience.

Education based on research and lived experience

This research intends to honour the lived experience of those directly affected by a VSC and provide a perspective based here in Aotearoa.

Self-Reflection

Taking time to reflect on our own beliefs, privileges, stereotypes, and conscious and unconscious biases we may have about the way gendered bodies should look and function.

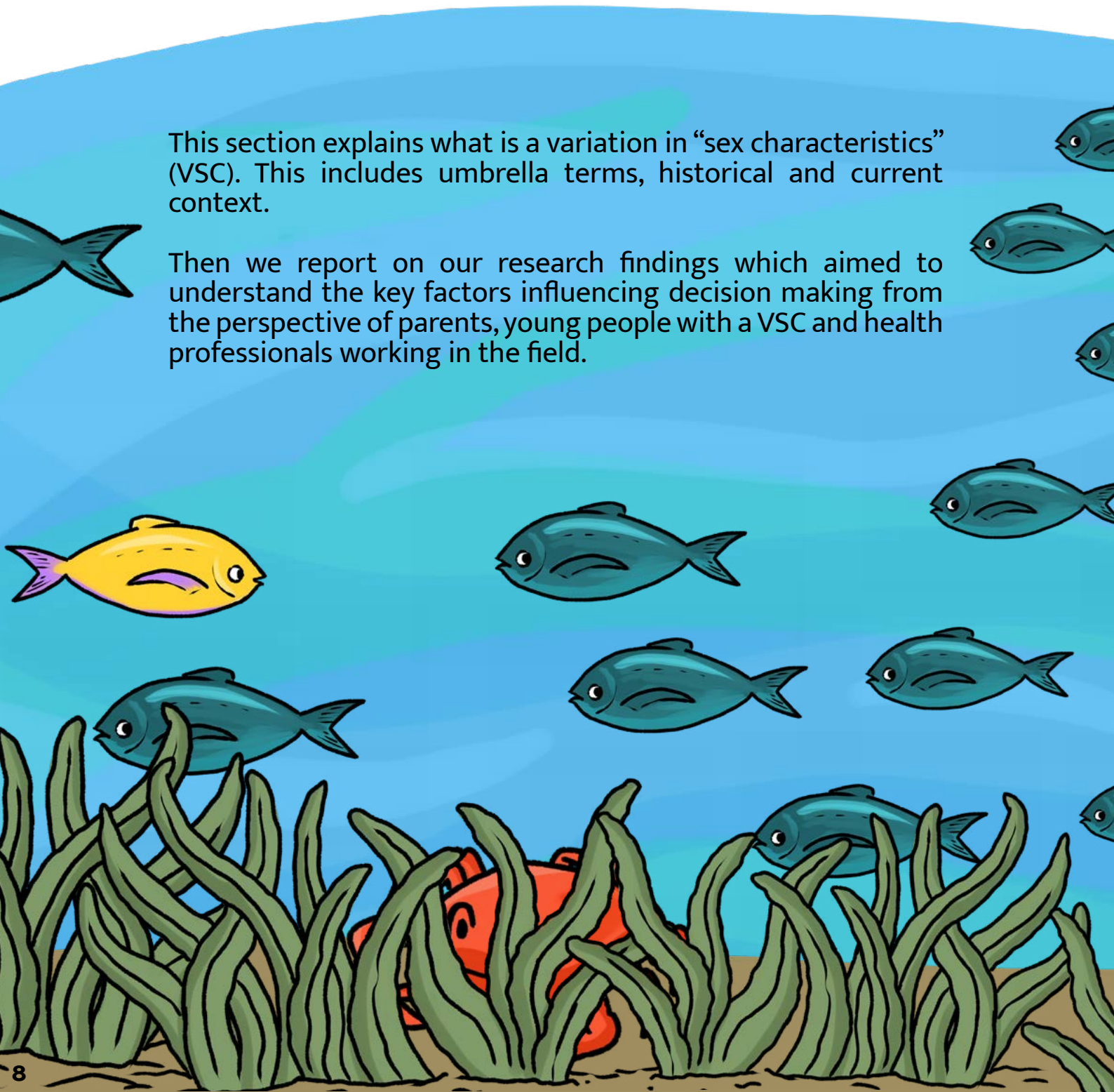
Informed Consent

This guide aims to support parents/caregivers to access fully informed consent i.e. all the information needed to weigh the costs and benefits for the decisions that you make on the behalf of your child/tamaiti and their future.

Part One: BACKGROUND

This section explains what is a variation in “sex characteristics” (VSC). This includes umbrella terms, historical and current context.

Then we report on our research findings which aimed to understand the key factors influencing decision making from the perspective of parents, young people with a VSC and health professionals working in the field.



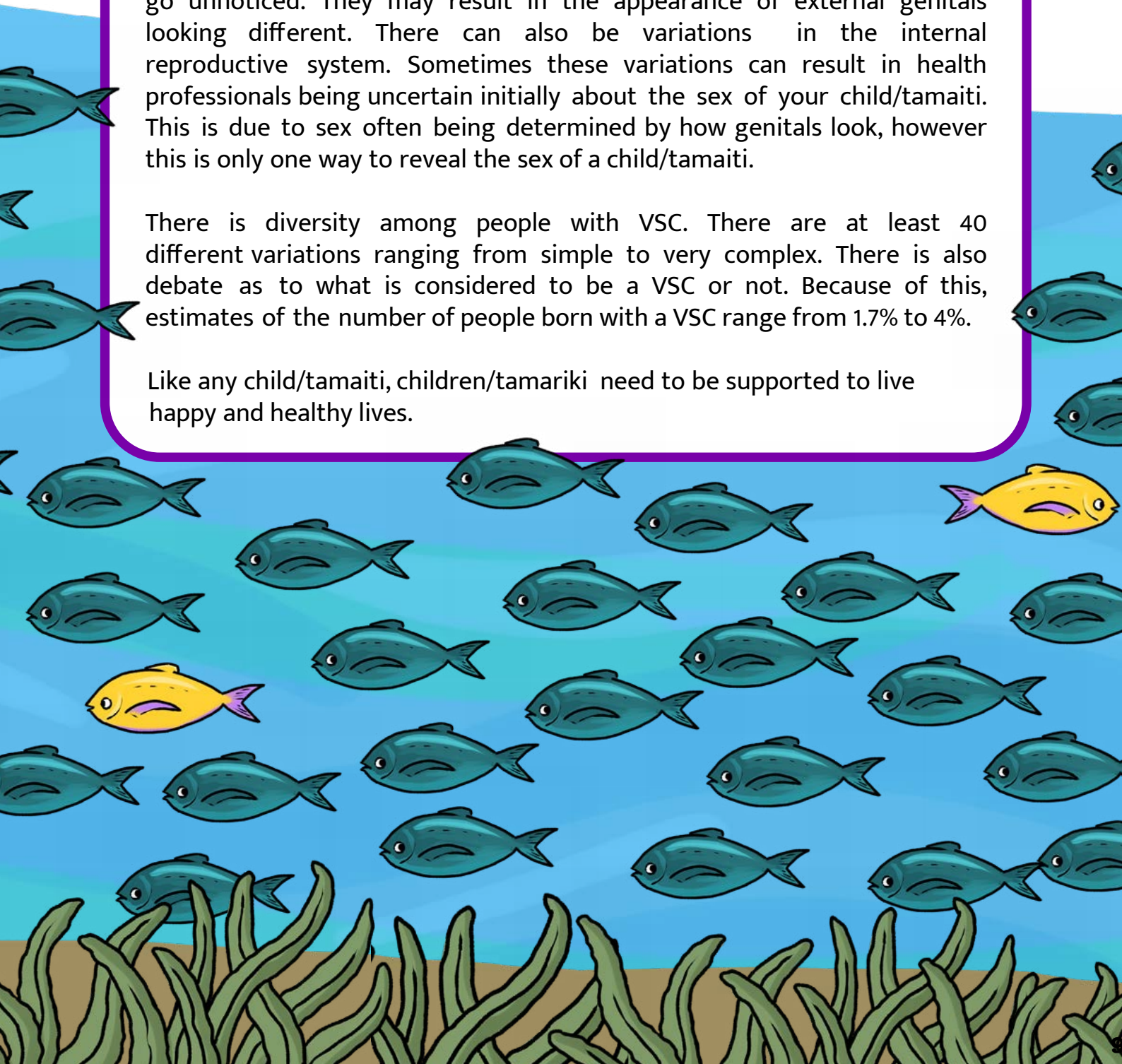
What is a VSC?

Every person's body is unique. Innate variations in sex characteristics are understood to manifest in a spectrum of ways, many occurring naturally and in most cases not life threatening. Science tells us that some variations result from a genetic anomaly, while others may be the consequences of variations in chromosomal makeup, hormonal processes, or gonad formation. In some cases, there is little understanding of cause. There is still a lot for us to learn.

These variations may be diagnosed at birth or present at puberty and may go unnoticed. They may result in the appearance of external genitals looking different. There can also be variations in the internal reproductive system. Sometimes these variations can result in health professionals being uncertain initially about the sex of your child/tamaiti. This is due to sex often being determined by how genitals look, however this is only one way to reveal the sex of a child/tamaiti.

There is diversity among people with VSC. There are at least 40 different variations ranging from simple to very complex. There is also debate as to what is considered to be a VSC or not. Because of this, estimates of the number of people born with a VSC range from 1.7% to 4%.

Like any child/tamaiti, children/tamariki need to be supported to live happy and healthy lives.



Umbrella Terms

Umbrella terms group together more specific variations into a broader category.

People may not be familiar with umbrella terms, or feel comfortable using them.

Differences of sex development

Variations in sex characteristics

Intersex

Ira Tangata* or Takatāpui.²

Here are some of the variations:

- Congenital adrenal hyperplasia (CAH)
- Androgen insensitivity syndrome (AIS). Can be partial (PAIS) or complete (CAIS)
- Mayer-Rokitansky-Kuster-Hauser syndrome (Also called MRKH, Müllerian agenesis and vaginal agenesis)
- Gonadal dysgenesis (partial and complete)
- Swyer syndrome
- 5-alpha reductase deficiency
- Hypospadias Epispadias
- XY cloacal extrophy

*See Glossary and endnote for more detail on these Māori terms.

Historical and current context

Past

Many people here in Aotearoa and globally have been negatively affected by the treatment that was thought to be best practice before the turn of the 21st century. This resulted in the development of VSC advocacy groups worldwide in the late 90's and early 2000's.

In post-colonial Aotearoa there had been a culture of silence, non-disclosure and stigma attached to an individual born or diagnosed with a VSC. In Aotearoa, ITANZ was established in 1996 with the purpose to advocate for change and offer support and education.

Medical institutions have reviewed and revised the treatment protocols and guidelines for people born with a VSC. In 2006 and again in 2016, a global consortium of experts made suggested changes, and called for better communication, cessation or delay of appearance based genital surgeries, psychological support and more research.^{3,4} These guidelines and recommendations are constantly evolving.

Current

There have been many positive changes in this current century, including full disclosure around diagnosis and better communication. More work is being done to provide vital access to support parents and children/tamariki.

The Human Rights Commission has hosted two intersex roundtables (2016, 2017) to bring together national experts across many sectors and those with lived experience to foster collaboration for change and consistency.^{5,6}

There continues to be robust debate and differing opinions on the way forward for some healthcare options facing some individuals born with a VSC. This variety of viewpoints is understandable when there is such diversity.

All people with VSC have some things in common. No matter the variation, all healthcare options are presented and discussed in depth both to parents and to children/tamariki in age-appropriate ways. This is one of the many motivators for the development of this guide: to contribute to the ongoing conversations between healthcare professionals, whānau and children/tamariki.



Our research findings

Parents

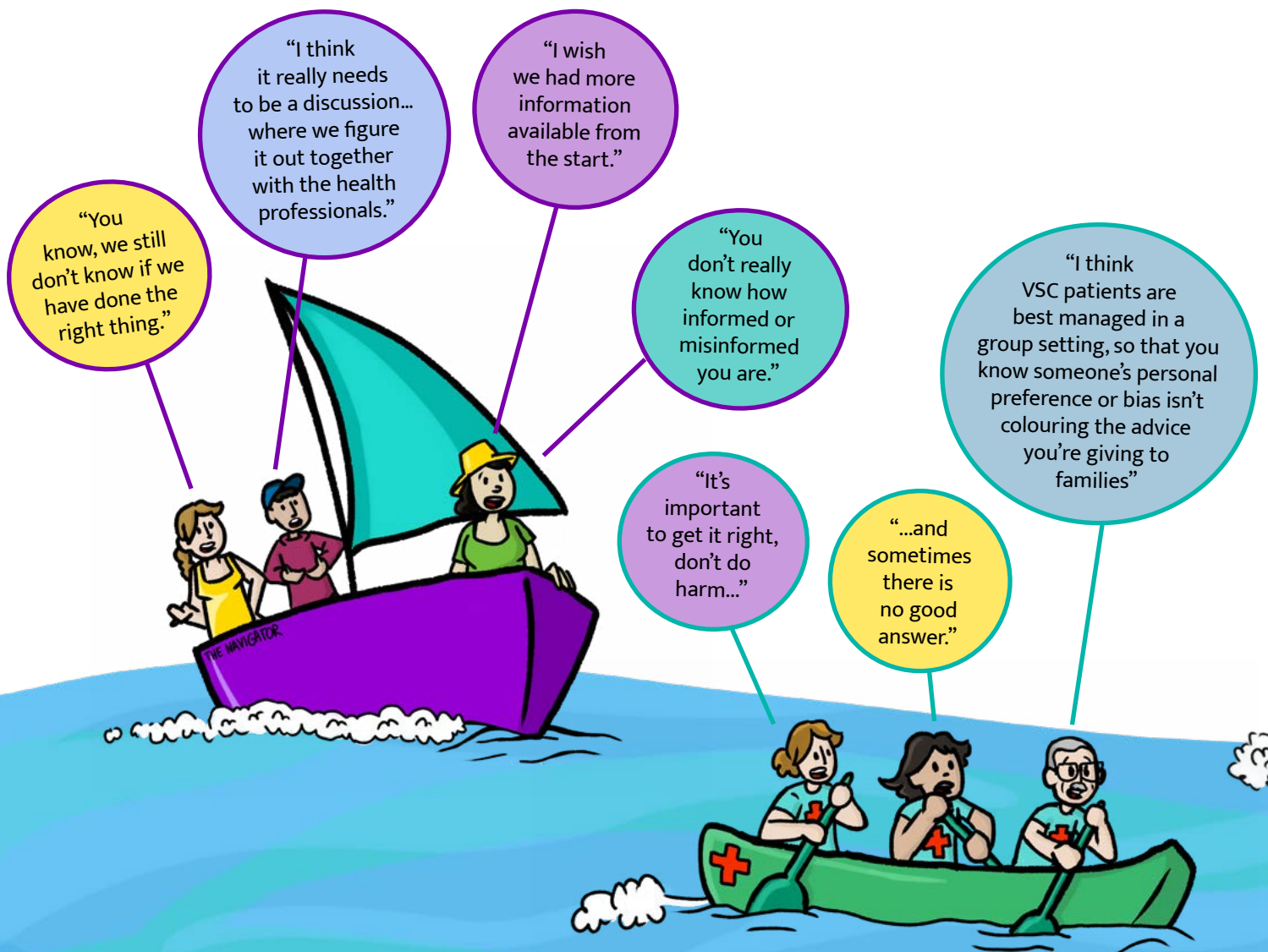
Parents in our research worried about what was the right thing to do to support their child/tamaiti. They also worried about the future of their child/tamaiti and how they would manage dealing with a VSC diagnosis and whether their child/tamaiti would be happy with the decisions their parents made on their behalf.

Parents had concerns about having access to ongoing support in future years, especially about navigating challenges that may occur in puberty. Parents wanted more guidance from medical professionals to help understand and navigate decision making.

Health Professionals

Health professionals recognised the implications of the historical mistakes of the past and were mindful of not repeating those. They also had concerns about meeting everyone's expectations, which may at times differ from current medical guidelines, and those of VSC advocates as well as the parents or young person themselves (if they are older).

Sometimes complex decision-making is involved. Nevertheless, presenting all the options is important. This includes the possibility of delaying optional medical interventions until the person concerned is old enough to decide for themselves.



Young People

Young people in the research made two key points. The first was their right to bodily autonomy, that is, having the chance to decide what, when and if medical interventions are performed on their bodies.

Young people were aware parents are in a tough spot trying to work out what is in their best interests. However, they were clear that they wanted to have input into decisions when possible. This relates to decisions than can be delayed until the child is older (not to life-saving decisions).

Overall, young people, parents and health professionals believed there needed to be better communication, support and greater awareness of personal bias and normative thinking when it came to the stereotypes of what it means to be male and female, especially regarding genital appearance.

Secondly, young people highlighted the issue of identity and how that develops over time and place. Again, this must be considered when navigating decisions.

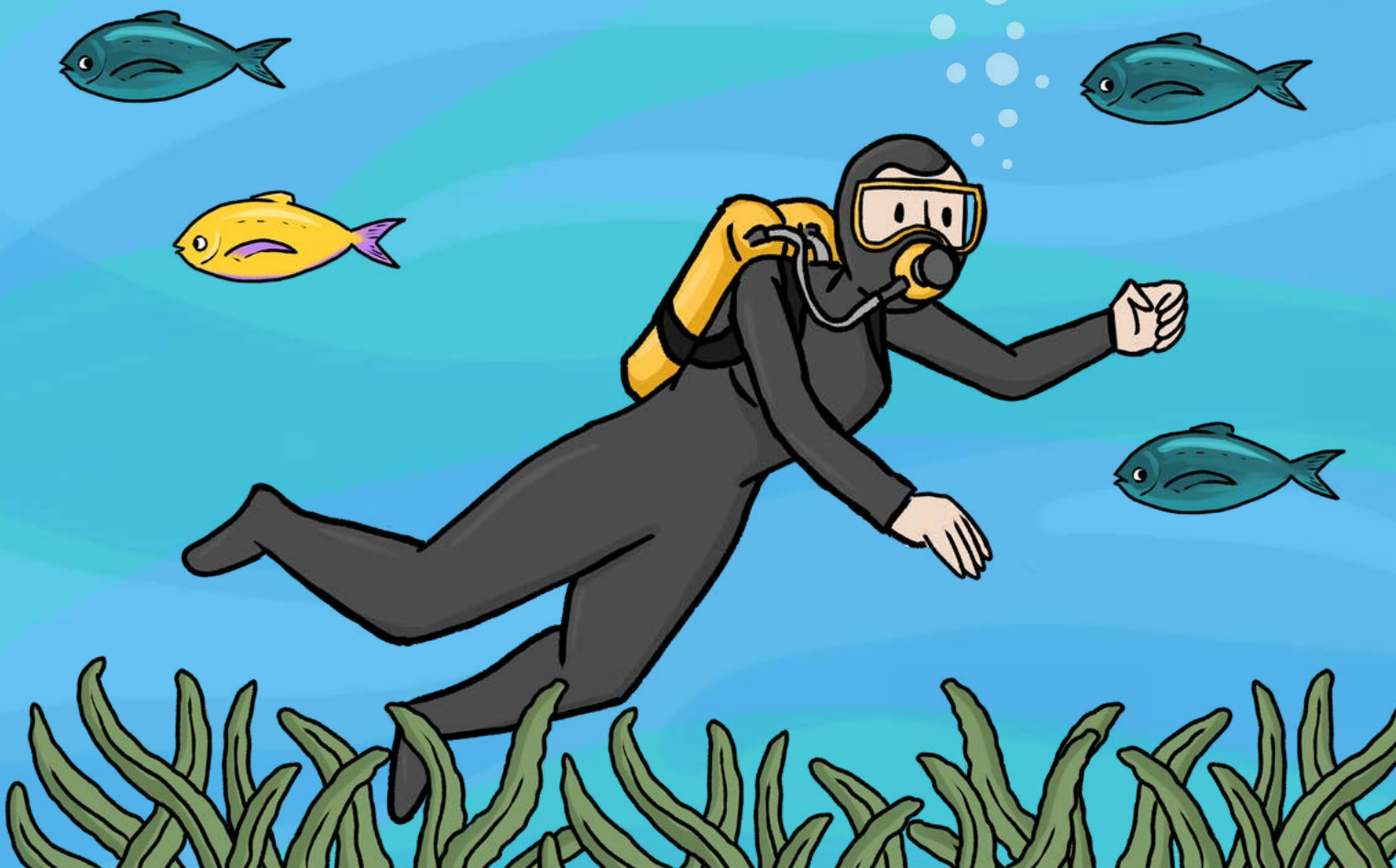
All this requires trust which all three groups recognised as important for decision-making.



Part Two: NAVIGATING DECISION MAKING



This section of the guide explores how you think and feel when trying to make decisions for your child/tamaiti. Some decisions may be simple and some more complex.



Every parent's situation is unique. This guide offers some common themes that were reported to us by participants in our research.

Finding out you have a child/tamaiti with a VSC can be challenging at times and knowing what to do can be complex and confusing. There can be a number of options and diverse opinions about which way to proceed, adding to the confusion. Parents themselves can have different points of view as well as health professionals. This is also true for adult people with lived experience who you may access online through peer support groups. It is important to remember and respect that even though points of view may differ between people they can all be valid points of view.

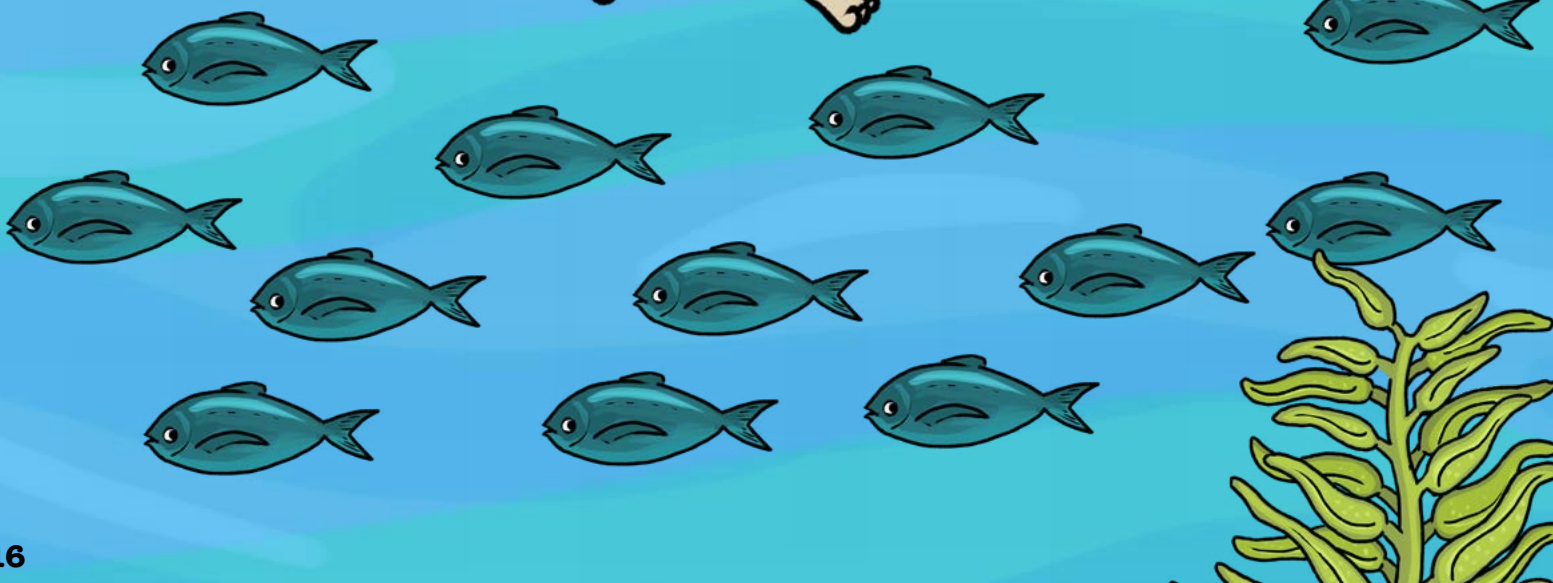
This next section explores what is happening at the point you find out that your child/tamaiti has a VSC. There are some ideas about what might be helpful to consider when moving forward into discussing treatment options for your child/tamaiti.



What is happening?

Parents often feel overwhelmed in the first instance, which is totally understandable when you are informed your child/tamaiti has a VSC. Like any news given in a health context it can come as a shock and induce anxiety, confusion and a sense of fear. Some parents may even experience a sense of loss or grief for the child/tamaiti they were expecting. These are all natural feelings and something that your health professional can help you process.

It is important to take a deep breath, take stock of what you know, which may be little as most of us have not heard about VSC before now. Is your child/tamaiti healthy and well in this moment? Then think about what you need to know.



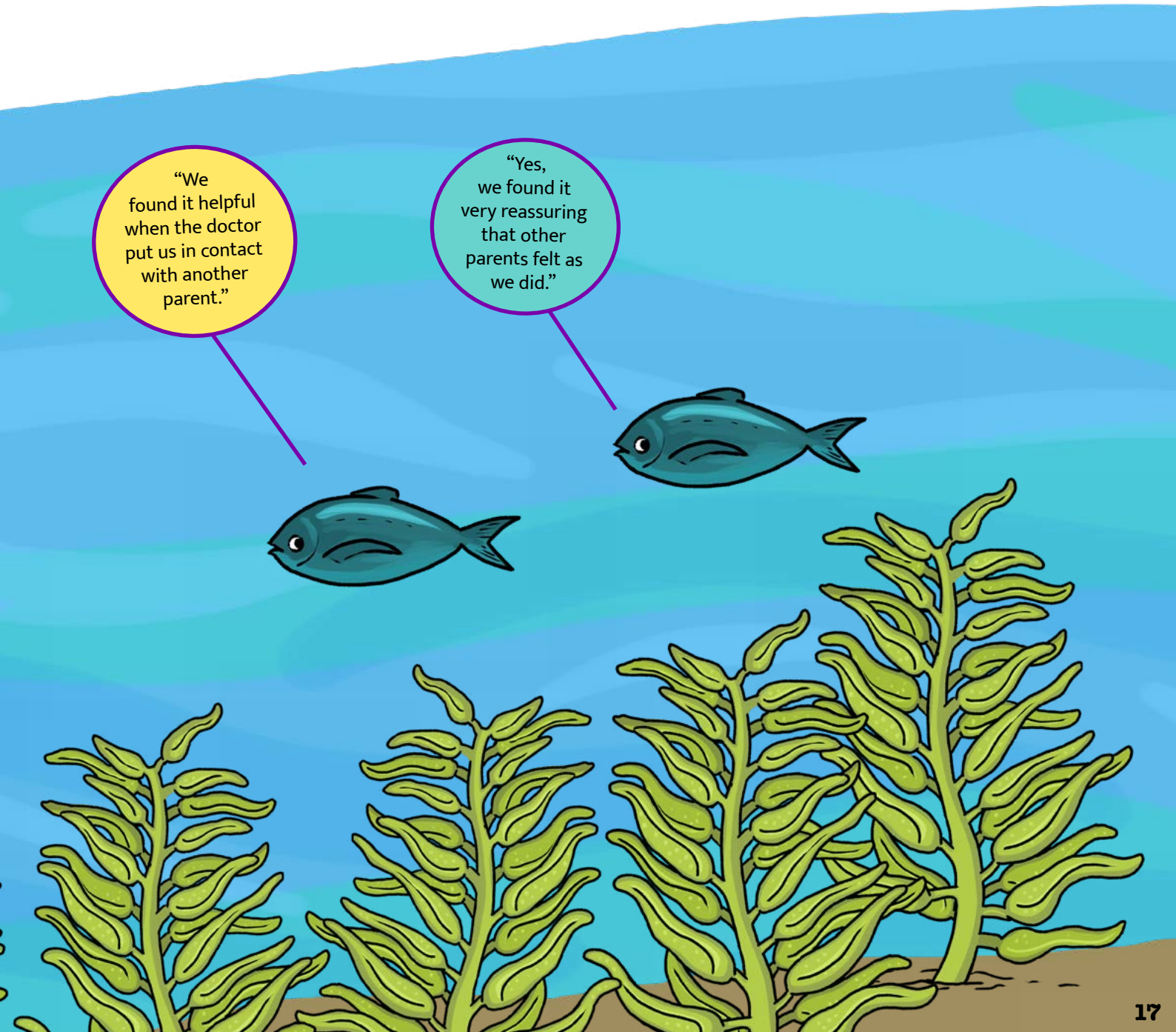
What do we do?

The most important thing to do is to get support early. Ask for as much information as possible so you can make an informed decision about what having this particular variation means for your child/tamaiti and for you as parents.

Take the time you need to become informed.

Talk with people you trust and feel safe and supported by. Ask to talk to other parents who have lived experience of having a child/tamaiti with a VSC. Sometimes health professionals can help you access other parents or you can try through online VSC support groups.

Take time to consider not only what this means for your child/tamaiti now but for their future.



"We found it helpful when the doctor put us in contact with another parent."

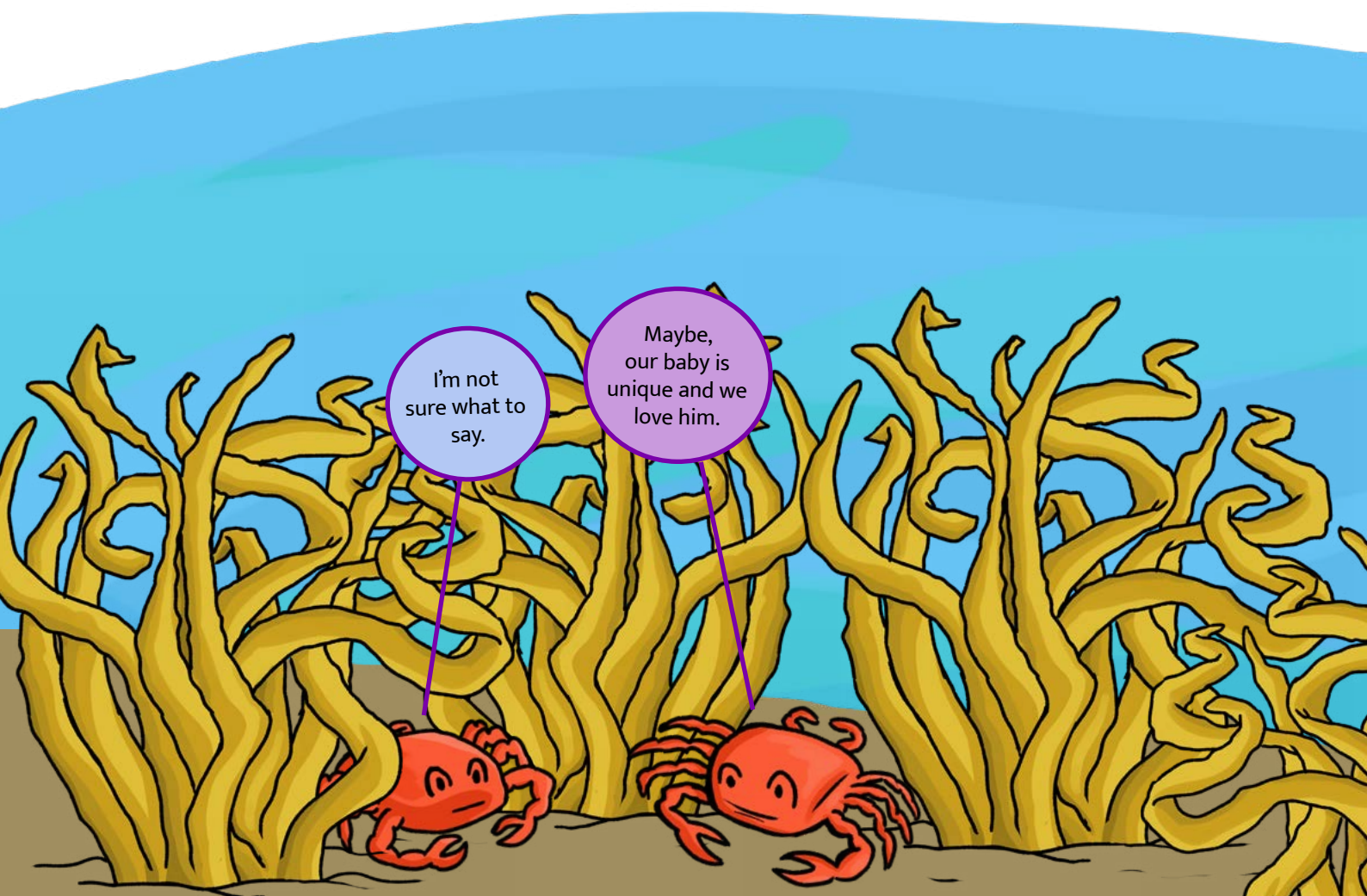
"Yes, we found it very reassuring that other parents felt as we did."

Privacy vs. secrecy

It can be difficult deciding who to tell about your child's/tamaiti's variation. You may want to keep things private until you feel clearer in your own mind and have processed your own feelings and thoughts.

Privacy is about taking time to be with your own thoughts and feelings. Everyone is entitled to privacy, including your child/tamaiti. Maintaining privacy can involve choosing a small circle of trusted people who you can talk to. It can also mean that you and your child/tamaiti can choose over time what you share with others. Secrecy, on the other hand is intentionally hiding information; this can be unhelpful and even hurtful. Secrecy often creates an atmosphere of shame for those who are at the centre of the secrecy. Keeping things secret can mean you don't access the support you need.

Being open with the people you are close to and trust is recommended. Having a VSC is one part of what makes your child/tamaiti unique. Encouraging acceptance early on will enable your child/tamaiti to feel confident in their own body.



Telling friends and family

Most people will be supportive when you talk with them about your child's/tamaiti's variation. Just like you, some people may have little knowledge about what a VSC is and therefore may be overly curious. This can lead to some people saying unhelpful comments and at times being insensitive. You don't need to answer all of their questions, only those you feel comfortable with.

Try to be calm and respond by informing them that VSCs are more common than they think. Even though public awareness is limited, explain that having a VSC is just part of human diversity.

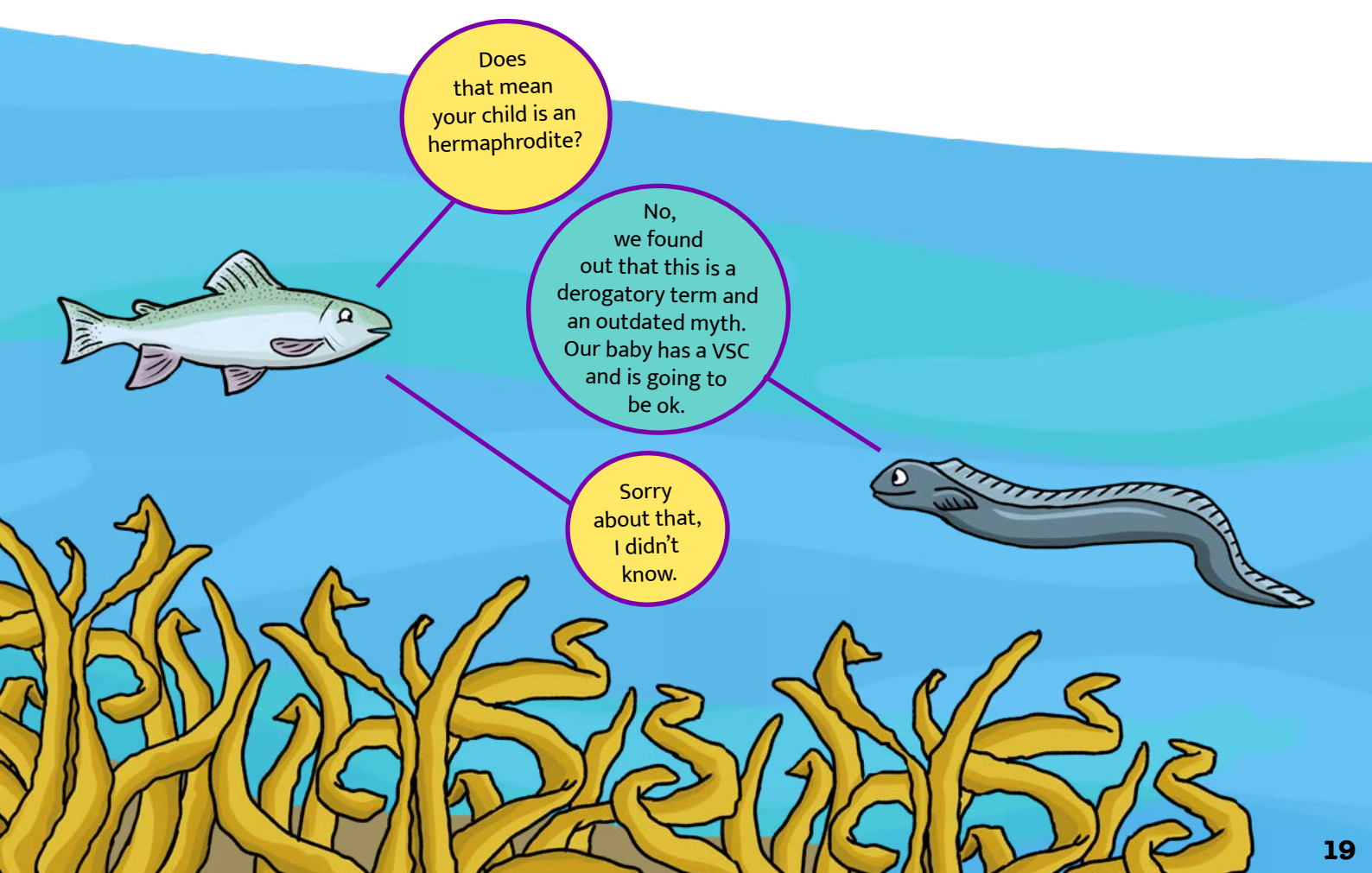
People are often keen to know whether your child/tamaiti is a boy or a girl, if this is unclear (which sometimes happens) and you are waiting on a test result to clarify you can respond by saying something like:

“We have a beautiful baby, 3.5kg, we are all doing ok. Just tired and need a day or two to rest. Be in contact soon”

or

“Our lovely baby has arrived! We are just waiting on a few tests to clarify a few things. We are all very excited and look forward to telling you more soon”

The more comfortable you are, in talking with your child/tamaiti and the people you can trust, the easier it may be for your child/tamaiti to experience acceptance.



Does that mean your child is an hermaphrodite?

No, we found out that this is a derogatory term and an outdated myth. Our baby has a VSC and is going to be ok.

Sorry about that, I didn't know.

Taking a balanced approach



Parents and health professionals are tasked with balancing the health needs of their child/tamaiti and with thinking about their child's/tamaiti's right to have agency over their own bodies. This means gaining understanding about what is essential for your child/tamaiti now and what may be delayed until your child/tamaiti becomes a young adult/rangatahi. This would give them the opportunity to choose to consent to what happens to their body.

Healthcare needs may, in time, require you to evaluate risks of organ dysfunction, cancer, incontinence and future potential for fertility.

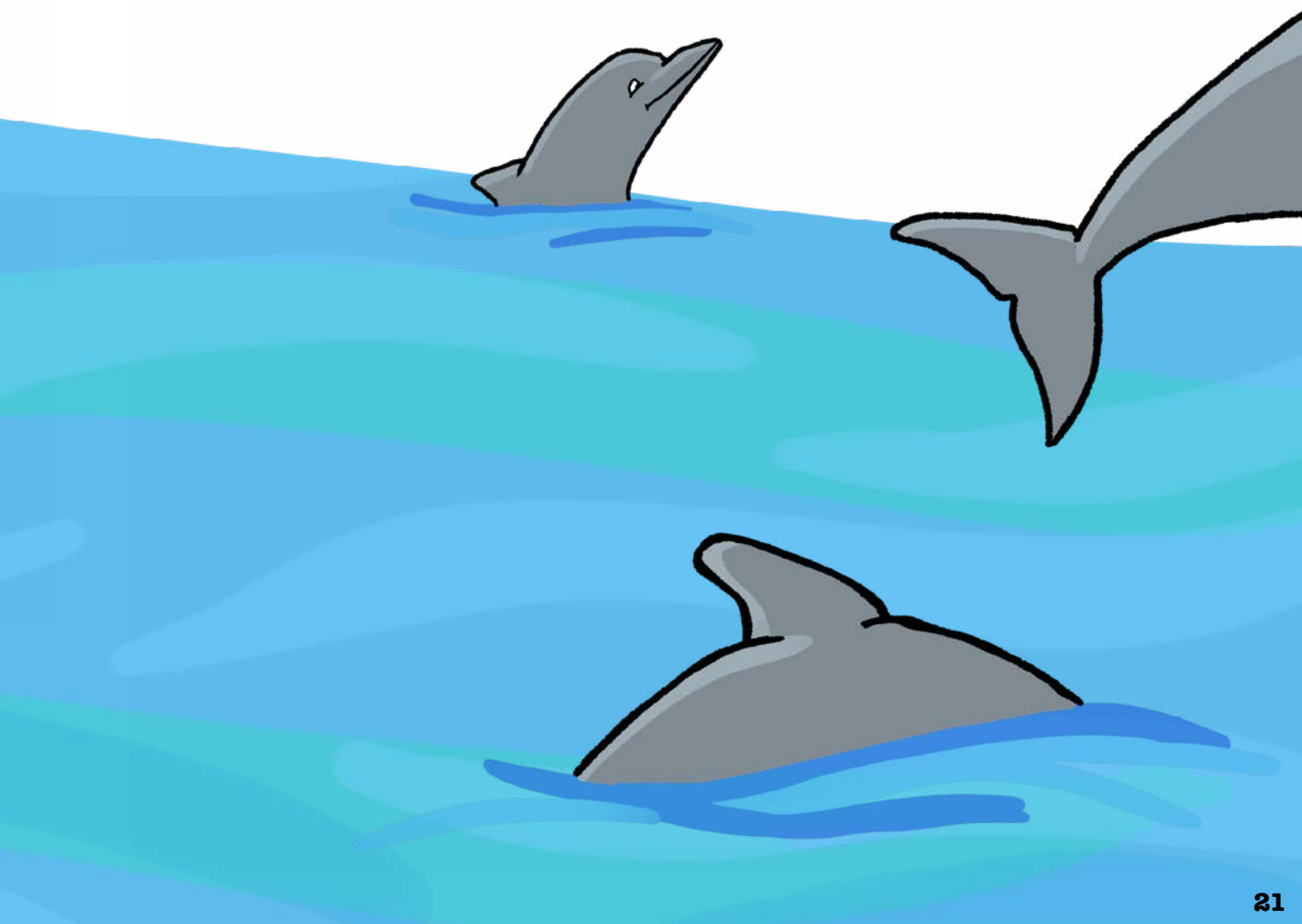
Options for healthcare may be straightforward depending on your child's/tamaiti's variation. It is best to find out what the options are for your child's/tamaiti's specific variation as they will all have different variables to consider. In some instances, there is limited robust research as to outcomes for a number of interventions. This includes timing of interventions, that is, whether to do them early or later or some would say not at all.

This is where things can become complex and confusing especially if opinions vary between those you speak to or read about from online VSC peer based support. Take your time, don't rush, gather as much detail as you can from a variety of sources, health professionals and VSC support groups. Remember it is alright to ask for a second opinion, whether that be from a doctor or a parent with lived experience. Seek out information that balances different opinions so you can weigh the pros and cons. Make sure the information is specific to your child's/tamaiti's VSC.

Issues around whether to delay a treatment so your young person/rangatahi can decide for themselves what happens to their body are challenging, as it is hard to know what is best especially in the absence of robust outcome data. These decisions are always difficult.

It is important to be aware that guidelines for best practice treatment protocols from both a medical and human rights perspective are always evolving, not just here in Aotearoa/NZ, but internationally.

The next few pages aim to help you think about these issues further based on the voices of what young people in our research discussed and hoped their parents would take into consideration.



Self Reflection

It is important to take the time to reflect on your own point of view and how this may impact on your decision making. Our own views and beliefs can blind us to different ways of thinking about what is considered “normal.” It is helpful to try and expand our understandings of the norms we might take for granted as truth when in fact it they can be driven by certain societal structures we have adopted at any given point in time.

Some questions you might like to ask yourself -

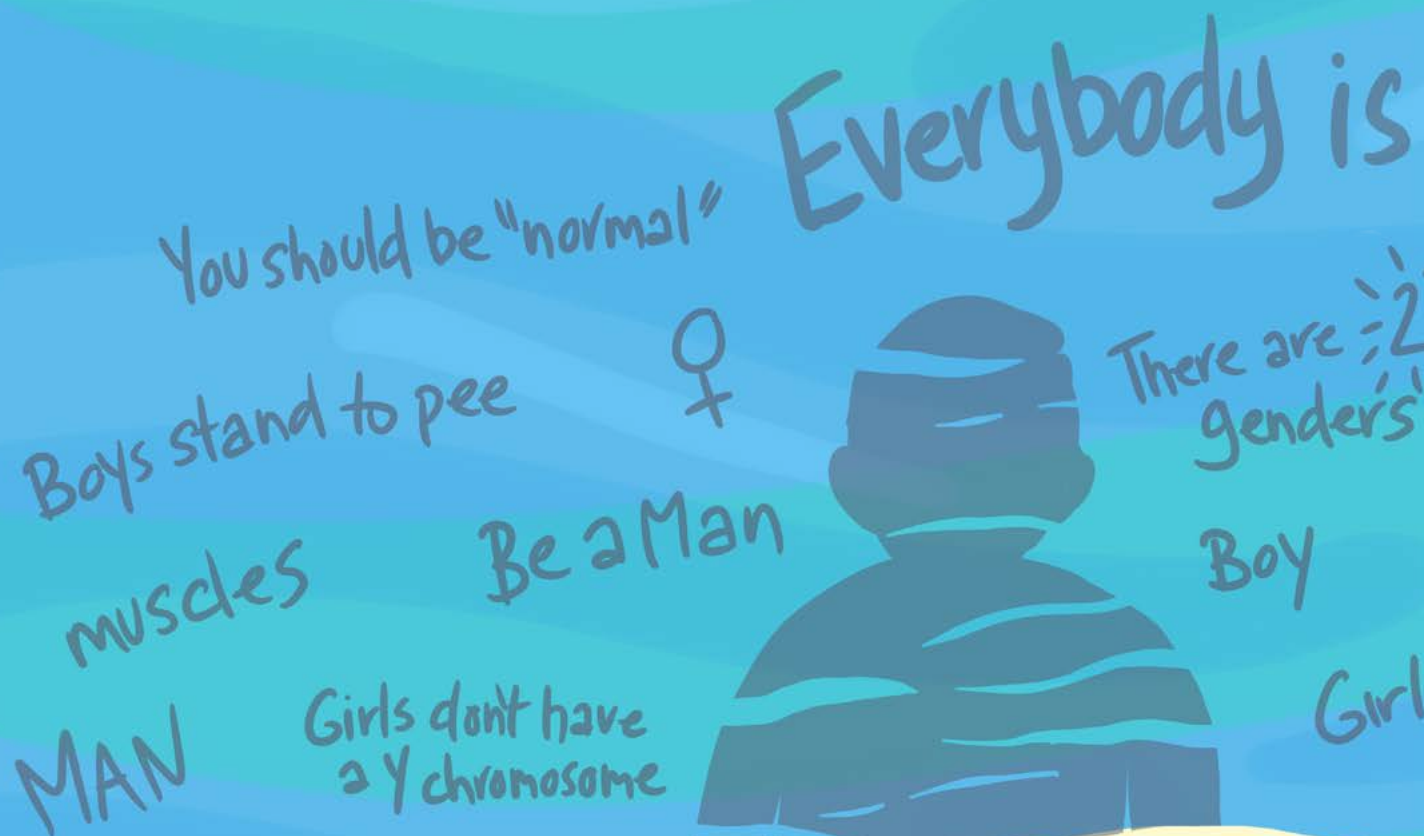
Do my personal beliefs bias the way I think about gender stereotypes or how bodies should look? (for example, do you believe a male has to urinate standing in order to be real boy/man?)

Are the decisions I am making for the benefit of my child/tamaiti or are they for me? (for example, am I choosing a particular treatment as it will help me feel more comfortable? Feeling this way is natural, however, consider is it a reason enough to choose a treatment option?)

Have I sought information from those with lived experience, especially young people so I can consider how my child/tamaiti might feel?

Have I given myself permission to take the time to be expand my thinking and consider different points of view?

Am I being norm critical? (i.e. challenging normative thinking)



It is vital to allocate time to discuss these issues with your partner, trusted friends, family, health professionals and VSC advocates, so you can expand your thinking and recognise any bias.

Ask questions of your health professionals and if you are struggling to get answers to your questions, seek a second opinion. Contact a VSC support group like Intersex Aotearoa.

The more you reflect on and understand what is driving your decision making the more confident you will be about making a truly informed decision not clouded by personal bias or pressure of outdated societal norms.



Different



Girls should be feminine

WOMAN

dresses

Boys don't cry

What is normal?

Either/or
Not both

girls like boys
I feel uncomfortable

Identity

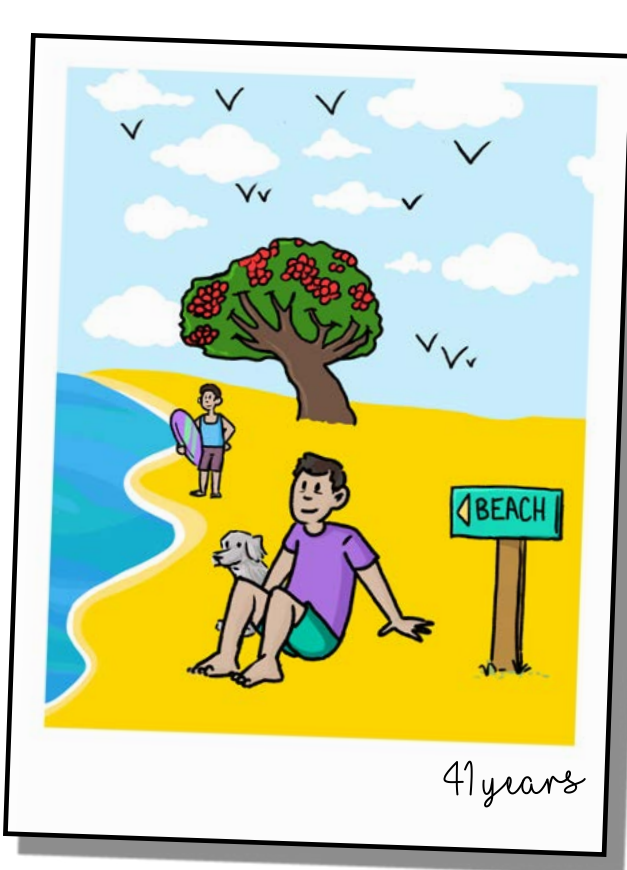
Identity changes over time and place.



Take time to remember how the world has changed over the last few decades. Think about how societal views have changed in relation to gender, sexuality and gender expression. Imagine what it might be like in 20 years from now when your child/tamaiti is a young adult/rangatahi.

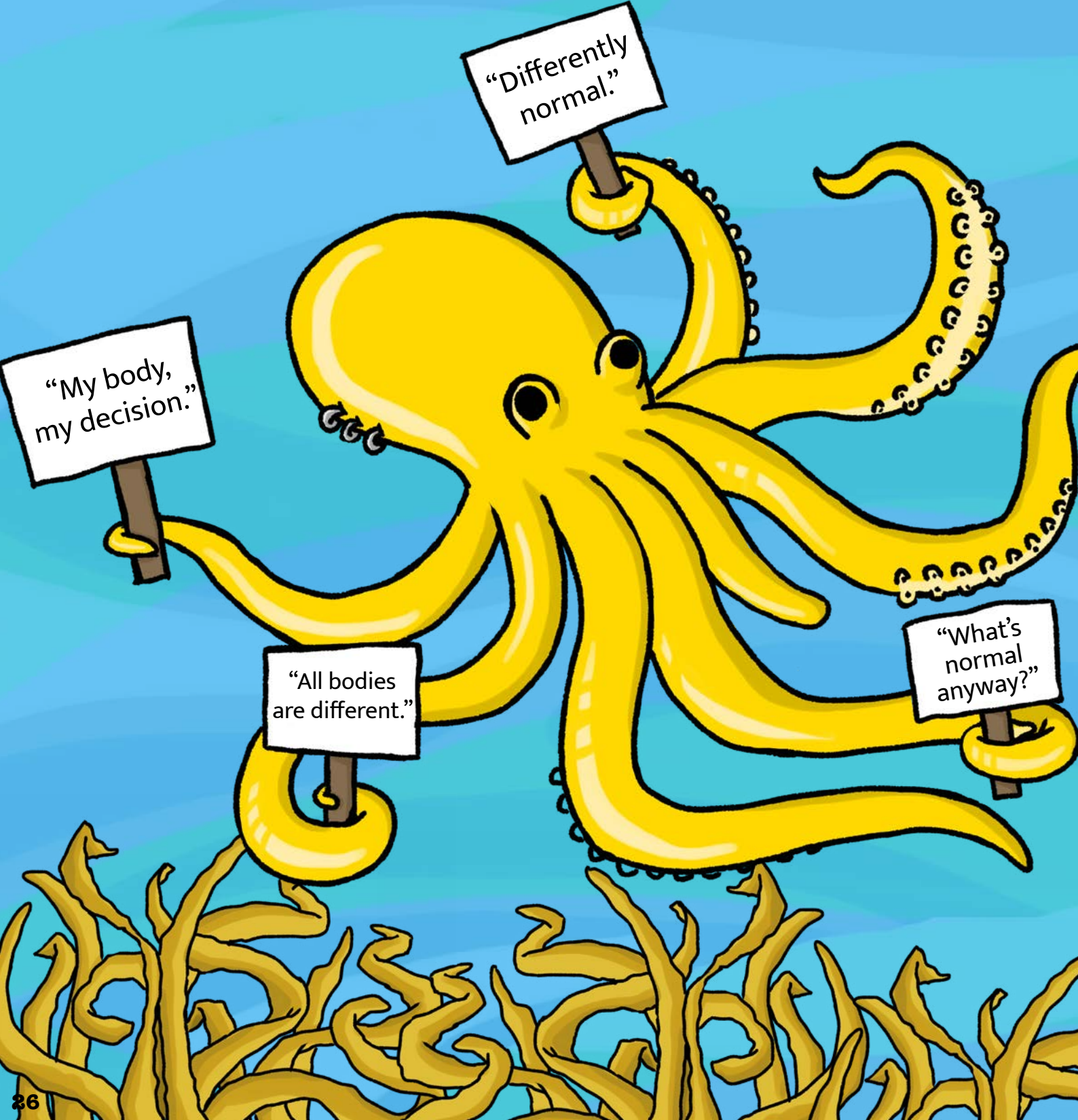


When thinking about the identity development of a child/tamaiti, consider the way you thought about things 10 or 20 years ago and how that may have changed now you are older.



We often fear how our child/tamaiti will be accepted in the world. Remember to consider that social constructs such as gender, gender expression and diversity are evolving all the time and are likely to become more expansive and inclusive as time goes on.

Bodily Autonomy



"My body,
my decision."

"Differently
normal."

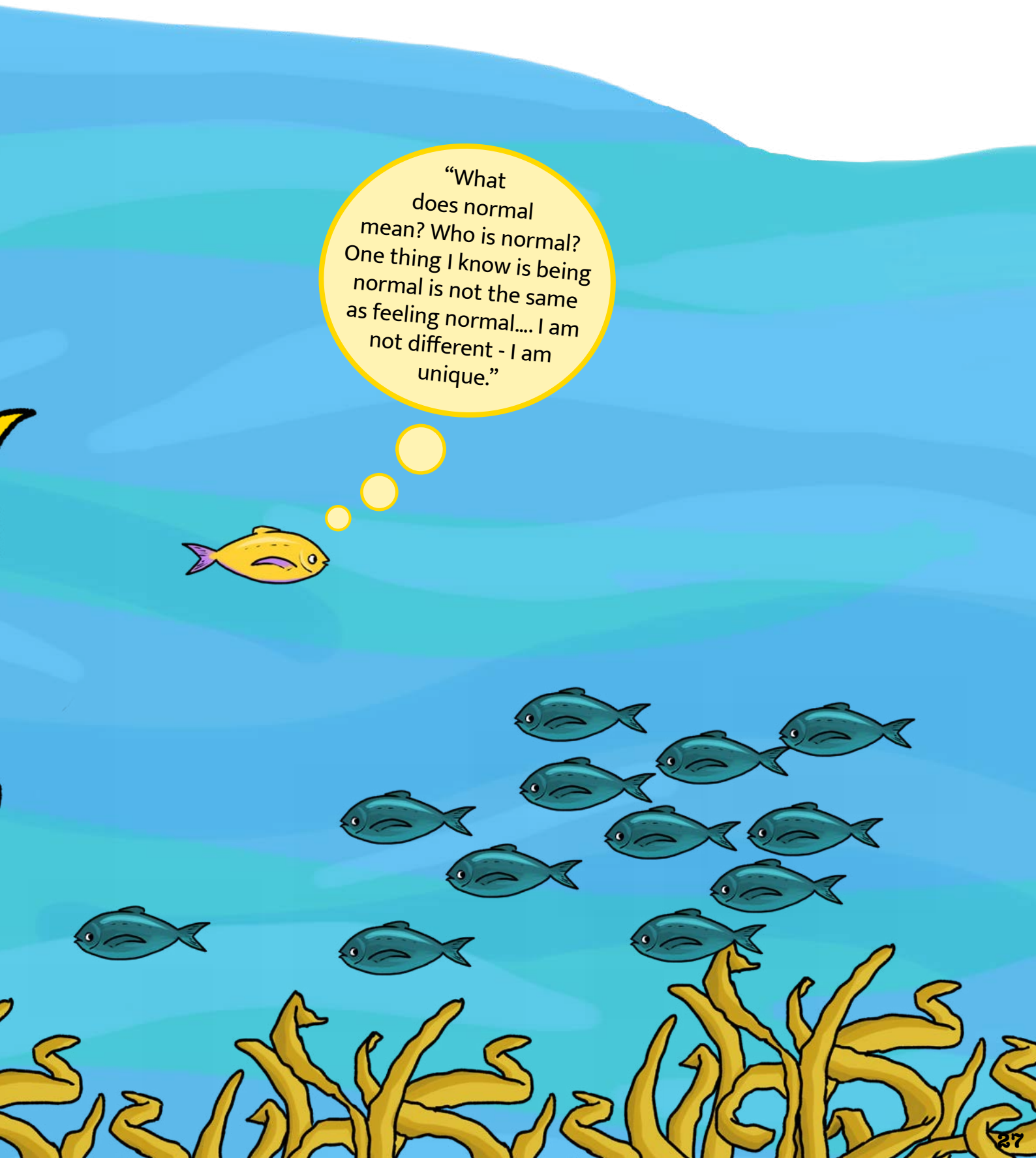
"All bodies
are different."

"What's
normal
anyway?"

The young people/rangatahi gave a strong message that they wanted the right to decide what happens to their bodies where possible.

Young people/rangatahi acknowledged some decisions will need to be made when they are young, especially to preserve life or to support a functional urinary and reproductive systems where possible.

Consider whether interventions can be delayed, especially those related to appearance based surgeries that are very personal and may impact on intimacy in the future of your child/tamaiti.



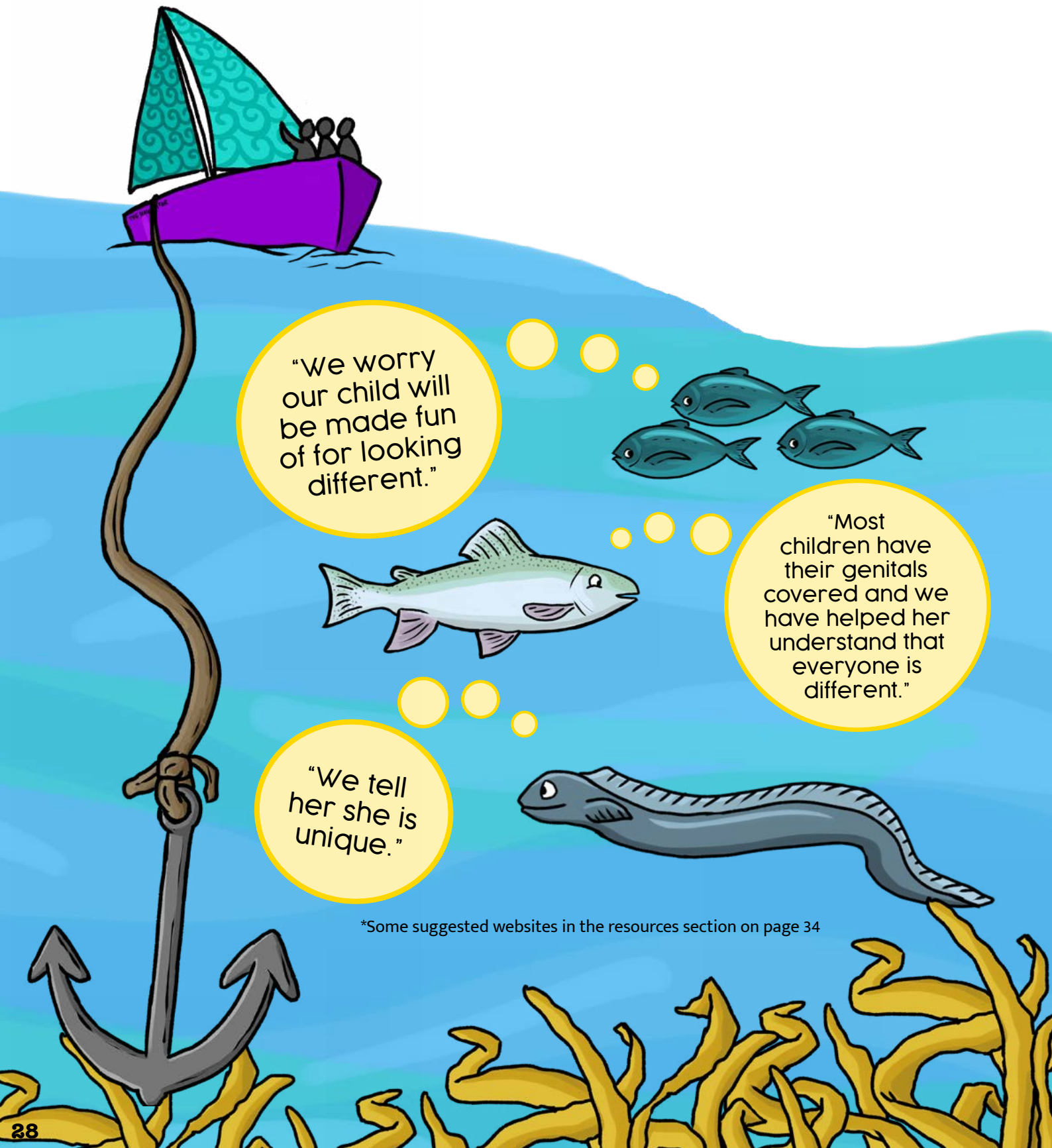
“What does normal mean? Who is normal? One thing I know is being normal is not the same as feeling normal.... I am not different - I am unique.”

Take Time

Remember you are not alone.

Talk to other parents

Ask health professionals to link you to other parents and VSC support organisations, look online* and do your own research.



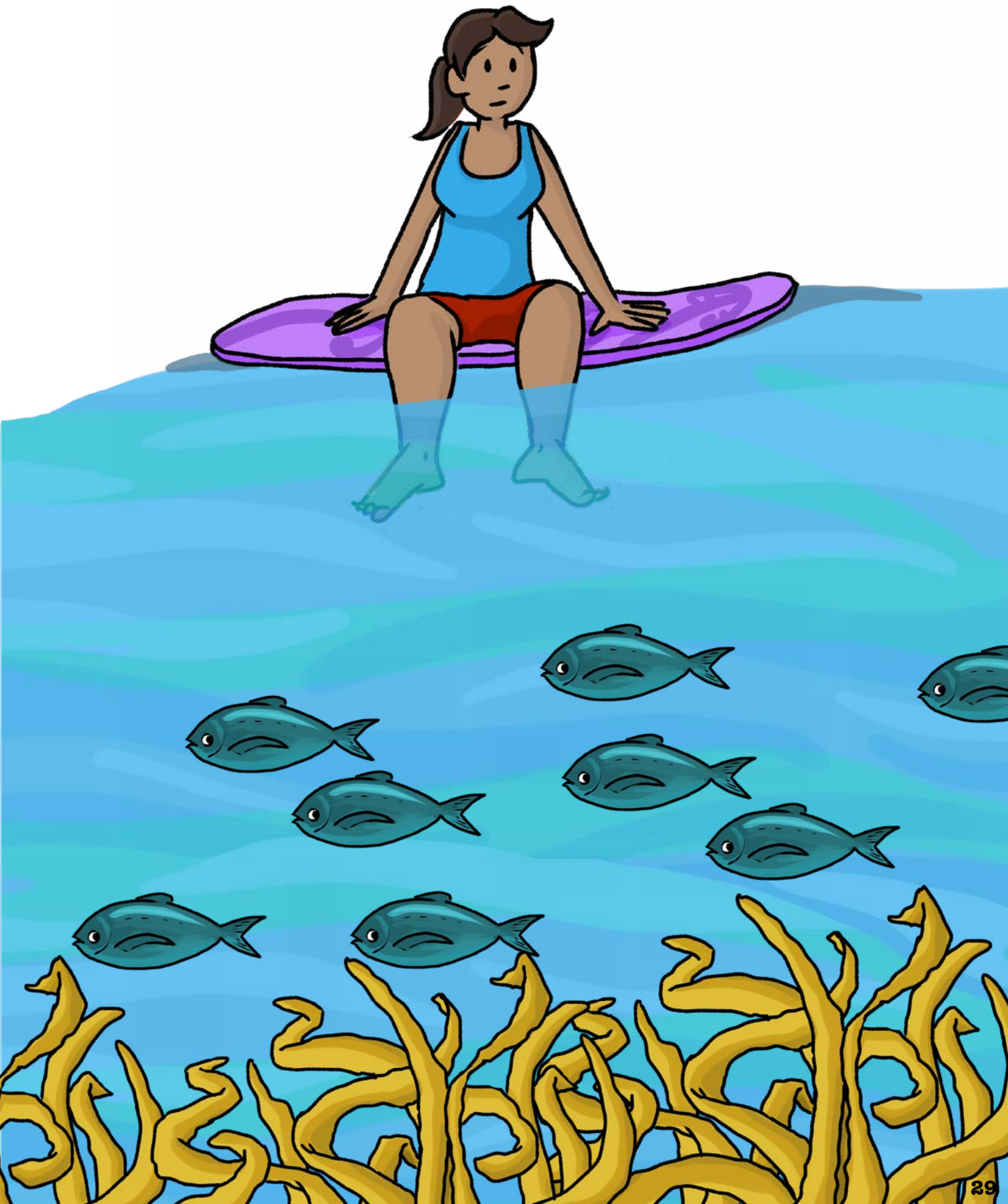
"We worry our child will be made fun of for looking different."

"Most children have their genitals covered and we have helped her understand that everyone is different."

"We tell her she is unique."

*Some suggested websites in the resources section on page 34

The next two pages (p30/31) provide a summary of the main themes from the research we did, some of which we have discussed in more detail in the navigating decision making section. The decision making process summary suggests some questions to ask yourself in relation to the research themes that were identified in the research.



Decision Making Process Summary

- Have I been offered and got the support needed?
- Have I got access to peer support?

Support

- Whose expectations am I meeting - mine, society's, my family's and friends', or what I think is the child's/tamaiti's?

Expectations

Future worries

- Will my child/tamaiti be happy with my decisions in the future?

Recognition of the past

What's right?

- Have I considered what those with lived experience have said?

- Is this decision making for me or for my child/tamaiti?





- Have I checked my privilege and bias?



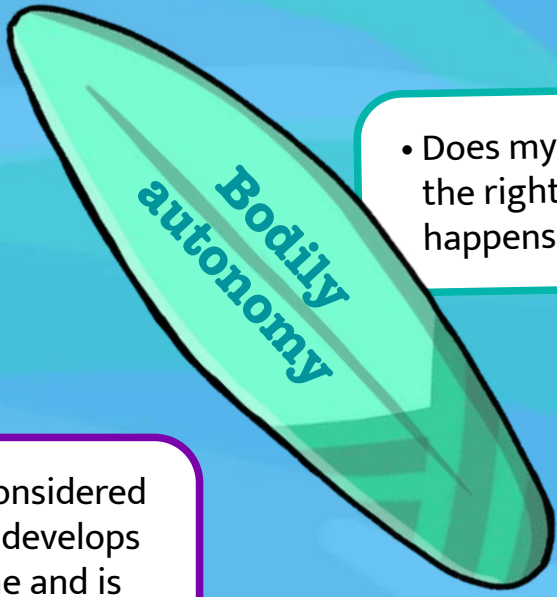
- Have I considered what norms I am accepting or rejecting?
- Is diversity and acceptance of difference a part of my thinking?



- Have I been provided full information?
- Have I been given options?
- Have I been offered supportive and sensitive language?




- Have I considered identity develops over time and is deeply personal?



- Does my child/tamaiti have the right to decide what happens to their body?

Take home tips

-  Take time before making decisions.
-  Don't rush. Ask questions of your health professionals.
-  You are not alone! Seek support from those with lived experience.
-  Self-reflect: understand what is driving you decision making.
-  Think about your child's/tamaiti's right to bodily autonomy and self determination.
-  Seek psychological support and peer support when you are ready.
-  **Loving your child/tamaiti is the best medicine for a healthy, happy child/tamaiti.**



Glossary

Bias is where we hold a preference for something or someone over another often resulting in prejudice and judgement. We are often unaware of our bias and at other times very aware.

Gender refers to the characteristics of women, men, girls, boys and nonbinary people that are socially constructed. This includes norms, behaviours and roles associated with being a woman, man, girl or boy, as well as relationships with each other. As a social construct, gender varies from society to society and can change over time.

Gender Binary refers to the social construct that there are only two genders, male and female rather than viewing gender as a spectrum that is inclusive of those who are nonbinary.

Gender stereotypes refer to the norms that are held within society about what it is to be a male, female or nonbinary. For example, females have long hair, men have short hair and nonbinary might have either. Often these are out dated and many qualities are just human but become gendered as a result of societal norms. For example, only females can be sensitive when in fact any person is capable of being sensitive. Sensitivity is a human quality, not a gendered quality. Another common one is blue is for boys and pink is for girls. What we know is that pink and blue are simply colours.

Innate - born with, for example eye colour.

Ira Tangata (Ira - Genetics/whakapapa, Tangata – Personhood) is a Māori reference for Identity and Whakapapa. This term acknowledges in te reo that Māori are Indigenous first and not defined by any one characteristic or variation. The term comes from Tu Chapman, of Ngāti Kahungunu and Ngāti Awa descent and is the co-chair of Intersex Aotearoa.

Norms are constructed expectations often reinforced by societal rules, often these can be entrenched and out dated (similar to stereotypes).

Norm critical means challenging societal norms to be more inclusive of difference and diversity so as to not label those that fall outside the norm as “abnormal.”

Sex generally refers to the binary notion of male and female bodies determined by their genitalia, gonads, sex chromosomes and hormones. There are variations that can occur that don't fit into the binary and these are referred to as variations in sex characteristics (VSC). Also known as intersex or Differences in Sex Development (DSD)

Takatāpui - traditional Maori term meaning “intimate companion of the same sex”. It has been reclaimed to embrace all Maori who identify with diverse sex characteristics, genders and sexualities such as whakawahine (trans women), tangata ira tane (trans men), lesbian, gay, bisexual, transgender intersex and queer. These are often grouped under the term “rainbow communities”.



Endnotes

- 1 Steers, D. M. 2020. “Gender Mender, Bender or Defender: Understanding Decision-making in Aotearoa/New Zealand for People Born with a Variation in Sex Characteristics.” PhD diss., University of Otago. <https://ourarchive.otago.ac.nz/handle/10523/9986>
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Supports

Aotearoa

Intersex Aotearoa

<http://www.ianz.org.nz/>

<http://www.facebook.com/intersexaotearoa>

Aotearoa’s own website, office based in Wellington

International

Intersex Peer Support Australia

<https://isupport.org.au/>

Australian online peer support

Intersex Human Rights Australia

<https://ihra.org.au>

InterACT

<https://interactadvocates.org/>

A USA based youth advocate organisation

DSD families

<https://dsdfamilies.org/>

UK website -links for parents and teens



Resources

<http://www.ianz.org.nz/supporting-parents-of-intersex-youth/>
NZ guide for parents of intersex youth/Rangatahi

https://dsdfamilies.org/application/files/4115/3780/1476/Top_Tips_for_Talking.pdf
A resource for talking to your child/tamaiti about their variation

“Intersexion” documentary
Available at your local library.

<https://youthandi.org/>
YOUTH&I- stories from young people with a VSC



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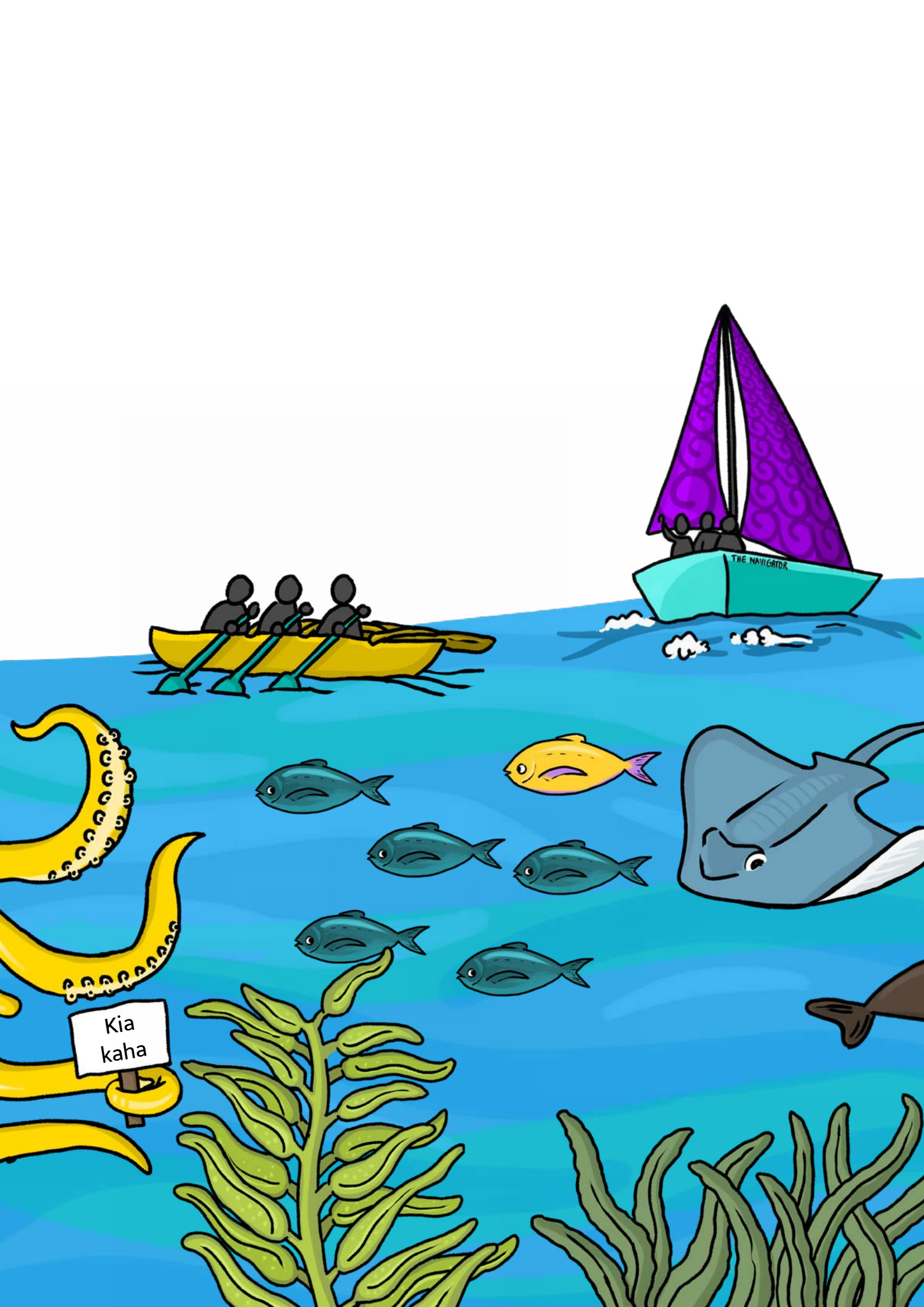
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