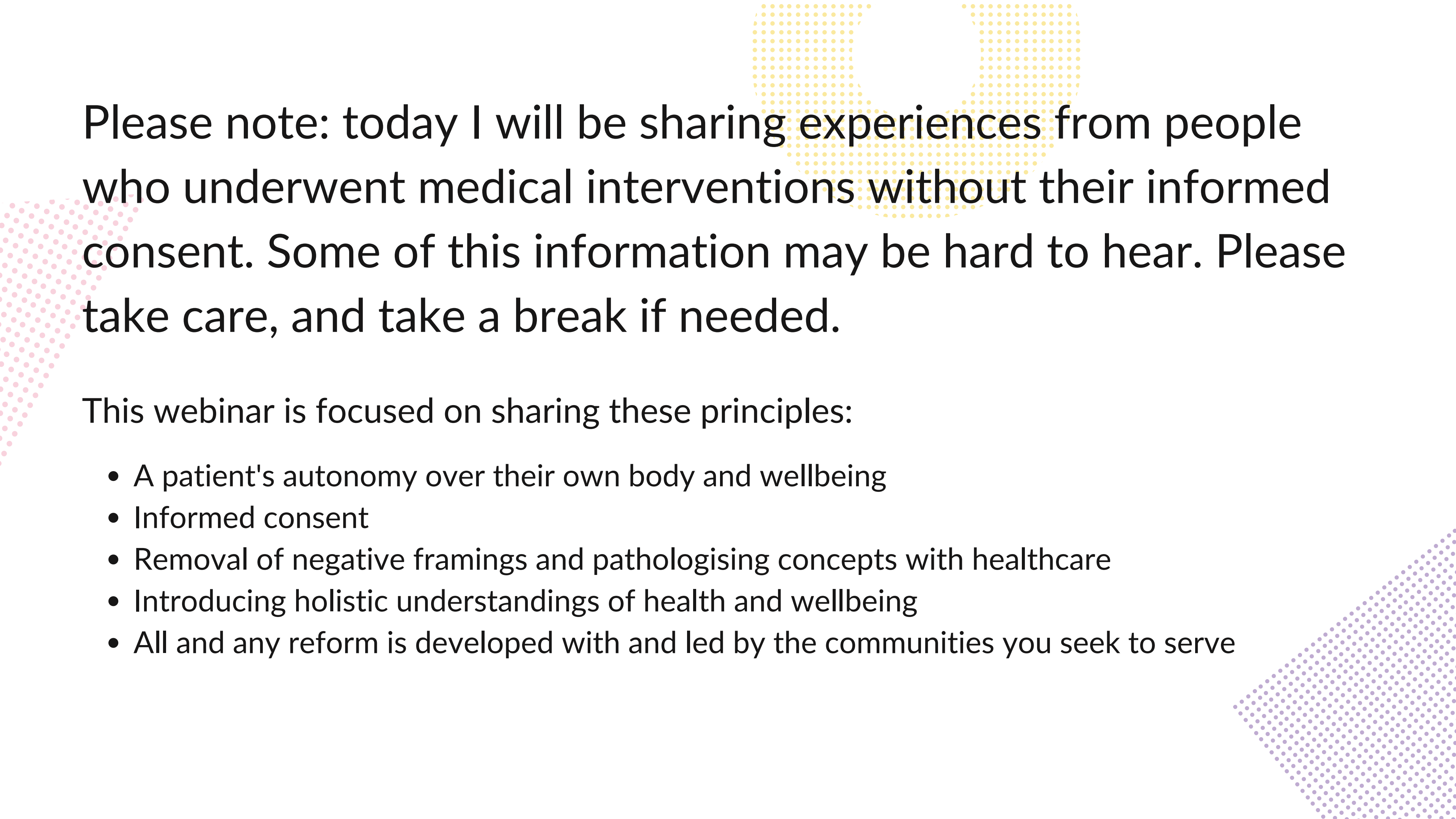


A human rights
approach to healthcare for
intersex communities



Please note: today I will be sharing experiences from people who underwent medical interventions without their informed consent. Some of this information may be hard to hear. Please take care, and take a break if needed.

This webinar is focused on sharing these principles:

- A patient's autonomy over their own body and wellbeing
- Informed consent
- Removal of negative framings and pathologising concepts with healthcare
- Introducing holistic understandings of health and wellbeing
- All and any reform is developed with and led by the communities you seek to serve

He pātai

This webinar is intended to be a place of learning, where there are no silly questions, nor are only the 'right words' allowed.

This is a learning space:

- If you hear a new word or term and want to know what it means, please write it down and ask at question time.
- If you get to the end and you need more information about an idea introduced during the presentation, contact us at Intersex Aotearoa.
- You can contact me and we can make a time to go through things in more depth if needed. Ngā pātai e pai ana.

Creating systems change across healthcare

"We have the same range of health needs as everyone else, and we need a healthcare system that is competent, safe and respectful."

Lead the change

Shift the paradigm

What's next after cultural safety?

What we mean when we use the term 'intersex'

Intersex is an umbrella term that provides a "catch all" to describe innate variations in sex characteristics/ VSC.

Sex characteristics include a person's chromosomes, genitals, reproductive systems, gonads, hormone sensitivity and production. I will use intersex person, intersex variation and VSC interchangeably.

Intersex variations are **innate** = natural/born with. So, in medical terms, a person with an intersex variation has innate variations of sex characteristics.

To be "**endosex**" is to have innate typical sex characteristics.

Medical pathology may classify only certain variations as intersex, those which are considered as being "between sexes." Examples of such variations include 46 XX, 46 XY, and true gonadal intersex. The hierarchies created by medical pathology can lead to the further isolation of individuals with diverse bodies, both within and outside of specific diagnoses. This can ultimately hinder the well-being of all individuals born with VSC.

Terminology you may come across in medical settings:

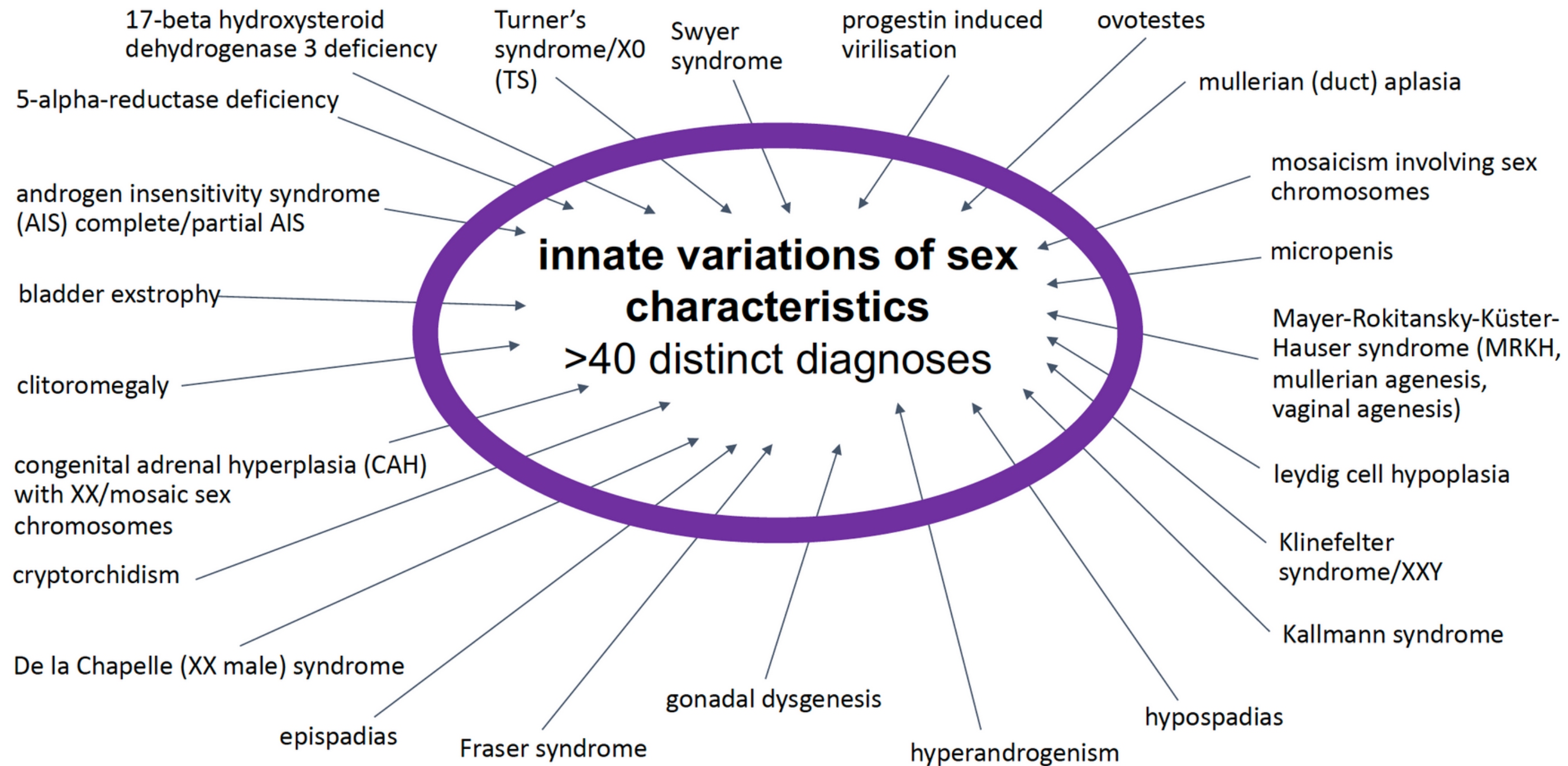
Intersex, intersexual, variations of sex characteristics (VSC), **disorders** of sex development/ differences of sex development (DSD) **hermaphrodite***, **atypical sex anatomies**, **doubtful sex**, **mutations, conditions, abnormalities...**

'...Objections to the language of “disorders of sex development” began immediately after it was clinically adopted in 2006 and have continued to the present time.’ (Carpenter M, 2018)

5-alpha reductase deficiency, Androgen Insensitivity Syndrome (AIS), Aphallia, Clitoromegaly (large clitoris), Congenital Adrenal Hyperplasia (CAH), Gonadal dysgenesis (partial & complete), Hypospadias, Klinefelter Syndrome, Micropenis , Mosaicism involving "sex" chromosomes, MRKH (Mullerian agenesis; Vaginal agenesis; Congenital absence of vagina) , Ovo-testes (formerly called "true hermaphroditism"), Partial Androgen Insensitivity Syndrome (PAIS) , Progesterin Induced Virilization ,Swyer Syndrome , Turner Syndrome

There are up to 40 different variations known, occurring in approx. 1.7 - 2.3% of the population.

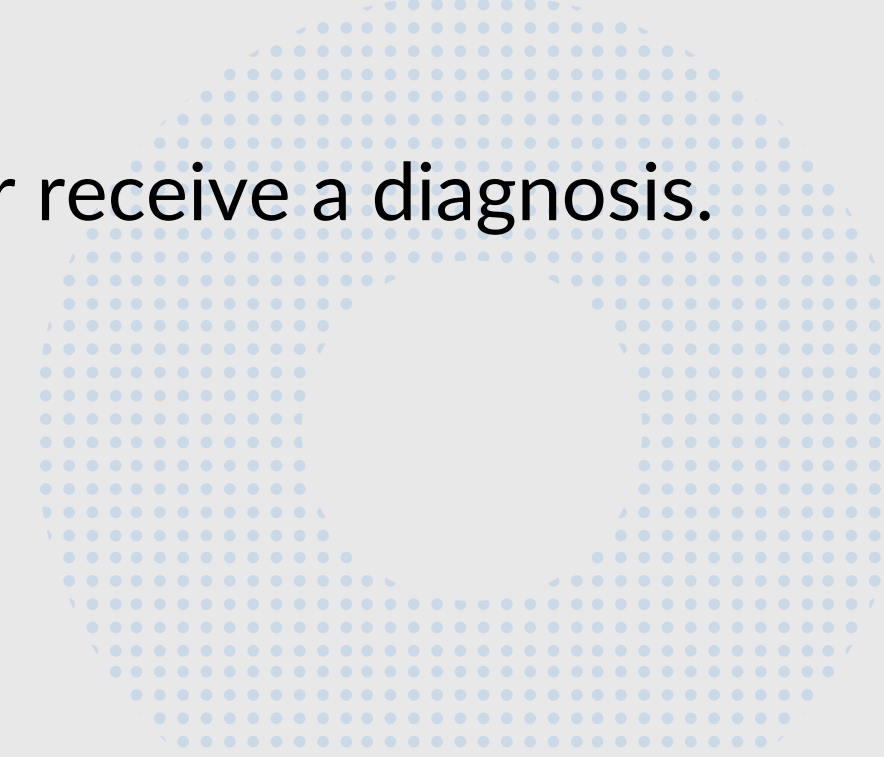
Sex characteristics in clinical settings



*Morgan Carpenter, Bioethicist and Executive Director of Intersex Human Rights Australia



It's important to recognise that each individual's experience and journey will be unique and different

- Some people are born with certain intersex variations that have visible traits. This will make them more susceptible to pathologisation and intervention as an infant.
 - For others, the VSC may not become apparent until during, or after puberty. This is another significant period for medical intervention.
 - The variation may not be identified until much later, perhaps during fertility treatment.
 - Or for some, they may never receive a diagnosis.
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To begin to shift the paradigm, we need to know what it is.


..."intersex individuals have been pathologized by the medical profession's insistence on a strict binary model of sex, gender and sexuality; this is true in the past and in the contemporary context" (Davis et al., 2016)

- Prior to WW2, small numbers of adults with intersex variations were seeking out treatment options, and engaging in medical interventions. where possible within gender affirming clinics (UK and Germany).
- Post War surgical techniques have advanced dramatically. But socially, things were changing. Between **1930 and 1955**, so-called 'sex change' operations were becoming controversial, while **intersex surgeries were becoming routine, including the removal of healthy gonadal and genital tissue.**
- Post WW2, new surgical technologies emerged. In the late 1940s a new specialty was developed – paediatric urology.
- 1955 Psychologist Dr **John Money** published guidelines **that recommended early surgical intervention on genitals that did not conform** to normative constructs of **what male and female genitals** should look like. Dr Money **recommended consistent rearing in one corresponding 'gender'.**

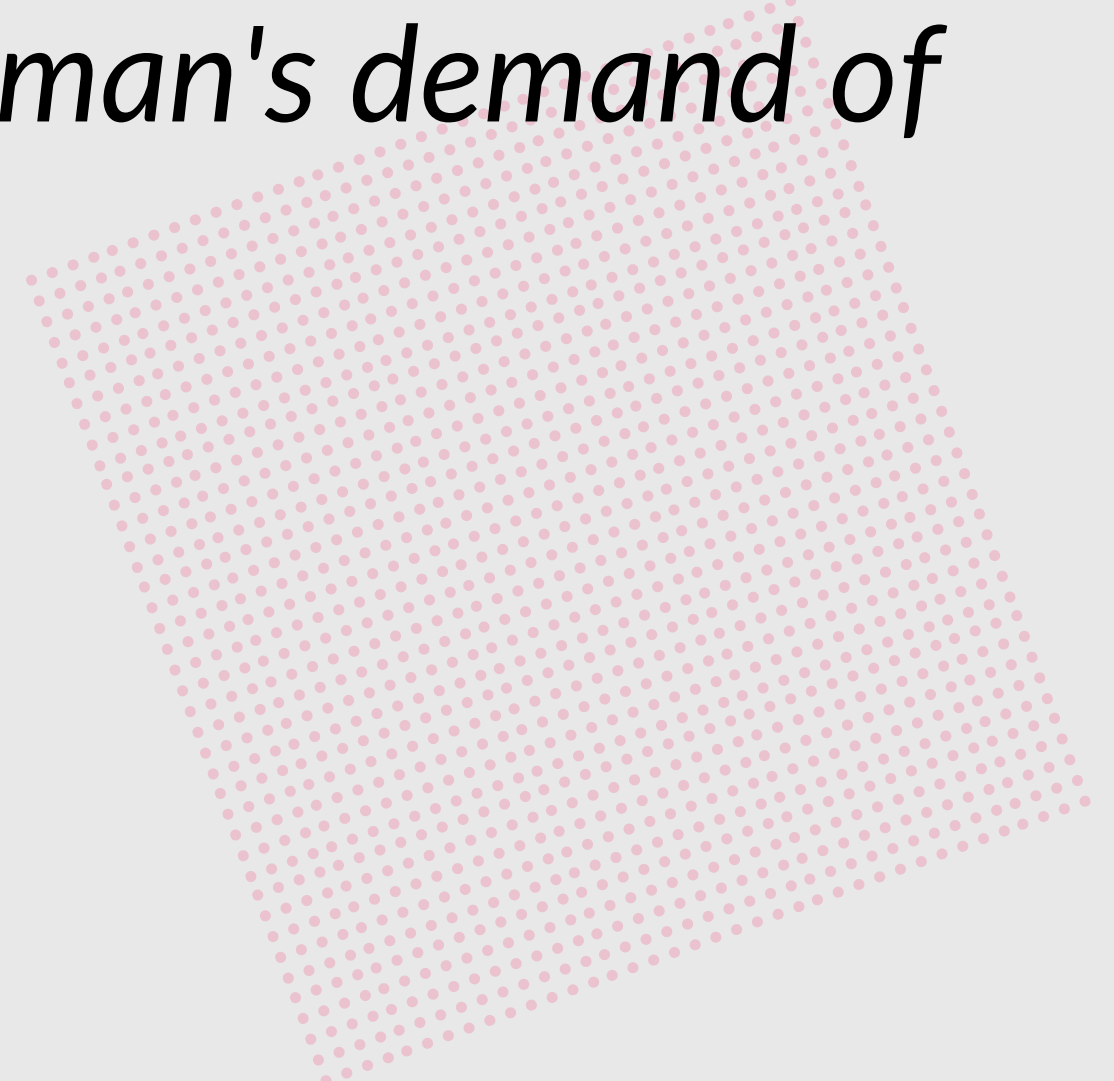
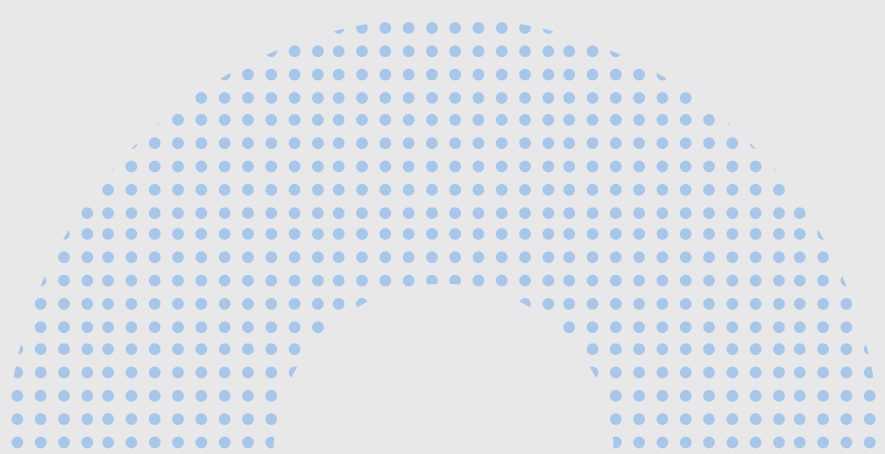
Dr. Money recommended surgery in order to study the psychology of gender, and his findings have influenced modern medical practices. However, he believed that it was important to reinforce traditional male and female bodies and behaviours, and this is still present in current medical protocols.

“As a result of operative treatment it has been discovered that these patients show not only a general and immediate tendency to lose their acquired male characters, and revert to their normal feminine ones, but also to return to normal sexuality psychologically, when this has been abnormal before operation. (Broster et al, 1938)”

This interventionist approach may continue to reflect outdated ideas from the 1950s that promote unrealistic body standards and conformity.



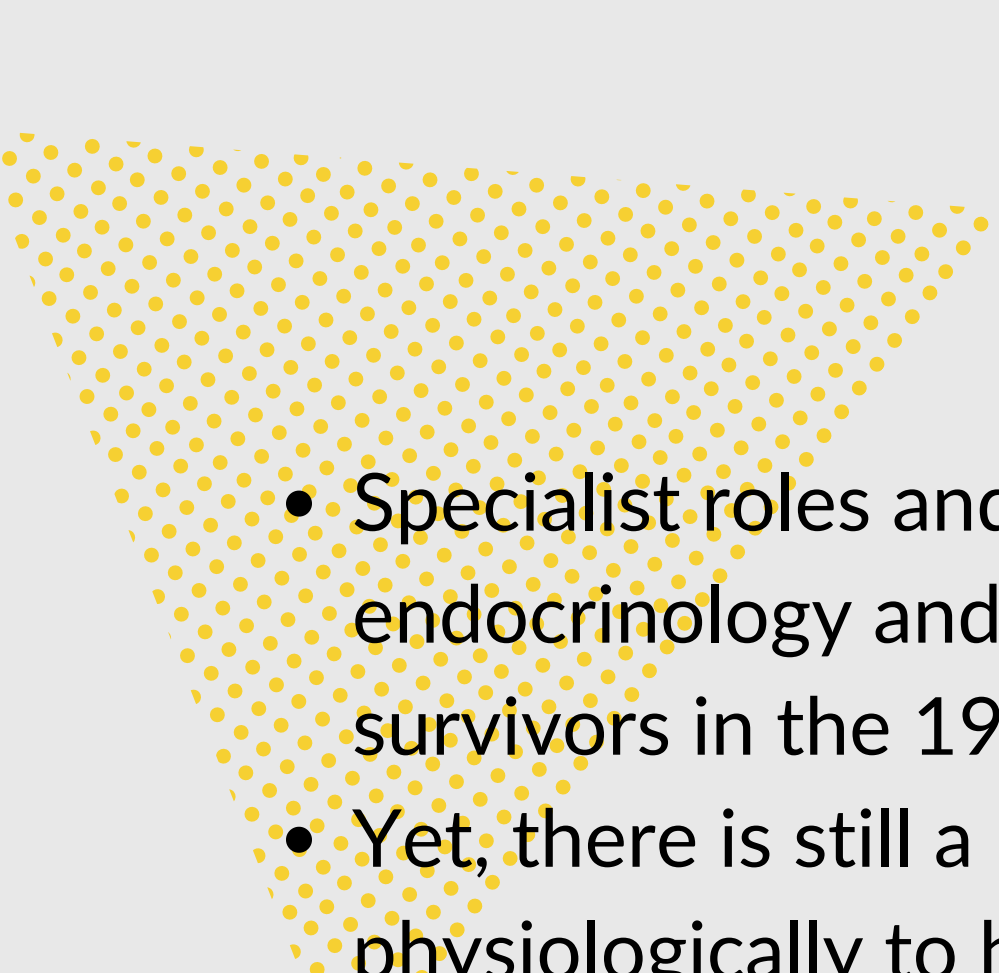
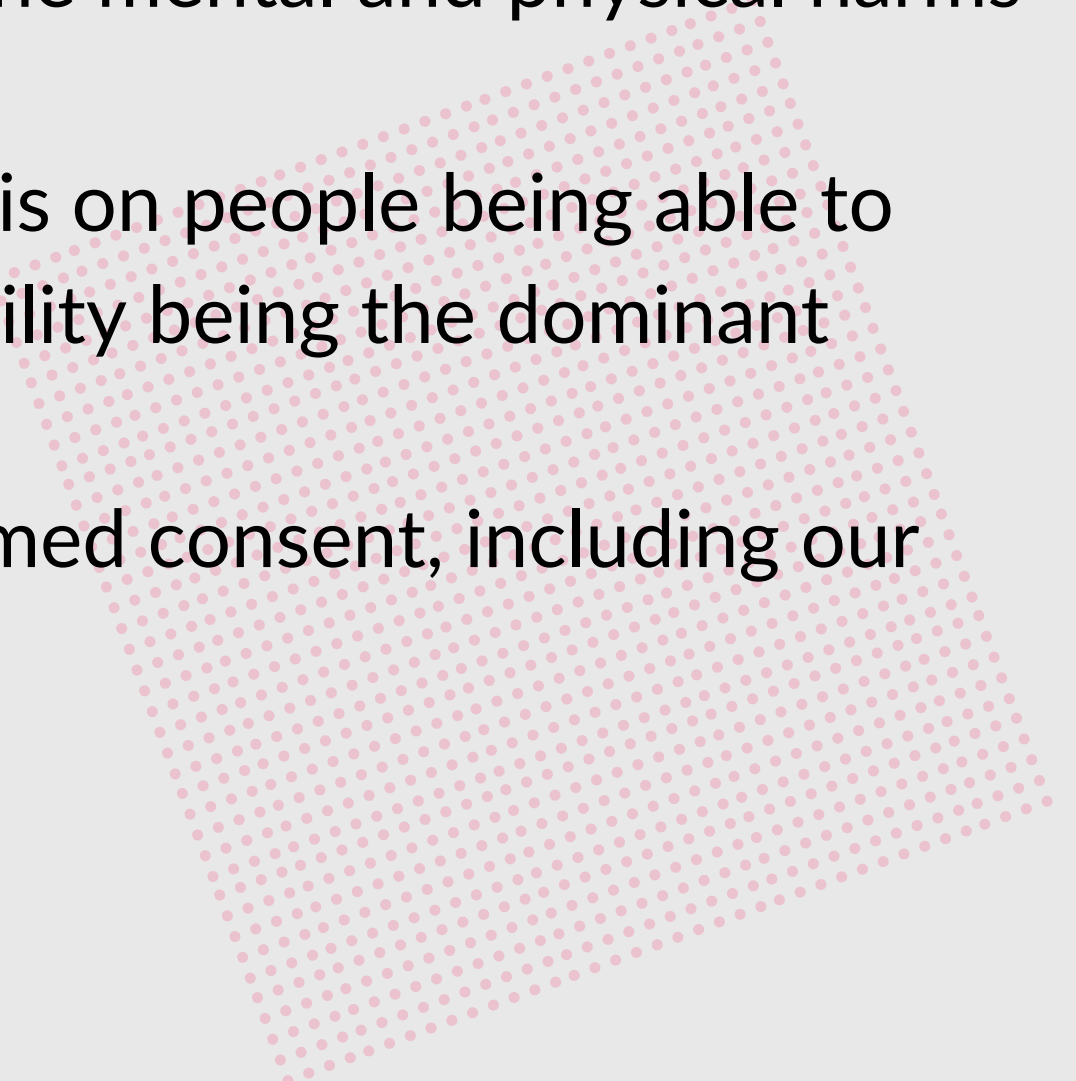
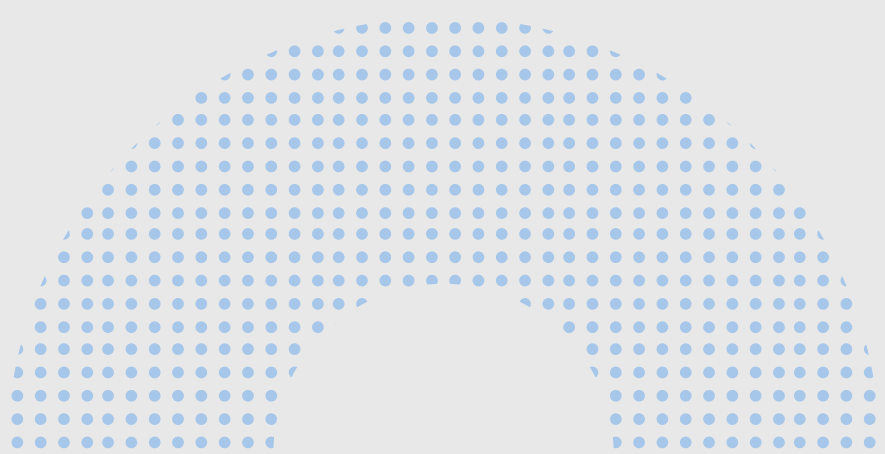
"The results of these processes are that those with intersex variations are made to bear the brunt of man's demand of order over nature."



Providing protection through surgical intervention:

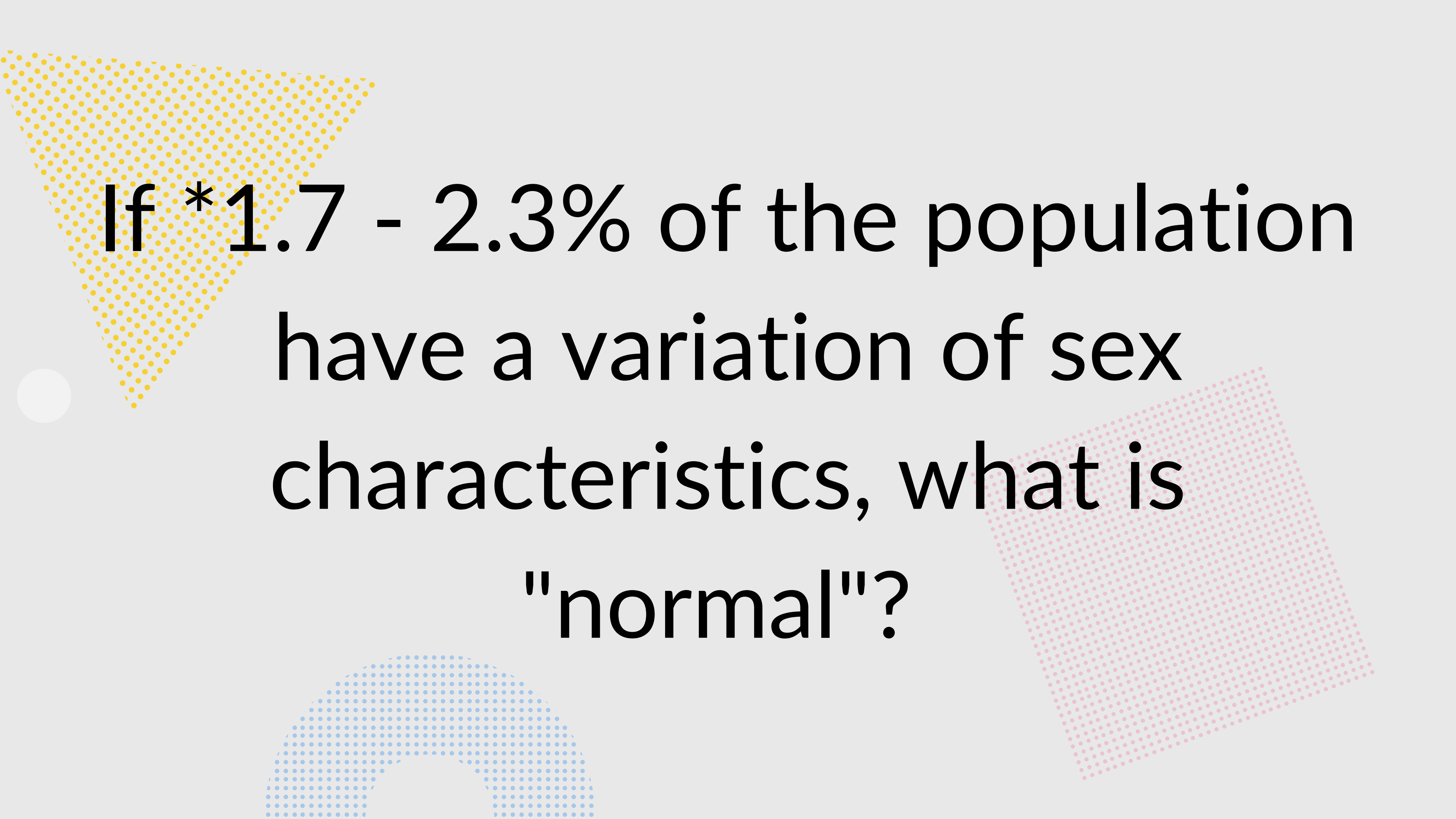
Societal norms are influenced by bias, often driven by the fear that individuals with VSC would face social exclusion if they were allowed to remain in their natural state

- Intersex medical interventions are **presented as a means of protecting individuals** from a world that may **struggle to accept them as they naturally are.**
- The fragility of **childhood psychological development** is used as a **justification for early intervention.**
- **Parental anxiety** is also invoked as a threat to psychological development, and one which **surgery on the child can manage.**

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- Specialist roles and improved surgical techniques are applied within gynaecology, endocrinology and paediatrics for 'DSD's' due to the gathering momentum of activism by survivors in the 1990's
 - Yet, there is still a lack of addressing any underlying health implications of what it means physiologically to have a intersex variation, as well as ignoring the mental and physical harms that can come from interventionist protocol.
 - A continuation of the normalisation of genitals, with an emphasis on people being able to perform heteronormative (penetrative) sex, with a focus on fertility being the dominant motivations within healthcare and from parents.
 - Most often interventions occur on those that cannot give informed consent, including our tamariki and rangatahi.

"It took me so long to understand that what was wrong with my body wasn't just a medical problem, but that mostly it was about making sure my teenage body could, well, you know, have sex with a penis. But my mum and I really weren't told that at the time. We weren't told a lot. As soon as it was diagnosed it was like everything sped up. And now I am left with all this scar tissue, prolapse, and incontinence and, for what? Who was this all for? I know my mum feels guilty, but both didn't understand what was happening and why. Now, the irony is; I do have real medical problems that were either ignored, or created by the normalising surgeries themselves"

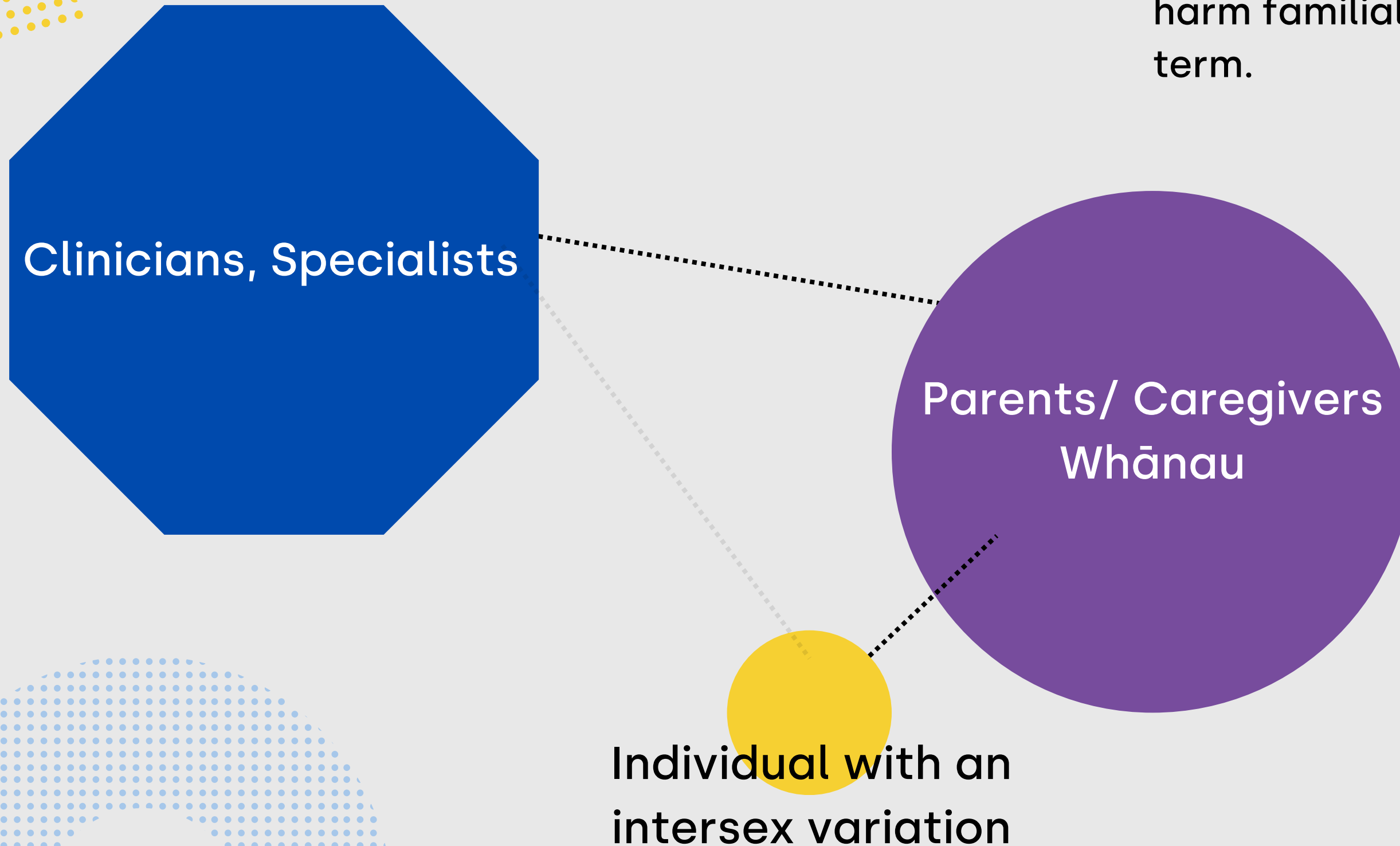
Anon, 37 yrs. 2022

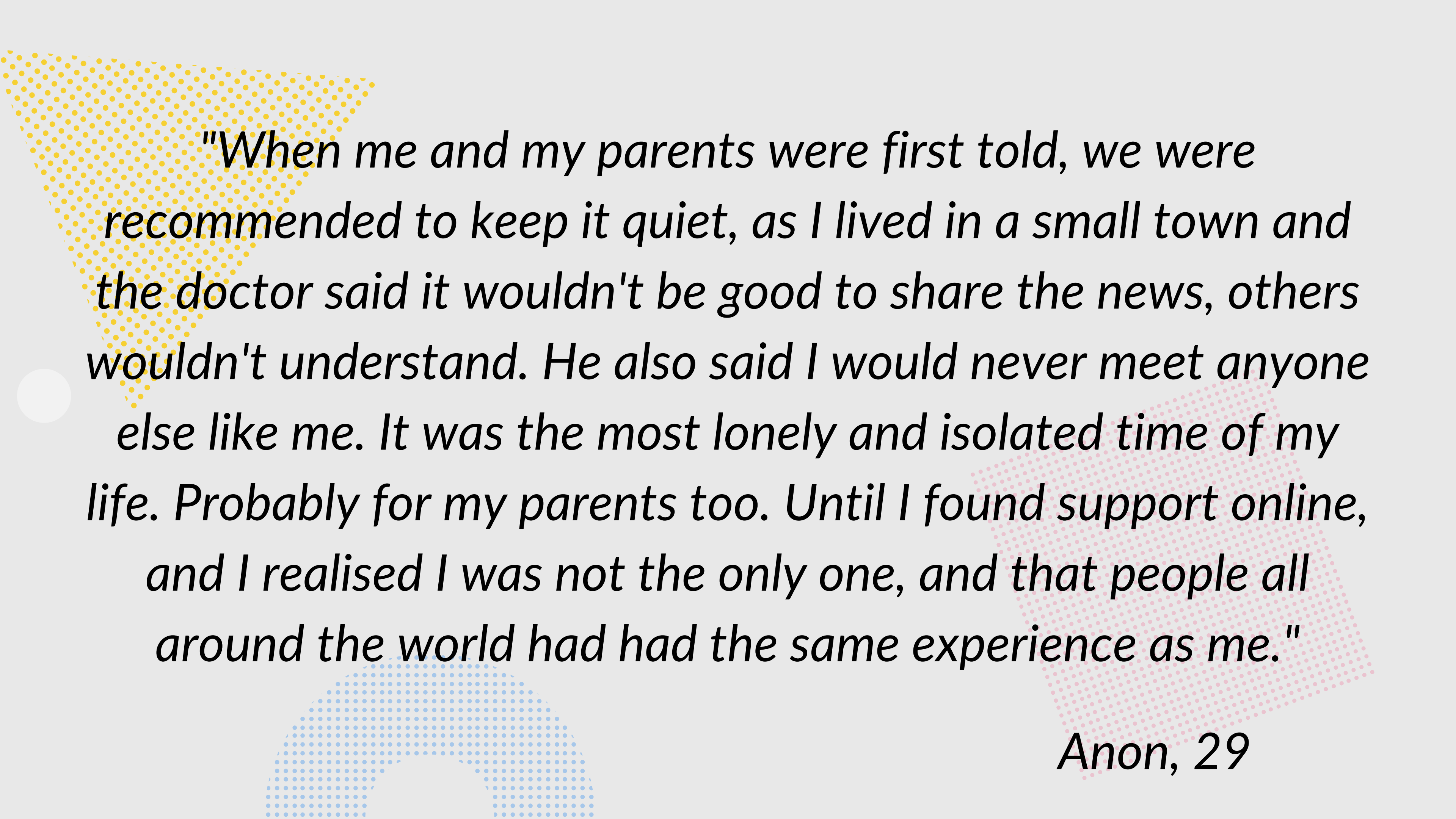


If * 1.7 - 2.3% of the population
have a variation of sex
characteristics, what is
"normal"?

Healthcare approach to VSC today

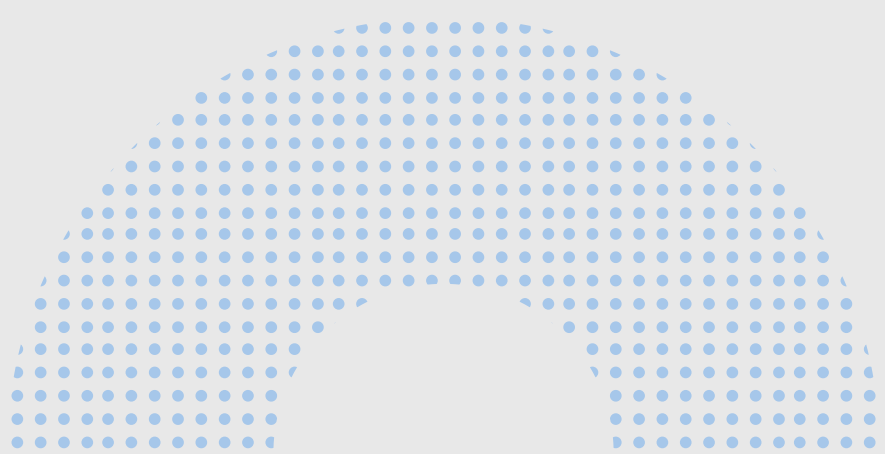
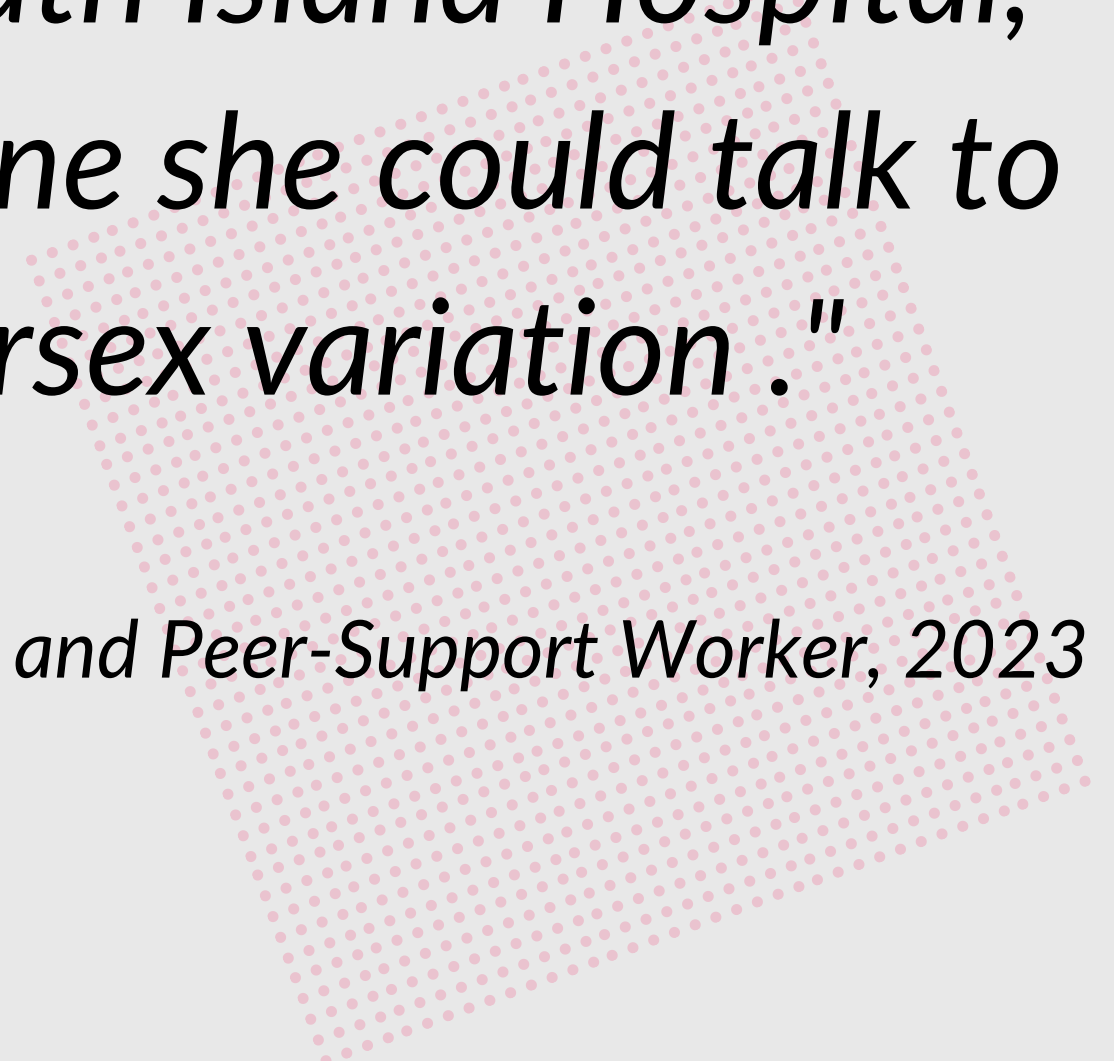

A concealment model: Keeping intersex variations a secret can induce shame and negatively affect the well-being of both individuals and their families. If information is withheld, this can also harm familial relationships in the long term.





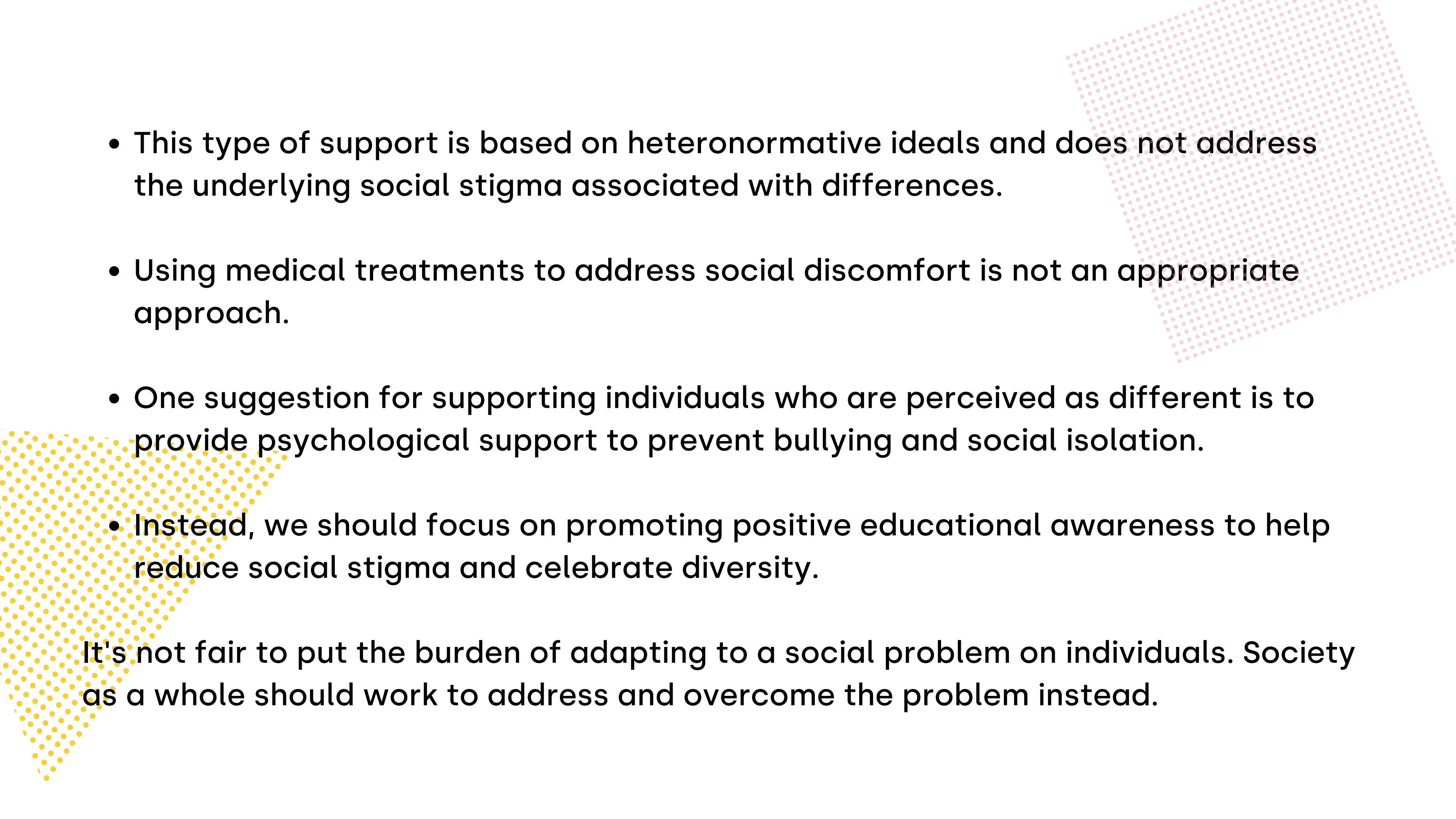
"When me and my parents were first told, we were recommended to keep it quiet, as I lived in a small town and the doctor said it wouldn't be good to share the news, others wouldn't understand. He also said I would never meet anyone else like me. It was the most lonely and isolated time of my life. Probably for my parents too. Until I found support online, and I realised I was not the only one, and that people all around the world had had the same experience as me."

Anon, 29



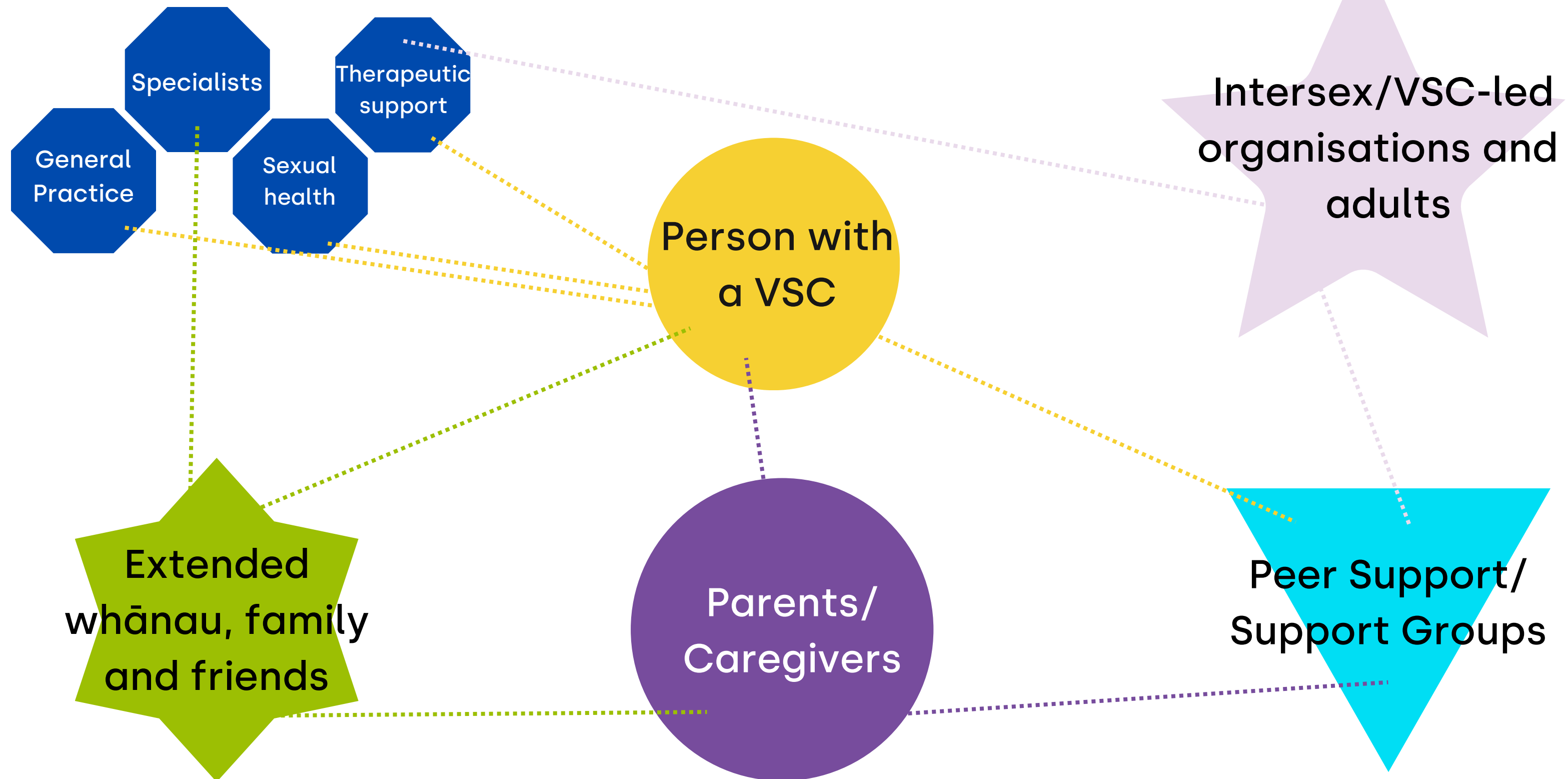
"Only this year, a new parent reached out through the parents support group to get help and advice for her newborn with a VSC. She had been told in that South Island Hospital, that there was no support groups or anyone she could talk to in New Zealand about her babies intersex variation ."

Intersex Adult and Peer-Support Worker, 2023

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- This type of support is based on heteronormative ideals and does not address the underlying social stigma associated with differences.
 - Using medical treatments to address social discomfort is not an appropriate approach.
 - One suggestion for supporting individuals who are perceived as different is to provide psychological support to prevent bullying and social isolation.
 - Instead, we should focus on promoting positive educational awareness to help reduce social stigma and celebrate diversity.

It's not fair to put the burden of adapting to a social problem on individuals. Society as a whole should work to address and overcome the problem instead.

The vision of intersex healthcare and holistic well-being in Aotearoa - shift the paradigm



Human rights : sexual orientation, gender identity and expression, and sex characteristics (SOGIEISC)

- Human rights advocates use **SOGIEISC** as a framework to clearly show the spectrum of experience and being within a person's sexuality, gender and **sex characteristics**.
- In relation to intersex, sex characteristics is important. SOGIEISC framing can be helpful to understand to start to separate out areas where discrimination can occur.
- Categorisation systems within our society have used the recording of sex and gender interchangeably, which has led to confusion and lack of distinction.
- The term "sex" has been weaponised by some people who use biological essentialism to exclude transgender communities. Let's shift to inclusive understandings of bodies and recognise the diversity of our sex characteristics, instead of thinking in just binary terms.

Intersex and The Rainbow - The 'I' in LGBTQIA+

- The word intersex was used in the early 19th Century in medical spaces. This was later reclaimed by activists in the 1990's to replace the term hermaphrodite* and was added to the LGBT acronym, along with Queer and Trans communities
- LGBTQIA+ activism has fought for the rights of people who fall outside of expected binary sex and gender norms
- The term 'intersex' has become associated with activism and advocacy since the 1990's.
- Intersex is a term that can mean different things to different people. Some may come to feel connected to the term as part of their central identity. For most people, it would be just one part of their life-experience.
- The inclusion of intersex within The Rainbow can hold its own tensions for some. Parents and doctors who have negative beliefs of queer and trans communities may resent its association. It also doesn't sit right for those adults with VSC who identify as cisgender and heterosexual.

Intersex and the Rainbow - The 'I' in LGBTQIA+

"Another problem is the assumption that all intersex people identify as Rainbow. While some people may identify as such, many do not. Even when policies or funding include the 'I' (in LGBTQIA+) for intersex, it generally is in name only and does not enhance the lives of intersex people. "



Dr Rogena Sterling
Co-Chair Intersex Aotearoa

What's the difference between trans and intersex?

Transgender is an umbrella term that refers to individuals whose gender identity differs from the sex they were assigned at birth.

Intersex is a term used to describe individuals who are born with physical sex characteristics that do not fit typical definitions of male or female.

Even after years of criticism from intersex people, many providers are quick to perform surgery on bodies of babies and young children that they consider abnormal... At the same time, they hesitate to act in cases where trans individuals request surgery. (Davis et al., 2016: 491)

What's the difference between trans and intersex?

You can be trans and endosex. You can be intersex and trans. You can be intersex and cis-gender.

Combining or confusing the experiences of transgender and intersex individuals can pose challenges when developing appropriate healthcare paths.

Intersex and Trans peoples needs do align - both communities are asking for the bodily autonomy they deserve. Both represent natural ways that diversity can show up in humanity. The differences between trans and intersex communities are important too.

Te Ao Māori

Tangata whenua scholars and Mātauranga leaders are revitalising pre-colonial understandings of embodiment, that sit separate to western colonial framings.

Intersex Aotearoa Co-Chair Tu Chapman (Ngāti Kahungunu ki Heretaunga, Ngāti Awa ki Rangitaiki) shares her experience by connecting her Māori whakapapa being the most important aspect of her, as well as defining her intersex personhood as being intertwined within her Ira Tangata.

Dr Elizabeth Kerekere explores in her doctoral research on Takatāpui, a reclaiming of pre-colonial concepts and the removal of western projections of shame.



Tu Chapman
Co-Chair of Intersex
Aotearoa

Te Ao Māori & Pasifika

- Te Ao Māori and Pasifika understandings and language may differ from the descriptions and terms shared in this presentation so far.

Many hapū and iwi in Aotearoa tell pūrākau that speak of tūpuna that can be understood as having diverse sex characteristics. Some ancestors were carved into Marae and celebrated.

- Pre-colonisation, all members of the whānau were accepted as they are. Yet, with the colonisation of Aotearoa by British settlers, this brought British values, norms and knowledge systems, as well as their social, cultural, political, legal, scientific and medical systems.
- The western approach to dissecting us up into individuals with distinct and separate body parts, continue to be at odds with mātauranga Māori ways of being, and understanding.

Lead the change

- Ensure that Te Whatu Ora upholds a rights based approach to intersex health and well-being by supporting its advancement.
- Support intersex-led advocates providing insight and resources in healthcare, relationship and sexuality education, policy development, inclusion andremember - nothing about us, without us!
- Talk to your staff, colleagues and practice about VSC and how as a clinic you could improve your intersex cultural safety, all the way from reception to clinicians.
- Let intersex patients know that peer support and connection to others with similar experiences is available to them. This could be through our organisation or via another VSC organisation.

Beyond Cultural Competency

- You can provide a patient's autonomy over their own body and wellbeing
- Informed consent is an on-going process. It never ends.
- You can participate in the removal of negative framings and pathologising concepts with healthcare, we need your help! It has to come from the inside, and led from community.
- You can introducing holistic understandings of health and wellbeing - think outside of a purely clinical framework.
- Q: How can you develop relationships with these vulnerable communities you seek to serve, and can you provide leadership and guidance opportunities for experts to assist in the change.

Mahi tahi, lets work together

- Use language that doesn't include: mutation, disorder, defects. Instead try "natural variations/diversity/sex characteristics"
- The ideas presented here are just one way of thinking about intersex, and people have their own feelings about how being intersex relates to them. Remember to follow each persons lead and mirror how they want to speak (or not to speak) about their own body, feelings and journey.
- Consider how colonial & western ideas of bodies effect us all, and uphold ableism. Let us all challenge our own transphobia, and question how endosexism maybe evident in our work.

But what can you do?

Read the Darlington Statement and sign as an ally!

Commit as a workplace.

Challenge the silence, isolation and shame of intersex people by exploring how we all uphold body norms and bring an end to endosexism in your own life. No more ("small d**k") genital jokes, assumptions about other peoples fertility and reproductive systems.

Acknowledge parental anxiety by supporting parents to understand more about their child's variation and connect them to those with lived experience and other parents in similar positions.

Parents support groups are a great way to connect.

Most importantly....

You do not have to be an expert in intersex variations.

We need you to support the person in front of you and their whānau to understand all the risks, implications and benefits from a range of options.

www.intersexaotearoa.org

info@intersexaotearoa.org

