Gender mender, bender or defender: Understanding decision making in Aotearoa/New Zealand for people born with a variation in sex characteristics

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In memory of my beloved Mum ❤️
Abstract

People born with a variation in sex characteristics (VSC) face the challenge of having atypically sexed bodies. This qualitative study recruited 10 young adults with a VSC (14 to 24 years); 18 parents of children with a VSC; and 22 health professionals working in the VSC field. Interviews were semi-structured, digitally recorded and transcribed. Using thematic analysis, we identified key themes regarding participants’ experiences of healthcare decision-making. This study has been conducted in collaboration with the Intersex Trust of Aotearoa/New Zealand (ITANZ).

This research is original and innovative in three ways: it demonstrates close collaboration between activists and academics through all stages of the research design and conduct; it provides a unique 360-degree perspective integrating the views of health professionals, parents and young people (possible because of the small size of New Zealand); and it fills a gap in the literature by capturing the voice of young people currently living with a VSC.

Health professionals, parents and young people must navigate complex and controversial healthcare decision making. This is often ethically challenging and involves multiple decision points throughout their life, with divergent and uncertain consequences. This study documents key elements that influence healthcare decision making as reflected in the data. These include understanding of diversity, communication skill, bias, conforming to or disrupting norms, psychological/peer support, bodily autonomy, identity, expectations, future worries, what’s right and recognition of the past. “Trust” was a meta-theme that underpinned all of these elements.

The implications of these findings include targeted education and training for health professionals to: increase their awareness and insight regarding bias and diversity; advance communication skills; understand patient perspectives; and address ethical issues. They also facilitate the provision of specialised psychological support and peer support for parents; increase their awareness and insight regarding bias and diversity; and enable future concerns with a focus on bodily autonomy for the child to be addressed. Young people need caring communities, established through peer and specialised psychological support, to explore their sense of identity, understanding of diversity and acceptance of self. Suggested health system improvements include: multi-disciplinary teams including psychologists and patient advocates; a specialist national centre in Aotearoa/NZ; a VSC patient registry; and ongoing research looking at outcomes.
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Outputs of this thesis

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Abbreviations

**AIS** - Androgen insensitivity syndrome

**APEG** – Australasian Paediatric Endocrine Group

**CAH** - Congenital adrenal hypoplasia

**CAIS**- Complete androgen insensitivity syndrome

**DSD** - differences (or disorders) of sex development

**DMS** - decision making scale

**HP** - health professional

**ITANZ** - Intersex Trust Aotearoa New Zealand

**IVSC** - Intersex/Variation in sex characteristics

**IYA** - Intersex Youth Aotearoa

**LGBTTTQIA+** Lesbian, gay, bisexual, transgender, *Takatapui, questioning, intersex, asexual (+ usually means allies, queer, pansexual** and any other names that are evolving into popular culture)

Rainbow community is another common term

*Maori name for those with diverse sexes, genders and sexualities

**pansexual refers to some who is attracted to male, female, nonbinary and gender nonconforming people

**MRCH** - Melbourne’s Royal Children’s Hospital

**MRKH** - Mayer Rokitansky Küster Hauser Syndrome

**NZHRC** - New Zealand Human Rights Commission

**OGR**- Optimal Gender of Rearing

**OII** - Organisation of Intersex International

**PAIS** - Partial androgen insensitivity syndrome

**SDM** - shared decision making

**SOGI** - sexual orientation and gender identity

**SOGISC** - sexual orientation and gender identity and sex characteristics

**VSC** - variation in sex characteristics

**VSC/DSD** - variation in sex characteristics/differences (or disorders) of sex development
Chapter One

Introduction

“Once upon a time there was a boy and a girl...”

This sentence reflects the dominant narrative most of us take for granted when considering sex and how gender is represented in western society. What happens when this binary construct is challenged or different, for instance when a child’s anatomy is different to the normative ideals representing the majority understanding of what it is to be female and male? This question is the foundation of this thesis.

In this research I have focused on the population of people that fall outside these norms, i.e. those born with a variation in sex characteristics (VSC). The variations these people are born with are currently considered to be driven by genetic, chromosomal and hormonal factors. A range of terms are used to refer to these variations. Terms such as “intersex” and “variation in sex characteristics” are common in activist, academic and human rights communities, and “disorders of sex development” or “differences of sex development” (DSD) is preferred in medical and scientific circles.

Gender identity is fundamental to how we define ourselves as individuals and in society; it is at the core of our psychological and social functioning. In most societies gender identity is dichotomised in line with biological sex characteristics; that is, it is seen as binary, male or female. For those born with VSC bodies, the relationship between gender identity and physical appearance may be unclear. These variations are individually rare but as a group affect up to 1 in 4,500 people (Warne & Mann, 2011). The societal and clinical response includes complex and controversial decision-making, often including gender assignment, hormone replacement and the possibility of genital surgery.

Decision making in relation to people born with a VSC is ethically challenging, involving navigation of multiple decision points with divergent consequences. The

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1 In this thesis I use a combination of the terms VSC, DSD, VSC/DSD and IVSC. An explanation for this use of a variety of terms is found in chapter 3, section 3.6.3.
The process of decision making is often criticised for not being transparent and for being based on the bias of the treating clinicians, rather than on evidence of best practice. There is a lack of sound evidence to inform decision making. In the absence of a clear empirical base, many would argue that the basis for decision making should then shift to an ethical foundation.

The social and cultural contexts in which decisions occur are highly relevant on the nature of decisions. For instance, some cultures (e.g. Māori and Pacific) have more diverse concepts of sex and gender, while most clinical guidelines are directed by Western societies’ values and beliefs. Often the influence of these contextual factors is minimised or completely ignored when considering how decisions are made for those born with a VSC (Lang & Kuhnle, 2008; Schmidt, 2010).

Concerns have been expressed about research based on countries where children have not had medical intervention (e.g. some of the Pacific islands, South American and Asian countries) and have been ostracised as a result: this has then been used as an argument for intervention. Critics would argue that other reasons such as religious or cultural beliefs may influence the child’s treatment as much as lack of medical intervention (Feder, 2014). The literature also reveals a lack of research more generally on what informs decision making about health care for children born with a VSC. Also, of concern is a common assumption that children are treated and go on to live their lives with no further complications associated with to their VSC despite there being limited long term follow up.

Internationally there are a variety of perspectives on approaches to the management of VSC. These range from a more conservative viewpoint based on some of the traditional treatment protocols to a more contemporized point of view that is rapidly evolving. For example, in the United States appearance based genital surgery is still practiced on those born with a VSC in early infancy. In contrast, some European countries are trending towards treatment protocols that favour leaving appearance based genital surgery until the child is of an age they can contribute to the decision making about their health care themselves.
In Aotearoa\textsuperscript{2}/New Zealand (Aotearoa/NZ) there is little research about the state of current practice, and no research providing any understanding about what informs decision making and whether that is based on sound evidence or best practice guidelines. There have been strong links to Australia due to its larger population and resources, and it appears Aotearoa/NZ has been led by some of the research and guidelines created by the larger teaching hospitals such as Melbourne’s Royal Children’s Hospital.

However, much of the research has been perceived as having a medical bias, with those directly affected by VSC not having an opportunity to present their experience. In some cases, the experience of people with a VSC has simply been ignored or dismissed as the viewpoint of a few disgruntled people who had treatment before the revised guidelines that have occurred over the last 12 years.

The quality of research has also come into question, with criticism of the validity of data presented and misrepresentation of the facts (Diamond & Garland, 2014). A climate of mistrust has been created, resulting in a “them and us” situation between health care providers and those directly affected by VSC. Conflicting opinions between health care providers and VSC advocates have resulted in a call for more robust research that is inclusive of affected persons themselves.

My own impetus to do research in this area in part resulted from seeing a documentary, Intersexion (Lahood, 2012), that explored the views and experiences of people directly affected by a VSC from around the world. The documentary outlined the influences of John Money, a psychologist born in Aotearoa/NZ who lived and worked in the USA and, with colleagues, developed the treatment protocol (optimal gender of rearing) that would change the way people born with a VSC are treated. I was moved by the experiences of those who spoke about living with the consequences of such treatments.

I am a clinical psychologist with a background in child, adolescent and family mental health and had not appreciated the depth to which people had been deliberately deceived, surgically altered, inappropriately reassigned a gender, subjected to

\textsuperscript{2} Aotearoa is the Māori name for New Zealand and is one of the two official names - Aotearoa/NZ is used throughout this thesis.
repeated genital examinations and photography by many and generally told nothing about the true nature of their circumstances. The documentary concluded by indicating there were ongoing issues for this group of people born with a VSC, not just those who had been treated in the 20th century but also for those currently being treated by health care professionals.

This motivated me to explore the area further as I was curious if this was the case here in Aotearoa/NZ by undertaking doctoral research into the state of decision making regarding health care for children born with a VSC in Aotearoa/NZ.

The objectives of this research are to:

1. Investigate the factors and processes influencing contemporary clinical decision making for children born with a VSC in NZ, from the perspectives of the three key groups:
   - people who have a VSC
   - parents of children who have a VSC/DSD
   - health professionals who work in the area.
2. Explore barriers and facilitators to effective decision making.
3. Highlight what is working well and what can be improved on or if there is a gap in health care and explore possible solutions.

The historical context requires some close examination as it is the foundation on which all subsequent developments have occurred. This history is based on decades of controversial, sometimes ethically suspect research, and misinformation that has produced alarming stories involving secrecy and shame for both parents and children born with a VSC. I would argue that this historical context has not only contributed to the increased outcry for change and advocacy, but also to hesitation and caution among parents and health professionals alike. This has resulted in anxiety for all those charged with making health care decisions for young people who are affected by a VSC.

Little was known previously about how parents, young people and health professionals navigate decision-making within the Aotearoa/NZ context. This study reveals what is current practice in Aotearoa/NZ. Qualitative research was needed to
bridge the gap by providing a collaborative, inclusive and robust approach that allows for a representation of all those involved and affected.

This study is internationally unique in combining the perspectives of these groups, i.e. people who have a VSC; parents of children who have a VSC; and health professionals who work in the area. Aotearoa/NZ is the ideal place to address these issues as our mix of cultures provides an internationally unique opportunity to study a full range of current attitudes and approaches. The findings from this study will contribute to development of best practice.

In order to fully understand the research question, I conducted a part time qualitative research project that spanned six years, interviewing the three key participant groups as stated previously. I bring to the research my background as a clinical psychologist along with my recent experience in the research environment under the guidance of more experienced researchers.

The foundation of the research is the Treaty of Waitangi (Te Tiriti o Waitangi), which is the founding partnership document between Māori, the indigenous people of Aotearoa/NZ, and the mainly European settlers who colonized the country. The three principles of the Treaty can be summarized as partnership, participation and protection (Archives New Zealand. n.d.).

This research is underpinned by critical realism theory and allies with feminist principles of inclusion and understanding the role of privilege and power. This methodological approach aids in understanding the complexities that drive decision making, while at the same time honouring the voices and experiences of those participating in the research.
This thesis contains nine chapters that cover five main sections, as shown in Figure 1:1 below.

### 1.1 Thesis outline

![Thesis Outline Diagram]

**Figure 1:1 Thesis outline**

In this first chapter I briefly outline the topic of research and the motivations for the research.

The second and third chapters lay the foundations of the thesis, providing the backdrop of what has been happening in society and exploring all the various influences on the lives of those with VSC in relation to the way they view their VSC.
This involves two main groups: those in the medical world and those directly affected i.e. those with a VSC.

Chapter two specifically aims to help the reader navigate and orientate them to societal elements that influence and impact on the person with a VSC. I review the literature, covering historical perspectives on those born with a VSC. I also cover the main elements of influence over the past few decades, such as the rise of Intersex activists and advocacy groups and the consequential legal and human rights ramifications. Finally, I consider the wider influences from a societal level regarding the evolution of the way we view gender, sexuality and diversity.

The third chapter specifically covers the biological and science context and all its complexity, and cross references this to some of the historical issues raised in chapter two. I will examine the current literature regarding the main influences on the management of health care for people with a VSC. I conclude this chapter with a summary periodic table representing the key elements from both chapters influencing the context for health care decision making for people born with a VSC. This is to orientate the reader to the backdrop in which the three key participant groups are situated.

The fourth chapter explains the research design, methodology and challenges encountered and how the theoretical frameworks of critical realism, Te Tiriti o Waitangi, feminism and clinical psychology inform my methodology. I will discuss the practical partnerships developed and maintained throughout the course of the research. The chapter will also detail the research methods used to collect, collate and analyse the data from the three participant groups. Lastly, I will discuss research reflexivity.

In chapters five, six and seven, I cover the findings from each of the three participant groups in turn: the health professionals (HPs) in chapter five, the parents in chapter six and the young people in chapter seven. For each group I discuss patterns of engagement in the research, provide a brief sample recap and then present my findings for that group. These three chapters’ findings are structured in a way that incorporates the presentation of themes interwoven with some discussion of the key findings, as is common in qualitative research.
Chapter eight looks across all three groups and compares commonalities and differences. Firstly, I cover the decision scales that all three groups completed and the statistical analysis of the decision scales. Then I explore cross-sectional case studies between the groups and how they relate to the main elements influencing decision making. The main themes identified in chapters five, six and seven that were common to all participant groups (communication, norms, support and bias) are discussed. Then the remaining group-specific themes of bodily autonomy, identity, future worries, what’s right, expectations and recognition of the past are acknowledged. The overarching element that impacts across the whole of the research and all the participant groups is the element of trust.

The final chapter is the discussion chapter. It provides a summary of the research and its findings, including the key elements influencing healthcare decision making for children and young people born with a VSC, followed by a discussion of what the findings mean in relation to the current context and literature. Limitations of the research, along with reflections, implications, conclusions and final thoughts, are also presented.
Chapter Two
Creating Context
“It takes a village...”

2.1 Introduction
This introductory review chapter and the next set the scene for the research and examine the literature about those born with VSC/DSD in the 20\textsuperscript{th} and 21\textsuperscript{st} century. I will cover the major historical elements that have influenced the ever-changing complex developments concerning people with VSC/DSD. I will illustrate how the medical world and the VSC/DSD advocacy world, along with emerging sub-systems within them, have developed and intersected (Figure 2:1). There is a chequered history in the way people born with different sex characteristics have been viewed, presented, and cared for. This history is reflected in the world views of both medicine and those directly affected. The evolution of these two worlds is not always in synchronicity, as will become evident.

Health professionals, people born with a VSC/DSD and their families live in a world with many elements of influence. It is necessary to explore how culture, religion, human rights, social change around sexuality and gender, and even media have impacted on the lives of those living with a VSC/DSD. I will argue that these influences have created the current, often problematic pathway through healthcare for people born with a VSC/DSD, and outline some of the significant controversies and complexities that have (and continue to) surround the provision of their health care.

Science and medicine have a privileged presence in western society and are therefore major influences with regard to healthcare. This privilege has been challenged over the last 20 years, with people with VSC/DSD gaining much more recognition and support through their increased advocacy and sense of agency. In recognition of this power imbalance, this study will equally privilege the voices of those with VSC/DSD and/or their families.
Figure 2: Major elements of influence

All of these elements have the potential to intersect with one another; this diagram represents the two main spheres of influence of medicine/science and Intersex/VSC activism and the main influences currently impacting in society.

I will present arguments from both science/medicine and those directly affected, offering a critical reflection on these two perspectives. This chapter will focus on the viewpoints of those with a VSC and Chapter Three will cover the viewpoint of medicine and science.

Lastly, I will discuss intersectionality and othering, both of which are gaining more of a profile when it comes to considering the interactions and layering of factors that may contribute to discrimination and marginalisation of any given individual or group.
2.1.1 Literature review strategy

For the purposes of the literature search for this thesis I used Medline, PsycInfo, Scopus, and Google Scholar. In 2013, when I embarked on the literature search, it was an emerging area. As a result, I only identified 54 papers using these subject headings/keywords: Disorders of sex development, intersex, genital ambiguity or genitalia and decision making (VSC at this time was not in use). The subject topic evolved during the course of my study. I found other relevant papers through conferences and other pieces of grey literature and non-academic material written from the perspectives of those with lived experience. All papers for both literature chapters were reviewed by critically reading the abstracts and selecting the relevant papers for review, looking at the strengths and weakness. Books, and grey literature such as intersex websites, blogs, reports, news items etc were scrutinised for relevance and were incorporated into the reviews.

Where there were large numbers of papers (as was the case for Chapter Three where papers looking at the scientific and biological aspects of VSC numbered in their thousands), it became clear that reviewing all the literature available was beyond the scope of this thesis. There are over forty variations of VSC, hence the volume of research; much of this literature focuses on scientific aspects such as molecular biology and genetics which are beyond the scope of this research. Specific searches for the more prevalent variations such as Hypospadias and Congenital Adrenal hyperplasia also provided relevant papers for review. I selected the most recent papers that offered the most relevant research, and that explained the complexities of human reproductive biology and the causes of atypical sex development and its classification from a medical and science based perspective in a way that a lay person could understand.
2.2 Ka mua, ka muri: Walking backwards into the future

This Māori proverb suggests that we have to look back in order to understand the future. In order to understand the influences on how people born with DSD/VSC are viewed, represented and cared/not cared for by others we need to understand the historical context. It provides the foundations for the ideas and beliefs that have developed and changed over the decades. Like any subject matter, we rely on what is recorded over time to understand and validate its authenticity. This relies on the skill of those making such recordings and the time and the lens through which they are looking.

The little history that is recorded is by those who are generally privileged, white, and based in western societies. I have included as many varied sources as possible when I summarise this poorly recorded and complex history. Equal privilege is given to the knowledge of those with lived experience, as previously discussed. I will briefly look at the early history and then shift the focus to the 21st century, as this is the time where there is rapid change and development.

2.2.1 Dinosaurs were probably intersex!

As Pigeon Pagonis, a young American intersex advocate, states, “there were probably dinosaurs with intersex traits roaming the earth” (InterACT, 2015). VSC/DSD is not new; however, little was previously known about it and the first comments relate to the Greek myth of Hermaphroditus.

Hermaphroditus was the mythic Greek god said to have been both male and female. This is the origin of the term hermaphrodite, which was used up until the mid-1990s to describe people born with VSC/DSD who were not considered typically male or female. “Intersexuals” was also a term used. Pre 19th century little is recorded from a medical perspective and it is thought that people were not treated as being particularly different, and just got on with their lives. There is little reported other than stories about someone’s different genitals, often found once a person was deceased, as this would be the only time the genitals were revealed. For example, those people who had what we now know as salt wasting Congenital adrenal hyperplasia (CAH) likely died soon after birth due to the lack of knowledge about the condition and its treatment.
2.2.2 19th century

In the late 19th century, medicine was developing into a modern science that strived to describe and accentuate the commonalities in human health, illness and anatomy. More people were being studied and more sought help from doctors. Hermaphrodites presented a conundrum that needed resolving, as explored in the books “Hermaphrodites and the medical invention of sex” (Dreger, 1998) and “Intersex in the age of ethics” (Dreger, 1999). Essentially Dreger argues that hermaphrodites challenged the social norms of the time and that doctors in Western Europe were also struggling at that time with what was considered a distressing increase in the incidence of homosexuality and with women who were demanding equal rights. This gave rise to what she calls “the age of gonads”, where male and female became defined by gonads (i.e. having either testes or ovaries), despite any other features of the genitals. Tellingly, hermaphrodites who could be assessed as either a male or female, were labelled “pseudo-hermaphrodite”, thus reinforcing the predominately binary construct of sex and gender. Those individuals that could not be determined to be either male or female were labelled a “true hermaphrodite”.

2.2.3 20th century

However, new advances in medical science meant that by 1915 the gonadal definition was being challenged, especially with developments in endocrinology. Surgeons like William Blair Bell from England suggested secondary characteristics should also be considered. Bell went a step further by stating that surgery could assist those people “by (helping) establish more completely the obvious sex of the individual” (Bell, 1915). Dreger goes on to refer to this as the beginning of the “age of surgery”, as this was the time surgery was introduced as a way to correct a person's sex.

Hugh Hampton Young was a surgeon specializing in genital and urinary tract surgery who joined John Hopkins University Hospital and established one of the first urology clinics. He developed surgical techniques and was a pioneer in reconstructive genital surgeries. He also published one of the first detailed surgical texts, “Genital abnormalities, Hermaphroditism, and Related Adrenal Diseases” (Young, 1937).
2.3 Scientific milestones in medicine affecting VSC/DSD in the mid to late 20th century

In 1905 Nettie Stevens first identified sex chromosomes and discovered they were in fact inherited, which was a radical new theory at the time (Abbot, Norden, & Hannsson, 2017). Genetics became increasingly important as the science advanced; it informed medicine of possible aetiology for VSC/DSD.

John Money, an Aotearoa/NZ psychologist who studied in America in the late 1940s at John Hopkins University, became a renowned sexologist. He did his PhD research with “hermaphrodites” and concluded that they generally did well psychologically despite their atypical bodies. He also noted that the upbringing of a child, not just hormones, was important when it came to sexuality (Karkazis, 2008).

2.3.1 Multi-discipline paediatric clinic established

Money joined one of the first paediatric clinics established by paediatric endocrinologist Lawson Wilkins, who was a pioneer in understanding and treating CAH. Establishing a multi-disciplinary team, Wilkins became the director and appointed Howard Jones (gynaecologist), William Scott (urologist) and Joan and John Hampson (psychiatrists). He invited Money to be the ‘first paediatric psychoendocrinologist” (Karkazis, 2008).

This milestone is important as it brought together for the first time specialists from a variety of fields to cover all aspects of proposed assessment, treatment and research. This was the start of such collaborations, which still form best practice standards today. Interestingly endocrinology still holds the lead in steering guidelines and protocols.

Money believed that gender was largely a socially constructed concept and that “nurture” (environment /culture) not “nature” (biology) was the key ingredient. This basically meant that it did not really matter what sex you were born; in fact, you could be nurtured into being the sex desired if you were given the correct social guidance on how to be that identified gender. This was quite radical from the accepted wisdom at the time, but ironically from the present perspective this framing of sex and gender ultimately led to practices that are now challenged as being based in gender essentialism (Christmas 2010).
2.4 John Money and Gender

Money's work with people born with VSC/DSD and transsexuals lead him to believe that one's biological sex is not always consistent with one's gender (Downing, Morland, & Sullivan, 2015). This was the beginning of the treatment protocol for children born with VSC/DSD.

The popularisation of the terms “gender identity” and “gender roles” is often credited to Money, who wrote extensively about gender and used “gender maps” to describe the complexity and developmental aspects of the way humans define their gender (see Figure 2 below). Money did acknowledge biology (especially the influence of hormones, particularly androgens) as having a foundational part in forming an individual's sex and gender identity. He also highlighted the importance of genital appearance as a defining influence on the way a person views their gender.
Money postulated that there were other powerful influences on gender, such as the way a child was reared, how others responded to them, learned behaviour/schemas, and cultural norms. His gender maps were an attempt to capture this complexity and show the “total” pathway to how gender is defined (see Figure 2). Money believed there were critical gateways that an individual goes through which are the stepping stones to grounding gender identity, and that once they have been passed through there is no changing those influences (Money, Hampson, & Hampson, 1957).

In this model the most critical stage occurred before a child develops speech. This is a key factor influencing Money’s support and subsequent recommendation for infants to have genital surgery to help their genitals look “as they should” for the gender they had been assigned. This would seemingly help the child believe/accept their gender as “true”. Money states:
“The most emphatic sign of all is, of course, the appearance of genital organs. Presumably, it is the very ambiguity of the external genitals that makes hermaphrodites so adaptable to assignment in either sex, though it requires to be emphasized that the less ambiguous our patients could be made to appear as a result of well-timed plastic surgery and hormonal therapy, consistent with their rearing, the sturdier was their psychological healthiness”  

(Money et al., 1957).

Money felt it was best not to disclose to the child anything about their difference and/or treatments, especially surgery, so they did not have to cope with the psychological burden of being different to their peers. This optimal gender of rearing (OGR) would fast become one of the longstanding treatment protocols for children born with VSC/DSD from the 1950's through to the late 90's. It would have a profound and polarising impact on the care of children during this period.

2.4.2 Money’s critics

Sullivan (2015) critiques Money’s theory in detail through a series of critical essays entitled “Fuckology”, a term that Money used to describe the study of sexology. In summary, she remarks that it is undeniable that his influence was far reaching and critical to the debate regarding sex, gender and sexuality. Sullivan introduces the idea that Money's “preconceived ideas and values” shaped his scientific endeavours, in particular his non-questioning belief in the binary and that male and female gender roles were a function of cooperation and were needed to ensure the evolution of humankind (Downing et al., 2015).

Sullivan draws on the work of gender scholars such as :Fausto-Sterling’s, “Myths of gender (Fausto-Sterling, 1992); Cordelia Fine's “Delusions of Gender” (Fine, 2010) and Judith Butler’s “Gender trouble”(Butler,1990). These scholars all highlight the point that the science of gender reflects the biases of those describing it, and that much of this bias is based on a heteronormative agenda that legitimises the binary in biological science. Whilst Money's contribution to providing psychological support for issues in endocrinology and his theories on gender were catalysts for changes in the way medicine, science, sociology and psychology intellectualised VSC/DSD, his original research, which concluded that most people with VSC/DSD would live normal lives despite their difference, seemed to become lost. His OGR
protocol asserted that people born with a VSC/DSD were best served by appearance based genital surgery to align their gender with their genitals. This included reassigning gender: for example, when a male child was born with a micro penis they would be reassigned as female and have surgery to remove male genitalia (internal and external) and construct a vagina.

2.4.3 The John/Joan case study

John Money’s most famous case study is the one based on his work with David Reimer and his family. After a botched infantile circumcision, Reimer’s family was referred to Money, who advised the family to bring David (then named Bruce by his parents) up as a girl and to have gender reassignment surgery so that his genitals would match his new gender identity. This happened when Bruce was 22 months old. Money advised the parents to move and never disclose that newly named Brenda had been anything other than a girl. David had a younger twin brother, Brian, and Money saw this as an opportunity to follow the family, believing this would prove his theory on gender development and validate his OGR protocol. Money referred to this as the John/Joan case and would publish much about the twins and in particular how “Joan” was living as a well-adjusted girl and later as a young woman.

This, however, was not the case, as at 14 years old, after experiencing mental health issues and discovering the truth of what had happened, Bruce transitioned back to a male, taking the name David. He later married and adopted his wife’s three children. He felt completely betrayed that he had not been told about his situation of being born a male and lived a life with much sadness that ultimately resulted in him taking his own life in 2004.

Milton Diamond, a professor of anatomy and reproductive biology, challenged Money’s OGR protocol, with a back and forth battle between the two men developing. This resulted in scrutiny of Money’s claims, revealing that the John/Joan case was not as reported by Money. The revelations of John Colpinto’s (a journalist who interviewed David Reimer) book about David Reimer’s life story, along with criticisms from academics like Milton Diamond, dented Money’s ethical integrity.
2.4.4 Consequences of OGR protocol

Genital surgery, gender reassignment, and non-disclosure were common practice, often stemming from the belief it would protect the child and in some instances the parents from being psychologically scarred or overwhelmed. Ironically this was proven to create the opposite effect, with many affected individuals feeling betrayed, lied to and having a sense of shame. Individuals had to endure constant focus on their genitals, involving regular genital examinations (often with many unrelated onlookers due to the novelty of such cases). This also included medical photography of the patient standing naked, typically printed with the eyes covered with a simple black bar to supposedly ensure anonymity (Dreger, 1999; Feder, 2014; Karkazis, 2008; Kessler, 1998). Many people born with a VSC/DSD felt different but did not understand why due to the treatment protocols based on non-disclosure that created secrecy and shame. There are many stories of children being completely unaware of their VSC/DSD and not discovering the truth until they were adults (Kessler, 1998; Dreger, 1999; Feder, 2014; Karkazis, 2008).

Many of these children who had been subjected to the OGR protocols realised there were others who had similar experiences and they started to connect, beginning to discover support through the sharing of their stories.

2.5 The 21st century

The 21st century bought some change to treatment protocols, in particular the realisation that nondisclosure to parents and the patient were no longer acceptable. These changes took place alongside the growth of intersex advocacy. Intersex was the term used by people born with a VSC and also some health professionals during this period. I will shift the focus to the development of intersex advocacy and return to the developments of medical protocols in chapter three. It is salient to provide an understanding of this increasing advocacy, which started in the late 1990s and gained strength and prominence in the 21st century.
The birth of Intersex (I/VSC\textsuperscript{3}) advocacy

2.6.1 Making connections

The creation of the internet and its increasing accessibility was a significant milestone for intersex advocacy, as it enabled people to reach out and connect with each other. This meant like-minded people with a variety of experiences could exit a place of isolation and shame. They started sharing their stories with one another, and realised they had many commonalities. This collective of people became the foundation of what is now a diverse network of intersex advocacy groups.

This increasingly audible voice of people born I/VSC confronted some of the health care that was provided to them and raised questions about the need to conform and the acceptance of diverse bodies. Brian Still tracks the rise of internet-based intersex advocacy and the creation of “virtual intersex neighbourhoods” that established and defined intersex communities globally (Still, 2008). People who were intersex who once felt isolated were now relating to one another, disseminating information and building a collective advocacy voice.

The “missing vagina monologues” is a post by Esther Morris, who has Mayer-Rokitansky-Küster-Hauser syndrome (MRKH) and started the MRKH.org website, which provides support for women born without a vagina (or with an undeveloped vagina) as a result of having MRKH. The website encourages women to talk about their bodies and others’ expectations of what it means to be a woman. Many women made comments reflecting their feeling about judgements from others; that just because you don’t have a functioning vagina that does not give someone the right to challenge your gender (Still, 2008). Still’s book gives credibility to the voices of intersex people, who have often been portrayed as a disgruntled few when in fact the intersex virtual community “illustrates otherwise” (Still, 2008, p. 138).

These groups often started as like-minded people reflecting on similar health care experiences for support and understanding, but ended up growing into advocacy groups recognising that the health care they had experienced had in many instances caused harm, resulting in them experiencing shame, silence, fear of intimacy and feeling isolated and alone. People were able to talk about their experiences, for

\textsuperscript{3} I will use the term I/VSC which means Intersex/Variations in Sex Characteristics in this section to reflect the language predominately used in the advocacy space.
example repeated genital examinations often involving multiple health professionals as discussed earlier. Some people expressed how these examinations felt exploitive and abusive. Others who were I/VSC wished they had been left to make choices about their bodies when they were older, especially regarding genital surgery and removal of internal genital structures and/or gonads (Douche & Mitchell, 2018; Feder, 2014; Kessler, 1998).

These communities created a sense of connection and caring these people had previously thought impossible. It was a natural progression for people in these communities to find not only comfort and support, but an opportunity to express themselves and come out from behind the wall of shame and silence to share their experiences with a wider audience. This exposure drew interest from others and as numbers grew globally the role of advocacy and activism found its place.

2.6.2 From support to advocacy

This meant people with lived experience were no longer the only ones highlighting the issues of health care for those born with I/VSC. Others, such as historians, ethicists, human rights agencies, psychologists, social scientists and many others, including those in health care provision, began to add support and scholarship. Collaborations started to develop in order to help facilitate a movement for change.

The United States lead the way with the Intersex Society of North America (ISNA), founded by Cheryl Chase (who was intersex) and researcher Alice Dreger, two major players in shaping the intersex advocacy movement. ISNA was one of the first organisations to make an impact by getting the experiences of people with I/VSC heard. It started in 1993 and ceased in 2008 as other organisations had developed and taken on the role of advocacy. Other organisations in North America included the Androgen Insensitivity Syndrome-Differences of Sex Development (AIS-DSD), InterAct (youth support), Congenital Adrenal Hyperplasia Support Education and Research (CARES), MRKH Foundation and Advocates for Informed Choice (AIC).

Academic researchers started to raise questions about the healthcare people who were I/VSC were receiving. Some of the first major publications included Suzanne Kessler’s “Lessons from the intersexed” (1998), Alice Dreger’s “Intersex in the age of ethics” (1999), Anne Fausto-Sterling’s “Sexing the body” (Fausto-Sterling, 2000) and journalist John Colapinto’s “As nature made him” (2000). These authors provide
some of the first glimpses into the experiences of those who are I/VSC and how their atypical bodies have been seen as problematic and needing to conform to the gender binary. Collectively these advocates questioned whether altering bodies based on appearance was appropriate. I mention these specific authors as they put the experiences of people with I/VSC on the world stage in collaboration with advocacy groups or advocates.

Advocates with lived experience began to challenge the literature, in particular the need for appearance based genital surgery in early infancy. Appearance based genital surgery was often justified by the psychological benefits of helping the child confirm their gender identity, as discussed earlier with the OGR protocol developed by John Money (refer back to 2.3.3). Many authors, however, commented that the long term psychological effects from genital surgery were in fact worse than the expected benefits of feeling and looking normal (Moreland, 2011; Diamond, 2011).

2.6.3 Intersex/VSC researchers

Building on the work of Cheryl Chase (1998,1999) in the 1990’s, Intersex researchers, such as Georgiann Davis (2015), Morgan Carpenter (2018), Mani Mitchell (2018), Hilda Viloria (2017), Tiger Devore (2015), Pidgeon Pagonis (2015) and Valentino Vecchietti (2018) began to publish their own critiques and accounts of lived experience and research. Various collected stories were also published through organisations such as Organisation Intersex International (OII). This increase in academic publications authored by a I/VSC people critiquing current treatment of I/VSC people elevated their voices in the ongoing debate on best health care practice.

These intersex (their preferred term) advocates and researchers have pushed for a global campaign of awareness, change and a call to action. Attempts at collaboration with the medical establishment and the resulting frustrations due to a perceived lack of change have meant that the intersex movement has progressed to more political realms. Global connectivity led to global representation and the opportunity to put forward a collective voice to try and encourage awareness and change.
2.6.4 Global intersex activism

The international Lesbian Gay Association Europe’s (ILGA-Europe) Malta declaration brought together 34 intersex activists from around the world in Malta in 2013. The activists prepared a declaration that has a list of 17 demands, ranging from stopping appearance based surgical procedures that are “normalising” through to ensuring anti-discrimination legislation. Additionally, the Malta group challenged others with influence to support change, particularly asking:

- **International, regional and national human rights institutions to take on board, and provide visibility to intersex issues in their work.**

- **National governments to address the concerns raised by the Intersex Forum and draw adequate solutions in direct collaboration with intersex representatives and organisations.**

- **Media agencies and sources to ensure intersex people’s right to privacy, dignity, and accurate and ethical representation.**

- **Funders to engage with intersex organisations and support them in the struggle for visibility and the building of knowledge, to increase their capacity and to affirm their human rights.**

- **Human rights organisations to contribute to building bridges with intersex organisations and to build a basis for mutual support. This should be done in a spirit of collaboration and no-one should instrumentalise intersex issues as a means for other ends** (Malta Parliament, 2015).

This declaration marked a shift to a more political stance and towards holding nations accountable for what they are doing to support the needs of those who are I/VSC.

2.7 Aotearoa/NZ advocacy and its Australian ally

In New Zealand, advocacy grew from the personal experience of Mani Mitchell, who was named Bruce at birth, then reassigned to a female gender as an infant and renamed Margaret. Mani is the founder and CEO of Intersex Trust Aotearoa New Zealand (ITANZ), which is an organisation supporting people who are I/VSC and their families. Mani is an advocate for raising awareness about issues affecting
people who are I/VSC. This attention and awareness building are crucial as it means that the world’s media and agents for change (such as human rights commissions, legal experts, ethicists and those working with in health care provision) are starting to reflect on the need for change. Mani Mitchell was part of the Malta delegation of intersex activists.

Australia and Aotearoa/NZ also arranged a delegation of intersex activists in Darlington, Sydney to produce the Darlington Statement (March 2017). The statement raises 59 points and actions that express the need to be acknowledged as people who exist, are diverse and deserve equal rights when it comes to “bodily integrity, physical autonomy and self-determination.”

The 59 points cover human rights and legal reform, health and wellbeing, peer support, allies, education, and awareness and employment. The Darlington Statement, under the section health and wellbeing, attacks the lack of transparency and inadequate care for people who are I/VSC. The group directly calls for action from “the Australasian Paediatric Endocrinology Group (APEG) and other medical/health bodies to stand alongside intersex-led community organisations to develop human rights-based lifetime standards of care” (point 18, Darlington Statement 2017). It is the intention of this statement to follow on from the Malta declaration as it demands action and clearly moves the advocacy and responsibility to the human rights domain (see full statement in the appendix).

2.7.2 Other Intersex/VSC activist national delegations

Other collected nations have also made statements, with the first African Intersex meeting, which included 7 African nations, taking place in Johannesburg, South Africa in November 2017. Whilst similar to the other statements mentioned, they had the additional demand of “an end to infanticide and killings of intersex people led by traditional religious beliefs” (Intersex Day Project, 2017).

Latin American countries released a statement in March 2018, after meeting for the first time in Costa Rica. The delegation had three clear demands:

- *Immediately prohibit any practice that modifies a person’s sexual characteristics without irrefutable medical reasons and the full and informed consent of the person affected.*
• Abolish “sex” as a legal category to be recorded in official documents (birth certificates, identity cards, passports, etc.).

• Reject any notion and labelling of intersexuality as a “third sex”, “third gender”, “indefinite sex”, “non-determined sex”, “ambiguous sex” or similar at birth, along with the practice of leaving blank the box corresponding to sex assignment after birth, because these categories do not reflect the diversity of the bodies we inhabit and violate our right to privacy.

(Intersex Day Project, 2018b)

Intersex Asia also released a statement of the first consensus for Asian nations in February 2018 from Bangkok, Thailand. Along with the Latin American counties, they also endorse the global Malta Declaration and have similar demands to those of previous statements. They note that in the future gender should be not used as a marker for identity on official documents, recommending: “In the future, as with race or religion, sex or gender should not be a category on birth certificates or identification documents for anybody.” (Intersex Day Project, 2018a)

The I/VSC advocacy movement has organised and created global connections and called upon the world’s governments to ensure their human rights and healthcare is protected. There have been attempts to engage in collaborations with medical and scientific communities and there are continual efforts and continual struggles and frustrations for intersex advocates as the pace of change is painfully slow. This has been the impetus for moving into the legal and human rights arenas referred to the following section.

2.8 Human Rights development of Sexual Orientation, Gender Identity and Sex Characteristics (SOGISC) issues

As mentioned in the previous section, the human rights movement and institutions have increasingly become an avenue for supporting the rights of those born I/VSC. Initially sexual orientation and gender identity (SOGI) issues were championed and in the last decade sex characteristics have been included.

The Yogyakarta Principles, published in 2007, list 29 principles pertaining to the international human rights law in relation to sexual orientation and gender identity (SOGI). They are named the Yogyakarta Principles as they were first drafted by a
A diverse group of human rights experts at Gadjah Mada University, Yogyakarta, Indonesia in 2006. Aotearoa/NZ has signed this international agreement along with many other countries.

Principle 18, “protection from medical abuses”, is particularly relevant as it states under section A and B that children should be protected by the law from appearance based surgical procedures (see text box below).

“that the state shall take all necessary legislative, administrative and other measures to ensure full protection against harmful medical practices based on SOGI, including on the basis of stereotypes, whether derived from culture or otherwise, regarding conduct, physical appearance or perceived gender norms” and “that no child's body is irreversibly altered by medical procedures in an attempt to impose a gender identity without the full, free and informed consent of the child in accordance with the age and maturity of the child ....”(Principle 18, UNHR, 2007, p. 23)

In 2017 the Yogyakarta Principles were updated to include 10 extra principles, reflecting changes internationally in regards to human rights. The addition of VSC specifically to SOGI issues raised the profile and rights of those who have a VSC/DSD. Principle 32, for example, states clearly the right to bodily and mental integrity (see text box below).

“No one shall be subjected to invasive or irreversible medical procedures that modify sex characteristics without their free, prior and informed consent, unless necessary to avoid serious, urgent and irreparable harm to the concerned person.”
(Principle 32, Yogyakarta principles Plus 10, 2017)

Importantly, this is where human rights law specifically references that medical procedures should not impose gender norms. This argument continues to develop. The key issue is that it is the individual’s right to decide what happens to their body and therefore decisions need to wait until a person is able to make those decisions for themselves. This principle does not apply to treatments that are life preserving.

In his opening speech to the United Nations, Ban Ki-moon, Secretary-General of the United Nations, addressed issues of discrimination regarding sexual orientation and gender identity (SOGI) (The Office of the High Commissioner for Human Rights, 2012, Mar 7). The strategy of using human rights falling under the scope of SOGISC issues has given rise to increased support for other minority groups, including those born with a VSC/DSD.
The UN Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment included under the section “marginalised groups” that of “intersex persons” (United Nations General Assembly, 2013):

*Children who are born with atypical sex characteristics are often subject to irreversible sex assignment, involuntary sterilisation, involuntary genital normalising surgery, performed without their informed consent, or that of their parents, “in an attempt to fix their sex”, leaving them with permanent, irreversible infertility and causing severe mental suffering*


This increasing interest from human rights advocates raised the profile as of variation in sex characteristics internationally leading to further investigations and reports.

### 2.8.1 Intersex Human Rights Documents

Several nations have developed human rights documents explicitly tackling these specific human rights issues. Notably in 2015 the council for European Human Rights and the Australian Human Rights Commission released issue papers for intersex people, outlining a need for review and further research. The issues identified included a need for appropriate counselling and the cessation of all “normalising surgery” which “compromises the individual’s rights to bodily autonomy, integrity and dignity and the right to self-determination in regard to self-identification”. However, the Council of Human Rights Commission’s report (COE) in 2015 was rebutted the following year by Cools et al. (2016) as having four major flaws (see below), indicating that health professionals were listening and disputed the claims being made by I/VSC activists about the health care provided. The rebuttal points were:

- *Does the LGBTQI community have the right to speak on behalf of the VSC/DSD community?*

- *Support and advocacy groups and associated health care professionals are underrepresented and only “activists” are heard*

- *Current medical practice is misunderstood*
• **The term “intersex people” is not representative i.e. it doesn’t represent the “ordinary” person with a VSC/DSD.**

(Cools et al., 2016)

I/VSC becoming a human rights issue provides a legitimacy and clearly establishes “the wrong” experienced by people with sexual orientation and gender identities that do not conform to a heteronormative, cisgender, binary and traditional view of gender (Beasley, 2016). This elevates the advocacy for these SOGISC issues by focusing on the principle of non-discrimination. In 2013 the UN launched its free and equal campaign. There was a number of resources shared via social media and in more traditional fact sheet forms covering SOGISC issues. As noted above, high ranking people within the United Nations, such as Ban Ki-moon and Navi Pillay, have championed new SOGISC norms and this places such issues on the “threshold or tipping point” that will eventually result in pressure being put on those nations that discriminate against those affected by SOGISC issues (Beasley, 2016).

2.8.2 “To be who I am/Kia noho au ki toku ano ao”: Human rights in Aotearoa/NZ

The Aotearoa/NZ Human Rights Commission (NZHRC) led the world’s first inquiry into discrimination experienced by transgender people, “To Be who I am/Kia noho au ki toku ano ao” (Human Rights Commission New Zealand, 2008). Their report included submissions by intersex people highlighting “significant human rights issues affecting intersex people that warrant urgent attention” and identified the paucity of data as a key concern as it hampers informed decision making.

This prompted a specific NZHRC inquiry for people born I/VSC. An intersex roundtable meeting took place in July 2009, with a second being held in Auckland in February 2010. The meeting discussed human rights issues for people born with a VSC/DSD and their families. While it was an important step and some key recommendations were made, little action for change occurred.

In 2015, ITANZ members requested to meet with the NZHRC to further raise issues and concerns. The group raised concerns that the Aotearoa/NZ government has not acted regarding these issues. ITANZ argued that “respecting the autonomy and integrity of the individual to make full and informed decisions about their care”, as
stated in the Code of Health and Disability Services Consumer Rights Act, should to be upheld (ITANZ briefing notes for ITANZ-HRC meeting 2015).

The NZHRC has responded by organizing a small group including representatives from ITANZ, medicine, academia, and Māori to convene another intersex roundtable to explicitly explore avenues of action.

2.8.3 Intersex roundtables

Another intersex roundtable took place in April 2016. It gathered over fifty key players (as mentioned above) and produced a report (Human Rights Commission, 2016a). A second roundtable was held the following year (Human Rights Commission, 2017), the outcome being that the Ministry of Health would establish a paediatric clinical reference group to review and develop specific national guidelines and recommendations.

The NZHRC is using the universal periodic review process (a process where the various conventions of the UN review a specific country's progress against aims they have claimed to have achieved) as a platform to address the discrimination against those born with intersex traits in this country. Conclusions from the fifth periodic review included 4 sections under “harmful practices” pertaining to those born I/VSC (see below).

NZ 5th periodic review: sections related to I/VSC:

(25)(b) “Develop and implement a child rights-based health care protocol for intersex children, setting the procedures and steps to be followed by health teams, ensuring that no one is subjected to unnecessary medical or surgical treatment during infancy or childhood, guaranteeing the rights of children to bodily integrity, autonomy and self-determination, and provide families with intersex children with adequate counselling and support”;

(25)(c) “Promptly investigate incidents of surgical and other medical treatment of intersex children without informed consent and adopt legal provisions to provide redress to victims of such treatment, including adequate compensation”;

(25)(d) “Educate and train medical and psychological professionals on the range of biological and physical sexual diversity and on the consequences of unnecessary surgical and other medical interventions on intersex children”; and
(25)(e) “Extend free access to surgical interventions and medical treatment related to their intersex condition to intersex children between the age of 16 and 18”

(Human Rights Commission, 2016b)

In January 2017, as part of the 5-year periodic review that holds the NZ government accountable for their actions, the ITANZ advocacy group put forward a submission to the Human Rights Commission under the convention against torture. Five key points were highlighted and the recommendations of 2016 were repeated (as above).

ITANZ submission points for Aotearoa/NZ Review 2017:

- The preservation of life and the right to genital autonomy
- Bodily integrity
- Legal protections
- Education and professional development
- Whole of life approach to health care

(Intersex Trust Aotearoa New Zealand, 2017)

In addition, ITANZ advocated for three specific actions to occur:

- “Seek assurance from the NZ government that they will end the practice of non-life-threatening surgery on intersex children through legislative protections and the implementation of a set of professional standards for the medical profession that affirm bodily autonomy of intersex children.”

- “Require that the population data on intersex people is accurately and uniformly recorded, allowing truthful records to be kept and monitored while preserving the privacy of individual intersex people.”

- “Question the NZ government on what financial commitments it will make to ensure that appropriate advocacy and social support services are made available to intersex people for the whole of their lives.”

(Intersex Trust Aotearoa New Zealand, 2017)
The submission was driven by concerns the Aotearoa/NZ government and the health sector were not adequately aware of or taking responsibility to ensure the human rights of those born intersex. The document highlights the need for current research, development of a database, and to stop all appearance-based surgery. The aim of the ITANZ submission is to capture support from international human rights organisations to pressure and challenge the reported inaction and lack of current knowledge within Aotearoa/NZ.

This is in line with international human rights groups and in most instances, this is not new, however the submission goes further by suggesting that what is perceived as current medical practice is in fact a violation of human rights. This is a very difficult concept for health professionals to accept, as from their point of view they are following best practice guidelines and operating within a code that is founded on the premise of “do no harm”(paediatric endocrinologist and paediatric surgeon, personal communication, March 2015).

2.8.4 Separating SC from the SOGI

One could argue there is no need to create new human rights for people born I/VSC, but rather to ensure that the same rights apply to people born I/VSC as apply to everyone else. However, as outlined above, it is likely that it is more effective to be specific, as was the case with LGBT advocacy groups within the human rights arena. While equality may be theoretically expected for all, history indicates a lack of equality, especially for marginalised groups. Moreover, human rights targeting I/VSC people need to be explicitly outlined, as expecting rights for I/VSC people to be covered under general and/or LGBTQIA⁴ (or rainbow communities) human rights has proven insufficient and is arguably inappropriate in any case. I/VSC issues can be lost in the rainbow issues or conflated with transgender concerns.

From this vantage point, addressing the needs of people who are I/VSC specifically, is likely to be a strategy used within human rights forums around the world going forward, and countries like Aotearoa/NZ will not escape such scrutiny. The specific

⁴ LGBTQIA is the acronym for lesbian, gay, bisexual, transgender, Questioning, intersex, and asexual -also referred to as rainbow community.
targeting of I/VSC issues has indeed begun internationally, with the 2017 List of Issues Priorities to Reporting (LOIPR) for the seventh periodic report that was released by the Committee against Torture requesting New Zealand provide specific information on treatment for intersex children in NZ.

Whilst change is likely to be a long and slow process, as has been the case so far, especially from the point of view of those most affected, there are signs of increased engagement. For example, the government of Norway is being proactive and requested information from its Ministry of Health regarding surgical procedures that have taken place in the last 3 years and whether they were for life-threatening purposes or for psycho/social benefits (Katrina Roen, personal communication, 2016). Similar steps will likely follow within Aotearoa/NZ because of the work of advocacy groups.

This separation to specifically target I/VSC issues has begun internationally, with the 2017

2.9 Gender theory

While the purpose of this thesis is not to focus on gender theory, it is important to note that it has a place in the scientific literature and is relevant here in that John Money’s beliefs and subsequent writing and development of his gender theory had a profound impact on people born with VSC/DSD. From the 1970’s onwards, with the rise of feminism, gender studies developed and is now common place (Butler, 1990). Social science and biology and neuroscience have all made commentary on what role sex and gender play in our lives and how they function. Money’s viewpoint and theory of gender fitted with contemporary views but they now differ from more recent understanding in recent time, especially over the past 20-30 years., as noted below.

Sex is often described as being “biologically” determined in utero (this is discussed in more detail in chapter three) by the action of genes and hormones, whereas gender is regarded as socially determined. Both biological and social research and subsequent commentary often has a focus on the differences between males and females, particularly in Western culture. There has been criticism of such studies, in that similarities are not reported, only differences (Fine, 2010; Jordan-Young, 2012). More recently it has been more commonplace to claim that sex and gender are
inseparable and neither is either purely biological nor purely socially acquired, and therefore it is recommended that “sex/gender” be used (Kaiser, 2012).

As an example, brain organisational theory (BOT) states that fetal hormone exposure permanently organises the brain for gender, sexual attraction, temperament and whether you will prefer typically boys’ or girls’ toys. An example of this related to VSC/DSD is that girls with congenital adrenal hyperplasia (CAH), who are often born with ambiguous genitalia and have been exposed to high levels of prenatal androgens, are seen to be “virilised” and therefore likely to be interested in more “masculine” activities and to develop same sex attraction (Hines et al., 2016). However, this research has been attacked as having a narrow perspective that has ignored the complexity of the social environment and experience that interacts with the development of the brain (Jordan-Young, 2012; Fine et al., 2013).

Behavioural neuroendocrinology has shown “the power of the individual’s behaviour, the behaviour of others, and aspects of the environment to influence the brain and the behaviour through reciprocal modulation of the endocrine system” (May, 2011; van Anders & Watson, 2006). In other words, this suggests that BOT is too simplistic, making assumptions that “sex” hormones are dimorphic and somehow hardwired prenatally, which is incorrect. New evidence suggests there is a great deal of plasticity of gendered behaviour and that gender is ever evolving due to complex biological and environmental influences that are not static, including those in the brain and endocrine system (Fine, Jordan-Young, Kaiser, & Rippon, 2013; Kaiser, 2012; Wraga, Helt, Jacobs, & Sullivan, 2007).

“Neuroanatomical data reveal that sex interacts with other factors in utero and throughout life to determine the structure of the brain, and that because these interactions are complex, the result is a multi-morphic, rather than dimorphic brain….and that human brains are composed of an ever-changing heterogeneous mosaic of “male” and “female” brain characteristics (rather than being all “male” or all “female”) that cannot be aligned on a continuum between the “male brain” and the “female brain” (Joel, 2011).

The idea that gender is not in fact a fixed and static notion that is defined by either nature or nurture has thus become much more widely accepted in recent decades. In this view, gender identity is thus always in a state of transition, and is influenced
by biological, sociological and many other variables, some of which we are still to fully determine and understand (Browning, 2016 pp. 225-227).

This evolving understanding and scholarship of gender supports the premise that we are more fluid in our gender make up than traditionally believed, and that the binary model is no longer as relevant as it once was.

2.10 Bioethics as an advocacy ally

The field of bioethics has the task of being the ethical and moral compass of some of the more challenging biological and medical issues that humans face, such as issues around genetics, end of life, right to refuse treatment, etc. Medical bioethicists are being consulted more on the area of VSC/DSD, especially in the absence of clear outcome data.

Switzerland is one of the only countries where the government has produced a specific report with recommendations based on ethical considerations. The report’s first recommendation and summary states:

“The suffering experienced by some people with DSD as a result of past practice should be acknowledged by society. The medical practice of the time was guided by sociocultural values which, from today’s ethical viewpoint, are not compatible with fundamental human rights, specifically respect for physical and psychological integrity and the right to self-determination.”

(Swiss National Advisory Commission on Biomedical Ethics, 2012)

The main focus was that they should base management on “ethical and legal grounds” that protect a child’s right to make decisions for themselves about their own bodies as no one, not even parents, can predict the child’s future thoughts and feelings around how they view their VSC/DSD. This document was ground-breaking as it highlights the ethical issues, especially of the child’s basic right to what we now call bodily autonomy. The importance of ethical guidance as a principle basis for setting protocols is also championed.
Below is a list of summary points for future consideration from the Swiss bioethics report:

- **Involve the child if they have “Gillick competency” (see glossary for definition)**
- **There is a need for quality professional psychological interventions that are without cost**
- **Those working in the area need specific training and guidelines**
- **There is a need for research involving patients who have not had invasive interventions**
- **There is a need for a legal review about liability for unlawful interventions in childhood**
- **Use of terms such as “differences of sex development” or “sex variations” and “intersexuality” are preferable**

(Swiss National Advisory Commission on Biomedical Ethics, 2012).

2.10.1 “Monster ethics”

Alice Dreger comments on the “division of ethics” that occurs for children born with a VSC/DSD i.e. that there are two standards of ethics, those for “normal children” and those for children born with a VSC/DSD. She goes on to say that children don’t get the same ethical consideration until they are “normalised” or “brought up to human standards” (Dreger, 2004).

“Monster ethics” is a term used in relation to Siamese twins, reflecting that it is so monstrous to consider two people living in a conjoined body that it may justify the loss of one child’s life in order for the other to live a normal life (Annas, 1987). Dreger asserts that this may apply to children born with a VSC/DSD. For example, when a baby girl is born with an enlarged clitoris it might be considered as freakish as it resembles a penis, and it would be “monstrous” for a girl to resemble a boy, especially in the genitals. Another researcher concurs that doctors see a baby being born with different genitals as horrific for parents (Feder, 2014). This belief that genital difference is horrific results in the compulsion to “normalise” genitals so the child can be seen as normal. There is a “long history” of doctors normalising children
whose bodies don’t fit the norm, e.g. children with cleft palate, efforts to stunt the growth of tall girls and the reverse for short boys (Feder, 2014, pp. 120-121).

2.10.2 When inaction becomes unethical

People with atypical bodies are seen as having the problem, when it could be equally argued that it is society that has the problem. Societal views that are so embedded in the binary create an environment that excludes diversity when it comes to variations in sex characteristics. If society was more inclusive and accepting of difference, people with a VSC/DSD may not be seen as having a problem that needs fixing.

In 2015, after twenty years of advocacy and scholarship on the care of people born I/VSC, Alice Dreger released a statement alongside Tiger Devore, an US intersex advocate. In this statement Dreger effectively says she has had enough of the inaction, which she refers to as the “tranquilizing drug of gradualism”, a phrase originally used by Martin Luther King. Dreger believes her involvement with the medical profession has let them off the hook, as they have had the hard discussions but are somehow able to continue without making any change of note. Dreger ends by stating:

“...Until clinicians interrogate their issues of shame and anxiety around human sexuality and disability, they will continue to enact that shame and anxiety on the bodies of children who deserve better, who deserve doctors that let their parents know unequivocally that, while life can be challenging, nobody is shameful.”

(Dreger, 2015).

This statement was in part a result of Dreger’s being an ethics advisor on a large USA longitudinal study (DSD-Translational Research Network or DSD-TRN) with children who are VSC/DSD, run by geneticist Eric Vilain and psychologist David Sandberg, who are experts in the field of VSC/DSD and had been seen as sympathetic to the concerns of advocates. Dreger was one of nine bioethicists and activists who left as advisors due to their frustrations and concerns about the study.
2.10.3 Where is the evidence?
From an ethical standpoint the question is raised: Is it ethical to continue doing treatments where there is little or no evidence to support the claimed benefits? (Diamond & Garland, 2014; Karkazis, 2008). Health professionals have been criticised for using anecdotal or clinical experience to support their own current treatment practices due to the “the paucity of data on outcomes for intersex patients” (Karkazis, 2006, p.289). Ironically, this is also what health professionals say of activists with lived experience, according to Karkazis. Interestingly, in 2016 David Sandberg (psychologist co-leading the DSD-TRN study) is quoted as saying “I never question people’s experience...what I do question is whether they are generalizable” (Reardon, 2016).

Karkazis raises a number of key questions about the value of genital surgery, such as: what does it achieve? Does it help someone feel more male or female? Why make gender variance invisible? To what extent do we let chromosomes and genitals define us? She also questions the value placed on norms and whether norms are not just seen as an average but also an ideal (Karkazis, 2010).

2.10.4 The power of determining gender
Another ethical consideration following on from the questions raised by Karkazis is whether it is appropriate to view gender as something that can be defined at birth. For many gender will remain the same from birth to death, though its expression (i.e. the way we chose to perform our gender identity) may vary over time. As mentioned before, (2.10.1) the idea of atypical bodies not conforming to the gender binary can be viewed as horrific.

The ethics of genomics and its role in VSC/DSD management have also been questioned. Genomics in relation to VSC/DSD is all about “securing a cisgendered future” and that determines what is considered to be “really” male and female (Clunie-Taylor, 2018). Clunie-Taylor states this cisgendered future is “an abstract, normalised trajectory of development overtime, characterised by coherence across multiple characteristics of sex, gender and sexuality (including one's identity as cisgender).” She goes on to state that gonadectomy and genitoplasty are mechanisms by which to enforce these future cisgender aspirations. This is reminiscent of John Money and his OGR protocol, which states that if medicine
supports the future gender and aligns the body to match that gender this will result in a psychologically healthy and “normal” individual.

Clunie-Taylor raises 5 main ethical issues, which she breaks into local and global as follows:

Local

- *Violation of the right to autonomy and bodily integrity*
- *Clinician failure to uphold professional duty to beneficence and non-malfeasance*
- *Failure to engage in evidence-based Medicine*

Global

- *Is it ethical for one to (attempt to) determine the gendered future of another?*
- *Is it ethical for one to (attempt to) secure a specifically cisgendered future for another?*

(Clunie-Taylor, 2018)

These ethical questions echo issues raised by human rights forums, medical codes of conduct, bioethicists and of course those directly affected. The global ethical consideration is a new perspective. I would argue that securing cisgendered futures is an extension of OGR, with the addition of recent developments in genetics. Clunie-Taylor rightly asks how we can predict the future and whether that is something we should be doing? (Clunie-Taylor, 2018). She asks what genomes actually tell us? Do they provide evidence for anything, other than showing what might cause specific variation in one particular set of genes? Genomes will be discussed in more detail from medical and bioethics standpoints in the next chapter.

While these bioethical questions are often not easily answered, they are very important to think about and explore. The raising of these questions and/or concerns holds us all to account, especially when it comes to research and the subsequent treatments and guidelines that are developed.
2.10.4 The power of bias

Bias occurs when we hold a prejudice/assumption against someone, something or a group; it often arises due to stereotyping based on our previous experience of the world (Oxford Dictionary, 2015). Bias can be explicit or implicit. An explicit bias is one the person is conscious of and is therefore able to assess and reflect on it (Perception Institute, 2018). For example, an explicit bias could include a preference for certain foods, political parties or religious views. An implicit bias is where a person is unaware of the bias, sometimes referred to as unconscious or unintended bias (Perception Institute, 2018). For example, this might include assumptions that women are natural caregivers, or that signs of aggression and assertiveness are more acceptable in men. Often implicit bias can conflict with explicit bias. For example, I might hold an explicit preference for diversity and equality in workplace leadership, but my hiring and promotion decisions may be influenced by an implicit preference for white male candidates as they more closely resemble existing stereotypes of effective leadership.

It is difficult to tell whether a person’s bias is explicit or implicit unless they acknowledge an understanding of their bias, therefore making it explicit. Bias in the healthcare field is well documented (Hall et al, 2015, FitzGerald & Hurst, 2017, Marcelin et al, 2019). These studies indicate that health professionals are just as likely to be affected by bias as anyone else in the population when it comes to race, gender, and body size often resulting in poorer decisions and outcomes. It will be important to understand if bias has a part in the Aotearoa/NZ provision of healthcare for those born with a VSC (Hall et al, 2015, FitzGerald & Hurst, 2017, Marcelin et al, 2019).

2.11 Legal Issues

The complexity and controversy of working in the area of those born with VSC/DSD has led to the involvement of the legal system as a means to try and set legally sanctioned guidelines for health professionals. In addition, parents and activists have sought legal action to prosecute those who they believe are committing a crime by providing treatment without consent.
2.11.1 Legal precedent

Legal precedent was set in the “M.C.” case in the USA, where parents have sued the Medical University of South Carolina Hospital for operating on their adopted child who was born with a VSC/DSD and assigned a female gender. At 16 months, while in the care of social services, “M.C.” had surgery to normalise their genitals to resemble those of a typically female infant and remove any structures or genitalia that resembled those of a male infant.

“M.C.’s” adoptive parents stated that their child identified as a boy as he grew and “suffered as a result of the surgery.” Lawyers at the Southern Poverty Law Centre (SPLC) have taken on the case on behalf of the parents Mark and Pam Crawford. The case, taking 4 years, resulted in a settlement of $US440,000 for “M.C.”; there “was no admission of liability or wrong doing.” (Ghorayshi, 2017). This was the first time that the law was used to pursue a case of this nature and despite there being no admission of wrong doing, this case highlighted there is now a legal precedent for pursuing legal action regarding what may be deemed failure to preserve bodily autonomy.

Malta was first in the world to introduce a law effectively banning genital surgery. The Gender Identity, Gender Expression and Sex Characteristics Act (GIGESC) was introduced in 2015. The law recognises that individuals have the legal right to decide what happens to their bodies and that decisions should be deferred so that the person can decide for themselves (Malta Parliament, 2015).

Interestingly, the Ministry of Health (MOH) in Chile also made a decision, based on advice from the Chilean human rights committee and the WHO, to stop normalising surgeries, soon after the Malta legislation. The MOH stated it would investigate current practice and research and develop some clear guidelines/protocols. This led to a change in the MOH perspective when they introduced their new Circular 7 in 2016, which overrides the previous human rights-based circular and reverted back to a more conservative viewpoint (Government of Chile, 2016).

Intersex activists Laura Inter and Hana Aoi state that the changes are a step backwards for intersex people in Chile, and were critical of the use of DSD over intersex and the move back to parents making decisions with health professionals regarding treatment that is not essential for their children (Inter & Aoi, 2017).
The fact that legal avenues have been used to challenge health care for those born with VSC/DSD has strengthened both human rights and I/VSC advocacy. These attempts to hold health providers accountable reinforces the argument that closer attention needs to be placed on the way decisions are made in the health care of those born with a VSC/DSD.

2.11.2 Legal right to self-determination and consent

If gender was self-determined this would lessen the pressure for the “right” gender to be announced as it could be easily changed in a person's lifetime. Attempts were made to have “indeterminate” became an option on birth certificates in Germany in 2013. This meant there would be no requirement to put male or female on the birth certificate. An “X” could be used, with a subsequent choice of male or female should the person desire. This is not a third gender, just an absence on the birth certificate, but has also been criticised as potentially stigmatising and singling out the person (Carpenter, 2018).

The legal debate raises the issue that a VSC/DSD child’s rights are compromised “by medically reinforcing gender assignments on children without their participation and consent”, as asserted by (Scherpe & Garland, 2019). In concordance with Greenberg, however, they argue the law can no longer just debate the issue, it must consider judicial action. They state that there are surgical and hormonal interventions being done to infants “without long-term data confirming their necessity, safety and efficacy” (Scherpe & Garland, 2019). The authors believe the legal issues fall into two areas, namely: the need to have a legally designated gender; and the legitimacy of surgery and other medical interventions, subsequent harms and the lack of consent by the person affected (Scherpe & Garland, 2019). Both of these impact on whether an individual born with a VSC/DSD can have the autonomy to decide their own gender and consent to surgical procedures that can affect their gender.

2.11.4 The Aotearoa /NZ legal perspective

A review paper on intersex and the law investigated national and international trends regarding genital surgery, including those stemming from a human rights frame work, and highlight that there is little legal commentary in Aotearoa/NZ (McDonald, 2015). That critique largely occurs within the human rights focus of
SOGI forums where issues of genital surgery are raised, such as the Universal Periodic Review (UPR) that Aotearoa/NZ undergoes as a member of the United Nations (as mentioned in section 2.8.2). McDonald states that legally “there has been no uniform or universal response to the issue of surgery on intersex infants” (McDonald, 2015). McDonald concurs with Greenberg’s call for the legal profession to act:

“We should not continue to leave decisions about the treatment of people with an intersex condition solely to medical practitioners. In areas involving sex and gender, science is in its infancy and has engaged in a number of harmful practices based on unsupported theories that later proved to be incorrect.”

(Greenberg, 2012, p. 135).

2.11.5 Informed consent

Informed consent is an important aspect of the debate regarding bodily autonomy for children born with a VSC/DSD. Gillick competency relates to the way children under 16 years of age are viewed in regards to how competent they are to make their own decisions about their healthcare. The Gillick competency refers to a parent’s responsibility diminishing as the child’s own capacity or maturity develops. In Aotearoa/NZ Gillick competency applies.

In Aotearoa/New Zealand the Code of Health and Disability Services Consumers Rights (Health & Disability Commissioner, 1996) and the Care of Children Act (New Zealand Government, 2004) establish the baseline by which informed consent is obtained when it comes to children. Von Rooyan provides an excellent critique of the issues faced by health professionals when it comes to deciding competency. Informed consent is complicated and no single governing document, law, guideline or United Nation recommendation provides a consistent clarity as to what informed consent is. However, they all accentuate the point that we need to include children and hold their right to personal autonomy as paramount (Van Rooyen, Water, Rasmussen, & Diesfeld, 2015).

A health professional’s ability to communicate is also a contributing factor, i.e. being able to communicate with the child or young adult at an age appropriate level about the health care path being suggested. When the child is an infant this defaults to the
parents and/or caregivers who also need clear information. It would be useful to understand more about what support is offered to health professionals regarding this process and whether children and/or parents are providing fully informed consent when it comes to the health care of those born with VSC/DSD.

2.12 Media

In the 21st century the media and the interface with social media has created a platform for debate and education. There has been more representation of marginalised groups, with an increase in SOGI representation and also in the representation of those born with VSC/DSD.

2.12.1 Increasing visibility and awareness

Internationally renowned documentaries have been widely distributed with the aim of raising awareness. These include the Aotearoa/NZ documentary “Intersexion” (Lahood, 2012), which features a variety of people from around the world discussing their experience of being born with a VSC/DSD. This was shown at a variety of film festivals internationally and played on free to air national TV in Aotearoa/NZ, and a shortened version was even shown on Air New Zealand domestic flights. “Orchids, my intersex adventure”, an Australian documentary by Phoebe Hart, discusses what is like to live with Androgen Insensitivity Syndrome (AIS) as a young woman (Hart, 2010).

In the mainstream area of entertainment, a popular United States MTV series, “Faking It”, aimed at youth, featured a character with complete AIS. In March 2016, there was an episode introducing a character named “Raven”, a youth member from interACT (an advocacy and support group for young people with intersex traits) played by real life interACT youth member Amanda Saenz (Avery, 2016). In 2016 a play by Anna Ziegler, “Boy”, showed at the Clurman Theatre in New York City, inspired by the story of David Reimer and John Money (Shechet -Epstein ,2016).

Here in Aotearoa/NZ a popular tv soap opera, Shortland Street, had two of its main characters have a baby born with VSC/DSD. This was a first for prime-time TV and it caused a flood of mainly positive responses from the public, as reported by The New Zealand Herald online, e.g. “I never thought in my entire time of watching soaps that I would finally see an intersex child,” and “I think SS is revolutionary and it’s awesome that their storylines are highly inclusive.” However, there were others
who showed the strength of the commitment that some have to the binary, such as this comment: "This storyline is messed up why can't there just be normal baby either a boy or a girl not a bloody intersex baby." (The Herald, August 9th 2018).

These representations in popular media platforms raise issues for the general public to consider and start to challenge the idea that there is only the binary model of gender.

2.12.2 News

The news media has highlighted cases that challenge the binary. There are reports on high profile cases, such as the Australian high court decision to accept “non-specific” as a gender classification in the Norris versus the NSW Registrar of Births, Deaths and Marriages case (Bibby & Harrison, 2014).

The UK Guardian, a multimedia news source, ran a story about the Belgian fashion model Hanne Gaby Odiele, who revealed she has AIS. She did so in order to help raise awareness and to highlight issues re surgery on children born intersex (Khomami, 2017). This was followed up by a further article about Dawn Vago and Holly Greenberry, who are co-directors of the intersex advocacy and support group IntersexUK. Greenberry was quoted saying “The silencing and shame and stigma have to be abolished.” They believe people who like Odiele can help with public awareness and grow the understanding that being born with an I/VSC does not mean you are abnormal or need to be altered to fit the binary norms (Khaleeli, 2017).

In sports, Caster Semenya, a South African woman who won the 800m at the 2009 world championships, had her gender questioned, was subjected to over a year of tests and had her personal health history exposed i.e. that she was born with a VSC/DSD. She was subject to discrimination and was publicly attacked by other athletes, who considered her a man and therefore that it was unfair for her to run against them. The International Association of Athletics Federations (IAAF) was criticised for its handling of the situation, but eventually recognised Semenya as a women and allowed her to compete at the Olympics in 2012 and 2016, where she won silver and gold medals (Who2 Biographies, 2018).

However, since then there have been new rules established by the IAAF that effectively mean Semenya would have to have hormone regulation to bring down her testosterone levels. Semenya said recently in an interview "It is not fair. I just
want to run naturally, the way I was born." (Caster Semenya: Olympic champion will challenge 'unfair' IAAF testosterone ruling, 2018). She does not want to have to take medical interventions in order to compete.

The sporting world has its own rules regarding gender, and rules specific to performance enhancing drugs that are taken in violation of such rules. In the case of Semenya, her levels of testosterone are naturally occurring. Academics Karkazis and Carpenter criticised the international sporting authorities for requiring intersex women to make “impossible choices” that do not respect their gender identity and dignity, by making rules that effectively exclude them or make them have to compete with the men. It is as if these women are accused of taking testosterone to increase their abilities, when in fact it is a natural occurrence for them (Karkazis & Carpenter, 2018). Again, these individuals’ stories raise issues around people born with a VSC/DSD being treated differently because of naturally occurring variations.

2.13 Cultural perspectives
2.13.1 Māori and Pacific Islands
Aotearoa/NZ has Te Tiriti o Waitangi/The Treaty of Waitangi (TOW) as the nation’s founding document establishing the relationship between the state and Māori people (Archives NZ, n.d.).

The Ministry of Health-Manatū Hauora’s own website states that the three main principles outlined in the Treaty pertain to health care as follows:

- **Partnership** involves working together with iwi, hapū, whānau, and Māori communities to develop strategies for Māori health gain and appropriate health and disability services.

- **Participation** requires Māori to be involved at all levels of the health and disability sector, including in decision making, planning, development and delivery of health and disability services.

- **Protection** involves the government working to ensure Māori have at least the same level of health as non-Māori, and safeguarding Maori cultural concepts, values and practices

(Minstry of Health, 2014).
These principles from the treaty could be adapted and applied to the health care of all individuals, not just Māori and highlight the issues of equity and cultural awareness and sensitivity. It could be argued that under this protection, children have the right to decide for themselves what happens for their bodies when it comes to appearance-based medical interventions that may compromise their bodily integrity.

2.13.2 Takatāpui

“Takatāpui” is the term that captures gender, sex, and sexual diversity within Māori culture here in Aotearoa/NZ. Indigenous peoples around the world historically have had a broader view of sex, sexuality and gender. This is often still the case, however the influences of colonisation and the increased exposure to western religion have undoubtedly had a huge impact. In many places, this has meant western cisgendered, heteronormative world views and/or Christian-based faiths have become the dominant view within the culture.

The “emergence of Takatāpui identity” explores the strengths in the intersectionality of cultural identity and diversity of gender, sexuality and sex characteristics, and how this can foster acceptance and a sense of connection (Kerekere, 2017). In modern day Aotearoa/NZ there is a developing use of the term “Takatāpui”, which is an umbrella term embracing all Māori with diverse gender identities, sexualities and sex characteristics, including whakawāhine, tangata ira tāne, lesbian, gay, bisexual, trans, intersex and queer. A predominant definition is as follows:

“Takatāpui identity is related to whakapapa, mana and inclusion. It emphasizes Māori cultural and spiritual identity as equal to - or more important than – gender identity, sexuality or having diverse sex characteristics. Being takatāpui offers membership of a culturally-based national movement that honours our ancestors, respects our elders, works closely with our peers and looks after our young people”

(Kerekere, 2017).

In Aotearoa/NZ we have a large Pacific Islander population and they have some different cultural perspectives on gender. Fa'afafine is a Samoan word for a man “in the manner of woman” who is accepted for their feminine qualities and gender
expression. Other Pacific nations also express this acceptance of gender fluidity, for example Fa’afafine in Tokelau, fakaleiti in Tonga, fakafifine in Niue, akava’ine in the Cook Islands, and vakasalewalewa in Fiji (Schmidt, 2010).

It is important to note that while these more open and flexible beliefs are present, they are not always accepted, especially when there has been colonisation by dominant western cultures where religious beliefs and/or dominant coloniser norms may be expected and/or enforced.

2.13.3 VSC/DSD research in Aotearoa/NZ

There has been little research done in Aotearoa/NZ specifically on children born VSC/DSD. A qualitative study involved three older adult (30s to 40s) participants and its findings suggest that issues of disclosure, self-acceptance and society's representation of diversity (and lack of it) all impact on people who are I/VSC (MacKenzie, Huntington, & Gilmour, 2009). Mackenzie, a nurse, reflects “People with intersex conditions require particularly sensitive care and nurses can provide appropriate, supportive and ‘safe’ care if they are aware of the condition and its challenges” (MacKenzie et al., 2009)

Geraldine Christmas (2013) undertook a small qualitative study using a feminist theory/methodology. She reported that there was a need for more detailed research, especially from those affected directly, such as young people and parents. Christmas found it difficult to recruit for the study and consequently had small numbers (five), which was a significant limitation. Christmas asserts there was little acceptance of difference within the medical profession or training around issues for those with VSC/DSD. Given Aotearoa/NZ is small, international guidelines and research is relied upon (Christmas, 2013).

A more recent study is a single case study that covers the life of Mani Mitchell and their experience of living with a VSC/DSD and having interventions guided by the theory of John Money, which highlights the need for bodily autonomy and patient agency (Douche & Mitchell, 2018).

The fact that there are only a few studies and none with a focus on representation of youth with VSC/DSD highlights that there is a research gap within Aotearoa/NZ. Research in this area that includes the voices of young people is indicated.
2.13.4 International cultures and gender

Internationally there are many cultures who have broader concepts of gender, which mean that the society has awareness and acceptance of these differences and in some instances embraces the difference as a gift of wisdom. Some examples include Native Americans such as the Navajo, with “Nadleeho” or “Nadle” regarded highly within their communities. They are seen as knowing all as they have the wisdom of both male and female, so they can do the work of both (Lang & Kuhnle, 2008).

The “Guevedoce” in the Dominican Republic develop into a male at puberty, but prior to this will be brought up as female, knowing the change will come at puberty (Herdt, 1990). Papua New Guinean mountain communities of the Sambia have a third gender they refer to as the Kwolu-Aatmwol, again a female transforming into a male. They are seen as having “special spiritual powers. Both the Guevedoce and the Kwolu-Aatmwol are seen by western medicine as having a VSC/DSD, specifically 5a-reductase deficiency, which is characterised by virilisation occurring at puberty in females with the variation who are no diagnosed at birth (Herdt, 1994).

In contrast some cultures see such difference as horrific (as discussed in previous section 1.10.1). Africa is an example, with some tribes, such as the Pokot in west central Kenya, killing infants born with genital variation. They are called “serrer” and if not killed at birth are discriminated against by not being able to marry or adopt children. In India the Hijra are not elevated in their society like the Nadleehe; they are seen as low class, subjected to discrimination and ridicule and are effectively outcasts (Herdt, 1994).

There are many more examples of different genders and gender fluidity, such as the “Bissu” Priests in Indonesia, Shaman in Siberia, “Mustergil” in southern Iraq, “Banci” in Java and many more (Lang & Kuhnle, 2008). However not all pertain to VSC/DSD and while some cultures may support gender variation by recognising different gender categories or through social acceptance of difference, there are situations where this is not the case, as outlined above.

The research done by Lang and Kuhnle highlights the need for HP working with those born with VSC/DSD to recognise that their own cultural backgrounds and ideas on gender may not transfer to those of a different culture. It is also important
to be aware of the context of culture and the influences that can alter the cultural perspective, such as colonisation.

2.14 Intersectionality

Intersectionality refers to issues that intersect with one another to further disadvantage the person e.g. being intersex but also having a difference due to race, religion, gender, sexuality, disability, education, living situation and/or socioeconomic status.

One could argue this was the case for the aforementioned Caster Semenya, who is African and a lesbian and seen as not conforming to the social norms of femininity as a woman. Heteronormative ideals and a bias towards the perceived benefits of male status are also elements that intersect with those born VSC/DSD.

Research that examined the media coverage of the “M.C.” case mentioned earlier (section 2.10.1) noted that most news media used photos of white children despite the fact “M.C.” was African American. Lane believes this is because readers will be more sympathetic to a white baby and therefore to those who are intersex (Lane, 2018). Furthermore (he or she) notes there is a racist issue when it comes to the treatment of black intersexed bodies and cites the work of (Magubane, 2014) who states back people are seen as inferior.

Commentary about health care for those born with a VSC/DSD in the US and non-western cultures decisively concludes that:

> “physicians involved in intersex clinical management have a responsibility to respect patient autonomy, patient disclosure and informed consent. They also have an ethical obligation to pursue the patients’ best interests while promoting universal human rights. The obligation requires the physician to be primarily concerned with promoting concordance between the child’s assigned gender and his [sic]likely future gender identity in order to minimize the risk of gender dysphoria. Local cultural factors such as economics, politics and homophobia simply have no place in clouding clinical decision making” (Tell, 2016).
This is a challenge for any health professional involved in this field and it is important to understand whether these factors are in fact influencing decision making in Aotearoa/NZ.

2.15 Othering
Othering occurs when we believe a group of people are not like us or are not one of us, so we label them as “others”. Lois Weis defines othering as “the process which serves to mark the name those thought to be different from oneself” (Weis, 1995). Othering can inadvertently reinforce dominant discourses and make the othered person feel negative about being different. In regards to those with a VSC/DSD, othering is likely to be an influencing factor and it will be useful to explore it.

One intersex advocate and researcher suggests that “medicine constructs intersex bodies as either female or male, while the law and society construct intersex as neither male nor female” i.e. a third gender (Carpenter, 2018). Carpenter states that bodies are therefore “normalised” by medicine and that the law and society want to create an “other” category. People born with a VSC/DSD become “those people” or “other”, separate to the rest of us, until they can be changed to be more “normal”. Then and only then can they be one of “us”.

2.16 Summary
The saying that “it take a village to raise a child” could be adapted to “it takes a society and its elements of influence to decide a child’s gender”. What I mean by this is that there are many societal elements that impact the way gender is perceived, expressed and valued.

In this chapter I have illustrated the various elements that are likely influencing perceptions and the literature that surrounds these elements. I demonstrate the complexity of the various elements coming from shifts in society, such as changing views around sexual orientation and gender identity and the move to view sex characteristics in the same way. I address how culture and religion interact and impact on the way we see people with different sex characteristics. The development of theories surrounding gender has prompted intersex-led research to contribute to the growing debate regarding health care for people born with a VSC/DSD. Bioethics has an increasing role in considering the complexities of VSC/DSD care and providing frameworks to work through these complexities.
The way these all intersect; the potential for “othering” of those born with VSC/DSD; and the way those not directly affected gain awareness through the efforts of the media, film and television, art, literature and social media are important considerations. Documentaries such as “Intersexion” build awareness that different bodies exist and that our world must be accepting of diversity, seeing it as a human right and if not, challenging it to be seen as such.

The challenge appears to be finding a way to hold and consider (and for some, even be aware) all of the different viewpoints with respect and finding a common ground. There are many complexities involving the many people all vying to provide ideas for the way forward. Unfortunately, it seems that the voices of people with VSC/DSD, while being heard, are not privileged in the same way as those from science and medicine. This has resulted in advocates moving into the legal and political realms of human rights and legal action.

Medicine and science have changed dramatically, not just in the understanding of how we develop as an embryo and throughout life, but also by realising that what was seen as paternalistic protection was not a helpful practice. In fact, it was harmful, especially nondisclosure, encouraging secrecy and effectively making VSC/DSD as invisible as possible in order to help the child and parents feel normal. These enormous shifts have brought about a more patient-centred approach and informed consent procedures. Medicine and science are crucial and powerful elements in the way children and young people with VSC/DSD are responded to. Consequently, the next chapter will examine the dominant discourse of the medical world in detail as a companion chapter to this chapter, which explored the broader discourses in society.
Chapter Three

Human reproductive biology and medicine

“XX or XY...”

3.1 Introduction

In the previous chapter I provided a broad outline of some the history, elements and influences that have affected people who have been born with a VSC/DSD. Chapter two introduced how human reproductive biology and medicine have had a defining role in directing the health pathway for people with a VSC/DSD.

This chapter will provide more detail on the human reproductive biology and science that informs the medical perspective. The development of a human from an embryo to birth is especially complex and requires many sequential processes and actions to occur in order to produce a typical female or typical male baby. It is necessary to understand some of these complexities of human development as they are the antecedents to what makes this area of medicine so challenging. Chapter two demonstrated that many of the societal influences are complex and evolving; this is also the case for science and the understanding of embryological development.

Human reproductive biology is the focus of the beginning of this chapter, orientating the reader to the foundations of the current scientific understanding of human development in-utero. It covers both typical development and the atypical development that may result in the development of a VSC/DSD. Knowledge from the literature will assist the reader to gain some insight into the level of complexity presented to the health professionals working in the field.

In the first instance, I will start by describing typical sex determination and how this is currently understood within the literature. I will follow this by defining what a VSC or DSD means within the medical context, then more broadly within society. Next, I will discuss the variety of presentations regarded as VSC/DSD, outlining the common variations that fall under the VSC/DSD umbrella and which underlie the inclusion and exclusion criteria for this study, along with some of the advances in screening for VSC/DSD.
There is much debate around the terminology to describe someone with a VSC/DSD. I will clarify the variety of terms and provide some of the benefits and concerns around the use of some of these terms, in particular the umbrella terms i.e. “disorders of sex development”, “intersex” and “variations in sex characteristic”. A detailed explanation for the use of the term VSC/DSD throughout this research will be provided.

In the final section of the chapter I will comment on medical guidelines and medical training, including the role of ethics and communication within the education setting and how they might have an impact on health care provision for people with a VSC/DSD. I will provide a thumbnail sketch of the health care decision making regarding VSC/DSD and the limited information in the literature on this area.

In conclusion, I will use a table to visually represent all the elements of influence that may impact on the health care decision making for someone born with a VSC/DSD, as discussed in chapters 2 and 3. The table will draw together these main elements, providing a foundation for the development of the research presented in this thesis.

3.2 Human Reproductive Biology

In human reproductive biology, typical biological development leads to sexually dimorphic humans. Babies will typically be born either as a female or a male. However, as discussed in the previous chapter, there is growing debate as to whether the dimorphic, also referred to as the binary, is as absolute as first thought. Blackless et al. (2000) state of this binary that “absolute dimorphism as a Platonic ideal [is] not achieved in the natural world”. They go on to say that medical science uses this ideal as the normative standard for being the “single correct pathway” for determining the ideal male and female. Anything that deviates from this ideal is therefore defined as abnormal (Blackless, Charuvastra, Derryck Castel, & Lee, 2000, p. 24).

This raises the question of what the beliefs of those who work in this area are and how that impacts on the way they view VSC/DSD. I will now proceed to outline the predominant accepted knowledge regarding sex determination and differentiation from a scientific perspective.
3.2.1 The biology of sex determination/differentiation

In the beginning stages of pregnancy all babies have the potential to become a typical male or female and it is usually the sex chromosomes that set the path for sex determination. Babies with XX sex chromosomes are genetically female and those with XY sex chromosomes are genetically male. Following the development of the gonads, sex determination occurs depending on whether there is a Y chromosome (specifically the SRY gene) present or not. Sex differentiation, referring to the development of the foetal anatomical reproductive and urogenital structures, follows. In order for this to take place expression of specific genes and production of hormones from the gonads is required. “This is a sequential process initiated by the establishment of the chromosomal sex followed by the formation of the gonadal ridge, migration of the primordial germ cells and the sexually dimorphic differentiation of the gonads” (Lucas-Herald & Bashamboo, 2014).

Compared to other organs in the body that develop into one structure and function, gonads have the potential to develop into two different options i.e. the ovary or testis, which adds an extra level of complexity and requires a number of processes to complete.

3.2.2 Stage one- development of the gonad

The first stage is the development of the gonad, which is initially indifferent i.e. it is bipotential and can become either an ovary or a testis depending on a set of very complex and cascading influences that are affected by both hormones and genes. In the first instance primordial germ cells (PGC) migrate to the genital ridge, forming the earliest gonadal structure.

3.2.3 Stage 2- differentiation, ovaries or testes

The second stage of differentiation of the human gonad occurs usually around embryonic week 6 to 8. In babies with XX chromosomes, gonads develop into ovaries and those with XY chromosomes develop testes. If there is a Y chromosome the action of the sex-determining region Y or SRY gene effectively sets off a complex set of instructions and signals that start the development of the gonad to become a testis. If there not a Y chromosome (or SRY gene) then the alternative pathway will be towards developing an ovary (Koopman, 2001; Lucas-Herald & Bashamboo,
In either case the correct genes and hormones need to be in action in order for these to be directed on a sex specific path. (See Figures 1, 2 and 3 below).

This is a very complex and vulnerable stage of development and variation or diversion from what is typical can occur. I will discuss this further in the next section on atypical development.

**Figure 3:1 Gonadal development in mice (Koopman, 2001)**

Gonadal development in mice. (a) The gonadal primordium (genital ridge) is similar in males and females at 11.5 dpc. By 13.5 dpc, the testis has developed seminiferous cords whereas the ovary is smaller and less organized. In males, the Müllerian duct regresses and the Wolffian duct is promoted, whereas the opposite occurs in females. (b) Detail of the cellular structure of the developing testis. (Koopman 2001)
These specific pathways require transcription factors such as the SRY gene and Sox9 in order for the gonad to develop into the early stages of a testis. While ovarian development was historically considered to be a “default” if no Y chromosome was present, new information suggests that this is not the case, with key genes also required to activate ovarian development, including WNT4 and RSPO1 (Ohnesorg, Vilain, & Sinclair, 2014).

“The subsequent maintenance of the gonadal fate can be viewed as a battle for dominance between the male (Dmrt1, Sox9) and female (Fox2 and Wnt/B-catenin) regulatory gene networks” (Lucas-Herald & Bashamboo, 2014). In other words, “both pathways act by suppressing components of the opposing pathway to ensure proper development and maintenance of the gonads” (Lucas-Herald, Bashamboo, 2014) (see Figure 3 below). For a very detailed description see Ohnesorg, Vilain and Sinclair (2014). This intricate process of “mutually antagonistic pathways” is essential for typical gonadal development to occur (Lucas-Herald, Bashamboo, 2014).
3.2.4 Stages 3 and 4- development of internal and external structures

In males, once the gonad differentiates into a testes it secretes MIH, switching off development of the Müllerian ducts. It also secretes testosterone, which stimulates development of the Wolffian ducts that develop the internal structures. These internal structures include the vas deferens, seminal vesicles and ejaculatory ducts. The testosterone is converted locally to dihydrotestosterone to stimulate development of the external structures of the penis and fusion of the labioscrotal folds to form the scrotum.

In females, once the gonad differentiates into an ovary there is no MIH, so the Müllerian structures develop into the internal structures: fallopian tubes, uterus and vagina. As no testosterone is present, the Wolffian ducts regress, and as there is no dihydrotestosterone, the external structures of the clitoris and labia develop.

To summarise, there are 4 main stages involved:

1. Development of the gonad
2. Differentiation of the gonad into testis (male) or ovary (female)
Development of internal structures: Müllerian ducts (female) in the absence of MIH and Wolffian ducts (male) in the presence of testosterone

Development of external structures: clitoris, labia (female) (in the absence of dihydrotestosterone) or penis, scrotum etc. (male) (in the presence of dihydrotestosterone)

Other structures are developing adjacent to and at the same time as the genital structures, in particular the urinary system (including kidneys) and the bowels. As a consequence, development of these structures may also be adversely affected in atypical development. This can occur either because a specific gene is involved in development of both gonad and kidney/urinary system (e.g. WT-1, WNT-4), or because of a “developmental field defect” (developing structures and organs in the same area) leading to anatomic variation in several structures. For example, the mesonephros turns into a kidney and is very close to the gonad; in a variation like Mayer Rokitansky Küster Hauser Syndrome (MRKH), where a female’s reproductive system is affected, the kidneys can also be affected due to being in the same developmental field. See Figures 4 and 5 below for more detail.

Figure 3:4 Phenotypic differentiation of the female and male urogenital tracts

In females, the Müllerian ducts give rise to the fallopian tubes, uterus, and upper vagina, and the Wolffian ducts persist in vestigial form. In males, the Wolffian ducts give rise to the epididymides, vasa deferentia, seminal vesicles, and ejaculatory ducts, and the Müllerian ducts regress.
In females, the genital tubercle becomes the clitoris, the genital swellings become the labia majora, and the genital folds become the labia minora. In males, the genital tubercle becomes the glans penis, the genital swellings fuse to become the scrotum, the genital folds elongate and fuse to form the shaft of the penis and the penile urethra, and the prostate forms in the wall of the urogenital sinus. Graphic 65480 Version 4.0 © 2018 UpToDate, Inc. (Physiology Plus, 2017, Jan 8)

I have just outlined the current research demonstrating what we know at this point in time about the pathways that result in what is best described as dimorphic sex. It is important to note that most working in this area of sex development would acknowledge its complexity and that there is still much unknown, but that it is not as simple as black and white/male or female.
3.2.5 Biological sex as a spectrum

Ainsworth (2015) described research from prominent geneticists, scientists and biologists redefining sex as a spectrum rather than a binary or dimorphic. A table representing the “sex spectrum” that is inclusive of variation and VSC/DSD (Ainsworth, 2015) is shown below (Table 3.1). Eric Vilain, director of a major large longitudinal study tracking the wellbeing of children with VSC/DSD in the United States, and one of the contributors to Ainsworth’s article, commented “Biologically, it (sex) is a spectrum”. Vilain states that if we took the most inclusive definition of VSC/DSD, i.e. including mild hypospadias, incidence would be 1 in 100 as opposed to the 1 in 4500 people stated in the 2006 consensus (Ainsworth, 2015; Lee et al., 2006). Given the variations and complexity in defining sex Vilain believes gender identity is the most reliable way to check and that it is best to simply ask whether someone is male or female.

This area of research is emerging and likely to develop more with new scientific advances alongside more progressive ways of viewing diversity within humankind.

Table 3:1 The Sex Spectrum (Ainsworth, 2015).

<table>
<thead>
<tr>
<th>Typical male</th>
<th>Subtle variations</th>
<th>Moderate variations</th>
<th>46,XY DSD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chromosomes</td>
<td>Testes</td>
<td>Testes</td>
<td>Testes</td>
</tr>
</tbody>
</table>
| X and Y      | Male internal and external genitalia | Usually caused by variation of male sex-determining gene SRY | Male genit 
aux with anatomical variations such as prema 
termin 
ity shut 
down of ovar 
ies. Some caused by variation in sex development genes. |
| Gonads      | Male internal and external genitalia | Affects 1 in 250-400 births | Female internal and external genitalia |
| Genitals    | Other secondary sexual characteristics | Other characteristics' examples | Female secondary sexual characteristics |
| Other characte 
ristics' examples |                |                     |           |

3.3 Atypical sex development

A baby whose sex development is atypical due to a variation in the above processes or a broader anatomical issue affecting multiple structures may present with genitalia that make it difficult to determine the sex of the child.
3.3.1 The role of genes

It is not always clear exactly why this occurs in some and not others, however with advances in genetic science an increasing number of VSC/DSDs clearly result from specific gene mutations or disruptions in the complex sequence of processes taking place that was discussed above Ohnesorg et al. (2014) provide a table (see below) outlining a number of the currently known genes that have an influence on sex determination and how they might influence the development of a VSC/DSD if disrupted. There is still much to understand and uncover from a scientific standpoint and the search to clarify the processes at play continues (as discussed below).

Table 3:2 Genes involved in human sex determination (Ohnesorg et al., 2014)

<table>
<thead>
<tr>
<th>Gene</th>
<th>Loss of function</th>
<th>Gain of function</th>
</tr>
</thead>
<tbody>
<tr>
<td>CBX2</td>
<td>46,XY DSD</td>
<td></td>
</tr>
<tr>
<td>WT1</td>
<td>46,XY DSD, Denys-Drash and Frasier syndrome</td>
<td></td>
</tr>
<tr>
<td>SRY</td>
<td>46,XY gonadal dysgenesis</td>
<td>46,XX testicular DSD</td>
</tr>
<tr>
<td>SOX9</td>
<td>46,XY gonadal dysgenesis, usually with campomelic dysplasia</td>
<td>46,XX testicular DSD</td>
</tr>
<tr>
<td>NR5A1</td>
<td>46,XY gonadal dysgenesis, usually with adrenal failure</td>
<td></td>
</tr>
<tr>
<td>NR0B1</td>
<td>hypogonadotropic hypogonadism</td>
<td>46,XY gonadal dysgenesis</td>
</tr>
<tr>
<td>DAX1</td>
<td>with congenital adrenal hypoplasia</td>
<td></td>
</tr>
<tr>
<td>DMRT1</td>
<td>46,XY gonadal dysgenesis</td>
<td></td>
</tr>
<tr>
<td>ATRX</td>
<td>46,XY DSD</td>
<td></td>
</tr>
<tr>
<td>MAP3K1</td>
<td>46,XY gonadal dysgenesis</td>
<td></td>
</tr>
<tr>
<td>GATA4</td>
<td>46,XY DSD</td>
<td></td>
</tr>
<tr>
<td>FOG2</td>
<td>46,XY DSD</td>
<td></td>
</tr>
<tr>
<td>DHH</td>
<td>46,XY DSD</td>
<td></td>
</tr>
<tr>
<td>FGF9</td>
<td></td>
<td>46,XX testicular DSD</td>
</tr>
<tr>
<td>WNT4</td>
<td>46,XX testicular DSD</td>
<td>46,XY gonadal dysgenesis</td>
</tr>
<tr>
<td>RSPO1</td>
<td>46,XX testicular DSD with hyperkeratosis</td>
<td></td>
</tr>
</tbody>
</table>

Scientific advancements in genetics have been able to identify some of the genes that may result in these atypical presentations in children born with a VSC/DSD. Jessica Kremen and her colleagues reviewed such advancements in the literature and determined that “whole exome sequencing (WES) has greatly improved the ability to identify disease causing genetic variants” (Kremen, 2017, p. 2). These VSC/DSD genetic causal discoveries have grown from a few known related genes to at least 50 suspected genes, and this number is increasing all the time (Kremen, 2017).

A detailed description of the genetic and signalling pathways that can lead to VSC/DSDs is provided by (Arboleda, Sandberg, & Vilain, 2014). If the reader would
like to delve more deeply into the complexities of these interactions that are thought to lead to some VSC/DSDs, they expand on these influences in great detail.

**Figure 3:6 Genetic pathophysiology of human sex determination (Arboleda et al., 2014)**

Within the developing gonad, regulation of gene transcription occurs through cellular signalling pathways (WNT4–RSP01 in ovary determination, Map-kinase in testis determination) that activate genes through alteration of chromatin structures and modulation of epigenetic factors or by direct activation of transcriptional networks. In 46,XX individuals, WNT4 and RSP01 act through Frizzled or LRPS–LRP6 receptors to activate β-catenin (CTNNB1) transcription. β-catenin and FOXL2 promote expression of ovary-specific genes while inhibiting the expression of testis factors such as SOX9. In 46,XY individuals, Map-kinase signalling through MAP3K1 may alter chromatin conformation indirectly through histone modifications (dotted arrow). Map-kinase signalling also increases phosphorylation of transcription factors such as GATA4, which is thought to alter chromatin (dotted arrow) upstream of SRY, and was shown to directly bind to SRY promoter (solid arrow) to activate transcription. Within the nucleus, transcription factors GATA4 and ZFP FM2 bind and transactivate SRY and SOX9. Other important factors are CBX2 that has been shown to directly bind the SRY promoter and that, in conjunction with the NR5A1 protein, binds to the SOX9 promoter. The SRY protein can then turn on downstream genes such as SOX9, which initiates the testis gene expression network and represses ovarian-specific genes such as RSP01 and β-catenin. Ovary-promoting transcription factors are noted in orange and testis-promoting factors are noted in green. Abbreviations: ORF, open reading frame; P, phosphate
The complex process of human development in-utero makes it challenging for the lay person to fully appreciate the scientific aspects of this development. It is not surprising, given the scientific and technical advances that allow a gateway into the further intricacies of these variations/deviations, that science, biology and genetics are convinced of their causal link to VSC/DSD.

3.3.2 Current understanding of Genes linked to VSC/DSD
Currently about 40% of VSC/DSDs can be genetically diagnosed and it is hoped that with better technological developments this percentage will increase (Arboleda, Sandberg and Vilain, 2015). It is equally important to reflect that we do not know what may be uncovered in the future that may change the direction science is currently pursuing. For example, it was widely believed in the past that the development of the ovary was a “default” mechanism in the absence of the Y chromosome, whereas ovarian development is now known to require activation of specific genes.

This information has helped extend the knowledge of causes but more recently, increasing access to such technology has also indicated the spectrum of genetic influences on any one variation that may be present under the VSC/DSD umbrella. This has resulted in advances in our understanding of the role of gonadal development and the consequential variation (Baxter & Vilain, 2013; Kremen, 2017). Table 3:3 provides an example of a classification system for those born with a VSC/DSD. The classification is from the consensus statement on management of VSC/DSD (Hughes et al., 2006).
### 3.3.3 VSC/DSD Classifications

**Table 3:3 DSD Classification (Hughes et al., 2006)**

<table>
<thead>
<tr>
<th>An example of a DSD classification</th>
<th>46,XY DSD</th>
<th>46,XX DSD</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>B: 47,XXY (Klinefelter Syndrome and variants)</strong></td>
<td>B: Disorders in androgen synthesis or action 1. Androgen biosynthesis defect (e.g. 17-hydroxysteroid dehydrogenase deficiency, 5α reductase deficiency, StAR mutations) 2. Defect in androgen action (e.g. CAIS, PAIS) 3. LH receptor defects (e.g. Leydig cell hypoplasia, aplasia) 4. Disorders of AMH and AMH receptor (Persistent Müllerian Duct Syndrome)</td>
<td>B: Androgen excess 1. Fetal (e.g. 21 hydroxylase deficiency, 11 hydroxylase deficiency) 2. Fetoplacental (aromatase deficiency, POR) 3. Maternal (luteoma, exogenous, etc.)</td>
</tr>
<tr>
<td><strong>C: 45,X/46,XY (mixed gonadal dysgenesis, ovotesticular DSD)</strong></td>
<td>C: Other (e.g. severe hypospadias, cloacal extrophy)</td>
<td>C: Other (e.g. cloacal extrophy, vaginal atresia, MURCS, other syndromes)</td>
</tr>
<tr>
<td><strong>D: 46,XX/46,XY (chimeric, ovotesticular DSD)</strong></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Whilst consideration of karyotype is useful for classification, unnecessary reference to karyotype should be avoided; ideally, a system based on descriptive terms (e.g. androgen insensitivity syndrome) should be used wherever possible.

This classification tries to link the causation to the specific disorder/variation, for example the first column relates to VSC/DSDs that have different a chromosome make...
up to the typical 46,XY male or 46,XX female. As science continues to advance, particularly in the field of genetics, more such classifications (and terminology) are likely to evolve (Ohnesorg et al., 2014). This has been aided by the development of international data registries such as I-DSD, which gathers data internationally for collaborative research and is also useful for understanding the long-term issues for specific variations e.g. cancer risk (Ahmed, Gardner, & Sandberg, 2013).

Some variations can appear in any of the chromosomal categories- an example is ovotesticular DSD (highlighted in blue in table 3:3, showing 4 different categories possible). This demonstrates how complex and challenging it is to create a system that accurately reflects the evolving science and understanding of these variations and explains the ambiguity in the language used in the management of these variations. The most recent consensus classification from Europe (Cools et al., 2018) is presented below and highlights some of the changes in classification.
Disorders of sex development (DSDs) are classified into three main groups on the basis of the karyotype of the affected individual (primary cause). Each main group encompasses several subgroups (secondary root) that orient towards a specific diagnosis (tertiary root). MRKH, Mayer–Rokitansky–Küster–Hauser syndrome.

3.3.4 VSC/DSD categories

These three categories of VSC/DSD are currently the most common classifications:

**46,XY,DSD** – this refers to babies with a 46,XY karyotype whose internal or external urogenital structures do not match those of a typical male. This may result in genitals looking ambiguous, i.e. closer to those seen in a typical female in appearance (including a micro penis, an unfused scrotum, undescended testes, and urinary...
opening at the base of the penis rather than the tip), or having a typical female appearance. This often results from the baby not being able to produce the testicular hormones required or not being able to respond to them. Testosterone and dihydrotestosterone are needed in order to develop male-appearing genitalia.

The most common presentation in this group would be hypospadias, which ranges from mild to severe. Only severe hypospadias is considered to fit under the VSC/DSD umbrella currently (Heath point, 2019).

Other variations include: Androgen insensitivity syndrome (AIS), which can be partial (PAIS) or complete (CAIS), resulting from mutations in the androgen receptor (i.e. disorders of androgen action), mutations in enzymes involved in androgen biosynthesis (e.g. 5α-reductase deficiency, 17-β hydroxysteroid dehydrogenase deficiency, some forms of congenital adrenal hyperplasia); other causes of impaired testosterone production (e.g. Leydig cell hypoplasia); syndromes (where variation in chromosomal appearance is part of a variation affecting multiple parts of the body).

Denys-Drash syndrome is a variation that affects the kidneys and genitals and is related to gonadal dysgenesis. Cancerous tumours can develop in the kidneys, called Wilms Tumour. There are also fertility issues for this group.

**46,XX DSD** – this refers to babies born with a 46,XX karyotype whose internal or external urogenital structures do not match those of a typical female. This can include a “more male-like” appearance of the genitalia such as enlarged clitoris, fused labia or rugosity of the labia. This is usually the result of androgen exposure during pregnancy.

Congenital adrenal hyperplasia (CAH) is the most common variation in this group and among VSC/DSDs overall. CAH is a group of variations where there is a block in steroid biosynthesis in the adrenal glands, leading to deficiency of some hormones (particularly cortisol and aldosterone), which can be life-threatening without treatment, and excess of adrenal androgens, leading to virilisation in a 46,XX fetus, i.e. female external genitals looking ambiguous or closer to those of a typical male. There are milder forms of CAH where the adrenal glands are partially functioning. Male infants with the common forms of CAH do not have ambiguous genitalia, but
have a life-threatening illness resulting from deficiency of the other adrenal hormones, although in some rare forms of CAH, where there is a block in cortisol production, but only relatively weak androgens are made, an infant with a 46 XY karyotype may have ambiguous genitalia.

**Sex Chromosomal DSD** – this is where the variation is in the sex chromosomes themselves. This group includes variations that may be missing a sex chromosome or have an extra sex chromosome, such as Turner syndrome (45,X) and Klinefelter syndrome (47,XXY) and their variants. These occur because of non-disjunction of chromosomes during cell division, with uneven pairing of sex chromosomes.

Chimerism is where there are two different cell lines in an individual from separately fertilised zygotes (that might otherwise have become twins). This is very rare.

Gonadal Dysgenesis is incomplete or abnormal development of the gonad. It can be complete or incomplete and can occur in any of the three major divisions of classification.

Mixed gonadal dysgenesis (45,X/46,XY MGD) is a VSC/DSD associated with a numerical sex chromosome abnormality resulting from Y-chromosome mosaicism and leading to asymmetry of the gonads.

In 46,XY complete gonadal dysgenesis, also called Swyer syndrome, XY individuals have female reproductive structures. People with Swyer syndrome have typical female external genitalia. Often there is a uterus and fallopian tubes, though these can be undeveloped, but the gonads (ovaries or testes) are not functional; affected individuals have undeveloped clumps of tissue called streak gonads. The residual gonadal tissue can develop cancer, so it is usually removed surgically early in life.

**Ovotesticular DSD** – is the most complex VSC/DSD grouping and can be included in any the three categories above due to its complexity. In this condition there is both histological testicular and ovarian tissue (although neither may be functional for reproduction). This is an especially difficult VSC/DSD as it requires medical professionals and parents to determine which sex to assign to the child based on what is often a very unclear picture. It is unclear why this occurs but advances in science may reveal answers in the future.
In the past there was stigma and shame attached to the term “true hermaphrodite”, which was used in previous classifications. This group of VSC/DSD variations has had the most significant historical and present-day profile as it was/is so unique and therefore has had the most medical and public interest. Consequently, there has been much information and misinformation about this group, who at times have been a novelty and subject to exploitation and curiosity.

**Other Non-specific DSDs** – in addition, some VSC/DSDs are due to anatomical variation (e.g. Mayer Rokitansky Küster Hauser Syndrome (MRKH) and Cloacal Anomaly), or the variation in the genitalia occurs as part of a broader syndrome affecting multiple parts of the body (e.g. Smith-Lemli-Opitz syndrome).

**3.3.5 Disagreement about what is a VSC/Intersex/DSD**
There is debate over whether variations such as hypospadias, CAH, Turner Syndrome and Klinefelter syndrome should even be considered as being under the umbrella of Intersex, which for some implies “in between the sexes”, whereas VSC/DSD is seen as a broader term. In these variations, there are normally no issues of genital ambiguity, sex of rearing or gender identity and for this reason it is not considered appropriate that they come under the umbrella term Intersex. For example, hypospadias is regarded as specifically a matter of function, is seen by the medical world as largely straightforward to correct, and most would say it is curable (O’Connell, 2016). One surgeon commented that it may even be caused by fetal position in the womb e.g. the heel pushing against the genitals results in the variation, rather than hormones, congenital or other related causes (surgeon, personal communication, June 2016). It is only the severe cases of hypospadias that are seen as warranting inclusion as a VSC/DSD.

Because of the disagreement about what should be included (e.g. hypospadias), the prevalence of variations is unclear. Rates vary in different countries: Australia, Aotearoa/NZ’s closest continent, estimates a prevalence between 17.1-34.8 (from two studies ) per 8/10, 000 (Springer , van den Heijkant, & Baumann, 2016). The authors go on to note that data is difficult to gauge due to methodological issues in reported data.

Arguments often given in support of surgery for hypospadias are that it may improve appearance, avoid recurrent urinary tract infections, avoid
incontinence, avoid painful erections (at all ages) and achieve urination standing i.e. have flow from the end of the penis as opposed to mid or at the base of the penis, which implies needing to urinate sitting. There is also an argument for possible improved fertility; this is supported by long-term data, especially for those with curvature of the penis (Bhat et al., 2016). However, recent studies investigating fertility potential by comparing men with hypospadias and a control group indicate that fertility is comparable to that of the men without hypospadias, except for those with additional genital variations (e.g. micropenis and ambiguous genitalia) and those with proximal hypospadias i.e. where the urethral opening is close to the base of the penis or scrotum (Asklund et al., 2010; Bhat et al., 2016). Both studies reported no difference in fertility potential whether surgery was done in childhood or as an adult.

Others suggest that no intervention is needed. Research involving men who have had no intervention shows many have coped well and, in some cases, not even been aware of variation (Dodds et al., 2008). This raises the question of what is best practice, no intervention or intervention? It will be important to understand health professionals’ perspectives on this in Aotearoa/NZ.

In regards to CAH, again there is no perceived issue regarding gender as females with CAH have XX chromosomes and are therefore genetically female, and most women with CAH identify as female. Many believe CAH is not a variation leading to biological sex being questioned; there is no question of being “between sexes” or having a Y chromosome.

3.4 Natural variation in genitals

There is a great deal of variation and difference in the general population when it comes to the appearance of genitals internally and externally. Medical professionals have often seen hundreds of different people and therefore different bodies and know this to be true. In fact, a DSDfamilies website comments on natural variation (DSDfamilies, 2019).

British artist Jamie McCartney’s “Great wall of vaginas” sculpture panels exhibit plaster casts of 400 different vulva from women who volunteered to participate in the creation of the art piece. It clearly demonstrates variety and difference, contesting the idea that there is a typical presentation of the female external genital
structures (McCartney, 2011). Other researchers explore the history of clitoral conventions and indicate how the representation of the clitoris alone has varied dramatically in anatomy texts (Moore & Clarke, 1995).

Apostolou’s research on variation in the penis indicates that there is a great deal of variation which is typical and should be viewed as natural variation, not a medical problem (Apostolou, 2016).

A UK hypospadias support group also tries to remind men that penises come in all shapes and sizes, and, while they acknowledge hypospadias as a variation, they do not see it as always needing to be “corrected”. They go on to say that surgeons take a “somewhat paternalistic approach (that) appears to be based on the idea that there is a “perfect penis”; that all men should look alike so that there is no mocking by peers or sexual partners; and that the “perfect penis” also contributes to a healthy body image” (Hypospadias UK, n.d.).

This raises the question of what the norm is when it comes to the way genitals look, both internally and externally. There are phenotypical norms and measures used in medicine that provide some guidance, such as the Prader scale for clitoral size. Normally, the length of a new born boy’s penis is between 2.8 to 4.2 centimetres (Shonefeld & Beebe, 1942).

Norms and their measures have an important place in medicine and form the basis for deciding what is considered atypical. What is considered within the normal range and a variation when it comes to VSC/DSD is somewhat unclear. Understanding what role norms play in the VSC/DSD field and the impact of this would be helpful within the Aotearoa/NZ context.

3.5 Prenatal screening

Screening for some intersex variations is possible (along with other tests such those for Down syndrome) using a blood test from the pregnant parent. NIPT (non-invasive prenatal testing) is available in Aotearoa/NZ at a cost (approximately $600 plus consultation fee). The testing usually occurs from the 10th week of pregnancy. It can detect “sex chromosomes abnormalities” including Turner syndrome, Klinefelter syndrome, Triple X and XYY syndrome (Fertility associates, 2019).
Preimplantation genetic diagnosis (PGD) is where an embryo is tested before implantation. Nisker raised concerns about the ethics around informed consent and PGD (Nisker, 2013). This has been offered and used in some instances with parents who have a child who has CAH so they can choose to re-implant an unaffected embryo and discard the affected embryos.

Parents may be offered antenatal dexamethasone therapy in some health care settings, which is given prenatally to prevent a female baby from developing in-utero virilisation due to the possibility of CAH (Chiu et al., 2002). This treatment has been controversial due to potential complications for both the mother and child (Dreger, Feder, & Tamar-Mattis, 2012; Hirvikoski, Nordenström, & Lindholm, 2012).

3.6 Terminology- What's in a name?
There is no clear term that covers all the variations that may be present in the development of a human’s sex characteristics. There have been many attempts to capture a collection of VSC/DSDs under one umbrella term. Medicine has had a significant role in the various iterations, none of which have satisfied those directly affected. As mentioned above there has been contention regarding what variations are in fact covered by the umbrella terms intersex VSC/DSD. Historically terms like “Hermaphrodite”, “Pseudohermaphrodite”, “testicular feminization”, “over virilisation” and “under virilisation” were used but are now out of favour due to their insensitive and pejorative nature.

The evolution of terminology is affected by many factors, not least the reaction of those affected by the variation being labelled. Not unlike the reformation of language used in the intellectual disability sector, VSC/DSD has undertaken a similar process of changing with the times.

Most notably, in 2006 at the Chicago consensus, a consortium of professionals specializing in the field of VSC/DSD and representatives from the Intersex Society of North America (ISNA) worked together to try and develop terms that they believed would reduce stigma and increase wider understanding.

The consensus statement notes that the purpose for the changes in nomenclature was to align with the increasing advances in genetic understandings of VSC/DSD and therefore to be more descriptive in relation to these advances. In addition, it
articulates the need “to use terminology that is sensitive to the concerns of patients” (Lee et al., 2006, p. 149). The table below generated at the consensus demonstrates the changes that were proposed and which are now accepted.

Table 3:4 Proposed revised nomenclature (Lee et al., 2006)

<table>
<thead>
<tr>
<th>Previous</th>
<th>Proposed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intersex</td>
<td>Disorders of sex development (DSD)</td>
</tr>
<tr>
<td>Male pseudohermaphrodite</td>
<td>46,XY DSD</td>
</tr>
<tr>
<td>Undervirilization of an XY male</td>
<td></td>
</tr>
<tr>
<td>Undermasculinization of an XY male</td>
<td></td>
</tr>
<tr>
<td>Female pseudohermaphrodite</td>
<td>46,XX DSD</td>
</tr>
<tr>
<td>Overvirilization of an XX female</td>
<td></td>
</tr>
<tr>
<td>Masculinization of an XX female</td>
<td></td>
</tr>
<tr>
<td>True hermaphrodite</td>
<td>Ovotesticular DSD</td>
</tr>
<tr>
<td>XX male or XX sex reversal</td>
<td>46,XX testicular DSD</td>
</tr>
<tr>
<td>XY sex reversal</td>
<td>46,XY complete gonadal dysgenesis</td>
</tr>
</tbody>
</table>

Since the Chicago conference in 2006, “Disorders of sex development” has been widely adopted as the collective term for “medical conditions that cover genetic and medical conditions affecting the urogenital and reproductive organs” (Hiort & Ahmed, 2014). In other words, it covers a variety of variations that are biologically determined when there are atypical variations in chromosomes, hormones, gonads, genitalia and the urinary system. This may result in babies being born with ambiguous genitalia or where their anatomical appearance does not match the chromosomes/genetics typically found in males and females.

There has been ongoing debate about how we should refer to this collection of variations. There is often dissent from those living with VSC/DSD, many of whom do not see themselves as having a “disorder”. Many within the advocacy world prefer the term “intersex”. The medical profession and scientists have preferred the use of the “DSD” terminology of the 2006 consensus, or variations on the acronym “DSD”, such as “differences in sex development”, “diverse sex development” or “disorder of sex differentiation”. Just as there are a variety of variations, there are many variations in the terms used within the medical world.
Critiques of the term DSD focus on the negative impact the term has on a person who is labelled as DSD, i.e. that a person labelled with a disorder will take on the stigma and shame associated with that term and not be able to view themselves as normal (Davis, 2013; Topp, 2013).

Topp provides an overview of the pros and cons for use of the term “DSD” versus the term “intersex”, which I have summarized below. One of her main points is the damage to collaboration between the medical word and intersex advocates that results from the use of the term DSD (with the exception of Cheryl Chase (ISNA), who was the intersex representative at the consensus). The criticism of the medical terminology has fuelled the divide between I/VSC activists and health professionals advocating for the new terminology. Many affected by an I/VSC see “DSD” as having stigmatising effect and argue that such language gives greater power to the medical profession to control what is deemed normal. The use of disorder sanctions the need to alter bodies to make them as close as normal as possible. Georgiann Davis, a sociologist and intersex advocate, asserts that the use of DSD is a deliberate act on the medical profession’s part to claim back their power (Davis, 2013).

Interestingly, the editors of a special endocrinology monograph in 2014, Hiort and Ahmed, elected to title their edition “Differences and disorders of sex development” to reflect a broader approach that was not simply focused on the physiology of atypical sex development. They stated “differences” and “disorders” do not exclude each other, but demonstrate the bridging from biological understanding to medical care” (Hiort & Ahmed, 2014), indicating awareness from those within medicine that there is a sensitivity to language. “Differences” is more palatable for many as it acknowledges that variations exist and removes the notion that a person with a VSC/DSD is only their medical variation (Diamond & Beh, 2007).

Medical specialists and scientists view their attempts to be sensitive as genuine to those with a VSC/DSD. Often for medical specialists and scientists the focus is on the science and specifics of what they know and understand about the variations and linking that to the language used around the various presentations they see. There is concern that risk could be minimised by labelling the potentially life-threatening aspects of some variations as merely a variation or difference; for example, a child
with CAH may die without treatment, and there is a cancer risk associated with some other variations e.g. in gonadal dysgenesis or PAIS.

It is important to recognize that there is no “one size fits all” approach for collating VSC/DSD that everyone will agree with or accept, and thus it is not surprising that there is a lack of consensus from all concerned. This is the inevitable result of the inherent difficulty in trying to group VSC/DSD presentations that are numerous and vary greatly within each of the specific variations. DSD is an attempt to provide a place and space for shared understandings and advancement in understanding cause, diagnosis, treatment and healthcare outcomes. However, given some of the historical issues (non-disclosure, stigmatizing language, lack of consent and lack of shared decision making) discussed in chapter 2 it is not surprising that there is a heightened sensitivity around terminology.

3.6.1 Disability classification and terminology
This is not unlike other areas in medicine such as intellectual disability, where classification changed from mental retardation to intellectual disability. The editor of *Mental Retardation Journal*, Dr Taylor, supported changing the journal’s name to the *Intellectual and Developmental Disabilities Journal*. Taylor clarifies “the term intellectual and developmental disabilities is simply less stigmatizing than mental retardation, mental deficiency, feeble mindedness, idiocy, imbecility, and other terminology we have cast aside over the years”. He asserts “anyone who believes we have finally arrived at the perfect terminology will be proven wrong by history” (Prabhla, 2007, Feb 20). This will likely be the case for the rapidly evolving terminology in the VSC/DSD field internationally.

This debate will no doubt continue and change as insights from all concerned are considered. Increased collaboration between those affected and health professionals and scientists will be a way to progress this at times fraught debate. It is important to gather more data to understand the intricacies of this ongoing area of contention from the perspective of all those involved, especially those affected. It will be important to understand the context for language used in Aotearoa/NZ when considering this research.
3.6.2 Pros and Cons for current terminology

Here is a summary of the pros and cons of the main two terms (DSD and Intersex), as suggested by (Topp, 2013), with some additional information that I have added.

Table 3.5 Pros and cons – terminology

<table>
<thead>
<tr>
<th><strong>Pros</strong></th>
<th><strong>Cons</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>About the variation not the person’s identity</td>
<td>Pathologising</td>
</tr>
<tr>
<td>Medical professionals understand it and use it/common language between medical professionals</td>
<td>Impact of language on the evolving world view of those born with variation in sex characteristics</td>
</tr>
<tr>
<td>More medically/scientifically correct for classification and evolving genetic understanding</td>
<td>Limits those who are non-binary</td>
</tr>
<tr>
<td>Moved away from stigmatising language like hermaphrodite</td>
<td>Alienates many advocate groups</td>
</tr>
<tr>
<td>Health professionals are using the term more in an attempt to create a collective term within medical teams internationally.</td>
<td>Not well known in public space</td>
</tr>
<tr>
<td>Non-pathologising</td>
<td>Can label the person rather than the variation</td>
</tr>
<tr>
<td>Positive for some, especially advocates</td>
<td>Can imply a different gender, which is upsetting for some</td>
</tr>
<tr>
<td>Inclusive of non-binary people</td>
<td>Some medical professionals don’t recognize it as an umbrella term</td>
</tr>
<tr>
<td>More exposure in the public space</td>
<td>Can confuse biological sex, sexuality and gender identity</td>
</tr>
<tr>
<td>Politically powerful, especially within the Human Rights sector</td>
<td>Can alienate those who are not political</td>
</tr>
</tbody>
</table>
In medicine, “Disorders of Sex Development” would be viewed as a broader and more inclusive term, whereas “Intersex is narrower”, in that it refers to variations where the sex is not clear. However intersex advocates would argue that intersex is an equally broad term.

More recently the term “intersex and variations of sex characteristics (I/VSC)” has been adopted by some as being the most inclusive for all and free from the potential pathologising/stigma of “DSD” (whether the first ‘D’ stands for differences or disorders). In a recent report the authors recommend revising the use of DSD in favour of I/VSC (Monro, Crocetti, Yeadon-Lee, Garland, & Travis, 2017).

Johnson et al. invited members of the Androgen Insensitivity Syndrome-Differences of Sex Development support group in the USA (AIS-DSDSG) to complete a survey. 202 members with a VSC/DSD out of 508 responded (61% were people with a VSC/DSD; 39% caregivers; and 16% non-gender binary), “with only 24% using “disorders of sex development” to describe themselves or their child”. 69% had a negative response to the term and consequently 81% of those people changed their care as a result. Results revealed preferred terms were intersex, closely followed by variation in sex development and differences in sex development. Affected individuals also described the need for flexibility and said that doctors talking to doctors may use DSD terminology but should use different terms when talking with patients. For example, many preferred the specific variation name, e.g. AIS. The terminology used can affect research participation, e.g. CARES Foundation (research, education and support for congenital adrenal hyperplasia) will not participate in studies using the term DSD. Ongoing evaluation of DSD terminology is recommended (Johnson et al., 2017).

Another study in the US looked at survey responses regarding use and comfort of terms from 286 health professionals (101 endocrinologists, 81 urologists, 91 genetic counsellors and 6 psychologists). They found that most just used specific diagnosis, but favoured DSD over intersex, which was also reflected in the use of DSD in publications in recent times (L. Miller et al., 2018). It is important to note the sample only included 6 psychologists, reflecting how few psychologists are working in this specialised area. Other researchers have found similar results (Davis, 2013;
Pasterski, Prentice, & Hughes, 2010), and it would be useful to understand what the case is here in Aotearoa/NZ.

In Aotearoa/NZ, as is the case internationally, there will be many people born with VSC/DSD variations who would never view themselves as “intersex”. Many would not have any issues with the way they view their gender and/or sexuality in relation to their sex development being different to that which is seen as typical.

It is similar to the case of people being attracted to people of the same sex who would never identify as being gay, lesbian, bisexual or pansexual. This is of course totally appropriate as people need to be self-determining in the way they view and identify themselves; after all it is not compulsory to adopt a specific label. However, many documents, especially identification documents e.g. passport, birth certificate etc., still require a choice to be made between male or female, so it would seem that the gender binary is still pervasive when it comes to many aspects of our daily life.

Terminology is complicated and there are no clear definitions. In the medical world, DSD is seen as the standard and in the advocacy world intersex is generally the preferred term. In medicine there is a progression in terminology and they acknowledge that the terminology used is not perfect but nonetheless represents a step forward in the medical management of such variations.

3.6.3 Terminology used in this study

It has been a struggle to find terminology that sits comfortably for this piece of research. I have opted to use the DSD terminology when talking to medical professionals as that is the current term in use (with the “D” representing “Differences”). In all other instances, I have used a combination of intersex and variation in sex characteristics (I/VSC) and provided the context for these alongside the medical umbrella of Differences of Sex Development.

To acknowledge this, I will use variations in sex characteristics/differences in sex development (VSC/DSD) when working in the health professional space and intersex or variation of sex characteristics (I/VSC or VSC) when working with those directly affected such as parents, young people and advocacy groups. This evolution of my own thinking has occurred during the time I have been working with this research, adding to my appreciation of how challenging it is to find adequate terms.
I realise these are somewhat cumbersome terms, but nevertheless, it is important to reflect the values of the people represented in this group and the changes in nomenclature since starting this research. The variety and fluidity in terminology is likely to continue to grow and change in the future.

3.6.4 VSC and transgender

It is important to note while there are some similar issues, e.g. both populations experience stigma and often require involvement from health services, there are also important differences between the experiences of people who are transgender and those who are I/VSC. People who are transgender do not feel that their body matches the sex they identify with, whereas those born with VSC/DSD are dealing with a variation in their bodies that makes them different to that which we typically consider male and female. Transgender people may be wanting surgery to change their bodies and struggle to get this done, whereas some people with VSC/DSD may have surgeries they do not want, especially if this was decided for them without their consent when they were children.

Both transgender people and people with a VSC/DSD seek bodily autonomy and the right to self-identify and have access to the health care they desire. They are allied to the LGBTQIA+ movement, though not all people with a VSC/DSD would want to be associated or identify with such a movement as they identify strongly as heterosexual.

This research is not addressing issues related to transgender people unless they intersect directly with issues for those who have a VSC/DSD.

3.7 Genital examinations

Assessment of the genitalia is a necessary component of diagnosis. Given the sensitive nature of such examinations and some of the historical issues associated with these, as discussed in the previous chapter, it is important to restrict them to a minimum. Preparation and informed consent are important, and the investigating health professional and appropriate support person only need to be there to respect the individual and reduce anxiety. Gaining consent from the child or young person is equally as important as getting parental consent, even if the former is not legally required. It will be important to note the standard practice here in Aotearoa/NZ in this research.
3.8 Medical education and VSC/DSD specific training

Specific training around working with VSC/DSD in Aotearoa/NZ has been limited. There is a VSC/DSD interest group that is available to be consulted regarding specific cases through paediatric and adult endocrinology. Australasian Pediatric Endocrine Group (APEG) holds a symposium every second year at their annual scientific meeting where paediatric endocrinologists, scientists and allied health professionals discuss current issues within the field. Within the specific disciplines of endocrinology and surgery there is some training but very little occurs in allied health fields such as psychology, social work, nursing, midwifery and physiotherapy.

Internationally there are moves to develop some training specifically for health professionals, for example some training has been established in Phoenix (Phoenix Childrens Hospital, 2017, July 13). Other initiatives have been set up to further knowledge globally by attempting to pool data, encouraging collaboration and facilitating the collection of data. This includes: International–DSD (I-DSD); e-learning and e-consultation from the European Pediatric Society for Endocrinology; DSD genetics; DSD-Life and the DSD family’s websites (Kranenburg et al., 2016; Muscarella, Kranenburg-van Koppen, Grijpink-van den Biggelaar, & Drop, 2014). These sites recognise the difficulty of having small numbers of health professionals within a country, but that combining with other countries can help produce research collaborations and better quality research together with reviewed and updated resources.

3.8.1 Health professional training

There is little focus in the training of health professionals, especially medical students, in the area of diversity around gender, sexuality and sex characteristics. While there may be a few short tutorials there seems to be limited opportunity to discuss such fundamental and important issues.

There seem to be even fewer opportunities to help trainee doctors develop communication skills around difficult or sensitive subjects such as diversity around gender, sexuality and sex characteristics, though there is more training than previously given. While some attention may be directed to working with people of different cultures and addressing issues of cultural sensitivity, there is little on other areas of diversity.
Medical educators here in Aotearoa/NZ have recognised that more needs to be provided in this area but state the curriculum is full. It often comes down to what is considered essential learning and there being no time and/or space to “slot in” such additional learning (personal communication with medical educators within Aotearoa/NZ, March 2017). There was however an indication that this is being raised more and more at international medical education conferences (personal communication, medical education Professor Ellis, April 2017).

3.8.2 Anatomy teaching

Even in such basic science as anatomy the “standard male” and “standard female” body are presented and any variation from the perceived norm is deemed abnormal. There is little attention paid to less stigmatising terminology such as “atypical”, “variation” or “difference”, perhaps reflecting how embedded the binary biological model is in the world of medicine and its educational institutions.

Anatomy is one area in medicine where there has been an attempt to stabilize the concept of the physical aspects of anatomy in relation to gender and genitals. These researchers’ focus is on representation of the female genitalia, in particular the clitoris, in 20th century anatomy text books (Moore & Clarke, 1995).

Medical text books in general try to focus on sameness and the essential elements reflecting the binary position as fact. The authors suggest this singular presentation of the body becomes standard, whether it be in schools in general or medical school. It becomes an unchallenged “ingrained abstract body” by which we measure all others. In other words, it forms a norm for the body (Moore & Clarke, 1995).

They illustrate how anatomies are socially constructed by reviewing the way female genitals were represented over the 20th century. They summarise that “anatomy as a discipline constructs men’s penises to vary individually. However, for women, it has constructed standard normalized clitorises for all.” (Moore & Clarke, 1995). This reinforces gender stereotypes and the duality of gender. The placement of genital anatomy was also discussed, as it is placed within anatomy texts on reproduction, often ignoring sexual pleasure aspects.

This is relevant to mention as there has been criticism levelled at surgeons for doing clitoral reduction and/or vaginal reconstruction to make it easy for assumed penetrative heterosexual sex to occur once the person is an adult (Roen, 2009).
Similarly, for males with hypospadias, one of the drivers for corrective surgery is that it is seen as socially essential for boys to be able to urinate standing up. Also, historically some boys with a micro penis would have had their gender reassigned to female and consequently had genital surgery (as discussed in chapter two).

Anatomy is often represented in a singular way due to necessity and expediency, as it would be challenging to show the depth of variety within a single text. This, however, is likely to reinforce that there is a correct way for our genitals to look from a medical perspective. While it is impractical to constantly be showing variations in educational materials, it is important to express that there is diversity in presentation.

A recent study of an ancient medical text indicates that we have shifted away from looking at the body as a whole and incorporating the context (the political and religious values of the time) within which that anatomy is perceived. In this book, there were diagrams of the whole body with flaps that revealed more detailed pictures of the inner workings. The author states that this allowed for a more honest and person-centred approach as it reflected the whole person and not simply a part of the person, which is more the case in modern medical texts and anatomy teaching (Hall, 2017).

I am not suggesting that detailed anatomy drawing of specific parts of the human form be banned in favour of a return to the old whole body anatomy drawing, but rather that there are ways to help students remember that each body part is embodied within a whole person who lives within a specific context within a specific part of society and that it is important not to lose sight of the whole picture. Hall says it is important for doctors and trainee doctors to be aware of the person and the context within which they live, just as it is important for the doctor to be aware of their own beliefs and the context within which they live.

Taking all these views into account it would seem a holistic approach is of value as it incorporates all aspects of the person, including their medical presentation and the context in which they live. It would be useful to have a greater understanding of what is provided in Aotearoa/NZ with regards to learning opportunities. There is no literature indicating the learning opportunities as yet in Aotearoa/NZ.
3.8.3 Communication

Communication is something that is vital in healthcare, not just for effectively gathering information but also in the delivery of information, both essential components of being a good health professional. It is unclear if there is formal training in the art of providing clear and user-friendly information. It would be useful to know how information is delivered to parents and young people affected by VSC/DSD here in Aotearoa/NZ.

Some of the e-learning platforms are offering training and it is interesting to note that the European Society for Pediatric Endocrinology e-portal has started focusing on the way information is communicated. Some researchers have developed a specific resource highlighting some of the issues surrounding communication e.g. using words like less common /atypical instead of abnormal (Muscarella et al., 2014)

This demonstrates a sensitivity and a change in the awareness of health providers, with increasing insight about the best ways to communicate medically and emotionally complicated information. It clearly indicates a willingness to do better by those affected with VSC/DSD. These resources are available through e-learning and it will be interesting to see the uptake by Aotearoa/NZ health professionals.

3.9 Ethics

All doctors and health professionals have to follow a code of ethics, the most famous being the Hippocratic oath which essentially is summarized as “first, do no harm”. The preference is for modern day versions, usually based on the World Medical Association’s endorsed declaration of Geneva. This was revised recently and some of the changes are pertinent to this thesis include:

- “THE HEALTH AND WELL-BEING OF MY PATIENT will be my first consideration”.
- The addition of a clause highlighting the importance of respecting patient autonomy.
- The addition of a clause reflecting the obligation of the physician to share medical knowledge for the benefit of the patient and the advancement of healthcare

(World Medical Association, 2017, Oct.)
Doctors and other health professionals who also have specific codes of ethics, e.g. clinical psychologists, will interpret these ethics in their own way. I introduce ethics here as they are the foundation, alongside documents such as the Treaty of Waitangi, that can serve as a baseline for considering the complexities of issues presented by those with VSC/DSD. The NZMA Code of Ethics (New Zealand Medical Association, 2014) reflects the principles stated above.

3.9.1 Best interests
Deciding what is in the best interests of the child is complex. Consequently, medicine uses ethical principles for guidance in complex areas, such as when considering a child born VSC/DSD. To act in the best interests of the patient, decisions should be tested against ethical principles. As stated above, doctors are guided by their own set of ethical principles (e.g. NZMA Code of Ethics) that obligate them to assess and provide treatment that is safe and beneficial to the patient. In relation to a child not able to make decisions, due to their age or inability to do so, decision making shifts to the parents (as discussed in the previous chapter, section 2.11.4).

In Aotearoa/NZ parents have the right to make decisions for their children and it would be believed that most parents are acting in their child’s best interest. This right would only be removed if the parents were considered to be causing serious harm to their child or to not be acting in their best interests (e.g. Jehovah’s Witness parents refusing a lifesaving blood transfusion for their child).

Gillam, Hewitt and Warne (2011) developed seven principles to use as a process for decision making when considering options for care in “DSD”. They include:

1. Minimising physical risk to child
2. Minimising psycho-social risk to child
3. Preserving potential for fertility
4. Preserving or promoting capacity to have satisfying sexual relations
5. Leaving open options for the future
6. Respecting the parents’ wishes and beliefs
7. Consider the views of older children and adolescents

(Gillam, Hewitt, & Warne, 2010).
As discussed in chapter two, there is a lot of commentary that raises issues of bodily autonomy and the complexity of making decisions for someone’s future without knowing how they will feel about those decisions, especially regarding what most of us consider deeply personal i.e. our body (especially our genitals) and how that equates with our sense of self and our gender identity. Guidelines, such as Gillam et al. (2011), provide a framework to consider decision making but do they also create contradiction, when, for example, point 6, “respecting parents’ wishes and beliefs” may be at odds with other points? Note the different language used in points 6 and 7, “consider” and not “respect”, indicating a hierarchy of parents where parents’ wishes and beliefs are placed above those of young people (Gillam et al., 2010). Understanding what ethical considerations are used in Aotearoa/NZ and their place in decision making would be of interest.

3.9.2 Guidelines and decision making

There are some guidelines internationally for best practice when it comes to the diagnosis and treatment of people born with I/VSC traits, however there has been no clear consensus on some of the more controversial areas such as surgery. There are professional codes of conduct and best practice guides but they are just that, guides, and it is still up to the individual health professional to decide where they want to head with their practice.

The 2006 Chicago consensus is the founding worldwide attempt to try and address the variety of complex issues raised and one of the first attempts to involve those directly affected in the development of a guiding document for all involved in the care of people born with intersex traits (Lee et al., 2006).

While it was considered by many to be ground-breaking, particularly around terminology, it was widely criticized as not going far enough to protect the rights of those born with a VSC/DSD, as has been discussed earlier.

In 2016, it was revised and the “global consensus” made attempts to include a variety of known advocates and international professional groupings to advocate a best practice approach. It is an extensive document that makes some important changes, again advancing the need for collaboration and inclusion of those affected and advocates. It also provides advances in science (Lee et al., 2016). However, it falls short in a number of areas, in particular in coming from a heteronormative
point of view. While it raises issues around terminology, autonomy and human rights, it does not actively provide specific guidance. In fact, APEG and other international groups did not endorse the publication as it had not had its criticisms acknowledged.

The most recent consensus from the European group, edited by Cools et al. (2018), has shown a striking evolution in the consensus process that leaps ahead of the previous two consensus documents. They have provided more input from those with variations/advocates and have been much more specific about the assessment and care of people with a VSC/DSD. An example is the table below which has the most detail and inclusive language of any consensus guideline produced thus far (Cools et al., 2018).

![Table of Care and Data Collection in VSC/DSDs Across Ages](image)

**Figure 3:8 Multidisciplinary care and data collection in VSC/DSDs across ages**

Multidisciplinary care and data collection begins at diagnosis and continues across the lifespan of the individual. The focus of the information process gradually shifts from parents to the affected child. Psychological and peer support are key elements at all ages. Although timing and topics may vary according to individual circumstances, it is generally agreed that children should be informed about their condition at an early age. Suggested themes to be discussed by team members are shown in blue boxes at the top of the figure, and (non-exhaustive) lists of important topics within these themes are represented in pink boxes in the centre of the figure. DSDs, differences of sex development; GCC, germ cell cancer; PE, physical examination; PS, psychosexual; QoL, quality of life. (Cools et al., 2018)

The language used in this latest consensus recognises advocates and the concerns regarding nomenclature of those directly affected. This is demonstrated by the use of more inclusive and less pathologising language throughout the document, e.g. “differences” is the default term rather than “disorders”, and “naturally occurring variations” is used. The authors also spell out in detail what is meant by psychological care and emphasise the specific ways to communicate information,
acceptance, support and sensitivity. See figure 3:9 below, which summarises the essential components for psychological care.

**Basic requirements for dealing with patients**
- Acknowledge variety, complexity and individuality
- Create an atmosphere of appreciation and acceptance
- Provide time, empowerment and encouragement

**Information for parents**
- Biological: explain the condition as a naturally occurring variation
- Medical: explain sex and gender as non-binary concepts and in the context of sex determination and differentiation; provide precise information on the specific condition; provide information on vital, functional and elective medical interventions, including risks and benefits; and offer alternatives (for example, guidance on how to tackle potentially difficult situations and on how to raise resilient children who have a genital difference)
- Gender-related: discriminate between childhood (play) behaviour and adult gender identity; explain that the initial decisions on social gender role may be subject to later change according to the self-expression of the developing child; and put forward gender contentedness as the ultimate goal
- Use sensitive and respectful language (for example, avoid using terms such as malformation and disorder)
- Communication: listen, repeat information and ask for questions
- Promote contact with support groups and participation of appropriately trained peers in the decision-making process or in the multidisciplinary team

**Psychological counselling**
- Discuss communication within the family and social environment and support decision-making on (provisional) gender role, medical interventions and judicial options or regulations (for example, birth certificate entry)
- Promote acceptance of individual development
- Avoid emotionally driven decisions, delay non-urgent decisions (such as those on surgery) until psychological counselling has been given and promote participation of trained peers in the decision-making process

**Figure 3:9 Essential components for psychological care to affected families (Cools et al., 2018, p. 420)**

This reflects the rapid changes taking place in the field and the willingness for collaboration between those affected and those providing assessment and healthcare. It also indicates and reinforces the ongoing need for research and new information from all involved.

**3.10 Decision making**
Decision making is complex at the best of times and none less so than in the area of medicine, especially in the area of those born with an I/VSC variation. There are some guidelines within professions, as stated previously, and of course those recommended on the two consensus statements.

Specific decision making tools have been promoted in the literature, one of the first being shared decision making (Karkazis, Tamar-Mattis, & Kon, 2010) where Kakarkis suggested the shared decision making (SDM) as an evolution away from
previous paternalistic approaches taken in medicine. I will discuss this in more detail as we move through the chapter.

In 2013 the Australian state of Victoria, in collaboration with a number of experts, developed a resource for decision making in Victoria. The resource attempts to be inclusive of a number of disciplines and reflects the complexity of the decision making process. While it provides the ideal to aim for it does not provide how to achieve this. It states:

The following section summarises the principles to apply to decision making about the healthcare of infants, children and adolescents with intersex variations in Victoria, including:

- principles for supporting patients and parents during decision making
- medical management principles
- human rights principles
- ethical principles
- legal principles

(Senate Community Affairs References Committee Secretariat, 2013).

3.10.1 Decision making and Surgery

“Despite the increasing number of publications on this topic, evidence-based recommendations still cannot be made” (Creighton, Chernausek, Romao, Ransley, & Salle, 2012). This statement sums up the advice from the 50 experts that made up the VSC/DSD working party that took place in Annecy, France, in 2012. Diamond and Garland (2014), following the Annecy report, go one step further and suggest a mortarium is required on early surgical intervention unless the condition is life threatening until the child is of an age they can consent (Diamond & Garland, 2014).

In an editorial of the Journal of Pediatric Urology in 2014 a standpoint piece was presented by VSC/DSD surgeons on behalf of the European Society of Pediatric Urology (ESPU) and the Society of Paediatric Urology in the United States (SPU), to try and clarify what they believed to be “inappropriate and biased statements”, in particular that surgeries are “cosmetic”. They listed issues such as fertility, gonadal
cancer risk, enlargement of the clitoris and possible issues of body image and painful erections, incontinence, poor penile development and ability to menstruate. They mentioned gender identity and how “anatomical appearance likely plays a role”, which is reminiscent of the John Money theory of gender (Mouriquand, Caldamone, Malone, Frank, & Hoebeke, 2014).

The surgeons then outline arguments for and against early and late surgery, highlighting that early surgery is less technically difficult and may have less psychological impact, whereas if surgery is put off until the person concerned is an adolescent, it will be more complicated, with a higher risk of morbidity and mortality, and there are few experienced surgeons. Somewhat pointedly they end the section on timing with “it is of interest that the opponents to early surgery have no evidence that latter surgery is better, however, neither do they provide any evidence for early surgery. They go on to dismiss reports (humans rights based) as biased and lacking in evidence” (Mouriquand et al., 2014). This is in contrast to the opinion expressed by the opening quote above from Sarah Creighton.

A French study examining participants with CAH found that 100% of parents they interviewed preferred early surgery and so did 89% of their CAH participants (aged 16-40yrs, mean 27yrs, N=21). All of the young people who had surgery early thought surgery should be done at an early age and 89% of the young people who had surgery as adolescents thought it would be better to have the surgery at an early age. The matched control in contrast, only 52% believed surgery should be done early. The authors acknowledge there may be bias such as cultural/social factors (Binet, Lardy, Geslin, Francois-Fiquet, & Poli-Merol, 2016). This is one of the few studies providing such information and is in contrast to the argument provided by activists. It is important to note the limitations of this study, it is a very small study and is limited to CAH variation only. Much more research is needed to see if these views are able to be replicated.

Arlene Baratz, an advocate who also resigned from the Vilain and Sandberg longitudinal study (see chapter two) states that she has never had anyone come and say how surgery has helped them. Vilain counters this by asking why they would when they are happy living their lives? (Reardon, 2016).
White and Cartmill’s (2016) book “Communication in surgical practice” has a chapter exploring the psychological effects of surgical decision-making. Ansara, the author of this chapter, discusses a variety of factors that occur when trying to make a decision affecting health. These include not only the patient but also the surgeon. The hope is that we all make rational decisions based on fact. However, Ansara points out this is unlikely and that we are all affected by the way information is delivered- this is referred to as the “framing effect” (Ansara, 2016, p. 68). Surgeons have to consider how their own personal beliefs affect their viewpoint and practice and make use of critical thinking to examine their biases, to ensure they avoid these biases clouding their clinical decisions.

He also presents a study that reflects on how a specialization can impact on decision-making. Reitsma, Mourits, Koning, Pascal, & van der Lei, (2011) asked gynaecologists and plastic surgeons to rate a set of pictures of labia according to how natural and how attractive they appeared, along with their personal preference and what they considered to be society’s ideal. There were 4 pictures of labia minora of different sizes. The smallest size was the one considered by most as socially ideal (Reitsma et al., 2011). This is particularly relevant to children with CAH where there may be variation in the size of the labia and/or the clitoris. If a health professional comments or presents their view that something is too large or too small, how does that impact on the patient before them? Does that create a problem that may not even exist? These are questions that require further investigation?

Another study highlights the risk of general anesthesia on children under four years of age. Children in a large study (over 25,000 children exposed to a general anesthesia) had less development ability when starting school compared to peers, in particular poor numeracy. The authors did acknowledge the limitations of the study; there may be other influences they were unable to measure impacting on the participants in the study. The effect of general anaesthesia is an important factor to consider when contemplating surgery on infants (Schneuer et al., 2018).

3.10.2 The genital surgery debate

In the previous chapter issues regarding surgery are raised by I/VSC advocates and human rights organisations around bodily autonomy where surgery is appearance based. On the one hand I/VSC advocates want genital surgery banned, or at the very
least delayed, in order to promote a young person having agency over their bodies so they can actively participate in decision making. I/VSC advocates ultimately argue that the decision to have surgery that alters one's genitals needs to be made by the person whose body it is. Likewise, these advocates challenge norms that aim to “normalise” I/VSC in favour of a recognition of diversity, as discussed in chapter two. I/VSC advocates assert appearance-based surgeries such as clitoral reduction, labial reduction and hypospadias repair have caused more harm than help (Morland, 2009, Feder, 2014, Carpenter 2018, Hypospadias UK, n.d.).

On the other hand, health professionals working in the field of VSC/DSD would argue that there are significant health risks to not undertaking such surgeries. They cite the benefits of improved fertility and quality of life, as mentioned previously regarding hypospadias repair. Health professionals have concerns that a blanket ban, as proposed by I/VSC advocates, does not take into account that some surgeries considered to be appearance-based are in fact related to minimising health risks e.g. some genital surgery is to reduce incontinence (Asklund et al., 2010; Bhat et al., 2016).

There are contrasting concerns based on historical experiences, bodily autonomy and diversity from advocates for I/VSC and from health professionals regarding the need to balance the concerns for health risks such as fertility and quality of life. More qualitative research is required to answer these questions.

3.10.3 Shared decision making (SDM)
SDM has become the preferred approach, especially in the complex areas of genital surgery and sex determination. Karkazis developed a model that set out six stages of the SDM process when faced with complex situations and/or “no best choice”. This is similar to the SDM that has been used with paediatric cancer care, with an emphasis on the development of communication skills (Karkazis et al., 2010).

Six stages for SDM:

1. *Set the stage and develop an appropriate team*
2. *Establish preferences for information and roles in decision making*
3. *Perceive and address emotions*
4. *Define concerns and values*
5. *Identify options and present evidence*

6. *Share responsibility for making a decision*

(Karkazis et al., 2010).

Karkazis and her co-author Mary Moran developed a protocol for developing a functional MDT team in order to develop expert specialised teams and/or a Centre of Excellence (CoE) for VSC/DSD. They promote a six stage protocol that essentially supports a team that has clearly identified their beliefs, values and opinions in relation to best practice and their vision for a CoE or specialist service (Moran & Karkazis, 2012).

The authors stress that without fully understanding the individual players and the team dynamics this can result in “a source of tremendous difference of opinion and tension among team members, confronting not only longstanding habits, but deeply held beliefs about gender, sexuality and the role of surgical interventions” (Moran & Karkazis, 2012, p. 4).

They highlight the importance of developing a MDT with transparency, ongoing conversations and reflection so that diverse viewpoints can be accommodated and welcomed. It will be useful to clarify whether such protocols and/or SDM processes occur here in Aotearoa/NZ.

Since Karkazis’ early work on SDM there have been some other developments in this space, particularly the development of what have been referred to as “decision aids and support tools (DASTs)”, which are aimed at facilitating SDM. Siminoff and Sandberg (2015) believe DASTs can help parents and young people to be more fully informed, not just about the VSC/DSD they are presented with, but to also explore their own values and beliefs in order to make decisions they are less likely to regret (Siminoff & Sandberg, 2015). However, they do not comment on such tools for their own exploration around beliefs and values as suggested by Karkazis.

Graziano and Fallat (2016) developed some SDM tools that are online to assist families and health professionals to specifically go through the controversial areas of irreversible surgeries, such as genital and gonadal surgeries.
The tools include a variety of checklists that have the following components:

1. Overview/introduction of goals/review of patient’s values
2. Preferred words/review of nomenclature
3. List of short-term and long-term topics
4. List of questions that need to be addressed by providers
5. Management options including nonsurgical options

(Graziano & Fallat, 2016).

They are based in Phoenix Children’s Hospital and these are part of the ongoing effort to develop specialist training, best practice for VSC/DSD and supports for parents and young people.

3.11 Summary
This chapter provides the context from the human biological, reproductive and medical perspective which reflects the dominant lens by which health professionals and scientists view bodies/anatomy and more specifically genitals and the reproductive system. The chapter highlights the complexities of working in the field of VSC/DSD, especially the ever-evolving research, scientific discoveries, guidelines, and the challenges of inclusion and collaboration with advocacy and support groups.

It raises many questions for how we provide health care to those here in Aotearoa/NZ; do we match the international protocols and guidelines, in particular those around shared decision making in relation to appearance-based surgeries or organ threatening surgery and specialised psychological/peer support?

This chapter and its previous companion chapter, which focused on perspectives outside of medicine, notably of those directly affected by a VSC/DSD and their advocates, provide the backdrop to the development of the current research. We need to consider both perspectives, in order to truly understand the basis by which these views and beliefs affect the spectrum of same, different and dysfunctional. Medicine and VSC/DSD advocacy perspectives are often at odds with one another, which can lead to conflict; our understanding of how this dynamic impacts on today’s health care for people born with a VSC/DSD needs clarification.
There has been little research done in Aotearoa/NZ as mentioned in chapter two (2.13.3). Consequently, this research intends to provide new knowledge regarding the current state of health care for those born with a VSC.

By way of summary, table 3:6 (see insert at the end of this chapter), is a visual representation of all the major influences in recent history discussed in this and the previous chapter. It links back to the major influences (figure 2:1).

I have presented some of the key elements in a periodic table format to represent the complexity of these elements and the broader categories in which they exist, such as societal, medicine and science, I/VSC advocacy and human rights. While not exhaustive, they provide a window into the many elements of influence.

I have separated the two dominant categories of medicine/science and I/VSC advocacy in Aotearoa/NZ to highlight our country’s specific influences. It is important to note that the global elements are equally important in Aotearoa/NZ; they have had and continue to have a strong impact.

Considering all these elements of influence impacting on the care of those with VSC/DSD (noting that some of these elements arose after starting my research), it became clear that gaining understanding from all the main people involved would be essential.

There is a knowledge gap about what is actually happening in Aotearoa/NZ regarding the care of children born with VSC/DSD and more importantly in our knowledge of the factors that impact on decision making. The experience of younger adults i.e. young people who have are now in their teens or early 20’s is not known either. There is little research that has represented all those involved, despite the fundamental importance of doing so.

The qualitative research outlined in this thesis will address this by taking a 360 degree look from the perspective of the three key groups, that is, young people with a VSC/DSD, parents of young people with a VSC/DSD and health professionals working in the area of VSC/DSD. The next chapter will discuss the design and methodology of this research and the processes involved.
Table 3.6 History of key global elements influencing those with a VSC
Chapter Four
Methodology and Methods
“Practical partnerships”

4.1 Introduction
In this chapter I will discuss the methodological components of the study and the pathway taken to develop the research design. I will outline the qualitative approach and thematic analysis, highlighting the challenges and the mechanisms by which I chose to manage these, in particular the “practical partnerships”. Methods used for ethics approval, recruitment, conducting interviews, observations and data analysis will be discussed. Lastly, I will comment on my own positioning within the research and the reflexive approach I employed throughout the research process.

Research in the area of VSC/DSD is increasing, and it has begun to explore the experiences of those directly affected, that is, people with a VSC/DSD and their parents. While there is still a research focus on underlying causes and case studies, there is increasing interest in addressing some of the issues outlined in the previous chapters, such as patient experience, bias, stigma and lack of inclusion. Research involving young adults with VSC/DSD and parents of children with VSC/DSD is needed, to investigate the psychosocial experiences and impacts of the health care provided (or not provided).

4.2 Theoretical framework
I took a critical standpoint to frame my research. I took the lead from the critical realism (CR) framework developed by Bhaskar in the 1970’s. CR is inclusive of both ontology (study of being/reality) and epistemology (theory of knowledge/how we know) and has been widely used in health psychology. It holds that we can observe what is happening in the world but must consider events and experiences through the eyes of those experiencing them (Danermark, Ekstrom, Jakobsen, & Karlsson, 2002).
In the CR approach, participants' accounts are seen as socially constructed, while at the same time their telling of their experiences is understood to have meaning in reality (Lyons & Chamberlain, 2006). While I was not rigidly adhering to CR, its philosophical principles underpin my methodological approach. I was also influenced by feminism and feminist epistemology (Anderson, 2017; Haraway, 1988) and my clinical psychology training, both of which also turn a critical lens on society and history.

CR and feminism have been used in other studies. For example, Parr (2015) used a combination of CR and feminist methodology to make sense of an intensive family support service that provided support to at risk families. The qualitative study involved interviewing parents about their experiences of the support they received. CR helped “clarify complex relationships and the processes that (were) unlikely to be captured by predetermined response categories or standardised quantitative measures” (Parr, 2015). In her study, Parr stated she was mindful of the participants' context and reporting of their experience, which was to be respected. In order to make “authoritive claims”, researchers have to “reconstitute” those experiences “through sociological conceptualisation and theorising” (Parr, 2015). The aim of the current research is to make sense of the participant's context in each individual situation and be able to extrapolate what lies behind the telling of their experience, particularly when it comes to their decision making.

The philosophical act of self-critical reflexivity from feminist theory also contributed to my research. Being transparent about how we produce knowledge is as important as the knowledge itself (Broom, Hand, & Tovey, 2009). I wanted to adhere to the principles of inclusion and equality and to ensure that each group had equal opportunity to be heard and for their “active voices” to be represented throughout the research process. Where possible I wanted to gain information and process it in a way that would provide a human rights perspective for all concerned in this area.

These aspirations heavily influenced the way I approached this research seeking to understand the decision making for children born VSC/DSD in Aotearoa/NZ. I wanted to understand the reality for the three main contributing groups, that is, the young people with a VSC/DSD, parents of children with a VSC/DSD, and the health professionals that specialise in the area of VSC/DSD. In addition to understanding
their experience, particularly around decision making, it was important to discover the underlying processes and mechanisms behind these experiences.

**Figure 4:1 Contributing perspectives to theoretical framework**

### 4.3 Research design

Qualitative research offers an in depth and nuanced approach to understanding the research question around what informs decision making. Qualitative research takes the lived experience of those directly affected and in their own words provides the researcher with a level of detail that is otherwise elusive using other methodologies.

**4.3.1 Research challenges**

In designing this study, I was aware of the limitations of previous studies (especially historically), as mentioned in chapters two and three. A key limitation of many studies was the lack of inclusion of VSC/DSD people themselves in the design or process of the research. I wanted to avoid “doing research to them” and wanted to honour the clear message from VSC/DSD advocates of “nothing about us without us”. I was mindful of the history of secrecy and shame in this area and therefore
concerned that people with lived experience may be suspicious about the intentions of the research, which could harm recruitment. I therefore sought to develop practical partnerships from the outset to minimise any such concerns.

The prevalence of VSC/DSD is relatively rare, though not especially uncommon if hypospadias is included; this results in a prevalence of 1 in 4500 live births (Warne & Mann, 2011). Aotearoa/NZ is a small country with a population of 4.9 million people (Stats NZ, 2019). Due to the infrequency of VSC/DSD presentations in Aotearoa/NZ, finding participants would be challenging.

Another barrier was the protectiveness that clinicians have towards this client group. This is understandable, given some of the historic practices where people born with VSC/DSD were seen as a curiosity and “teaching opportunity”. They were often subjected to scrutiny by many who were there for no purpose other than to observe (2.4.4).

The nature of VSC/DSD can lead to the assumption that parents are vulnerable; consequently, health professionals may believe the last thing that parents will want to do is talk to a researcher about their experiences. Parents may also feel very protective of their child's privacy. Parents may have concerns about their teenage children being interviewed, again for reasons of privacy and also because of fear that they may not have the capacity to make sense of or fully understand their condition, let alone feel confident discussing it. Young people may be wary of participating due to a number of concerns, such as not wanting to be identified as having a VSC/DSD or to relay their experience of having a VSC/DSD. It may also be challenging to get information about the study out to affected young people.

All of these factors make doing research in this field challenging and open to controversy. It was important to take this into consideration when designing this research.

4.4 Partnership Approach

4.4.1 Treaty of Waitangi

As stated in my introductory chapter, Te Tiriti o Waitangi/the Treaty of Waitangi is the fundamental kaupapa (foundation/principles) underpinning this research project. It is the foundation document in Aotearoa/NZ that sets out the need for
partnership between Māori and the Crown. In summary it sets out three principles: partnership, participation and protection (Archives New Zealand, n.d.). It is important to honour these principles as the basis of any research done in our country. These principles guided my approach to the research throughout the course of this project.

To create a partnership with Māori, I consulted with the University of Otago’s Māori research committee during the development of this project and have been granted approval from the Ngāi Tahu Research Committee. Māori consultation was also obtained from various DHBs through the locality agreement process. I also consulted with various researchers from Te Rōpū Rangahau Hauora a Eru Pōmare (the Eru Pōmare Māori Health Research Centre) based at University of Otago, Wellington throughout the study.

4.4.2 Research Partnerships

In this research the partnerships identified as crucial were with the two main realms that encompass the research topic (see figure 4:2 below).

Next I approached Mani Mitchell and the ITANZ board, who have been long time advocates for people who identify as I/VSC. They were very happy to collaborate on the research project. Their inclusion was especially important given the historical lack of involvement of people born I/VSC in research about them. ITANZ involvement would provide a level of integrity, safeguarding the research in a way that I, as someone who does not have a VSC/DSD, could not. Mani and I formed a strong working relationship and met regularly throughout the course of the research. ITANZ’s wealth of experience and Mani’s standing within the international and domestic intersex communities was an invaluable addition to the research. It enabled me to access information and key people to help facilitate the research.
It was equally important to access allies within the medical field, as this was another group of key informants for the research. This ally was my supervisor, Dr Esko Wiltshire, who is a paediatric endocrinologist and associate professor at Otago medical school. Esko was crucial in connecting me to key people who would become participants in the research and link me to other participants. Through joining the Australasian Paediatric Endocrine Group (APEG), I was able to meet other clinicians and hear what the latest developments in the field of VSC/DSD were. Joining APEG helped enormously as it provided me with some credibility with health professionals and indicated a shared investment in understanding all perspectives of the research topic. I attended several annual scientific meetings and was able to present some of my early findings and receive feedback.

4.4.3 Additional partners to the research

In addition to my main partnership groups, Rainbow Youth (RY) decided they would support the research by using their extensive networks to share the message about my research, which aided recruitment.

Professor Elisabeth McDonald (Canterbury University) also became involved. She had previously been on the ITANZ board and had experience of and a special interest in the legal ramifications for those born with a VSC/DSD. Due to the increasing call for legal change occurring worldwide I felt it important to keep abreast of the events occurring internationally.

All of these collaborative and “practical partnerships” became woven into the research process. This was both challenging and rewarding, and reflected the dynamics of the issues inherent to experiences of those living and working with VSC/DSD. Fostering relationships between the different partners involved supporting the collaboration and having a shared understanding of creating new knowledge. The research was a uniting factor for all. The willingness to work together and navigate different points of view was supported by robust discussion and respecting each other’s right to express their point of view.
### Table 4.1 Key informants

#### Key informants for the study

<table>
<thead>
<tr>
<th>Māori</th>
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<tbody>
<tr>
<td>• Te Rōpū Rangahau Hauora a Eru Pōmare (University of Otago, Wellington), consulted with various staff who have an interest in the area of gender and sexual diversity, such as Dr Keri Lawson-Te Aho. Dr Lawson-Te Aho also provided access to her extensive networks nationally.</td>
<td></td>
</tr>
<tr>
<td>• Dr Elizabeth Kereker-e, founder of the Tiwhanawhana Trust, a Takatāpui (Māori word for LGBTTQIA+ people) community group that celebrates the diversity of sexualities, gender identities and sex characteristics.</td>
<td></td>
</tr>
<tr>
<td>• Moira Clunie of the Mental Health Foundation, who was willing to disseminate information through the Foundation's networks, including their annual national Takatāpui Hui.</td>
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</table>

#### Intersex/VSC and allies

- Mani Mitchell of Intersex Trust Aotearoa New Zealand (ITANZ), with whom I developed a collaborative relationship that extended throughout the research process.
- ITANZ board members I presented my research proposal to, all of whom were all very supportive.
- Georgia Andrews, co-chair of ITANZ and project leader for Intersex Youth Aotearoa (IYA).
- Tommy Hamilton, the national coordinator for Rainbow Youth and Aych McArdie, Rainbow Youth Education director.
- Professor Elisabeth McDonald, Canterbury University law department.

#### Health professionals

- Dr Esko Wiltshire, Paediatric Endocrinologist, Wellington Children’s Hospital and Associate Professor at Otago medical school, Wellington.
- Australasian Pediatric Endocrine Group (APEG)

### 4.4.3 Reciprocity

These partnerships also involved some reciprocity, for example sharing of resources, involvement in training, and facilitation of collaboration between advocates and health educators and health professionals. Specific examples include:

1) supporting a collaborative presentation (including sourcing funding) at an international conference focused on academic and advocate collaboration

2) contributing to the paediatric reference group established by the Ministry of Health as an outcome from the intersex roundtable in the final year of my research.

In addition, Rainbow Youth decided to test the demand for an intersex youth group by establishing an online presence and gauging whether there were people who identified as I/VSC who wanted to connect in a safe space. It was humbling to think...
that simply discussing the research could lead to the establishment of a youth support group. Intersex Youth Aotearoa (IYA) went live in September 2015, becoming a subsidiary of ITANZ.

This partnership approach also included Georgia Andrews, who developed a role as a young advocate for people born I/VSC. Alongside Mani, Georgia became a supportive ally in collaborating on the research. This culminated in the joint development and delivery of a presentation at the inaugural Intersex social science: activism, human rights and citizenship conference held on June 4-5th 2018 in Bologna, Italy.

This reciprocity was a very satisfying part of the research process. I especially valued the opportunity to support one of the research participants, Georgia Andrews, to go to Bologna to present together my findings on young people’s experiences. Georgia, who is developing her youth advocacy role, benefited greatly from meeting other young advocates from around the world (personal communication,2018).

These partnerships, alongside my multi-disciplinary supervisor group, meant I had a strong representation of the diversity of elements reflected in this complex field of research. Without the establishment and maintenance of these partnerships I believe the research project would have not been as rich and expansive.

4.5 Ethical Matters

Ethical Approval was obtained via the University of Otago Human Ethics committee (Ethics Committee reference number H13/031) and latterly by the Health and Disabilities Ethics Committee (HDEC), as Auckland District Health Board required HDEC approval to participate. The HDEC Reference is 15/CEN/89. The fact that I am a clinical psychologist provided some reassurance to the two committees, as they were understandably concerned about the vulnerability of all three participant groups, but in particular the young people.

4.5.1 Data collection

The data collection process is outlined in figure 4:3 below.
4.5.2 Sampling

Sampling began once information sheets, consent forms and interview guides had been developed. Data was collected over three years, from August 2014 through to March 2017.

![Outline of data collection]

**Figure 4.3 Outline of data collection**

4.5.3 Inclusions/Exclusions

This study included individuals or families with a clinical diagnosis of a VSC/DSD, according to the Pediatric Endocrine Society/European Society for Paediatric Endocrinology (PES/ESPE) classification (2006). This includes, but is not limited to, sex chromosomal DSD (Klinefelter syndrome with genital anomaly, mixed gonadal...
dysgenesis, Turner syndrome, ovotesticular DSD), severe (perineal) hypospadias, gonadal dysgenesis (pure and mixed), defects in steroid biosynthesis or action (including CAH, androgen insensitivity, androgen biosynthetic deficits and exogenous exposure) and anatomical abnormalities (including cloacal anomalies, MURCS, syndromes). Exclusions included people with mild hypospadias and non-English speakers.

4.5.4 Definitions/terminology
“Intersex” and “DSD’ and/or a combination of those terms was used throughout the recruitment process, as at that stage the term “variations of sex development (VSC)” was not known to the research team. However, VSC is used throughout the thesis, as stated in chapter three. See glossary for all other terms.

4.6 Sample groups
There are three sample groups in the research; see figure 4:4and table 4:5 below.

Figure 4:4 Participant information
Table 4:2 Sample groups

<table>
<thead>
<tr>
<th>Group one - Health professional group</th>
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</thead>
<tbody>
<tr>
<td>22 health professionals who had directly cared for infants and children with VSC/DSD were interviewed. This group included paediatric endocrinologists, paediatric surgeons, paediatric urologists, neonatologists, paediatricians, adult endocrinologists, adolescent gynaecologists and any allied health professionals.</td>
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<table>
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<tr>
<th>Group two- Parents of children with a VSC/DSD</th>
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<tbody>
<tr>
<td>18 parents of children with a VSC/DSD and who are the primary care givers were interviewed. This included 5 couples; 4 heterosexual and one lesbian couple. The remaining 8 parents were interviewed on their own due to the other partners being unavailable. These 8 parents were all women and heterosexual, except for one mother who was in a lesbian relationship.</td>
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<table>
<thead>
<tr>
<th>Group three - Young adults with a VSC/DSD</th>
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</thead>
<tbody>
<tr>
<td>10 young people aged between 14 and 24 were interviewed from around the country, including 8 from cities and 2 from smaller towns.</td>
</tr>
</tbody>
</table>

For the sake of clarity, the procedures for each sample group are described separately.

Particular care was taken to maintain confidentiality, given the nature of the data obtained from each group.

4.7 Health professionals

4.7.1 Recruitment

Suitable health professionals (HPs) were accessed via professional networks, such as APEG and the DSD interest group, and invited to participate in the study. Locality agreements were sought from the various district health boards in order to gain consent for health professionals to participate and to contact patients to see if they wanted to participate in the study.

In order to further network I attended two DSD interest group meetings, which are a part of the annual scientific meeting hosted by APEG. This meant I had face-to-face introductions to many of the key local people in the endocrinology field. As a member of APEG I received regular updates and information on other opportunities.
to meet and maintain contact within the group. I built on relationships that I had already made and these enabled me to identify other appropriate HPs to contact.

I started by contacting each paediatric endocrinologist and seeking their consent to participate in the research. At that time, I would ask for the names of other people who worked in the field who they thought it would be useful for me to contact. I maintained contact by regularly sending out reminders and updates to those who had consented to participate in the research.

In regard to recruiting other HPs, as mentioned above I asked paediatric endocrinologists to identify who was on their team and what professional group they belonged to. I then made contact, explained the research, sent information and consent forms, and arranged a time to follow up if they indicated they were willing to be involved. I then made arrangements to interview them.

(Information and consent forms are in the appendix).

4.7.2 Data

Face-to-face semi-structured individual interviews were developed for HPs to explore their experiences of dealing with patients and parents who present with a VSC/DSD. Questions focused on what is involved in their decision-making processes, and especially on understanding their ethical considerations around gender assignment and early genital surgery (interview guides are in the appendix).

Demographics included standard data such as age, sex and ethnicity. In addition, I gathered some extra demographic detail for HPs. This included asking if they were a parent, the number of years they had worked in their specialty and approximately how many patients they had encountered who had a VSC/DSD. I asked where and with whom they had trained in order to address whether a particular person or group had provided training and therefore had an impact on creating a “knowledge lineage”. For example, most of the surgeons were trained by Professor John Hutson from the Royal Children’s Hospital, Melbourne, Australia.

Interviews were audio recorded using a digital recorder. All recordings were transcribed verbatim.
4.7.3 Interview process
Consent forms and information sheets were emailed and/or posted to the recipient to complete. Consent forms generally were completed at the time of interview. Interviews were arranged to be convenient for the consenting interviewee and were held in their place of work or at home. Most interviews lasted between 35 and 90 minutes (median 45 minutes), though there were a few that went to two hours.

Interviews were flexible and open-ended, covering a range of topics, for example the language used to describe the child’s condition, the support and information offered, and what their experience is like during this process of providing care and management for their patients. I also probed for potential improvements they might consider needed in order to provide the best health care.

4.8 Parents
4.8.1 Recruitment
Parents were recruited via the caseloads identified through health professionals who were providing services to people with a VSC/DSD. The majority of parents were recruited by this pathway.

Recruitment was also attempted through support and advocacy groups such as ITANZ and Congenital Adrenal Hyperplasia NZ (CAHNZ). Support groups posted information inviting parents to take part on their websites/newsletters, along with an information sheet outlining the study.

ITANZ, who are very supportive of the research, actively promoted it where possible. I also made contact with other support and advocacy groups in order to get the widest reach possible (see recruitment information and consent forms in appendix).

4.8.2 Data
Face-to-face semi-structured individual interviews were developed for the parent group to explore their experiences of having a child with a VSC/DSD and what their hopes and fears might be. Interviews also explored how they experienced the process of making what are often complex ethical decisions with potentially long-standing consequences, especially regarding gender assignment and early genital surgery for their child.
Some demographic information was gathered e.g. age, sex and contact with support groups (interview guides are in the appendix).

4.8.3 Interview process

Interview times were arranged that were convenient to the consenting interviewee/s (where there were two parents raising the child, I gained consent from both and saw them together, separately or only saw one, depending on their preference). The interviews were audio recorded using a digital recorder. All recordings were transcribed verbatim. Interviews were often long, lasting two to three hours (median 100 minutes).

Interviews were flexible and open-ended, covering a range of topics, for example the language used to describe the child’s condition, the support and information they were offered and received, and the process and nature of decision making about care and management. Potential improvements were probed for. I followed up with some parents recruited in the initial years of the study to explore the nature of their unfolding experience.

4.9 Young people

4.9.1 Recruitment

Young people were recruited via the caseloads identified through HPs who were providing services to people with a VSC/DSD. They were also recruited through support and advocacy groups such as ITANZ and CAHNZ. Support groups posted information inviting young people to take part on their websites/newsletters, along with an information sheet outlining the study.

The research was endorsed by ITANZ. Both Mani Mitchell and Tommy Hamilton (ITANZ advocates) advised on and assisted in the recruitment of young people through their extensive networks. I also made contact with CAHNZ, LGBTQIA+ groups (for example Rainbow Youth) and any relevant groups that I become aware of during the course of my research (Information and consent forms in appendix).

4.9.2 Data

Face-to-face semi-structured individual interviews were developed for young adults to explore their experiences of having a VSC/DSD and what they thought of decisions made on their behalf, if applicable. Interviews also sought to understand their
thoughts on decision-making processes, especially regarding gender assignment and early genital surgery.

Some demographic information was gathered at the end of each interview e.g. age, sex and contact with support groups (interview guides are in the appendix).

Two of the participants provided additional information: one a school speech and the other a presentation.

4.9.3 Interview process

An interview time was arranged at a time convenient to the consenting interviewee. The interview was audio recorded using a digital recorder. All recordings were transcribed verbatim. Interview times varied from 30 minutes to several hours (median 70 mins). The young people were asked if they would like a support person to be present. Only one young person took up this option, requesting that her mother stay. Written consent was obtained before commencing the interview.

Interviews were flexible and open-ended, covering a range of topics, for example the language used to describe their condition, the support and information offered, and the process and nature of decision making about care and management. Potential improvements were probed for.

4.10 Decision Making Scale

To further understand whether there was a sense of consistency around the decision making process, I wanted to use a measure to represent where the responsibility for decision making lay between parents and health professionals. The measure would indicate where participants felt the responsibility ultimately lay for decision making when it came to the child and/or young person in question i.e. with the parents/caregivers, with the health professional or somewhere in between. The scale ranged from 1-20 with 10 being the medium point, which would indicate a shared responsibility for decision making. To obtain data for this measure I developed a decision making scale (DMS) that asked participants to place an X on a continuum (see figure 4:5). This was based on Miller's visual analogue scale (S. Miller, Duncan, & Brown, 2003).

Most found the task straightforward and tended to place the X in or near the middle. However, some found the process challenging as they felt it depended on the specific
case e.g. whether it was a life-threatening situation or not. To address this challenge, the task of choosing was moved from one DMS to two i.e. one DMS for life threatening situations and another DMS for when situations were not life threatening.

![Decision making scale](image)

**Figure 4.5 HPs and parents decision scale**

For the young people I included an additional DMS considering those times when they were able to participate in making decisions. I included the parent and health professional DMS also as I was interested in their view of who should hold the responsibility for decision making (see figure 4.6). As was the case for parents and HPs, some young people also wanted to split the task into life-threatening and non-life threatening conditions.

Measures from the DMS’s were uploaded for statistical analysis using the statistical software SPSS (IBM, 2016). Results are presented in chapter eight.
Figure 4:6 Young person’s decision scale

4.11 Data Analysis

Thematic analysis (TA) was used to analyse the data as it is compatible with CR and is flexible, allowing for an analytical process that would go beyond the surface of the reality reported and understand the processes and mechanisms behind it (Denzin & Lincoln, 2013). TA is often seen as a tool and/or process of qualitative analysis; however, Braun and Clarke have developed a model where TA is itself the research method and can be used in conjunction with a theoretical framework (Braun & Clarke, 2006). TA was developed by psychologists and is used in health science, so was appropriate given my background in psychology. It was also appropriate for the volume of data that was gathered in this research.

Transcribed interviews, along with data as mentioned earlier (4.10.2), were uploaded to Nvivo 11, which is a qualitative data analysis computer software system (QSR International, 2015). This was the platform used for storing and organising data and checking the data matched the audio recordings. Nvivo 11 has tools to help categorise and classify data, making the analysis of large data sets more manageable as the user can visualise results and map ideas. Other tools facilitate text searches, enabling exploration of the data in detail so as to easily compare and contrast in an
organised manner. This removes some of the risk associated with more traditional pen and paper analysis where data can be lost, missed or difficult to manage (Bazeley & Jackson, 2013).

Data was analysed from each individual interview separately, then within their respective groups and finally collectively across all three groups.

The health professionals and parents’ groups were allocated a number linked to their transcripts as an identifier that would maintain the privacy of their identity. For example, there were 22 health professional participants and they were identified as HP1, HP2, HP3 etc. The parent’s participant group consisted of 18 individuals who were also allocated a number e.g. P1-father, P2-mother and so on.

As there were only 10 young people I gave them a pseudonym e.g. Amber, Bridget, Tess etc. rather than a generic group identifier and individual number. This was because they were at the heart and centre of the decision making process.

When presenting the data, I use direct quotes from the participants where possible, in order to honour their voices. I have provided direct data to ensure the participant’s voice is not lost by way of interpretation and theorising. My intent is to maintain the integrity of what was said by the individual participant. This is also reflected in each participant group having their own chapter to express in detail their experience and my analysis of those experiences.

There is a tension, however, between maintaining the integrity of what is said by participants and the integrity of the analytic process in developing themes and in-depth understanding of those themes. The TA model, along with the frameworks previously discussed, provides a safeguard to managing this tension. The analysis is then reflected in the way these quotes are ordered, presented and the commentary I provide alongside them. Additionally, a data session for each of the three groups was held with supervisors to discuss the data analysis and further clarify the themes. This process was also an opportunity to identify and challenge my own biases and those of the supervisors. Researcher reflexivity was a constant and is discussed in more detail in an upcoming section (4.13).

Braun and Clarke (2006) provide clear and specific phases of the analytical process that was followed in this study (see figure 5, which outlines the process in more
detail). Once all three data sets were complete a cross sectional analysis was undertaken. Similarities and differences were identified and themes grouped together (Braun & Clarke, 2006).

Figure 4:7 Phases of thematic analysis  (Braun & Clarke, 2006)
4.12 Researcher position and reflexivity and theoretical framework

I am a clinical psychologist with a background working in child, adolescent and family mental health services. I am a relatively new researcher, having worked for three years on other research projects before undertaking my own PhD research.

I have attempted to use critical reflexivity, defined by Dowling as “a process of constant, self-conscious scrutiny of the self as researcher and of the research process. In other words, being reflexive means analysing your own situation as if it were something you were studying” (Dowling, Lloyd, & Suchet-Pearson, 2015, p. 34).

Gender, VSC and their intersections with identity combine to represent a socially contested space in society. Critical realism and feminist theory (Danermark, Ekstrom, Jakobsen & Karlsson 2002, Anderson 2017) were selected as appropriate theoretical frameworks to underpin the research, because I wanted to facilitate a deeper understanding and deconstruction of the socio-cultural normative structures and processes in play for the participants, including issues of equality and power (Lyons and Chamberlain 2006).

Group data sessions were held with supervisors to discuss the analysis and further clarify the themes. Reflexivity ensured that the research remained true to the participants’ voices (Probst, 2015).

I think this reflexive process has been helped by the practical partnerships with Mani and the extended I/VSC community, who have provided feedback on my research, especially around safe and respectful processes. I have checked my potential biases with those with lived experience and sought direct feedback individually. I have also been challenged as a researcher in collective settings, such as at conferences/scientific meetings.

Involvement in the intersex roundtables and observing robust debates around differing viewpoints has also informed my thinking.

I have been especially mindful of my own privilege as a cisgender, white, educated woman. This research has challenged me to think more broadly in regards to gender, the range of diversity, and the diversity within that diversity.
I have always considered myself very aware of difference and diversity, given my own experiences of having a family outside the dominant heteronormative frame. My family consists of my female partner, our teenage son and two cats. Being part of the LGBTTTQIA+ community has meant I have been exposed to a great deal of diversity and visibility. However, the “I” representing intersex has been the least visible and at times is treated as a token. I am aware my lived experience gives me some degree of insight, though I am also aware my situation is very different as I/VSC is not about sexuality but rather about the way a person views their sense of identity around gender, including their physical variation and all the complexities that come within that.

There is also a great deal of criticism by some intersex advocates (personal communication, July 2018) that the inclusion of the “I” in the wider rainbow community is undesirable as it conflates sexuality and gender. Many feel having a VSC/DSD has nothing to do with sexuality, so being allied with a group that largely consists of groups of people who have been discriminated against based on their sexuality confuses the issue. Some people with VSC/DSD don’t want to be associated with LGBTTTQIA+ people due to their own homophobia and concerns about the potential additional stigma association could cause.

I have therefore been very mindful to check my own biases by talking with my supervisors and advisors. This research has stretched my own horizons even further when it comes to the complexities of gender fluidity and the ‘norms’ many of us take for granted.

4.13 Summary
This research was undertaken using the principles of Te Tiriti O Waitangi and this partnership approach extended to include key partners within the I/VSC community and medical world. These “practical partnerships” established and maintained collaboration, with the key partnerships at times allowing for reciprocity.

This collaboration also supported the research to uphold the highest standards of integrity, representation and ethically responsible research. I ensured throughout the research process that those most affected were consulted regularly.
This qualitative research employed TA as the methodology and Nvivo software was used. The theoretical base of critical realism was the framework for the analysis findings. Critical reflexivity ensured that the research remained true to the participants’ voices and enabled bias to be identified and resolved.

Chapters two and three provided the context for the research and this chapter explained the methodology and methods of the research. The next four chapters cover the findings of the research. I start in chapter five by presenting the health professionals perspective as this is the dominant discourse and the institutional setting which parents encounter when they have a child with a suspected VSC. Consequently, chapter six reports the data from parents as they are faced with decision making for their children. Chapter seven reveals the perspective from a young person living with a VSC and the consequences of their health care. They comment on their experiences of decisions made or supported by their parents. Chapter eight compares all three groups before I finish with chapter nine, which houses the discussion.
Chapter Five

“Land of the long white coat”
Health Professionals perspective.

“I feel a little bit damned if I do, damned if I don’t”

5.1 Introduction
In this chapter I will provide the findings from the first and largest of the three participant groups (22 participants): the health professionals (HPs). I first provide some information about the sample, then discuss the patterns of engagement, followed by the findings. These include areas of commonality before moving onto the influences on decision making, which were, recognition of the past, expectations, communication, norms, bias and support.

Next, I provide some findings on decision making around genital surgery, given this is an area of contention before ending with a summary.

5.2 Sample
HPs included DSD specialists from the areas of endocrinology, paediatric surgery, adolescent gynaecology and allied health professionals.

The HPs were interviewed between August 2014 and November 2016. The HP specialists working in the area of DSD were located in Dunedin, Christchurch, Wellington and Auckland.

The various HPs included paediatric and adult endocrinologists, paediatric urology and gynaecology surgeons and allied services from neonates, psychology and physiotherapy. The HPs numbered 22 and their interviews varied from 30 minutes to 90 minutes.
5.3 Patterns of engagement

The first group were the “cautious responders”. These HPs were guarded and very considered in their responses. At times, some of these participants seemed anxious as to whether they were giving the “right” response. One participant even asked if this was what other participants were saying when asked that question. It was clearly somewhat anxiety-provoking to be talking about the work in this highly complex and contentious area.

The second group were the “open engagers” who willingly gave of themselves in an open manner and at times expressed vulnerabilities that they experienced in this area of work. These participants offered personal feelings and at times reflections on their experiences as the interview process developed.

The last group were “authoritarian defenders” who were very direct. They were instructive and very matter of a fact. At times these participants seemed somewhat defensive and dismissive and their responses felt “managed”.

Most participants fell in the second category and at times the cautious responders eased into more open engagement as the interview progressed. While each
participant has the capacity to present in all or occasionally each of these categories, they represent the main style of presentation of the participants.

This is interesting to reflect on, as some of the participants may have felt this was potentially a process that may expose vulnerabilities in their views or about their practice. Others took a very commanding approach and at times responded in a somewhat abrasive or defensive manner. Still others relished the opportunity to discuss their experiences and views and the chance to express the complexity and challenges of working in this field. Many participants enjoyed the process and it was obvious that many HPs were open to reflecting on their practice. Some participants’ approaches could also reflect my engagement, with some not feeling comfortable, though that was never the intention.

Initially, I was not expecting many people to take part due to the controversial nature of the topic and the time pressure participants were under. I felt a great sense of privilege that the participants made time to meet and explore this research topic.

5.4 Findings

5.4.1 Common Ground

While there were a diverse range of experiences and opinions expressed, there were areas of clarity and commonality. These included the process of clinical assessment, risk, developing a clear plan, terminology and shared decision making. These areas are discussed in turn, including any outlier opinions, before moving to the six core themes of influence on decision making.

5.4.2 Difference and Clinical assessment

It was evident that it was important to acknowledge that there was something different about a child, that the sex characteristics were unclear. A series of tests would need to be done to clarify the situation soon after birth. These initial tests would, in most instances, supply the eagerly awaited answer as to whether the child was a girl or a boy, as stated by the HP below.

“well there's the obvious question from the parents being is this a girl or a boy and not being able to answer that question exactly for them and it is the most important question”

HP22
These HPs demonstrate the dilemma which occurs when the child’s sex is not clear and tests are inconclusive.

“There’s always a different way but nobody knows which is the best and that’s where the dilemma comes. I mean we try and do what we think is best for the child um and that’s done in consultation with the parent, but there is no easy answer. It’s not written in black and white.”

HP4

These tests covered the areas of genetic coding (karyotype), hormones and physical appearance (phenotype). Most of these would be completed within 24 hours (e.g. ultrasound) though some may take up to a week if they needed to be sent to Australia.

It was important to try and get the information to parents as quickly as possible as it was seen as very distressing for parents to not know the sex of their baby. There was a sense of urgency to provide as much clarity and factual evidence as the HP could. This was prioritised by all specialist HPs who were often called in after another HP had discovered a baby with “atypical genitalia”. This was most often a midwife or obstetrician. Generally, an endocrinologist would be called to come and assess the child.

“the really basic genetic information you can usually get within 24 hours, so you can get a...a FISH, which shows you whether there’s Y chromosome material or not, so it’s not a definitive Karyotype, it’s not a detailed one. So, (in Main centres) certainly you can get that straight away almost within a day. So, we usually say to parents it’ll be 48 hours before we can really have enough information to sit down and start going through things. But that is for the more straight-forward kind of cases. There are other ones that...I think sometimes the easier ones are the virilised females...The under virilised males can be a bit harder... and we have to do a few more hormonal tests that take a lot longer to come back,...it can be several days in that case, and sometimes longer.”

HP 17
5.4.3 Risk

The top priority was to check the child was not in immediate risk of any life-threatening complication, e.g. salt wasting congenital adrenal hyperplasia (CAH) or cloacal anomaly, where there may be major issues with voiding bodily waste or organs outside of the body. It was clear the two main factors were to clearly diagnose the child’s condition and to ensure the child was not in a life-threatening situation.

The next priority was to provide a definitive understanding regarding the sex of the child i.e. the sex the child should be reared as. This was what was perceived as the most important information parents wanted alongside knowing their child was healthy.

“...initially while we’re working out what the diagnosis is, it’s sensible to keep a close eye on what’s happening, because there are some conditions that are life-threatening in the kind of middle, towards the end of the first week of life, so it’s important to be somewhere...safe until that’s been clarified whether we’re dealing with one of those disorders or not.”

HP 1

“I guess there’s a first phase, where in the first couple of days there’s a, look this is where we’re at...this is the problem. Let’s get some urgent tests to work out whether we’ve got a...a medical emergency on our hands...”

HP4

5.4.4 Developing a clear plan

The next priority was to develop a clear plan for treatment and, where possible, to include the parents/caregivers in that process. How much parent involvement was considered desirable varied from HP to HP and many factors influenced this, the main ones being the culture and the perceived educational/intelligence of the parents by the HP. Many felt that sometimes the child’s presentation is so complex that many HPs without specialised knowledge do not understand, let alone a parent who has no medical expertise. Some HPs felt it was their responsibility to strongly guide parents, as that was their job because they had the knowledge base and expertise.
Transparency when communicating with parents was seen as essential. Many emphasized the importance of being clear. Simplifying very complex and at times medicalised language in ways that could be easily understood and digested by parents/caregivers was important.

Often HPs would use visual resources to help explain the way babies develop in utero with regards to sex determination. (see example-figures 3:4 and 3:5)

"I’ll give them as many printed resources as I’ve got. So, there’s Garry Warne’s little booklet about androgen insensitivity, is really nice. And A.P.E.G. little booklets. But I won’t give them the booklet until we’ve got the diagnosis, cause I’m not setting them on a wild goose chase."

HP3

“I sort of talk about sex determination as not just there’s your karyotype and this is the other, it’s a little bit like we’re all, humans are computers and we’ve got different software and different hardware, and if there are errors along the way, then you can get different combinations of things, but it doesn’t mean you’re not still a good computer. It’s just that it’s different.”

HP18

All acknowledged there was little support for parents other than what was provided by the HPs themselves. Consequently, HPs often went over and above what they might usually offer. Many would give their emails or direct dial and have longer and more frequent consultations as these HPs below state.

“I give them time, so that they can tell me what they’re struggling with, ’cause sometimes people...you just need to talk. And certainly...um...a lot of the things that they’re dealing with, there’s a certain point where...I don’t have any magic answer for them; I don’t have a pill I can give them, that takes away what they’re telling me...I can normalise what they’re experiencing, you know? Because it’s completely appropriate for them to be having some difficulties, or some challenges...ah, and these emotional sorts of...you know, worries and thoughts. I give people my email...so it’s very easy for me to give them a little bit of my time.”

HP4
“you have to allot a reasonable amount of time to the clinical appointments for these cases in order to be able to have those conversations in a non-pressured environment and I put them at the end of my clinic list for that day. I can say look we’ve got this much time but I’m happy to sit for longer …and we can sit and go through things...”

HP22

5.4.5 Terminology

Generally, the participants had no expectation of using such terms as DSD and intersex. These terms were not spoken or even discussed with patients in most instances. When HPs did use “DSD” it was mainly with other HPs or at various training. The HPs used the name of the specific condition, for example congenital adrenal hypoplasia (CAH). One of the reasons for not favouring intersex over DSD was that many felt the term related more to those who were both male and female variations such as 46,XX/46,XY. Others felt it was a misleading term and uncomfortable for some people especially due to its alliance to the LGBTQIA rights activists and support groups.

There were a few HPs who expressed strong views indicating it did not really matter or that it was going to be impossible to please everyone.

“You know, when they come and see me, we’re just dealing with what the issues are. You know, the...sometimes the words are almost, ah, irrelevant at a certain point. We just deal with things... and work our way through them in whatever way we can. ...I think that’s the biggest problem with the terminology thing, ...I want the majority of people to make a decision, ‘cause you can’t keep everyone happy. And...I think it’s incredibly well-meaning to think that we’re gonna get consensus, but it’s absolutely impossible”.

HP4

This HP went on to describe a “minority” of people who complained and were not representative of the majority of people with VSC but it was unclear what this was based on.

“I think D.S.D. is my preferred terminology, and I...again, I guess, over my training, and my time, the terminology’s changed a number of times already. I...I’m fairly keen for it not to change too much more. I find that just as confusing...for the
majority of people ... the... changing the terminology to suit a minority group.

HP4

Lastly, this HP commented DSD is a “medical problem” after all implying it is best to “call a spade a spade”.

“I think disorder of sexual differentiation sounds fine to me. I think that...I mean, they have a medical problem...”

HP4

Another HP also felt strongly, stating that it was basically “political correctness” that drove the debate and disappointment with terms such as DSD or “ambiguous genitalia.”

“I mean to some extent the names are immaterial, you know it, ok your child doesn’t look normal, the penis hasn’t developed normally or the vagina hasn’t developed, let’s discuss what the issues are rather than come up with a nice little name, I think the name’s irrelevant largely, most of that, I’m gonna be really politically incorrect but it’s driven by political correctness more than what’s gonna be useful to parents, you know can’t say ambiguous genitalia anymore (laughs)...”

HP13

A senior HP in their field outlines their understanding of terms in relation to advocacy groups such as Organisation of Intersex International (O.I.I) and Intersex Support North America(I.S.N.A). Then comments how doctors are perceived as “evil” when in fact they are sensitive to parent’s needs. These are long quotes but they represent the investment some HPs have in approaching collaboration and the investment they have in medical classification.

“So, there are certain extreme groups, like O.I.I., who don’t like D.S.D. There are certain other intersex groups, and I know I.S.N.A. was like that, it didn’t like intersex. So O.I.I. insists on intersex... I.S.N.A., who they’ve changed their name now, said don’t like that name, don’t like D.S.D. much either. Umm... the reality is, that they are arbitrary names. ...there’s this perception we’re the great evil, I think. ... but saying that, we
when we see a child, we don’t say to the mother, well that child’s got D.S.D., or we don’t say they’re intersex. We talk about the issues they’ve got; they’ve got some ambiguity there... we need to work out how best to raise a child as a boy or a girl. We don’t use terms like DSD, intersex, those don’t... those aren’t in our lexicon”.

This HP ends the conversation by emphatically stating that VSCs are medical conditions and are in fact disorders and it is “silly” to deny this fact.

“the term D.S.D. is a good term in the sense that it... the classification is logical, and sensible, and they... and despite what O.I.I. says, the majority of these are disorders. ‘Cause the typical, normal... differentiation is male or female. So, anything in between is a disorder by definition, even if they don’t feel like they should be called a disorder. The reality, at a medical level, is that they are. But that’s not how we put it to them, or the family, ... it’s more a convenient way of classifying, which I think is very important, ... and I’m quite resistant to changing it, because there is no proper term. And no matter what people you talk to, C.A.H. hate the term... umm, intersex... as do Turner’s, as do Klinefelter’s... so... and they don’t mind the term D.S.D., they think it’s... see, I know the Androgen Insensitivity Syndrome Society in the UK feel the term D.S.D. makes sense, because it’s talking about an abnormality in the androgen receptor. So... I think what we’ve got here is a... a group of people who have all got their own thoughts. Some of them are very, very..., angry, and are looking at ways of expressing that anger, and some of it’s about they see society labelling... or medial people in particular, labelling them in certain ways. They don’t want to be considered a disorder. And I don’t have a problem with that. But the reality is, is that what’s caused this is a genetic mutation... or sometimes is an underlying genetic mutation with a disease associated, like C.A.H., where you actually have treatment. So... to my mind, it’s a silly argument...and I said to the O.I.I. people and the P.A.I.S... or the Androgen Insensitivity Society in Australia, we don’t use those terms to the individuals. Those are terms that we would use in a... in an abstract... an oral presentation... talking to other doctors. They’re not terms that are designed to label individuals. They’re terms to explain conditions. and I suspect there will be ongoing issues around this area, and despite what we’ve said, the O.I.I. still insists that D.S.D. should be removed, and it should be replaced by intersex. I had equally strong opinions from other groups that... ah, that D.S.D. is the
preferred term, and they dislike intersex intensely. So, no... you can't win! [Laughs]

HP6

These three HPs were of the viewpoint that medical accuracy was most important and that the views of a few should be dismissed. However, there is little or no research indicating what people with VSC would prefer. Given that many HPs would not use either intersex or DSD terminology with the majority of their patients it would be difficult to ascertain what people’s experience is. There is some indication there has been some discussion using the DSD and intersex terms as HP6 reports of some people not liking the term intersex and liking DSD which appears to contradict the earlier comment that those terms “those aren’t in our lexicon” (HP6).

It is clear though that a number of people who have lived experience do find the terms difficult (3.6). One of the things to consider in this debate is that it is a sensitive topic about a part of the body that most people consider private and deeply personal, therefore arguably sensitivity around language does matter.

Little understanding of the possibility of using less stigmatising language of difference was evident e.g. Atypical or variation as opposed to disorder or defect.

5.4.6 Shared decision making
The overall consensus was that decision making was generally shared. The participants saw their responsibility to be the provider of clear clinical information and guidance, with the parents or young person ultimately responsible for final decisions.

The HPs’ personal expectations, along with perceived expectations of their colleagues, parents and those affected, had enormous impact on decision making. Discomfort and/or avoidance of the discussion of complex issues around gender, body autonomy, sexuality and diversity were identified. HPs reported varying degrees of confidence in their ability and or comfort in discussing such issues.

Communicating effectively about these issues, especially over the life span, was seen as very challenging. At times unintended bias could limit provision of adequate
information about treatment options which included no treatment or delayed treatment and possible psychosocial impact.

Most HPs reported the issue of data or outcome research as discussed in chapter two and three. This next quote is an example of the current state regarding outcome research.

“one of our frustrations is our databases are appalling. They're... and if we’re going to look at outcomes with these kids, we need to have better... documentation of who’s got what... umm, even if it's just D.S.D. Because the numbers are relatively small. ... I'm hoping it will evolve into ...a D.S.D. database, that we can then use to look at outcomes. 'cause unless you can recognise them, and follow them, you can't look at outcomes. And therefore, you're making statements about care, when you’ve... you’ve implemented a care programme, but you don’t know what the outcome is.”

HP6

The same HP later says that decisions are “not really based on good science or outcomes”.

“Well, the only thing we seem to be doing is making things worse for them{people with VSC/DSD} by... by aggressively making decisions which are arbitrary, and not really based on any good science or outcomes.”

HP6

This HP discusses that it is easier making decisions when the young person is able to contribute themselves.

“I think the complexity is when we’re making decisions... on behalf of our child, when they have no ability to help. Ah, once the child’s making...voicing their own ideas, then I think...in some ways that's much easier. You know, you can then just work your way through it. So, I'd be 100% supportive of what they wanna do.”

HP4
Below is one example of a discussion with parents regarding their 3-year-old daughter who was diagnosed with Androgen Insensitivity Syndrome (AIS) and whether to leave gonads in or take them out at an early age. The HP outlines the decision-making process below:

“I went through with them what’s the different, so it’s really just about timing, so you go through what the potential advantages and disadvantages of early is versus late um...in that situation we would advocate having surgery done at some stage but it doesn’t have to be, you know but it can be in early adulthood and so...

She’s a perfectly normal female but she doesn’t have a uterus and she has testes instead of ovaries and those testes do need to come out um...at least kind of by the time she’s 30 because they’re intra-abdominal and therefore there’s a risk of malignancy so you need to explain all that to the parents but the risk is in adulthood and they can, they, so you know, probably previously they whipped them out as soon as they diagnosed it and the advocates of that state that it’s less traumatic and confrontational for the child to go in and have an operation in the toddler stage when you don’t have to discuss what it’s all about and that kind of thing and the advocates of later surgery say that well actually the testes can be left in, it’s quite safe to leave them in for adolescence at least and then that they help to, they produce testosterone which is converted to estrogen so they help to, help to push the girl through puberty spontaneously as opposed to us having to give her hormones to put through puberty and so you just explain all those, so I just explained all of that to them, I fished out the parent information, gave that to them so that they had a chance to think about it and then I brought them back you know, relatively soon to go through it again and see if they’ve made a decision and they’ve decided to keep them in and that’s perfectly fine, I think that’s perfect, you know a good decision and we just keep monitoring her once a year...”

HP5

This is an example of the HP providing full information (both verbally and visually) and allowing time for the parents to consider all the information and providing another appointment to have further discussion and clarification. Demonstrating good communication and informed consent.
This HP was open about the fact that most people will be guided by what the HP says in contrast to it being a truly shared decision.

“Ultimately, most will be guided by what the medical profession say. That’s the reality. So, I think we have a... we have a really important role to make sure we don’t do any harm, or as less harm as possible. So, umm... but I try and keep those options as open as possible, and say look there are a number of options, which... and none of them are bad. So, these are the options, one, two, three, four. If you want to ask what I want, if they do that, I say well I think this one is, because this is... this is seems to be the most likely. But it is not necessarily the only option.”

HP6

Problems can result from this approach. For instance, if the HP is not providing full information or is presenting the information in way that is biased or does not incorporate alternative options difficulties arise. Problems can also occur when parents and/or a young person who has a VSC/DSD themselves, access information online or from support groups that contradicts the treating HPs assessment.

These commonalities along with some of the few contrasting viewpoints illustrate that there is some consistency in relation to process of clinical assessment, risk, developing a clear plan terminology and shared decision-making in Aotearoa/NZ.

In the next section the central findings in relation to decision-making, which is the main focus of the study, are presented.

5.5 Influences on Decision making - main themes

There were a six main themes with reference to the elements influencing decision making. They are illustrated below in table 5:1 below.
5.5.1 Recognition of the past

Many HPs acknowledged the past history in relation to the care of those born VSC/DSD, including the impact that John Money's theory had over many decades and the complete lack of inclusion of the person concerned (and parents /caregivers). Money's prescriptions included nondisclosure, “normalising” surgery, inappropriate gender assignment, multiple genital examinations and photography etc (2.4.4).

In keeping with the Treaty of Waitangi (2.2) it was salient to reflect on the past, given that John Money was a powerful and influential figure and his theory and practice was far reaching. The fact that Money was from Aotearoa/NZ was a powerful influence on the participants.

“Well in the early days if you go back to sort of the Money theory and there was a lot of emphasis put on whether males for example would have adequate genitalia to be able to stand and pass urine and that was considered quite important. And if it was felt that they weren’t able to be then it was more appropriate in that setting perhaps to raise them under the female gender. But over time that has changed considerably and now there’s more emphasis put on what might have happened in utero and in particular exposure to androgen and whether that will have imprinted the brain and had an effect on how that child will respond in later life. So, it has become a lot more difficult I think to try and anticipate what the future holds”

HP5
Another HP comments below on how listening to a patient’s lived experience had impact on their learning and this is important as it shows how powerful patient experience can be on the way HPs view what they are doing. This has consequences for learning /education opportunities.

“I think, meeting Mani(Mitchell) and listening to her story and recognising what terrible things she went through and knowing what had been done ...to kids in Melbourne when I was doing my training there where they just got a clitorectomy, end of story you know, I’ve tried to learn from those mistakes, I hope that most of the mistakes have been other people’s and not mine (laughs)...”

HP13

In the next instance the HP below explores the fact it was not only the surgical intervention but the lack of support and bad practice and processes around the surgery. It is also of note that the HP draws on the idea that being different from everyone else is an issue and the question is how is difference dealt with. In the past he indicates surgery was seen as the answer without additional support. The HP then states prefixing it with “hopefully” (similar to the HP above) there is better management now, but do we effectively get rid of the surgery, which is what many people with lived experience advocate for.

“I understand that when there is an issue with trying to normalise everyone but there is an issue with growing up thinking that you’re different to everyone else and you’re uncomfortable about getting changed around other people or you’re uncomfortable about wearing a swim suit around other people, that’s really difficult to quantify because whether you operate or not, you do actually have to deal with that side of it and I think historically people operated and then thought because they’d operated, they didn’t have to deal with that side of it and the children were not told or it was hidden and you know, looking at some of the stories of harm and poor outcome, when you strip it away, not so much about the surgery although there are some surgical aspects that are clearly not good but the never being told what was going on, being submitted to multiple examinations, parents being told not to tell them because it’s shameful, and so the psychological burden of that management strategy, I think, having you know, read and watched people’s sort of stories about these things, that’s had a far greater impact on them as to whether or not they had one
single good operation or not, now so they used to operate on everyone and have bad management and so now, hopefully we’ve got better management, the question is whether you have to get rid of the operation or not as part of that.”

HP16

The fact that these two HPs “hope” they are doing better reflects the lack of evidence and outcome research (as mentioned in chapters two and three). This highlights the vulnerability of HPs working in this area. They have been criticised for basing their decision making on their own experience and judgement.

This last example is indicating the shift from the previous mode of “paternalism” to a more patient-cantered way of working with patients so that they have a sense of agency.

“well medicine in general is a lot less paternalistic than it used to be... and health professionals hopefully realise that it’s important to involve patients and families in their own care ... and that they have a right and should be involved in the decision-making process rather than just being told what to do by someone in an ivory tower with a stethoscope around their neck.”

HP5

There was one HP who had concerns about the advocacy groups promoting non-binary concepts of gender and that the more paternalistic approach “at least gave people an identity.”

“Well you know some of the louder groups particularly I think in the US is sort of the group where it’s ok to be neither one gender nor the other. And those issues if they get portrayed strongly and become part of standard practice, I’m concerned that they’ll be individuals down the track who won’t cope with that and that perhaps will be doing people a grave injustice. Whereas the previous system perhaps paternalistic as is was, at least gave people an identity. So, I have worries about that.”

HP20
This theme of acknowledging the past is significant as it validates the experience of those who lived through it and highlights the vulnerability of working in this field. In contrast, past experiences also demonstrate that while there is a more patient-centred approach now there is still a reliance on “hope” that we are getting it right particularly for the future. This degree of uncertainty I would argue creates a degree of anxiety in the HP again because there is virtually no meaningful outcome data.

5.5.2 “Great expectations”

Many HPs felt there were great expectations upon them but the most overriding one was to “do no harm” and or “get it right”. The first sums up the overwhelming feeling from HPs, the second goes one step further, indicating the pressure to not only get it right but to make a decision.

“It’s quite vexed, you know, trying to get it right.”

HP12

“. . . it’s important to get it right. It’s important to . . . not only to. . . well, not to get it right, but don’t do harm. And sometimes there was no good answer. . . there was no right answer. . . but the worst you could do was try and pretend there is a right answer. And. . . and I think that doctors often feel like they’ve gotta make a call. And, umm, doesn’t matter what that call is, just gotta make a call. . . sock it in the arm, you know? You’ve gotta make a decision here. . . decision’s good, just make a decision.”

HP6

In this situation the HP is describing their reaction to having to make a decision regarding a gender assignment for a baby with a micro penis. In this situation there is still the question of whether a male can survive in the world with a micro penis. This reflects the dilemma of weighing doing the right thing in regards to the science, that is, this child is male with will they cope socially and psychologically in the world with a micro penis?

“I looked after. . . who is extremely under-virilised. . . and, umm, I mean a tiny, tiny micro-phallus, . . . and sweated on it for months really, before we decided to gender assign male.”

HP3
Some HPs felt they had to make everything right or correct the child’s variation so that the child presented to them would be look “normal”, especially for some parents where gender stereotypes were perceived by the HP to be of importance.

There were a number of explanations for this, some felt it was going to be socially difficult for a child to cope in the world if their genitals were different from their peers. This was particularly so for girls who had an enlarged clitoris and for boys with hypospadias, where it was felt that if a boy could not urinate standing, he would find this troubling. In both examples, there was concern that the children would be at risk of social ridicule and bullying and that this would create psychological issues.

“I think well, you have to think about what parents want and what their expectations are…”

HP6

“It’s just a peer pressure and having a normal child, you know that’s as simple as that and especially in situations where you’ve got, you know your child’s genitals are exposed to other people in day care centers and nurseries and things like that, that it’s to be really difficult to handle”

HP13

For this next HP and many others, trying to manage parents’ expectations and the future expectations on the child for whom you are making the decision was challenging. The following comment indicates the complexity and weight of responsibility in making a decision.

“I think probably the most challenging thing is expectations of a parent and expectations of a child who’s yet to make decisions and on the basis of that, knowing what the right thing to do is and there’s not necessarily a right thing but there’s decisions that have to be made and there are two different expectations that you’re trying to meet, one of which hasn’t yet actually got to decision making power so that’s probably the most difficult thing... meaning the child can’t make decisions for themselves but they will have expectations when they become an adult which have consequences based on decisions that are made collectively by their parents and healthcare workers collectively and so you’re never gonna get right all of the time.”

HP12
This pressure or expectation is driven by norms which was in itself its own theme.

5.5.3 Norms

Stigma around difference, i.e. that all boys’ and girls’ genitals should look the same, or be within the norm, was a major theme. Most doctors will have examined many different bodies and been exposed to the realisation that there is great variety and scope for difference. There is a predominant belief that it will be difficult for parents if their child has different looking genitals and though not all would suggest surgery as a fixative, it is presented as one of the possibilities.

Additionally, it was clear that the majority of HPs took a very biomedical, binary worldview of sex and gender and only one mentioned the fact that sex and gender are diverse and more fluid.

“I think it's opened my mind to the various...to the differences in how people think...you know, because they don't think exactly like me. You know, ah...but it's, I guess, no surprise, 'cause I guess in so many...areas of medicine and...and the world...we have different ways of thinking about things that we take for granted...you know, where it's very obvious that we all think about things differently. So...so it's no surprise, ... it's opened my eyes. I've become more aware of...the differences.”

HP4

This HP states that by delaying the timing of treatments it is possible to avoid the risk of getting caught in parental or medical stereotyping at any given time.

“...the thing is that you’re probably not going to get things 100% right all of the time and that’s life, it’s not 100% right all the time, the second thing is that there’s no rush, so taking time is important and the third thing, is over time surgical treatments become more delayed so that there has been more involvement of the child in decision making at a time where it's thought they could make those decisions so, you're not rushing into trying to alter a patient early on, to try and fix something that's a parent or medical decided stereotype at that stage so there's delays in decisions, delays in definitive care in an attempt to involve that but that has its own potential pitfalls as well.”

HP12
There was strong heteronormative/cis-gendered theme that was reflected in a variety of comments made by HPs. There was a sense of discomfort for some in raising issues around sexuality or responding to questions from parents about sexuality issues. This may be due to heteronormative point of view, bias or homophobia. The discomfort may also be due to lack of communication skill and finding it challenging to discuss such issues (Communication will be discussed in the next section.) The following quotes are examples.

“It’s more a fashion statement than a true orientation... (that high school girls) are attracted to the same sex, they’re more heterosexual (laughs)”

HP19

“I mean what are the schools going to do in the future? They going to have a male a female and another toilet for those who don’t quite know?”

HP2

The default setting for what a baby’s gender should be is still strongly embedded in the gender binary version of what it is to be human. What appears to be more important is that a baby is a typical girl or typical boy, as described by societal norms and in turn the HP’s norms. We are all affected by the environments we come from and live in and this goes not only for the parents of the child or young person presented to the HP but the HP themselves. Norms are therefore powerful elements of influence on decision making.

5.5.4 Communication

It was stated by many HPs that it was difficult to communicate with parents about these sensitive areas as it was uncomfortable and it was difficult to find the right words. Often it seemed easier to retreat to facts about a particular variation than to deal with feelings.

Some stated it was not their area and it was best left to the experts i.e. psychologists, social workers etc. However, in many cases psychologists and social workers were not available or had no knowledge or experience of VSC/DSD themselves.
“My job’s a hormone doctor and I’m not a head doctor”

HP2

“Availability of any psychological support as in professional psychologists, you know and getting that or trained social workers who would be willing to come in, involved in that situation is, from my perception on zero…”

HP15

Some HPs wanted more resources on how to deliver information to parents and how to discuss the more complex and sensitive issues of what it meant to have a female child who had an enlarged clitoris or a boy with a micro penis. This was especially the case around issues of sexuality which often arose after discussing fertility prospects for the child or androgen exposure in utero. One HP even said they do not discuss issues of sexuality unless the parent brings them up to them.

Some HPs were more than aware that communication was key. They had thought seriously about trying to make sure they were mindful of the families right from the first point of contact and articulated their respect (and I would argue empathy).

“the thing that makes or breaks your future relationship with the family and the patient is your communication right at the beginning and your respect for them and for what they’re having to deal with and so I think that that’s really paramount and most ethical guidelines don’t talk about that at all”

HP5

The next HP expresses awareness that some conversations are uncomfortable and it can be difficult to even raise some of the issues, especially around future outcomes such as fertility, cancer risk, sexuality and so on.

“So, it’s not always easy as the health professional to have the conversations and you understand very well when you’re on the other end of the table, you don’t always want people to raise things so you’re trying to do a good job and you’re trying to think of the entirety of the issues”

HP20
Unsurprisingly, many HPs said it is difficult to communicate within such sensitive areas where they did not know how parents would receive the information. I wonder if the difficulty is not just limited to the patient or their parent’s/caregiver’s reception of information that is perceived to be difficult but also the HPs own discomfort in delivering that information. It can be equally challenging for some HPs to manage the discomfort of such conversations if they do not have the skills or training in talking about what are typically viewed as very personal topics such as gender, sex characteristics and sexuality.

It requires a confidence and level of understanding of what it might be like to be different in the world; to be different from that which we might perceive as “the norm”. Many of the interviews revealed a sense of wanting to help a child affected by a VSC/DSD to become more like the “the norm”. This was perceived as the desired outcome by all concerned. That is, it would make life easier for all if you were more like everyone else.

In fact, there are a great variety of body shapes and sizes and this includes genitals. Realistically no one person is the same as another. HPs can develop a bias to what they perceive to be the ideal standard for how a body should look. This leads directly into the next theme which examines bias.

5.5.5 Bias

When examining the data, it became clear the HPs own bias featured as one of the elements of influence regarding decision making. There were varying degrees of awareness around bias influencing decision making. This is sometimes referred to as unintended bias or implicit bias. Explicit bias is when someone is aware of their bias, whether they decide to mitigate such bias is a personal choice. Of course, bias suggests that there is somehow a way of having no bias, which I would suggest is impossible. We all bring our own life experience, beliefs and values to our work and whether we try to or not they will inevitably have an impact on our thinking and the way we present our communications with others. Bias was evident throughout the interviews, evidenced by heteronormative and biomedical points of view. Some examples of such bias are represented in the following quotes:-
“I try and say do you have a partner (and I just forget) ... look I’m just a product of my generation, you know it’s just, yeah and I shouldn’t be”

HP21

'No, I don’t think it’s correct to give parents a list of options because that’s ‘Sophie’s choice’, I mean they don’t know what to do, I think you need to give them an educated clinical opinion...”

HP15

Some HPs were aware of bias and stereotyping and felt that there needed to be consultation within a multi-disciplinary team (MDT) or at least with other HPs within their own profession.

“...always being careful that our own personal opinions aren’t overriding everything. And again, that’s why I think all of these patients are best managed within a group setting, so that... you know, someone’s personal preference or bias isn’t colouring the advice you’re giving to the families.”

HP17

This HP was aware and working with people with VSC/DSD had "opened his eyes to “differences” and that he was now more accommodating of difference.

“I think it’s opened my mind to the various...to the differences in how people think...you know, because they don’t think exactly like me... it’s opened my eyes. I’ve become more aware of...the differences.”

HP4

HPs may unintentionally express opinions coloured by personal belief. These opinions come across as biased to the parent or young person before them. It would be difficult for a parent or young person to differentiate between an HP’s personal opinion and something that is based in the rigor of evidence-based practice. This is especially true in the field of VSC/DSD where there is limited evidence-based outcome research.

Interestingly a few HPs commented on the bias that they observed when Intersex advocates expressed their point of view, but did not seem to acknowledge their own. While a few HPs indicated some awareness of their own bias, it was limited.
I have already established there is little focus on such matters within medical training and unless there are allied health professionals like a psychologist, social worker or nurse specialist involved it is unlikely that such processes would be raised.

In the area of VSC/DSD, where navigating decisions can be extremely complex, it is essential to be aware of how bias may interfere with decision making. There is a need for the development of systems which encourage safe and transparent practice.

There are also issues of inclusivity in the diverse world in which we live in. HPs live in an ever-changing world that is now tending to give greater acknowledgement to diversity and the benefits derived from such diversity. However, diversity still requires the HP to demonstrate an understanding of what that means from a practical point of view.

5.5.6 Support
HPs raised the issue that there was generally a lack of specialist support from a psychological perspective, many stating that there were few or no specialist care providers who had specialist training in understanding VSC/DSD. This lack of a practical resource was seen as a consequence of us being a small nation with a small number of people affected and wide range of DSD/VSC presentations. The low numbers of VSC/DSD presentations mean that there would not be enough of a case load to warrant such specialists unless there was a national centre for DSD/VSC.

“I would like to be able to support them much more... the fundamental answer is that there is certainly a service gap that we have generally in New Zealand, and in quite a lot of the western world”

HP1

“one of the biggest issues is psychological support and is having no availability or limited or almost none, and certainly not of experienced psychologists, who have any experience whatsoever with this, why would they, you know this is rare.”

HP15
Many did have some profession-specific paper resources such as the Australasia Paediatric Endocrine Group booklets on CAH and hormones.

5.5.6.1 Consequence of lack of specialist support

There was concern that there was, at best, very limited support but more commonly no support at all for parents and young people. Often they had to resort to the internet, which was problematic for many HPs. Many HPs felt internet-based support groups, especially those driven by people with lived experience, who had become advocates, was often unhelpful. They also thought that these websites presented a biased point of view, that was often based on personal experience of treatment protocols no longer current. Therefore, it was not the ‘right’ support. There was concern the sites would be misleading and too much for parents and/or newly diagnosed young people who would be in a vulnerable state of mind. The following two quotes are indicative of the response to local and international online support groups.

“I have been quite upfront with families, and said that there are groups around New Zealand if you’re interested, but... you know, that they need to be aware that some people may have very strong opinions on things, and umm, you may, or may not, want to be in touch with them.”

HP17

“often the quality of it was very poor and you had some very vocal prominent quite aggressive special interest groups and lobby groups in the US in particular which were perhaps giving parents mis-information, not deliberately but they were combining all DSDs together as if it was the one disease when it’s actually, the implications of each is actually quite different and they were clumping them together and making blanket statements like you know, none of these should have surgery or this and that which weren’t very helpful”

HP11

Some groups were seen as appropriate, such as the Turner syndrome and NZCAH support groups that operate in Aotearoa/NZ. These groups are patient led and not funded and as a result may be at times less active which is a problem.
Some HPs preferred to offer parent to parent support from their own caseloads. This would involve asking parents they have worked with whether they would be happy to talk to a new family who has just had a child diagnosed with the same variation. The quote below reflects the situation where parents have even offered to provide support to other parents.

“There’s a couple of families who’ve offered... if we get a new family, I’ll say them, you know, these are the people who... who have put their hand up and said we’d be willing to talk.”

HP17

HPs did caution they had to be selective as some families may not always be helpful. HPs tried to put parents who have the same variations together.

“I try to be a bit selective, though, with families I put together... but I always make sure they’ve got each other...”

HP3

Most HPs would take on providing the support themselves by offering extra appointments and opportunities for patients and their families to call them if they wanted to discuss things, even if they were not directly related to a medical concern. HPs talked about ideally having a national center where resources could be pooled and specialist psychological support developed. However, some HPs had concerns about providing support not based in the area where the patient lived as was the case for the following HP.

“I remember a patient, and it was suggested that they went you know up to Auckland and had the whole shebang there and it actually turned to custard...you take somebody out of their environment... you take them up there as if you’re going to fix it all overnight and I think learning from that you realise that that’s not going to be the answer.”

HP2

A few HPs had definitive views about providing any sort of emotional or psychological support themselves as they did not feel qualified to provide such input as expressed by the following quotes.
“I don’t try and delve into that ’cause I don’t have that information at my finger tips and therefore it’s someone else’s role.”

HP12

“I’d certainly do my best but I’m not sure that I’m expert enough to do all of that so I’d probably wanna do it in conjunction with somebody else.”

HP5

5.5.6.2 Personal support

In relation to the support HPs get themselves for managing their work in this area, most commented on peer support and how beneficial that was especially when they were uncertain about a specific case.

“the biggest support actually is peer support”

HP3

Most people, even if they were the sole HP in the area, had access to other HPs nearby or in other centres to call upon and occasionally there would be group phone consultations to discuss more complicated cases with peers. Others commented on the importance of getting up to date information at conferences and special interest groups trainings.

Many commented there is a lack of evidence base, data outcomes and when asked about guidelines many were not sure what the current guidelines were. One HP who is a leader in their field and active in their professional group states that there is no evidence to support “how good” or “how bad “ the clinical management has been.

“in reality... you’ve gotta remember that those guidelines are experiential rather than evidence-based. Some of its evidence-based, a lot of its experiential, though. A lot of it is... this is what the expert say is the approach, this is what really is proven. And I think we’ve gotta be very careful... in the area of DSD, is that there is not nearly enough... umm, long-term outcome data. And that is what we’re working... one of my major goals in A.P.E.G. is to set up a database that we can actually look at outcomes. So, we can follow these kids in 20 years’ time, we can actually look, and start actually getting an understanding of how good we have been, or how bad we’ve been... in our management.”

HP6
These six elements of influence on decision making indicate the complexity of working in this area as a HP. In the absence of good outcome data, many influences not based on the usual rigor of evidence are impacting on decision making such as bias, norms, expectations, lack of both support and communication skills. This segues into the next section which discusses decision making specifically around genital surgery.

5.6 Genital surgery

In this section on genital surgery there were a range of views expressed, some taking a very conservative view of surgery, especially when it came to females and clitoral reduction. In regards to boys and hypospadias there was a clear view that surgery was needed and it would be unusual for it not to occur. Given the variability and controversy in this area in particular, the opinions of surgeons working in the area will be discussed specifically.

5.6.1 The conservative view

There were some surgeons who had a more conservative approach to appearance-based genital surgery. One surgeon who took a more conservative view made this comment about early surgery for clitoral reduction on infant girls with clitoromegaly (i.e. enlarged clitoris).

“It’s not routinely done, no, no, this is where we’re different here, well at least I’m different from say (a specialist surgeon) in Melbourne where he quite strongly proposes that (clitoral reduction), whereas I have a much softer stance I think mmm.”

HP11

One HP had a strong stance that cosmetic surgery should not be done on infants and raised concerns about the effects of anaesthetic on children (3.10.1).

“I think infant surgery to make things cosmetically clear one way or another is wrong, yeah it’s, you know any operation on a small person has to be done with a very robust justification that it is clearly in the child’s best interest, you know anaesthetic is not kind to small people, it’s not good for their brains, it’s not good for them.”

HP10
One HP spoke of about teaching others to manage rather than physically reducing the clitoris if it was their child.

“If I had a, if I had a CAH daughter I would train her caregivers up rather than have her clitoris reduced.”

HP19

Another HP commented that it is important to be clear why such surgery is being done and that these are very challenging conversations and some doctors may not be skilled at doing this.

“I think surgery is a, it’s a permanent step and one has to be very clear why you’re doing it, you know and is it the child that’s at the center of that really if you’re completely honest or is it the parents or you know, the grandma or whoever, the extended family or whānau that’s driving what happens and being able to get to a place where people can be completely honest about what they want and why they want it and that conversation’s often not well done by doctors.”

HP10

Another HP with previous experience working in a European setting spoke about the importance of the young person being able to decide for themselves.

“I’ve worked for a very conservative group whose management I agree with that allows children to make or young adults to make decisions for themselves on the future of their surgery and I agree with that...”

HP22

They stated they would not see the need for interventions of a surgical nature unless it was for a life-threatening or function issue, for example a child being born without an anus or with salt wasting CAH. It was stated by one HP that in regard to girls born with an enlarged clitoris, that this was best left till they were of an age when they could decide for themselves. He suggested that there could be support given to parents in order to help them manage this for their child. He added that genitals
were private and are unlikely to be an issue if the child and parents were provided with resources.

This HP felt in relation to CAH, where most of the controversy lies regarding female clitoral reduction, that most can be left. This HP is not suggesting a ban on surgery but rather that the young person, whose body it is, gets to make that decision. Below they highlight it is for the young person to identify whether there is even a problem.

“I would say to them that the majority of decisions and especially with CAH and clitoral reduction don’t need to be made at an early age...they can be made post puberty or when someone has identified it’s an actual problem for them or not and they can make the decisions and how their genitalia look, they may be happy with it, they may be unhappy with it...”

HP22

The same HP made an observation about increasing awareness of difference and variation of genitals and the impact this is having on the surgical world.

“...um many years ago, people wouldn’t have an idea of what other people’s genitals look like and now with the internet, there’s a greater and wider variance in what’s normal and what’s expected so I think there’s a great change...So expectations of function and outcome and aesthetic appearance are very high but I think that’s driven up standards to a certain degree and outcomes are now looked at in fine detail and are presented at national meetings on technique and coverage and you notice that there is a difference across the world in technique and coverage but with medicine moving forward, international meetings, internet, shared discussion groups and connectivity between groups performing the surgery, you’d hope that would raise the standard of the outcome for all.”

HP22

Lastly, this HP states that there is a need for better data so we can say with clarity with whether women can have good sexual sensation without surgery in the first place and then what is the case if they were to have surgery.

“So the big component of the female American advocate of no clitoral surgery because she was rendered reduced sensation, the question really there was what was the sensation going to be if you haven’t have operated and I think that's the question...
that we’re not gonna know the answer to until you have large numbers and group together findings and outcomes and I think that’s the difference now that it’s becoming a little bit more open to talk about and people are consenting to studies like yours where they can talk about their ideas and expectations and pool data globally to get outcomes.”

HP22

5.6.2 In favour of early surgery
In contrast some HPs expressed that early appearance-based surgery has some benefits. This senior HP felt early surgery for CAH was indicated and recommended it to parents as long as it was done by a surgeon who was an expert in the field.

“I think early surgery does make a difference. Umm, C.A.H. is one of them, you know there’s good evidence that those girls... those children all... umm, have female orientation, in terms of their... of their gender identity. And so of course, the difference between gender identity... ah, and, umm... the sort of gender... play gender, which tends to be male in those kids... and, umm... and sex of attraction, which often is... is someone in between, but a bit more female orientated than male orientated, generally. Umm... but... but those other things set aside, they identify as female. And so, to my mind, normalising the genitalia... so long as you don’t take away... umm, sensation... and the new surgeries don’t do... ah, are very good at doing that... and the outcomes that I’ve seen, and they’re... most of them are informal, unfortunately,”

HP6

In another situation the HP discussed genital surgery for a baby girl with CAH with her parents. The HP was accepting of the parent’s decision not to proceed with a clitoral reduction for their child as the HP felt they were more “accepting parents “because they were a lesbian couple.

“...the mothers’ comment was gender is fluid; and it doesn’t matter what the external genitalia looks like, if the chromosome’s xx, the baby’s got a uterus, and has ovaries that are functioning, then it’s a girl... we’ve talked about surgery with them... umm, and talked about the traditional approach of a vaginoplasty and a clitoroplasty, and they don’t want that...they’re happy to have the vaginoplasty, and that’s part of... you know, to for women’s health, the vagina needs to be
patent.... they're very happy to go ahead with that. But they don't want any... the clitoris touched at all...”

HP3

“I think with medication, and you'll find, the size of the phallus reduces when the C.A.H. is well treated, so it looks small. And they've already seen that in this... in this little girl, ... it's just their beliefs, that they don't think... you know, that's... every woman is slightly different, and...they just... they just both cringed when you... when I talked about a... umm, clitoral reduction, or... a clitoroplasty. They said no....It's actually quite a relief, because given the controversies about surgery... timing of surgery, what kind of surgery to do... and actually, it's a relief they don't want... 100% normal-looking external genitalia in their little baby. They're quite happy to accept the variation... because then it, it buys time... for the child then to... develop as... 'cause the parents are very accepting. And we'll just watch this space.”

HP3

This demonstrates the complexity of this HPs views on one hand they are recommending the option of genital surgery but on the other hand are relieved when the parents are happy to accept a child who does not look “100% normal”. It appears that there is an assumption that heterosexual parents would be less accepting and would want their child to look “100% normal”. By contrast the assumption is that same sex couples are more accepting of having a child that is not “100% normal”. This can be a dangerous assumption as this may not be the case in every instance.

5.6.3 Gender and genital surgery
There appeared to be gendered response to genital surgery. The opinion that young boys should have surgery for hypospadias was held but that there would be no surgical intervention for micro penis or aphallia (absence of a penis). However, opinions were mixed when it came to young girls with enlarged clitoris and or labia as discussed above. This HP is discussing boys with micro penis :-

“the reality is ultimately...they have got what they've got...and you can... I think you can explain it to them very clearly, that..., people are not clearly always well-hung.”

HP6
It seemed it was acceptable for a boy to live in the world without a penis as stated in the quote above, however when asked about reducing a large clitoris it was seemed more difficult to tolerate a girl with an enlarged clitoris/phallus. When I asked one HP who had commented on both as to why there was a difference between the situation of a boy with a micro penis and a girl with an enlarged clitoris, they responded by simply saying the following:-

“...Yeah, a girl who has got a penis... just got a penis, yeah.
[Laughs]”

HP6

This HP indicated, with sarcasm, that “just a penis” was ridiculous to consider. Later he said you can't have a girl with a penis. This was interesting and of course for some having an enlarged clitoris that resembled a penis may be distressing, especially if in addition there was fused labia resembling a scrotum. In the next section there are a couple of interviewees who seemed not to even be aware that there was a marked variation in clitoral size (section 7.13.1). Some women might consider it an advantage having an enlarged clitoris as was the reported from one of the females interviewed in the Intersexion documentary (2012).

There has also been some research indicating some CAH females do decide to live as males, in which case they would probably want to have the opportunity to decide for themselves (Houk & Lee 2010).

One could speculate this is because it is more difficult to create a phallus that is not there than to remove what is considered “excess” phallus such as enlarged clitoris. It may be a case of what’s practical surgically, or is it psychologically challenging to imagine that a female child may have what some would consider masculine like genitals as they would be unbecoming for a female.

5.6.4 Surgical dilemmas -two case examples

In this next section two specific cases are discussed to highlight the complexities of decision making in this area and how the HP responds has far reaching consequences.
5.6.4.1 Case 1

The first case where the surgeon was discussing a situation with a girl with different sized labia and colouring. The HP was concerned about the young girl getting teased and reflected on how this resulted in her electing to have a labial reduction. Notice the uncertainly here in this next selection of quotes as the HP debates in their mind the issues, firstly the reality is they might get teased for their difference.

“they used to have to get changed for swimming and gym and stuff but she had quite, I mean I’m gonna say large but not abnormally large labia and she hadn’t grown into them ‘cause she was just a little wee tiny thing and she had this very pale skin and she had very browny, you know so the girls were calling her lips...isn’t that terrible?, so she was mad keen on having a labia reduction and she did end up having one in the end, I’m pretty sure she did once everything else was sorted out so it is, that’s the problem isn’t it, you know girls can be so mean...”

HP21

Secondly, pondering whether surgery would be good or not :-

“So, I don’t know, so from a physiological point of view, I would say just leave it and wait and see but that’s my just own personal feeling but if I had a child that was getting teased, I dunno...”

HP21

Thirdly, the HP highlights that what one HP considers large may be different from another HP and that there is a lot of variation.

“sometimes I get patients referred and you might read the notes and large clitoris blah blah blah and I look at it and I think well actually it’s pretty normal, to me it looked, because there’s such a range you know...”

HP21

5.6.4.2 Case two

This next case involves an HP who was discussing operating on a teenager (14 or 15 years old) who has CAH, the young women’s mother was present at the
consultations. There were issues of incontinence and “urinary trapping” and because the young person wanted to be able to use a tampon, she wanted her vagina lengthened. She was referred for a vaginoplasty. The HP raises the issue of not basing practice on one patient experience but then says that we need to hear the good news patient stories.

“I think she’s an interesting story and I was gonna say you can’t base your whole practice on one patient right because we try and be scientific about it and think about groups of people but it is about patient stories and a lot of the negative talk about operating on genitals is driven by individuals, you know so you can’t have it both ways, you can’t say well you can’t talk about the good news stories ’cause they’re just one-offs but we can talk about the bad news stories, but anyway…”

HP16

The HP then goes on to discuss their thoughts on what they thought regarding the way her clitoral hood looked and how they thought it “was a bit of a shame” that she did not want the “extra” skin removed, but was going to go with what the patient wanted.

“...so her initial response was she came in to see me and she just wanted the vaginoplasty done ’cause she’d got to the point in her life where she realised that she needed a vagina and that was fine and quite favourable anatomy and she didn’t have an outrageously large clitoris but she had a quite pronounced clitoral hood so there was a lot more skin than there was body of clitoris but she came in... wanting to have a vaginoplasty and so I had that conversation with her and she sort of basically said I don’t really want to have anything done with the clitoris and the referral had sort of spelt out that she didn’t want to do anything about that, I thought well it’s a little bit of a shame because although we wouldn’t necessarily operate on the clitoral body at all, there’s a lot of spare skin there that might moveable, you know ’cause if you just do a vaginoplasty, then there’s kind of vagina sitting in the middle of nowhere but I was happy to do whatever she wanted…”

HP16

Then on the day of the operation this young woman decided she did have a protruding clitoral hood and would give permission for the removal of the extra skin.
“but then on the day when she came for surgery and we went through things again and we said is there any more questions, there was one of sort of pregnant pauses and she looks at her mum and her mum looks at her and there’s that well you say it, no you say it and then she goes well I’ve been thinking about it, I think my clitoris really sticks out a lot and is there something you can do about that so she actually, she completely wanted, you know so she drove the whole thing and asked for what she wanted...”

HP16

This case highlights some of the main themes identified by the research. In the first instance, recognition of patient experience and its impact. Although the HP’s bias that there are only negative stories presented and no positive ones came through you could say this is a positive story as the HP is clearly intending to honour the wishes of the patient. However, you have to wonder what influence his discussion with the client had on her, in that after seeing him she then came back with a decision to change her clitoral hood having previously being adamant that she did not want it altered. Of course, it is entirely possible this young woman did change her mind of her own accord after getting the information from the surgeon but equally it is possible that the way her surgeon communicated with her about options had an influence not only on her but on her mother also. They went home and thought the surgeon thinks there is too much clitoral hood so maybe it is best to have the clitoral hood reduced.

One HP who is not a surgeon highlighted the fact that surgeons generally want to do surgery.

“...by the time you talk to the surgeons they... generally will wanna do some surgery, you know, ...so I’d try and keep them away from the surgeons until myself and the family...know what we’re doing. And then once that’s happened, I’d get the surgeons involved, ‘cause then we’re...to essentially tell them what we would like to do, and then they will do it. ...ideally the surgeons would be involved in a multi-disciplinary team right from the start, but I wouldn’t wanna give them free rein, without having some other people involved in what’s happening.”

HP4
Whereas a surgeon commented it is not always about doing surgery.

“There is an increasing tendency to delay surgery, not necessarily surgical involvement, surgical involvement isn’t just surgery…”

HP12

5.6.4.3 To say or not to say?

One question raised is how a HP comments that an individual’s genitals will potentially have an impact on that individual’s view of themselves. Should an HP acknowledge that there is a genital variation/difference? The HP below is discussing what do you do when the patient and their partner seem content with the variation as was the case in this situation.

“She needs to make the decision as an adolescent. ‘Cos we’ve had a young woman in here with an extended clitoris and none of us have commented on; both her and her naïve partner have no idea that it’s extended... So, we just leave it alone. I mean I don’t, that’s a bit of a dilemma. Do you point it out? You see some HPs would be more likely to say you have an extended clitoris, and I think it was about four centimeters, so it’s quite extended. She just accepted it as part of her body and she didn’t know it was different and her boyfriend who was one of the most naïve lovers I’d ever come across didn’t know so does it matter? [Laughs].”

HP19

This highlights key themes around norms, bias and communication. For this couple it was clearly a non-issue. If, however, the HP communicated that the difference was abnormal and that he would recommend a clitoral reduction, would that have had an effect on the way the patient (and her partner) felt about her genitals? The next situation discussed highlights this issue.

There was clarity and consensus about when to leave gonads so as to support puberty naturally as opposed to removing them in early childhood and the possible risk of malignancy (3.10.1). This is very specific to the condition e.g. for Denys-Drash
syndrome, it is recommended that gonads are removed due to the risk of malignancy.

“I think there are some situations where doing no surgery...ah, you know, other than essential, say surgery for malignancy, or something like that, you know again I...that’s another whole...difficult issue, ’cause actually the malignancy... ...it’s a bit complicated, isn’t it? ...I don’t feel completely trust...trusting of the data we have on malignancy, so some of it sounds very scary...ah...where there is a bit more uncertainty than that probably states ...so I think it’s a very complicated one. But we...we probably have to use the technology and the science...to the best of our ability...and then...live with that to some degree.”

HP4

There was agreement that preservation of life surgery needed to happen such as in the case with cloacal extrophy. There are of course issues around what is considered to be surgery to assist with function or form (appearance only), e.g. with hypospadias some would argue that is about helping the child to urinate, prevent infection, prevent painful erections and possibly improve appearance (3.3.5). Whereas others might say that is more about form and stereotype norms i.e. so the penis looks like others and a male is able to stand to urinate. The same goes for CAH and clitoral reduction, vaginoplasty etc, there are some who are in favour of early surgery and some opposed. All agree there is not enough good outcome data to base protocols on.

This HP’s perspective is that genital surgery is a “minefield”. That the people who are happy with their surgery don’t tend to be vocal. Only those who are unhappy speak out and that is likely to be the same in 20 years, unless outcome data improves.

“I think the whole thing’s a bit of a minefield because we’re...sometimes I feel a little bit damned if I do, damned if I don’t, because I’m gonna...if I do what they’re saying...and essentially we don’t do much at all...and we go for very little intervention, I think there’ll be quite a number of people who will then come back to us, and...are gonna be upset with us. ’Cause there’s a whole group that are not vocal at the moment, who are saying nothing, because they’re actually relatively happy...and there’s a group that aren’t happy, who are vocal. Well, we’re just gonna turn them around, and in 20 years we’ll have the other guys who are now not vocal, they’re gonna
complain and they’re gonna say why didn’t you do something? I went through my teenage years...with this abnormal genitalia...why did you do that to me? You could have just done surgery. You know...and the other people...you know, the other guys will be quiet, ’cause they’ll be happy that nothing happened. So yeah, that’s my fear.”

HP4

To summarise the main two points of view in relation to appearance based genital surgery, I will end with comments by two HPs. The first taking a more conservative viewpoint and the second more in favour of surgery when discussing what they would do if the patient were their own child.

“You know, my goodness me, the answer’s different to...if it’s someone else’s child. A lot of us would do less if it’s our own child. We’d be less invasive...I think that’s simply because, you say in the end of the day you’ve gotta take them in and have surgery, you’ve gotta take them in and you know the risks.”

HP7

This HP was clear if it was his own child who had hypospadias, he would want surgery indicating his personal bias.

“If it was my child ... I’d want their genitalia fixed.”

HP4

5.7 Summary

The findings for the group of 22 HPs indicates there is a great variety of opinion with regards to the care of those born with a VSC/DSD in Aotearoa/NZ. There were areas of commonality especially regarding assessment, risk, the importance of developing a clear plan, shared decision making and for most using variation-specific terminology. Specific conditions were referred to by their name as opposed to DSD, intersex or VSC, which were reserved mainly when discussions between HPs or in teaching sessions.

The six main Influences on decision making included recognition of the past, expectations, bias, communication, norms, and support. These six elements of
influence guided how HPs presented information about a variation and the possible treatment options.

Support for parents and patients was seen as a service gap and it was clear that the HPs themselves ended up filling the gap. Many wanted better resources and specialised psychological support as internet-based resources were seen as potentially more harmful than helpful.

Ideally a national center would be established incorporating specialist services including surgery, endocrinology, gynaecology, geneticists, bioethics, specialist psychological support and those with lived experience.

There were still some elements of paternalism and hangovers from the John Money era. The most obvious were the protection of the child by limiting information to the alignment of the child’s genitals with the gender of choice or reinforcing what is considered the norm for a male or female body. The belief, that if a child is born with an atypically sexed body it will cause psychosocial issues unless they have bodies that look more representative of the “the norm”, is still prevalent for some of the HP sample. This results in the HP reinforcing their own bias rather than highlighting that a difference has occurred and this is not wrong, it is merely a difference in genital appearance. However, the majority of HPs had moved to a more conservative approach to appearance-based surgeries, although there was no clear consistency reported.

There were some voices amongst the HPs who were more inclusive and tended to be more self-reflective of their practice, wanting to encourage a self-agency orientated approach, supportive of bodily autonomy for their patient. This meant all decision-making pertaining to appearance-based intervention was left until a young person was able to make decisions for themselves. These HPs showed awareness of the issues raised by those with lived experience and their expressed right to bodily autonomy.

HPs were motivated to facilitate informed, shared decision making but they acknowledged this is difficult to achieve in practice. In the next chapter the findings for the parents will be discussed in detail before moving to the findings from the young people in the chapter seven.
Chapter Six
Is it a boy or a girl?
Parents’ perspective
“the power of expecting normality”

6.1 Introduction
In this chapter I introduce the findings from the analysis of interviews with 18 parents from 13 families who all have children with VSC/DSD. I first provide some information about the sample and the parents’ patterns of engagement. I then discuss their reported experiences of the initial diagnosis of having a child with VSC. Then the key elements of treatment planning are identified: communication, norms, future worries, ‘what’s right’, and support. Next, I discuss the process of decision making as reported by the parents, on which many of the themes impact. In this section, I present two case examples that focus on genital surgery, as I did for the HPs (see, 5.6.4), given this is an area of contention.

6.2 Parent sample
There were 13 families where one or both parents agreed to be interviewed, and 18 parent participants in total. Eight interviews were with one parent only. They were all female. This was largely due to availability and timing. Nine couples were married, and four were in de facto relationships. Six families were from the South Island, two from small towns and four from main centres. The other seven families were based in the North Island, four in main centres and the remaining three in smaller towns. There were 11 heterosexual couples and two lesbian couples. All but one family was recruited via health professionals. The final couple was identified as result of my discussing the research with a friend who said they knew a couple with a baby with CAH. I approached that couple and they agreed to participate in the study. In addition to these interviews, I have included two presentations from a parent representative at both Intersex roundtables in 2016 and 2017 in Wellington (see 4.9/4.12).
The children had different variations/conditions, as shown in table 6.1.

6.2.1 Parents’ patterns of engagement
Many of the parents commented that they were glad to take part in the study, and that they had benefited from telling their story. Reporting on their experiences created an opportunity for them to reflect, and for some parents this seemed to be very empowering and affirming. I got the impression that, for these families, being asked about having a child with a VSC and how it impacted on them was something new. Most of their reports showed that they felt a sense of validation. They were pleased that their thoughts mattered and it was a relief to share their stories. For others reflecting on their experiences raised issues of frustration and concerns about the health system and the care they received. They were very pleased that the research was happening and were hopeful it would create more awareness and effect some change.

Figure 6:1 Parent sample
I was struck by the level of openness, expressed emotion and the deeply thoughtful responses shared with me, and was moved by the stories shared and the generosity of their narratives. I felt a sense of privilege being invited into their lives and hearing what it was like for them having a child and/or children with VSC. Many of the parents have kept in contact and all were happy to be contacted in the future should there be a follow up study.
Table 6.1 Parents interviewed and details of their children’s variation.

<table>
<thead>
<tr>
<th>Parents Interviewed</th>
<th>Children with VSC/DSD diagnosis and age at time of parent interview</th>
</tr>
</thead>
<tbody>
<tr>
<td>A Parent 1-father, Parent 2-mother</td>
<td>Two teenage boys with PAIS Diagnosed at birth</td>
</tr>
<tr>
<td>B Parent 3-mother, Parent 4-father</td>
<td>Two girls with CAH ages 2 and 5 Diagnosed at birth</td>
</tr>
<tr>
<td>C Parent 5-mother</td>
<td>One son aged 5 with severe hypospadias Diagnosed at birth</td>
</tr>
<tr>
<td>D Parent 6-mother</td>
<td>One son aged 4 with severe hypospadias Diagnosed at birth</td>
</tr>
<tr>
<td>E Parent 7-mother, Parent 8-father</td>
<td>Two children, one boy aged 6 with PAIS. Diagnosed at birth One teenage girl with CAIS. Diagnosed as a teenager</td>
</tr>
<tr>
<td>F Parent 9-mother, Parent 10-father</td>
<td>Daughter with CAH aged 12 Diagnosed at birth</td>
</tr>
<tr>
<td>G Parent 11-mother</td>
<td>Daughter with Cloacal anomaly Diagnosed at birth</td>
</tr>
<tr>
<td>H Parent 12-mother</td>
<td>Daughter with Turner Syndrome aged 17 Diagnosed at 16</td>
</tr>
<tr>
<td>I Parent 13-mother</td>
<td>Daughter with Denys Drash aged 9 Diagnosed at birth</td>
</tr>
<tr>
<td>J Parent 14-mother, Parent 15-mother</td>
<td>Daughter with CAH aged 2 years Diagnosed at birth</td>
</tr>
<tr>
<td>K Parent 16-mother</td>
<td>Daughter with CAH aged 8 Diagnosed at birth</td>
</tr>
<tr>
<td>L Parent 17-mother</td>
<td>Son with severe hypospadias aged 2 Diagnosed at birth</td>
</tr>
<tr>
<td>M Parent 18-mother</td>
<td>Son aged 3 with micro penis and additional unknown DSD/VSC Diagnosed at birth</td>
</tr>
<tr>
<td>N Parent feedback from the intersex roundtable</td>
<td>Adult daughter and son with CAH Diagnosed at birth</td>
</tr>
</tbody>
</table>

6.3 Initial disclosure

Most parents reported that receiving the diagnosis that their child had a VSC was a shock, though they were eventually able to accept, adapt and find a way forward. This sometimes involved surgical intervention. This intervention was most often functional, though some parents did opt for the more controversial appearance-
based surgical procedures. They were driven by social needs such as wanting their child to look and feel normal.

Parents found out about their child’s diagnosis in a variety of ways. For this mother, who had a son with PAIS, the disclosure that their newborn was different was quite shocking.

“Cause we were quite traumatised when we first, you know we’re back in the hospital with him and we were traumatised about, first we didn’t know whether we had a boy or a girl for a start off and we were, you know that was hugely shocking for us, it was me, I sort of went, I became depressed I believe in hindsight...”

AP 1-mother

By contrast, these parents, who had a newborn with CAH, stated they accepted their child’s difference in the first instance (though it is interesting that the father does use the term “slightly deformed “and his partner corrects him).

FP 9-mother “my perception or my thoughts about {our daughter} was that she wasn’t very different, ok yes a little bit but not, we’ve never thought of...we’d never thought of her as an intersex child...because she’s always been a girl...”

“She was just ...”

FP10-father “...with slightly deformed genitalia...”

FP 9-mother “She just had an enlarged clitoris...which is actually not a bad thing if you think about it, to have an enlarged clitoris, how great (laughs)...

FP 10-father “I understand that there’s quite a few different ones around (chuckles) apparently.”

Interestingly, after discussing with HPs, this couple went ahead with a minor clitoral reduction (See 6.5.1).

In this next interview, the mother reports feeling “gobsmacked”, when they found out their first baby had a rare VSC/DSD, though by contrast, her husband was a calming influence.
“So I remember sitting outside of the hospital with my husband thinking oh my God, ...I was just completely gobsmacked about the whole thing basically and my husband was way more, I was quite a wreck about it to be honest, I thought oh my God, you know identity, male, female, don’t even know that so I was just sort of, went into shock about it really and my husband was really good, he said: “oh well it’ll be character building”, was what he came up with and I was like: “uh well yeah we can”, so yeah, so that’s basically that that’s the first boy of the two, but anyway so they said he was male and you know there was no female parts to him at that stage so...”

AP 2 -mother

Some other parents were also very calm and accepting, as in the next two examples. The first is a mother whose young son had severe hypospadias, and the second is a mother whose daughter has CAH.

“guess for us, it’s not a major thing so it’s never been like a real issue for us as a family, it’s just kind of been something like oh he’s just a bit different. I guess for us it’s almost cosmetic, it’s almost like if you had a scar on your arm that you wanted fixed or yeah, so with him growing up and that, it’s, yeah just kind of just part of life.”

LP 17-mother

“I guess each child that’s born something different happens or changes and that’s what happens in life so...”

KP 16-mother

6.3.1 Relief that their child had survived

While there was a range of responses to having a child with a VSC/DSD, a number of the parents reported they had felt overwhelming relief that their child had survived or didn’t have a more serious health issue, and the variation was secondary to that fact.

“I kept telling myself that I had a, my baby was alive, that’s the main thing and we can face anything”

MP 18 -mother
“I think it just opened my eyes up to the fact that so many people have different things come up for them and yeah and that these things happen to people and aren’t we lucky that this is the thing that’s happened for us at this stage and it isn’t anything terrible, I mean it felt terrible but it didn’t feel as terrible as what I saw other people coping with you know, in hospital...”

DP 4-father

However, parents came to terms with the diagnosis for their child, the next challenge for many was having to face other people and inform them that their child had a VSC.

6.3.2 What will others think?

Some parents expressed the concern they had felt over what friends and family might think about the news that they had a child who was different, and/or that they may not be able to say whether the child was a girl or a boy. One father was very open about initially being worried what others would think, as he had a child with PAIS (see glossary).

“...my first reaction for myself personally was what’s everybody else gonna think? I soon got that out of my head pretty quickly because we’re the type of people, we don’t care what anybody else thinks ...”

EP 8-father

In this next instance the mother has two daughters with CAH and discusses seeing other “brave mums” but again, worries about what others will think of the choices she has made for her children.

“I’m sure people are much more open and I know that now, I mean I see other brave mums doing things, you know when it comes to gender issues, gender issues just feel like one of the last big issues that people don’t understand and that there’s prejudice around but yeah it takes sort of brave people to step out of that and I sort of don’t feel, I feel like we’re not totally, we’re not fully in that camp because CAH is not quite the same but I think it’s, I don’t, I think it’s, I think I’m scared of other people’s prejudice that I see, that’s the thing that worries me...”

BP 3-mother
Other parents talked about the strategies they had used to manage the possible reactions of other people. For example, one set of parents consciously used neutral language when announcing the birth while they were waiting for some clarity about their child’s gender.

“we also did some really tactful kind of texts that just said baby is healthy and beautiful and mother is well and...just avoided the issue completely (laughs)...”

JP 14- mother

Overall, once parents had worked through in their own minds their perceived reactions of others, they could generally find a way to let people know that their baby was born and to communicate that their child had a VSC/DSD, even if they were uncertain of the sex. The next section discusses how parents then navigated to whom, when and how they would disclose their child’s variation.

6.3.3 Disclosure to others

One tension that had to be managed was whether the disclosure of their child’s variation was to be seen as a secret or private and when it should be communicated to others. Most parents were open with close family and some friends. This father explains why they chose to be open with friends and family and the challenges associated with such openness.

“...yeah we decided we’re not gonna lie, we’re not gonna hide anything so, I’d have nights at the clubrooms, ..the boys would sort of come and sit down beside you ...“um you know so what’s going on, haven’t had a chance to ask you, I don’t wanna make you feel uncomfortable but what’s the deal” and we’d just straight out and tell them....and that was the best things that we could’ve ever done.”

EP 8-father

The use of stigmatising language by others who don’t know about VSC/DSD can be upsetting for parents as discussed by the same father in the example above.

“We don’t know if we’ve got a boy or a girl... and they, how is that, and then of course the thing that pisses me off though is people straight away go to... “Have you, oh... ...ok you’ve got a hermaphrodite”

EP 8-father
This father continues to add insightfully how it is the adults that are struggling with difference, not the child.

“(our son) don’t give a shit and he’s happy to flop it out everywhere... and it’s us that have got the problem with it, not him ...”

EP 8-father

6.3.4 Disclosure to the child

Parents also had to navigate the task of talking to their child about their variation once they reached a certain age. This was very challenging for some parents, and they varied in how they managed disclosure, some finding it easier than others. Many felt there was little support to help them talk to their children in an age appropriate way. In the next example, couple E (EP 8, EP 9) discuss their process for disclosure to their son:

“We’ve gotta treat {our son} the same way as we treated {our older daughter} and we’ve gotta be upfront, honest and hide nothing because...there’s no point in lying ...it’ll only backfire.”

EP 8 father

“It’s only gonna make things harder for him and he’ll end up despising us because we tried to hide it from him, to me it’s along the same lines as adoption, you know you’ve gotta be honest about it otherwise if they find out the way they’re not supposed to, you’re gonna be the one that’s in the wrong and...”

EP 9-mother

Another parent with an infant son with severe hypospadias articulates her perspective that if she were to keep her son’s variation a secret that would create shame. This aligns with the comments of older affected adults discussed in chapter two (2.4.4).

“...I mean it’s their body and it’s not something they need to be ashamed of and so if you treat it like it is a secret, then they’ll think it is something they’re supposed to be ashamed of, yeah.”

Parent 17- mother
One mother’s strategy was to attempt to put it in the “you’re just built differently category”, and to frame her daughter’s difference as a positive, indicating she was a child who was strong enough to cope.

“To be honest, I don’t think I ever sat down, not when she was little and had a conversation with her until, probably wasn’t even until she went to school and someone may have made a comment to her...I just said that she was different, she wasn’t, you know there was nothing wrong with her, she was just built differently, ...I never made it a negative.”

GP 11-mother

6.3.5 Guilt

Some parents felt a sense of guilt and responsibility for creating the variation in their child, and consequently causing their child to suffer more hardship in their life. This was especially true in the case of parents who had genetic testing. Most parents who experienced guilt were able to resolve these feelings. However, one mother who had two children with AIS (see glossary) was fearful that if she had more children, they would also have AIS. If they did, they would have to endure the related challenges so she decided to have a tubal ligation, rendering her infertile.

“I think because they did the genetic testing and because it was a mutated gene in me, then I played the blame game and I was like well this is my fault, it was no-one else’s fault, it’s mine, they’ve come from me, it’s my genes that have done this and oh, that still gets to me sometimes but not often, I’m better with it now but I think my biggest fear was they were gonna always come to me one day and go I hate you for doing this to me mum, this is your fault and that will always be my biggest fear ’cause I wouldn’t choose to do it which I why I had my tubes tied ’cause I was like, I said to (my husband) well that’s it, I’m done, shop shut, I said I will not knowingly do this to another kid, they’re happy, they’re healthy, they’re wonderful kids but they have a power load of shit to go through for the rest of their lives and I’m not doing it to another one...”

EP 7- mother

This mother clearly felt a strong sense of responsibility and expressed self-blame and guilt for what her children had to go through. Despite this she and her partner
were very positive and supportive of their children. Her husband was quite sad at the outcome, as he said he would have liked to have more children.

6.4 Main elements influencing decision making

Next, I will discuss the main elements influencing decision making, as summarised in Table 2 below. The parent interview data revealed six elements of influence on decision making: norms, communication, bias, support, future worries and ‘what’s right?’, each of which will be discussed in turn. These elements form the platform by which parents contemplate what would be the best decision to meet the health care needs of their child.

Table 6.2 Parents’ elements of influence on decision making

<table>
<thead>
<tr>
<th>Communication</th>
<th>Norms</th>
<th>Support</th>
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</thead>
<tbody>
<tr>
<td>Bias</td>
<td>Future worries</td>
<td>What’s right?</td>
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</tbody>
</table>

6.5 Communication

Communication is a fundamental part of any interaction and especially important when parents are having to make decisions about their children’s health care. Many parents reported wanting clearer communication and more informed interactions with HPs. Some parents strongly expressed a need for greater sensitivity and awareness in the way HPs communicate, whilst others commented that they had some excellent communication from HPs, as was the case in the next quote.

“I know he found it quite anxiety producing going to the medical professionals but we’ve been so spoilt with our (endocrinologist) that we don’t want to leave them.!”

AP 1-father
This parent recalls their experience of having a paediatric endocrinologist who was an excellent communicator. The family were reluctant to be referred to adult services for fear they would not get the same level of communication as they had experienced poor communication from HPs based in adult services.

6.5.1 Evidence for change

The interview data indicates several reasons why there is a need for change in the way HPs communicate with their patients. A number of parents reported experiencing stress and at times anger as a result of poor communication skills of HPs. The next quotation demonstrates how HPs can sometimes be insensitive to parents, both when communicating with parents and with others around them. It highlights the way information is delivered and the fact that the language used has an emotional impact for parents.

“…he was doing an ultrasound on {our daughter’s name}, is what we had named our baby girl and he was talking to the other girl there and he said I don’t see testes or the testes haven’t come down and I said what are you talking about, testes and he said testicles, I said why are you talking about testicles, we’ve got a girl and the reaction from the (HP) was well that’s not my problem that you haven’t been told what’s going on, you need to go and talk to someone else, I’m doing my job and I had to walk out before I started losing the plot…”

EP 8-father

Some parents were so concerned HPs would not be able to communicate in a professional and sensitive manner that they proactively sought to prepare HPs to ensure they would not frighten their children. The next quote is an example from a mother who has two boys with PAIS (see glossary).

“Well I got to the stage where I was going into specialists and leaving the boys outside and saying look before you start, before we start here, you know you don’t know about this condition and I probably know more about it than you do and I really appreciate that you don’t scare monger my children.”

AP 2-mother
In the next situation the surgeon is talking to the parents about their child’s genital surgery to reduce the size of the clitoris and potential risk to sexual satisfaction later in life.

“…the sensation he reckons, there shouldn’t be no problem, even women with clitoris’ don’t have orgasms, some women, so I don’t know but yeah...so that’s, that’s where it was left…”

*FP 9*-mother

The surgeon, in this instance, is trying to reassure the parents things will go well even if there is loss of sensation, but they are not to worry as there are women who have not had surgery who don’t have orgasms. The mother in this situation did not feel the statement from the surgeon offered any reassurance.

In the next situation the HP did not offer the parents any explanation for the medication they wanted to give their child who had CAH (see glossary). The mother (KP 16) said it was only when she “lost the plot” that they responded to their need for information, and an endocrinologist came and explained things to her.

“I refused her to have medication until they could say well what the medication was for and what they were doing and they just said look it’s just best that we do this”

*KP 16*-mother

“…at this stage, I was getting a bit pissed off, ...I just lost the plot and said I’m fuckin’ taking my baby home, you can’t keep us here and that and that’s when the lady said well you can go but your baby will be staying in here, you cannot take your baby out of the hospital so I freaked out by that but then...within about five minutes I guess...my mobile rang and it was {the endocrinologist} and she said look we will have a scan for {your baby} this afternoon and I was like oh you know, when you say a few naughty words, you get what you want you know…”

*KP 16*-mother

The situation above where the mother (KP16) was left without information could have been avoided had there been a timelier response. At this stage it had been 6 days since the baby had been born and the HPs were saying they would have to wait another 4 days to get information.
It got worse for this family as they raised a concern that their daughter had no vaginal opening. The endocrinologist said that was not the case and had wanted a catheter inserted. This could not be done as their daughter had no vaginal opening and it was very distressing for the baby and the parents as the procedure was attempted. The family asked for another endocrinologist.

The HP in this instance did not listen to the parents. This shows that when good communication is lacking there can be harmful consequences, as was the case for this baby who had to endure an attempt at a procedure that was not possible. This family did not receive clear information, right from the birth of their daughter, and the family felt they had no choice but to ask for a different endocrinologist.

Many parents raised issues about communication that resonated with the issues raised by the parent representative who presented at the Intersex Roundtable and reinforced the importance of good communication (2.8.3). The parent presenting at the roundtable commented that HPs have to “focus on relationship building, active listening and recognising parents are “the primary healthcare providers to their children” as they are with them 24/7” (HRC intersex roundtable report 2017).

Below is a mother’s account of her communication with a surgeon about options for her daughter, who was born with a cloacal anomaly, (see glossary), after the child had “trap door “surgery (see glossary) to promote a natural defecation process instead of using a colostomy bag. The daughter had told her mother she wanted to resume the use of the colostomy even if it meant it would be permanent. The mother tells her version of events leading to the decision-making for her daughter, and the extreme steps she felt were necessary to ensure her HP listened to her point of view.

“Yeah, ...like you know she’d have to sit there for an hour sometimes for it to flush out properly and yeah, nah, she wasn’t having that, wasn’t pleasant for her and it didn’t, like it’s meant to keep them continent in between times and for her it didn’t, she’d still have accidents and stuff so yeah, it just wasn’t what she wanted and so she, yeah said to, well she said to me that she wanted this and so I told (the surgeon) and he was like “no, no, no” and so, yeah it got to a point where we were down in hospital for something else... (my daughter) had brought it up saying that she wanted to go back to a colostomy and it came to a head and I had a screaming match at (the surgeon) and got social workers called in and stuff, which is the only time we haven’t been on the same page, everything else we’ve always
been on the same page but seeing her so upset, like you know she was a mess crying her eyes out, it just got to a point where I said to (the surgeon) look, ‘I’m sorry but this is what she wants, you need to start listening to her now, she knows how it is, she’s at an age where she can understand yes, you know if she goes back to a colostomy, that’s how it’s gonna be for the rest of her life, she understands that, she’s had a colostomy before, she knows exactly what to expect’…”

GP11-mother

This mother’s account reflects that the surgeon was not listening to her daughter’s wishes for her own body. The mother felt she had to resort to screaming in order for the surgeon to hear her and accept that her daughter was able to decide for herself. The surgeon eventually concurred and her daughter reverted back to a colostomy bag and was much happier. The issues of agency and bodily autonomy are underscored by the experience of this mother and daughter. The surgeon was clearly wanting to support this young woman so that she could have rectal functioning as close to “normal” as possible. This would enable her to avoid the embarrassment of the colostomy bag. However, the surgeon missed the essential point that while this was an option that seemed the best course of action from a medical perspective, it was not working for this young person.

There will be a more detailed discussion of this case in chapter 8 (8.3.1) from the perspectives of all 4 key players in this situation, including the mother, daughter, endocrinologist and the surgeon involved.

The reality that specialist doctors were often not able to provide sufficient time to communicate clearly and give full information was noted by some parents as especially challenging. Some parents felt they got better communication and information from nurse specialists.

“The nurse specialist, yeah but that might’ve been what her job was, you know ‘cause they’re (the doctors) busy but she was more in-depth and was there for anything we wanted to ask and if she couldn’t answer anything, she’d get that answer for us sort of thing, she was so much better than the doctors in that way but I know they’re busy so…”

GP 16-mother
Lack of communication skill was evident for some HPs, as reported in the stories told by parents. Recurring reports told of a lack of awareness about how their words may be received by parents who were often in a vulnerable state having just had their baby. In this next situation the parent was left wondering after giving birth what was happening as no one said anything for some time. The mother gives an account of what she wished they had said and what was actually said:

“even if they said look you know, we're not 100% certain on baby's gender, we've got you know, one of the ...yeah, we've got an endocrinologist coming to see you in the morning but you know, at the moment know baby's healthy... Instead she was told “we don't know the gender of your baby, do you want us to throw away the placenta.”

Parent 18-mother

One couple reported the HP directing their communication only to the father and not engaging with the mother at all.

AP 1-father-“he didn’t really talk to {my wife} that well, he talked to me but he talked badly, he talked past {my wife} like...

AP 2- mother - “Yeah that didn’t go down very well. I was basically not in the room so he was talking to my husband about a male thing and I was, it was, he was rude to say the least...I think he struggles to talk to females full stop... He couldn’t talk in an emotional perspective if he tried.”

This parent was talking with the endocrinologist about potential gender issues for their child and she was shocked the HP was not aware of gender fluidity.

“I said to her oh well gender’s quite fluid thing and she said, and she remembered that I’d said that and she’d never heard that before and I thought for an endocrinologist who had never heard the idea of gender being fluid is just terrible you know (laughs)”

JP 14-mother
This highlights the ongoing education around current terminology for HPs in relation to gender. The lack of such knowledge can clearly affect the way a parent views their HP and the confidence they have in them.

6.5.2 Facilitating shared communication

Some parents wanted to have a communication with all the specialists involved in their child’s care to facilitate sharing of information and provide a space to ask questions. Multi-disciplinary meetings were not reported, and more commonly parents would have to meet with different specialists separately.

In the next case, the parents wanted to know their options for their baby who had severe hypospadias and micro penis (see glossary). They were told about what was going to happen surgically. The parents requested a meeting with all the relevant HPs so they could make a more informed decision and this was reluctantly agreed to as reported by the parents. The parents had more questions, so then wrote a letter. Most of their questions were not responded to and they felt they were labelled as challenging the HP’s view of what was the best way forward for their child.

“I said how do we make decisions about that stuff and so we asked for a meeting with everyone involved in {my son’s} care and endocrinologist came to that meeting and I also asked for a number of meetings with our endocrinologist during that journey ‘cause I couldn’t understand, like I needed to understand more deeply what was going on and I also was asking the question well what if {my son} isn’t male and what if {he} decides as a young person that he likes his ambiguous genitalia so it was, you know I was asking questions that they were quite uncomfortable with, some of the health professionals because they’d give me answers like he’s not intersex, he’s a boy, in fact his surgeon said to me he’s a boy, I can tell ‘cause he, you know he looks and acts like a boy and this is at, he was like 18 months old...”

DP 6-mother

In the case above, the parents asked if it was possible to talk to other parents as they were unsure about the surgery proposed for their son’s hypospadias. The surgeon had just seen the mother of another child who had hypospadias, so organised for the mother to talk to the parents in this study that same day.
The parents then spoke to a young mother who had just done what the surgeon had suggested for their son. The parents felt the surgeon recommended the young mother to them as she had not questioned the surgeon’s treatment plan and happened to be in the waiting room. The following quotes summarise their experience.

“she didn’t know anything about what had happened for her son other than that it was correcting the problem that he had with his penis and making him more you know, normal so that he could stand up and pee and that’s essentially what we got from her...”

DP 6-mother

“(The surgeon was) really difficult to talk to, like we wrote a letter to him with questions and stuff...they’re not very good at being challenged or questioned, particularly by parents, you know they see themselves as the people that fix the child that’s got something wrong, ...that’s my impression of them and they have a lot of power and people don’t question surgeons ’cause they’re seen as being the, you know the top of their profession.”

DP 6-mother

“all of them were saying, were pretty much, they weren’t being patronising but they were pretty much saying look (DP 6-mother), you know lots of kids get this surgery, it’s not that big a deal, it will be better for (him) in the long run, that’s essentially what they were saying, don’t question it.”

DP 6-mother

6.5.2.1 Asking questions

These parents struggled to get opportunities to ask questions and when they did they felt they did not get answers. They felt that asking questions was somehow seen as challenging the HPs, whereas, from their perspective, they were just trying to gather information and clarify their concerns.

“So one of the questions we’d asked was, ‘cause we’d, his scar tissue so, but when they get scar tissue on their genitals, they can lose sensitivity...and because the surgery’s on the tip of the penis and around it, my question was well how much scar tissue is {he} gonna have and what will that take away from him in terms of sensual feeling and you know sensitivity and {the surgeon} said oh no I don’t think there’s much scar tissue, no it
shouldn’t be an issue and I’d say well how do you know that and he wouldn’t answer the question...”

“...and then I’d say why does it need to be fixed now, can’t {he} decide when he’s a young man whether that's what he wants to do, oh it’s much more straightforward to do it when they’re one because he won’t remember the pain and it heals better and the body grows with the change and there can be ongoing issues of incontinence if you don’t get it fixed now and {he’s} a boy, so they’d be the kind of answers we got...”

DP 6-mother

The surgeon felt this was a routine operation on a boy who needed to have his penis repaired so he could have a penis that was functional and looked normal. The parents reported they just wanted the surgeon to take the time to listen and answer their concerns in a more constructive manner. This was in the hope of creating a helpful dialogue between them to support their decision making. Instead they experienced the exchange as dismissive and were left with more uncertainty and the feeling they were being pressured to proceed with the surgery for their son.

Some HPs may have felt uncomfortable or did not have the communication skills to discuss such complex and personal issues. The surgeon above may have been concerned an open dialogue may result in a delay or no surgery. Given no surgery was not what the surgeon had recommended, they chose to avoid answering the parents’ questions. The result of this was that the parents were left feeling frustrated, uncertain and guilty for not doing what “was best“ for their child.

This is an example of the power HPs hold through the way they choose to share or withhold information. The consequence of this power imbalance is that parents struggle to get the information they need in order to make fully informed decisions.

6.5.3 Good communication

While there were many stories indicating a lack of good communication, as stated above, there was one example where a parent reported excellent communication by an HP, see below. There was some examples of positive communication, warmth and a strong sense of connection and attempts to build a relationship with parents. There were HPs who made every effort to be open, honest and available to parents and their children.
“the boys are really settled with him and um he’s so personable and really interested and supportive of them…”

AP 2-mother

This parent talks about her surgeon being very open and discussing the pros and cons.

“No I think the doctor was very good at being in the middle, like they just told us information, they said our recommendation is to do it, obviously they said but it’s completely your choice and they did lay out a few pros and cons…”

LP-17-mother

One endocrinologist reassured the parents their daughter would be able to live “normally”.

“(our endocrinologist) came in and he was amazing, he was so calming and he sat down and he said she’ll be fine, she’ll be fine and he said she’s got his thing called congenital adrenal hyperplasia, blah blah blah and he explained a little bit about it, as long as she takes some medication, she’ll be fine, I just remember...Just live normally, yeah.”

FP 9-mother

These examples above attest to the importance of good communication and the power that HPs’ words have, especially in relation to a child’s future and the cost and benefits of treatment options.

6.6 Norms: conform or disrupt

Norms are an integral part of our social lives and are important in the field of VSC/DSD. One way to view norms is as simply being “the average”. There will be people who fall outside the norm and that is to be expected. The other alternative is that the norm becomes the ideal as Karkazis (2010) suggests, and this then places a pressure to fit within the norm.

As discussed in the previous chapter, there was an assumption by many HPs of a heteronormative cis-gendered future for the child, where the use of the term “normal person” implies that anything other than heterosexuality is not “normal”.

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For the mother quoted in this next example, this was not the priority as there were other more life-threatening issues going on at the time. As well as the element of norms, this example also raises the issues of timing and communication.

“I remember him telling me, after the surgery saying that he’d made this vaginal pouch for her and saying to me so it’ll mean that she can have sex like a normal person and I was like she’s 9 months old, that’s the last thing I wanna be talking to you about (laughs).”

GP 11 -mother

Here is a contrasting example of a four year old talking at preschool about his penis after having had hypospadias surgery (as reported by his mum). This exemplified the family’s (and preschool’s) approach of being open and matter of fact about his surgery.

“a couple of months ago where they had a doctor come in to preschool and talk to the kids, you know what a doctor does and I think apparently she asked, ’cause the preschool’s wonderful and the doctor asked the question, you know to the kids ’who’s been in hospital to have an operation’ and {my son} put up his hand and said “I did, I’ve fixed my willy”...

CP 5-mother

This positive and open attitude was reinforced by those around the child and was reported by the mother as being a product of the preschool’s openness to diversity.

6.6.1 Conforming to the norm

Some parents felt it was important to have appearance surgery so that the child looked like other children. Their decision to do so was socially driven. They were concerned it would be more difficult for their child if they looked and consequently felt different, and that if their child was not altered to fit the perceived norm they would suffer as a result. This is reflected in the concerns that persisted in the John Money era as discussed in (2.4.4). The next quote is an example of how strongly a parent may feel about having a child that is “normal” especially in the new born period.
“Well we, you know, yeah I mean it was, I think the power of expecting normality can’t be underestimated when you’re having a baby...”

BP 4-father

All but one of the children with CAH (4 out of 5 children) in this sample had surgery to make their genitals look “more normal”. This was so, even for those whose parents were able to appreciate there was a range in size and proffered the idea that a bigger than average clitoris could be acceptable (see conversation from couple F, section 1.3 above). Some were strongly directed towards surgery by the comments or advice of the HP. The family who chose not to do the clitoral reduction were offered the option but were supported in their choice not to.

All the boys with severe hypospadias had surgery so that they could urinate from the end of the penis or to correct a chordee (see glossary). One family did decide they would stop their family member having repeated hypospadias surgeries as they did not see them as effective. These surgeries were presented by HPs as addressing issues of function such as reducing infection and supporting fertility. There were also social reasons for the surgeries like being able to urinate standing. Two teenage boys with PAIS (see glossary) had the gynecomastia surgery (see glossary) to give them a more masculine chest appearance. The decision to have these surgeries was in part driven by social norms to conform to the male stereotypes.

The conversation below is between couple B (BP 3 and BP 4) where they remember an example of their parents struggling with their granddaughter playing with stereotypically “boy” toys or having interests they perceived to be stereotypically male. The parents reported that their grandparents gave the parents advice about directing the children to more feminine activities. Additionally, they gave the grandchildren “correctional” toys they believed were more suited to their grandchild’s gender.

BP 3-mother - “So sometimes poor old {daughter with CAH} gets the sort of correctional toys, like the Barbie and the frilly stuff to try and...”

BP 4-father –“Yeah, I mean we’ve been told that she shouldn’t be playing with...”
These parents had pressure from their own parents to insist their daughter conform to the expectations or norms of being a little girl. This pressure at times made them doubt they were taking the right approach when they allowed their daughter to express her interests in the form of what she liked rather than what she should like.

6.6.2 Disrupting the norm

By contrast, some parents shifted their idea of what was “normal” in relation to how their child might be in the future by rejecting “the norm” and creating a new norm within their family. These parents opted to see their child as normal and their variation as just part of life, and if other people couldn’t cope, they considered that to be their issue.

“I’ve brought her up as well, you know it’s just normal, we just deal with it, it’s not something that we’re gonna feel sorry for ourselves about or you know, why me all the time, it’s just life, that’s how it is, you know and there’s worse off people than we are so yeah.”

GP 11 - mother

“Yeah, I mean I don’t think people would ever say anything ’cause you know, yeah I mean like even now he still looks different and you know, we go swimming and we’ve been swimming this morning and {our son}, I take his nappy off and he runs around, you know and he is different looking to the other boys that are lining up on the table all getting their nappy on and I guess I’ve just become a bit more relaxed and that’s who {our son} is and you know, it’s their issue, if they’ve got an issue, that’s their problem, yeah.”

DP 6 - mother

Other parents said they just accepted that their child was different, and thought that if they were accepting of their child’s differences then their child would be also. These parents understood that their child’s variation was going to have an impact on their life, for example, that they might need to have medication, but it did not
need to impact them psychologically if they were accepted as normal within the family and hopefully in their community.

6.6.3 Redefining “normal”
Some parents changed their world view to be more inclusive of diversity as a result of their child’s variation. In particular, two fathers recalled how they had previously had a “narrow” view of the world regarding sex, gender, gender stereotypes and sexuality. This next quote is one father’s recollection of how being a parent of two daughters with CAH meant he was forced to reevaluate how he looked at gender stereotypes and sexuality.

**BP 4-father** –“My Pentecostal charismatic Christian upbringing, yeah (laughter), yeah yeah, I mean and yeah that’s part of I s’pose you know for me and one of the things for me I s’pose just on a personal level going through all this, it’s changed my framework quite a bit about how I see the world and sexuality and people you know and it’s, yeah…”

**BP 4-father** –“I think it’s just made me realise that there’s a big spectrum out there of things you know…it sort of entrenched us more in our feeling like actually she’s allowed to play with whatever she wants, you know don’t stigmatise her play, she’s fine. There isn’t real normal, we’re all completely unique and different in our own kind of ways” I mean these are things I would never have probably engaged with unless you know, we had to work through this stuff but yeah, I’m getting there with it…it’s been a catalyst for me to engage much more on that issue and be much more open minded about it, I think just from where I’ve come from, my upbringing, I had quite narrow ideas about things and it’s, yeah just widened my understanding of the world I think and yeah, so I think it’s been really positive in that sense for me, yeah.”

Another father, EP8 is a parent of a child with PAIS and stepfather to another with CAIS (see abbreviations) and like parent BP 4 above, he felt the experience of having children who are different has made him more open minded, in particular about homosexuality, as the HPs informed him his daughter has the potential to develop same sex attraction.

“it opened my eyes up to the world of homosexuality, I was a great big huge homophobe…

and I’ll never deny it, as far as I was concerned, they were wrong, wanted nothing to do with them …now they’re people
just like the rest of us, we’ve got a very good friend of ours who is gay, he got engaged, {I} went up and gave him a big hug and he shit himself and oh yeah, no I’m good now (laughter)…”

EP 8-father

“I’m thankful for my children and …I have them to be thankful for having this condition in a way for opening my eyes and making me so much of a better person as such, you know ‘cause {my wife} and I, we’re completely different, you know and that’s, me and the kids are all lucky, where {my wife} was never judgemental so it helped me to make that transition as well…”

EP 8-father

The father below was very proud that he had this realisation and goes onto say he is able to support his children no matter who they choose to love as in the next quote.

“I always say to them is to love and be loved is the greatest gift you can ever get and it doesn’t matter who it’s with, as long as you’re not hurting anyone, who fuckin’ cares.”

EP 8-father

The experiences of these two fathers illustrates the power of discussing diversity and inclusion so that people realise that there are different options for people. The possibility that their children may grow up to be gay or to question their gender identity meant these issues came into their own orbit as parents by making these relevant and personal. They were able to be more “open” and “better” people as a result. I would assert that while no one knows or can predict what their child’s sexuality or gender will be, having to think about these possibilities and discuss them has meant these fathers have made a shift to be more aware and inclusive in their lives in general. More importantly they will be able to join their partners in offering a supportive and non-judgmental environment for their children no matter who they decide to form relationships with.

6.6.3.1 Moving forward

The parents of two girls with CAH (couple B) had a conversation about how they managed the second child’s situation much better as a result of going through the same situation with their other child. They reported that this helped them to grow
accustomed to the situation and also to adjust their understanding. They stated they were adjusting to a “new normal”, thus in a sense rejecting the concepts of “the norm and consequently feeling less anxious.

**BP 3-mother** - “It’s funny how we only talk about {our first child with CAH}, I guess because she’s a bit older and it’s come out a lot more…”

**BP 4-father** - “Yeah that’s true, they will tell you, that’s right…”

**BP 3-mother** - “...but I was saying I just don’t have the same level of emotion with {second child with CAH} …”

**BP 4-father** - “Our normal shifted though you see…”

**BP 3-mother** - “...or concern or worry...yeah that’s true…”

**BP 4-father** - “...we think {our second child with CAH is} normal because she fits in a previous normality there I think.”

**BP 3-mother** - “Yeah it’s our new normal.”

Both the father's (EP 8 and BP 4) commented that their partners were more open minded and inclusive of difference and diversity. This is represented in the mothers (EP7) comments below.

“You've just gotta be there for them and just let them know that it doesn't matter what happens, we're there to support them, 'cause once we start judging them, that's when they've got nothing going for them, if we judge them, why wouldn't anybody else and you just can't.”

**EP 7 - Mother**

### 6.7 Bias

Perceived bias was also evident from the parents' accounts, with HPs leaning towards stereotypical norms regarding how bodies should look. This was apparent in a number of the examples mentioned above (e.g. that it would be better for a child to be able to use a trap door than a colostomy bag as this is more normal). Some parents raised the issue of bias directly as is expressed in the conversation below.

**DP 6-mother** - “I think there's a lot of learning that needs to happen amongst medical professions and I think they've got their own bias about that stuff too and so there's not a lot of
leadership there at all around any of that stuff and you know, they’re, yeah they’ve all got real bias but…”

Rechercher “bias, can I just get you to clarify by what you mean by that,”

DP 6-mother – “Well that children are either male or female... and that they need to be fixed…”

Another parent talked about the struggle people have if a child is not clearly male or female, including medical staff and the lack of preparedness to manage such a situation.

“Well because you know you’re male or you’re female in New Zealand and in most cultures so there’s no other options, you know and if you’re anything other than that, then people kind of, I mean it’s gross generalisation but people struggle with that or don’t, they don’t understand it so... I mean I experienced that a lot with the medical staff, you know that didn’t know quite know what to do with that {lack of clarity around the gender of their child}.

AP 2-mother

One parent in a lesbian relationship expressed that some HPs felt they would be biased due to their sexuality and therefore were potentially at risk of not doing what was in the best interests for their son as a result.

“what do two mums know, how can we make a decision and are we just questioning it because we don’t respect, you know there’s this perception that lesbians don’t respect men and you know maybe we just want our son to be a girl…”

DP 6-mother

This mother went on to specifically comment on the medical bias around hypospadias and mentioned how it was important for a boy to be able to urinate standing and it was like their life depended on it. This parent articulates the difficulty of “navigating” such a situation and discusses how the opportunity to have an advocate like Mani Mitchell would have been a great help, but this was not offered.
“I mean it’s their model that we’re working them, we, you know we entrust our medical care for our children and we seek advice from them, they’re the professionals and so it’s their model that we’re operating under, it’s not ours so we’ve got to navigate through their model which is kind of not working really and is extremely biased when it comes to you know, children with hypospadias I think...I’d loved to have had someone like Mani in the room in the really early stages showing us a different way, yeah and challenging some of what was being said... ...I’d love to have had someone advocating for us, yeah, who had a different view or had a more balanced view and didn’t have a bias ’cause I don’t think that you know, we had so much going on, yeah.”

DP 6-mother

The role of advocates for parents (and arguably for the child) in presenting lived experience can be an key for some families, and would have helpful for this mother.

Another mother recounted the concern she had around both her husband and younger son pressuring her oldest son to have his breasts removed because of their biased view of what a young man’s chest should look like. The situation was exacerbated by the plastic surgeon exclaiming that he had never seen such growth in a young man (and had not read the notes that their son had PAIS). The combination of the perceived bias from the male doctors and males in his family meant that this mother was concerned her oldest son would feel pressured into a surgery he was not sure he wanted.

“I was saying that I felt that (my oldest son) needed some psychological support around that because I actually felt that he needed to be sure that’s what he wanted to do and that it wasn’t our need...and not his and so, you know like my husband’s need was yes, he needs to do that you know because, but I was saying to my husband actually that’s your need, not {our sons} so we need to be really clear that that’s what he wants to do without any pressure so yeah,.”

AP 2-mother

This mother raises the issue that the medical perspective is different from a parent’s perspective and alludes to HPs research goals/career as possibly influencing their recommendations.
“I think the way the doctors talked, it was all very serious and I think they kind of almost liked, this is something with medical professionals is that just getting to grips with their perspective on the situation compared to your perspective as a parent and their perspective is being medical, it’s all about their research and their career and their um, yeah just their job and professionalism and um, whereas for you, it’s just all about your child’s best interests, that’s all we care about so yeah, you know that people like to feel important in their jobs I guess and there’s a range in the hospital but some people are much more focussed I think just on, well I think lose touch a little bit of the person at the centre of their I guess, interesting case, at the centre of the case, yeah…”

Bias is not limited to the HPs (5.5.5). In this next situation the parents are discussing family members’ bias as to how genitals should look. For some parents such comments were upsetting, especially comments that suggest the child will not be able to cope with being different. They believe it is their child’s body and that having a differently sexed body should not impact on her life socially. The conversation mentions the grandparent’s comment on the size of their granddaughter’s clitoris and how they could have reduced the size to ensure she does not feel embarrassed in the future.

**JP 14-mother** - “...even when family members say oh it’s a pity, they couldn’t just snip it off ...it’s just like gutting, it’s like that’s part of her body you know... I think it just comes from, ... how {she is } gonna feel as she becomes more aware of her own genitalia and how it’s different from other kids...”

**PJ 15-mother**- “It’s a changing room thing isn’t it,... I really want her to feel like she’s got a strong and beautiful body...”

**JP 14-mother**- “…but I can see why people would make those decisions {having clitoral reduction}, ... I can see the sense in that as well but I think, I would hope that we would be able to help her navigate the social stuff while still keeping her physicality intact as well you know...”
However, these parents wanted to keep their child physically intact and support her emotionally and mentally to “navigate” the social challenges, should they occur, rather than changing her body.

In this sense they are challenging the perceived need to reconstruct one’s body to cope with psychosocial issues by opting to support their child’s bodily autonomy. They plan to give their daughter strategies (e.g. like using a towel discreetly as mentioned above) to maintain privacy for herself.

The power of the binary and the pressure to be “normal” is a strong factor, and in many of the cases with CAH girls it seemed incredibly difficult for parents not to conform to these pressures especially if they were not supported by health professionals. Similar biases were evident for hypospadias and many other variations in this sample.

6.8 Support

Support was a major theme. All parents reported the need for more support for themselves and their affected child or teenager. While some parents did receive some support from HPs, they said that there were very few written resources about specific variations. They needed material that was user friendly and not too medical. Also, there was a lack of resources and support focusing on the management of the range of emotions that they, their partner, and their family were experiencing after diagnosis. Then as the child grew and passed different milestones such as starting preschool, school, puberty etc more support was needed. Parents also raised specific concerns around how to communicate to others, including their child, about the variation and what it might mean for them in the future. Parents felt it would be useful to have specific guidance about what to say to others and how best to explain to their child what was happening to them.

Others expressed concern about the lack of education in both the health setting and other environments such as schools where there is still a focus on discussing puberty and sex education in a very gender binary and heteronormative fashion. Some parents were concerned that their child may not be able to relate to such presentations of male and female bodies and a focus on fertility that is presented generically as a possibility for all. The next quote by a mother of a daughter who has Turner syndrome (see glossary) was concerned that her daughter would feel
different due to the lack of diversity that is represented in the school environment and more broadly in society.

“Yeah I think these conversations need to happen before the puberty or the hormones set in though because suddenly we’ve got this situation...and these kids are coming through this and things aren’t happening as they have been either taught they would at school or when they’ve read the books, they don’t match the pictures in the books and then there’s a oh my God, I’m, you know I’m not normal or what does that mean and, because the development of that self-identity is so important at that age, I think they, it’s really important if they have some of that information beforehand so that they know that this array of things could you know...”

HP 12-mother

The following sections are broken down into the five key areas of support discussed by the parent sample. These include being able to access a key support person, parent peer support, support for their children, practical support and support and education for HPs.

6.8.1 Key contact person

Many parents commented the system would have been more supportive if there had been a designated person who coordinated everything, helping them navigate all the different specialists and health care systems. This key person would be the main point of contact and would be able to explain the processes in more detail, as HPs often had limited availability to answer questions or concerns (though as mentioned above there were some HPs that offered extra time). Often this role went to the endocrinologist by default as they were often the person coordinating other health specialities.

Parents wanted support people to have specialist knowledge about VSC/DSD as they were often frustrated at the lack of understanding by HPs and had to end up educating them, especially those HPs based in general health care. The conversation below captures the essence of what many parents wanted in relation to support i.e. is someone to coordinate and go over information and link them to resources and specialist support as their child develops.
**JP 14-mother** - “it would be really good to have like a designated person ...and they would kind of just help you..., take all the information and process it...”

**JP 15-mother** - “Explain everything”

**JP 14-mother** - “...how to talk to her about it and have the words... you know when you’re making those decisions and stuff... cause it was all kind of separated as well, and even though I think (the surgeon and the endocrinologist are), gonna work together, they’re completely separate actually”

**JP 15-mother** - “I think it would be really beneficial to have, you know the right kind of support, it would have to be really specialised and the right kind of counselling... yeah I just think having someone who’s somehow overseeing...that was helping you navigate, ... ‘cause it is beyond the scope of an endocrinologist ...but someone like yeah a nurse specialist...”

Parents wanted specialised support and counselling as recommended in some of the guidelines discussed in chapter three (3.9.2) unfortunately, this was often either not available locally, or not offered (or if it was offered, it was from generic services where there was little understanding of VSC/DSDs). Parents also discussed wanting to have access to other parents who had children with the same or similar variations as their own child.

**6.8.2 Parent peer support**

Many parents stated it would be beneficial to have another parent to talk to and in some instances, this was arranged through the HP who suggested another parent they had worked with or in some other situations it was through a support group such as Congenital Adrenal Hyperplasia New Zealand (CAHNZ). There was a mixed response with some parents finding parent peer support helpful and for others not. Some parents felt the support offered was from people who had adult children who had been through a treatment era quite different to their own newly diagnosed child, and would have found it more helpful to have parents with younger children. They would find it easier to relate to them.

“I would’ve liked it that I would’ve been able to have someone come to see me when I was at {main centre children’s hospital} waiting about what the procedures are, what happens, what doesn’t happen, ‘cause everyone’s situation is different, what happened to us might be totally different to someone else, you
know... but it would be nice if there was someone else in that situation with the club I belong to, like I said, most of them are all grown up or you spoke to their parents that are probably in their 50s or 60s now...”

GP 11- mother

“maybe it would be good to talk to other parents of little girls who have got big clitoris’s or something or look a little bit different...”

JP 14-mother

Other parents felt that sometimes other parents shared difficult aspects of having a child with a VSC/DSD, and they experienced this as uncomfortable or unhelpful. For example, one couple talked about a parent peer support indicating that often having a child who has a VSC/DSD leads to parental relationship breakups. Some parents felt having a child with a difference made them support each other more as a parenting team and that they became closer as a result, and that was the only support they needed in reality.

In relation to advocacy support groups, few parents had been referred to or knew of Intersex Trust Aotearoa New Zealand (ITANZ) or international support groups. Some parents had sought groups out themselves online, but realised most were overseas. Two separate parents had contact with ITANZ. One parent had gone to a presentation by Mani Mitchell and found that helpful. The second parent had contacted Mani directly and again felt this was useful. She wished Mani was part of the hospital support system, as it may have helped the HPs understand broader issues in relation to genital surgical procedures. Having heard Mani’s personal story, the parents began to question some of the decisions they had made for their child. Parents reported HPs had given them some basic written material. Parents whose HP mentioned support groups commented that the HPs cautioned them not to look at online support groups. The HPs felt that they were often contained biased points of view and were likely to be more unhelpful than helpful. Few parents were aware of websites seen as positive by HPs such as DSDfamilies.

6.8.3 Peer support for the children

Peer support for their children was reported as a concern as again there was not seen to be any specialist support available for their children. Many others stated the
importance of having some sort of support network for children, especially other children and young people. This is echoed in the quotes below.

“It’s important to have that parent support that you can access, I think it’s equally as important for children to have that access to talk to other children as well and she, you know she’s grown up without having that just because we didn’t know anyone really and now that she’s, now that she’s come out about it and everything, she’s been able to access, not in New Zealand so much but Australia and England …other kids are struggling with the same kind of thing that she’s able to talk to so I think yeah, that would be a huge thing if we had …that kind of network for the kids to be able to access.”

GP 11-mother

“peers or something, you know like other kids that are her age that are in the same situation or something but you know, how you bring all of that together…”

JP 14-mother

The lack of specialised support in Aotearoa/NZ highlights a gap in the health care provision. Apart from one main centre there were no specialist staff trained to provide for the psychological needs for children, young people or parents.

6.8.4 Practical support

Another kind of support raised was practically based information around child benefits, medication costs etc, for example, what to do when a child ‘s sex is undetermined and you need to register your child’s details. This is especially important if you are reliant on government-based child support as was the case below for the parents of a newborn. In this case the sex of the child was undetermined and it was going to take some months to be clear.

“we needed that family tax credit because my husband had had 14 weeks off work with the double hip replacement, we had no savings left... and it was, I think they pay the first six weeks without a birth certificate but then it was we need your birth certificate.”

MP 18-mother
This type of support could be linked to the suggested key person of contact (which is discussed in 6.8.1) who could offer this information and support. The other issue parents wanted to discuss was the practicalities of their child’s examinations and whether they have the right to say no to having students present. For some parents this was very distressing and they were unsure if they could decline. The conversation below highlights this concern which highlights the element of communication as well as practical support to navigate such procedures and the process about who is privileged to be there.

**BP 3-mother** - “I think there’s probably stuff that could’ve been improved around, at the outset, see when our endocrinologist did the first examination of (our daughter), he had a whole group of students with him

**BP 4-father** - “Yeah at diagnosis, no student should be allowed to come to a diagnosis…”

**BP 3-mother** - “Cause they go oh is it alright if this horde of students are part of this and you go…”

**BP 4-father** - “Yeah they asked”...

**BP 3-mother** - “…oh ok (laughs), you know but it’s such a loaded situation…but at the time we had already been told, we were really emotional and it was our first time in hospital so I didn’t even really know… (I could say no)

This mother discussed developing the personal agency to say no to students being involved and explained her reasons as outlined below.

“I asked the students to leave… she’s not a curiosity and that’s a little bit how I felt like she’s actually a person, she’s not something just to check out and the other thing is that with the young students, they don’t, they’re just sort of getting a taste of everything and they haven’t chosen to specialise and I kind of think well, they don’t need to actually see all this stuff until they’ve decided which area they want to be in”

**BP 3-mother**

6.8.5 Support and training for HP
Some parents raised the issue of support and training for HPs, particularly for those HPs who were not specialists in the area, i.e. general staff such as general
practitioners, nurses, neonatal staff, midwives, radiology staff and emergency staff including doctors. Many parents felt that some HPs had never encountered a baby or child with VSC/DSD before and as a consequence were at risk of responding in an unhelpful or misguided way.

These initial conversations and contact with HPs have an enduring impact on parents, hence the need for HPs to be supported to have more awareness of VSC/DSD and some basic information and skill in how to respond in such circumstances. MP18 reinforced this need for HPs getting more and training.

“my midwife had never come across and didn't know how to deal with it, she hadn't had that education and... being awkward, just... I mean he's, at the end of the day (my son ) is a baby...and it doesn't matter what the gender was.”

MP 18-mother

The mother below wanted HPs to be more aware as she had to educate the nurses and other staff about severe hypospadias and for HPs to be aware of their own bias

“(I wanted my child to) be cared for by people that were well informed and trained so that they could be respectful and you know, I didn't, yeah it felt a bit unsafe actually 'cause I wondered if they didn't know then where did they go to talk about it and how were they, yeah it seemed a bit odd that a parent would be telling them what hypospadias was...(HPs need) more training around it so that they're 1) knowing about it; 2) perhaps having a wider perspective”

DP 6-mother

One parent suggested it would be beneficial to ascertain what worked well for parents and to share that with HPs so they can benefit from such knowledge and that can flow on to benefit other parents.

“even the good things, you know well this is my experience and you know, what this person did worked really well...so you know, use that to then yeah, go and do that again sort of thing or, yeah or the other way around that you know, this didn’t work and this was bad so they need to change that or something, yeah”.

Parent 11-mother
Support for all concerned i.e. parents, children and young people and HP was regarded as important by this parent sample group and HPs in the previous chapter (5.5.6) and will be highlighted by young persons in the next chapter (7.8).

6.9 Future worries and working out “what’s right”

Two other elements influencing decision making were “future worry” for their child and whether parents were doing “what’s right”. These two elements are closely linked, hence they are discussed together. Parents talked at length about their worry that they had made the right decisions, especially when they didn’t know what their child would think about the those decisions in the future. Many parents were anxious that their child would be angry at them for the choices they did make on their behalf. Others felt confident with their choices as they followed what was advised by the HPs.

On the other hand, when it came to life-threatening issues such as approving medications or surgical procedures to ensure that their child lived, they had no such concerns as the priority was to keep their child alive.

“with this kind of adrenal stuff and the hormone kind of treatments around that, ‘cause it’s life threatening that that’s a, I s’pose a relatively easy decision to make in the sense of ‘cause, or else my child’s of well my gonna get sick..”.

FP 10-mother

“So her uterus like structure and her ovaries were about streak gonads so she had to have them removed before her transplant...the kidney was the priority ‘cause it’s gonna be life threatening..”

1P 13-mother

6.9.1 What’s right

Parents often worried whether they were doing what was in the best interests of their child, and expressed anxiety as to whether they had made the right choice. The reported experiences below are a representation of the parent sample’s concerns about their decisions. Most were questioning their decisions and were left with a sense of uncertainty, though others reported they had questioned initially, and then found resolution and felt that they had made the right choices.
“you know we still don’t know if we’ve done the right thing by our son, I can’t say to you hand on heart yes we made the right decision ’cause I have days where I think we didn’t and days where I think we did and that’s really hard, you know that’s a really hard place to be...”

DP 6-mother

“questioning if we’d made the right decision, like how would I feel in 15 years’ time if my son comes and says to me “you ruined my chances of being a woman” and that’s why we haven’t had the internal structures removed... ...because they’re healthy at the moment, they’re not causing any issues and if {our son} wants to identify as a woman when he’s older, he’s still go that, I suppose that... that womanly part.”

MP 18-mother

“Yeah, I mean there wasn’t too much questioning, there was a little bit of, well some people, there does seem to be a few people who strongly feel like you need to wait until a child can make their own decision but it didn’t seem to be so much around CAH cases and from you know all the doctors that we’d spoken to, CAH girls are girls who just need corrective surgery on their genitalia ‘cause everything else is girl so yeah, and my husband was really keen to get it done as soon as possible I think...”

BP 2-mother

A mother’s experience in this “what’s right” section demonstrates the complexity of knowing that you have done what is best. Both the parent and the HP may not always be well informed. Most parents accepted that they had done what they considered to be “what’s right” in terms of their child’s best interests based on the information and guidance they were given at the time.

“...I would say that the parents are gonna have some ideas about things but you don’t really know how informed or misinformed they are and the health professionals have got all the medical knowledge, they’re not always right either... so I think it really needs to be a discussion and you know, a conversation and let’s figure this out together, that’s for us anyway um and...”

GP9-mother

The majority of parents were comfortable with their decisions, despite some of their uncertainty about the outcomes. Their next greatest concern was for their child’s future which is discussed next.
6.9.2 Future worries

All parents in the sample worried about the future for their children, as do most parents. In particular they worried about their children’s future relationships and their ability to find partners who would be accepting of their variation. This was especially true for parents of children who had fertility issues or a perceived obvious variation with their external genitalia. These parents had concerns that a prospective partner may reject them if they realised they could not conceive a baby of their own. There was also concern that, if their child had micro penis or an enlarged clitoris, they may not may not feel confident sexually as an adult. This could lead to their child avoiding becoming sexual or becoming subject to rejection from intimate partners. Some were thinking of strategies that their children could employ once they were adults. The quotes below are an example from some of the parents regarding such concerns.

“{My Husband} concerned that {our son} won’t have a fulfilling sexual life as an adult...”

*MP 18-mother*

“now she’s gonna have to go through the fact of finding a partner that’s gonna ok with her not being able to have children and that’s gonna be hard”

*EP 8-father*

“I s’pose my biggest concerns were just being able to find someone to love her for her and not judge her on her condition and just, yeah just being able to just live like we do I guess and just, you know have that happily ever after ending,”

*EP 11-mother*

“Um well it’s almost kind of like, like what does it mean to have this Y ... chromosome but totally look like a girl and how does that, yeah, you know does that affect her in other ways or, I mean ’cause she’s very much a girly girl of pink and sparkly and Barbies and all that kind of stuff so she’s um,...yeah so and just how the whole puberty thing’s really going to work and I guess what that’s gonna look like for her, yeah...”

*IP 13-mother*
Some parents were worried about their children starting school and how they would manage especially if they had a different genitals from their peers or expressed themselves in a non-stereotypical fashion pertaining to their gender. The situations below are reported by some parents who struggled with worrying how their children would cope. They worried about school, where their children would probably first realise that they may look different. They worried too about whether the children would be accepted socially and feel as if they were part of the community.

“she {the principal} just sort of said like I totally get your fears and that and we’re just gonna have to cross that bridge when we come to it, like don’t panic just yet ‘cause swimming’s not at the moment, that’s gonna be later on this year and it’s just, that’s me, that’s all me, that’s my fears and I’m just trying not to put them onto {my son} is the biggest thing and I guess that’s probably gonna be the start of it for us too, I mean he knows that… he’s different.”

EP 7 mother

“…other people’s penis’s look different to his but he’s just not that concerned about it at the moment, but I think as he gets bigger, he probably will be and that’ll be when the questions start coming, well there’s a lot of boys that I don’t look like me, and what’s going on there.”

EP 8 -father

“I was kind of concerned about her future a lot in those first few years, I was concerned about socially how she’d fit in, yeah probably, just even seeing her now being able to find her place in the playground so to speak, it’s a bit harder for her ‘cause she, all her interests are things that stereotypically boys are into so football is her big passion…so she doesn’t connect with the girls so much but then at the same time, sometimes she is a little bit, you know she crosses the boundaries a little bit so she’s not quite in with the guys either, she doesn’t quite know how to be, so I do worry”

BP 3-mother

Parents suggested there was little support provided within the health care system to process or manage these issues and the emotional stress they generated. I end
this section with a quote from a parent who is aware of the challenges that face her child in the future and the way she intends to help him manage such challenges.

“My darling (son) is a special character; he’s got the most amazing sense of humour you have ever come across... and he’s gonna need it... because life is gonna be hard for him and all I can do is teach him and support him to learn as much resilience as now to help him through that because there is going to be issues when they go swimming at school and you know, or changing at school ...”

MP 18-mother

6.10 Decision making

When it came to decision-making, trust was raised and for many parents they had to trust their HP’s expertise, consequently many concurred with HPs’ recommendations because they trusted they were acting in the best interest of their child. In contrast some parents felt there was not really a choice in the matter. This opinion is represented in the quotes below where the parents were asked if they felt they had a part in the decision-making for their children.

AP 1-father -“Oh, not really, they just told us what was going on, I just felt that if they were having surgery for whatever reason, they were doing it for the kid’s benefit and I just had confidence that they knew what they were doing and I wasn’t gonna say no you’re not doing that... ’cause I, you know I trusted them.”

AP 2-mother “ so initially they both had hypospadias and so the decision was kind of taken out of our hands really, I mean they were peeing at the base of their penis and so you know they wanted to channel up the urethra and that was something that had to be done basically as far as we understand and so they were both in nappies at the time and it was horrendous and we weren’t supported through that at all”

AP 2-mother

“I did feel that they told me what needed to happen but I put my trust in them and it wasn’t a negative and it isn’t a negative thing, it was me taking that step back and going actually they’re the medical professionals...”

MP 18-mother
Many parents expressed these sentiments. While they were anxious for their children, they had to trust that the health professionals had their child’s best interests at heart. This attitude has implications for training as HPs have a great deal of power. What they say is going to be received as the right thing to do in many instances. Consequently, it is vital that HPs are presenting all relevant information. It must be information that includes all options. There must be time to process discussions and there must also be someone to be a key person for contact.

6.10.1 Genital surgery - two examples
Decision-making around treatment is complex in some areas for VSC/DSD, especially relating to reduction of the clitoris for children born with congenital adrenal hyperplasia/CAH (see glossary). In this section two case examples will be discussed as they contrast the different approaches taken by HPs and the parents concerned (see table 6:3).
Table 6.3 case examples

<table>
<thead>
<tr>
<th>Parents</th>
<th>Children diagnosed with CAH at birth</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 BP 3-mother BP4-father</td>
<td>Two daughters aged 2 and 5 years</td>
</tr>
<tr>
<td>2 JP 14-mother JP 15-mother</td>
<td>One daughter aged 2 years</td>
</tr>
</tbody>
</table>

The families live in different parts of the country. The first family’s parents said that they wanted to get back to “normal” especially with their first daughter who had CAH as demonstrated in the conversation below.

**BP 4-father** - “I think it was quite significant and I felt, I think quite affected by it at the time and not knowing how to deal with it, I had a lot of, I think I wanted to get back to normal as quickly as possible, I think it was my initial reaction so for me, the surgery was a bit of a no brainer, like I was just like well you know...”

**BP3-mother** - “Do it as quickly as possible.”

**BP 4-father** “...you know and I remember you would ask a lot of questions and you know kind of engage with the issue about well, you know what would our child, like she’s born this like, should we mess with how she’s made and stuff like that and I remember not quite sharing those thoughts but just going with that you know, I mean going within the sense of letting you process it and I think ultimately trusting that you would get to where I wanted to be...”

**BP3-mother** - “I mean there was strong, do you, what do you remember the doctors saying, like what... “

**BP 4-father** “They were just, it was a no brainer for the doctors as well you know... It was standard procedure aye, ...”

In this situation the parents went through the process of trying to weigh up whether they should even “mess with” how their first daughter was born, especially for the mother, and the father alludes to concerns about what the child might think. Ultimately the father was hopeful his wife would come around to his thinking but interestingly did not really discuss it with her (“not quite sharing those thoughts but just going with you”). He wanted to respect her process. It is curious what role the gender had to play in that decision making. The mother was the only female in the room, and initially the only one raising questions about whether surgery on the clitoris was warranted. One could argue that because she has direct experience as a
woman, she may be more cognizant of the impact this could have on a female both emotionally and physically. The father and doctors were male and therefore perhaps more focused on the aesthetics and the social impacts of being different.

The second case example, the parents had a different experience with their daughter who had CAH where they chose not do a clitoral reduction.

**JP 14 - Mother** - “I sent a big email to our surgeon, asking him like zillions of questions and what he came back to me with made us both feel really comfortable about the decisions that we’d made to have the surgery which was great, ‘cause what I thought was really good is that he was really available to answer questions and was happy to really answer our questions quickly...so that was great, so even though the surgical team which was him and his people..... they didn’t present us with options but they’d been really willing to talk about our questions with us and talk about our, you know...”

**JP 15 - Mother** “Yeah, really sensitive”

**JP 14 - Mother** - ‘And they also, were saying you know, giving us, saying it’s the...the surgery would be minimal, ...but they have left it really quite open and what I’ve really enjoyed about actually the whole surgical team is that they’ve always been really positive about talking about her genitalia in really beautiful language, you know, like they come out and they go oh look, look at her cervix, it’s so, look at this beautiful cervix”

**JP 15-Mother**

In this instance the parents were presented with the option of clitoral reduction alongside surgery to reduce issues of incontinence for their daughter. They had questions and they had an open dialogue with the HPs who were accepting that the parents did not want to have the clitoral reduction procedure on their daughter.

There are many influences on how people decide what is best for their children. The decision may be largely based on what health professionals say and the way that they say it. Parents are often completely baffled by their child’s diagnosis or unaware such variations even existed. Added to this is the pressure to conform to social norms around the binary, and the biases of both parents, family and the HP’s which may include cis-gendered, heteronormative, gender stereotyping and religious bias. These factors all contribute to the way parents think about making
decisions. If people have specific beliefs and personal bias towards a certain ideal around gender, these will guide our decision making.

In these examples both sets of parents were concerned with how others may respond to their daughter's difference. The Christian family wanted to ensure their girls did not feel or look different so they would not be subjected to possible teasing or be somehow shamed. Surgery provided the answer as the children would be corrected so as to pass as normal.

In contrast, the other family was also concerned about how their daughter might be treated, but opted to focus how they could support their daughter to develop the skills to manage possible teasing. These parents wanted to give their daughter the message that everyone is different and she was perfect just the way she was. They felt that surgery would likely cause harm and shame, as it was saying there was something wrong with the way her body looked and this had to be fixed.

These two examples capture the complexity and challenges of making decisions and how ‘who your parents are’ can make a difference to what is decided. It also illuminates the importance of separating out form and function, in that both were happy for surgery to help with functional urinary tract issues but only one set of parents were happy for the clitoral reduction which is focused on appearance or form.

Future worries were also a factor in this decision making process and both sets of parents worried whether they were managing things in the best way or doing “what’s right”.

Each of these families chose what they considered to be right for them and their child at that point in time. However, the question remains: did they have all the information they needed to make a truly informed decision? Were they supported to think about options and the ramifications of each of those options? Did they have enough time and space to consider what was driving their decision making? Did the health professionals involved check their own biases? Was the child’s bodily autonomy ever discussed?

There will be further discussion of these cases in chapter 8 (8.4.2 and 8.4.3) where contributions from the HPs perspectives are included.
6.10.2 Prenatal treatments

Scientific advances mean that there are proactive treatments to try and reduce the risk of VSC/DSD developing in the womb. This is the case with CAH. Dexamethasone is given to the mother from the early stages of pregnancy to prevent virilisation if the child is female. It is considered as a controversial treatment as there are concerns about side effects on the child and mother (3.5).

Use of dexamethasone was suggested to two of the parents with children who had CAH so that they may mitigate the possibility of having a female child with an enlarged clitoris.

“I’d need to look into it you know because I’m not sure that taking Dexamethasone for nine months and all the complications of that and hearing about how that can actually affect the baby in other ways and maybe metabolic ways that might be actually more detrimental to them than a bit of virilisation…”

FP 9-mother

“we had a second meeting with another person…who had quite a dim view of the medication…And really talked up the negative side effects for the mother…I was completely put off by that. And I’d also, I also kind of thought well there’s a one in eight chance… {and does} the baby need it, ‘cos it’s only if it’s a girl. And I would be taking it for the first three months of the pregnancy regardless.”

BP 3-mother

This reflects the difficulty of trying to decide whether to prevent something that may or may not happen to your child and contemplating the unknown side effects of such medications on the child and mother. It also raises ethical issues, as discussed previously in chapter three, (3.5) as to whether it is reducing risk or erasing variation that can be managed postnatally with the right support.

Surgery involving the genitals is complex and controversial as has been discussed throughout the thesis. For parents simply trying to make decisions about something so personal for their child is difficult. The information provided and the way this is communicated, along with the support offered to parents, is going to directly impact on their decision making. Although both parents and HPs are trying to do what is
right for the child at the centre of the decision making, their respective views regarding social norms and their personal biases will also constrain the way they make decisions.

6.11 Summary
The parents interviewed for this study came from various locations around the country and had children with a variety of differing VSC/DSDs. Just as HPs in the previous chapter had a variety of differing viewpoints, so did the parents. Parent experiences also varied in relation to whether they viewed their child’s care as positive or negative.

Key themes around communication, bias, norms, support, future worries and ‘what’s right’ all impacted on the decision making process. All parents reported that there was room for improvement, especially around training, awareness, communication and sensitivity of HPs.

Parents worried about their child’s future as most parents do, and some were deeply affected by the uncertainty of what may happen and whether the decisions they made were the right ones. They ultimately had to trust that the guidance received from their HPs was going to serve the best interests of their child. One parent was so profoundly affected by having two children with a VSC/DSD she took measures to ensure there was no chance of producing another child (tubal ligation).

Genital surgery was common for both males and female, and though this was not always based on appearance, there were examples where this was the case. Surgery for clitoral reduction was clearly common for this sample, with just one of the five children not having the surgery. Boys with severe hypospadias in this sample all had surgery to alter the urethra so they could urinate from the tip of the penis.

Parents stated there is a need for clearer information to be given, and that more written resources would be helpful. Access to specialist psychological support for the parents themselves and for their children was viewed as a gap in health care service provision.

The next chapter explores the experiences young people aged between 14 and 24 years of age, and will provide some insight into the questions raised by parents and HPs in this and the previous chapter. In particular, it examines young people’s
thoughts on their parents making decisions for them when they were young, and the consequences of those decisions.
Chapter Seven
Disrupting the Norm
Young people perspectives
“This is the new normal. I am the new normal. The new normal starts now.”

7.1 Introduction
In this chapter I will be exploring the experiences described by the 10 young people who participated in the research. First I will present a review of the participant group and then patterns of engagement. Second, I will present the main research results. For this participant group the key factors influencing decision making were: communication, challenging the norm, support, bodily autonomy, bias and identity. In addition, I will discuss the young people’s experience of the health care they received.

Figure 7:1 Young people sample group
*The gender queer person self-identified as non-binary and preferred the term gender queer. Within the New Zealand health system this person would likely be defined as transitioning from female to male.
7.2 Sample

I interviewed ten young people; they were aged between 14 and 24 years of age from across Aotearoa/NZ. Interviews were conducted between April 2015 and March 2017. Eight participants were referred by health professionals I had interviewed. The HPs would describe the study and if the young person was interested in participating in the research the HP would request permission to provide me with access to the young person’s contact details.

The remaining two were recruited via different social media avenues, one via rainbow youth networks who contacted me directly. The second young person was recruited via discussing my research with Mani Mitchell after seeing it on the Intersex youth Aotearoa Facebook page. They also made contact directly about being willing to participate.

In total, 12 young people were invited to participate in the research. Of these, two young people declined once contact was made. The first stated she was going overseas and decided not to participate. The second participant’s mother decided participating in the interview would not be the right timing for her son as he was struggling emotionally.

In addition, one participant requested to take part in the study after I had interviewed her mother. This approach required an amendment to the ethics approval because of the age of the young person. The original ethics approval granted permission to recruit young people 16 years - 26 years. In New Zealand minors of 16 years and over are presumed to be competent to make decisions regarding to medical care and research themselves (New Zealand Government, 2004). In 2015 the Health and Disability Ethics Committee granted an amendment to permit the 14 year old to participate. The young person's mother provided consent and the young person assented.

Interviews ranged from forty minutes to just over two hours, with most lasting approximately 60 to 90 minutes. All interviews were digitally recorded and transcribed verbatim. All took place either at the person’s home, or in an interview room on the University of Otago campus (in Dunedin or Wellington) or the University of Auckland.
Participants’ pseudonyms and variations are in table 7.1 (refer to the glossary and 3.4 for greater detail regarding variations)

Table 7:1 Participant details

<table>
<thead>
<tr>
<th>Name</th>
<th>Age</th>
<th>Variation</th>
<th>Age of Diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Amber</td>
<td>14</td>
<td>Cloacal anomaly</td>
<td>Birth</td>
</tr>
<tr>
<td>Bridget</td>
<td>17</td>
<td>Complete androgen insensitivity syndrome (CAIS)</td>
<td>Early teens</td>
</tr>
<tr>
<td>Julie</td>
<td>17</td>
<td>Turner syndrome</td>
<td>16</td>
</tr>
<tr>
<td>Tess</td>
<td>18</td>
<td>Mayer Rokitansky Kuster Hauser (MRKH)</td>
<td>Mid-teens</td>
</tr>
<tr>
<td>Anna</td>
<td>19</td>
<td>Gonadal dysgenesis</td>
<td>16</td>
</tr>
<tr>
<td>Katie</td>
<td>20</td>
<td>Mayer Rokitansky Kuster Hauser (MRKH)</td>
<td>Mid-teens</td>
</tr>
<tr>
<td>Sarah</td>
<td>20</td>
<td>Congenital adrenal hypoplasia (CAH)</td>
<td>7</td>
</tr>
<tr>
<td>Alex</td>
<td>20</td>
<td>Congenital adrenal hypoplasia (CAH)</td>
<td>Uncertain</td>
</tr>
<tr>
<td>Georgia</td>
<td>23</td>
<td>Swyer’s syndrome</td>
<td>16</td>
</tr>
<tr>
<td>Penny</td>
<td>23</td>
<td>Mayer Rokitansky Kuster Hauser (MRKH)</td>
<td>Mid-teens</td>
</tr>
</tbody>
</table>

7.3 Young people’s patterns of engagement

The young people were all enthusiastic participants and appeared eager to share their experience. The participants aged 20 and above tended to talk for longer and reflect on their experience over time. These older participants commented on the changes they noticed in the way they thought about their health care at different stages of their lives. Younger participants tended to be more focused on the present, though some had reflected on past experiences, especially those who had had an early childhood diagnosis.

Several young people commented that they found it helpful and rewarding to reflect on and talk about their experiences. Two participants in particular seemed to strengthen their sense of identity and confidence as they progressed through their interview. It appeared to be an affirming experience for them, with one person moving into an advocate role soon after the interview and one stating she will continue volunteering to support other young women who identified as Intersex.

Many participants thanked me for the opportunity to discuss their experience. One participant expressed her desire to have been given the same opportunity to reflect and discuss issues openly during the course of her healthcare.
As with the previous participant groups, I was moved by the candour with which the young people spoke of their experiences. I was especially touched by their generosity and willingness to participate, despite some of the deeply personal and, at times, potentially embarrassing subject matter. I felt privileged to be able to listen to their stories.

7.3.1 Additional data collection

In addition to the interview there were two additional sources of data collection that I was granted permission to use. First, two participants had independently produced data about their experience as a young person with a VSC and I drew on this data in the analysis. One had made and shared on YouTube a school speech about their experience and was subsequently interviewed by media both in print and on television. A second participant read a speech about their experience at the Intersex Round Table (June 2017) (2.8.3) and also was interviewed by media.

Second, I collected observational data by attending a number of conferences where young people with VSC spoke of their experiences. I met informally with some of these young people and had a dialogue with them about my research and their experiences. This additional information has also been incorporated into this research (4.10.2 and 4.12).

7.4 Participants

I will briefly introduce the 10 young people I interviewed. I have given nine participants pseudonyms to protect their privacy. One participant, Georgia, requested that she be identified because she has become an advocate for people with VSC. I will give a brief outline of each person’s situation.

**Amber** is 14 years old and asked to participate after I interviewed her mother. Amber had done a class speech which had gone viral once posted on YouTube. In her video and during the interview Amber spoke about being born with a cloacal anomaly and the life threatening complications she had as a baby and what life has been like subsequently. Her variation means she has no uterus and takes hormones to support puberty and growth.

**Bridget** is 17 years old and was interviewed before I interviewed her parents. She has a complete androgen insensitivity syndrome (CAIS) and is infertile as a result.
She was not diagnosed until her early teens when her brother was born with partial androgen insensitivity syndrome (PAIS) and as a result she was tested. She had lived her childhood not knowing that she had the variation. Bridget lived without feeling different or experiencing any psychological issues up until the point of diagnosis. Once diagnosed she had her gonads removed due to risk of cancer. This was distressing as Bridget was scared of having an operation. Bridget is on hormone replacement therapy.

Julie is 17 years old and was diagnosed at 16 as having Turner syndrome after developing facial hair which she found very distressing. Julie spoke to me after I interviewed her mother and asked her mother to be present for the interview. She takes hormones and will need to take those for the rest of her life.

Tess, 18 years old, was diagnosed as a teenager as having Mayer Rokitansky Küster Hauser Syndrome (MRKH) and she has no uterus. She was very matter a fact about it all, once reassured by her HPs that she would be otherwise healthy.

Anna is 18 years old, and was misdiagnosed by her GP as having AIS at 16. She then saw a specialist and it was revealed she had gonadal dysgenesis, not AIS. Anna had surgery to remove her gonads due to the risk they may be cancerous. Results showed the gonads were cancerous and she had a second surgery to remove her surrounding lymph nodes. Her most significant concern was the surgeries, as she gets very anxious seeing doctors and dislikes hospitals. Anna is infertile and states she prefers not to think about this.

Katie is 20 years old and was diagnosed with MRKH as a teenager when she did not begin to menstruate. She has no uterus and had to create her vagina through dilation. She was not sure how to navigate this process and it took a while for it “all to sink in”. She is a university student and feels she is now more open and upfront about sex and her body as a consequence of her experience with dilation.

Sarah is 20 years old and was diagnosed at seven as having congenital adrenal hypoplasia (CAH). She was aware she had atypical physiology because she has been a swimmer all her life and was therefore regularly exposed to female nudity. Sarah has not had surgery for an enlarged clitoris and never thought of it as “abnormal”. It was only when a HP raised that her clitoris would be considered to be enlarged that
she became aware that it was not considered normal. She is on hormone medication and is concerned about her weight and feels this is as much a barrier to her having relationships as anything else.

Alex is 20 years of age and has CAH and was not sure when they were diagnosed. Alex identifies as nonbinary and does not like to be forced to choose a gender but if they do need to, they prefer genderqueer. Alex is Asian and notes that the intersectionality of being “brown, queer and born female” and non-gender conforming means they are subject to systemic discrimination and bias. They have an enlarged clitoris and are happy with that fact and have no intention of having surgery. They are in the process of taking male hormones in order to transition, but still consider themselves as non-binary.

Georgia is a 23 year old, diagnosed at 16 as having Swyer’s syndrome and had her gonads and fallopian tubes removed within 3 months of being diagnosed. She is on hormone medication and was only recently told she has XY chromosomes. Her family was advised by their GP not to tell Georgia or anyone else that she had a Y chromosome as she would be stigmatised and shunned. They lived in a rural community. Georgia has taken years to process what it means to have a VSC and is currently taken on an advocacy role with the ITANZ and is project manager of the Intersex Youth Aotearoa (IYA).

Penny is 23 year of age and has MRKH. She was diagnosed as a teenager and was told that “we need to check if you are a girl”. This came as a shock to her and took her some time to process. She has no uterus and had to create her own vagina which she experienced as empowering once she worked out what she had to do. She has taken on the role of educating other girls about dilation and educating surgeons that dilation is a real alternative to surgery. She argues that girls should be properly informed about dilation and surgery.

7.5 Main themes
Participants described a variety of positive, negative and neutral experiences in regards to their health care. Six themes emerged during the analytic process (See table 7:2) and I will discuss these in detail and how they impact the health care experience for those young people born with a VSC.
As with the previous participant groups, communication was a factor in how young people made their decisions. A lot of young people commented on the lack of clear information they were given and the lack of time to process the information, let alone make a decision. In particular, young people experienced a lack of support for discussing psychological issues, such as feelings around what their variation meant for them emotionally. Younger people expressed a need for HPs to communicate with them about what it means to have a VSC and their feelings associated with having a VSC. Some examples are expressed below.

“It needs to be so much clearer (information given by doctors) so ...that people feel ...I can still be normal and live in this body the way that it is...”

Penny

“like no one wants to talk about us as people really, they want to talk about us as case studies and not think about our feelings because doctors don’t deal with feelings.”

Alex

In relation to the language used to describe their variations, most participants went with the specific diagnosis and few were aware of broader terms such as DSD and/or intersex. Some participants resisted labels altogether. Georgia discussed how she became increasingly more comfortable with the term intersex as she got older. Penny and Alex explained that while they do not refer to themselves as intersex frequently, they feel comfortable engaging with the intersex community.
How HPs communicate to young people about their variation can have lasting impact on that person’s sense of self and emotional wellbeing. Participants in this research indicated there is a need for change in the way HPs communicate with their patients, especially young people.

7.6.1 Need for change

There were a number of experiences that demonstrate there is a need for change within the New Zealand health system. Participants stated they wanted better communication with their HPs and for the communication to be more sensitive, thoughtful and convey a depth of understanding of how they as young people might be feeling.

“My GP at the time said to me, he said oh what was the results and I said ‘oh I’ve got MRKH, that means that I won’t be able to have children’ and he said ‘oh lucky you, you’ll be able to sit and have a glass of wine while somebody else gives birth to your baby’. I thought...I cannot believe you have just said that to a 17 year old who’s just been through a life changing experience. I honestly feel like there needs to be some serious sensitivity treatment when it comes to, especially people who work in the field of gynaecology and stuff...”

Penny

“The GP who first told my parents about the diagnosis said that um, that it shouldn’t be discussed too much with me in case I went off the rails and became a flag waver; quote.”

Georgia

This next example indicates a lack of sensitivity talking to a teenage girl about being uncertain of her chromosome composition. In the second quote the young person offers an alternative framing that she would have found more acceptable.

“It can be, come across quite hurtful to say things you know, like we need to check to see whether you’re a boy or a girl because what’s going on there you know...yeah it was absolutely shocking as a child.”

Penny

“I mean you know they could’ve said like in these cases we conduct sort of like mandatory or systematic chromosomal tests, you know to see if there’s anything that we need to investigate, that would’ve been like a little bit better.”
Participants expressed frustration, especially in generic services such as the emergency department, with doctors not being aware of VSC/DSD. Amber also wanted doctors to talk to her as a young adult and not like she was a child. She talked about having one doctor who was good and “upfront” with her.

“most of them that are like understudies or whatever, he (my regular doctor) will tell them to be like upfront and honest and do, like not treat me like a four year old but the ones that don’t know me that are like emergency doctors sort of are like oh can you explain this and explain this and explain that because like they don’t really have that much experience with it so yeah…it’s sort of weird being the explainer and in a way the doctor telling them what to do so yeah”

Amber

Another important component to communication is creating a safe space for open discussion of sensitive and at times potentially embarrassing topics such as sexual activity, sexuality and what the young person understands about these topics. Many of the young people said they were thinking about these things but were too shy to bring them up with HPs or parents. Tess reports talking with an allied HP about such issues and explains how relationship building helps create a sense of safety.

“At first it was a bit, I was a bit more shy about that topic but I think the more that I met with her, um the more open I was about it.”

Tess

Sarah reflected on having her mum with her at appointments, until recently when she had left school and started university. She suggested young patients should have some time with a parent present during consultations but should also have some time on their own with the HP.

“...so you kind of get that dual, you know so you get a bit of an opportunity to talk about things, especially as you, you know becoming a teenager that you get a bit more independence I guess...
Some young people only talked with their friends about their experience of having a VSC which resulted in mixed outcomes.

7.6.2 Communicating with peers

Young people wanted to communicate with friends about having a VSC but had concerns about how their friends may respond. The lack of public awareness and understanding of VSC, coupled with the sensitive nature of disclosing personal medical details, means that talking with peers was often fraught. Young people may not get the support or understanding they need to work through issues if they do not have a safe space to discuss what they are going through.

“I've got one friend and so I spoke to her about a year after high school finished and I brought up Swyer Syndrome and she said “Oh, I've heard about Turners,” and then she, she freaked out and she goes “So are you a guy?” And that completely threw me. I just, I, I couldn't have conversations with people after that. And like it's not, I've got nothing against people identifying as who they want to identify as but for me that was really hurtful.”

Georgia

In this next situation Katie describes telling some friends about her diagnosis. She found their response unhelpful as she perceived them to be focusing primarily on themselves, with one of her friends saying “I'm not going to be your surrogate” and others being insensitive.

“...I had a few other friends who also kind of made it sound like oh wow that would just ruin my life aye, like man that sucks, man I'm so glad I'm not in that situation and they'd sit there like that and it was just like I am in this situation...”

Katie

Participants' challenges with peer communicating highlights the need for support which will be discussed later (7.8) on VSC peer support.
7.6.3 Communicating with parents

Young people said they had to navigate communicating with their parents. Many young people commented that their parents were able to talk with them about their variation sensitively. Other young people talked about their parents being awkward and overwhelmed and being unsure how to discuss their child’s variation. Some young people with variations that affected their fertility were very conscious of how difficult it was for their parents to adjust to this reality and manage their expectations. In some instances, the parents seemed more affected than the young people themselves about fertility issues. Katie’s example below indicates how her parents struggled with what to say; and highlights the different responses from her mother and father.

“I think my parents were quite uncomfortable with it at first, like they didn’t know how to react so my mum took it real hard when she first found out, like she was, you know had a big breakdown, so she cried about it a lot at the beginning and my mum would go on little rants about how she could be a surrogate, ...I was like no it’s not, just drop it... but no, she kind of, I dunno, I think she blamed herself a little bit.”

Katie

“I don’t think he (father) knew how to react ‘cause he was kind of like, when I first found out, like they keep making like weird jokes but I was kind of like, like going oh well we still expect kids from you, like everyone in this family’s having kids and it was just kind of like at that time, it was like real fresh and it was kind of like I didn’t wanna hear that at that time and I was kind of like but it was their way of coping, it think it was their way of pretending that, well not pretending but just kind of try and act like everything was still normal...”

Katie

This indicates a need for parent support, specifically around managing their responses. Katie’s experience reinforces the comments from parent participants in this research that there is a lack of support for them and their children (previous chapter, 6.8). Support surrounding what would be helpful and unhelpful when communicating to their children about their variation was indicated. The “knowing how “to talk their children/teenager concurs with the findings of another study where parents of children with CAH where interviewed. The parents reported
struggling with how to talk with their children (Lundberg, Lindstrom, Roen, & Hegarty, 2017). Katie also raises the issue for her parents that they just want everything to be “normal”.

### 7.7 The “old Norm”, challenging “the Norm” and the “new Norm”

Some young people struggled with feeling different and coping with having a VSC. For most there was a strong emphasis about challenging normative structures or ideals presented in society through its various mediums. This process appeared to break down into three stages, some merging into each other:

- the young person feeling different and wanting to be normal especially at diagnosis
- the young person challenging the norm, exploring difference as a positive and reaching a point of self-acceptance and comfort with their variation
- the young person disrupting the norm and reframing their variation as normal

#### 7.7.1 Feeling different

At some point, most of the young people felt different to their peers as a result of their variation. Adolescence is a time when young people are developing a sense of identity, and wanting to be a part of their peer group. Having a VSC can accentuate feeling different for young people making it difficult for them not to perceive themselves as abnormal. The messages young people get from HPs, parents and peers will impact on the way young people understand the meaning of having a VSC. Adolescence is a time they can be vulnerable, where they are trying to understand the complexity of their variation and what that means for them. Most young people interviewed took variable amounts of time to come to terms with their diagnosis. Some felt like this process was taken over by the urgency of medical procedures. This urgency was particularly common in those who were diagnosed as teenagers (mainly due to cancer risk of gonads and subsequent surgery to remove the gonads). Progression from diagnosis to surgical or other interventions often happened quickly, with the young person struggling to understand what was happening.
Below are some examples of how young people came to understand the status of having a VSC. Georgia reports what it was like finding out about her condition and feeling like an alien i.e. not normal.

"My life had been turned upside down in the space of three months. The pain of surgery was beyond physical. Why was there nobody else like me? What had I done to deserve this? Why did I have an abnormal 'condition', 'syndrome', mutation'… Was I an alien?"

Georgia

“I dunno, I felt kind of weird, like I didn’t, at first I didn’t really wanna talk to people. I kind of didn’t really want to tell them because it was sort of just a bit awkward and that made me sort of different and I didn’t really wanna be different”

Julie

Julie opted to use hormones to make her appearance “look normal”. Julie, as a young female adult (16 years), made the decision to take hormones to reduce facial hair that she found distressing. However, she remains undecided about any surgery to reduce her clitoris as she is not sexually active and does not want to make that decision at this point in her life. Her parents support her decision and want her to have her autonomy in regards to her body. Julie made the comment that she was always going to feel different even though she could make efforts to look the same as her peers. This is consistent with scholarship suggesting that medical intervention is not always going to produce the intended psychological benefits (Morland, 2009).

Anna said she even pretended to menstruate in order to fit in with her peers.

“I would feel like different about was that like my friends like would always talk about having their period…so I just kind of like pretended I was like, you know when they were kind of like talking about period stuff.”

Anna

Participants in this study reported that the pressure to conform to norms was at times overwhelming and they just wanted to be like any other teenager. Young
people’s worlds were turned upside down as they tried to make sense of how they could fit in and adapt to having a VSC. One way for young people to make sense of this was to contemplate “what does it mean to be normal and what is normal?” This is discussed in the next section.

7.7.2 Challenging the norm

Many of the young people discussed going through a process of exploring how they could feel positive about their VSC. For some participants this simply meant accepting that their VSC was part of them and not something to be ashamed of. Often these young people were supported by parents to see themselves as “unique” (as discussed by some of the parents in the previous chapter, 6.5.2). In these instances the parents often role modelled to their child/young person that they had accepted their difference by incorporating a broader view of what is considered normal (e.g. parent conversation 6.5.3.1).

Amber, who has a cloacal anomaly (see glossary), challenged the social norm by disclosing her variation to her school class during a speech competition. Amber stated she was not going to accept the “old norm” and questioned what is the norm anyway. She hoped her speech would raise awareness, and as a consequence her peers would accept her as the “new normal” rather than reject her if they chose to perceive her as “abnormal”.

“Let’s take a stand and make a new normal, a normal where no matter who, or what you are, is normal. “This is the new normal. I am the new normal. The new normal starts now.”

Amber

During her speech, Amber reflected on past experience of feeling isolated, bullied and teased because of her variation. Amber found a pathway to accepting herself by challenging the norm and she wanted others to take up that same challenge. Amber reports that many of her peers cried as she spoke, and that the whole class gave her a standing ovation at the end of her speech. Amber felt more accepted by her peers as a result of her speech. Amber's strategy to be her authentic self, by sharing some of the hardships of having a cloacal anomaly and challenging herself and others to accept her as just a normal teenager, is a powerful example of redefining normal.
In the example below Penny challenges the concept of what is normal, specifically the fluidity of what and how someone may think about their genitals, in this case the vagina. Commenting that not all women want a vagina and may change their mind about maintaining the depth that is deemed normal.

“I'm always like very critical of what it means to be normal in society but I like that with dilation (see glossary), if one day a girl goes you know what, I actually don't feel comfortable having a vagina, she can, basically with dilation, if you don't maintain or continue to have a sexual intercourse for a certain period of time, you can actually like close up your vagina again, ...like you'll have to re-create it again and I like that idea that as a woman, if you, somebody hasn't corrected your body, you've just manipulated it in a way that works for you and if you choose to not embody anymore, you don't have to and I like that, I really do like that and I talked to one girl who said actually she identified as a lesbian and she just decided she wasn't gonna maintain her dilation and she was like, I almost feel like I wasn't supposed to be born with a vagina 'cause I don't need one and I thought that was really cool that she was able to go back to how she was...”

Penny

Penny’s comments highlight the heteronormative focus on what HPs consider as a functioning vagina may differ for different people and as a consequence what is needed for a satisfactory sex life.

“the reality is you don't need a vagina to have a, like a satisfactory sex life, you don't need a penis to have a satisfactory sex life”

Penny

Amber and Penny challenged normative concepts of normal anatomy and normal sex lives directly. Many other participants indirectly challenged the norm by redefining what was included as normal. Having a broader and more inclusive concept of normal allowed for participants to move towards self-acceptance.

7.7.3 Self-acceptance through redefining the norm
As mentioned above, young people in this study had started to challenge the binary concept of male or female. Many of the participants came to the realisation that just
because you may have a differently sexed body that does not mean you are not normal. The young people were redefining normal, broadening the definition to accommodate their variation.

Next are some examples of how some of the young women in the sample have redefined themselves, or offer a way of accepting difference as normal and developing self-acceptance. In the first instance Bridget describes herself and her brother as “unique”.

“Like I’d just say we’re different or unique to most people.”

Bridget

“I just believe that if we start to like accept abnormal bodies as normal, then like this is not so much of a problem, this is not so much of a trauma, the only reason it’s so traumatic to not have a vagina is because there’s someone out there telling you that you need to have a vagina.”

Penny

Penny articulates here how external implicit or explicit assumptions and expectations influence how we will perceive our bodies. In turn, these norms have a direct impact on how we feel about and see ourselves. If young people are supported to understand the concept of norms they are empowered to decide if they want to conform or not.

Georgia comments in the next quote that some health professionals want to normalise intersex bodies, so that they are achieve normalcy.

“I think ... that intersex bodies aren’t seen as being normal in a lot of circumstances, and a lot of surgeons, not all of them but a lot of them are wanting to do surgery to normalise someone. Why should I have to change who I am physically as an identity of gender whatever, to meet social constructed normal needs of the rest of medical society?”

Georgia

These three young people are all suggesting that what is considered “abnormal” should be accepted as a “new normal”. They have effectively not conformed and don’t see themselves as deformed as a result. Even though they had to alter their
bodies due to health risks (such as cancer) and other functional complications, they have come to a place where they have disrupted the idea of what is considered “the norm”, and redefined that to accommodate themselves as being seen as a normal human being.

Diversity is the concept of respecting difference in others and not simply showing tolerance but embracing and celebrating that difference. I suggest, from what is being said here by these young people, that they are trying to engage a level of diversity that is naturally at odds with the norm. Many of the young people interviewed not only began to respect their difference, but embraced it, and for some celebrated their difference by coming out about their difference. They have resisted the urge to be defined by what is often presented as the ideal norm i.e. the norm as an ideal that we should all aspire to achieve. Instead they redefine the norm.

Martin (1964) talked about the concept of the norm as two norms. The first, reflecting the average which he called the “typical” norm, the other, where typical norm becomes an “ideal”, the one we “ought” to do or achieve (Martin, 1964). I would argue this has not changed. For those with VSC there is pressure to conform to the ideal of what it is to be a typical female or male.

Penny, Georgia and Amber claim their difference and literally aim to rewrite what the norm is, with the use of their terms such as “new norm” and “accepting abnormal as normal”. Some of these young people are refusing to be subjected to normative standards of the medical world or those more broadly accepted in society.

The next young person demonstrates insight into how parents can support their children to accept their different bodies by supporting them to be themselves and to say “there’s something different about you but you are all good”. It is acceptable to be intersex. How and what we are told about a variation in one’s body has a huge impact, as commented on by the following participant.

“I've known people who, like, didn’t really have a problem with being intersex really because their parents were just, like, no fucking way are we letting you operate on my kid. Like, and just you know, like, raise them as the gender the doctors assigned them in the first place, but like, being, like, hey you know there’s something a little different about you, but you’re all good. You know you can work shit out when you’re older. And, like, that’s fine, that’s, like, it’s not, you know we’re not saying that ‘oh if
you have a kid who's in any way intersex you've got to raise them as a gender-neutral child."

Alex

Helping parents support their children to understand difference and reframing their VSC as something unique about them is a coping strategy. In the previous chapter some of the parents employed this type of strategy to support their children (6.3.4.)

7.7.4 Diversity, difference and a sense of belonging

In partnership with challenging or disrupting the norm comes education about diversity. For those born with a VSC, it can be a struggle for some to modernise or adapt their long-held beliefs and values; notably implicit assumptions about the norm. Diversity validates difference, whereas the norm, in particular the ideal norm, can stigmatise and alienate people who fail to conform. When there is an environment that validates diversity or difference, more people feel a sense of belonging as articulated by Georgia below.

“Because you’re physically seeing these people. And they’re just human beings like you, and they have diverse lives and diverse beliefs and different family structures. Some are single, some identify as queer. Some identify as gender neutral. Like, there’s an amazing amount of variance and it’s, you don’t, you’re not judged.”

Georgia

The importance of what a HP says to a young person can make all the difference to the way the young person thinks and feels about their variation as is the case below.

“Cos at, yeah at first when I found out I was, like, oh my god, I’m so different... until my gynaecologist addressed that it actually is quite common and then made me feel a bit better. So, I’m not the only dysfunctional one or anything in this world. [Laughs].”

Tess

This section reflects the process that young people cycle through in order to come to a place of self-acceptance. Implicit and explicit messages from peers, parents, and HPs all play an important part.
7.8 VSC peer support - establishing caring communities

These young people talked about seeking support by finding others like them, usually through online support groups. As mentioned before, Amber initially sought support from her classmates via her school speech. However, once her story was online, she was connected to others like her. Amber found this very affirming, as it provided her with peers with shared experience.

Georgia, who was diagnosed at 16 with Swyer’s Syndrome was 23 when I met her. She describes setting up a group to connect to other young people with a VSC.

“I couldn’t talk to my parents. I couldn’t talk to my doctors about it because I just felt like they didn’t care. So I thought why not connect with this community? So I’ve started up a, um Skype group. So it’s, it’s completely secret, so you’ve got to be invited in. So there were five of us in the Facebook page when I started and there’s now sixty of us.”

Georgia

Georgia decided to move into an advocacy role and has since become the co-chair of ITANZ and project manager of IYA. I invited Georgia to come and co-present with me at an academic conference in Italy (Steers & Andrews, 2018). She agreed. For me, it was a remarkable experience to observe Georgia meet some of the young people she had previously only communicated with online. Seeing the connection that was built online suddenly become a reality face to face was a totally unique and transformative experience for these young people. They reported that being together to share their experiences as peers in person was “awesome”. They were able to socialise, build new positive experiences together and find a sense of belonging (personal conversation July 2018). This was reflected in this excerpt from Georgia’s conference report (see full report in appendix).

“The opportunity to network with a multitude of activists and academics in person for the first time, many of whom I had extensive relationships with online for many years, was a life-changing experience. After being told by medical professionals at the time of my intersex diagnosis that I would never meet another person with a variation of sex characteristics like me in New Zealand, let alone overseas, this experience was an absolute privilege.”
As a researcher, it was moving to see these young people, who had reported struggling with difference and self-acceptance, being totally at ease. They reported being comfortable in their own skin and exuded a sense of belonging and confidence with each other (personal communication July, 2018).

The power of peer support and the benefits that come with finding a group of individuals with whom you have shared experience are a pathway to self-acceptance. Brian Still describes the intersex movement developing “virtual intersex neighbourhoods” online (2.6.1).

It was evident how important it was to find like-minded peers or “find your people/tribe”. Many young people interviewed spoke of the benefits of talking to others with similar variations, even if that was via social media, often closed Facebook groups. Georgia refers to these as “caring communities”.

“Intersex individuals need to have access to caring communities of like-minded people who have lived similar experiences.”

Caring communities allow for connection and, most of all, to feel like you are not the only person going through this experience. It removes isolation and the “not only me” feeling.

“I used to think that it was really rare but ever since I’ve done my speech, we’ve found so many people with similar things and yeah, it’s nice to know that it’s like not only me, like I know one other girl that has the same condition to me but she’s got spina bifida as well so like she’s the only girl I ever knew of so yeah, it’s real nice to just have more people.”

Bridget talked about the benefit of hearing from others who are older and have been through what you are going through and provide some insight for the future.

“Like if the two people who are going through whatever it is they’re going through, are of similar age or can you know have
enough literate skills to like understand what the older person’s talking about, I think that’s a really good opportunity for the younger person just to know what they’re probably going to have to experience later on and how to deal with that.”

Bridget

These caring communities are crucial to providing a safe place to discuss issues that young people at times felt uncomfortable talking to parents or HPs about, or may not feel they had the opportunity to discuss.

“there’s nothing to really address ...the way you feel about it in yourself or how it’s affecting you now, all that kind of stuff, the psychological part of having it.”

Sarah

These caring communities exist predominantly online due to the small numbers of young people with a VSC and lack of connectivity between other young people within Aotearoa/NZ. As a result, many young people from Aotearoa/NZ connected with young people from other countries such as the USA, Australia and Europe, where there are larger numbers of individuals with a VSC and more established support networks.

The other purpose these communities serve is to create a safe place for young people to explore their difference and identity. Young people can gain awareness about diversity and support to accept themselves as individuals. Online VSC support groups serve a specific educative function. They provide alternative messages to mainstream endorsement of the norm, and embrace diversity that allows for their difference without prejudice. Georgia articulates in her interview the educational power that young people can garner from each other.

“Sharing medical and social experiences stories between people with a VSC can reveal to individuals for the first time pockets of shared lived experience. Over time a deeper understanding and acknowledgement of how justified medical interventions are/or have been across the collective group.”

Georgia
When making important health decisions, young people should be fully informed and this requires having access to peers and others who have had similar experiences. Peers provide first-hand accounts and subjective experience, and therefore provide a qualitative different source of information to HP or parents. Nothing is static, least of all the way we feel about ourselves and our bodies, and it is important for young people to understand what they think/feel about themselves at 16 may be very different to what they feel/think at 21 or 24. This temporality is another element that makes decision making so complex and challenging. Caring communities provide an avenue to explore and understand this complexity from others who have been through what they are going through.

Discussing personal concepts around one’s sense of identity and embodiment are even more challenging. Additionally, the temporal fluidity indicates the need for a combination of specialist psychological support and peer lead support.

7.9 Bodily autonomy

The concept of bodily autonomy, that is, being able to decide for oneself what and when things happen to or for your body is very important to the young people interviewed in this study. Bodily autonomy is something most of us take for granted, however for young people born with VSC this is not always the case. The young people who participated in the research believe they should have the same rights as other young people when it comes to decisions regarding their own bodies. This is reflected in Bridget’s statement.

“I’m aware that my body is different... And I guess over time I’ve just come to terms with that. Just you know well this is the way I am you know I have the power to do what I want with my body and you know it’s my choice to do what I’m doing and it’s within my power to change myself to give me a normal people function I guess is what you could call it.”

Bridget

When discussing early genital surgery versus waiting till a person is older, the young person can see “both sides”, but they tend to express a preference for the person to exercise their right to decide for their own body.
“I can see both sides, I can see why you wanna do it earlier [genital surgery] but I think it would be better to wait for the person to decide for themselves.”

Sarah

As expressed earlier by Alex (7.7.3), if parents are able to support their children to manage their differently sexed body, they can reassure them they are ok as they are. Parents are then able to support their child’s right to bodily autonomy ensuring that the young person can work things out for themselves when they are older.

Bodily autonomy has come under the auspices of human rights. Legal challenges, as discussed in chapter two (2.8), where many countries Human Rights authorities (and some legal ramifications e.g. Malta - 2.10.5) have advocated for change. This change involves allowing young people the right to make decisions for themselves regarding their health care in situations where their where it does not involve function or preservation of life. Julie talks about non-functional surgery supporting the premise of bodily autonomy.

“If it’s non-essential, then they should be able to have that decision themselves.”

Julie

There is a clear message from the young people in this study that young people deserve to have the right to bodily autonomy and that this is a basic human right.

7.10 Identity and Embodiment

The participants discussed the journey of working out their identity and how complex this journey was. They commented it took time to work through and also would change over time. Factors such as “ideal norms” and feeling less of a woman due to fertility issues and or other conditions of their specific VSC had a clear part to play in their sense of identity. Young people had to process what it all meant and often this was with less information and /or support than they felt they needed. Identity and self-acceptance intersect with one another.

“I struggled a lot with identity stuff, like I struggled a lot with feeling like a proper woman and a proper girl, not only can I
not have kids ...I already had quite a boyish looking figure and I guess I sort of like really struggled with the idea of like my femininity being something that I could still embody with, still with having MRKH.”

Penny

“Like I just thought like does that mean I’m half man or something?”

Tess

Some of the young people diagnosed later in life might have greater challenges re-evaluating their identity. Bridget who has CAIS and was not diagnosed until her teens and discusses the challenge she faced when she was diagnosed.

“It was a bit of a shock at first ‘cos I’d just gone through my whole life thinking that “Oh I’m normal... Yeah like it wasn’t just that I just felt different, you know that I wasn’t the person who I thought I was”

Bridget

Bridget’s sense of her core identity was challenged by her diagnosis and she had to process the impact of having CAIS and what they may mean for her self-concept.

Georgia talks about the process she has undergone to get to a place that she feels comfortable with her identity as an intersex person. Initially, she adopted the beliefs of her parents who reiterated that she was “completely normal”. But Georgia still experienced a consistent and unsettling disquiet, which was not resolved until she had the “full story” about her VSC. At this point she was able to better process what was truly going on and find a sense of peace within herself and with her variation.

“it’s all been very recent that I’ve really come to terms with the fact that I have an intersex variation and I’m happy to identify as intersex ... I haven’t even known within myself how I feel. And so finally putting together the puzzle of the whole XY chromosome scenario. Cos I only made that full discovery just over a year ago.”

Georgia
Adolescence and young adulthood is a time for establishing one's identity, and young people with a VSC have the additional challenge of factoring in the ramifications of their VSC. For Georgia, it was developing an understanding what having a Y chromosome meant for her as a woman. Once she connected with other people with a similar VSC who had been through the process of self-discovery she felt enabled to establish an identity she felt comfortable with.

For some of the young people interviewed they reported that their VSC was not much of an issue and therefore did not impact on the way they viewed themselves. Some were matter of fact about their variation but realised it might be different for other people. This was the case for Tess as reported below.

“For me I guess I, I guess I dealt it pretty easy, I just kind of just left it as well but I understand that some people might not take it as well.”

Tess

There was an age range difference from 14 to 23 years of age for the participants in this part of the study. They were all at various stages of forming their identity and processing the way they think about themselves in relation to their bodies, their variation and their lives in general. Their VSC was not the whole of their identity and for some it was only a small contribution to how they identified themselves. For others their variation had a significant impact on their identity and the way they viewed their body. All participants reflected on the temporal nature of the way they considered their variation and the recognition that it had or may change over time.

7.10.1 Relationships

Young people worried about the impact of their condition on future relationships. In the last section I presented data about young people's self-identity. In this section I look at how young people understood their romantic and sexual relationships with other people. Physiological features that were important to both self-identity and relationships to other include: the absence of a uterus, presence of a typical vagina, and inability to produce gametes and/or to carry a pregnancy. Nine of the participants self-identified as female and discussed concerns about future partners’ feelings about their fertility. For a few of the participants this was a significant barrier to thinking about becoming sexually active or pursuing a relationship.
However, for some of the young woman interviewed it gave them a sense of confidence in their approach to relationships. An example is as discussed by Penny below.

“I mean it’s just about being honest really and I think that was like my main thing and just like I think psychologically preparing yourself for the fact that that person might not be ok with that. I think I’ll always be upfront...and yeah, I mean I’ve definitely had guys gone sorry but like I, like that’s too much for me to deal with... but I mean that’s just, ....almost feel like I lucky, I think of it like super power, like I can weed out the dicks who aren’t gonna be able to hack it when things go bad...”

Penny

Anna, who has gonadal dysgenesis, talks about the challenges of disclosure and that at first she was uncertain whether to tell people, especially boys, with whom she had a romantic interest.

“Like I always kind of think about... with like friends or with guys or whatever,...at what point do you kind of tell them like everything, now I like kind of tell people, anyone who asks, I kind of just like tell them about it...

Anna

Relationships are another important part of young people’s lives. Navigating these can be challenging, as reported above by participants.

7.11 Bias

As we saw in the data from HP and parent participants, normative biases regarding ‘normal’ development, bodies and secular function had an influence on their perceptions of the meaning of VSC/DSD. Bias can be implicit or explicit or both (5.5.5. and 6.7). Biases were also influential in young persons’ understanding of their diagnosis. Young people were aware of issues that would cause bias in their HP’s approach to the VSC (even if they perceived that HPs were themselves unaware of this influence).

“The doctor said that their own child was gay, and that if they came out in a community it would mean everyone would know as it is a small rural community. The GP had to recommended
that my parents tell no one I have Swyer Syndrome at all. Not family, not friends, no one and don’t let me move back home after I finish school.”

Georgia

“I think a lot of medical professionals aren’t aware of how much they’re buying into standard stuff…majority of doctors are …Cis and straight and not intersex, right?”

Alex

“no matter how much corrective surgery you perform on someone, you’re telling them that there’s an ok body and there’s a not ok body and …the fact that they have to intervene early tells you that, you know, …you couldn’t possibly live this way”

Penny

In the instance below, Georgia perceives the HP’s bias when the HP instructs her about safe sex. The HP assumes she is heterosexual and that young people at 18 will be engaging in sexual activity. The HP did not take the time to ask about Georgia about her intimacy experience or attitude to relationships, sex and sexuality.

“Like just because you’re infertile doesn’t mean that you don’t need to use a condom and you still need to use lube. And you’ve got these STI risks like any other person. And gave me this massive blimming lecture about having sex with men because she just presumed that I was in a straight relationship. And meanwhile here I am totally insecure, petrified about being in a relationship. There’s no way on earth I’m going to have sex with someone, let alone even think about having sex with someone. And here she is lecturing me like “Oh well, you’re eighteen. You’re female. You’re going to have sex…Are you interested in being in a relationship? Not even that came up. You think you could ask some questions. But you know it was just the assumption …”

Georgia

Young people reported that HP bias was a barrier to effective care. This suggests the need for training and support for self-reflection to help HPs be mindful of their potential bias about normal bodies and relationships.

7.12 Vaginal dilation and surgery

Four of the nine young women had experience of dilation (a procedure to lengthen and widen the vagina - see glossary). The young women had a diverse range of
educational support, from limited instruction to very clear preparation and assessment for readiness.

In this first example Penny talks about her initial experience of not knowing what to do regarding dilation, then getting to a place of empowerment and even advocacy for other girls by educating surgeons.

“I was literally given …this discreet little kit…see how you go kind of thing and I was like where do I put it...I remember at first just being what the hell and feeling so frustrated, like I have no idea what to do...like overwhelming sort of thought that you need to embody that normalised perspective of what it means to be a female so yeah.”

Penny

“So I actually didn’t know this while they were doing it until like now but the way you like form your vagina is quite critical because ...it can actually cause a lot of problems so you need to be constantly checked as you’re going through the process to make sure that you’re keeping the right slope...”

Penny

“I think the one big thing for me is telling the girls that this is a choice, you can choose to not do anything, I feel like that really needs to be emphasised, for me that was never spoken about, ...it was like which way do you wanna correct yourself...”

Penny

“I feel like I’m actively helping other young girls make a non-invasive decision because the surgeons, you know now go,... she’s done it really well...”

Penny

“...I still am weird about the whole normalisation of the vagina aspect of it.... I’m glad that I can help them see that surgical intervention is not always the right thing because you’re giving a girl who has no vagina, two days later you’re giving her a vagina, that’s a huge process to go through as a person whereas when you engage in dilation, you’re actively working towards your own sexual comfort ...”

Penny
Penny literally took creating a vagina into her own hands via dilation and got to a point of readiness whereby she felt comfortable creating and maintaining her vagina. She wanted to help educate surgeons because, in her experience, they did not think dilation could create a good enough vagina. She let them examine her for the greater good so other girls would be given a choice. The bonus, as she described, is that you are working toward your own sexual comfort. In a way, the girls in the study are far more intentional and conscious of their sexuality as a result of their dilation.

Penny goes on to talk about the need to be ready psychologically and emotionally before undertaking dilation. Readiness for dilation was echoed by the other participants as important and commented they were given a choice when to start even if there was an absence of information of how to dilate correctly.

“I think like, well I mean I think the big thing personally is like if you can’t talk about yourself as a sexual being, like if they can’t talk about things like masturbation or like if they can’t talk about partners or what they have or have not engaged in sexually, that’s a huge red flag for me...”

Penny

Katie, who has MRKH, talks about it not really affecting her at 16 but as she got older and started having relationships. She was sent to a main centre to get support from allied health members for psychological support and practical support from a specialist physio to show how to use the dilators.

“.., it didn’t really sink in properly then so it was kind of like, you know like when someone tells you something and you’re like oh ok and but like it doesn’t feel real because it’s not affecting you currently... it affected me more later on... when I had like relationships and stuff”

Katie

“There’s no [dilation] guidelines for me because there’s no, so where most people, like when you think about it with a normal vagina, when most people normally have sex, like when they have sex, it’s already, there’s already a path...and it’s already at the right angle and so for me, what I found really difficult is there’s no path so I don’t know it’s supposed to go and because I, obviously I’d never had sex either, I had no idea where it was supposed to go and so what my issue, what I found like the
The majority of young people interviewed felt it was important that they got to decide about their own bodies and had the opportunity given to them to make decisions. Most of the young people understood that some decisions would need to be made for them to improve function or to preserve life. However, in situations that
were not about function or preserving life, especially appearance based surgical procedures, they would prefer to delay so they can decide when they are older.

“If it’s non-essential, then they [young people] should be able to have that decision themselves.”

Julie

“like if either of my parents had known as a child, I would really hope to think that they would wait until I was 16 to let me make my own decision”

Penny

7.13.1 A matter of choice

Sarah has CAH and was not diagnosed until age 7. She reflects on her decision making for whether to have a clitoral reduction or not. Sarah notes that the manner in which HP’s present information is influential directing patient’s reasoning and decision-making.

“My thing is that they [HPs] probably know best, they know a lot more about it than I do, they’ve had a lot more experience with lots of different people about it [clitoral reduction]. So they’d know better than what I would if they said do it, but because they said do you want to, it seemed like well you can and you can’t if you don’t want to, it’s not like a necessary thing to do, yeah.”

“I didn’t think I needed to have surgery, I didn’t know it was [an issue, as] hasn’t been an issue for me.”

Sarah

Sarah did not think there was anything wrong with her clitoral size and had not experienced any problems associated with it being enlarged. Perhaps if the HPs stated that she should have surgery it would have been likely she would have conceded and had the surgery as the HPs “probably know best”.

Younger people valued information about options and the possible benefits and risks, not just physical consequences but psychological consequences as well. Katie’s reported that HP supported her to make an informed and voluntary choice about whether to use dilation.

“...well for me personally, then I think it was like all my decision really ‘cause it was like oh they were basically like if you want
In some cases, parents had to act as advocates to have their children's voices heard in relation to their bodily integrity and own agency to decide for themselves what happens to their bodies. Amber made the decision to have a permanent colostomy, and if you remember in the last chapter her mother had to advocate for her with the surgeon (6.6.1 - PG 11-mother). Amber was pleased her mother was able to support her to be heard as she was frustrated that the surgery was delayed due to the surgeon's reservations. In the following quote she reflects on how, at the time, she just wanted to have the colostomy for ease, but is happy she made the decision.

“Um...oh when I was doing It [making the decision], I didn’t really think about it..., I was like oh yeah I just want a colostomy, it’ll be easier for me but now that I look back, it was a pretty big decision because I’ve got to have this for the rest of my life but yeah, I’m glad I made the decision.”

Amber

Amber’s quote highlights the different motivations for decision making and the temporal nature in the way an individual will frame their decision making. Amber’s mother wanted her daughter to have agency in making decisions for herself, but also had the knowledge the trapdoor (see glossary) that had been recommended by the surgeon was not delivering the benefits promised. Amber, some years on from making that decision, was confident she had made the right choice.

When it came to life threatening decisions, most of the young people felt that their parents would need to make the decisions on their behalf as the risk was too great if they did not make the choice. Bridget had her gonads removed as a young teenager and was pleased her parents made the decision.

“It was really only up to my parents to suss that out. But um, with me I think because it was potentially life threatening, I think my parents made the right decision... in just playing it safe.”

Bridget
As mentioned before in (7.9) on bodily autonomy, young people in this study were clear they needed agency to decide for themselves about what and when things happen to their own bodies.

7.14 Future forward

There were concerns for the future, especially around relationships and whether they would be accepted or not for who they are. Fertility issues and the possibilities around having a family should they wish were also raised.

“For someone like me it would be a bit of a... big step to get intimate in a relationship. Just ‘cos of my condition about not being able to have children and the fact that I wasn’t born with a fully functional vaginal cavity. But as long as you’ve got the right person with you, you know they shouldn’t judge you for that. Like that’s the difficult thing for me in thinking about that is you know do you tell them like up front?”

Bridget

“I have a little sister who loves me more than anything and that makes something like surrogacy a lot more of a possibility as well but I mean, I can see myself adopting children... you’ve just gotta be willing to be flexible I think with the way you see your future and family but I definitely know I will have kids one day.”

Penny

Georgia talks about trust being an issue and how she has lost some of her confidence as a result of the way her health care provision has occurred.

“A big thing with me is trust. I’ve, I’ve struggled to trust people. I was, I was quite, quite a confident person prior to being diagnosed. Since my diagnosis, I’ve been very much excluding myself from those social situations. And I find that if I’m in big groups of people, I can be really, really awkward. And it’s not a natural response for me. And that’s, I, I really think that’s an implication of the way in which my diagnosis took place because there hasn’t been transparency within those, I don’t feel there’s been transparency within those relationships I’ve had with those medical specialists and in terms with my family about what we talk about and with my friends. And so I’d, I really struggle to trust, to trust people now.”

Georgia
Sarah talked about having to be on medication for the rest of her life and some of the challenges for starting a relationship when you are 20. Sarah was not sure what she could do about it and at the end of the interview said this was the first time she had discussed these feelings. Sarah reflected on always being socially awkward and though she has a good peer network she is anxious about intimacy. She later discussed she felt this was because of her weight and that was the main barrier to her pursuing intimacy. It would be easy for people to attribute her having CAH as the cause and though, at times, Sarah wonders if that is part of her shyness she does not believe it is the main reason.

“like it’s weird to, like I haven’t had a relationship before with anybody else which is hard when you get to University and you know everybody else has had boyfriends or whatever and you’re like well I haven’t and then I start to think is it because I’ve got this[CAH] ...or is it just me and so that makes it difficult to think about in the future,... the social part, ...that’s what I kind of worry about a bit more and I’m not really sure how to deal with it or fix it (laughs).”

Sarah

In Sarah’s case (and as mentioned before by Katie), a process of self-discovery occurs as a young person/emerging adult, regardless of the circumstances of having a VSC. This process of self-discovery also involves navigating peer and intimate relationships. Other factors such as one’s perceived weight and social skills can have an influence on confidence and identity. Young people without a VSC may encounter the same issues. It is important not to conflate normal developmental stages that all young people go through with having a VSC.

7.15 Education

Young people stated that education about VSC/DSD was important. This includes education for themselves, parents and HPs. Many of the young people had examples of why education would be helpful, as previously discussed in earlier sections around communication, bias and support in this chapter. Penny reflected on the valuable role that people with VSC can play in educating HPs, and her positive experience of contributing to HP education.
"I mean but it helps me to talk about it as well, especially in the field, like I give talks on infertility at University and stuff about my experience but like I think being candid about it almost makes everyone else feel ok about it, it's like oh she's fine, we're all fine you know... “

Penny

“Doctors should not be put in a position where they do not know about intersex issues. They must be adequately funded and resourced, and wherever possible connect with other healthcare professionals to seek appropriate advice.’

Georgia

These young people highlight the need for better communication with HPs and awareness raising around what these variations are in the first place. There is also a need for better support, not just for themselves, but also for their parents. In the next quote Alex makes the point that HPs need education around bodily autonomy and to consider the mistakes of the past (2.8.1 and 5.5.1).

“I think like it [education] would definitely be about centring the child’s bodily autonomy because like um, historically you know parents making decision hasn’t gone well. But like that’s to say that confused parents with no idea what’s going on can be very pressured by medical professionals who seem like they know that this is the only solution.”

Alex

The young people in this study all thought it would be useful to have access to others their own age or a bit older in order to educate themselves about their diagnosis, share experiences and strategies for coping.

7.16 Summary

In summary, these 10 young people present a variety of experiences regarding their health care, including a mixture of both positive, negative and neutral. Positive experiences were largely driven by access to a wide range of diverse support for decision-making, for example access to peer support, specialist psychological support and practical physical support if needed.
Young people need to be supported to understand that norms are only culturally constructed expectations. Norms may be presented as ideals, but young people can be effectively empowered to critique these norms and actively choose to endorse or reject them, rather than passively conform. Young people need to be given the time and space to be able to make these decisions. Access to caring communities established through peer networks was vital to young people coming to terms with a VSC, as it functions as a gateway to challenging and disrupting norms, which in turn provides space to accept difference and diversity.

Young people also need access to psychological support to explore feelings of difference and navigating relationships. Young people are at various stages of forming their identity and need some support to help explore these intensely personal concepts of identity and embodiment. The temporal fluidity of identity over an individual’s life, especially the teenage and early adult years, must be held in mind when providing information to young people. All involved in decision making, including the providers of potential treatment, must consider that what is decided at any time point in their life may be thought about differently in the future. Therefore, interventions that leave space for a wider range of future options may be preferable.

These young people are strongly in favour of bodily autonomy as they want the agency to make decisions about their bodies. In order to make such decisions they need to be fully informed so they can make decisions with confidence. This research suggests that younger people felt they were lacking in access to information about the ramifications of treatment options. They need to understand the benefits and risks, not just from a medical/physical perspective, but also a psychological perspective and consider the future ramifications. Parents also need to be aware of these ramifications from a young person’s perspective.

Parent support was also raised in general by the young people interviewed. They felt there needed to be better support provided to parents, so parents can cope with the young person’s diagnosis. The way parents responded to the diagnosis, especially if the diagnosis occurred in adolescence, had consequences for the young person, for example the expectation to have children despite having fertility issues.
Resources, like online resources such as the recent DSDTeens website (Glasgow Childrens Hospital Charity, 2019) which offers information and advice for ages 10+, 11+ and 14+ respectively, would be useful. It provides information on issues around conformity, identity, gender, sexuality and surgery.

Young people report that there is a need for better training for HPs, particularly around awareness of VSC/DSD, especially the case for HPs not specialising in VSC/DSD such as general practitioners, emergency department staff and midwives. These interviews suggest a need for further training for HPs regarding sensitive communication skills and awareness of normative biases.

Decision making for young people was influenced by six main elements: communication, norms, support, bodily autonomy, identity and bias. Some of these themes emerged in the other key participant groups. Communication, norms, bias and support are four elements of influence that are consistent across all the three groups of HPs, parents and young people. The next chapter examines the themes across all the participant groups and explains comparisons, similarities and contrasts in the experiences and views of these three groups.
Chapter Eight
A matter of TRUST
Participant group comparison
“having that circle of trust for us was huge”

8.1 Introduction
In the last three chapters I have discussed the main themes that came from the data of the three participant groups and highlighted their collective voices as well as attending to those with unique or divergent viewpoints. This chapter draws together the main themes that cut across all three participant groups (i.e. the HPs, parents and young people), and explores the interrelationships between these key themes. There are four key elements of influence on decision making that are consistent across the three groups: communication, norms, bias and support. These are components of the overarching element, trust, that encapsulates the driving factor underpinning decision making.

In the next section, I discuss the way the participants engaged with the decision scale undertaken by all three groups along with a statistical analysis (8.2). Next, I will discuss three individual ‘integrated’ cases where I interviewed more than one key group participant in relation to the specific young person. These illustrate a crossover of the themes discussed in chapter five, six and seven. Each case illustrates the complexities of decision making and the way that the three participant groups can find common ground and form strong working relationships. They also demonstrate there are times when decision making is conflictual and relationships tenuous.

After this, I discuss four further integrated case studies involving three younger children (under six years of age). In these cases, the children were not interviewed, because they were too young. I look at crossover themes and differences in these cases, again to illustrate the decision making processes and to link them to the key elements described above.
The chapter concludes with a discussion of the elements that became themes across the groups, and discuss those in common and those that are different.

Table 8:1 Decision making elements for the 3 participant groups

<table>
<thead>
<tr>
<th>Decision Making elements for the participant groups</th>
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<tbody>
<tr>
<td>YOUNG PEOPLE</td>
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<tr>
<td>Bodily Autonomy</td>
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<tr>
<td>Identity</td>
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<tr>
<td>Bias</td>
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<tr>
<td>Support</td>
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<td>Norms</td>
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<td>Communication</td>
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<td>TRUST</td>
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<td>PARENTS</td>
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<tr>
<td>What’s right?</td>
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<td>Future worries</td>
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<td>Expectations</td>
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<tr>
<td>Recognition of the past</td>
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<td>HEALTH PROFESSIONALS</td>
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8.2 Decision making scale

At the end of the interview all participants were asked to fill in the decision making scale (DMS) (4.11, figure 4:5). The aim was to get their overall impression of where the responsibility lay for decision making when it came to deciding for the child who was born with a VSC/DSD. Each participant was given the task to place an X on the DMS, indicating where they felt the responsibility for decision making lay between the parent and the HP when their child was an infant. The young people were also given the scale and asked to provide their opinion on who should have the most responsibility for decision making for when the situation involves a young child.

The young people in the study had an additional DMS task (4.11, figure 4:6). The second DMS was to garner the opinions of the young people about where the
responsibility lay for decision making when the young person is of an age they can decide for themselves.

I will present the statistical analysis first, followed by some commentary on the patterns of engagement while participants were completing the DMS. The conversations during this process revealed some interesting insights on the complexity of decision making.

8.2.1 Statistical results

The participants found the DMS challenging and wanted to separate out not life threatening situations from life threatening situations. This meant for four of the parents and HPs provided two responses, one for each situation. This was also the case for the two DMS’s for the young people. To account for this variation, analysis was conducted twice; for example, once using the not-life threatening responses for the four HP’s who had two recorded responses; and once using the “life threatening” responses from these four HPs. This dual analysis was also done for the parents; of whom four gave two responses and for the young people; two that gave two responses (see table 8.2).

There were no significant differences in the participant groups when it came to divergence from the midpoint of 10 on the scale (The scale was 1-20, 4.11). There was also a wide range from the minimum and the maximum for each group (table 8:2).
Table 8.2 Descriptive Statistics for all 3 participant groups

<table>
<thead>
<tr>
<th>Group (1=child, 2=par, 3=HP)</th>
<th>First scale Parent-HP (life threatening*)</th>
<th>Parent -HP (not life-threatening **)</th>
<th>Second scale YP-HP (life threatening*)</th>
<th>YP-HP (not Life-threatening**)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Young people</td>
<td>Mean 11.72</td>
<td>11.17</td>
<td>10.78</td>
<td>7.11</td>
</tr>
<tr>
<td></td>
<td>N 9</td>
<td>9</td>
<td>9</td>
<td>9</td>
</tr>
<tr>
<td></td>
<td>Std. Deviation 3.25</td>
<td>3.04</td>
<td>4.79</td>
<td>4.01</td>
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<tr>
<td></td>
<td>Median 10.00</td>
<td>10.00</td>
<td>12.00</td>
<td>6.00</td>
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<tr>
<td></td>
<td>Minimum 7.00</td>
<td>7.00</td>
<td>2.00</td>
<td>2.00</td>
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<td></td>
<td>Maximum 15.00</td>
<td>15.00</td>
<td>17.00</td>
<td>12.00</td>
</tr>
<tr>
<td>Parent</td>
<td>Mean 8.64</td>
<td>8.39</td>
<td></td>
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<tr>
<td></td>
<td>N 18</td>
<td>18</td>
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<td></td>
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<td></td>
<td>Std. Deviation 5.04</td>
<td>4.98</td>
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<td></td>
<td>Median 10.00</td>
<td>10.00</td>
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<td></td>
<td>Minimum 1.00</td>
<td>1.00</td>
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<td></td>
<td>Maximum 18.00</td>
<td>18.00</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Health Professionals</td>
<td>Mean 8.95</td>
<td>8.80</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>N 19</td>
<td>19</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Std. Deviation 3.06</td>
<td>3.25</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Median 10.00</td>
<td>10.00</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Minimum 1.10</td>
<td>1.10</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Maximum 15.00</td>
<td>15.00</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* analysis for life-threatening included responses to decision making under life-threatening circumstances for those individuals who gave two responses  
** analysis for not-life-threatening included responses to decision making under not-life-threatening circumstances for those individuals who gave two responses

I used the one sample t test to test whether the mean response to either task was significantly different from 10 (the middle point). None of the responses, on average, showed any difference from the middle point (10). See Figure 1 and Figure 2 below.
As there was no significant difference from the median, possible explanations include no specific preference or a tendency to shared decision-making or that it was difficult for them to decide one way or the other. There were some outliers for each group with a wide range between the minimum and maximum values see table 8:2 above for details.

While there are no statistically significant differences, it is clear from the means that overall they are closer to the centre value of 10 (range 8.39-11.72) for the parents - HP DMS, indicating that, overall, people are leaning toward shared decision making.
8.2.2 Comparison between the two scales; YP-HP and Parent-HP

Lastly, I asked whether or not the responses differed systematically from the two situations, those being Young person - HP and Parent - HP. I used a paired t test to look at the differences in scores for each person, and to test whether those differences were different from zero.

When the situation was not life-threatening, the difference between mean score differences reached statistical significance, (Paired t(8) = 2.906, p = .020). That is, the young person considered that when the young person was too young to decide, there was an almost equal preference for either the parent or the HP (mean of 11.17), but when the young person was able to decide, there was, on average, a stronger preference for the young person over the HP (mean of 7.11). This difference in degree of preference did not exist for life threatening situations.
T-TEST

Table 8:3 Descriptive statistics for decision scales for young people

One-Sample Statistics

<table>
<thead>
<tr>
<th></th>
<th>N</th>
<th>Mean</th>
<th>Std. Deviation</th>
<th>Std. Error Mean</th>
</tr>
</thead>
<tbody>
<tr>
<td>Par-HP</td>
<td>9</td>
<td>11.72</td>
<td>3.25</td>
<td>1.08</td>
</tr>
<tr>
<td>Par-HP not life threatening</td>
<td>9</td>
<td>11.17</td>
<td>3.04</td>
<td>1.01</td>
</tr>
<tr>
<td>YP_HP</td>
<td>9</td>
<td>10.78</td>
<td>4.80</td>
<td>1.60</td>
</tr>
<tr>
<td>YP_HP not life threatening</td>
<td>9</td>
<td>7.11</td>
<td>4.01</td>
<td>1.34</td>
</tr>
</tbody>
</table>

Paired Samples test

Table 8:4 Statistical analysis of decision scales for young people

<table>
<thead>
<tr>
<th></th>
<th>Mean</th>
<th>Std. Deviation</th>
<th>T</th>
<th>df</th>
<th>Sig.(2-tailed)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pair 1</td>
<td>Par-HP – YP-HP</td>
<td>.94444</td>
<td>4.55826</td>
<td>.622</td>
<td>.552</td>
</tr>
<tr>
<td>Pair 2</td>
<td>Par-HP not life threatening – YP-HP not life threatening</td>
<td>4.05556</td>
<td>4.18662</td>
<td>2.906</td>
<td>.020</td>
</tr>
</tbody>
</table>

The response YP-HP ranged from 2.0 to 12.0, with a median of 12 and a mean of 10.78 (SD = 4.79). On average, then, the respondents preferred to make decisions themselves rather than having a HP make them for them. For response Parent-HP, the range was from 7.0 to 15.0, with a median of 10 and a mean of 11.17 (SD = 3.25). On average, then, the respondents had a slight preference for having the HPs make the decisions over their parents.

So, in this sample, this difference reached statistical significance (p = 0.02) for young people wanting to have the responsibility for decision making as opposed to the HP having the responsibility. The young people respondents were more likely to select the HP over their parents in the younger child (infant) situation, and more likely to select themselves over the HP in the older child (teenager) situation.
Figure 8:3 Box plot young people participants choosing between young people and HP for decision making when the situation is life threatening.

Figure 8:4 Box plot young people participants choosing between young people and HP for decision making when the situation is not life threatening.

Figure 8:4 indicates that young people would prefer to make decisions for themselves if they can. This is supported by participants’ comments as expressed in
chapter seven where the young people spoke of wanting their own autonomy and agency to decide about their bodies (7.9).

8.2.3 Pattern of engagement
The DMS was challenging for some of the participants, with many saying it was too complex to put a response into a linear scale. Participants commented it depended whether it was a life threatening situation or not. Therefore, they wanted to respond with two answers for each situation, or a range. The HPs also added other factors such as complexity of the diagnosis, education of the parents and that the child needs to be the central focus and what they might want.

HPs
Out of the 22 HPs 19 responded and three people declined to answer. One HP did not want to complete the DMS task and two others could not find a way to respond on the decision scale saying it depended on too many variables. This meant I had data for 19 of the 22 HPs who completed the DMS.

Four HP’s had to split it into complex/life threatening situations versus simple non-life threatening. These HP’s therefore had two responses to the task, which was handled by conducting the descriptive analysis twice (as described earlier).

Nine of the HP’s felt the decision making was shared, with an additional 3 HPs also agreeing when it was not a life-threatening situation or not too complex. These HPs expressed it should be a shared responsibility. Two HPs were more toward HP making the decision as they asserted it was not fair for parents to have to take responsibility for decisions in an area they would not have expertise in and it was the role of the HP to provide guidance based on their expertise. Some HPs were inclined toward the parents having the greater responsibility as it was their child and they therefore held the responsibility.

There was some internal contradiction, as throughout the main interviews all HPs felt in the end it was really the parents who ultimately had responsibility for decision making, as discussed in chapter five.

Parents
All parents completed the DMS. Some parents gave a range rather than a specific answer. For these parents it depended on the situation. If it was life threatening or
very complex it would lean more toward the HP. If it was more straightforward the responsibility for decision making would be more towards the parents. Others felt that the responsibility was definitely shared between the HPs and themselves. Six parents felt that they had the majority of the responsibility for decision making.

Two parents felt that the HPs had more responsibility for two very different reasons. The first was a father who completely trusted the HP to do what is best by his children, he thought that a “circle of trust” was established and that HPs earned that trust. Another parent expressed that while she wished parents had more of the responsibility and that this would be the ideal, the reality was that the HP had more of the responsibility.

**Young people**

Of the young people sampled, 9 completed the DMS with one preferring to just give her opinion verbally as she did not want to be confined to a scaled representation.

Young people clearly indicated they would prefer to have autonomy over their bodies as young adults. Interestingly, they were more inclined to select the HP to take responsibility for their care at a young age (infancy). There was a perception from some young people that parents would be too emotionally invested to not just focus on making their child normal. Conversely, they expressed a belief that HP would be more objective and see the big picture for the child.

**8.2.4 Summary**

There are limitations with the DMS as not all people could fill it in due to struggling with the linear nature of the DMS. In hindsight it may have been useful to ask the parents and HPs to complete the second DMS of young people–HP. Then a comparison could be drawn between all three groups.

However, it was useful to get their commentary which may not had occurred had the DMS been more straightforward. This data also highlights that participants can often say one thing and then contradict themselves later. This was the case with most HPs saying they felt parents were ultimately responsible, even though this was not borne out in the results of the scale. Perhaps this was because when it was put in a visual form they felt compelled to answer in a way that was closer to the norm, i.e. closer to the middle. There may be a perception that this mid-point represents shared decision making which is seen as the ideal.
8.3 Integrated case summaries

For three of the young people that I interviewed, I also separately interviewed the HPs taking the lead in their health care and their parents (see table 8:5). While my intention was to talk to each participant only about their own personal experiences, they spontaneously made a number of comments about the other groups. In the three cases where I had interviewed the young person, their parents and a lead health professional, it was therefore pertinent to systematically compare whether they had the same impressions as each other regarding decision making. In this section, I will now discuss these 3 cases and the elements that influenced decision making.

Table 8:5 All key groups related to young person care interviewed.

<table>
<thead>
<tr>
<th>Young person</th>
<th>Parent</th>
<th>Health professional</th>
</tr>
</thead>
<tbody>
<tr>
<td>Amber</td>
<td>P11 -mother</td>
<td>HP14</td>
</tr>
<tr>
<td>Bridget</td>
<td>P7-mother P8-father</td>
<td>HP3 HP2</td>
</tr>
<tr>
<td>Julie</td>
<td>P12-mother</td>
<td>HP4</td>
</tr>
</tbody>
</table>

8.3.1 Case 1: Amber

Amber was born with a Cloacal anomaly (see glossary) which required emergency surgery in order to ensure Amber lived, as she had no way to void waste from her body. Her mother reported having total trust in the decisions being made in order to save her daughter’s life.

The surgeon commented after conducting the lifesaving procedure, that he had also created a vagina for Amber so that she could have “normal sex” when she was older. There had not been any discussion prior to the surgery about this.

The surgeon later performed surgery to create a “trap door” as an alternative to a stoma. As a young teenager, Amber decided she no longer wanted this, preferring to return to a colostomy. There was a difference in opinion about this between the surgeon and the family (6.5.1 & 7.13.1 for more detail). Amber, with her mother’s support, was able to assert her agency and have the “trapdoor” removed in favour of a colostomy.

Amber won a speech competition at her school where she talked about the challenges of having a VSC. She challenged her classmates to disrupt the norm and think about a “new normal” that was more inclusive.
The focus of discussion here is the process of arriving at the decision to opt for a permanent colostomy, rather than accepting the surgeon's recommendation to persist with the “trapdoor” (see glossary).

Amber stated in the interview, that this should be her decision and had extensively discussed with her mother the pros and cons for both options. Amber’s mother raised with the surgeon the fact that Amber wanted to revert to the colostomy, knowing that it would be permanent. She was not experiencing the expected benefits from the trapdoor, and while she was aware of future concerns regarding a potential partner, she was more conscious about what a partner would think about fertility issues than her having a colostomy. The surgeon responded initially by saying no. This was upsetting for Amber and her mother, and Amber's mother felt she needed to advocate strongly for her daughter to be heard, reporting that it took her having a “meltdown” in order for the surgeon to “hear” her daughter's decision to have a permanent colostomy. Once the surgeon did hear more about Amber’s decision and accepted that it was what she wanted, he eventually conceded and agreed to do the procedure.

I would argue that the elements of bias toward the “ideal norm”, communication issues and disrupting the norm all contributed to this situation.

The surgeon genuinely considered the “trapdoor” option to be in Amber’s future best interests. The overall basis for his clinical recommendation appeared to be his opinion that the “trapdoor” was closer to “normal” functioning and appearance, and as such would make life easier for Amber. He also expressed a view that this option would be helpful when Amber became interested in having a sexual partner (i.e. that she would be more attractive to a partner if she did not have a colostomy bag). His recommendation was also based on clinical experience (namely that the “trapdoor” had worked very well for another patient, who had achieved continence using the trapdoor), and his concern that Amber was still very young (early teens) and that she may therefore change her mind. The surgeon thus reasoned there were a number of benefits to retaining the “trapdoor”, despite the concerns and difficulties raised by Amber.
Communication issues also clearly played a part. Amber was clearly saying the trap door was not working for her and she wanted the colostomy, and Amber’s mother felt frustrated by the surgeon’s directive approach, despite feeling like they had a good patient-doctor relationship. There was communication breakdown between the family and the surgeon, that was only resolved by Amber’s mother strongly asserting herself in a way that the surgeon could not ignore.

From Amber’s perspective, there was a need to disrupt a number of prevailing societal norms relating to bodily function and appearance, and also to the ability of youth to make important decisions for themselves. Although, as gatekeeper, the surgeon had the power to decline his patient’s request, Amber considered that it was her body and she wanted him to recognise her right to bodily autonomy. The desire to be “normal” was outweighed by the desire to have a treatment option she was comfortable with, and she was confident in this choice, in the full knowledge that it would be permanent. Amber went on to continue challenging the norm and find others who were like her. She was effectively saying “you have to change the way you see normal instead of trying to make me fit the norm”.

In this situation all three participants were unquestionably committed to basing their decision making on Amber’s best interests. One point of contention is what was in Amber’s best interests? The other point is who ultimately should be making the decision? Initially, the surgeon asserted his point of view and took charge of the decision making. Amber and her mother had to team up to contest this, and ultimately Amber’s mother had to challenge the surgeon on her behalf. This case exposes the need for HPs to be aware of their own bias and how this affects the way they communicate and discuss issues of agency when there are differing points of view, rather than just asserting their position of power, no matter how good their intent may be.
8.3.2 Case 2 Bridget

Bridget has complete androgen insensitivity syndrome (CAIS). This was discovered as a result of her brother being born with partial androgen insensitivity syndrome when she was in her early teens (see glossary).

When the younger brother was born it was unclear what gender to assign and the child HP specialist worked with the family to provide support for Bridget and her brother. In this situation the HP caring for both children declared how stressful this situation was, and how worried they were as to whether they had made the right decision regarding the sex of Bridget's brother. Once Bridget was older, an adult HP specialist took over her support. These HPs communicated well with the family, who referred to the HPs as being in “the circle of trust”.

<table>
<thead>
<tr>
<th>Bridget</th>
<th>EP 7-mother</th>
<th>E P 8-father</th>
<th>HP 3(child)/ HP 2(adult)</th>
</tr>
</thead>
</table>

The focus for decision making in this case was sex assignment and whether they had got the gender assignment correct. Both HPs discussed the complexity of the situation for this family, with one HP in particular talking about “sweating over” making the decision regarding gender assignment and the pressure to get it right, indicating the pressure of their own expectations and that of the parents. It took nearly a year to assign the male gender after a multitude of tests and seeing if the baby would respond to testosterone. Initially the parents had referred to their baby as a girl and given her a girl's name. The parents were very open and had good support from each other and had complete trust in their HPs. They commented that there was little in the way of support groups for parents and young people in Aotearoa/NZ. The support they did find from other parents, with similar but not the same condition as their children, was deemed unhelpful (6.8.2).

The elements of norms and bias were exhibited by both the HPs and the parents. The HP had raised that the children’s variation may have an impact on their interests and sexuality. The father (EP 8) discussed openly his bias around homosexuality and that he disrupted his normative thinking and intentional bias towards gay people. He was able to see it would help his children feel more accepted should they express interest in the same sex. He also felt it made him a better human being (6.6.3).
Bridget did reveal she was “pan sexual” (someone attracted to anyone regardless of their sex or gender identity) and she herself was not sure whether this was the result of her variation or it would happen anyway (she remarked about her friend who did not have a VSC who was also pan sexual). These are questions neither science nor society can conclusively answer. The facts tend to point to greater understanding that both gender and sexuality are on a spectrum and can be fluid within that spectrum. Bridget accepted herself as unique after initially questioning her identity when diagnosed (7.7.3 & 7.10).

Both HPs asserted that any potential same sex attraction would be the result of their variation. However, there are many young people who do not have these variations and may be equally non gender conforming with their choices of play and sexual partners. This heteronormative perspective was pervasive among HPs and some of the parents interviewed.

The child HP was relieved about the male child exhibiting “boy like behaviour” playing with trucks. The other adult HP remarked about Bridget coming for a consultation wearing makeup and dressing in a more “feminine” way, and that was reassuring that she was indeed identifying as female according to gender stereotypes.

This case amplifies the importance of communicating acceptance of diversity and in the most part HP3 was able to do this, HP2 less so. The parents, in particular the father came to the point of acceptance and the mother, while more accepting of diversity, still harboured guilt for having the gene “mutation” that created these variations in her children. This mother had a tubal ligation to prevent her having any other children “as life is hard enough” without having a VSC. It was apparent that both parents would have liked to have more children. You have to wonder whether the mother may have felt differently if she had more support and it was clear there were more supports for young people.

The case highlights the elements of disrupting the norm, identity, communication, support and bias and how they impact on the experience of having a VSC.
8.3.3 Case 3 Julie

Julie has Turner syndrome (see glossary). She is of very short stature for her age and this has been the case all her life. She is on hormone treatment and will be for life.

Julie was not diagnosed until 16 when she began to develop facial hair and was referred to HP4. Julie’s Mother (HP 12-mother) has supported her daughter throughout the process of diagnosis and treatment.

<table>
<thead>
<tr>
<th>Julie</th>
<th>HP12-mother</th>
<th>HP4</th>
</tr>
</thead>
</table>

- Julie has the option to have surgery to reduce her clitoral size (due to added complexity in addition to Turner diagnosis) but has chosen not to proceed at this stage of her life (at 17 years old). She is unsure if she will opt for surgery in the future.

- There was frustration by the family that Julie’s variation was not picked up when she was younger. In particular her short stature is a feature of her variation. This was particularly upsetting for Julie’s mum as she felt she had raised issues when Julie was an infant especially regarding her height. It was only once she was seen by HP 4 it became evident that Julie had Turner syndrome. Julie’s mother felt that had this been picked up earlier things would have been easier for Julie. She felt education for GPs was essential.

- However, this case otherwise illustrates good communication between all three key players.

- HP4 was very open and communicative with the family and provided options regarding treatment. Julie and her mother reported HP4 supporting them by offering them time to discuss things and time to think about what Julie wanted. Julie had not made any decisions regarding a clitoral reduction and HP4 and her mother expressed there was no rush. Both HP4 and Julie’s mother gave Julie full agency over deciding what she wanted for her body and when. Julie was not ready at 17, so was going to leave making a decision until later. Julie did comment she would find it helpful to talk to someone about the possible surgery.

- In this case the HP provided time, space and options for Julie to consider regarding possible genital surgery and what is best for her, thus ensuring bodily autonomy. He
has provided hormone therapy to aid in her growth and to suppress the secondary sex characteristics found typically in males. Both Julie and her Mum commented they would have benefited if there was some specialist support on a psychological level. As such, this case also illustrates the importance of appropriate support for decision making.

Julie’s experience also suggests that more information needs to be provided at the primary care level, as some HPs not experienced in VSC do not have the level of awareness/specialist education to diagnose or refer on for these variations. Julie was also uncertain if her differently sexed genitals would have an impact when she becomes interested in forming an intimate relationship, thus highlighting the temporal nature of such decision making.

**8.4 Younger children born with VSC**

There were also a number of cases where I talked to both the HP and the parents of younger children. I will discuss three cases in particular, their details are in the table below. All the children were diagnosed at birth or within a week. The ages in the table indicate what age they were when the parents were interviewed.

**Table 8:6 Case details for younger children discussed between HP and parents**

<table>
<thead>
<tr>
<th>Parents</th>
<th>Health professional</th>
<th>Child</th>
</tr>
</thead>
<tbody>
<tr>
<td>4</td>
<td>Parent 6-mother Only one parent interviewed</td>
<td>HP14 HP1</td>
</tr>
<tr>
<td>5</td>
<td>Parent 3-mother Parent 4-father</td>
<td>HP16 HP1</td>
</tr>
<tr>
<td>6</td>
<td>Parent 14-mother Parent 15- mother</td>
<td>HP3 HP11</td>
</tr>
</tbody>
</table>
8.4.1 Case 4

The baby in this case had severe hypospadias, and a micro penis with chordee (a bend in the penis), and was in the neonatal ward due to other life threatening issues. The birth mother was also unwell. Once their son’s other urgent health issues were addressed, the parents had questions about their son's gender and about the surgeries proposed. The parents sought to gather information and requested a meeting with all the HPs involved. The parents came prepared with questions and reported getting limited responses to their questions. The parents were unhappy with the response, and wrote a letter reiterating some of their questions and concerns. They again received no response and reported feeling pressure to concur with the surgeon's recommendations (HP14).

<table>
<thead>
<tr>
<th>DP 6 -mother</th>
<th>HP 1 /HP 14</th>
</tr>
</thead>
<tbody>
<tr>
<td>The main issue in this case was around communication between the parents and the HPs. This parent reports HP1 visiting her to discuss her son's condition and the complexities of the condition. At the time she was very unwell and started vomiting and HP1 continued with the discussion rather than postponing it. The mother in this situation was in no state to retain information or make sense of the complex conversation being had.</td>
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</tr>
<tr>
<td>In the parent’s letter that they sent after the first surgery, they asked questions to clarify the following concerns:</td>
<td></td>
</tr>
<tr>
<td>1. His full diagnosis</td>
<td></td>
</tr>
<tr>
<td>2. Was his surgery for hypospadias or full genital reconstruction (the latter being what one of the surgeons had stated loudly after examining the child after his first surgery-as reported by parents)</td>
<td></td>
</tr>
<tr>
<td>3. Are there any immediate medical problems related to these surgeries?</td>
<td></td>
</tr>
<tr>
<td>4. Can the surgeries be delayed so our child can decide?</td>
<td></td>
</tr>
<tr>
<td>5. Will surgery diminish sexual satisfaction in later life, create scarring, have a poor cosmetic outcome?</td>
<td></td>
</tr>
<tr>
<td>6. What is the outcome evidence of such surgeries?</td>
<td></td>
</tr>
<tr>
<td>7. Have you had other patients with this condition?</td>
<td></td>
</tr>
<tr>
<td>8. What are the psychological and physical wellbeing outcomes?</td>
<td></td>
</tr>
</tbody>
</table>
The parents also raised their concerns of giving their son the message that he had to be “fixed” in order to be accepted. The letter was ignored. These are questions that are difficult to answer as there is very little outcome data as discussed in earlier chapters (two and three). These parents were wanting to make a fully informed decision taking into consideration the future of their child.

HP 14 was focused on making the penis function so he could urinate standing and remove the bend (chordee) in the penis. This HP could not understand why the parents were asking all these questions when the child was obviously a male and therefore needed to have surgery that would help him have close to normal function as possible.

The parents expressed that when they asked questions of HP14 it was received as though they were attacking or were questioning the expertise offered. In their minds they were simply trying to attain some clarity so they could make the best possible decision for their child.

In this situation the communication had broken down from both HP14’s and the parents’ perspective. Both the parents and HP14 reported that they were not listened to. HP14 stated this to be the case because the parents would not accept and trust in the treatment recommendations, although the power imbalance in this decision making scenario in fact favours HP14 who is in a stronger position to assert their authority.

There was no support for the parents from HP14 to enter into a dialogue and have their concerns addressed. The parents reported feeling pressured into agreeing to surgery they did not feel confident about. These parents had worries for their child’s future and were not sure they were doing what was right.
8.4.2 Case 5

In this case the two children (aged two years and five years at the time of interview) have congenital adrenal hypoplasia (CAH). The girls have both had genital surgery for both function and form (appearance). The initial consulting surgeon was passed over for a more experienced surgeon as recommended by HP1. The first child with CAH had ambiguous genitalia at birth and was first thought to be a boy. The parents had sent out an email saying the child was a boy but then had to send another to say they had got it wrong. This was particularly upsetting for the mother. They were more prepared when their next daughter was also born with CAH. They waited to confirm the gender before they informed family and friends. The new surgeon, HP16 reassured the parents that surgery was for the best and the parents agreed, although the mother did report she had some worries about altering her daughters. The father asserted the surgery was a “no brainer” and was confident his wife would come to that way of thinking also, which she eventually did (6.10.1 for more details).

<table>
<thead>
<tr>
<th>BP 3-mother BP 4-Father</th>
<th>HP1/HP16</th>
</tr>
</thead>
<tbody>
<tr>
<td>This case reflects that parents can be just as invested in the norm as HPs. Nevertheless, the parents still felt they were directed by the HPs to have surgery. HP1 suggested they have a surgeon who was specialised in the surgery rather than a local surgeon who was not as experienced as a different surgeon based in another region. The parents were appreciative of HP1 advocating for a specialist surgeon as they wanted to feel confident that their daughters were in competent hands. HP16 offered them support and suggested they be open with the girls about CAH and tell their first child with CAH that they were misgendered initially, so that there would be no surprises. HP16 was mindful of the harm caused by non-disclosure. The parents however, in particular the mother, was unsure how to convey this to her daughter who was only 5, indicating the need for more specialist psychological support around how to have conversations with the children. The mother struggled about whether appearance based surgery was the right thing and reported continually worrying for her children’s future. The older of the two girls with CAH showed an interest in what would be considered typically boys’ interests (such as soccer, pirates etc). The parents both worried about this as they...</td>
<td></td>
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</tbody>
</table>
were concerned that their daughter may be isolated as a result. The father commented he had revised his heteronormative and homophobic thinking as he may have a daughter who might express an interest in same sex relationships when they were older.

This family illustrates the complexity of managing future worries by parents choosing to help their daughters’ bodies “conform” to the norm. However, the parents were willing to adjust their own normative thinking to be more accepting of different behaviour and possible future diversity around sexuality and gender expression in their children. Both HPs were offering support to the parents; however, the parents said they would have liked more specialised psychological help to manage communicating with their children as they grow and develop, reflecting the need for support.

8.4.3 Case 6

In this case the 2 year old daughter has CAH and was diagnosed at birth. The parents, two mothers, had similar concerns to the family in case two regarding whether to do genital surgery for function and form (appearance). The HP advised them of all the options and said in regard to clitoral reduction this was not something they had to do now and could be delayed till the child was old enough to decide for herself. However, the usual recommendation would be to do the surgery early. The HPs felt the surgery to ensure continence would be advised. The parents agreed but opted to not proceed with the clitoral reduction. They did not see any function served by reducing their daughter’s clitoris. The parents did get some pressure from family members about why they had not opted for the clitoral reduction (see 6.10.1).

This situation had the same issues regarding the desire to conform to the norm and both parents felt some pressure from within themselves and from family. Both parents expressed the same concerns as BP3 in case 5; namely, wondering if they had done what was right for their daughter’s future. They talked with both HPs and wrote a long email to HP11 regarding surgery, and asking lots of questions. HP11 responded immediately and answered all their concerns openly.
HP3 expressed that she was not sure how things would be for this little girl as she grew up with her differently sexed genitals, and was also somewhat concerned that she may not have typical girl interests. However, HP3 was comfortable because the parents were lesbian and had personal experience of being different. HP11 also felt a sense of relief that this little girl was with these parents, as he felt he did not have to convince them to leave the clitoral reduction until the child could decide for themselves, which was his preference. HP 11 had a different approach from HP16, being in favour of delaying clitoral reduction, and was aware that this was different to other surgeons.

This case reflects how similar clinical situations can be responded to and handled differently. In this instance the parents were supported to ask questions and were offered options by both HPs. Both HPs were happy that the parents had a broad perspective and were accepting of difference and diversity. However, both mothers expressed concern and uncertainty. (JP 15 was more worried about the effects of not having the surgery than her partner, but felt reassured by HP11 and HP3). HP3 harboured the same concerns about the future for this child but was able to recognise that it was what the parents wanted and was able to support their decision. It would be interesting to know if there would have been a different response (i.e. in favour of clitoral reduction) from the HPs had the parents been a heterosexual couple, though HP 11 was, in any case, in favour of a delay.

The parents reported that it would have been helpful to have had support options around how to communicate to their daughter about her variation as she grows. They were linked to CAHNZ which they found helpful, but also wanted some peer support from parents who were younger (the support person they spoke to had children that were now adults). They specifically wanted ideas about how to talk to others about their daughter and how to build her resilience so that she felt good about her body.
8.5 Common themes across the 3 participant groups

All three groups had themes in common, in particular issues of communication, bias, norms and support.

8.5.1 Communication

Communication issues were the most common theme. Participants from all three groups reported experiencing difficulties in relation to communication, though it is important to note that not all communication was difficult. Although many parents, young people and HPs indicated good communication, there were, nevertheless, many examples of poor communication. This provides a clear indication that there is a need for changes. These include a need for more sensitivity when discussing issues around diagnosis of chromosome variations, especially when talking to the young person concerned. Many HPs themselves said it is difficult to find the right words and would themselves appreciate more support/training in this area. HPs also acknowledged the limited resources for both parents and young people.

In order to understand and make decisions around complex issues, information needs to be presented in an accessible and sensitive manner. It was reported that the information provided needs to be more comprehensive to allow for fully informed consent, and the way information is given also needs to change. Many parents and young people gave instances where only part of the information that they needed was given. This is very relevant when it comes to providing options for treatment, including the options of no treatment or delayed treatment.

HPs raised issues around the delicacy of talking about personal issues such as genitals, sexuality, uncertainty of gender, and the emotions surrounding these sensitive topics. For some HPs this was incredibly difficult or awkward and they wanted other avenues of support. Unfortunately, such support is not widely available, and even where generic psychological support is available, this may not be specialised enough to understand the nuanced experience of VSC/DSD. HPs also
had concerns about support groups for parents and young people that they felt were "biased" or holding differing opinions to those of the HP.

Parents and young people talked at length about needing more time, more open communication, and better listening skills from their HPs.

8.5.2 Bias

Discussion of bias featured in all groups, with each group saying they had witnessed it in the other groups. HPs often talked about advocacy groups being biased, and parents having bias and expectations of them regarding what they can provide.

Some parents talked about the heteronormative and gender stereotype biases they encountered from HPs and for some, from their partners. Young people talked about experiencing bias themselves, then becoming aware and shifting to be more inclusive of diverse views. This was also the experience reported by two of the fathers who discussed leaving their homophobia behind (6.6.3).

Young people seemed the most in tune with difference and diversity compared to the other two participant groups. This is not unexpected, given young people are growing up in a more open and diversity promoting society, compared to others who were at least one or two generations older. Some younger HPs made comments that once some of the older HPs retire, some of the more old fashioned ideas and biases will leave the health care environment.

Other biases included the binary model of viewing sex and gender as simply male or female. Despite increasing science suggesting sex and gender are more of a spectrum, and at times fluid, a strong societal bias remains towards the binary (3.2.5). The expectation to be able to clearly define whether a child is male or female is still the dominant discourse. This is complicated by the fact that the reality for most people born with a VSC/DSD is that it will become clear whether they are male or female. It is only for a small percentage of people born with a VSC/DSD that sex/gender are totally unclear, and even then a gender is usually assigned with the proviso that this may change in the future (though of course this is potentially true for any of us).

Lack of awareness of bias was evident across all three groups but particularly in the HPs and parents. As noted above however, it was interesting that young people felt
that HPs were better to decide their fate as a baby than parents, suggesting they believe that their parents may have more bias than HPs.

The biases discussed above correlated with a tendency to want to reshape the person with a VSC/DSD to fit the binary norm, which I will address in the next section.

8.5.3 Norms

The norms regarding the human body and human gender stereotypes are very strongly based on the dominant discourses in the society in which a person is based. In Aotearoa/NZ that dominant discourse is primarily based on the gender binary of male and female, and the associated normative stereotypes of what these genders should look like. This relates to not only the way genitals should look, but also to the body in general, and who one is attracted to sexually.

The way participants addressed gender norms in their lives produced some major ramifications across all three groups. These included; trying to conform to the norm; challenging the norm; and finally, disrupting and redefining the norm.

There was a strong desire by parents to have a child who was “normal”, and that expectation was also reflected in the medical world with their commitment to the binary and the ideal norms that represents. There is nothing wrong, as such, with wanting your child to fit in to the mainstream, and many of us feel the pressure to conform to norms. The point here is that there is a clear and well documented history of the damage caused by making children conform to prevailing gender norms under the guidelines of John Money and his colleagues at John Hopkins Hospital. HPs talked about learning from the past and learning from patient voices (5.5.1.).

Despite these insights, there still seems to be tendency to promote or accept non-life threatening (non-urgent and/or appearance based) procedures that are more for social reasons, such as not having to “look” or “feel” different. There is a corresponding barrier to accepting that such procedures are not needed or best left for the young person to decide for themselves (no matter how challenging that may be for the young person to navigate).
Young people, once aware that difference is an option, report they are empowered to disrupt the norm and establish “new norms” for themselves. Parents can also be supportive in this process, as can HPs. It does require an acceptance of diversity and resisting the urge to go for the “quick fix” so that parents and others can feel comfortable and assured of their child’s gender.

If a young person decides to conform to a norm regarding their body and the way it looks or performs, then that is a choice they can make as someone who has autonomy and agency to make their own decisions. Otherwise we are at risk of creating another binary of “conformity or deformity”, when in fact, if we disrupt the norm, rethink what is normal and reimagine what is possible, then we can recreate or reinvent existing norms. Figure 8:5 below visually represents this cycle. This cycle was originally used for business branding. I use it here to conceptualise how young people, parents and health professionals could hold what is present in the way of norms but also have a future focus and consider how things might be different.

Figure 8:5 cycle of disruption (Personal Branding &Design Consultants, n.d.)

In the next table, I present an imagined version of this process based on some of the interviews with parents. (This could equally be applied to young people or health professionals). Table 8:8 below illustrates how the cycle of disruption might apply to case five above in section 8.4.2. The first row highlights the normative thought that needs disrupting; the second shows a rethinking of how it could be; the third reimagines the validity of the norm; and the final row illustrates how the norm could be reinvented, thus allowing for a broader concept of the old norm.
Table 8.8 exploring the cycle of disruption

<table>
<thead>
<tr>
<th>Disrupt</th>
<th>“Girls must have a small clitoris to be normal”</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rethink</td>
<td>“Everyone is different, clitoris size will vary”</td>
</tr>
<tr>
<td>Reimagine</td>
<td>“Just because my baby’s clitoris is bigger, that doesn’t make her abnormal”</td>
</tr>
<tr>
<td>Reinvent</td>
<td>“I can help her understand she is unique and normal in a world of diversity”</td>
</tr>
</tbody>
</table>

The other issue which may seem obvious once attention is drawn to it, but one that is rarely raised, is the simple fact of altering a person’s genitals to look “normal” or surgically reshaping them to reflect the ideal norm is in itself a permanent message to that person that they were born “not normal”. The permanence of surgery can lead to internalised stigma and psychological distress, as reflected in chapter two. That has proven to be psychologically very harmful, including the loss of sexual sensation, formation of scar tissue and the need for possible reparative surgery. These risks are often lost on HPs and parents, as their focus is on how to make the child appear normal rather than how can they make the child feel accepted as they are. The lessons from the past tell us that shame and stigma often grow from trying to make genitals look normal.

Moreover, it is not simply the genitals; the removal of gonads or other internal structures that may be involved, and the way hormones are administered can also impact the way a young person views them self. This is where the thorny issue of function over form, cancer risk and availability of different types of hormones come into play. Some young people for example may wish to keep their gonads intact if given the choice so as to support puberty, whereas some parents and HPs may recommend that they be removed to avoid future risks.

8.5.4 Support

All the young people participants thought it would be useful to have peer support in Aotearoa/NZ. Those who had sought peers through online support found it very helpful and for some it was life changing (7.8). This support was vital for young people, especially peer support, as this was often seen as a gateway for acceptance of oneself and entry to a “caring community” of peers. These caring communities enabled a sense of belonging and personal strength that helped young people feel
connected and accepted. This in turn encouraged the strength to reject the norms imposed by the binary and form an identity free from shame and stigma. Some young people had worked through these same processes with support gained from their parents and HPs, though this was less often the case.

Some HPs feared that such groups would cause radical thinking or “flag waving” as one HP was reported to have said (personal communication, November 2016). This fear was not well-founded. While two of the young people I spoke to had become advocates for VSC human rights and awareness raising, this does not need to be regarded as negative. The majority who had talked to peer support groups were just getting on with their own lives doing study or working. The gains from peer led groups were that young people had support to feel less isolated and alone with their difference. They had a sense of belonging and connection after having previously been given the message that they would not find others like them.

Parents wished they had support from other parents, though one set of parents found the parents they spoke to unhelpful due to a focus on the effects on the parent’s relationship. Others wished there were younger parents closer to their age to talk to, rather than parents whose children had now grown up and left home. Some parents also shared the concerns that HPs raised regarding peer support for their teens. Parents were at times overwhelmed by the online presence of information especially round the controversial nature of some of the debates, particularly around surgery of the genitals and gonad removal before puberty.

HPs wished they had options of support to offer including, peer and psychological support, and resources for which there are either none or very few when it comes to the specific variations. Some HPs also highlighted they would like more support themselves, especially in terms of advanced communication skills around sensitive topic areas such as sexuality and the emotional impacts of genital and reproductive variation; opportunities for training from those with lived experience; and self-reflection (5.5.1 & 5.5.6.2).

Young people, parents and HPs all wished for better specialised psychological support for all concerned. Overall, each group wished there was better access to written and visual resources, peer support, individual specialised psychological
support and support in how to talk to your child or teen about the complexities of sex, gender and sex characteristics.

8.6 Unique elements affecting decision making

The remaining elements of influence of decision making for the three groups are illustrated in the Table 8:9 below. I will only briefly summarise them here, as more detailed discussion can be found in chapters five, six and seven.

Table 8:9 Unique elements effecting decision making

<table>
<thead>
<tr>
<th>YOUNG PEOPLE</th>
<th>PARENTS</th>
<th>HEALTH PROFESSIONALS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bodily Autonomy</td>
<td>What's right?</td>
<td>Expectations</td>
</tr>
<tr>
<td>Identity</td>
<td>Future worries</td>
<td>Recognition of the past</td>
</tr>
</tbody>
</table>

8.6.1 Young people

In addition to the four common elements influencing decision making, young people identified the importance of bodily autonomy and having the right to decide what happens for their own bodies. This agency for young people was difficult to achieve due to the fact that some of the decision making was made for them by their parents at a young age. Parents’ decision making was often guided by HPs. Most young people wanted medical procedures that were appearance based to be left for them to decide when they were able.

Identity was another area of concern. Of course, all teenagers go through stages of discovering and redefining their identity, and there is temporal fluidity. For this group of young people there can be particular issues around what it means to have a different chromosomal and or hormonal make up that makes development of self-identity different to what is typical. For example, some of the young women participants struggled initially with the idea that they had a Y chromosome, and whether that meant they were really male. With support they were able to accept
that having a Y chromosome did not exclude them from being a woman, but rather that it was just one unique part of them and not something that had to define their whole identity.

Bodily autonomy and identity are elements of influence that are important to young people as they are deeply personal to them, and as a consequence HPs and parents need to be very cognisant of such elements.

8.6.2 Health professionals
HPs had to manage the expectations for themselves, from their professional organisations and from the parents and young people who were their patients. In addition, there were normative expectations, the expectations of advocacy groups and human rights organisations, and increasingly, the worry of legal interventions. Expectation was at times an overwhelming influence on the HPs and their decision making. Balancing the tension and level of emotion resulting from such expectations was challenging for some.

These expectations were all sitting on the recognition that past health care provision for young people with a VSC had led to great harm and stigma, and this also created pressure not to repeat the mistakes of the past. Many HPs mentioned the impact of hearing the devastating stories from those under the previous health care guidelines of the John Money era. The HPs reflected on how such lived experience had made them think more carefully about the treatment options they employed. Some HPs commented there was value in learning from those directly affected by the treatment offered at a given point in time. However, such knowledge garnered from lived experience often intensified their self-expectation to “first do no harm”. The reality, given the lack of outcome data, is that they were left feeling somewhat trapped as they often had to make their best guess without the benefit of good evidence.

These various expectations and the weight of past mistakes, combined with a lack of certainty, makes working in this area very challenging for HPs.

8.6.3 Parents
In the case of life threatening and function focused medical procedures parents were less concerned about the decisions they had made. When it came to non-life threatening procedures based more on appearance and socially motivated reasons,
parents were stuck in the middle. Parents had fears for their child’s future and which side their decision making would fall (i.e. whether it would be what the child ultimately wanted or not). The parents had to contemplate dilemmas such as choosing whether to go with what they think is the right thing for their baby now, or to go with what may be best for the child by delaying treatment and letting them decide. On the one hand they may be aware of the right to bodily autonomy for their child, while on the other hand thinking of society’s expectations of what is considered normal. These are huge dilemmas with the underlying question being whether they should be making that decision for their child.

The pressure of what was right for their child and worries about what their decisions may mean for their child’s future were very overwhelming for parents. However, their concerns may not always be the same as the main concerns from a young person’s perspective. In particular, parents may want or think it important for their child’s body to look more normal (e.g. reduction in clitoral size, or removal of adolescent breast tissue in a male), whereas the young person could have a different point of view, if they were able to decide for themselves.

All of these elements, whether they be the four common ones of communication, norms, support and bias or the unique ones specific to the individual participant groups, are all connected by an overarching element of trust which I will discuss next.

8.7 Trust

Decision making in the health care of children born with a VSC is extremely challenging, as has been expressed by members of all three participant groups, and supported by the literature. I would argue that the presence of trust was the all-inclusive foundational element that underpinned the perceptions of all three participant groups. Trust is the element that ultimately forms the framework for shared decision making. The other elements of communication, bias, norms, support, autonomy, learning from the past, and awareness and acceptance of diversity all require trust in one form or another. Trust is created through relationship and is a very personal and powerful construct that accordingly informs what decisions participants will make. As one parent put it “a circle of trust” is
established, as demonstrated in Figure 8:6 below. The circle of trust between all three groups begins when the child is young.

![Figure 8:6 Circle of Trust regarding Decision making](image)

First of all, parents need to trust each other and have “each other’s back” as is the case in this statement where the father is talking about the strength of his partnership with his wife:

“Yeah it is hard 'cause we've had, we've had each other's backs so like I trust a lot of, I place a lot of trust in our decision making and what we do for our kids now ...”

*EP 8-father*

Many HPs stated the importance of a positive relationship with parents and young people in order to provide the best care, and acknowledged that, as in any relationship, trust is an essential element.

“If the family are trusting of their doctors...and there's a good relationship...then the ups and downs can be worked through over time. You know, there'll be...you know, if there are issues, or there are changes in treatment required, or...then that can be worked through with a trusting relationship.”

*HP4*

“you foster a relationship with them over time, build up a trust

*HP15*
Many of the parents and young people reported a high level of trust in the HPs they worked with, as in these examples.

“they said it was our decision but we had that much trust in the doctors up there, it wasn’t our decision, it was theirs, they just had the word it in a way where we were the ones that made it in the end…”

P8-father

“I did feel that they told me what needed to happen but I put my trust in them and it wasn’t a negative and it isn’t a negative thing, it was me taking that step back and going actually they’re the medical professionals…they should know what they’re doing or they’ve dealt with something similar…”

Parent 18-mother

“so it’s like I’ll just do whatever they say and just, yeah just trust they know what they’re doing and like yeah…”

Anna

Sometimes, however, a child’s parents had differing experiences of trust in their HPs.

“...’cause I, you know I trusted them.{HPs}”

AP 1 -father

“I guess I was less trusting ...”

AP 2-mother

HPs also talked about how they have to trust in what they are doing, and trust the experience of others who advise them, as in this quote:

“I have to trust the people that have gone before me that have 20 years of experience under their belt”

HP16

Another HP talked about lack of trust in the scientific evidence on which he has to base his decision making.

“I don’t feel completely trust...trusting of the data we have on malignancy”
Here Georgia makes an observation about the influence of older HPs on newer HPs, and the power dynamics that influence opinions.

“it's these young doctors who are training. I mean you've got such a strong influence with the senior medical team they're working with. And they're going to trust them and they're going to have a rapport with them. They need to be given context in which they can compare if they choose to, the opinions of those senior staff they’re working with and the reality of patients’ lives because it's, the discrepancies there potentially can be humungous”.

Georgia

In addition to the basic “circle of trust”, young people also spoke about having to trust before they can disclose about themselves and their VSC to others.

“I've told my close friends that I can trust with things like that but there's only like two people that know.”

Bridget

“you have to build of level of trust with people too (re peer group)”

Georgia

In all of these instances, trust is the anchor. Trust is what creates the relationships that are often long lasting throughout a child’s life before they are transferred to equivalent adult services. Trust is the element that can sway a parent or young person to agree to what has been discussed as a treatment option. Parents are trusting each other to make the right decision for their child in the present and the future without knowing what the future will bring. The young person for their part is totally reliant on their parents or carers as a baby, but as the results of this study show, they are hopeful that parents will trust them with their bodily autonomy in the future, so that they can make decisions for themselves in the future.

Trust also underpins the HPs’ desire to “do the right thing” and “do no harm”. However, HPs are basing that on what they often know to be data that is either
limited or poorly researched and at times based on a “best guess” or caseload experience and bias. HPs are also having to place their trust in professional guidelines that are constantly evolving.

8.8 Summary

In this chapter I have taken a comparative look across all the three participant groups starting with the decision scale which showed a significant difference for young people preferring the HP over their parents to take more responsibility for the decision making when a child is a baby. This shifted once young people were old enough to decide for themselves, at which point they would choose to do this rather than have HPs (or parents) make the decisions.

The key thematic elements in common across all groups were communication, norms, support and bias. These impacted on each group in nuanced ways reflecting the complexity of decision making. Applying a critical lens and analysis also indicates the layers of influence arising from a desire to conform to normative ideal standards reflecting the dominant binary conceptualisation of biological sex and gender.

The pressure to either conform to certain aspects of the norm and/or to reject some or all of the norms link to acceptance of self. Both can apply to the same situation and the way in which this plays out will depend on the individual person, their support networks and the way in which information is communicated to them. This also varies according to whether we are talking about a child or a young person. Health professionals, parents and young people need to be aware of bias and that “norms are just norms”. Difference and diversity are perfectly acceptable and can exist alongside more normative ideals, as illustrated by the parents that decided to proceed with a vaginoplasty for their daughter to meet her immediate health needs, but not to include a clitoral reduction, preferring to leave that for their daughter to decide for herself later.

Issues with communication and lack of support indicate a clear need for change and improvement. Issues of availability of support were identified, especially appropriate support for parents and young people. Participants consistently reported experiencing a lack of access to peer support, whether that be for parents or young people. Lack of connectivity of HPs to support groups here in Aotearoa/NZ
was evident, and there were reservations expressed by some HPs about connecting parents and or young people to advocacy and support organisations such as ITANZ. Young people found connecting with other young people was transformative and reduced isolation and shame. Connecting with peers was psychologically empowering and was a gateway to acceptance of difference and diversity, reframing the norm and at times rejecting the norm in favour of creating new norms and identity.

Trust was an overarching theme that scaffolded all the other themes and intersects with them across all three groups. It is vital to facilitating effective processes of decision making. Trust is aided by good communication, awareness of bias, good support and understanding of what is possible and what is not. Trust has to exist between the parents, young people and the HPs, and each party has to trust that they are making the right call for their child (or themselves) now and for their future. The young person will want to know that both their parents and the HPs are holding their best interests at the heart of any decision making.

When trust is diminished or eroded for any of the three participant groups it can cause anxiety and loss of faith in the decisions that have been made in relation to health care.

I will expand further on these interrelated themes and other implications of the trust element in the discussion chapter, where I look at what these findings mean in relation to decision making, and draw together my conclusions.
Chapter Nine
Discussion
“Stretching beyond the binary”

9.1 Summary of the research

This research set out to understand the elements that influence contemporary decision making for children and young people born with a VSC/DSD in Aotearoa/NZ. One of the unique aspects and strengths of this research was taking a 360-degree perspective by exploring the experiences of three key groups: young people who have a VSC/DSD; parents of children who have a VSC/DSD; and health professionals who specialize in the area.

In the spirit of Te Tiriti o Waitangi/the Treaty of Waitangi (Aotearoa/NZ’s founding document), I wanted to honour the principles of partnership, participation and protection. Therefore, I developed “practical partnerships” with Māori, people born with a VSC/DSD and health professionals. This research demonstrates close collaboration between activists and academics through all stages of the research design and process. I established and maintained working relationships with Intersex Trust Aotearoa New Zealand (ITANZ) and its representatives. Through their networks I was able to connect with people born with a VSC/DSD and those advocating for people born with a VSC/DSD. ITANZ’s role as an advisor has been invaluable to the conduct of the research. I also established strong links with medical professionals who focus on the care of individuals with a VSC/DSD.

Health professionals and I/VSC advocates/activists have often been at odds with each other, or even openly adversarial; therefore, doing collaborative work with both groups can be challenging. Central to the success of this research was the practical partnerships I developed within the advocacy and health communities. These partnerships were a strength of the research design and will support future collaborations and reflect a commitment to supporting “nothing about us without us” (4.3.1).
Chapter two introduced the main elements of influence on healthcare presented in the literature, including culture, religion, media, medicine, science, intersex activism, human rights and legal constraints. Chapter three detailed the complexities of VSC/DSD from a scientific and biological perspective. These chapters highlight the importance of involving all the key people in the research (practical partnerships). I developed a table (table 3:6) to outline all the main elements of influence on the care of those born with a VSC/DSD over the last century. The table visually summarises and indicates the complexity of all the elements that have had an impact on the approaches and opinions to health care. Taken together, these chapters provide the context within which the research is situated.

Critical realism and feminist principles underpin my methodological approach, emphasising inclusion and ensuring that participants’ realities are expressed and understood within the constructs of society, as discussed in chapter four.

Chapters five to seven give an active voice to all three participant groups and demonstrate the diversity of experiences and opinions regarding the drivers of decision making. There were a number of common themes influencing decision making among the three participant groups: trust, communication, bias, norms and support. Other themes were specific to each group: these included bodily autonomy and identity for the young people; what’s right and future worries for the parents; and expectations and recognition of the past for the health professionals. The overarching theme was trust, which is important in forming the foundation for decision making. These themes, along with the findings of the decision scale, were discussed in chapter eight (table 8:1).

In this chapter, I will discuss findings; the key elements of decision making; a decision making tool based on the research findings (figure 9:1); limitations; and conclusions.

9.2 Discussion of findings

In this section I will consider the elements that influence participant decision making. I will discuss the meaning of these findings, how they relate to the existing literature, and the implications for those working in the field of VSC/DSD and those directly affected by VSC/DSD.
Many of the issues raised in this research relate to the concept of gender. My research demonstrated the persistent dominance of a discourse that reflects the binary notion of sex and gender. But a counter narrative was also present in the data. Does gender have to be a defining factor in our lives? Many societies, and especially younger generations, are more accepting of diverse expressions and presentations of gender (2.13.2 & 2.13.3). Furthermore, we are not expected to present our genitals in order to demonstrate our gender to others. Therefore, the anatomy of an individual’s genitals does not have to be a critical factor in their gender identity or their gender presentation. In fact, it is becoming more challenging to discern someone’s gender, given the increasing acceptance of more fluid representations of gender and decreasing reliance on traditional/stereotypical way of presenting as male and female.

My research demonstrates that people living with VSC/DSD have diverse anatomy, experiences and opinions about the role of the VSC/DSD in relation their sense of self-identity. This was illustrated by the variety of experiences of the health care provided: some positive, some negative and for many a mixture.

While the dominant socio-cultural lens in health remains tied to binary conceptions of gender, it is possible that younger HPs have more liberal and progressive notions of gender which will influence the culture of medicine over time. HPs interviewed in this study were at various ages and stages of their careers. One of the younger HPs observed that change is likely to occur once older HPs start to retire, taking with them notions of the binary and gender stereotypes that are less progressive. However, while there were some examples of younger HPs presenting more progressive views and some older HPs offering the opposite in this research, such an assertion was not supported by the data. Moreover, while there are some older HPs that hold fewer progressive viewpoints and may retire, this is does not address the fact that many of these HPs are currently in positions of power and influence, including advisor and/or teaching positions.

It is important to address issues of the power dynamics within the Aotearoa/NZ health system. Medicine is hierarchical and it is often challenging for younger HPs to challenge older, more seasoned, and consequently more powerful HPs. In smaller countries like Aotearoa/NZ this can be especially difficult because younger HPs are
heavily dependent on the references of their senior colleagues and there are a limited number of specialist centres.

One way to counteract the power dynamic would be to follow the example of Melbourne’s Royal Children’s Hospital (MRCH). At the MRCH they are trialling a VSC/DSD clinical coordinator role. The coordinator role could support more progressive point of view which in turn would support younger HPs’ who also hold similar points of view. The role has the aspirations of: “improving patient and family access to Multi Disciplinarian Team (MDT) and opportunities for open dialogue; enhanced MDT discussion and clinical pathways; increased transparency in decision making and medical management, improved access to information, appropriate resources and support for young people and their families and promotion of patient understanding and autonomy” (Hanna, O’Connell, & Grover 2017).

Hanna et al’s findings reinforced the importance of good communication, and timing and pacing of the information provided, especially for parents and also young people (Hanna et al., 2017). The advantages of a coordinator role could include ensuring information is provided to families in a timely manner, along with the opportunity to ask questions. The coordinator could reinforce to HPs the need for taking time to consider options discussed. The opportunity for families to have all the relevant HPs present at a MDT meeting is likely to be valued by families, as one of the parents interviewed commented that this was not offered until she requested it (6.5.2). A significant advantage of a VSC/DSD co-ordinator role is increased transparency, access to appropriate resources and promotion of autonomy. Ongoing education of staff and resource development could be part of the role, ensuring broader understandings of gender and encouragement of staff self-reflection. A coordinator could ensure parents and young people had “thinking space” to make informed decisions.

9.2.1 Key elements of decision making

This research demonstrates the challenging nature of decision making for children born with a VSC/DSD. Historical elements that have affected health care, and more broadly the social status, of people born with a VSC/DSD are represented in table 3:6. This collation of historical events and milestones explains the context within which the research with all three participant groups is based. Previous research has
established that the history of health care for people born with a VSC/DSD has had profound consequences (chapters two and three) and has resulted in endeavours by both HPs and I/VSC advocates to improve the delivery of care for these patients. It is essential to hold this history in mind when considering the elements that influence decision making.

The data from the three participant groups indicated a number of elements that were common for all, and some that were group specific. The key overarching element was “trust”, as is visually represented in table 8:1 below (reproduced from Chapter Eight for convenience).

Table 8:1 Key elements in decision making for each participant group
9.2.2 Trust

Trust was the overarching theme across all groups and is the foundation of all the other aspects of decision making. In the medical setting, trust can be defined as “the belief that another person or entity will act in your interest in the future” (Hardin, 2006). Trust is relational, whether that be with another person, persons, group, institution or yourself. Trust is related to vulnerability, because trust is important when one is vulnerable and dependent on the care and assistance of others. Trust is therefore foundational to good medical care due to the vulnerability of patients (A. Hall, Dugen, Zheng, & Mishra, 2001). Given the degree of complexity and uncertainty associated with the treatment of VSC/DSD, trust is critical to ensuring positive outcomes. This is reflected in the emphasis on trust in the data collected from all three participant groups.

HPs want to be confident to trust their own judgement and the quality of the care they are providing. In particular, HPs want to conform to the ethical principle of non-maleficence: “first do no harm”. However, self-trust is difficult for HPs to achieve, given the poor outcome data and on-going debates about best practice.

The findings of this study indicate that in one part of Aotearoa/NZ one treatment option may be favoured, whereas in another part of the country it could be the opposite. The implication of discrepancy in clinical approach between centres is that standard treatment will vary due to geography (i.e. the same patient would be provided different treatment options depending on where they were seen). Such discrepancy heightens the vulnerability for patient care and can threaten trust in the health care system due to perceived inconsistency and the absence of clear and current guidelines for practice. Consequently, families’ trust in HPs may be eroded.

HPs are in a position where there is a lack of compelling evidence (despite efforts to improve research internationally) to support their clinical judgement and therefore their advice to their patients (3.10.1). In particular there is a lack of evidence to inform decisions about genital surgery that is not for functional reasons, such as clitoral reduction and surgery for severe hypospadias (3.10.1). In the absence of compelling evidence, HPs can consult with other experienced HPs. As suggested by some of the consensus guidelines (lee et.al. 2016, Cools et.al. 2018). However, there is no clear avenue to do this, except in some larger main cities, and it is up to the
discretion of the HP to seek such support. In my view, it would be beneficial to make these informal arrangements more formal and therefore more consistent, transparent, and accountable. This would provide security for the health professionals that they are not on their own making decisions or advising families.

HPs also need to be supported if they indicate they are not certain of the path to take with a case. While it is optimal to be referred to a specialist centre, this should not be at the expense of maintaining supports in a patient’s local area. Care should consist of a combined approach involving specialist advice and treatment as well as open dialogue and support back in the patient’s home town. This may be challenging at times due to a lack of trained staff and resources. My research shows examples of effective solutions to this problem, led by HPs, including ensuring resources and information are available to local locations via Skype or teleconferencing.

It is important HPs be open with the patient and/or parents concerned about uncertainty. Some HPs indicated that they felt the need to provide clarity rather than present uncertainty (5.5.2). Some research indicates that HPs are uncomfortable sharing uncertainty, or at the least are unsure how to communicate such uncertainty without fearing they are increasing parent or patient anxiety in what is already a stressful situation (Armstrong, 2018). A HP’s reluctance to discuss uncertainty may be misguided, as in fact trust increases when HPs are open about the uncertainty (Gordon, Joos, & Byrne, 2000). This was borne out by some of the data in this research. Parents and young people stated that they especially valued transparency and openness from HPs.

HPs also need to feel comfortable having robust conversations with each other if they have differing opinions, in order to optimise patient care. I suspect this is especially true for more junior staff who may hold different and more broad understandings of sexual orientation, gender identity and sex characteristics (SOGISC) issues than older and more senior staff. A significant advantage of developing specialist VSC/DSD services in Aotearoa/NZ would be to create a formal space for robust conversations to occur.

Whether, and to what extent, HPs feel connected and supported in their practise has a direct impact on the experience of parents and young people in their care. If HPs work in a clinical environment of openness and collaborative decision-making, it is
more likely they will create trusted spaces for open discussion with patients and families.

People born with a VSC/DSD and their parents are therefore especially reliant on trusting relationships with their HPs. This is due to the historical legacy of harm experienced by people with a VSC/DSD in the health system (2.4.4). Historical injustices create an environment of distrust, and HPs working with current VSC/DSD families need to work especially hard to establish trust. Prior research suggests that creating trust is especially important for those with negative histories (Armstrong, 2018).

Due to the extensive historical issues in the treatment and care of people born with a VSC/DSD there is understandably some distrust of HPs amongst I/VSC advocates; this scepticism is expressed in the public domain, especially via social media. Some I/VSC support groups are openly critical of HPs. Advocates’ animosity and scepticism can be seen by HPs as a barrier to patients establishing trust within the HP-patient relationship. As a consequence, some HPs reported that they are reluctant or unwilling to involve or refer parents or young people to activist websites and/or support groups (5.5.61). This finding concurs with a recent paper that conducted a critical review of psychosocial health care research and found that health care provision does not routinely include referring those affected to relevant support groups (Roen, 2019).

Some HPs in this study reported referring patients and families to online advocate support, along with “a caution” that information from advocates may be an unbalanced, overly pessimistic view of medical intervention, dominated by the voices of a few disgruntled patients (5.5.61). I think these warnings are unnecessary and potentially counter-productive. Research on how to develop trust within health care shows that honesty and openness are important factors in building trust (Dawson, 2015; Hardin, 2006). I would contend that not being open about the current debate and not referring to advocate or peer support is harking back to the days of non-disclosure, as it does not give parents and young people the full picture so that they can evaluate the various debates and concerns. Competing and conflicting information from HPs and advocates may raise concerns and confusion for parents and patients. However, if they are given support, time and space to
consider these different perspectives, and if HPs frame advocates’ competing accounts as an important alternative perspective on healthcare, future thinking and issues pertaining to bodily autonomy, then I believe that can only increase trust between HPs and the parent/young person.

Warnings about the potentially biased nature of advocates’ advice imply distrust on the HP’s part, diminish the importance and relevance of advocates’ experience, and suggest that parents and young people cannot be trusted to cope with or manage such information. Such warnings are given even though several HPs reported being affected by the individual stories of those born with a VSC/DSD to the point it made them reflect on their own practice. Several parents in this research reported that they would be appreciative of “upfront” and open discussion of competing narratives about early intervention for children with a VSC/DSD.

Research by Skirbekk and colleagues differentiates two types of “mandates of trust”: “limited” (focused purely on medical concerns) or “open” (a willingness to understand the whole person, not just their medical condition), with the latter being particularly important in complex cases (Skirbekk, Middelthon, Hjortdahl, & Finset, 2011). Skirbekk and colleagues identified five elements to building an open mandate of trust: “an early interest in the patients’ wellbeing; sensitivity; giving time/continuity; building alliances; and bracketing normal role behaviour for short periods of time.” Many HPs in my study would employ some of these elements, in particular taking an early interest and making extra time (as reported by HPs, parents and young people). Skarbekk’s study also indicates where some HPs can improve, for example in terms of sensitivity and breaking normal role behaviour (e.g. sharing a sense of humour). An open mandate for trust is established when the patient considers the HP trustworthy, and the HP aiming for good medical communication will demonstrate the five elements to ensure trustworthiness (Skirbekk et al., 2011).

Trust can be misplaced. Just because the role of a HP is held in high regard, this does not automatically mean the HP is trustworthy (Dawson, 2015). Are young people misplacing their trust in HPs if they believe HPs would make better decision than their parents? My research suggests that in some cases the answer would be yes. Parents and young people in this study reported receiving biased information from
HPs about the clarity of treatment options and the potential ramifications in the future (6.7. & 7.11). This suggests that in some cases young people are overly trusting of HP advice. In other instances, this research provides examples of justified trust that has been built and maintained between HPs, parents and young people.

Trust underscores all the elements of influence in decision making, and was central to the experience of the cohort of 50 participants in this research. Trust is crucial in the way the other elements of influence are perceived in relation to the weight they receive when balancing decision making. Trust intersects with the other common elements of communication, bias, norms and support across the three participant groups.

9.2.3 Bodily autonomy
The young people in this research indicated that bodily autonomy was extremely important and was, in their view, a human right they should not be denied. This view is also consistent with human rights organisations and some bioethics and legal positions, as presented in chapter two.

Young people are wanting to place trust in their parents when it comes to parental decision making for their best interest (3.9.1). For the young people in this study, that meant they hoped their parents would delay non-medically necessary treatment so they could decide for themselves when they developed capacity and maturity. However, young people also expressed doubt that their parents could achieve this. This was reflected in the decision scale, where young people trusted the HP over their parents to make decisions in their best interest retrospectively. Some young people believed HPs would have a broader picture and be less emotional when making decisions. This is another example of placing trust in the HP and concurs with other studies which show that HPs are inherently trusted (Calnan & Sanford, 2004; Hall et al., 2001).

Young people in this study did not want either their parents or HPs to make decisions for their future in regards to the appearance of their genitals, as neither party is in a position to accurately predict the child’s future needs, preferences and desires. There is no way of “future proofing” for a child that is yet to develop their own sense of being and discover what they will think and feel about their gender identity, sexual orientation and sex characteristics. These are all complicated
personal processes and have a variety of influences that happen over a life span. Trying to predict what an individual will think 15+ years ahead, and what the societal norms will be at the time, is implausible, especially when it comes to the anatomy of intimacy. Obviously in many situations, both medical and social, parents are forced to make time-sensitive decisions that involve predicting what will be in their child’s future best interests. But here, young people are emphasizing that where there is scope to delay decision making or ensure a more open future, parents should choose these options. This is supported by the human rights stance as discussed in chapter two (2.8).

Bodily autonomy needs to be considered when thinking about “best interests” for the child, as young people expressed hope that parents and HPs would think bodily autonomy was in their best interest. Young people had concerns parents would “future predict” for them based on the parent’s own beliefs and preferences (e.g. that a smaller clitoris or being able to urinate standing are more socially acceptable). Young people emphasised the personal nature of these preferences and the inability of parents to accurately predict their child’s future views. Could any of us say what we would want in 15-20 years’ time? We may have hopes, just as parents may have hopes for their children in the future- but they are just that, hopes, and not something we should gamble on when it comes to an individual’s own body. The theme of bodily autonomy intersects with the elements identified by parents of future worries and what’s right, and will be examined further under their respective headings later in the discussion.

The point is that some of these procedures may not be medically necessary, and these are areas that are deeply personal to an individual. For example, several of the young people in this study who had not had surgery for what was considered an enlarged clitoris commented that, had their parents been given the choice to do surgery, they would have wanted them to delay such a decision so they themselves could decide. This was also the case for Penny regarding surgical construction of the vagina; she would have wanted her parents to delay such a surgery so she could decide for herself. After all, it is when we become a young adult or adult that we are emotionally and socially able to engage in intimacy and truly decide how we want to express our sexuality and gender. This could equally apply to sex characteristics,
i.e. each individual should decide if they are happy with the appearance of their genitals or secondary sex characteristics (e.g. breast development, facial hair, genital appearance etc).

It is important to note that genitals are private and not usually on public display. This means that, unlike some other physical anomalies, there may be greater scope to delay decision making until young people are able to participate. Unlike the case of a cleft lip, which is visible, genitals are generally covered, so if the intervention is appearance based (as opposed aiming to improve function) then a delay is appropriate to ensure a young person can take part in decision making. In my view, we should protect the agency of a young person to decide on surgery affecting their genital appearance, sexual function and future intimate relationships, particularly if there is no urgency and there is a risk that intervention may reduce sexual sensation and pleasure. Critically, delaying appearance based surgery or other interventions shifts the power from HPs and parents to the young person and restores agency.

Another issue is that, regardless of whether a young person has appearance based surgery or not, they will still have to manage feeling different. Some research would suggest that appearance based surgery accentuates feelings of difference, shame and stigma (Chadwick, Smyth, & Liao, 2014; Liao, Tacconelli, Wood, Conway, & Creighton, 2010; Roen, 2019) when its aim is to reduce shame and stigma by normalising the atypical. This correlation of appearance based surgery and stigma concurs with the findings of my research, with some young people reporting that the suggestion they needed to be fixed was stigmatising in itself (7.7.3).

The theme of bodily autonomy intersects considerably with the way norms are constructed in relation to gender and what is considered the norm for the way bodies should look and behave; this is discussed in detail in the following section. Communication, support and identity are also important elements for young people when navigating how they feel about their difference, and these themes will be elaborated on later in this chapter.

9.2.4 Norms

Norms are the anchor that can tethers us to societal expectations reflecting what is considered to be appropriate regarding gender. Conforming to norms is seen by many parents and HPs as the preferred option, offering the benefits of psychological
wellbeing and social acceptability. Alternatively, adherence to rigid norms can be an anchor that weighs us down to unrealistic and unfounded “ideals”, denying diversity and difference and causing psychological harm or social isolation as reported by those with lived experience (Davis, 2015, Devore, 2015, Pagonis, 2015, Viloria, 2017, Carpenter, 2018, Douche & Mitchell, 2018, and Vecchietti, 2018).

Martin postulated the theory that there is a distinction between the typical or standard norm, based on statistical average, and the social norm, which is seen as the ideal norm. The ideal norm dictates what is morally correct and ought to be adhered to (Martin, 1964). Other researchers have developed this idea further in relation to VSC/DSD, stating that the standard or average is often conflated with what is considered the ideal (Carpenter, 2018; Howarth, Sommer, & Jordan, 2010; Karkazis, 2010).

Norms are culturally based and ever-changing. As expressed throughout this thesis, these norms often shift to being “ideals”, creating one standard for all humans to live up to and placing undue pressure/expectations on HPs and parents to make a child conform to the norm or risk being seen as abnormal or deformed. The need to conform to norms intersects with the element of expectations (5.5.2), where HPs are trying to align their clinical care with socio-cultural norms and meet the expectations of parents (5.5.3).

A review paper on psychosocial health care in this area critiques prior research from 2007-2017 (Roen, 2019). Roen argues that the idea that parental distress about their child’s different genitals is only addressed by genital surgery to normalise their child is unfounded. Roen concludes that there is “no clear psychosocial evidence” that such surgery on infants “reduces psychosocial issues” for the child (Roen, 2019).

Actively disrupting norms allows more freedom for people to redefine what is normal. This process was apparent in the data from some young people and parents(6.6.2/6.63 & 7.7.2/7.7.3). It is important for all- parents, young people and HPs- to be norm critical so they are more conscious of which norms they are endorsing when making decisions.
9.2.5 Communication

Communication is a major theme that intersects with many of the other elements of influence in decision making, in particular trust. The relationship between trust and communication that emerged in my research supports existing evidence (Dawson, 2015; Liao & Roen, 2013; Sanders, Carter, & Lwin, 2015). Parents and young people perceived a spectrum of communication skills amongst the HPs they engaged with: they reported cases of excellent communication as well as the potential for improved communication (6.5 & 7.6).

Participants reported a mixed level of skill and comfort with communication about the sensitive and at times awkward topics of sex, gender and sex characteristics (6.5 & 7.6). Some HPs felt it would be useful to have scripted examples of how to discuss some of these more delicate issues, because they felt uncomfortable or anxious about entering into these conversations, especially around gender, sexuality and the variation. For instance, if the variation resulted in a young women having a Y chromosome, they may feel awkward discussing this fact for fear that the young person would “freak out”. My research with young people demonstrated that HPs fear in this regard was well founded, as young people did react negatively when they perceived HPs to be insensitive in their communication. For example, a young person complained about a HP using the terminology “we have to check if you are a boy or a girl” (7.6.1).

HPs can find support in “practical approaches” reported by other HPs working in the field who have developed strategies to manage challenging communication with parents and young people, such as the work by (McCauley, 2017). In her article McCauley advocates for “clearly worded, frequently reviewed medical disclosure by adding a discussion of practical implications and strategies to help digest and work with the information provided” (McCauley, 2017, p. 298). McCauley also emphasises the need to check that the parent or young person understands what has been said, and that the HP has to help the parent or young person script how to talk to others about VSC/DSD.

My results concur with McCauley’s (2017) findings that parents were uncertain how to communicate with friends, family and their children about their child’s variation. All parents requested ideas and resources to help them with this, as they were
struggling with the fact that their child was “different”. I will discuss this issue in greater detail below in the section on support (9.2.7).

There were also power dynamics in play, for example where HPs would speak with a predetermined outcome in mind for the child or young person in question. HPs may not present treatment as options and if they do, they may privilege their preferred option. This is particularly concerning because many parents spoke of trusting or putting their faith in doctors’ hands. Given the power imbalance between HPs and parents (which sees parents give HPs’ views special weight), HPs need to be especially careful not to abuse this power, by actively working to ensure there is space for questioning and offering alternative perspectives to parents.

Young people felt communication could be improved, especially around transparency and sensitivity (7.6.1). The data indicated HPs need to be aware of the assumptions they make about a young person and their future. Young people pointed out that the HP’s assumptions about what is going on for the young person may be completely erroneous. Young people in this study want HPs to ask them what they want and need, rather than telling them what they should want and need.

They way HPs communicate matters. It can make someone feel confident in themselves, or it can make them doubt themselves or plunge them into a crisis of identity. Overall, young people perceived that HPs’ communication skills were lacking and in need of improvement. My observations suggested that HPs expressed a lack of awareness around their own biases and privilege apart from a few who acknowledged the risk of their bias, stereotyping and privilege influencing the health care provided.

9.2.6 Bias
The data from all three participant groups highlighted how bias is evident in many aspects of decision making, whether it be heteronormative bias towards cisgendered futures or ideas around how a male or female should look and what their respective interests should be. My research demonstrated the presence of both explicit and implicit bias which is reflected in many studies in health care provision (Hall et al, 2015, FitzGerald & Hurst, 2017, Marcelin et al, 2019). Bias also included HPs judging the cognitive ability of parents and or/young people, i.e. their capacity to be able to make “the right” decisions. The belief was that some parents would
think it implausible a child could cope with having a differently sexed body and would fear that others would bully them, causing psychological harm. While this view was not the case for all parents, HPs and young people themselves raised this many times (5.5 & 7.11).

Many HPs and parents were arguably unaware they were even expressing a bias (implicit), and this can come from a place of privilege i.e. being a member of the dominant culture and discourse. One young person commented that most HPs are cisgender, white and straight and it is likely that this is indeed the case. HPs and parents should be given the space and support to reflect on their biases (both explicit and implicit) and how this could be influencing and distorting their perceptions, decision making and actions. The young person/adult may become resentful towards their parents/HPs if they were not mindful of their potential biases and the impact these could have on the child as a result of the decisions made on their behalf. Self-reflection and awareness building around bias are being incorporated into professional training in health professions (O’Toole, 2016).

We all have our own bias; the challenge is to be aware of them and be able to hold them in check, which is no easy task. The first step is awareness and a willingness to examine one’s own beliefs and values. In order to do this parents and HPs need time and tools to support such self-reflection and understanding, for example Project Implicit run by Harvard University that supports people exploring their implicit bias online (Project Implicit n.d). Having a diverse mix of people including I/VSC advocates, ethicists, and psychologists on health care teams can also facilitate self-awareness and mitigate bias (Roen & Pasterski, 2013).

9.2.7 Support

Support is fundamental in VSC/DSD healthcare. In general HPs were offering good support by allowing extra time for parents to discuss issues and providing them with their email or phone contact. These efforts also contributed to building trust between families and HPs (Skirbekk et al., 2011). However, the effectiveness of the support offered also depended on the HP’s communication skills, bias and the HP’s perspective on cultural norms regarding anatomy, gender and sexuality. This affected whether parents or young people were directed to peer support groups and
psychological support, and whether ongoing offers of support throughout the affected person's development were made.

The data from all three groups revealed the need for better support in terms of written, online resources; trained support staff such as nurse specialists; and social workers or psychologists to offer one-to-one support to parents and young people. This finding is consistent with existing research suggesting additional support is needed, especially to assist parents and young people to navigate the often complex information and healthcare systems (Liao & Simmonds, 2014; Lundberg, Roen, Hirschberg, & Frisen, 2016; Roen, 2019; Tamar-Mattis, Baratz, Baratz Dalke, & Karkazis, 2013).

HPs acknowledged that they were often not equipped to manage families' psychosocial needs. However, this function often fell to HPs by default, as there were no resources available to fund specialised support (5.5.6). It was thought that getting support from generic psychological services was unhelpful, as psychologists did not understand the complexities of this patient population, and this was also the case with many general medicine and general practice health professionals (5.5.6.1).

Data from some young people showed that peer support was vital for them in finding a pathway to acceptance and feeling a sense of belonging (7.8). Through peer support networks, usually online, young people felt less isolated and therefore more accepted. They also felt supported to challenge the norm and accept themselves and their variation. For some young people this experience was both liberating and a pathway to becoming aware about diversity and difference. Some young people reported that access to peer-support provided a new lens through which to view their variation, and allowed them to develop a new norm and reject the confines of their previous gender norms.

Both HPs and parents expressed concern regarding the potential influence of peer groups led by advocates who are themselves living with a I/VSC. These concerns included the fear that advocates might express negative views of health care providers or of the treatment the child had received. For HPs, an additional fear was that the young person or parent may be indoctrinated with unhelpful ideas that would lead them to question the HP's suggested treatment. The data showed the contrary for the young people, who reported feeling more confident about
themselves and developed a sense of resilience that strengthened their identity. Georgia and Penny did develop a leadership role in I/VSC advocacy; others simply felt connected to peers and supported. Peer support is important for young people and should be supported by HPs and parents.

Finding peer support was a challenge for young people. Many young people discovered these peer groups themselves as no one had directed them to them. Another potential barrier to young people accessing support groups is that the labels “intersex” or “DSD” may be off-putting. Most young people in Aotearoa/NZ would not use or be familiar with these terms.

Overall, support was lacking for all three groups, despite it being recommended by many HPs and I/VSC advocates (Cools et al., 2018; Lee et al., 2016; Liao & Simmonds, 2014; Lundberg et al., 2016). There is still a long way to go in Aotearoa/NZ before all families affected by a VSC/DSD and all doctors working in this area have access to recommended supports. The level of support is likely to either compromise or enhance decision making, depending on the quality and availability of the support.

9.2.8 Expectations and recognition of the past

Data from HPs indicated that many were mindful of the John Money era and some were even in the early stages of their careers when such protocols were still considered best practice (5.5.1). Many HPs spoke of being affected by stories of the hardships people with lived experience of a VSC/DSD endured. This had the effect of changing some HPs’ views around bodily autonomy and diversity.

However, many HPs were cautious about the need for further advocacy because they believed treatment protocols had changed dramatically since the Money era. HPs reported there were better surgical techniques; open and full disclosure protocols around gender assignment; evolving science; and advances in genetics and testing. HPs were clear a boy would now never be reassigned as a girl for simply being born with a small penis and girls would not have their clitoris removed.

HPs’ reactions to hearing the experiences of those directly affected by VSC/DSD indicate the importance of hearing stories from those with lived experience and the potential benefits for raising awareness and self-reflection. However, not all HPs will be open to such information and may dismiss it as complaints from a minority.
Expectations were another element of influence. These might come in the form of self-expectation “to do no harm”, as represented in HPs’ code of ethics (2.9). HPs perceived that parents had expectations they would be able to “fix” their child. HPs were also concerned about how the child might feel about health interventions in the future. HPs found it difficult to balance these considerations and meet the various expectations that were at times challenging to manage, especially with parents (5.5.2). These expectations are complicated by the ethical issue of there being a lack of robust data to inform decision making as discussed in chapter five and reflected in the literature (Karkazis, 2008, Diamond & Garland 2014, Roen 2019).

9.2.9 Future worries and what’s right?
Parents were worried about what the future would hold for their child, whether the health decisions they had made were right for their child, and whether the future young person would endorse the decisions (6.9.1). Many parents had fears that their children would come to them in the future angry and ask “what were you thinking?” (6.8.2). Parents felt an acute responsibility to make the right choice for their children (6.8.1). This is where other main elements of influences intersect, particularly the way a HP communicates to a parent about their child’s variation, the bias they express and also the parent’s own bias.

Parents often felt overwhelmed with the responsibility of anticipating their child’s future needs and interests. In some cases, children had more serious, potentially life threatening, health challenges and these took priority over concerns about the VSC/DSD. Some parents experienced uncertainty and sometimes wondered whether they had caused the issue in the first place due to “bad genes”. In these circumstances’ parents need psychological support to help manage and mitigate these anxieties (Engberg, Moller, Hagenfeldt, Nordenskjold, & Frisen, 2016; Lundberg et al, 2017). My research indicates a lack of access to specialised professional support and parent peer support and little opportunity to discuss these concerns in a health context (6.8).

9.3 Decision making tool based on research findings and visual summary
As demonstrated by my research, the decision making process is complex and I have summarised this visually in Figure 9.1. One solution suggested by all three groups was to have more resources hence the development initial development of this
decision making tool. This diagram captures the key elements of influence on decision making regarding health interventions for children with a VSC/DSD. The diagram is based on analysis of data from the three key participant groups. For each element of influence, I have developed questions that help decision-makers reflect on important features in order to improve their decision making.

The questions in the diagram could be adopted to fit any or all of the three participant groups. They are a prompt to consider the elements of influence in turn and how each impacts on the way decisions are made. This decision making tool could help raise awareness and facilitate self-reflection. These questions are designed to ensure that decision making is robust, systematic and considers a comprehensive range of elements. The aim is to aid those supporting shared decision making, i.e. HPs, and those directly affected, i.e. parents and young people, to increase their ability to make fully informed decisions.

Figure 9:1 Decision making process tool
This diagram prompts the individual (who could be a HP, parent or young person) involved in decision making to consider a variety of elements and issues when trying to make complex decisions. The purple layered circle represents the “circle of trust” that can be developed when the other elements of decision making are effectively addressed. The questions are some examples of the questions that the decision makers can ask themselves. This list of questions is not exhaustive or exclusive, but it is a comprehensive review of issues to consider in the decision making process.
9.4 Limitations

This research has relatively small numbers of participants, especially young people (n=10). However, given that Aotearoa/NZ has a population of only 4.5 million and prevalence of VSC/DSD is low, this was to be expected. My research does provide a sample of 9 young woman, 1 gender queer person and 18 parents; collectively 28 participants were directly affected.

While the 22 HPs interviewed represented a wide range of health professions, some professions were not included, in particular midwives and nursing staff. This was due to the primary research focus on HPs who have a direct responsibility for guiding decision making processes. Future research could explore the views of midwives and nurse specialists working in this area.

This study also had limited representation from Māori and Pacific Island communities. There were no male participants among the young people interviewed, despite my specific recruitment efforts. This will mean a bias to the female perspective for the young people data. Despite my attempts to recruit Māori people by working with Māori networks, the fact I am a white woman may have been a barrier. In addition, Māori may have the cultural barrier of feeling “whakamā” (shameful or embarrassed) about talking about such personal matters. This would be equally true for people from Pasifika cultures. Future research should endeavour to represent these populations. Consequently, for this research we need to be cautious not to draw conclusions for these particular participant groups that were not represented.

Seven of the young people were diagnosed as teenagers. Of the remaining three, two had CAH and neither reported having surgical interventions. Therefore, only one young person had surgery as an infant. This means the majority of comments by the young people about the merits of early versus delayed surgery were hypothetical, instead of being based on personal experience. However, these young people provided a window of opportunity about their preferences had their variation been diagnosed at birth. Two of the remaining three diagnosed at birth or as a young child were able to comment on living with differently sexed bodies not operated on. The young people were all very clear about their opinion that interventions that were not required to preserve life or function should be delayed until the young
person was able to make a decision for themselves. It would be valuable for future research to compare this finding to the views of young people who had experiences of surgery as infants.

The recruitment of parents and young people was largely via HPs themselves and this may have introduced a selection bias in terms of the families included in the research. HPs may have been more inclined to recommend families who they believed had had positive health care experiences. This also meant we recruited people currently in the health care system which was a strength as I wanted to understand their health care experiences. Two participants approached me directly as a result of online recruitment through ITANZ and allied support services. Recruitment via these support services would be more likely to attract people identifying with the term intersex and the political nature and advocacy role of such organisations.

A limitation was that the decision scale was not completed by all participants and only the data from young people proved statistically significant. However, the process of collecting the data, provided useful insights into participants’ decision making processes, even for those who could not complete the decision scale.

Some may see the “practical partnerships”, particularly with the two dominant players (i.e. the medical establishment and I/VSC advocates) as a potential limitation in the sense of creating bias toward one or both of these groups. In my view these relationships ensured a deep level of partnership with both stakeholder groups, meaning they were actively participating and consulted with throughout the research process. This approach provided a balance of opinion and input which strengthened the research. Regular supervision throughout the research process and contact with my advisors, along with my own reflective process, provided robust checks to identify and challenge my own potential biases.

9.5 Conclusions

In conclusion, I will present some critical reflections on the research process and findings, then make suggestions for future research.
9.5.1 Critical reflections on process and findings

In an area where it has proven difficult to provide hard evidence, due to the research challenges and the history of secrecy, it is striking that there is not more effort to create an equitable space that privileges the scholarship and voices of people who are I/VSC themselves.

Instead of reconstructing genitals, maybe it is better to help restructure the way we think about difference/variation. History has proven that the process of reconstructing bodies is not always the answer, especially when it comes to surgery or treatment deemed cosmetic or more about form than function (Morland, 2009; Roen, 2019).

We can start by being aware of and reflecting on the way we construct our own sense of self in relation to our bodies, gender, sexuality and sex characteristics. Secondly, we can think about how we construct and practice norms and whether we might be better to disrupt these norms so as to allow opportunities for diversity and acceptance. Thirdly, and most importantly, we should remember that each person is entitled to bodily autonomy. When it comes to our genitals, gender and our futures, we need to be accorded the greatest possible scope to make decisions for ourselves. Every effort needs to be made to make this possible as it is a fundamental human right and that agency requires HPs and parents to relinquish their power to decide for their patient/child in the instance of appearance based surgical interventions. In some cases, parents and HPs will have to make decisions on behalf of infants where their variation causes a serious risk to their life or physical health. Parents and HPs should avoid interventions to prevent potential mental health harm in the future by physically “normalising” the infant or child.

HPs and parents are faced with the challenge of making decisions in the best interests of the child. Given the range of VSC/DSDs and the various complexities, it is necessary to balance the health issues with the specifics of a child’s personal identity, which is temporal. “The best interests of the child are widely seen as a guide to societal ethical decision making in relation to children” (Forbes 2015). Parental autonomy to make decisions on behalf of their child is a responsibility as well as a right. Parents are legally and ethically obliged to promote their children’s interests.
Acting in a child’s best interests requires both beneficent intentions and good judgment. The vast majority of parents have good intentions towards their children, but there can be considerable debate about what counts as a good judgement. Determining what exactly is in a child’s interests, especially what is in their future interests, is difficult. There will often be competing values and interests at stake. For example, parents may think it is important for their child to look normal in order to be socially accepted and therefore favour particular appearance based treatment. The child as an infant is unable to contribute to this decision and therefore is reliant on the judgment of parents and HPs. The difficulty of this decision making process is exacerbated by the lack of robust outcome data, leaving parents and HPs basing their judgement of the child’s future interests on limited information. In the absence of robust evidence of outcomes, bias, socio-cultural norms and the pressure of expectations can dominate decision making. This is made worse by a lack of support for HPs and parents during the decision making process. In combination, these factors risk tipping the balance of decision making towards the parents’ and HPs’ pre-existing assumptions and fears, rather than allowing space to reflect and challenge biases. HPs and parents should wherever possible be aiming to create an open future for the child, who can be involved in decision making when they reach maturity.

Difference is the key. Is it offensive to be different? Or is it simply a matter of accepting that we are not all the same, that there is natural variation? How we perceive difference influences our judgements about what course of action needs to be taken when faced with a child with a differently sexed body. This highlights the need to be “norm critical” and the ability to reflect on one’s own biases.

It is impossible to “future proof” decisions made at an early age for any child, including those born with a VSC/DSD. The difference seems to be that children with a VSC/DSD are not accorded the same right to bodily autonomy as children who don’t have a VSC/DSD.

Two comparison cases worth considering are female genital mutilation (FGM) and male circumcision. FGM is banned in many countries (including Aotearoa/NZ), with human rights advocates and legal authorities having acted to shift this traditional ritual because it is seen as violating human rights (Costello, M., Tatchell, Jordan, &
Neophytou, 2015; Forbes, 2015). In Aotearoa/NZ and Australia male circumcision has come under increasing criticism. Critics have likened male circumcision to FGM and have argued that the evidence of the benefits of circumcision has not been substantiated. However, parents have the right to decide to have their son circumcised if they choose to, usually for religious reasons (Forbes, 2015).

I/VSC activists believe the appearance based surgery performed to normalize infants’ genitals should be viewed in the same light as FGM and call for increasing human rights and legal support (2.7.1/2.8). By contrast, most HPs reject the idea of a blanket ban on appearance based surgery because this may threaten surgical procedures that are necessary for health and function, particularly surgery for hypospadias (O’Connell, 2016).

Genital surgery is different from other appearance based surgeries, such as cleft lip, for a number of reasons. First, a cleft lip is more visible and therefore the argument that a person with an uncorrected cleft lip would be socially stigmatised is more compelling. By contrast children with a VSC/DSD can more easily maintain the privacy of their genitals. Second, genitals are physiologically the focal point for sexual pleasure (although they are not the only place sexual pleasure is experienced) and therefore are integral to the way an individual experiences sexual pleasure and intimacy. Surgery to the genitals carries a greater risk of reducing sexual sensation than other appearance based surgeries, and this can have a significant impact of the wellbeing and quality of life of the future adult.

I suggest the best we can do to “future proof” decisions for a child with a VSC/DSD is to ensure they have the same consideration as any other child when it comes to bodily autonomy. Supporting young people to make decisions for themselves regarding issues that are focused on the appearance of their genitals. I believe our health providers could be leaders by taking an ethical stance that supports the human rights of self-determination and bodily autonomy when considering appearance based surgical procedures as suggested by the Swiss national advisory commission on biomedical ethics (2012).

9.5.2 Implications for future research and better health care

There is an opportunity for Aotearoa/NZ to aspire to collaborative research and guideline development if I/VSC advocates and HPs can find common goals regarding
the health care of those born with a VSC/DSD. There has to be an opportunity for these key players to have an equal say. Creating opportunities for these key players to have an equal say will be key if the collaboration that has been developing in Aotearoa/NZ between these groups is to grow into an equal partnership.

My research demonstrates the feasibility of developing and maintaining strong partnerships between HPs, I/VSC advocates and researchers. I played the essential role of conduit, liaising with both I/VSC advocates and HPs. To develop relationships with HPs I attended several of the annual APEG scientific meetings and presented some of my early findings to garner some feedback. I also presented at an inaugural intersex activist and academic conference in Italy (4.4.2). I was committed to presenting in partnership with Intersex Youth Aotearoa (IYA) because I was specifically reporting my findings on the young people participants. Consequently, I invited Georgia (one of my participants who had moved into an advocacy role not long after I interviewed her in 2015) to co-present and I successfully initiated fundraising efforts to cover her costs. Our approach generated interest because it demonstrated that the relationship between researchers and people born I/VSC can go beyond mere consultation to genuine collaboration. The co-presentation format embodied my ethical commitment to research integrity, active partnership and actively privileging the voices of young people born I/VSC by providing the opportunity for those directly affected by a VSC/DSD to speak for themselves.

The NZ Human Rights Commission intersex roundtables and the subsequent formation of the NZ Paediatric Clinical Reference Group coincided with the research and I was able to provide some input as a consequence of my research. For example, I recommended potential people to include as participants and provided information on current research and fostering relationships between I/VSC advocates and HPs. The implications for future research could be to use methodologies that foster collaboration and include all the key people involved, which has been a strength of this research.

9.5.2.1 Solutions for improving health care

Implications from the research findings regarding the specific participant groups include the need for targeted professional development that focuses on helping HPs to reflect on their practice and develop awareness and insight regarding how their
beliefs and values create bias. It is particularly important to assist HPs to recognise their negative biases regarding sex and gender and replace them with positive and progressive ideals.

Training in communication skills is also needed, particularly around providing difficult information about sensitive and deeply personal topics such as genitals, sex, sex characteristic variations and gender. Workshops and role plays would be a useful way to look at providing this education, as well as providing online video resources for those who may struggle to attend a workshop.

The Harvard “Project Implicit” (n.d.) as aforementioned, has been doing research in the area of implicit bias and have produced a number of implicit association tests, including one that looks at implicit associations about race, gender, and sexual orientation. This could be a starting point in order for health professionals to become aware of their implicit bias. Though this would not necessarily remove bias as it is reliant on the user’s motivation to change an implicit bias that has been made explicit, it could be a starting point.

Development of eLearning tools specific for the Aotearoa/NZ context (and similar to European resources provided though International-DSD) would be useful. Perhaps APEG or Royal Australasian College of Surgeons could develop such resources for their members. Whatever the training, inclusion of people who are I/VSC is vital.

There is a role for bioethics to explore in more detail the ethics of this field, especially around appearance based genital surgery and removal of gonads. Bioethics could offer advice in the “too hard areas” by taking an ethical framework and applying it to these instances. The Swiss National Advisory Commission on Biomedical Ethics produced a document (2012) that stated that medical practice guided by sociocultural values are incompatible with human rights, “specifically respect for physical and psychological integrity and the right to self-determination” (Swiss National Advisory Commission on Biomedical Ethics, 2012). Bioethics in this country could build on the Swiss premise that ethical guidance can be a principle upon which protocols in the areas of VSC/DSD can be based. In particular bioethics can champion a human rights and ethics based framework elevating the need to protect a child’s right to bodily autonomy and good health outcomes.
Aotearoa/NZ could investigate a bioethics framework that supports HPs, professional bodies and/or MOH policy makers to take a stand on the specific human rights issues for children and young people born with a VSC/DSD. It is not reasonable to expect HPs to manage this alone and without an ethics framework to help ensure thorough consideration of issues, consistency and transparency. It would not resolve all the issues but could help this country make a stand when it comes to the right to make decisions about one’s own body.

Health system improvement could include the establishment of a VSC/DSD registry to record the number of people born and to track their progress, similar to that for cancer patients. This would allow for better research opportunities and potential long-term outcome follow up studies. Participants in this study indicated they would be willing to be contacted for future follow up research if it were conducted by me, as they had formed a relationship with me by discussing their experiences.

Another solution to support better health care would be to establish and fund a national specialist centre in Aotearoa/NZ that has a specifically trained multi-disciplinary team including not only medical specialists such as endocrinologists and surgeons, but also psychologists, I/VSC advocates, bioethics and nurse specialists. This team could advise other services around the country and develop collaborative relationships with I/VSC advocates with the view to developing increased awareness and understanding of different perspectives. It would also provide an opportunity for training.

There is a need for better support for parents; both peer group and specialist psychological support is needed. Clear and comprehensive information resources need to be developed that are specific to Aotearoa/NZ. These could be online and in video form as well as including some supporting written material. HPs need to make time for parents to discuss options, including what it means to have a child with a VSC/DSD. Parents need to be assured that their baby is going to able to lead a happy and healthy life and that their VSC/DSD not necessarily a crisis (though clearly there are circumstances where it is, as was the case with Amber, who needed immediate surgery soon after birth).

Young people need better support systems, especially I/VSC peer support. This again requires inclusion of I/VSC advocates in health care provider training, to
increase HPs’ awareness of what is in existence and what is being developed. Ideally HPs would refer to and support the development of peer networks such as IYA. Stronger collaboration between advocates and healthcare providers is required to build trust so that such support is viewed as helpful. Funding support is crucial as this is a barrier to developing and maintaining support services.

Psychological support for young people and parents also needs to be provided by trained nurse specialists or other allied health professionals such as psychologists or social workers. This psychological support needs to be offered to help both parents and young people manage difference and make sense of their situation. There are also the issues of identity and desire to fit in or achieve a sense of belonging which teenagers and young adults may need support to navigate. This specialist psychosocial support requires psychologists and other allied health providers to access specialist training specific to those born with a VSC/DSD (Roen, 2019). This is currently not available in Aotearoa/NZ; instead practitioners here must access larger specialist VSC/DSD services overseas where such training has been developed.

Coordination of services is also a potential role for an allied health member (9.2). A role similar to that at MRCH, where a key person is allocated to all new families with a child diagnosed with a VSC/DSD, could be trialled here. The role involves coordinating with all involved, including various HPs; going over information with families and clarifying any questions or concerns; connecting with support groups and referring new families to them; and the development of resources (Hanna et al., 2017).

Outcome research continues to be a priority. Research should include those who opt not to have genital surgeries for clitoral reduction and hypospadias, as well as those who do decide to have such surgeries, so that the psychological outcomes for each group can be explored. As stated in the limitations of this research it would be important to succeed in the inclusion of more Māori, Pacific Island, male participants in future research. Longitudinal studies following up with both parents and the child or young person would be helpful to track their experiences at different developmental stages in their lives. More research looking at the key
elements of decision making is indicated, and it will also be necessary to evaluate decision making tools when they are developed.

9.5.3 Final thoughts

The findings of this research demonstrate there is a need for change in the care of those born with a VSC/DSD. There has already been rapid change in this field since I began this research six years ago, especially in the human rights and legal areas. Medicine is also making strong efforts to support change although, as discussed in chapters two and three, it is restrained by its own adherence to ideal norms. I fear it will take a push from national and international human rights committees and possibly legal ramifications to effect change to ensure the bodily autonomy of infants and young people.

This thesis is titled “Gender mender, bender or defender?”, referencing the idea that HPs, parents, and young people with a VSC/DSD having the option of “mending” or “fixing” gender, or “bending” or “disrupting” the rules of gender so they have can reclaim what many may perceive as “deformed” as the new norm. The last part of the title, “defender”, means defending the right to bodily autonomy, informed consent and comprehensive support. This means the individual concerned should have the agency/power to make decisions for themselves when they are ready to consider what is important to them as a young adult exploring their sense of identity, sexuality, gender and how they feel about their unique sex characteristics. Young people with a VSC/DSD deserve to decide who and how they want to be in the world in terms of SOGISC issues. Parents and young people deserve to be fully informed and to have comprehensive support, and HPs need support to provide this level of health care. This is of course complicated by the need to balance this bodily autonomy with the right to good health and to mitigate health risks such as fertility issues, such as in the case of hypospadias where repair may be indicated.

This research does not suggest there should be no medical intervention. Rather, the findings suggest young people deserve the right to make informed decisions about their own bodies and that is worth defending. If a young person decides they want to “mend” their body that will be (and where possible should be) their choice. Additionally, opportunities to “bend” the rules and “disrupt” increasingly outdated concepts of the binary and ideal norms are to be encouraged.
As much as these variations can be accepted, there will always be a need for intervention, as they do carry real medical consequences and for some they can be life threatening. No one would suggest banning interventions that make a person be able to function without fear of incontinence or stop an adrenal crisis etc. Just as it is important to defend the rights of the young person, it is also important to acknowledge and defend the position that HPs are doing interventions that are warranted.

Many families may choose to have surgeries that support continence or separate the urogenital “plumbing” but decide to leave clitoral reduction, vaginoplasty, repeat hypospadias operations and even gonadal removal in some instances until the young person is old enough to be involved. Hormone treatment is going to be a necessity for many and again HPs provide a valuable service to those who require such treatments.

There is room for improvement and that is what has been demonstrated in this research. HPs in this country can do better; this will require not only willingness to make change, increase awareness and undertake some self-reflection but also resourcing to establish specialist services, better databases and training.

HPs are committed to doing their best in the absence of robust evidence and they must be supported to have difficult conversations with each other, I/VSC advocates, bioethicists, parents and young people to further their understanding of broader perspectives. The process has started here in Aotearoa/NZ, with it now possible to do something different that will be significant for all concerned. Collaboration is key.

There is hope that the efforts at collaboration being made by HPs and I/VSC advocates here in Aotearoa/NZ will find a way forward. Such collaborations could develop guidelines that ensure: the rights to bodily autonomy; acceptance of diversity; increased awareness of bias and privilege and better education and supports for health professionals, parents and young people affected by VSC/DSD. We will need to develop specialist services, facilitate to peer supports and encourage active participation of advocates within the medical system and an increase in bioethics involvement.
I am hopeful that we can do things differently in this part of the world. Despite the legacy of John Money, we are a progressive nation and can offer leadership in this area. We can demonstrate that while the population largely exists of people who identify as male or female, including the majority of those with a VSC/DSD, we are also accepting of diversity within the gender spectrum. We can accept differently sexed bodies and put the human rights of individuals before normative ideals. Let’s reshape our prejudices rather than our children’s bodies.

There will always be those who want to conform to the norms at any given point, which is their right. My hope is that the findings in this research help those in the position of making decisions for their children with all the options, including disrupting the norm or at least being “norm critical”, being explored before decisions are made.

To end as I began, this time with the benefit of what I have learned through this doctoral process: let’s hope for a future that makes common stories such as “Once upon a time there were two children who lived in a world where diversity was valued and acceptance of difference was common place, after all we are all 100% human regardless of what our sex characteristics are.”


InterACT. (2015 Mar 28). *What it's like to be intersex* [Video file]. Retrieved from https://www.youtube.com/watch?v=cAUDKEI4QKI


Reitsma, W., Mourits, M. J., Koning, M., Pascal, A., & van der Lei, B. (2011). No (wo)man is an island—the influence of physicians’ personal predisposition to labia minora appearance on their clinical decision making: a cross-sectional survey. Journal of Sexual Medicine, 8(8), 2377-2385. doi:10.1111/j.1743-6109.2011.02321.x


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Glossary

Adrenal glands
The adrenal glands, located above the kidneys, are the pair of glands that are responsible for secreting various hormones, including androgens.

Androgens
Androgens are hormones (molecules or chemical messengers) made mostly by the testes, but also made to a lesser extent in the adrenal glands located above the kidneys, and in the ovaries. They stimulate male reproductive organ (sex organ) development and secondary sex characteristics such as facial hair and lower pitch of voice. The two major types of androgens involved in sex development are testosterone and dihydrotestosterone.

Bifid scrotum
A scrotum that is separated by a deep cleft or groove into two parts.

Anti-Mullerian hormone
A hormone normally produced by the testes in the early stages of male foetal development that prevents the Mullerian ducts from developing into the fallopian tubes, uterus and upper part of the vagina. (also referred to as Mullerian inhibiting substance)

Chordee
A curving of the penis that can cause very painful erections.

Chromosomes
These are the long strands of tightly curled DNA that reside within the nucleus of all cells (except red blood cells). The chromosomes contain the body’s genes, which are specific segments of DNA that contain the body to develop, grow and function. Most people have 22 pairs of closely matching chromosomes called autosomes and two sex chromosomes, designated by the letters X and Y. Most females have two so-called X chromosomes, and so we say they have the karyotype 46,XX (i.e. ; 46 chromosomes in total with two X chromosomes). Most males have one X chromosome and one Y chromosome, and the karyotype 46,XY. However, there are many other patterns of chromosomes. Some people have an extra X or Y, some are missing an X, some females have a Y chromosome and some males have two X’s.

Cloacal Anomaly
Cloacal Anomaly is where a female’s lower abdominal structures merge resulting in the rectum, vagina and urethra all merging into one exit point or sometimes no occurs. This is life threatening and requires surgery to create a functioning of voiding bodily wastes. There may be an absence of a uterus and or vagina.
**Cisgender**
Cisgender is where an individual's gender matches their sex at the time of birth as opposed to Transgender when a individual's gender does not match the sex they were born with.

**Complete Androgen Insensitivity Syndrome**
(CAIS) - AIS affects the section of the 46,XY population that is physically unable to react to androgens, due to mutations in the androgen receptor. In Complete AIS (CAIS), testes exist in the abdomen while the external genitals are female. CAIS individuals grow breasts but do not menstruate. The testes are sometimes removed from the abdomen because they may develop cancer.

**Congenital adrenal hyperplasia**
(CAH) - classic CAH is classified as having the salt-losing form, while one-third have the simple-virilising form. In both forms, affected females may have genital ambiguity.

**Cosmetic**
A cosmetic surgery is one that only affects appearance, rather than making a body part work better or curing an illness (also can be called normalisation, corrective and appearance/form in relation to surgery).

**FISH**
fluorescence in situ hybridization (FISH) probes – allows scientists to see more detailed structure in chromosomes, one of the tests used to determine biological sex when uncertainty at birth

**Diagnosis**
This usually means the name of a cause of a DSD (for instance, “congenital adrenal hyperplasia” or "complete androgen insensitivity syndrome"). Doctors decide on a diagnosis by considering the signs and symptoms, the family history, and the results of various tests. In many cases, it is not possible to arrive at a definite cause. In that case, doctors may use a descriptive word, like “ambiguous genitalia” for the diagnosis.

**Dihydrotestosterone**
A potent androgen (male sex hormone) made in the tissues of the genital region, by converting testosterone into dihydrotestosterone.

**Disorder of Sex Development**
When a less common path of sex development is taken, the condition is often called a “disorder of sex development” or DSD. DSDs happen in animals as well as humans. Variation in sex characteristics, VSC, is another term used as well as intersex.
Elective
An elective medical procedure in Aotearoa/NZ is a surgical procedure scheduled on a regular operating list rather than being on an emergency procedure list. The procedure may be important even though it is not an emergency.

Estrogens
Estrogens are hormones (molecules, or chemical messengers) mainly produced in the ovaries. They are responsible for certain types of secondary sex characteristic, like breast development. Estrogens are also responsible for female reproductive processes like helping to regulate the menstrual cycle.

Gender
While “sex” usually refers to a person’s physical anatomy, the term “gender” usually refers to mental, social, and cultural characteristics, regardless of anatomy, related to being a boy, girl, man, or woman in our society. (or nonbinary)

Gender assignment
When a child is born with a VSC/DSD and his or her sex is unclear, the child is given a “gender assignment,” which means the parents decide whether to raise the child as a boy or a girl. Gender assignment is a system of labelling a child and treating a child as a boy or a girl. (For this reason, no surgery is required for gender assignment.)

Gender identity
A person’s innermost sense of himself or herself as boy or man, girl or woman (or nonbinary). This is not simply determined by “sex chromosomes,” gonads, surgery, or by how a child is raised. It is also not chosen by an individual.

Gender role
A part that a person plays as a boy, girl, man, or woman (or nonbinary) in our society. So, for example, being a mother is a gender role.

Genital folds
No matter how they end up in terms of sex development, all embryos have genital folds early in the womb, prior to sex development. These folds later develop into the labia majora in most girls and the scrotum in most boys. Children with DSDs sometimes have external genital structures that look in-between labia and a scrotum.

Genital tubercle
Present in all embryos in early development, the genital tubercle is a structure of the external genitalia that develops into the clitoris or penis.

Gillick competency
Gillick competency refers to when a child under the age of 16 is deemed able to understand make their own health care decisions without the knowledge or need of consent from their parents.
Gonadal ridges
Common in all embryos prior to sex development, gonadal ridges consist of tissue that develops into gonads (ovaries, testes, ovotestes, or gonadal streaks).

Gonadal streaks
Gonadal streaks are poorly developed gonad tissue present in place of testes or in place of ovaries in some people with DSDs.

Gonadectomy
"Gonadectomy" means to perform surgery to remove the sex glands (ovaries, testes, or ovotestes).

Gonads
“Gonads” is a general term for the sex glands. The term “gonad” can refer to an ovary, a testis (testicle), an ovotestis, or a streak gonad. Mature ovaries usually release eggs until menopause, while mature testes usually produce sperm. In addition, the gonads release hormones that affect the development of the reproductive organs at puberty and affect other physical traits that, after puberty, usually make men and women look different, such as pitch of the voice and body shape and size.

Gynecomastia
Gynecomastia refers to the enlargement of an adult man’s breasts, usually due to a hormone imbalance or to hormone treatments. In adolescence this is a normal part of male puberty in up to two thirds of boys.

Hormones
Hormones are molecules that carry messages from one group of cells to another through the blood, stimulating (“waking up”) somebody processes and inhibiting (“shutting down”) others. Reproduction, growth, sleep, libido (sex drive), and hunger are a few of the things that are affected by various hormones. Hormones are produced by many organs and body tissues but mainly by the endocrine (hormone) glands.

Estrogens and testosterone are two types of sex hormones.

Intersex
Intersex is a term sometimes used to refer to the condition of having a sex anatomy that is not considered standard for a male or a female. Like disorders of sex development, it is an umbrella term that covers many different conditions that appear in humans as well as other animals. The term is often used by adults with DSDs to talk about their bodies and their experiences. Using the general term “intersex” has allowed many adults with different kinds of DSDs to come together and work for progress in the way families with DSDs are treated.

Karyotype
A karyotype is a picture of the chromosomes in a cell. A karyotype is used to see what kinds of chromosomes a person has. It is created by taking a blood or tissue sample from a person, and then staining the chromosomes with dye and photographing them through a microscope.
Mayer Rokitansky Küster Hauser Syndrome (MRKH) - congenital absence of the uterus and vagina. Can also have kidney and bone density issues.

**Mosaic karyotype**
A person is said to have a “mosaic karyotype” when he or she has one kind of karyotype in some of his or her cells, and a different karyotype in other cells. An example is when a person is said to have a 45,X/46,XX karyotype; that means she has 45,X in some cells, and 46,XX in other cells. Mosaicism happens because sometimes cells divide incorrectly early in the life of an embryo.

**Mullerian ducts**
Present in all embryos in early development, in most females the Mullerian ducts develop into the uterus, fallopian tubes, and the upper part of the vagina.

**Multidisciplinary team**
Multidisciplinary team care happens when a team of medical specialists at a medical centre helps a child with a DSD and his or her family. Multidisciplinary teams that treat DSDs may include a child psychologist and/or child psychiatrist, a geneticist, a genetic counsellor, a Pediatric or adolescent gynaecologist, nurses, a Pediatric endocrinologist, a Pediatric urologist, a social worker, and other specialists as needed. They may operate a multidisciplinary clinic.

**Ovaries**
The ovaries are the female gonads (sex glands) located in the lower abdomen of most girls and women, usually one on either side of the uterus. The ovaries have two basic functions, ovulation and the production of hormones, mainly estrogens and progesterone which influence a woman's feminine physical characteristics and affect the reproductive process.

**Ovotestes**
Ovotestes are gonads (sex glands) containing both ovarian and testicular tissue. These are sometimes present in place of one or both ovaries or testes in people with DSDs.

**Paediatric endocrinologist**
A paediatric endocrinologist is a children's doctor who specializes in the endocrine system, commonly known as the hormonal system.

**Paediatric urologist**
A paediatric urologist is a children's doctor and surgeon specializing in the reproductive organs (sex organs) and the organs of the urinary system.
Raphe
A line (like a groove or a seam) in the body where two halves developed before birth and fused together. The line along the underside of a penis that runs from the tip of the penis to the anus is called the penile raphe (along the penis) or the scrotal raphe (along the scrotum). This raphe reminds us that before birth, male and female genitals start out looking the same. In most male genitals, the two sides fuse together, leaving a line down the middle.

Secondary sex characteristics
These are changes that typically occur at the time of puberty. They can include body hair growth, change in pitch of voice, genital growth, breast development, muscle development and growth of the Adam’s apple.

Sex
Sex usually specifically refers to a person’s physical anatomy as female, male, or intersex.

Sex development
This is the term for the step-by-step changes that relate to the biological (physical) features of a person’s sex. The development of sex begins at conception with the combining of sex chromosomes from the mother’s egg and the father’s sperm. Sex development continues in the womb with the prenatal development of the internal sex organs (including the gonads) and the external sex organs (like the penis, clitoris, labia, and scrotum). For most people, sex development continues naturally little by little through all stages of life, including most noticeably at puberty (which brings many changes including altered sexual arousability, fat distribution, voice pitch, hairline, pubic, underarm, and body hair, genital and nipple appearance, breast development, skin oil and texture, and body odour) and at menopause.

Sex differentiation
The process by which males and females grow to be different from each other. Until about seven weeks after conception, all embryos regardless of their chromosomal makeup have the same structures of the gonads and genitalia (genital folds, genital ridges, genital tubercles, Mullerian ducts, and Wolffian ducts). Most develop according to what is considered standard for males or females, but some develop differently.

Sexual orientation
This refers to whether an individual is sexually attracted to men or women or both.

Sywer Syndrome/Gonadal dysgenesis
The person is born without functional gonads (gonadal streaks). The person looks like a typical female and will not develop most secondary sex characteristics without hormone replacement (both estrogen and androgens).
Testes
The testes (also called testicles) are the male-typical gonad, usually located in a scrotum. Mature testes typically produce sperm, though this is not the case with some DSDs. Before and after puberty, the testes produce the hormone testosterone which is responsible for the development of the male reproductive organs and the male-typical secondary sex characteristics.

Testicles
See testes.

Testosterone
Testosterone is the main male sex hormone that is produced in the testes. One of its functions is to stimulate ("wake up") the development of the male internal genital structures in the fetus. Testosterone is converted in the external genital tissues to a more potent hormone, dihydrotestosterone, to cause male development of the external genitals. It is also produced during a brief period in early infancy, then again at puberty, when it stimulates enlargement of the penis, deepening of the voice and other typical features of male secondary sex characteristics. During adult life it is responsible for maintenance of male-type body structure and is involved in sex drive (libido) and sexual function.

Trap door
A trap door device intended to instil fluids through a cecostomy into the colon to promote evacuation of the contents of the lower bowel through the anus, and is intended to be an aid in the management of faecal incontinence. (product Website 2018)

Turner Syndrome
affects only girls and women, results when a sex chromosome (the X chromosome) is missing or partially missing. Turner syndrome can cause a variety of medical and developmental problems, including short height, failure to start puberty, infertility, heart defects, certain learning disabilities and social adjustment problems.

Urethral folds
Present in all embryos early in development, the urethral folds typically develop into the labia minora in females and the urethra and the shaft of the penis in males.

Uterus
This is the organ that typically connects with the vagina in females. It is located in the pelvic region and is where babies develop, and is also the source of menstrual flow.
**Vaginal dilation**

This is where the vaginal cavity is stretched to increase the width and length of the vagina using different sized plastic dilators shaped like a tube. Dilators increase in size as the vagina's elasticity increases and the desired length and width is achieved over time. Dilation may be done one or more times daily for a period of time.

**Wolffian ducts**

Present in all embryos in early development, the Wolffian ducts typically develop in males into the vas deferens, the epididymis, and the seminal vesicles. The vas deferens is the passageway that carries sperm from the epididymis to the ejaculatory duct. The epididymis is an organ located on the *testes* that has passageways (ducts) that carry sperm from the testes to the vas deferens. The seminal vesicles are glands that produce the fluid component of semen.


Appendices
Appendix A: Darlington Statement

Preamble

A. Intersex people are born with physical or biological sex characteristics (such as sexual anatomy, reproductive organs, hormonal patterns and/or chromosomal patterns) that are more diverse than stereotypical definitions for male or female bodies. For some people these traits are apparent prenatally or at birth, while for others they emerge later in life, often at puberty (see UN definition\(^5\)). We recognise our diverse histories and use the word intersex inclusively, and acknowledging our right to self-determination.

A. We observe that, despite the best efforts of intersex human rights defenders, discrimination, stigmatisation and human rights violations, including harmful practices in medical settings, continue to occur in Australia and Aotearoa/New Zealand.

B. We observe the 2013 Senate Community Affairs References Committee report, Involuntary or coerced sterilisation of intersex people in Australia, and the 2016 Family Court of Australia case, Re Carla (Medical procedure). We observe the Concluding observations on the fifth periodic report of New Zealand by the UN Committee on the Rights of the Child in 2016.

C. We recognise the international obligations of our countries, having signed the Convention against Torture, the Convention on the Rights of the Child, the Convention on the Elimination of Discrimination against Women, and the Convention on the Rights of Persons with Disabilities.

D. We note that intersex peer support remains largely unfunded, advocacy funding remains precarious and limited, and intersex-led organisations rely on volunteers to address the many gaps in services left by other, well-resourced health, social services and human rights institutions.

E. We acknowledge the kind support for this event from the National LGBTI Health Alliance, Twenty10, Astraea Lesbian Foundation for Justice, and an anonymous donor.

F. Recognising these issues, this gathering of Australian and Aotearoa/New Zealand intersex community organisations and individuals in March 2017, meeting on Gadigal Land in Darlington, Australia, acknowledges and respects the work of support organisations and human rights advocates over past years and acknowledges -

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6 http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Involuntary_Sterilisation/Sec_Report/index
7 Re Carla (Medical procedure) [2016] FamCA 7
9 http://lgbtihealth.org.au
10 http://twenty10.org.au
11 http://astraefoundation.org (Page 2 of 8)
We acknowledge

1. The Malta Declaration of the Third International Intersex Forum in 2013.¹²

2. That intersex people exist in all cultures and societies, throughout history, and that the existence of intersex people is worthy of celebration.

3. The diversity of our sex characteristics and bodies, our identities, sexes, genders, and lived experiences. We also acknowledge intersectionality’s with other populations, including same-sex attracted people, trans and gender diverse people, people with disabilities, women, men, and Indigenous - Aboriginal and Torres Strait Islander, Tangata Whenua - and racialized, migrant and refugee populations.

4. That the word ‘intersex’, and the intersex human rights movement, belong equally to all people born with variations of sex characteristics, irrespective of our gender identities, genders, legal sex classifications and sexual orientations.

5. Our rights to bodily integrity, physical autonomy and self-determination.

6. Our opposition to pathologising terminology such as “disorders of sex development”, not only because such labels are inherently disordering, but also because this promotes the belief that intersex characteristics need to be “fixed”.

Human rights and legal reform

7. We call for the immediate prohibition as a criminal act of deferrable medical interventions, including surgical and hormonal interventions, that alter the sex characteristics of infants and children without personal consent. We call for freely-given and fully informed consent by individuals, with individuals and families having mandatory independent access to funded counselling and peer support.

8. Regarding sex/gender classifications, sex and gender binaries are upheld by structural violence. Additionally, attempts to classify intersex people as a third sex/gender do not respect our diversity or right to self-determination. These can inflict wide-ranging harm regardless of whether an intersex person identifies

with binary legal sex assigned at birth or not. Undue emphasis on how to classify intersex people rather than how we are treated is also a form of structural violence. The larger goal is not to seek new classifications but to end legal classification systems and the hierarchies that lie behind them. Therefore:

a. As with race or religion, sex/gender should not be a legal category on birth certificates or identification documents for anybody.

b. While sex/gender classifications remain legally required, sex/gender assignments must be regarded as provisional. Given existing social conditions, we do not support the imposition of a third sex classification when births are initially registered.

c. Recognising that any child may grow up to identify with a different sex/gender, and that the decision about the sex of rearing of an intersex child may have been incorrect, sex/gender classifications must be legally correctable through a simple administrative procedure at the request of the individual concerned.

d. Individuals able to consent should be able to choose between female (F), male (M), non-binary, alternative gender markers, or multiple options.

9. We call for effective legislative protection from discrimination and harmful practices on grounds of sex characteristics.

10. We call on governments and institutions to acknowledge and apologise for the treatment of people born with variations of sex characteristics, and provide redress and reparation for people born with variations of sex characteristics who have experienced involuntary or coercive medical interventions. There must be no time limit on access to redress and reparation.

11. We call for an end to genetic discrimination, including in insurance and employment.

12. We call for all adults to have the right to marry and form a family irrespective of their sex characteristics.

13. We note the difficulty that many intersex people have when travelling, including experiences of discrimination and harassment due to their bodily diversity,
through the requirements of gendered documents, gendered screening and restrictions on travel with pharmaceutical prescription documents. We call on our governments to work with states, countries and international regulators to resolve these issues.

14. We call for meaningful participation by, and consultation with, intersex people and community organisations in all issues and policies affecting us.

Health and wellbeing

15. We acknowledge the long-term physical and psychological implications of harmful and continuing medical practices, and limited access to support and peers.

16. Current forms of oversight of medical interventions affecting people born with variations of sex characteristics have proven to be inadequate.

   a. We note a lack of transparency about diverse standards of care and practices across Australia and New Zealand for all age groups.

   b. We note that the Family Court system in Australia has failed to adequately consider the human rights and autonomy of children born with variations of sex characteristics, and the repercussions of medical interventions on individuals and their families. The role of the Family Court is itself unclear. Distinctions between “therapeutic” and “non-therapeutic” interventions have failed our population.(Page 4 of 8)

17. We call for the implementation of advisory bodies to develop appropriate human rights-based, lifetime, intersex standards of care with full and meaningful participation by intersex community representatives and human rights institutions.

18. We call on the Australasian Paediatric Endocrine Group13 and other medical/health bodies to stand alongside intersex-led community organisations to develop human rights-based lifetime standards of care.

19. We recognise that intersex people have health and medical needs, sometimes related to having an intersex variation, and sometimes not. We recognise that for

13 http://apeg.org.au(Page 5 of 8)
people with an intersex variation, misconceptions and associated stigma can act as barriers to treatment. Current practices are often based on the needs of other populations.

20. We recognise access limitations in rural, regional and remote settings.

21. We call for resourced access to necessary and appropriate health, medical and allied services and treatment, including surgeries and hormone treatment, psychosocial, psychosexual and psychological support, and including reparative treatments. Standards of care must support reparative treatments, and must not require conformity with stereotypical and clinical norms for female or male bodies, women and men, nor impose inappropriate psychiatric eligibility assessments.

22. We call for the provision of alternative, independent, effective human rights-based oversight mechanism(s) to determine individual cases involving persons born with intersex variations who are unable to consent to treatment, bringing together human rights experts, clinicians and intersex-led community organisations. The pros and cons for and against medical treatment must be properly ventilated and considered, including the lifetime health, legal, ethical, sexual and human rights implications.


24. Some people need pap smears, some people need prostate examinations or mammograms, and some people need a combination of these. National screening programs and computerised systems must recognise the needs of people born with intersex variations.

25. We call for an end to the use of IVF and other forms of genetic selection to deselect variations of sex characteristics.

26. We call for access to reproductive services and fertility counselling for all intersex people, with protection of our reproductive autonomy, regardless of
whether or not our capacity for fertility is considered to be in line with our legal sex.

27. Intersex-led organisations must be resourced to develop patient rights and human rights toolkits for intersex people and our families to improve access to healthcare, and ensure enjoyment of the highest attainable standard of physical and mental health.

28. Children with intersex variations require clear, age-appropriate disclosure of their intersex variations, and affirmative support, including peer support.

29. We call for regular public disclosure of accurate summary data on all medical interventions to modify the sex characteristics of children, and disclosure of historical data.

30. We call for more research, including clinical, sociological and psychological research, led by community input. Clinical research, including longitudinal research, requires true, non-medicalised controls.

31. We call for improved and ongoing education of health, welfare and allied professionals in issues relating to intersex bodies, including human rights issues.

32. Children with intersex variations should never be subjected to medical photography and display.

33. We call for respect for the privacy, integrity, and security of our medical records.

34. Recognising the difficulty that some intersex people have in accessing childhood medical records, we call for full access to medical records. Paediatric hospital records should be kept indefinitely. The medical records of people with whole-of-life medical issues should also be kept indefinitely.

35. We call for access to sport at all levels of competition by all intersex persons, including for all intersex women to be permitted to compete as women, without restrictions or discriminatory medical investigations.

36. Hormone treatment is required for a lifetime after sterilisation or in cases where gonads do not produce adequate hormones. However, people with intersex
variations face **unnecessary costs and challenges in accessing and managing appropriate hormone treatment.** These include access to sex hormones, the unfair and undisclosed cost of treatment required as a consequence of unwanted medical interventions, accessing testosterone and estrogen at the same time, changing from one sex hormone to the other, accessing screening, and travel restrictions, including travelling with medication and physical screening. We call for national and clinical standards to address these issues.

37. We call for the implementation of **adequate clinical transition pathways** from paediatric to adult services.

38. We call for equitable access to social and welfare services for people with intersex variations. The needs of people with intersex variations in **aged care, home care, state care, and disability services** require further investigation, with full and meaningful participation by intersex-led organisations. (Page 6 of 8)

**Peer support**

39. We recognise the **trauma and mental health concerns** caused by the unnecessary medicalisation of intersex people, as well as stigmatisation of intersex characteristics that has resulted in a legacy of isolation, secrecy and shame.

40. We recognise the fundamental importance and benefits of **affirmative peer support** for people born with variations of sex characteristics.

41. Our peer support organisations and other peer communities need resourcing and support to **build communities and networks** inclusive of all intersex people. No intersex person or parent of an intersex child should feel they are alone, irrespective of their bodily variation or the language they use.

42. We recognise the needs and lived experience of **youth**, and of people coming from varied **cultural and faith backgrounds**. We recognise these experiences as valid and legitimate.

43. We recognise the fundamental importance and benefits of **peer support for parents, caregivers, and families** of people with variations of sex characteristics. We recognise the importance and benefits of peer support for
friends, partners, and others who support intersex people in their day-to-day lives.

44. **Peer support must be integrated** into human rights-based multi-disciplinary medical approaches, teams and services.

45. We call for **public, governmental, and philanthropic support** for funded, affirmative peer support.

46. We acknowledge that intersex people are the **experts** on our own lives and lived experience. Intersex people are experts in understanding the long-term effects of medicalisation and medical interventions.

**Allies**

47. Intersex is distinct from other issues. We call on allies to actively **acknowledge** our distinctiveness and the diversity within our community, to **support** our human rights claims and **respect** the intersex human rights movement, **without tokenism**, or instrumentalising, or co-opting intersex issues as a means for other ends. “Nothing about us without us.”

48. We encourage all organisations and bodies that support the intersex movement to **recognise this Darlington statement**.

49. We call for intersex people, and the intersex human rights movement, **to be allies** to the LGBTQ, disability, Indigenous, anti-racist, and women’s movements.

50. We call on intersex people to recognise our own diversity, and call for **intra-community dialogue and mutual support**.

**Education, awareness and employment**

51. We acknowledge that **stigma is often the result of misconceptions** about intersex which is compounded by a lack of education and awareness.

52. We recognise that the stigmatisation and theologisation of people born with variations of sex characteristics **hinders self-acceptance, access to community, help-seeking, and accessing of services** including healthcare.

53. We acknowledge the impacts of stigma, trauma and unwanted medical interventions on access to **education** and on **employment**, and consequences
that include high rates of *early school leaving, poverty, self-harm and suicidality*.

54. We call for the inclusion of accurate and affirmative material on bodily diversity, including intersex variations, in *school curricula*, including in health and sex education.

55. We call on education and awareness providers to develop content with intersex-led organisations, and promote delivery by intersex people.

56. We call on *employer groups, governments, institutions and trade unions to develop affirmative policies and practices* to support employees with intersex variations.

57. We call for policies in *educational institutions and employment* to recognise that some people born with intersex variations may benefit from *accommodations and reasonable adjustments*, including special needs requirements, workplace adjustments, job access assistance, and provisions for medical leave.

58. We acknowledge the *vital importance of positive stories and role models* and the existence of some positive media coverage of intersex people. We acknowledge that much media work unfortunately perpetuates the stigmatisation of intersex people and bodies. We call on the *media to work with intersex-led organisations* to improve their understanding of intersex people and our human rights issues.

59. We call for an *end to the stigmatisation and unnecessary pathologisation* of intersex bodies.
Appendix B: Māori Consultation for Research

NGĀI TAHU RESEARCH CONSULTATION COMMITTEE
TE KOMITI RAKAHAU KI KĀI TAHU

17/07/2012 - 58
Tuesday, 17 July 2012

Ms Steers
Dean's department
Wellington

Tēnā koe Ms Steers

Title: Disorders of Sex development: deciding what's best evidence or values?

The Ngāi Tahu Research Consultation Committee (The Committee) met on Tuesday, 17 July 2012 to discuss your research proposition.

By way of introduction, this response from the Committee is provided as part of the Memorandum of Understanding between Te Rītaunga o Ngāi Tahu and the University. In the statement of principles of the memorandum, it states “Ngāi Tahu acknowledges that the consultation process outlined in this policy provides no power of veto by Ngāi Tahu to research undertaken at the University of Otago”. As such, this response is not “approval” or “mandate” for the research, rather it is a mandated response from a Ngāi Tahu appointed committee. This process is part of a number of requirements for researchers to undertake and does not cover other issues relating to ethics, including methodology; they are separate requirements with other committees, for example the Human Ethics Committee, etc.

Within the context of the Policy for Research Consultation with Māori, the Committee base consultation on that defined by Justice McGechan:

"Consultation does not mean negotiation or agreement. It means: setting out a proposal not fully decided upon; adequately informing a party about relevant information upon which the proposal is based; listening to what the others have to say with an open mind (in that there is room to be persuaded against the proposal); undertaking that task in a genuine and not cosmetic manner. Reaching a decision that may or may not alter the original proposal."

The Committee considers the research to be of importance to Māori health.

As this study involves human participants, the Committee strongly encourage that ethnicity data be collected as part of the research project. That is the questions on self-identified ethnicity and descent, these questions are contained in the 2006 census.


The Ngāi Tahu Research Consultation Committee has membership from:
Te Rītaunga o Ōtepoti Incorporated
Kāti Huirapa Rūpaka ki Pukeruhi
Te Rītaunga o Meuruki

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Appendix C: Ethics Approval - University of Otago

H13/031

3 September 2013

Professor S Collings
Dean’s Office (Wgnt)
Faculty of Medicine
University of Otago, Wellington

Dear Professor Collings,

I am again writing to you concerning your proposal entitled “Disorders of Sex development: what drives decision-making for children born with DSD?”, Ethics Committee reference number H13/031.

Thank you for your letter dated 15 August 2013 and subsequent e-mail of 27 August 2013 addressing the issues raised by the Committee.

The Committee note that medical notes will no longer be necessary to access and as such has been reflected in the amended Information Sheets. The Committee is also grateful for the clarification and amendment made for the Health Professionals Information Sheet noting that the interviews will be semi-structured.

The Committee is grateful for the clarification of the age of the children who will be eligible to take part in group two, noting that parents whose children are aged between new-born and fourteen will be recruited for this group.

On the basis of this response, I am pleased to confirm that the proposal now has full ethical approval to proceed.

Approval is for up to three years from the date of this letter. If this project has not been completed within three years from the date of this letter, re-approval must be requested. If the nature, consent, location, procedures or personnel of your approved application change, please advise me in writing.
Appendix D: Ethics approval - health and Disability Ethics Committees

05 August 2015

Professor Sunny Collings
23a Mein st
University of Otago Medical School
Wellington 6021

Dear Professor Collings

Re: Ethics ref: 15/CEN/89
Study title: Disorders of Sex Development:navigating decision making in New Zealand

I am pleased to advise that this application has been approved by the Central Health and Disability Ethics Committee. This decision was made through the HDEC-Full Review pathway.

Summary of Study

1. The study investigates disorders of sex development (DSD). The study aims to understand how decisions are made and will navigate the experience and treatment pathway that occurs for children who experience DSD in New Zealand, as well as exploring the international context.

2. Earlier research suggests that historical treatment of children with DSD has been problematic. In 2006 there was an international consensus on how children born with DSD should be treated. Since this consensus there remains confusion around how this treatment actually happens. The researchers will assess if care providers adopted the recommendations from this consensus in New Zealand.

3. The study involves three groups - health workers (clinicians), parents of children with DSD and young adults (16+) who have DSD.

4. There has been research conducted with older participants who had experienced the pre-2006 treatment pathways. This study involves a younger group who will be able to comment on more recent treatment methods and will provide a new perspective on current treatment options, giving us a holistic picture.

5. The Otago ethics committee has approved the study.

6. The researchers explained that when they sought locality approval from ADHB their research office requested HDEC review due to the potential vulnerability of the patient population.

7. The Committee commended the study and noted that it was an important project.
Appendix E: Information sheet-health professionals

Decision making for Children born with Disorders of Sex Development
Information Sheet for Health Professionals

Thank you for showing an interest in this project. Please read this information sheet carefully before deciding whether or not to participate. If you decide to participate, we thank you. If you decide not to take part there will be no disadvantage to you and we thank you for considering our request.

What is the aim of the project?
This study is being carried out by the University of Otago Wellington and is for a PhD. The aim of this study is to investigate the factors and processes influencing contemporary clinical decision making for children born with Disorders of Sex Development (DSD) in New Zealand. The study aims to explore and describe the decision making process in relation to gender assignment, genital surgery and other treatments for children born with a DSD. We are collecting information from three key groups: people with DSD; parents of children with DSD; and health professionals. The decision making process for children born with DSD is a very complex and there is much ethical debate about what is the best approach to take when providing care and treatment for children affected by these disorders. This study appreciates that the decision making process is complicated and that all involved are making decisions with the best of intentions for children and their families. This study aims to gain a greater understanding of the factors influencing the decision making process and from the perspectives of those directly involved.

What type of participants are being sought?
We are seeking the participation of parents of children born with a clinical diagnosis of DSD according to the international classification and the health care providers at services who are principally responsible for their day to day care.

If you have a client who has a diagnosis of a DSD they (and you) may be eligible to take part in this study.

What participants will be asked to do?
Should you agree to take part in this project, we will ask you to participate in a semi-structured interview with the researcher lasting approximately 60 minutes. This interview will focus on your experiences of making decisions in relation to your clients born with a DSD. You will be asked about your treatment relationships with your patients and their parents.

I would ask you to recruit parents of new patients born with DSD into the study. This will provide an opportunity for the researcher to seek permission to interview parents of children born with DSD. This interview will focus on their experiences of making decisions in relation to their child. They will be asked about their relationship with you regarding the treatment of their child.

We will request permission from parents to discuss their affected child with you to get accurate diagnosis and test results. Additionally, if there was an opportunity for you to audio record a consultation with patient’s parents prior to the researcher interviewing the parents that would add valuable information to the study. It would give a real life example of how information is conveyed and the processes of decision making. This is optional and only if the opportunity presents itself.

The interviews will take place at a time and venue that is convenient to you and the parents.

This would involve:
- Providing an information sheet to parents about the study.
- Informing them the researcher, Denise Steers, will contact them to discuss participation and provide further information and answer any questions.

Can Participants change their minds and withdraw from the project?
Your participation is completely voluntary. You may withdraw from participation in the project at any time and without any disadvantage to yourself of any kind. Data that has been collected and used in ongoing study design refinement and analysis will continue to be used. All identifying information will be removed.

What data or information will be collected and what use will be made of it?
Interview data will only be available to the researcher Denise Steers and her principal supervisor, Professor Sunny Collings.

The results of the study may be published but every attempt will be made to preserve your anonymity. This will be achieved by use of codes and removing all identifying details. You are most welcome to request a copy of the results of the project should you wish. There is a yes or no section on the consent form that allows you to make your request known.

The data collected will be securely stored in such a way that only the researcher, Denise Steers and her principal supervisor, Professor Sunny Collings will be able to gain access to it. At the end of the study any personal information e.g. participant contact details will be destroyed immediately except that, as required by the University's research policy, any raw data on which the results of the project depend will be kept in secure storage for ten years, after which it will be destroyed.

What are the studies benefits and risks?
Benefits
- Children born with a DSD are a vulnerable group in society and more research is needed to support health professionals working in the field.
- The diagnosis of DSD and treatment raises a variety of complex ethical issues and more research is needed to inform the ongoing revision or development of guidelines and policy.
- Given the complexity and ethical issues for health professionals working in this area the study will provide an opportunity for self reflective practice.
- The study will contribute to the limited body of research in New Zealand.
• It will take in the perspectives of all those involved in the decision making process i.e. parents, health professionals and young people who are born with a DSD.
• Identification of what working well and what could be improved in the provision of care for children born with DSD.
• Recommendations for the development of resources for health professionals, parents and people born with DSD.

Risks
• This study covers a sensitive topic with a number of complex and ethical issues and you may feel uncomfortable when reflecting on your experiences or those of your patients.
• Confidentiality—you may have concerns that what you say in confidence may be at risk e.g. if you had a collegial difference of opinion. All data collected will be keep in strict confidence and stored on a password locked computer and only accessed by researcher Denise Steers and the principal supervisor Professor Sunny Collings. Interview data will not be shared with the participants from any of the three groups involved.

What if Participants have any Questions?
If you have any questions about the study, either now or in the future, please feel free to contact Denise Steers Denise.steers@otago.ac.nz, phone 04 806 1495 or Professor Sunny Collings Sunny.collings@otago.ac.nz, phone 04 918 5600

Information and Support
If you have any questions or concerns about your rights as a participant in this research study, you can contact an independent health and disability advocate. This is a free service provided under the Health and Disability Commissioner Act.
Telephone, NZ wide: 0800 555 050
Free Fax, NZ wide: 0800 2787 7678 (0800 2 SUPPORT)
Email: advocacy@hdc.org.nz

This study has been approved by Central Health and Disability Ethics Committee: Reference no.15/CEN/89
Appendix F: Consent form - health professionals

Decision making for Children born with Disorders of Sex Development

Consent Form for Health Professionals

I have read the Information Sheet concerning this project and understand what it is about. All my questions have been answered to my satisfaction. I understand that I am free to request further information at any stage.

I know that:

• My participation in the project is entirely voluntary
• I have had time to consider whether to take part.
• I understand that taking part in this study is my choice and that I may withdraw at any time at no disadvantage to myself.
• I understand that my participation in the study will be confidential and that all efforts to anonymise (e.g. removal of names and other identifiers) will be used in any reports on the study.
• I understand that any raw data on which the results of the project depend will be kept in secure storage for ten years, after which it will be destroyed.

I, _________________________________________________, hereby consent to take part in this study.

Signature: ________________________________

Date: ________________________________

Do you wish to receive a brief study report once it is completed?  Yes  No

Optional Consultation audio recording

Are you willing in principal to audio record a consultation with patient’s parents if they consent and should an opportunity present itself?  Yes  No

Signature: ________________________________

What if Participants have any Questions?

If you have any questions about the study, either now or in the future, please feel free to contact Denise Steers
Denise.steers@otago.ac.nz, phone 04 806 1495 or Professor Sunny Collings Sunny.collings@otago.ac.nz, phone 04 918 5600

Information and Support

If you experience any distress as a result of the interview please contact me Denise.steers@otago.ac.nz and I can help you find local support.

If you have any questions or concerns about your rights as a participant in this research study, you can contact an independent health and disability advocate. This is a free service provided under the Health and Disability Commissioner Act. Telephone, NZ wide: 0800 555 050 Email: advocacy@hdc.org.nz

If you require Maori cultural support, talk to your whanau in the first instance. Alternatively, you may contact the administrator for He Kamaka Waiora (Maori Health Team) by telephoning 09 486 8324 ext 2324

If you have any questions or complaints about the study you may contact the Auckland and Waitemata District Health Boards Maori Research Committee or Maori Research Advisor by telephoning 09 4868920 ext 3204

This study has been approved by Central Health and Disability Ethics Committee: Reference no.15/CEN/89

Other related support organisations:
Intersex Trust Aotearoa New Zealand (ITANZ)  www.ianz.org.nz  04 381 2221
Congenital Adrenal Hyperplasia New Zealand Trust (CAHNZ)  www.cah.org.nz  03 3584 506
Appendix G: Information sheet form -parents

Information Sheet for Parents

Understanding diverse sex development in NZ

Thank you for showing an interest in this study. Please read this information sheet carefully before deciding whether or not to participate. If you decide to participate, we thank you. If you decide not to take part there will be no disadvantage to you and we thank you for considering our request.

What is the aim of the project?
This study is being carried out by the University of Otago Wellington and is for a PhD. The aim of this study is to investigate the factors and processes influencing contemporary clinical decision making for children born with Diverse Sex Development (DSD) in New Zealand. The study aims to explore and describe the decision making process in relation to gender assignment and genital surgery and other treatments for children born with a DSD. We are collecting information from three key groups; people with DSD; parents of children with DSD; and health professionals.

The decision making process for children born with DSD is a very complex and there is much ethical debate about what is the best approach to take when providing care and treatment for children affected by these disorders. This study appreciates that the decision making process is complicated and that all involved are making decisions with the best of intentions for the children and their families. This study aims to gain a greater understanding of the decision making process from the perspectives of those directly involved.

Who can take part?
We are seeking the participation of parents of children born with a DSD eg congenital adrenal hyperplasia (CAH), Androgen insensitivity syndrome (AIS) - can be partial (PAIS) or complete (CAIS), severe hypospadias, Klinefelter syndrome, 5-alpha reductase deficiency, gonadal dysgenesis, 46,XX/46,XY, Cloacal anomaly etc.

We are asking health care providers at services who are principally responsible for day to day care of children born with a DSD to participate. They may be the one who has provided you information about this study. If you have a child who has a diagnosis of a DSD and is aged from new born to 14 years you may be eligible to take part in this study.

What will participants be asked to do?
Should you agree to take part in this study, we will ask you to participate in a semi structured interview with the researcher lasting approximately 60 minutes. This interview will focus on your experiences of making decisions in relation to your child born with a DSD. You will be asked about your treatment relationships with your primary health professional or team. We will ask your permission to contact your doctor so we can be accurate about diagnosis and the test results.

This will take place at a time and venue that is convenient to you.

Additionally, your health care provider may ask you to consent to a consultation with them being audio recorded to be used in the study. Should you consent, the researcher Denise Steers will contact you before and answer any questions you may have. Ideally the recording of the consultation would take place before the researcher interviews you. This would give an opportunity for you to reflect on the consultation process.

Can Participants change their minds and withdraw from the project?
Your participation is completely voluntarily. You may withdraw from participation in the project at any time and without any disadvantage to yourself of any kind. Data that has been collected already and used in developing further questions and direction for the research will continue to be used. All identifying information will be removed.

What data or information will be collected and what use will be made of it?
Interview data will be available to the researcher Denise Steers and her supervisors, Professor Sunny Collings and Dr Angela Ballantyne only.

The results of the project may be published but every attempt will be made to preserve you and your child’s anonymity. This will be achieved by use of codes and removal of all personal identifiers e.g. names, birthdates etc. You are most welcome to request a copy of the results of the study should you wish. There is a yes or no section on the consent form that allows you to make your request known.

The data collected will be securely stored in such a way that only the researcher, Denise Steers, will be able to gain access to it. At the end of the project any personal information e.g. participant contact details will be destroyed immediately except that, as required by the University’s research policy, any raw data on which the results of the project depend will be kept in secure storage for ten years, after which it will be destroyed. Interview data will not be shared with your Doctor.

What are the studies benefits and risks?

Benefits
- Children born with a DSD are a vulnerable group in society and more research is needed to support parents.
- Children born with a DSD are a vulnerable group in society and more research is needed to support the development of best practice for health professionals working in the field.
- The diagnosis of DSD and treatment raises a variety of complex ethical issues and more research is needed to inform the ongoing revision or development of guidelines and policy.
- Given the complexity and ethical issues for both parents and health professionals the study will provide an opportunity for self reflection.
- The study will contribute to the limited body of research in New Zealand.
- It will take in the perspectives of all those involved in the decision making process i.e. parents, health professionals and young people who are born with a DSD.
- Identification of what working is well and what could be improved in the provision of care for children born with a DSD.
- Recommendations for the development of resources for health professionals, parents, and people born with DSD.

Appendix G: Information sheet form -parents

Understanding diverse sex development in NZ

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The decision making process for children born with DSD is a very complex and there is much ethical debate about what is the best approach to take when providing care and treatment for children affected by these disorders. This study appreciates that the decision making process is complicated and that all involved are making decisions with the best of intentions for the children and their families. This study aims to gain a greater understanding of the decision making process from the perspectives of those directly involved.

Who can take part?
We are seeking the participation of parents of children born with a DSD eg congenital adrenal hyperplasia (CAH), Androgen insensitivity syndrome (AIS) - can be partial (PAIS) or complete (CAIS), severe hypospadias, Klinefelter syndrome, 5-alpha reductase deficiency, gonadal dysgenesis, 46,XX/46,XY, Cloacal anomaly etc.

We are asking health care providers at services who are principally responsible for day to day care of children born with a DSD to participate. They may be the one who has provided you information about this study. If you have a child who has a diagnosis of a DSD and is aged from new born to 14 years you may be eligible to take part in this study.

What will participants be asked to do?
Should you agree to take part in this study, we will ask you to participate in a semi structured interview with the researcher lasting approximately 60 minutes. This interview will focus on your experiences of making decisions in relation to your child born with a DSD. You will be asked about your treatment relationships with your primary health professional or team. We will ask your permission to contact your doctor so we can be accurate about diagnosis and the test results.

This will take place at a time and venue that is convenient to you.

Additionally, your health care provider may ask you to consent to a consultation with them being audio recorded to be used in the study. Should you consent, the researcher Denise Steers will contact you before and answer any questions you may have. Ideally the recording of the consultation would take place before the researcher interviews you. This would give an opportunity for you to reflect on the consultation process.

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Your participation is completely voluntarily. You may withdraw from participation in the project at any time and without any disadvantage to yourself of any kind. Data that has been collected already and used in developing further questions and direction for the research will continue to be used. All identifying information will be removed.

What data or information will be collected and what use will be made of it?
Interview data will be available to the researcher Denise Steers and her supervisors, Professor Sunny Collings and Dr Angela Ballantyne only.

The results of the project may be published but every attempt will be made to preserve you and your child’s anonymity. This will be achieved by use of codes and removal of all personal identifiers e.g. names, birthdates etc. You are most welcome to request a copy of the results of the study should you wish. There is a yes or no section on the consent form that allows you to make your request known.

The data collected will be securely stored in such a way that only the researcher, Denise Steers, will be able to gain access to it. At the end of the project any personal information e.g. participant contact details will be destroyed immediately except that, as required by the University’s research policy, any raw data on which the results of the project depend will be kept in secure storage for ten years, after which it will be destroyed. Interview data will not be shared with your Doctor.

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- Children born with a DSD are a vulnerable group in society and more research is needed to support parents.
- Children born with a DSD are a vulnerable group in society and more research is needed to support the development of best practice for health professionals working in the field.
- The diagnosis of DSD and treatment raises a variety of complex ethical issues and more research is needed to inform the ongoing revision or development of guidelines and policy.
- Given the complexity and ethical issues for both parents and health professionals the study will provide an opportunity for self reflection.
- The study will contribute to the limited body of research in New Zealand.
- It will take in the perspectives of all those involved in the decision making process i.e. parents, health professionals and young people who are born with a DSD.
- Identification of what working is well and what could be improved in the provision of care for children born with a DSD.
- Recommendations for the development of resources for health professionals, parents, and people born with DSD.
Risks

- This study covers a sensitive topic with a number of complex and ethical issues and you may feel uncomfortable when reflecting on your experiences.
- Confidentiality—you may have concerns that what you say in confidence may be at risk e.g. if you had a difference of opinion with a health professional. All data collected will be kept in strict confidence and stored on a password locked computer and only accessed by researcher, Denise Steers, and her supervisor’s professor Sunny Collings and Dr Angela Ballantyne. Interview data will not be shared with your doctor.

What if Participants have any Questions?
If you have any questions about the study, either now or in the future, please feel free to contact Denise Steers Denise.steers@otago.ac.nz, phone 04 806 1495 or Professor Sunny Collings Sunny.collings@otago.ac.nz phone 04 918 5600

Information and Support
If you experience any distress as a result of the interview please contact me Denise.steers@otago.ac.nz and I can help you find local support.
If you have any questions or concerns about your rights as a participant in this research study, you can contact an independent health and disability advocate. This is a free service provided under the Health and Disability Commissioner Act. Telephone, NZ wide: 0800 555 050 Email: advocacy@hdc.org.nz

This study has been approved by Central Health and Disability Ethics Committee: Reference no.15/CEN/89

Other related support organisations:
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Congenital Adrenal Hyperplasia New Zealand Trust (CAHNZ) www.cah.org.nz 03 3584 506
Appendix H: Consent form -parents

Understanding diverse sex development in NZ

Consent Form for Parents

I have read the Information Sheet concerning this project and understand what it is about. All my questions have been answered to my satisfaction. I understand that I am free to request further information at any stage. I know that:

- My participation in the project is entirely voluntary
- I have had time to consider whether to take part.
- I understand that taking part in this study is my choice and that I may withdraw at any time at no disadvantage to myself.
- I understand that my participation in the study will be confidential and that no material which could identify me or my child will be used in any reports on the study.
- I understand that any raw data on which the results of the project depend will be kept in secure storage for ten years, after which it will be destroyed.

I, ____________________________________________, hereby consent to take part in this study.

Signature:

I, ____________________________________________, hereby consent to take part in this study.

Signature:

Date:

Do you wish to receive a brief study report once it is completed?  Yes  No

If you have any questions about the study, either now or in the future, please feel free to contact Denise Steers
Denise.steers@otago.ac.nz, phone 04 806 1495 or Professor Sunny Collings Sunny.collings@otago.ac.nz, phone 04 918 5600

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Congenital Adrenal Hyperplasia New Zealand Trust (CAHNZ)
www.cah.org.nz 03 3584 506

This study has been approved by the University of Otago Human Ethics Committee. If you have any concerns about the ethical conduct of the research you may contact the Committee through the Human Ethics Committee Administrator (ph 03 479 8256). Any issues you raise will be treated in confidence and investigated and you will be informed of the outcome.
Appendix I: Information sheet - young people

Information Sheet for Young People
Understanding diverse sex development/ intersexuality in NZ

Introduction
My name is Denise Steers and I am based at the University of Otago Wellington. I am a researcher doing my PhD about how decisions are made for the care and treatment of children who are born with sex development that is different from others. Diverse Sex Development (DSD) (and/ or disorder of sex development) is the medical term used in New Zealand. My work has always involved young people and my supervisor, Professor Sunny Collings also a researcher has worked on a number of projects involving young people and diversity. There are lots of different terms used such as gender variant, diverse sex development and Intersex. Sometimes specific conditions are named for example Congenital Adrenal Hyperplasia (CAH), Androgen Insensitivity Syndrome (AIS and PAIS), severe hypospadias etc.

I am collecting information from three groups of people: people who are intersex or have a DSD; parents of newborns who are intersex/DSD; and health professionals.

I want to gain a greater understanding from the perspectives of those directly involved.

Who can take part?
You are invited to take part in the study if you have some experience of, or have been treated for sex development issues these include congenital adrenal hyperplasia (CAH), Androgen insensitivity syndrome (AIS)- can be partial (PAIS) or complete (CAIS), severe hypospadias, Klinefelter syndrome, 5-alpha reductase deficiency, gonadal dysgenesis, 46, XX/46, XY Cloacal anomaly etc.

We want young people aged between 16 and 26 years old.

This is an opportunity for you to have a voice and express your opinions about how you have experienced the health care provided and any changes that you would like to see happen.

What does it involve?
The interview will focus on your experiences living with decisions that were made for you when you were a child in relation to you being born with sex development different to others. You will be asked about any ongoing treatment relationships with your main health professional or team.

The interview is about 30-90 minutes long and will be done at a time and place that suits you.

Your participation is completely voluntary. If you agree to take part, you can later withdraw, at any time, and without any explanation. There will be no disadvantage to you as a result.

What happens to the information you give?
The information you provide will be kept private and confidential. It will be only available to me and my supervisor, Professor Sunny Collings. All identifying information will be removed.

The results of the project may be published but every attempt will be made to keep your identity and those that you mention (e.g. family, friends and health professionals) anonymous and private.

All personal identifiers e.g. names, birth dates, location etc. will be removed. The data collected will be securely stored.

Interview data will not be shared with your doctor or parents.

You can request a copy of the results of the study if you wish. There is a yes or no section on the consent form that allows you to make your request known.

What are the studies benefits and risks?

Benefits
- The views of people who identify as having had a different sex development DSD/intersexuality are needed to support the development of best practice for health professionals working with affected people. More research is needed to support young people born with intersex/DSD.
- The diagnosis of intersex/DSD and treatment raises a variety of complex ethical issues and more research is needed to inform the ongoing revision or development of guidelines and policy.
- The study will contribute to the limited body of research in New Zealand.
- It will take in the perspectives of all those involved in the decision making process i.e. parents, health professionals and you people who are born intersex/DSD.
- It will tell us what is working well and what could be improved when providing care for children born Intersex/DSD.
- Recommendations for the development of resources for health professionals, parents and people born intersex/DSD.

Risks
- This study covers a sensitive topic with a number of complex issues and you may feel uncomfortable when reflecting on your experiences.
- Confidentiality – All your personal information and views will be kept in strict confidence and stored on a password locked computer and only accessed by one researcher, Denise Steers and the principal supervisor Professor Sunny Collings.
- Interview data will not be shared with your doctor or parents.

Do you have any questions?
If you have any questions about the study, either now or in the future, please feel free to contact Denise Steers
Denise.steers@otago.ac.nz, phone 04 806 1495
or Professor Sunny Collings, Sunny.collings@otago.ac.nz, phone 04 918 5600

Information and Support
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and disability advocate. This is a free service provided under the Health and Disability Commissioner Act.
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This study has been approved by the University of Otago Human Ethics Committee. If you have any concerns about the ethical
conduct of the research you may contact the Committee through the Human Ethics Committee Administrator (ph 03 479 8256).
Any issues you raise will be treated in confidence and investigated and you will be informed of the outcome.
Appendix J: consent form -young people

Understanding diverse sex development/ intersexuality in NZ
Consent Form for Young People

I have read the Information Sheet concerning this study and understand what it is about. All my questions have been answered to my satisfaction. I understand that I am free to ask for further information at any stage. I know that:

- My participation in the project is entirely voluntary
- I understand that taking part in this study is my choice and that I may withdraw at any time at no disadvantage to myself.
- I understand that my participation in the study will be confidential and that no material which could identify me or my family will be used in any reports on the study.
- I agree to take part in the study.

Name:

Signature:

Date:

Do you wish to receive a brief study report once it is completed?     Yes     No

If you have any questions about the study, either now or in the future, please feel free to contact Denise Steers Denise.steers@otago.ac.nz, phone 04 806 1495 or Professor Sunny Collings Sunny.collings@otago.ac.nz, phone 04 918 5600

Information and Support
If you have any questions or concerns about your rights as a participant in this research study, you can contact an independent health and disability advocate. This is a free service provided under the Health and Disability Commissioner Act.
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This study has been approved by the University of Otago Human Ethics Committee. If you have any concerns about the ethical conduct of the research you may contact the Committee through the Human Ethics Committee Administrator (ph 03 479 8256). Any issues you raise will be treated in confidence and investigated and you will be informed of the outcome.
Appendix K: Information Sheet – young people under 16

Information Sheet / Assent Form for Young People (13-15 years)

Understanding diverse sex development/ intersexuality in NZ

Introduction
My name is Denise Steers and I am based at the University of Otago Wellington. I am doing my PhD which involves looking at how decisions are made for the care and treatment of children who have conditions like yours.

Diverse Sex Development (DSD) (and/or disorder of sex development) is the medical term used in New Zealand. There are lots of different terms used such as diverse sex development, and Intersex. These terms refers to a whole lot of specific conditions, some common ones being Congenital Adrenal Hyperplasia (CAH), Androgen Insensitivity Syndrome (AIS and PAIS) and severe hypospadias.

I am collecting information from three groups of people; people who are intersex or have a DSD; parents of children who are intersex/DSD; and health professionals. I want to gain a greater understanding from these three groups.

Who can take part?
You can take part in the study if you have a condition like congenital adrenal hyperplasia (CAH), Androgen insensitivity syndrome (AIS)- can be partial (PAIS) or complete (CAIS), severe hypospadias, Klinefelter syndrome, 5-alpha reductase deficiency, gonadal dysgenesis, 46 XX/46, XY Cloacal anomaly etc.

We want young people aged between 13 and 26 years old. This is an opportunity for you to have your say about the health care provided to you and any changes that you would like to see happen for other patients in the future.

What does it involve?
The interview will focus on your experiences living with decisions that were made for you by your parents. You will be asked about any ongoing treatment relationships with your main health professional or team.

The interview is about 30-90 minutes long and will be done at a time and place that suits you.

Your participation is completely voluntary. If you agree to take part, you can stop at any time, and without any explanation.

Whether you decide to do the interview or not, will not affect your healthcare.

You can have a friend or support person with your during the interview if you would like too.

What happens to the information you give?
The information you provide will be kept private and confidential. It will only be available to my supervisors at the University and me. All personal identifiers e.g. names, birth dates, location etc. will be removed.

The results of the project may be published but every attempt will be made to keep your identity and the identity of any family members, friends and health professionals that you talk about, anonymous and private. For example, the paper we write might say “A 14 year old girl with [insert condition] said that...” The data collected will be securely stored. Interview data will not be shared with your doctor or parents.

You can request a copy of the results of the study if you wish. There is a yes or no section on the consent form that allows you to make your request known.

What are the studies benefits and risks?

Benefits
• Treating conditions like yours raises a variety of complex questions and more research is needed to let doctors know the best way to treat patients with these conditions. This research will tell us what is working well and what could be improved when providing care for people like you.
• The study will contribute to the limited body of research in New Zealand
• It will take in the perspectives of all those involved in the decision making process i.e. parents, health professionals and young people.

Risks
• This study covers personal issues and you may feel uncomfortable when talking about your experiences. But many people like having the chance to tell their side of the story. Remember you don’t have to answer all the questions if you don’t want to and you can stop the interview at any time.
• People can worry about what happens to their information – All your personal information and what you say will be kept private and stored on a password locked computer and only accessed by one researcher, Denise Steers and her supervisor’s.

I have read the Information Sheet concerning this study and understand what it is about. All my questions have been answered to my satisfaction. I understand that I am free to ask for further information at any stage.

I know that:
• It is my choice to take part in the study
• I understand that taking part in this study is my choice and that I may stop the interview at any time at no disadvantage to myself.
• I understand that taking part in the study will be confidential and that no material which could identify me or my family will be used in any reports on the study.

• I assent to take part in the study.

Name:

Signature:

Date:

Do you wish to receive a brief study report once it is completed? Yes     No

Do you have any questions?
If you have any questions about the study, either now or in the future, please feel free to contact Denise Steers
Denise.steers@otago.ac.nz, phone 04 8061495 or Professor Sunny Collings Sunny.collings@otago.ac.nz, phone 04 918 5600

Information and Support
If you experience any distress as a result of the interview please contact me Denise.steers@otago.ac.nz and I can help you find local support.

If you have any questions or concerns about your rights as a participant in this research study, you can contact an independent health and disability advocate. This is a free service provided under the Health and Disability Commissioner Act. Telephone, NZ wide: 0800 555 050 Email: advocacy@hdc.org.nz

The University of Otago Human Ethics Committee has approved this study. If you have any concerns about the ethical conduct of the research you may contact the Committee through the Human Ethics Committee Administrator (03 479 8256). Any issues you raise will be treated in confidence and investigated and you will be informed of the outcome.

Intersex Trust Aotearoa New Zealand (ITANZ) www.ianz.org.nz 04 381 2221
Intersex Youth Aotearoa www.facebook.com/intersexyouthaotearoa
Congenital Adrenal Hyperplasia New Zealand Trust (CAHNZ) www.cah.org.nz 03 3584 506
Appendix L: Consent form— young people under 16

Understanding diverse sex development/ intersexuality in NZ

Consent Form for Young Persons Parents /Guardians

I have read the Information Sheet concerning this study and understand what it is about. All my questions have been answered to my satisfaction. I understand that I am free to ask for further information at any stage.

I know that:

- I understand my child’s participation in the project is entirely voluntary and they may withdraw at any time at no disadvantage.
- I understand that agreeing to my child taking part in this study is my choice and that of my child.
- I understand that information from my child’s participation in the study will be confidential and that no material, which could identify them or my family, will be used in any reports on the study.
- I agree for my child to take part in the study.

Parents/Guardians Name:

Signature/s:

Date:

Do you wish to receive a brief study report once it is completed?  Yes  No

If you have any questions about the study, either now or in the future, please feel free to contact Denise Steers Denise.steers@otago.ac.nz, phone 04 8061495 or Professor Sunny Collings Sunny.collings@otago.ac.nz, phone 04 918 5600

Information and Support
If your child experiences any distress as a result of the interview please contact me Denise.steers@otago.ac.nz and I can help them find local support.

If you have any questions or concerns about your rights of your child as a participant in this research study, you can contact an independent health and disability advocate. This is a free service provided under the Health and Disability Commissioner Act. Telephone, NZ wide: 0800 555 050 Email: advocacy@hdc.org.nz

The University of Otago Human Ethics Committee has approved this study. If you have any concerns about the ethical conduct of the research you may contact the Committee through the Human Ethics Committee Administrator (03 479 8256). Any issues you raise will be treated in confidence and investigated and you will be informed of the outcome.

Other related support organisations:
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Intersex Youth Aotearoa www.facebook.com/intersexyouthaotearoa
Congenital Adrenal Hyperplasia New Zealand Trust (CAHNZ) www.cah.org.nz 03 3584 50
Appendix M: interview guides

Interview guide for health professionals – doctors

Introduction
My name is Denise Steers and I am a clinical psychologist doing research as part of my PhD through Otago University on how decisions are made around the treatment and care of people born with Disorders of Sex Development. I am interviewing three main groups, health professionals who specialise in the area like you, as well as parents of affected children and young people. The goal of the research is to inform health professionals about the experiences of each group in the NZ context. We hope this research will contribute to improving care for young people and their families as well as supporting health professionals working in this area.

1. I’d like to start by asking you about how long have you been working in this area.
   *including as a registrar /in the speciality
2. Can you tell me a bit about your professional role in regards to working with children born with a DSD?
3. Roughly how many children/families do you think you have seen in your working career?
4. Where there any common issues that presented amongst the different cases?
   *tell me more about that?
5. Can you think of a particular case that stood out?
   *Tell me a bit more about that?
6. Tell me about some of the challenges you face as a health professional working in this area?
   *or complex or ethically challenging aspects
7. How do you explain the concept of sex and gender/gender identity to parents?
   *has working with these children impacted on the way you view sex and gender?
   * has your view of sex and gender changed over time?
8. What terminology do you feel most comfortable using with when discussing DSD with parents/children?
   *e.g. Disorders of sex development or differences/Diverse of sex development, intersex and so on
   *do you think there are any issues about the use of terms like intersex or atypical sex development?
   * how is it for you knowing that some affected people contest the terminology used for them?
9. How do you support parents who are struggling to make sense of having a child with DSD?
   *or who are uncertain of what options to take in regards to their child’s care
   * are there resources and or support groups you can help parents’ access? -if so what are they? Which would recommend/not recommend? Why?
   *can you tell me what support would you like or wish there was?
10. Can you tell me which best practice guidelines you follow?
    *can you tell me why you choose those particular ones?
    *Some guidelines are more helpful and some seem to miss the mark. How well do you think the guidelines you have mentioned actually guide your work?
    *or are some parts of the guidelines on balance you wouldn’t use?
    *Tell me more about that?
THE NEXT COUPLE OF QUESTIONS ARE GOING TO FOCUS ON CASES THAT RELATE TO DECISION MAKING PROCESSES AROUND GENDER ASSIGNMENT ETC
11. When it comes to the process of making a decision about gender assignment what factors come into play?
    *can you can help me understand by recalling a case and taking me through the various phases of the decision making process e.g. the conversations that happened, uncertainties that may have occurred, Tests done, options considered, factors weighed up…
12. When it comes to the process of making a decision about genital surgery what factors come into play?
    *under what circumstances would you recommend genital surgery?
    * some genital surgeries are specifically about function and others are more cosmetic as a consequence there is debate around when such surgeries should be carried out .can you tell me your view on this ?
    *again, can you can help me understand the kinds of processes by recalling a case and taking me through the various phases of the decision making process e.g. the conversations that happened ,uncertainties that may have occurred ,tests done, options considered ,factors weighed up and so on.
13. What is it like for you personally managing these cases?
    *what support do you get?
    *what support would you like or wish there was?
14. **What is most rewarding part of your work with children and families with DSD?**

15. **Tell me what you think about the current debates around management of DSD?**

* e.g. use of language, call for ban on “normalising” genital surgeries? Issues of consent etc.

16. **Any other comments you would like to add?**

* *any areas other areas you think research should be heading?*

**Decision scale**

<table>
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<tr>
<td>Are you a parent?</td>
<td></td>
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<td>Place of work</td>
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<td>Specific Training - When, who e.g. two day workshop etc.</td>
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<tr>
<td>Who else works in their area and may be appropriate to participate in this research?</td>
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<tr>
<td>What resources do you have for young people and parents?</td>
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**Thanks**
Appendix N: interview guides

Interview guide for health professionals – Non doctors

Introduction
My name is Denise Steers and I am a clinical psychologist doing research as part of my PhD through Otago University on how decisions are made around the treatment and care of people born with Disorders of Sex Development.

I am interviewing three main groups, health professionals who specialise in the area like you, as well as parents of affected children and young people.

The goal of the research is to inform health professionals about the experiences of each group in the NZ context. We hope this research will contribute to improving care for young people and their families as well as supporting health professionals working in this area.

1. I’d like to start by asking you about how long have you been working in this area.
2. Can you tell me a bit about your professional role in regards to working with children born with a DSD?
3. Roughly how many children/families do you think you have seen in your working career?
4. Where there any common issues that presented amongst the different cases?
   * tell me more about that?
5. Can you think of a particular case that stood out?
   * tell me a bit more about that?
6. Tell me about some of the challenges you face as a health professional working with children who have a DSD?
   * or complex or ethically challenging aspects
7. Have you been in a position where you have to explain the concept of sex and gender to parents?
   * has working with these children impacted on the way you view sex and gender?
   * has your view of sex and gender changed over time?
8. What terminology do you feel most comfortable using with when discussing DSD with parents/children?
   * e.g. Disorders of sex development or differences/diversity of sex development, intersex and so on
   * or do you think there are any issues about the use of terms like intersex or atypical sex development?
   * how is it for you knowing that some affected people contest the terminology used for them?
9. How do you support parents who are struggling to make sense of having a child with DSD?
   * or who are uncertain of what options to take in regards to their child’s care
   * are there resources and or support groups you can help parents’ access? if so what are they? Which would recommend/not recommend? Why?
   * can you tell me what support would you like or wish there was?
10. Can you tell me which best practice guidelines you follow?
   * can you tell me why you choose those particular ones?
   * Some guidelines are more helpful and some seem to miss the mark. How well do you think the guidelines you have mentioned actually guide your work?
   * or are some parts of the guidelines on balance you wouldn’t use?
   * Tell me more about that?

THE NEXT COUPLE OF QUESTIONS ARE GOING TO FOCUS ON CASES THAT RELATE TO DECISION MAKING PROCESSES AROUND GENDER ASSIGNMENT

11. When it comes to the process of making a decision about gender assignment what factors come into play from your understanding?
   * can you help me understand by recalling a case and taking me through the various phases of the decision making process that you are aware of and who was involved?
12. When it comes to the process of making a decision about genital surgery what factors come into play from your understanding?
   * under what circumstances do you think genital surgery is recommended?
   * some genital surgeries are specifically about function and others are more cosmetic as a consequence there is debate around when such surgeries should be carried out. can you tell me your view on this?
   * again, can you can help me understand by recalling a case and taking me through the various phases of the decision making process that you are aware of and who was involved?
13. What is it like for you personally working with these cases?
   * what support do you get?
   * what support would you like or wish there was?
14. What is the most rewarding part of your work with children and families with DSD?

15. Tell me about what you think about the current debates around management of DSD?

*e.g. use of language, call for ban on “normalising” genital surgeries? Issues of consent etc.

16. Any other comments you would like to add?

*any areas other areas you think research should be heading?

Demographic /specifics
Age sex Ethnicity
Do you have children?
Profession
Place of work
Years of work- general, specifically DSD
Who was the main person/people who trained you?
Specific Training –When, who e.g. two day workshop etc.
Who else works in their area and may be appropriate to participate in this research?
What resources do you have for young people and parents?

Thanks
Appendix O: interview guides

Interview guide for parents

Introduction
My name is Denise Steers and I am a clinical psychologist doing research as part of my PhD through Otago University on how decisions are made for the treatment and care of people whose sex development has been different from others. I am interviewing three main groups, young people, parents like yourself and health professionals who specialise in the area. This research will inform health professionals about the experiences of young people and parents and we hope the research will contribute to improving care for young people and their parents.

Opening question
1. Could you begin by telling me a bit about your child?
2. Could you tell me a bit about the time when you realised there was something different about your child?
   *when did you realise there was something different about your child?
   *what was that like?
3. What was it like knowing your child was different from others?
   *how did that impact on you personally?
   *what thoughts and feelings did it bring out?
   *what were your concerns?
4. Have you talked about this with anyone?
   *Family, friends etc.
   *Some people feel comfortable talking about ...... (Use their term), whereas others prefer to keep it private or even secret. I wonder if you could tell me who you have felt comfortable talking to and what you told them.
   * ask about how their family (and friends if they know) respond to talking about it.
   * How did you describe your child’s difference in terms of (use their specific dx if they have mentioned it e.g. CAH)/ having a sex development that is different than others?
   (People often use different terms ,e.g. whether they use DSD, intersex or the specific Dx if they know it CAH etc.)
   Also I want to use the term that you feel comfortable with during the interview.
5. What do you recall being told by health professionals about your child’s situation?
   *How effectively do you feel health professionals communicated with you?
   *where there things that in hindsight could have been done differently?
6. I would like to ask about support you have received . Were you offered anyone to talk to or given any contact in case you did want to talk?
   *If yes what type of support?
   *Did you use them?
   *what was helpful / not so helpful aspects?
   *what support would you have liked?
7. When a baby is born with (or the Dx or term they use) like yours there may be decisions that have to made in regard to treatment and care. Was this the case with your child? If so, can you walk me through that process of decision making?
   *ask them to go through the different DM processes for different procedure’s and or stages
   *if not -We are trying to understand how those decisions get made and wonder if you have any thoughts on that?
   * Some people think that some decisions are best left till a person is a young adult and can decide for themselves e.g. no life threatening surgery.
   *Draw a TIMELINE if they want
8. What were the challenging aspects in the decision making process from your perspective?
   *if not covered in previous question –seek info on what was that like for them personally
   –your thoughts, feelings
   *what helped you manage/cope throughout the process
   *do you think there is anything you would do differently (need to be cautious about this one)
9. If I could shift the focus to the future now. How do you think your child’s diagnosis (use their term) or treatment (if they have had treatment) will have an impact on their future?
   * In what ways? Tell me more
   *can you see it impacting on how you will respond as a parent?
10. Do you think you will discuss your child’s condition with them? (or how have you so far depending on the child’s age) If so, how do you think you will go about that?
   *What language will you use?
   *Is that likely to change over time as they get older?
11. Anything that you can think of that would help us improve health care for your child and for you as parent/s?
12. Are there other areas you think research should focus on in regards to children born with (use their term)?
13. Any other thoughts or comments you would like to add?

Demographic /specifics

Age    sex    Ethnicity
Relationship status
Other Children
Did you know anyone else in the family that had this condition/difference?
Do you know anyone else who may be interested in participating in this research?

Thanks
Appendix P: interview guides

Interview guide for young people

Introduce myself and the research
My name is Denise Steers and I am a clinical psychologist doing research as part of my PhD through Otago University on how decisions are made around the treatment and care of people whose sex development has been different from others. I am interviewing three main groups, young people like yourself, parents of affected children and health professionals who specialise in the area. This research will inform health professionals about the experiences of young people and parents and we hope the research will contribute to improving care for young people and their parents.

Opening question
1. Could you begin by telling me a bit about yourself in general? (Or how this research relates to you?)
   *Pick up on any terms or language they are using to inform language to use in the other questions
2. I would like to know something about how you like to describe yourself in terms of (use their specific dx if they have mentioned it e.g. CAH)/ having a different sex development than others?
   * People often use different terms .e.g. whether they use DSD, intersex or the specific Dx if they know it CAH etc.
   * If they refer to intersex /DSD explain a little bit about how people do not agree on terms and that is why I am keen to hear about what they think.
   * Also I want to use the term that they feel comfortable with during the interview.
   * What term do you put down when you refer to your gender? How do you feel about that?

3. Have you talked about this to anyone? Friends ,Family, relatives etc.?
   * Some people feel comfortable talking about …….. (Use their term), whereas others prefer to keep it private or even secret. I wonder if you could tell me who you have felt comfortable talking to and what you tell them.
   * Ask about how their family (and friends if they know) respond to talking about it.

4. Can you tell me the first time you remember being aware or told about your difference (or term they use)?
   * E.g. seeing a doctor or parents talking with them or noticing something about themselves that seemed different.

5. What do you recall happening to you as a result of having/being (term participant prefers)?
   * Try and map out what interventions if any occurred and or recommended (draw on a piece of paper if they want)
   * Gather their experiences and thoughts about those.
   * Address each intervention and stage separately.
   * Would they recommend things be handled in a different way

6. Communication around your difference/…… (Use term their term) is something we are interested in understanding more about. How well do you think information was communicated to you?
   * Note different periods of time throughout their life e.g. what they were told as a young child as opposed to being an adolescent.
   * What worked best?
   * In what ways could it be improved?

7. I would like to ask about support you have received. Were you offered anyone to talk to or given any contact in case you did want to talk?
   * If they did have support, what form was it in and how helpful was it?
   * If none offered would they have liked to have some offered and in what sort of support.
   * Do you know other people who are the same as you? How did you meet?

8. When a baby is born with (or the Dx or term they use) like yours there may be decisions that both parents and health professionals have to make in regard to treatment and care. Are you aware of any that were made when you were a child?
   * If not - We are trying to understand how those decisions get made and wonder if you have any thoughts on that?
   * Some people think that some decisions are best left till a person is a young adult and can decide for themselves e.g. no life threatening surgery.

9. I would like to shift the focus to the future now. Do you think your diagnosis and treatment has had an impact on the way you picture your future, if so how?
   * How about in relation to how you see yourself?
   * The way you view your body.
   * The way you view your relationships.

10. Anything that you can think of that would help us improve health care for you and others like you?
11. Are there other areas you think research should focus on; we want to make sure we are on the right track?
12. Is there anything that we have not covered you would like to add?

Demographic / specifics
Age   Sex   Ethnicity
Do you know anyone else who may be interested in participating in this research?
Appendix Q: Georgia Andrews report

MAURICE AND PHYLLIS PAYKEL TRAVEL FUNDING CONFERENCE REPORT

All applicants who receive funding to attend a conference, must provide a brief report (maximum one page) on the conference, their participation and the benefit to their PhD / DClinDent within 6 weeks of their return. This report should be emailed to the Health Sciences Divisional Office, c/o Dr Kerry Galvin (kerry.galvin@otago.ac.nz) and copied to your Research Advisor.

Name: Georgia Andrews

Conference title: Intersex Social Sciences: Activism, Human Rights, and Citizenship

Conference dates: June 4th – 5th 2018

Venue: Department of Philosophy and Communication – University of Bologna, Italy

Title of your presentation(s): Oral presentation-‘100% Human’

Is an abstract to be published? Proposed plans are in place to have it published

Report:

I had the immense pleasure in being invited by Denise Steers to co-present her PHD research, following my role as an intersex youth participant in her study.

Denise and I have returned from Italy where we had the very rewarding opportunity to connect with international human rights and health activists, and academics.

I have received an abundance of feedback from academics and activists alike regarding the power of the partnership approach that Denise took to include me in her paper. It is not common practice for academics working in the intersex field to include participants so directly. For my intersex peers, this process clearly demonstrated the power of unity with allies in promoting the voice of our community in a safe, sensitive and respectful setting. Our presentation not only set a precedent of how these relationships can work, but also clearly demonstrated Denise’s sensitivity in promoting a strong New Zealand consumer voice in her research. I feel this will set a strong standard for international influence in months and years to come.

On a more personal level, the opportunity to network with a multitude of activists and academics in person for the first time, many of whom I have had extensive relationships with online for many years, was a life-changing experience. After being told by medical professionals at the time of my intersex diagnosis that I would never meet another person with a variation of sex characteristics like me in New Zealand, let alone overseas, this experience was an absolute privilege. I have built many new networks following my participation at the conference and have taken on board
huge amounts of new knowledge which I will carry into my advocacy projects in the future.

Denise’s generosity in involving me with such genuine intent throughout this process has ignited my drive to work alongside allies from the wider community more extensively in the future, and to share my experiences within my intersex and human rights networks both domestically and internationally.

Presenters from the Social Sciences Conference have been asked to submit for a special edition journal (still to be determined) which Denise and I plan to follow through with.

I want to take the opportunity to express my immense gratitude to Otago University and MPPT for supporting this application as I realise that as a non-student it was outside the usual remit. The conference was a wonderful experience for both of us, which would not have been possible without this immense financial support. The powerful opportunity that was gifted to me was an extremely beneficial moment for both Denise and I which we will cherish and utilise in our work for years to come. If I am in Wellington in the next few months I would be very happy to share my experiences in person at Otago University. It would be lovely in future to see other research participants offered the tremendous financial support from MPPT that I have so generously been gifted.

Warmest regards,

Georgia Andrews

Intersex Youth Aotearoa Project Manager

Signed: [Signature]
Date: 6 July 2018
Background:
- Gender is usually seen as a binary construct based on biology
- This is challenging for young people with DSD
- Clinical management & decision making:
  - are challenging, complex and often controversial
  - are ethically complex
  - involve multiple decision points
  - have divergent and sometimes uncertain consequences

Research Question:
What influences decision making for young people with DSD from a clinician’s perspective?

Methods:
- One component of a larger qualitative study
- Interviews with 22 clinicians working with DSD throughout Aotearoa/NZ
- Iterative thematic analysis:

Findings:
The clinicians considered that overall decision making is shared. They felt a responsibility to provide clear clinical information and guidance to parents, but that it is the parents who are ultimately responsible for the final decision.

Influences on Decision making:
- Communication
- Culture
- Values
- Health system improvements:
  - Targeted professional development and reflective practice to help clinicians:
    - increase their awareness and insight
    - reduce unintended bias
    - develop advanced communication skills
    - understand patient perspectives
    - address ethical issues
  - Health system improvements:
    - Multi-disciplinary teams including psychologists and patient advocates
    - Specialist national centre in Aotearoa/NZ

Conclusion:
Clinicians are encouraged to be more informed, shared decision making. However, this is difficult to achieve in practice.

What’s needed?
Targeted professional development and reflective practice to help clinicians:
- increase their awareness and insight
- reduce unintended bias
- develop advanced communication skills
- understand patient perspectives
- address ethical issues

Acknowledgements
The authors would like to acknowledge the support of the Pediatric Endocrinology Working Group (PEWG) for their help in supporting the research.

Contact:
denise.steers@otago.ac.nz

References

Appendix R: Poster presentation Hobart 10th International Meeting of Pediatric Endocrinology Washington, USA, Sept, 2017
Appendix S: Poster presentation European Society of Pediatric Endocrinology Annual Scientific Meeting, Athens, Greece, Sept 2018

DisRUPTing THE NORM

Giving a voice to young people with Differences in Sex Development (DSD) or Variations in Sex Characteristics (VSC)

Denise Steers1, Esko Wiltshire1, Angela Ballantyne1, Maria Stubbe1, Georgia Andrews1, Sunny Collings1

1S uicide and Mental Health Research Group, Department of Pediatrics & Child Health, Department of Primary Health Care & General Practice, University of Otago, Dunedin, New Zealand

Background:
The experience of older people with a VSC/DSD is relatively well documented. But medical practice is changing rapidly, so we need to understand the recent experience of younger people with VSC/DSD.

Aim:
Qualitative research designed to document the experiences of young people with VSC/DSD living in Auckland/New Zealand.

Methods:

Health Professionals N=22

Parents N=18

Young people with VSC/DSD N=10

One component of a larger qualitative study

Demographics

Gender

Female 67%

Male 33%

Age Range

14-23 yrs

under 20 yrs 67%

over 20 yrs 33%

Variation

Gender identity

Gender expression

Variation in secondary sexual characteristics

Findings:

- Variety in individual experiences – positive and negative
- Diversity of support offered to young people by health professionals underpinned positive experiences

Conclusion:

- Many young people could embrace diversity and accept their difference when supported to consider the impact of breaking beyond the confines of "the norm" and disrupting long-held binary stereotypes
- Participants found this support amongst peers with VSC, but rarely from health professionals
- We recommend improved communication skills and bias training for health professionals, and delaying non-surgical ongoing interventions to enhance bodily autonomy

Main themes

Challenging the Norm

- "I’m sick of the old norm, I am the new Norm and the new normal starts now"
- "I just believe that if we start to like accept abnormal bodies as normal, then like this is not so much of a problem"

Bodily Autonomy

- "I can see both sides, I can see why you wanna do (surgical surgery) earlier but I think it would be better to wait for the person to decide for themselves"

Communication

- "No one wants to talk about us as people really, they want to talk about us at case studies and not think about our feelings because doctors don’t deal with feelings"
- "(Information given by doctor) needs to be so much clearer so... that people feel... I can still be normal and live in this body the way that it is…"

Support

- "There’s (no services) to really address... it’s about you feel about it in yourself or how it’s affecting you now, all that kind of stuff, the psychological part of having it"
- "I used to think that it was really rare, we’ve found (other peers with VSC)... it’s nice to know that it’s like not only me"

Identity

- "As much as it challenged my identity in the beginning, it almost like reaffirmed my identity towards the end, like knowing who I was and being ok with not being normal, you know..."
- "We are all 100% human"

Implications

Education and training for health professionals

Foster caring communities for young people by:
- Peer support – encourage contact with online support groups
- Parent support – help parents access resources and offer different points of view
- Psychological support – explore young people’s feelings around difference
- Developing sense of identity that supports diversity and acceptance

References

Hewitt et al. (2021) Using the voice of a young person living with female genitalia to influence public policy (unpublished paper).

Acknowledgements

Thanks to the young people who so generously agreed to be interviewed for this study

Research currently funded by the Health Research Council of New Zealand (OH710512).

Final thanks to the participating young people who contributed their insights and experiences that informed the study.

Contact

Denise Steers, University of Otago, Dunedin, New Zealand

1800620184

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Contact

Denise Steers, University of Otago, Dunedin, New Zealand

1800620184
Appendix T: Poster presentation European Society of Pediatric Endocrinology Annual Scientific Meeting, Vienna, Austria, Sept 2019

**Gender Mender or Defender?**
Understanding decision making in Aotearoa/New Zealand for people born with Variations in Sex Characteristics

**Background:**
People born with a variation in sex characteristics or Difference of sex development (DSD/VSC) face the challenge of having atypically sized bodies. This qualitative study recruited young adults with DSD/VSC, parents of children with VSC, and health professionals.

This study was conducted in collaboration with the Intega Trust of Aotearoa/New Zealand (ITANZ).

**Aim:**
To identify key themes regarding participants' experiences of decision making in the health care setting.

**Methods:**
Research participants N=50

- Young people
- Parents
- Health professionals

- Methodology: Semi-structured face to face interviews with participants
- Iterative thematic analyses (Braun & Clarke 2006)

**Demographics:**

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**Findings:**
Four common elements across the three participant groups influenced decision making: communication, bias, norms, and support.

- There were two additional themes for each participant group:
  - Health professionals: recognition of the past and expectations
  - Young people: bodily autonomy and identity
  - Parents: what's right and future worries

All these elements underpin the overarching element of trust. These elements of influence could be experienced as either positive or negative depending on the circumstances (e.g., the way information about diagnosis was communicated could be sensitive or insensitive, psychological/peer support could be offered or not).

**Conclusion:**
Better health care is needed and change can be supported by:

- Providing enhanced training and education for health professionals regarding communication skills and implicit bias
- Developing better supports for parents and young people, especially peer support and specialist psychological support
- Championing bodily autonomy, recommending delaying appearance based surgical intervention until a young person can have agency to decide for themselves
- Challenging the norm, and accepting that difference is part of a diverse society
- Always including people with a VSC in service development and delivery
- Ongoing research supporting active change

**Decision making process using research elements influencing decision making**

**References**


**Acknowledgements**

Thanks to the participants who so willingly agreed to be interviewed for this study.

Aotearoa Gender Health Research Group (GHD) is funded by and University of Otago for supporting the research.

Special thanks for the collaboration from Whakataika Tiaki & Whakataika Tarii汉族.

Louise Bracknell, University of Otago Wellington – Peer Graphic Design

Contact
Gender Health Research Group, University of Otago Wellington

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