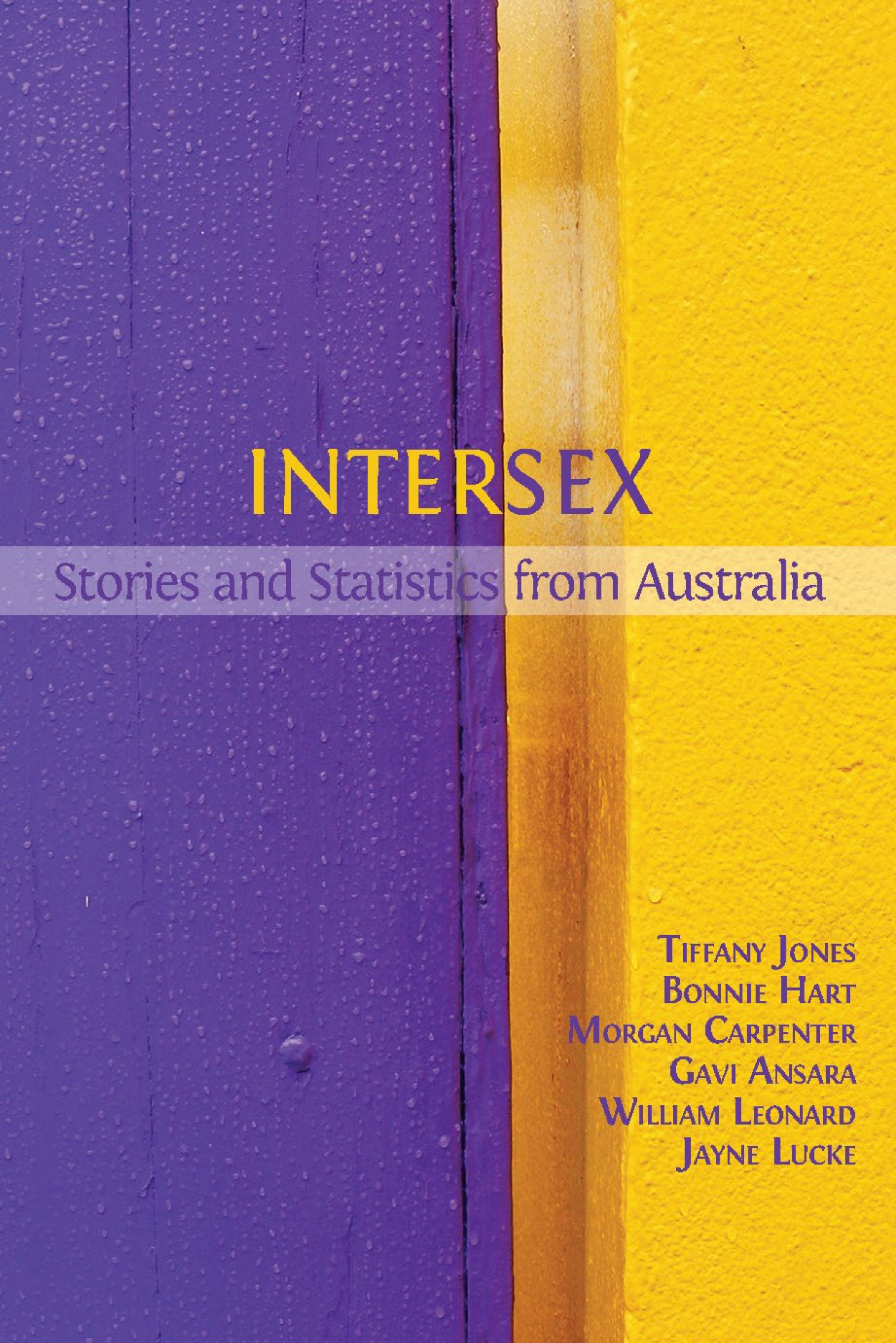


INTERSEX

Stories and Statistics from Australia

Tiffany Jones
Bonnie Hart
Morgan Carpenter
Gavi Ansara
William Leonard
Jayne Lucke

INTERSEX

Intersex

Stories and Statistics from Australia

Tiffany Jones, Bonnie Hart,
Morgan Carpenter, Gavi Ansara, William Leonard,
and Jayne Lucke

OpenBook
Publishers

http://www.openbookpublishers.com

Tiffany Jones, Bonnie Hart, Morgan Carpenter, Gavi Ansara, William Leonard, and Jayne Lucke, *Intersex: Stories and Statistics from Australia*. Cambridge, UK: Open Book Publishers, 2016. http://dx.doi.org/10.11647/OBP.0089

Updated digital material and resources associated with this volume are available at http://www.openbookpublishers.com/isbn/9781783742080#resources

ISBN Paperback: 978-1-78374-208-0
ISBN Hardback: 978-1-78374-209-7
ISBN Digital (PDF): 978-1-78374-210-3
ISBN Digital ebook (epub): 978-1-78374-211-0
ISBN Digital ebook (mobi): 978-1-78374-212-7
DOI: 10.11647/OBP.0089

Cover image: Purple&Yellow Wall – Kinsale (2008), photo by Sonia Luna, CC BY-NC-ND 2.0. https://www.flickr.com/photos/sonialuna/2942152110

All paper used by Open Book Publishers is SFI (Sustainable Forestry Initiative), PEFC (Programme for the Endorsement of Forest Certification Schemes) and Forest Stewardship Council(r)(FSC(r) certified.

Printed in the United Kingdom, United States, and Australia
by Lightning Source for Open Book Publishers (Cambridge, UK).

Contents

Acknowledgments

Dr Tiffany Jones is thrilled to thank and acknowledge the University of New England's Research Services which contributed various grants towards funding her research. This project benefitted from the enthusiasm of my community reference group: Bonnie Hart – President of the Androgen Insensitivity Syndrome Support Group Australia (AISSGA), Morgan Carpenter – Director of Organisation Intersex International Australia (OII Australia), and Gavi Ansara – representing the Australian National LGBTIQ Health Alliance. No funding was accepted from their organisations by the researcher and the group were not involved in conducting or writing up of the research; these individuals (amongst others from different groups) instead gave community insights into the project's framing of intersex issues, appropriateness of themes and word choices in the development of the questionnaire and strategies in the recruitment processes, and lastly were given an opportunity to comment on completed drafts of report chapters. They directly requested co-authorship, which was given to increase a sense of community ownership of the report hereafter and honour their assistance, however all conclusions made herein were drawn on the basis of university-based research only.

I want to thank Jayne Lucke from ARCSHS and William Leonard from GLHV for their work helping me with the report, and for taking this work seriously enough to picture it within the context of various valuable next steps for the field. The research also had the support of organisations, groups, medical practitioners and individual activists all over Australia promoting the project by putting it into both professional and personal e-list mail-outs, placing advertisements on Facebook pages and websites, including items in newsletters, and letting people know by word-of-mouth. Here I thank ACON, ACT Human Rights Commission, AISSGA, Anne-Maree, The Australian Safe Schools Coalition, Australian X & Y Spectrum Support, The Australian and New Zealand Gender Support Group, Bodies Like Ours, Dani Wright and The Freedom Centre, Duane Duncan, Genderqueer Australia, Genetic Network of Victoria, GSMA@Queerspace, Intersex United, Klinefelter's Syndrome Australia and SA, Laura's Playground, Le Syndrome De Turner, Matt Tilley, Monica Bray, The National LGBTI Health Alliance, NSW ADB, OII Australia, Olivia Noto, Phoebe Hart, PCOS Australia, Polycystic Ovarian Syndrome Support Group, Reddit Intersex, SA Equal Opportunity Commission, The Safe Schools Coalition, ShineSA, Sim Kennedy, Sistergirls & Brotherboys Australia, Susan's Place, Tony Briffa, Turner's Syndrome Girls (XOers), Two Spirits QAHC, UNDP, UNESCO, XXY Friends, XXY/Klinefelter Syndrome Society, XXY Klinefelter's Syndroom, YGender and many others.

I thank the media/press who promoted the study through reduced advertising rates, and generous interviews and stories on the research. I especially thank ABC Radio, The Armidale Express, Estelle Boschoff, Nance Haxton, The Gay News Network, The Gay News Network's Law Thread and many others. I also thank the medical practitioners including the doctors, endocrinologists, urologists and others who passed on information through their networks. I also thank Open Book Publishers for believing in this book and providing an innovative publishing model through which this important knowledge can be shared with readers around the world.

Most vitally, the project owes its largest debt to the people with intersex variations who completed the survey. You have written yourself into history. You have asserted a voice different to current discourses dominating discussion of your experience and what it means. Your contributions to research are greatly appreciated, and I personally hope this book can in turn be useful for you in your own lives as something you and a range of stakeholders/service providers can read, share with others and benefit from in a range of affirming ways.

List of Tables and Figures

Executive Summary

Introducing Intersex Studies: New Theory for New Research

This chapter introduces the first national study on Australians with intersex variations. People with intersex variations have long faced issues of visibility and stigma, although this is beginning to be challenged. This chapter outlines how new activisms in the last decade have secured greater recognition of the right to non-discrimination on the basis of intersex status in key global and Australian legislation. It underlines the lack of affirming sociological research; existing studies were conducted in medical frames positioning people with intersex variations as aberrations, or as subsumed within broader populations. The chapter outlines theoretical frames used in the field, showing how the minimal inclusion of people with intersex variations within medical/clinical, GLBTIQ, disabilities or other frames over-simplifies the group – erasing their most urgent concerns. It argues for a distinct 'Intersex Studies' framework devoted entirely to intersex issues; foregrounding the goals, perspectives and experiences of people with intersex variations.

Designing a Study On, With and For People with Intersex Variations

In 2015, the 'Australians born with Congenital Variations in Sex Characteristics (Intersex/DSD/hormonal, chromosomal or other biological variations/conditions)' study was launched to increase the visibility of Australians with intersex variations, and meet research gaps with a view to informing policy. The project's conceptualisation relied heavily from the outset on the insights and energies of people with intersex variations themselves, including some of the community reference group

http://dx.doi.org/10.11647/OBP.0089.14

(given co-authorship), other community allies and feedback from key organisations. An anonymous online survey was designed to gather basic data, combining both quantitative and qualitative questions to enable people with diverse identities and experiences to engage with the topics. Participants were recruited through a range of techniques including paid advertising and promotion in support groups and services, Facebook posts, e-lists, and media interviews. The team also utilised any unique opportunities available through their own academic or community memberships to promote the survey widely.

Basic Demographics for People with Intersex Variations

In total, 272 people with intersex variations participated in the 'Australians born with Congenital Variations in Sex Characteristics (Intersex/DSD/hormonal, chromosomal or other biological variations/conditions)' study in 2015 – the largest ever number in a Southern-Hemisphere-based study. This chapter provides basic demographic information about the respondents. Participants ranged in age from 16-85+, and 4% were Aboriginal or Torres Strait Islander. They came from all states of Australia in proportion to the broader population, a fifth lived internationally. Overall, 52% of the participants were allocated a female sex at birth, 41% male, 2% X, 2% unsure and 4% another option. Whilst most identified as female or male now, a smaller portion now identified as male compared to the portion assigned male at birth; and a greater portion now used X or another option. Participants mostly lived in stable situations with loved ones. Some (27%) had disabilities. Most had no religious affiliation.

Discovering, Experiencing and Discussing Intersex Variations

This chapter explores survey data on 272 people with intersex variations' discovery and feelings about their variation. Participants had over 40 specific intersex variations, ranging from 5-ARDS to XY Turner's Syndrome Mosaics. Whilst inter-family secrecy hindered many individuals' knowledge of intersex variations in their family, 22% knew they had relatives with their variation, usually more than one. These relatives included for example siblings, parents and parents' siblings. Experiences of the variation could differ between relatives; some were gene carriers or experienced different featured or grades of variations. Most participants (64%) learned about their variations aged under 18yrs, a third learned as adults. Whilst many were influenced by negative messaging and felt negatively about their variations when first told of them, over half felt positively about them now. Significantly more participants reported that they preferred the use of 'intersex' and related terms, to those related to 'DSD' when discussing their variation.

People with Intersex Variations, Health and Medical Services

This chapter explores the data on people with intersex variations' experiences of physical health and medical services. A strong majority of people with intersex variations considered themselves to be moderately to extremely healthy at the time of the survey. Most participants (60%) reported that they had experienced a medical treatment intervention related to their intersex variation. On average, they had experienced at least two interventions. The most commonly reported interventions were hormonal treatments and genital surgeries of varying kinds. Over half of all treatments were delivered to participants when they were aged under 18yrs. One fifth of the participants had been given no information at all about any surgical or hormonal treatments they had received and the majority were not told about risks related to the interventions, their right to not have these often life-changing treatments or other related information. Participants reported various physical, mental and psychological impacts from treatments.

People with Intersex Variations, Wellbeing and Mental Health Services

This chapter considers the data on people with intersex variations' experiences of wellbeing and mental health services. Most participants considered their mental health as good (or positively) at the time of the survey. The most frequently reported mental health diagnoses included depression, anxiety and PTSD. Wellbeing risks were high – 42% of participants had thought about self-harm and 26% had engaged in it; 60% had thought about suicide and 19% had attempted it – specifically on the basis of issues related to having a congenital sex variation. The group mostly attributed their wellbeing risks to negative social responses from others, difficulties around having undergone interventions or issues around gender/identity. Overall their mental health service experiences were mixed. Overall, 44% of the group reported receiving counselling/training/pressure from institutional practitioners (doctors, psychologists etc.) on gendered behaviour; and 43% from parents. Many participants desired improvements in training for mental health services/workers.

People with Intersex Variations and Education

Educational institutions have a powerful potential to reproduce, or challenge, social marginalisation. Most (62%) people with intersex variations surveyed had a post-secondary qualification, a portion similar to the general Australian population. Conversely, 18% had only had a primary school education – a larger portion than the general Australian population. Whilst national legal protections exist for students with intersex variations, education policies and guidelines at the national and state level were mostly lacking. The overwhelming majority of participants (92%) did not attend a school with inclusive puberty/sex education provisions. Most had not disclosed their variation to staff, although more than half had to their classmates. Appropriate school counselling services/referrals were widely lacking. Only a quarter of participants rated their overall education experiences positively and there were many reports of bullying based on physical or other aspects of having a variation. Participants suggested improvements to schools' information provision and support features.

People with Intersex Variations and Employment

This chapter examines data on employment for people with intersex variations. The majority of participants (65%) were working (full-time, part-time or casually). However, 12% were unemployed and looking for work – a higher portion than in the broader Australian population. The majority of participants (63%) earned an income under $41K per year. More than half the people with intersex variations surveyed had not told their employer/boss about their variation, and a similar portion had not told their co-workers about their variations. The responses to participants' disclosures from both employers and co-workers were mostly neutral/mixed. When asked whether having a congenital sex variation had impacted their work experiences, 48% said yes and 24% were unsure. Impacts participants had experienced included obstacles to gaining or maintaining work, particular workplace discrimination issues, the complications of wellbeing issues, and reported effects on some participants' comfort in engaging in particular working arrangements or industries.

Social Support for People with Intersex Variations

This chapter examines data on people with intersex variations' experiences of social discrimination and support. Of the key people in their lives, participants' doctors, mothers and friends were most likely to know about their intersex variations. Conversely, their priests/spiritual advisors and principals were the least likely to know. Participants were most likely to have experienced supportive responses around their intersex variation from a friend, partner, sister or mother; and least likely to have had a supportive response from people at school. Many participants (66%) had experienced discrimination from strangers ranging from indirect to direct verbal, physical or other discriminatory abuse. Most (70%) never or rarely discussed their variations with strangers, and many participants had been exposed to common myths about their identities in general. There was not strong support by religious/spiritual services, however 65% of participants said engaging with others with their variation or similar improved their wellbeing.

Sexuality, Romance and Relationships

Most people with intersex variations surveyed were currently involved with one or more partners or dates (62%). Whilst many were in long-term monogamous relationships, a diversity of relationship styles and dating attitudes were represented. The majority of participants had never formally or legally married, and a notable portion expressed concerns around inequalities in current Australian marriage legislation. Participants labelled and defined their sexualities in multifarious ways. Whilst 'heterosexual' was the most popular single label selected, only 48% of the group selected it and they defined it in ways ranging from traditional to non-heteronormative. Most participants (65%) said their variation (or related treatments) impacted on their sexual activities. Whilst many found current sexual protective devices adequate, some did not, and 14% had contracted STIs. Just over half the participants called for body-positive, community-led story-based sexual information packs; which could underline for young people how STI risks exist separately from fertility risks.

Fertility and Parenting

Most participants in the survey experienced barriers to their fertility: 48% could not reproduce directly due to their intersex variation; 17% could reproduce only with difficulties; and 15% could not reproduce due to treatments/surgeries around their intersex variation. Some did not see barriers to fertility as a major issue in their lives; others experienced emotional responses or pursued having children through various options including adoption and fertility treatments. Of the 42 parents in the study, 23 had discussed their own intersex variation with their children and 19 had not. Those who had made disclosures to their children mainly experienced affirming or accepting responses. The majority of the study's participants felt their parents were given inadequate information on their variation and wanted to see children's rights to bodily autonomy foregrounded. This suggested the need for changes to how parents of children with intersex variations are informed and consulted regarding variations.

Representation in Media, Activism and Research

Over half (58%) of the participants had seen 'real people' with intersex variations represented in the media (documentaries/books) – 10% were unsure and 32% had not. Participants assessed most of these representations of real people positively. Less than half (41%) of the participants had seen 'fictional characters' with intersex variations represented in the media (TV/film/books) – 12% were unsure and 47% had not. Participants assessed these representations of fictional characters as largely mixed. In response to questions on key activism themes, the overwhelming majority of participants were against people with intersex variations being treated in ways which did not privilege their access to key information, services or citizenship rights. Some participants had themselves engaged in activism, ranging from anonymous efforts via their computers, through to representation work where greater personal visibility was required. Participants called for more research in the field generally, particularly on health care and social themes.

Conclusion and Recommendations

Concluding this report on the 2015 study of 272 people with intersex variations, this chapter outlines the key implications of the data. The importance of the difference between the trends for people with intersex variations uncovered in the survey, and the differences in the unique set of experiences reported for any specific individual, is underlined. However, keeping this acknowledgement in mind, the chapter does provide some general recommendations. Recommendations discuss possibility of general campaigns to encourage understanding in social contexts and how the poignant value of social group support for people with intersex variations may be better supported to more widely support the wellbeing benefits experienced by those who had access to these groups. Specific recommendations are also offered around health services, policy and training; roles for parents/guardians in healthcare; mental health services and training; education policy and practice; employment policy and practice; media representation, advocacy and further research.

> *My first endo said if I have a Y chromosome I must be male and treated me accordingly, but I never agreed to that. My new endo believes I am female and we get along famously. My GP is confused! 'X' and 'Y' are simply the apparent shape of the chromosomes and have little, if anything, to do with gender and sexuality. One friend told me that when she was little everyone thought she was a tom-boy... in other words she missed the point entirely. (Intersex groups were) mostly positive, but even within intersex communities there is great opposition to including transgender people like me.*

Melissa, trans intersex male-to-female with 48XXXY chromosomes, 63yrs

> *I was christened male, but reassigned female at day 5, and then realigned back to my male self at age 29. I dislike that my testes were removed and the fact that I still have the makings of female genitalia which is embarrassing. I've always been positive, my main reason why I answer 'good' is because despite the incorrect surgeries and the pain and mental anguish this could cause if I thought about it for too long, my biggest sex organ I have is my brain.*

Mark, male with XY/XO Mosaics and Cloacal Exstrophy, 35yrs

> *I left school when I left home, and now I couch surf or live in my car. I never had support from my family. We just fought all the time over my body and what they let happen to it, and how they wanted me to act. They wanted the perfect quiet little girl. They got me and I can't help that. I feel really angry and lost right now. I hope you tell my story.*

Dany, intersex individual with Mosaicism/Ovo-testes, 16yrs

> *I was always a short pudgy man, never had a manly figure. I had no growth or development as a young man, and always had a smaller manhood. I have always had a poor sense of smell, part of the syndrome. I was placed on hormones as a young man, to help with growth and deepening my voice. It did not make an enormous impact to those things and seemed experimental. It did improve my sexual drives and feelings, and change my moods significantly. The surgery was on my doctors' advice and I feel it made some changes certainly. I suffered some scarring to the chest for example, which made me not want to continue on with other appointments they wanted to make. I felt it best to leave well enough alone. Through being married to a special woman, I came to know myself and my body in better ways, and to feel they are worth something more than what I had been told.*

Lucas, intersex man with Kallman's
Syndrome/Cryptorchidism/Micropenis, 77yrs

1. Introducing Intersex Studies: New Theory for New Research

> *(People believe) that we're paedophiles, perverts, Nephilim (the spawn of humans and demons), that we're Hermaphroditic, Homosexual, out to destroy society, that we're communists etc. That we're a tiny, tiny handful, one on a million – that's the most common myth. OK, my own condition (3BHSD) probably is one in several million, but Intersex as a whole is more like 1 in 60 (technically), 1 in 1000 (in practice, where symptoms can't be ignored).*

Scarlet,* female with 3BHSD Late Onset Congenital
Adrenal Hyperplasia, 40yrs

> *I have a penis but no testicles, and a vagina underneath. Starting puberty, I grew breasts. I always knew I had a penis and a vagina, but I didn't find out that it was abnormal until I saw a diagram of the penis at school when I was 8. I asked my parents why I didn't have testicles and they told me. I didn't consider it a bad thing, I was mostly just amazed that not everyone was like that. I didn't consider it a good thing either, because I knew I'd have to hide it from the other kids to avoid being bullied.*

Shannon, intersex person with ovo-testes, 17yrs

---

* Pseudonyms are used for all survey participants' quotes as applied by the researcher; all quotes were collected anonymously. There is no relationship between the pseudonyms allocated and the participants' actual names; beyond the researcher's attempt to align pseudonyms with participants' reported (current) sex and gender identity. The wording with which each participant preferred to have their variation discussed has been used in the parentheses to describe their variation/s.

http://dx.doi.org/10.11647/OBP.0089.01

Key Points

- Human sex is more complex than is widely assumed, and intersex variations are to be expected within the human race as a natural expression of this complexity.
- People with intersex variations have long faced issues of visibility and stigma, although this is beginning to be challenged.
- There has been a lack of affirming sociological research; existing studies on people with intersex variations were mainly conducted in medical frames in the past.
- There are many theoretical frames used in the field, most of these frames erase what are anecdotally people with intersex variations' most urgent concerns.
- There is a strong need for a distinct 'Intersex Studies' field devoted entirely to intersex issues; considering the perspectives and experiences of people with intersex variations themselves.

Intersex Variations

Sex is complex. Even if understood in purely material, biological terms. *Humans are simultaneously more similar in our material sex development, AND more diverse, than is widely appreciated.* Females and males are not made of wildly different ingredients; the potential to be intersex exists (however briefly) in all humans' prenatal development in the first few weeks. Research has generally estimated that 1.7% of people go on to actually be born intersex (Carroll, 2005; Dreger, 2015; Fausto-Sterling, 1993; OII Australia, 2012b). Given that many elements of sex are difficult to detect, these may be conservative estimates, and it is important to emphasise that many people who are intersex will never know. Intersex is an umbrella term for people who are born with atypical sex characteristics (OII Australia, 2012b); these sex characteristics potentially include: our chromosomes, genes, external genitalia, internal reproductive organs, hormones, or secondary characteristics (like body hair). People with intersex variations occur naturally in the human species. Some common intersex variations are diagnosed prenatally. Intersex differences may be apparent at birth.

Some intersex traits become apparent at puberty, when trying to conceive, or through random chance.

All human fetuses contain an X chromosome from the egg of which they are partially comprised; so until the turn of the millennia scientists generally believed in humans having a passive female default (Ainsworth, 2015) – that we start developing in the womb from a 'female' template whether we have XX or XY chromosomes, or less common combinations such as XO, XXX, XXY, XYY and so on. Thus even an 'XY male' has nipples (Pease & Pease, 2003), signifying their (mostly) unrealized potential to develop milk-producing breasts.

Around our sixth week of development in the womb, primordial tissue splits off into an internal reproductive system (Pease & Pease, 2003). This system consists of the Müllerian ducts (may develop into fallopian tubes, uterus, and vagina); Wolffian ducts (may develop into a seminal vesicle, vas deferens, and epididymis); and gonads (may develop into ovaries or testes). Thus at this point *all humans have the potential for diverse sex developments.* Gonads are not 'sexed' until our seventh week. Whether gonads become testes or ovaries is impacted by a gene called SRY, discovered in 1990 (Ainsworth, 2015); typically found on a Y chromosome (but also sometimes on the X chromosome, thus some people with XX chromosomes have testes). If SRY is present, it triggers the gonads' development into testes and commitment to sperm development, including production of testosterone and an anti-Müllerian hormone which usually breaks the Müllerian ducts down (though not always or completely, thus people can be born with testes and a uterus/fallopian tubes). The Wolffian ducts usually develop into the organs that create certain components of semen (although they may not, thus some people with testes may not ejaculate or be fertile). If SRY is not present, some genes on the X chromosome (e.g. DAX-1 and WNT-4) trigger the gonads' development into ovaries and commitment to egg development, including production of hormones which usually cause the Wolffian ducts to degrade (though not always or completely, thus some people are born with remnants of the Wolffian ducts/bumps on the sides of their vagina). The Müllerian ducts usually develop into a uterus, fallopian tubes, and key components of a vagina. Sometimes the gonads get combined signals and become intermediate between ovaries and testes; the hormones produced by each part interfere with the other, resulting in either infertility or only one type of gonad fully functioning. Sometimes neither the Wolffian and Müllerian ducts develop, or both (one or the other on each side), or just one or the other. The existence of genes like WNT-4, SRY and others (e.g. RSPO1 can also have an impact) have thus challenged many biological scientists' 'passive female default' explanation of sex (Ainsworth, 2015); it now appears we all have some potential to be male and some potential to be female.

The development of our genitalia and internal reproductive parts present further challenges to any models of human sex which delineate maleness and femaleness too clearly, or do not recognise the multiple systems involved in sex production. Our external genitalia, for example, develop throughout our ninth and twelfth week in the womb. Our *genital tubercle (phalloclitoris)* forms in a manner generally closer to a penis or a clitoris, or somewhere between the two, depending on length. Testosterone and other processes impact its size and the extent to which its body is internal or external, but it has as many nerve endings allowing the potential for pleasure, regardless of its size or level of protrusion. We all further develop the membrane that gives rise to the urethra and the anus. Some people develop one opening (often shallower than a vagina), some a urethra and a vagina, some just a urethra which may lengthen up to the tip of a penis (it might not migrate all the way up in some cases). Our additional parts swell into labia majora, or fuse together into a scrotum, or variations in between (e.g. pouch-like labia majora, partially unsealed scrotum). Finally, around our twenty-sixth week the gonads may descend (testes may descend into scrotums, ovaries into the ends of fallopian tubes) or remain in the abdomen undescended – sometimes permanently, sometimes until puberty. In addition, our genes (whether certain genes are present or missing) and hormones (influenced through a range of congenital conditions like Poly-Cystic Ovary Syndrome/PCOS, hormone insensitivities and so on) can also impact primary sex presentation such as genitalia and secondary sex characteristics such as the extent of our puberty-related changes and our facial and bodily hair growth (Huang, Brennan, & Azziz, 2010).

Sex development in the womb and beyond is more widely variable in humans than is commonly discussed or taught in schools (Dreger, 1998; Jones, 2015). We all have an internal, natural potential for diverse sex developments at various stages in our lives… before one even considers the possibilities of external catalysts such as the medication our mothers/parents were taking when we were in utero, or external hormone treatments or surgeries for example. *Current thinking is that we all were actually intersex initially for a brief period in our early weeks in the womb* (Ainsworth, 2015), however, clinical thinking *changes frequently*.

Stigma and Silence

Most of us, including some people with intersex variations, their loved ones, and many professionals serving them, know little about intersex variations. There are several reasons why. Firstly, people with intersex variations have faced deep stigma historically due to a belief (born of a lack of knowledge of human chromosomal, genetic and hormonal diversity) in the extreme rarity of intersex variations – leading to the assumption that they were simply bizarre modern aberrations: not normal or not worthy of consideration. Yet there have always been people with intersex variations, and they are by no means a contemporary discovery. They were referenced in Sumerian creation myths from over 4,000 years ago where those without genitalia were offered the privileged role of standing before kings by the father Enki (The ETCSL Team, 2003). They were referenced in Siculus' first century BC myths of the god Hermaphroditus who combined 'male' and 'female' parts (Siculus, 1935), in seventeenth-century English and American accounts of Thomas/sine Hall who engaged in court-ordered mixed dressing in keeping with their ambiguous genitalia and 'dual' nature (Floyd, 2010), in eighteenth-century Vietnamese accounts of the eunuch Le Van Duyet (Huỳnh, 2006) and so on.

Secondly, silence and stigma may be due to systematic institutional mistreatment; particularly within medical and clinical institutions. Whilst in the nineteenth century British and French physicians allocated people with intersex variations a male sex if they had testicular tissue and a female sex if not (on the assumption they likely had ovaries); the development of biopsies in the 1910s revealed that some people had combinations or absences of testicular, ovarian and uterine tissues disruptive to traditional constructions of sex (M. Diamond & Sigmundson, 1998). The medical profession moved away from a strict notion of gonadal 'true sex' toward a pragmatic concept of 'gender' – and towards medical methods of 'gender reconstruction' (fearing 'social havoc' if the sexes, and their social roles, did not remain distinct). This made the bodies of people with intersex variations fit the typical features of the sex that physicians allocated them

(Dreger, 2015). John Money's experiments initially appeared to suggest upbringing impacted gender more than biology (although his work was later revealed to be problematic), supporting further institutional embrace in the twentieth century of the belief that for gender identity to form psychosocially boys primarily require socially 'adequate' penises with no vagina, and girls a socially 'adequate' vagina with no easily noticeable phallus, along with a gendered upbringing (Donahoe, 1987). Specifically, clitorises were considered too big (socially) at over 1cm, and penises too small (socially) at under 2.5cm (Shah, Woolley, & Costin, 1992). Genital surgeries were developed particularly from the 1930s at the John Hopkins Hospital in Baltimore by urologists like Hugh Hampton Young and applied to 'correct' genital variations amongst infants and adults – reducing clitorises, removing gonads, widening vaginas, moving testes into scrotums (H. H. Young, 1937). Use of genital surgeries increased significantly in the 1950s when physicians like Lawson Wilkin's treatment of congenital adrenal hyperplasia (CAH) with cortisone increased infants with CAHs' survival rates, and they were also operated upon (Schnitzer & Donahoe, 2001). Hormone assays and karyotyping to ascertain sex chromosomes, and the availability of testosterone for treatment led to wider hormonal treatments from the 1960s, with intersex infants and teens typically made to physically and socially live out their lives as males *or* females and treated without their knowledge or consent (United Nations, 2012). More recent technological developments also permitted embryos and foetuses to be screened for intersex traits, enabling hormonal treatments in-utero or termination (Meyer-Bahlburg, 1990). Interventions are thus the result of many years of institutionalized privileging of traditional constructions of 'male' and 'female' bodily and identity based norms in the medical system. Doctors and surgeons believed they were 'helping' the infant by choosing their sex and keeping sex variation a secret, and the parents of the infant were made to feel there is something 'wrong' with their child such that their untreated bodily condition would be socially untenable (Jones and Lasser, 2015).

Thirdly, silence can also be due to the range of invisibility of certain intersex variations, across the many different types. For example, a genetic male with an extra Y chromosome may not show dramatic differences in physical or personality traits other than being slightly taller (Court Brown, Price, & Jacobs, 1968; Ike, 2000) and thus he or others may be completely unaware of his intersex status, whilst a genetic male with an extra X may conversely in some cases quite strongly experience themselves as or present as having some female physical and vocal traits in ways which more strongly challenge gender normativity (Herlihy & Gillam, 2011). Further, there are variations of presentation *within* a distinct type – for example, genetic males and females with Turner's Syndrome may experience very few physical signs or many features that are quite prominent (Miller, Kanter, & Wolfort, 1990; G. Ross, Holland, Kiser, & Douglas, 1965). Thus, intersex variations can sometimes be undetectable or easily mistaken as 'something else' and silenced by omission, or may instead be obvious enough to attract negative attention given the lack of social understanding and education.

A fourth and final key reason for stigma and silence is that some people with intersex variations have themselves simply desired to integrate unnoticed within the category of a male or female genetic or social sex; perhaps pushed by family/guardians/doctors/their religion; perhaps desiring privacy around their bodies and experiences; perhaps to avoid genuine safety or practical employment discrimination concerns or to simply live their lives unquestioned about matters they see as nobodies' business but their own. For this reason, intersex Facebook groups or discussion forums are often password protected, or membership-vetted and tightly moderated against external intrusions. However, there have always been some people with intersex variations who cannot or do not hide their intersex status. This can be due to more obvious physical differences, support from loved ones to make their own decisions about their bodies or identities, or because they feel frankly there is nothing that requires being hidden.

Since the 1930s intersex issues have been periodically globally visible in a stigmatised manner in relation to transnational sports competitions (Heggie, 2010), due to the belief of most sports organisations that people are either male or female, and men are inherently better athletes than females. Such organisations and related individuals have at times publicly expressed suspicions that males or people with intersex variations may attempt to compete in female-only competitions to use biological advantages (Genel, 2000). Around the 1936 Berlin Olympics the United States Olympic Committee president Avery Brundage requested that a system be established to examine female athletes; concerned about sex ambiguities related to Czechoslovak runner and jumper Zdeňka Koubková and English shot-putter and javelin thrower Mary Edith Louise Weston – who both had initially competed as women but later lived as men (Heggie, 2010). Various processes were developed and temporarily mandated from that point onwards to verify the eligibility of an athlete to compete in women's sports involving chromosomal, genetic, hormonal, physiological and psychological examinations or some combination of these. There were systematic tests administered for women from the 1940s, aimed at catching and banning so-called 'gender frauds' (Heggie, 2010). These processes – which at times have involved SRY and Buccal Tests, having one's genitals and chest groped, prodded or stared at and publicly denounced by panels of apparent 'experts' – have been deeply resented by many athletes (Lynch, 2004). Athletes have discussed their sensation of discouragement, abuse and humiliation being formally sent home after a series of tests or being informally encouraged to leave after quick dismissals of their breast size for example (Larned, 1976). Other sources of stigma in Australia for example have included the availability of marriage annulments on the basis of one member of the couple being neither male or female (OII Australia, 2012a).

The relative invisibilities of most people with intersex variations overall, and therefore general misunderstanding of the size and variation of the intersex community as a whole, has had pros and cons. To some extent invisibilities protect people in the intersex community from the frequency of negative stereotyping that transgender and gay people have experienced in public representations, the media and language historically; allowing some people with intersex variations to continue comfortably in the community or local sports competitions to varying extents and carry on with their lives being largely interpreted as fitting male or female norms, more or less. However, this protection has never been complete; there have been books, films and shows which use 'hermaphrodite/hermie' or 'boy-girl' as an insult (such as the teen show *Pretty Little Liars*) or representations of intersex bodies as punch-lines, and various individuals have suffered international and even local level sports bans. Invisibilities have also meant that parents and guardians of children with intersex variations often have little or no concept of what such variations entail or whether they should encourage/coerce their child into accepting available 'treatments'; that medical services operate on a default traditional model of healthy male and female bodies and try to shape any bodies outside of that model to fit it; that role models or information for people with intersex variations have been minimal; and that the potential to forge community connections, alliances and advocacy promoting bodily autonomy or other goals have often been missed. In addition, *celebration of the broad range of people with intersex variations' bodies and experiences has been undeniably lacking*.

Increased Networking and Advocacy

Recent years (particularly the last decade) have challenged both the silence and stigma surrounding people with intersex variations. Since the 1970s international-level athletes, global experts on endocrinology and genetics, and human rights advocates, complained that gender tests in sports were more scientifically complex, expensive, invasive and inaccurate than initially perceived by authorities and often misused (Amdur, 1977; De La Chapelle, 1986). The International Association of Athletics Federation ceased compulsory gender verification tests in 1992 before recommencing in recent years, with the controversial treatment of Caster Semenya in 2009, a South African teenage athlete who won the women's 800m race at the World Championships in London, setting the year's record. Semenya's win was overshadowed by global news media coverage of doubts about her sex and possible drug use due to her highly muscular body and masculine appearance (Slot, 2009). The results of gender testing were made public without her consent. She subsequently hired lawyers and was allowed to keep her medal and earnings for the race, and became a celebrated icon in South Africa, with prominent politicians and athletes criticising both Athletics South Africa's and the IAAF's handling of Semenya's case (Sawer & Berger, 2009).

A range of intersex social support and advocacy groups, networks, organisations and associations have formed since the 1980s. In 1983, Glenn Fisher founded the Turner Syndrome Support group (now a registered charity and company the Turner Syndrome Association of Australia, http://www.turnersyndrome.org.au) to combat the isolation and lack of information she experienced after the birth of her second daughter, Mandy, diagnosed with TS just after birth. Early meetings were held in Glenn's home, and from there became a support group in New South Wales; and eventually growing to become Australia-wide as it is today with branches in the ACT, NSW, QLD and VIC for example. It runs a newsletter, social events and runs an award celebrating community contributions. In 2003 the International Turner Syndrome Conference was held in Sydney, which brought together people from many countries around the world who shared a common link with TS. In 2005 Glenn received a Member of the Order of Australia (AM) for her volunteer services to Turner Syndrome. The current national president is Sean Kenny. Around 30 years ago, The Androgen Insensitivity Syndrome Support Group Australia (AISSGA, http://aissga.org.au) was founded as a peer support, information and advocacy group for people affected by AIS and/or related intersex variations, and their families. They support members (both in Australia and overseas). They hold annual national conferences, and disseminate support and information. Its current president is Bonnie Hart. The Organisation Internationale des Intersexués (OII, http://oiiinternational.com) is a decentralised global network of intersex organisations. OII Australia (https://oii.org.au), has been active in some form since 2008. It was registered by founder members and directors Chris Somers, Gina Wilson, Karin Gottschalk, Morgan Carpenter and Priscilla Quirk in May 2010 as a not-for-profit independent support, education and policy development organisation. It is run by and for people with intersex variations or differences, engaging in advocacy and supplying a range of resources for people with intersex variations, their allies and families, service providers and employers. Their volunteer-based work focuses on human rights, bodily autonomy and self-determination, and on evidence-based, patient-directed healthcare. Its current president is Morgan Carpenter. OII Australia and the AIS Support Group Australia are members of the National LGBTI Health Alliance and International Lesbian and Gay Alliance.

The last decade particularly has seen increased advocacy by such networks in relation to intersex issues including enforced and coerced surgeries, discrimination, education access, healthcare and medical treatments and social policy. A turning point was marked with the release of the United Nation's GLBTIQ-focussed *Born Free and Equal* policy (United Nations, 2012). This document outlined the UN's position in interpreting people with intersex variations' rights as inherent in 'human rights' for the first time, and asserted the protection of all people against discrimination on the basis of intersex status in international human rights law. The UN now takes a clear position of protecting intersex infants against enforced medical correction (United Nations, 2012), although as yet Malta is the only country to bring protection against enforced correction into its laws. It supports international and local intersex groups' call for their own bodily autonomy and their right to make decisions about their gender or any surgical intervention *only if they choose to* later in life. OII Australia/OII Aotearoa and British Psychological Society criticized the inclusion of people with intersex variations within the Gender Dysphoria concept in the DSM-V (Kermode, 2012), because unlike transgender people, people with intersex variations who are unhappy with their bodies may be unhappy *due to* surgical interventions (imposed against their will) rather than due to a desire for surgery based on their own discomfort with their gender. However, some people with intersex variations find the concept useful in gaining access to interventions or understanding sensations of disruption to their natural identities caused by enforced treatments (OII Australia, 2012b), but the emphasis in psychology is now turning towards supporting bodily autonomy (including access to any or no intervention; as wanted) and seeing natural intersex bodies as healthy (Jones & Lasser, 2015).

Like any movement, different organisations and activists may take different intersectional approaches: there is a question of where intersex issues 'fit'. There have been disagreements amongst advocates and allies and medical groups over whether intersex is inherently a disorder, whether intersex should be included in LGBTI issues and advocacy, whether they should be included in disability advocacy, and the value of intersex-only vs. collaborative advocacy.

In October 2005, 50 primarily US clinicians on intersex-related issues, such as paediatricians, endocrinologists, geneticists, and reproductive specialists, met in Chicago to build treatment protocols for individuals with intersex variations (Topp, 2013). They outlined new treatment suggestions, but also replaced the term intersex with Disorders of Sex Development (DSD) – which they justified later in European and American journals as being more descriptive in their view and supportive of people with intersex variations seeking intervention (Hughes, 2008; P. Lee, Houk, & al., 2006). However, notably, this 'consensus' was reached only amongst medical people at the conference and only two people with intersex variations, but no international or local intersex advocacy groups – Australia's OII and other groups have since expressed this dissent on DSD's use (Topp, 2013). People with intersex variations and groups/organisations have been having their own meetings with very different approaches being promoted as a result. Since 1996 some small international gatherings have been held – documented in films like *Hermaphrodites Speak* (1997). Larger-scale International Intersex Forums have been held in Brussels in 2011, in

Stockholm in 2012 and in Malta in 2013 – with strong contribution from Australian intersex rights advocates. At the Malta gathering the goals for intersex advocacy were established, including ensuring protection against terminations and enforced treatments, access to medical records and supportive medical/psychological services, inclusion in sports activities and other aims.

In 2015, the Council of Europe released *Human Rights and Intersex People* (Agius, 2015) outlining eight recommendations to member states for their treatment of people with intersex variations. These included recognising that people with intersex variations have the right not to undergo sex assignment treatments and ending medically unnecessary 'normalising' treatment, supplying counselling (including access to medical records) and peer support, review of pathologising medical classifications, legal recognition of self-determination in identity papers, protection in legislation, and active outreach from national human rights structures. Notably, research into the human rights protection needs of people with intersex variations in different settings was also recommended (with representatives' collaborative involvement, as in some examples from Germany discussed), alongside investigation of past rights abuses. During this same period, some intersex individuals in European countries like Germany started to sue their doctors on the basis of past abuses, including proceeding with genital surgeries and hormone treatments without their permission or knowledge (DPA Local Editorial, 2015; FAZ & DPA Editorial, 2015). More recently, parents sued doctors over what they termed as their child's unnecessary 'genital mutilation' in the USA (Magaldi, 2015) – their baby son had undergone various procedures on his atypical genitalia before they adopted him due to a doctor's attempt to allocate him a female sex/body without waiting for him to be of an age where he could have determined his own treatment options, if any.

New media have greatly enhanced visibility opportunities. A range of Facebook and Twitter pages and groups, both open and closed, have been developed to support both online and offline interaction and events. Individuals have also created their own blogs, video logs and channels on YouTube to document and share their experiences. A 2015 YouTube video featuring four intersex young people discussing their lives in simple language made by youth group Inter/Act Youth garnered over a million viewers and continues to make waves. In addition, the last few years have also seen an increasing level of visibility for people with intersex variations particularly in American and Australian TV Shows and media. For example, American activists have featured in interviews such as *XXXY* (2000) and mainstream television like *The Oprah Show* (1984, 2007), and Buzzfeed featured a viral video of intersex activists such as Pidgeon Pagonis from the intersex youth group Inter/Act (2015). The hit US teen series *Faking It* (2013+) featured the first central ongoing intersex character Lauren Cooper (who has Complete Androgen Insensitive Syndrome/CAIS) and Jeffrey Eugenides' American and international best-seller book *Middlesex* (2003) featured the intersex character Cal. In Australia, intersex activists such as Tony Briffa appeared on *ABC's Four Corners* with Andie Hider and *60 Minutes* with Chris Somers XXY (2000, 2005), and in *The Sydney Morning Herald* and other newspaper articles with Christy North and other activists (various). The Australian documentary *Orchids* (2010) captured Phoebe Hart's exploration of her own and her sister Bonnie's intersex variations and their loved ones' responses. This was broadcast on ABC1 in Australia in 2012, has appeared in more than 50 film festivals internationally and also been broadcast in Switzerland, Sweden, Israel, Spain, France, Russia, Poland, Germany and the USA. The New Zealand film *Intersexion* (2012) featured people from around the world with different intersex variations and experiences, including Australia's Gina Wilson. A new kind of visibility and thinking has also stemmed from increased activism efforts more broadly across the GLBTIQ and disability movements, but has particularly benefited from intersex-only networking and policy advocacy.

Australian Advances

These international rights advocacy movements and the notably strong Australian intersex rights efforts have certainly reinforced progress towards recognition of intersex rights in the Australian context, alongside the work of the Australian Human Rights Commission and various allies. Some of Australia's notable intersex advocates have become the world's first openly intersex Mayor (Tony Briffa), consulted in parliamentary inquiries (Gina Wilson, Morgan Carpenter), or were part of important firsts such as the world's first passport with an 'X' sex descriptor and Australia's first birth certificate with an indeterminate sex descriptor (Alex MacFarlane). The country features multiple social and advocacy groups, organisations and networks for people with intersex variations with various or distinct variations (OII Australia, AIGSSA, Turner Syndrome Association of Australia etc.). At the same time there has also been increased strategic allied advocacy by intersex and 'GLBTIQ' and disability groups/organisations/academics. For example, the last few years has seen joint statements to media by sex and gender diversity allies, networking collaborations, and the 2007 formation of National LGBTI Health Alliance* at Australia's Parliament House – a coalition of organisations from across Australia which provide related health programs, services and research.

Australian birth certificates can be 'corrected' to include indeterminate or unspecified sex at the State and Territory level. Under the Australian passport policy for applicants who are sex and gender diverse, a letter from a medical practitioner certifying that the person has had, or is receiving, appropriate clinical treatment for gender transition to a new gender, is acceptable evidence of gender identity. At the time of the study on which this book is focussed, an Australian passport could be issued to intersex, transgender and/or gender diverse applicants in M (male), F (female) or X (http://www.passports.gov.au/web/sexgenderapplicants.aspx). In June 2013 the Sex Discrimination Amendment (Sexual Orientation, Gender Identity and Intersex Status) Act 2013 (Cth) (SDA Amendment Act) inserted new grounds into the Sex Discrimination Act 1984 (Cth) (SDA), particularly protections against discrimination for all Australians on the basis of intersex status. Australia is the first country in the world to feature explicit protection through a specific attribute. The SDA provides protection from discrimination for people who identify as men, women, and neither male nor female. It does not matter what sex the person was assigned at birth, or whether the person has undergone any medical intervention. All states and territories had previously prohibited discrimination on some basis related to transgender issues. However, these grounds differed, having included: gender identity (ACT Parliamentary Counsel, 2010; QLD Parliamentary Counsel, 2010; VIC Parliamentary Counsel, 2010); transsexuality (NT Parliamentary Counsel, 2010; TAS Parliamentary Counsel, 2010); transgender status (NSW Parliamentary Counsel, 2010); chosen gender (SA Parliamentary Council, 2010), or gender history (WA Parliamentary Counsel, 2010).

---

* This organisation first formed as the National LGBT Health Alliance and later became intersex inclusive.

The Australian Senate has undertaken inquiries into topics relevant to people with intersex variations, such as the involuntary or coerced sterilisation of people with disabilities, and intersex organisations have been repeatedly called upon to respond in and outside of parliament (OII Australia, 2013). The Australasian Paediatric Endocrine Group and Royal Children's Hospital Melbourne made submissions to these inquiries. NSW Parliament passed a motion on the Senate committee report in November 2014, acknowledging the need to protect people with intersex variations and to raise awareness of the issue of sterilisation through recognising the 26th October as Intersex Awareness Day (http://oii.org.au/28073/nsw-motion-iad-2014). The Australian Government's (2013) *Guidelines on the Recognition of Sex and Gender* support individuals to consistently identify and be recognised within the community as a gender other than the sex or gender they were assigned at birth, as intersex, or as an indeterminate sex and/or gender in their personal records. Where a person requests the sex and/or gender information on their personal record be amended, the Australian Government will now recognise any one of the following as sufficient evidence regarding sex/gender:

a) a statement from a Registered Medical Practitioner or a Registered Psychologist,
b) valid Australian Government travel document, such as a Valid Passport, which specifies their preferred gender, or
c) an amended State or Territory birth certificate, which specifies their preferred gender. A State or Territory Gender Recognition Certificate or recognised details certificate showing a State or Territory Registrar of Birth Deaths and Marriages has accepted a change in sex will also be seen as sufficient evidence (Australian Government, 2013).

The Australian Senate report *Involuntary or Coerced Sterilisation of Intersex People in Australia*, although as yet not implemented by any Australian government, is referred to in The Council of Europe's *Human Rights and Intersex People* report (Agius, 2015), and Australian intersex activists such as Morgan Carpenter have notably contributed to international consultation leading to this report and other rights recognition efforts or inquiries in recent years. In relation to the eight recommendations issued by the Council of Europe (Agius, 2015), Australia's scorecard has yet to be determined, with no large-scale research into intersex Australians' experiences of 'normalising' treatments, counselling, peer support, medical classifications, identity papers, discrimination or services.

Lack of Social Research

There is a lack of research on people with intersex variations generally, and *almost all research is medical/clinical* in frame. Medical discourse frames the concept of intersex status in terms of disorder, a problem, a lack, an excess, or an aberration of some kind (in the sense of Disorders of Sex Development/DSD). There is much focus on what is wrong compared to the ideal model of the healthy body, mind, hormones or gender presentation, for example, and how to 'correct' this if possible. However work which gives people with intersex variations themselves *an actual voice* is rare (a few writers such as Morgan Holmes, Iain Moorland, Georgian Davis take this more critical perspective by writing on their own experiences or interactions with other individuals in the community) and has not yet considered large-scale samples.

Internationally research has mainly been conducted in Western countries (Europe, Northern America, and Canada). It has predominantly considered medical themes including the biological make-up of people with intersex variations (Appleby, Gibson, Norymberski, & Stubbs, 1955; Atkins & Engel, 1962; Balen, 2007; De La Chapelle & Hortling, 1962; Ferguson-Smith & Johnston, 1960; Jackson, Hoffman, & Makda, 1966; A. Ross, 1960; G. Ross et al., 1965; H. Turner, Greenblatt, & Dominguez, 1963). Such studies have often been based on analyses of a few individuals' physical presentations, buccal smears or chromosomal compositions and so on. This work has been the most widely promoted and is loosely paraphrased in the glossary for this book and therefore is not outlined here. However, the most notable (but lesser known) recent medical study for people with intersex variations was a large scale German, Austrian and Swiss clinical evaluation study on treatment satisfaction, coping, and problems associated with diagnoses and therapies in individuals with 'disorders of sex development' (DSD) (Lux et al., 2009). The multi-centre clinical evaluation study included short-term follow-up in some and cross-sectional assessments in all age and diagnostic groups fitting the criteria of DSD. The study mainly comprised a psychosocial inquiry for children, adolescents and their parents, and adults with standardized instruments and the collection of DSD-specific medical data by the attending physician; 439 children and adolescents, their parents and adults with DSD participated. Over 80% of participants had been subjected to surgeries due to their intersex diagnoses, almost 50% reported psychological problems. Two thirds of the adult participants drew a connection between sexual problems and their history of surgical treatment. Child participants experienced significant disturbances related to the interventions around family life and physical wellbeing, and teenaged participants who had undergone interventions were significantly less likely to experience petting and masturbation than the broader population in their age group. However, despite this data the research group nevertheless do not conclude that interventions into people with intersex variations' bodily presentations before the age of consent are potentially problematic, much to the frustration of many intersex activists, arguing instead that there is a need for further studies around the impacts of interventions. This is an essential tension in the field. Other researchers who do not yet have supporting data are already arguing against interventions based on anecdotal reports, but similarly stress the need for data on the impacts of not having any intervention (Creighton, Michala, Mushtaq, & Yaron, 2013). Additionally, emphasis is now being placed on non-categorical studies of optimal healthcare delivery to, and support of, people with DSD (P. Lee et al., 2014). The Swiss position on intervention debates already privileges the idea of involving people with intersex variations themselves in any decision-making about their sex and intervention needs, rather than imposing standards of sex upon them without consent (Swiss National Advisory Commission on Biomedical Ethics, 2012).

Another stream of international research has explored parental responses to having intersex children. The research on parental responses has mainly used frames drawn from psychology, used small group samples and positioned intersex young people as children with a disorder of sex development (DSD). Psychological research has shown parents of children with DSD may experience the diagnosis and subsequent decision making processes as traumatic (Pasterski, Mastroyannopoulou, Wright, Zucker, & Hughes, 2014; Streuli, Vayena, Cavicchia-Balmer, & Huber, 2013). One UK study assessed the prevalence/severity of posttraumatic stress symptoms (PTSS) of 47 parents of intersex children (termed children diagnosed with a disorder of sex development/DSD) (Pasterski et al., 2014). Reported PTSS was high: 31% of mothers and 18% of fathers met the threshold for cases for Posttraumatic Stress Disorder (PTSD), evidenced by high rates of PTSS in the current report. The researchers argued that it was cognitive confusion, and not emotional distress, which predicted PTSS – that direct cognitive psychological interventions may be applicable. A Swiss study considered why parents generally avoid postponing surgery until the child is old enough to provide consent (Streuli et al., 2013). The study used 89 medical students positioned as potential parents and surveyed their consideration of whether they would engage their imagined child in surgery during infancy given what was termed in the study as a 'DSD' diagnosis. Thirty-eight of eighty-nine 'parents' (43%) chose early surgery for 'their' child, including 27/41 'parents' (66%) shown a medicalized video explaining their child's condition vs. 11/48 (23%) shown a de-medicalized video. This suggested medicalization of the diagnosis may play a significant role in decision-making, although the study was not on the reasons of actual parents of people with intersex variations and certainly can't be considered conclusive. There was also a small study on diagnosis-related and gendering language use by intersex sociologist Georgian Davis, constituting interviews of 36 adults with intersex traits alongside a few parents and medical experts (Davis, 2015). Davis selected the participants based on their past involvement with organisations including ISNA, OII, AISSG-USA and Accord Alliance; utilising insider/outsider status as intersex to enhance the study's access to these participants. Davis found that although different terms (e.g., intersex and DSD) had their uses and problems for different people in the American context (with some parents and medical experts particularly finding the term useful), many intersex adults in the interview sample rejected the term DSD.

Australian research on people with intersex variations has largely followed the main international pattern of being based on small, qualitative clinical work which mainly views people with intersex variations through the lens of aberration or disorder needing intervention. A small Victorian clinical study of XXY Australians (Herlihy & Gillam, 2011) aimed to be progressive in that the authors suggested that not all people with XXY karyotype should be classified as having Klinefelter's Syndrome, as some identity as female and thus the 'symptoms' (for example, of feminine body presentation such as breasts) may not be 'abnormal' in those individuals (Herlihy & Gillam, 2011). However, to some degree such thinking still reinforced some gender expectations. A medical hospital-based study through the Murdoch Children's Research Institute assessing the long-term 'psychological outcomes' of only 50 'patients with intersex conditions' (aged 18-32 years) for medical intervention compared with two 'matched' control populations (the control groups were smaller and organised around having an alternate unrelated 'medical condition') (Warne et al., 2005). The study claimed the intersex group did not differ from controls on physical or mental health, depression, state anxiety, neuroticism, psychoticism or stressful life events – to other people cast as having a medical condition. However, it was noted that the intersex group were less likely to experience orgasm, experienced more pain during intercourse and were less likely to have sexual activity several times or more a week than the combined control groups in relation to the medical interventions to their genitalia. It was entirely unclear what the people with intersex variations themselves had felt about the interventions they were subjected to or their need for them, and the 'long-term' nature of the study completely overlooked the lived experiences of people with intersex variations beyond a few years. Reporting of the study in some ways minimised problems with sexual activity, and used results to promote 'early genital surgery carried out at a centre of excellence' (the researchers' own centre) as minimising long-term complication rates. However, no consideration is given to experiences of people with intersex variations that do not involve intervention, or what treatment people with intersex variations themselves would have preferred either at the time or years later in retrospect. This study seemed typical of the kind of work that does not give intersex individuals any real voice about their own experiences, but instead uses some basic information about them in medical experts' own self-affirming evaluations of their own pre-established positions promoting early genital surgeries and their own related work. From a sociological perspective, it may be more useful to understand individuals' views on their own experiences in more depth.

Interesting exceptions to most Australian work, which in the main does not question medical thinking, include a study comprised of 9 semi-structured interviews with primary health care practitioners in WA conducted by intersex and allied co-researchers (Somers xxy, Reibel, & Whyatt, 2008). The study pointed to the lack of distinction between the health care practitioners' understanding of terms including intersex, transgenderism, transsexuality and androgyny. Findings were used to argue that the professional knowledge base of health care practitioners in relation to intersex and androgyny may affect their ability to both identify an individual's status and provide appropriate treatment. Finally, full disclosure of an individual's sex/gender status was cast as 'paramount' to supplying appropriate treatment; therefore, practitioners were argued to need to be able to contribute to conditions where an intersex or androgynous individual could disclose. The researchers called for research into the concerns facing intersex Australians in order to improve their experience of primary health care. The first author's own work has also previously minimally included intersex participants or concerns in larger quantitative studies on LGBTIQ or transgender themes, with 3% of 272 participants in a study of FtM transgender Australians born intersex and a few participants in a same sex attracted students study born intersex (Jones, 2015; Jones, del Pozo de Bolger, Dunne, Lykins, & Hawkes, 2015). These subgroups were too small to be studied comparatively to the broader groupings in which they emerged, but confirmed the diversity of these groups.

However, the lead researcher has also done studies where including intersex participants was achieved with such little success that the intersex-specific data was ultimately held back from reporting (Smith et al., 2014). This wasn't because people with intersex variations weren't involved in developing the projects or participating in them, but because the low numbers impacted the way the data could be framed and the focus of the study. We learned that a research instrument can potentially make it difficult for participants with intersex variations to discuss their experiences if space for these experiences is not *actively privileged in the topics of questions selected for the survey*. The researcher learned that researching intersex issues with greater accuracy would demand a distinct project *entirely and only focussed on people who are intersex*. It would require *the aid of people with intersex variations themselves* as research allies and advisors, to capitalise on 'insider/outsider' access dynamics emphasised by intersex researchers (Davis, 2015), in order to foster more direct exploration of people with intersex variations' conditions, identities and experiences. There have been no large-scale national studies exclusively on people with intersex variations in Australia, no studies based on direct collaboration with intersex groups and investigation into the issues that interest them most, and no studies exploring the uses and problems of interventions/a lack of interventions in people with intersex variations' early years. A new study was needed to directly redress those lacks, and provide a sociological lens in a field where medical and psychological lenses are most dominant.

Research Frame and Aims

Despite a lack of large-scale research on people with intersex variations overall, a range of theorists have displayed strong investments in their construction of 'the meaning' of intersex identities. Those constructions differ greatly and can derive from entirely different models of sex identity. They sometimes even have little to do with the lived experiences of people with intersex variations themselves and more to do with theorists' desire to create a workable conceptualisation of the world, and the sex and gender identities at the core of their vision of it. A very brief history of the conceptualisation of people with intersex variations in theory will aid understanding of these debates, and the position offered in the research. It is important to emphasise that intersex issues have intersections with cultural constructions of identity, sex development, gender issues, disability issues, deconstruction of sex and so on. Therefore they have been considered from various angles whether in passing or in depth by anthropologists (Findlay, 1995; Martin, 1990), endocrinologists (Futterweit & Deligdisch, 1986; Laflamme et al., 1996), geneticists and chromosomal experts (De La Chapelle & Hortling, 1962), psychologists (Mazur & Clopper, 1991), Queer theorists (Butler, 2004; Hegarty & Chase, 2004), GLBTIQ/LGBTIQ researchers (Jones et al., 2015), lawyers and human rights proponents (Ford, 2001).

Table 1.1 provides a comprehensive overview of the dominant discourses on people with intersex variations in the literature. These paradigms were classified as conservative, liberal, critical or post-modern in orientation; borrowing from a framing of discourses as having an overall function in social systems towards or against the maintenance of dominant existing social power structures and social orders (Jones, 2013b). As argued elsewhere in relation to methodological frames of GLBTIQ people in sexuality education research, intersex identities are similarly used in research studies in ways which reflect or disrupt social orders (Jones, 2013a). For brevity's sake, the table here does not include all possible perspectives on people with intersex variations; for example, culturally-specific views which did not usefully apply to the Australian data presented in this book. The table allows comparison of the different views of people with intersex variations and the discourses from which they derive. It allows us to organise key critiques against certain perspectives, to clarify a rationale for why the majority do not serve as this book's analytic frame.

Table 1.1: Dominant Discourses on People with Intersex Variations.

Theoretical Orientation	Dominant Discourses
Conservative: reinforces the dominance of status quo identities through institutional powers, traditions and practices.	**Conservative religious/spiritual frames** alternately overlook people with intersex variations or cast them as mystified/magical, a bad omen, punished sinners, witches, evil or cursed. At best they are idealised/praised; at worst demonised, isolated, killed. Related research overlooked or tested them for (good/bad) powers.
	Socio-Cultural Sex Conservatisms alternately overlook people with intersex variations or position them as monstrous/freaks. At best they are quietly subsumed into the key male or female norms. At worst they are ostracised, bullied, harassed, displayed, or killed. Related research overlooked or sensationalised them.
	Biological Essentialism constructs people with intersex variations as aberrations outside biological templates for reproductively 'successful' males/females. Parents were supported to terminate or 'correct' them as males/females through treatments. Invasive research involved samples, photographs, observation and experiments.
	Mainstream Psychological Frames construct people with intersex variations as clients with disorders of sex development (DSD) needing support with their condition, and accessing processes around correcting it. Research on behavioral treatments for DSD used diagnosis-based frames, and also explored criminality.
Liberal: ensures the liberties and freedoms of the individual through minor reforms to current systems.	**Liberal Biological/Medical Sciences** view people with intersex variations as patients with DSDs – chromosomal/genetic conditions, hormonal insensitivities, excesses or production problems which may need treatment choices. Research conducted chromosomal, genetic and hormonal tests (buccal smears) with consent.
	Liberal Intersex Activisms argue the need for choice, tolerance and freedoms for diverse people with intersex variations as part of the range of 'normal' people with some medical conditions, in a person-first model. Research of legal and scientific significance was used to enhance knowledge and understanding. Consent is key.

Theoretical Orientation	Dominant Discourses
Critical: pushes for whole-scale reforms of existing systems in the interest of a marginalised group.	**Disability Studies** pushes to understand disability as a social construction, promoting an active affirming approach to meeting key groups' special needs through social services and social justice. People with intersex variations can be a group specified for inclusion, whether inclusion in debates or bioethical research.
	GLBTIQ/LGBTI Liberationisms push for whole-scale reforms and alternate segregationist spaces for people with intersex variations as part of the GLBTIQ (gay, lesbian, bisexual, transgender, intersex and queer) umbrella. Related research may include them directly (e.g. in surveys), or frame intersex as a gender identity.
	Critical Intersex Activisms/Studies construct people with intersex variations as a marginalized group whose rights to non-discrimination and self-determination are under threat from key institutions. Body positivity and intersex-run goal-setting/action are key. Research served group goals, and privileged collaborative work.
Post-modern: questions the norms of status quo, grand narratives, existing systems and labels.	**Post-modern/Post-Structuralist Intersex Studies** point out the broad and inconsistent range of sex developments, reproduction, and bodies, to disrupt grand narratives of biology/sex and disability. Universal identity 'truths' are rejected. Research included deconstruction and intersectional analyses of sex and intersex.
	Queer Theory uses people with intersex variations as subversive subjectivities that reveal the inauthenticity and disordering/unattainable norms of sex through their disruption to the traditional binary sex models. Research analysed how intersex bodies erased, re-appropriated or were clinically altered to uphold sex norms.
	Crip Theory exposes the assumptions of mainstream narratives on disability and reclaims the term crip (crippled); revealing how norms of able-bodiedness are made both compulsory and impossible to achieve. People with intersex variations can sit within 'crip' identities. Research explored concepts of crip/normalcy in key texts.

Conservative

The conservative theoretical orientation reinforces the dominance of status quo identities through institutional powers, traditions and practices (Jones, 2011b, 2015). Research discourses stemming from this orientation construct humans using a model of 'binary' sex/gender, where in only two normative identity models are available: either heterosexual masculine male or heterosexual feminine female (Jones, 2011a). Such strict expectations can mean that disruptions to the model are experienced as sinful, aberrant or traumatic. Trauma is particularly highlighted for parents, who are encouraged as co-conspirators in methods of hiding or repressing difference in their children. The conservative discourses could not drive the analyses because they function overall to keep people with intersex variations (and others who do not fit in with their particular privileged identity ideals) at the bottom of restrictive notions of the social order.

Conservative Religious/Spiritual Frames

Conservative religious and spiritual frames can reinforce the centrally-determined norms of religious identities via their leaders, spiritual texts and churches. In modern history norms of male dominance and female subservience, marriage as a structure sanctioned by God as the sole site for sex as procreation, and traditional families are particularly common in Judeo-Christian and Islamic discourses (Green, 2013). Whilst no Australian religious organisation has been able to present central or even peripheral religious ideological arguments against protecting people with intersex variations from bias in their organisations and none of the five key book religions actively denounce people with intersex variations in any of their key texts (Gahan & Jones, 2013; Gahan, Jones, & Hillier, 2014), they have not taken a stand in the favour of people with intersex variations through largely overlooking them, which in itself can be read as a condemnation leaving the deep significance of binary sex for many key theologies unchallenged (DeFranza, 2011; Fonrobert, 2009). The Bible discusses eunuchs, in terms of their presumed celibacy:

> For there are some eunuchs, which were so born from their mother's womb: and there are some eunuchs, which were made eunuchs of men: and there be eunuchs, which have made themselves eunuchs for the kingdom of heaven's sake (King James Version, Matthew 19:12).

Many conservative religious people interpret this as meaning that those who are intersex 'must' abstain from sex and relationships, and cannot marry in line with various church dictates against homosexuality (Gahan & Jones, 2013). Modern neo-conservative Judaism can overlook the range of mentions in texts in classical Judaism (Mishna, Talmud, classical midrash and Jewish law codes) of people who were 'androgynos (had mixed sex characteristics), tumtum (of indeterminate sex), ay'lonit (seen as female at birth, later developed male characteristics and were infertile) and saris (seen as male at birth, later developed female characteristics or had no penis) (Fonrobert, 2009). Some Judeo-Christian and Islamic anxieties about people with intersex variations have in practise led leaders to ensure people with intersex variations chose or were given a sex role, which could then be maintained so as to avoid homosexual deviance, issues with property inheritance or disruptions to norms of marriage and family (Green, 2013). Official decretals promulgated by Pope Gregory IX have even prohibited people with physical differences from serving in the higher orders of the Christian church (Metzler, 2006). Whilst various religions discuss deities, angels and characters (including early human groups) in terms of having both male and female aspects in a mystifying/magical manner or origin theory, missionary influences on religious interpretation in modern times have largely resulted in condemnation and fear of bodily differences in the Pacific Islands and Africa, low caste categorisation of Hindu culture's once revered 'hijra' and insulting reclassifications of North American intersex shamans as 'berdache' (Wilson, 2013). Some sects/spiritual groups cast people with intersex variations with physically obvious sex differences as being a bad omen, as being punished for past lives/sins, witches, or as evil or cursed; intersex infants have even been subjected to tests for special powers or stoned to death in some African contexts and few religious/spiritual church groups have spoken out in their defence (Wilson, 2013). Newer critical-conservative religious studies have applied gender studies lenses to a range of classical religious texts, critiquing more limited modern neo-conservative religious approaches to people with intersex variations (DeFranza, 2011, 2015; Fonrobert, 2009).

Socio-Cultural Sex Conservatism

Since medieval times people with intersex variations, where detectable, have mainly been viewed as threats to some Western socio-cultural orders – which have strongly privileged males in a model of two sexes (male and female) and related gendered social roles and responsibilities (Metzler, 2010). Apparently aberrant bodies had to be controlled and one method of achieving this was to ensure their identities were quietly subsumed into the traditional sex model (as a very traditionally acting male or female), regardless of rational and sometimes irrational medical explanations. Jurists and the populace expected the people with intersex variations to fit into the appropriate 'box' in order to continue functioning in society, and so that society could continue functioning without changes to key assumptions of patriarchal dominance (Metzler, 2010). Where people have presented as too obviously outside this limited notion of human reality, there have been constructions of people with intersex variations as freaks, monsters or people to fear and/or poke fun at, stare at in carnival displays or hide behind closed doors and institutional walls (Bezhanova, 2014). To this day, citizenship norms in most countries (family law, marriage law and other structures) are constructed through responses to corporeality (Grabham, 2007). Cultural conservatisms in many countries around the world limit the acceptance for people with intersex variations socially such that they can experience social exclusion, bullying/teasing/harassment, torture and murders. In recent years there were reported cases of people with intersex variations and their families from Middle Eastern countries who have felt pressured to engage in procedures to 'correct' physical difference from the social norm to avoid bullying and even threats to their life, and to take advantage of cultural favour towards genetic males (D. Diamond, Sytsma, Dreger, & Wilson, 2003). Further, Wilson (2013) discussed how to this day some intersex infants in Africa have been stoned to death on the basis of social conservatism (whether influenced by religious or secular thinking, or both) and support organisations for people with intersex variations have been formed in response to such killings in countries like Kenya for example (the Chigiti & Chigiti/Gender Minority Advocacy Trust). However, it is important to note that Socio-Cultural Sex Conservatism can exist within any context and is not limited to countries with conservative policies/laws. Research is not central to these frames, but polemics of so-called monstrosity have been inquired into alongside cataloguing of differences in manners that sensationalise subjects.

Biological Essentialism

This discourse derived from Darwinian theory and the work of G. Stanley Hall, Max Exner and Thomas Galloway (Moran, 2000). Hall and his contemporaries created 'adolescents' and argued about their 'sex instinct', and were thus 'bound to manage' both (Moran, 2000, p. 22). This discourse also functioned to control sensuality within 'primitive races': polygamy, promiscuity and incest (Moran, 2000, p. 14). It sees males as biologically pre-destined to be masculine and females as biologically pre-destined to be feminine, towards the purpose of reproduction of set social orders and the human species, based binary biology and some Darwinian principals. Alternatives to these two options are aberrant and inherently problematic, a form of illness or nature's 'mistake' (Blair & Monk, 2009). Conservative scientific 'facts' about how sexual intercourse propagates the human species, promoting understanding of 'correct' bodily functioning and physiology, are valued (Elia, 2005). Erotic, non-reproductive and homosexual acts are excluded. The binary sex model used may be framed within human and animal life cycles (De Schweinitz, 1939), anatomical systems or genetics (discussed in Bazzul & Sykes, 2011). Chromosomes (XX, XY) are assumed to determine (only) two clearly distinct sexes and genders in healthy humans, expressed in anatomical differences between males and females (genitalia, hormones, neurology, size, strength). Some texts mobilising Biological Science use developmental theories to link non-reproductive bodies or sexual acts to thwarted development (Shryock, 1951a, 1951b). Authorities include approved scientific bodies and textbooks. Critiqued as 'sex negative', heterosexist and essentialist (Elia, 2005, p. 786), this discourse casts people with intersex variations as an aberration, as they may not fit the biologically normative and reproductively 'successful' male or female identities it privileges. A current medical reference text on intersex, written by Australian medical practitioners, illustrates the sense of disruption to binary sex as a kind of trauma for parents of intersex infants within this discourse: 'Genital ambiguity in a baby is almost as devastating in the delivery room as a perinatal death' (Hutson, 2012, p. 103). Foetuses have been terminated on these grounds. Invasive research may be conducted without permission – taking of samples, observation, photographic documentation, physical measuring. Surgical, hormonal, aesthetic and behavioural treatments may be enforced upon infants/their parents, adolescents or adults or administered without knowledge or consent as 'necessary correctives'.

Mainstream Psychological Frames

Mainstream Psychological frames analyse disruptions to, and the reinforcing of, psychological health through corrective clinical practices. Thus, the emphasis on correction seen in biological science influential in this discourse despite its contrasting valuing of self-acceptance (L. Liao & Boyle, 2004) & Boyle, 2004). As a discipline psychology has been deeply implicated for over five decades in the lives of people with intersex variations, mainly within a 'brain gender' paradigm (Jordan-Young, 2011). John Money was a famous sexologist and psychologist who developed concepts of body-mind and gender identity through his research and experiments on people with intersex variations, and who was famously criticised by Milton Diamond and others for his sex reassignment of David Reimer (who had no penis due to a botched circumcision) (Money & Ehrhardt, 1996). In the 2005 Chicago convening of international medical experts on intersex-related issues, treatment protocols for individuals with intersex variations were established in conjunction with the declaration that these clients of psychologists had 'Disorders of Sex Development' (DSD) (Hughes, 2008; P. Lee et al., 2006), without wide consultation with people with intersex variations themselves but only with a few individuals (Topp, 2013). This discourse's labelling of people with intersex variations with DSD conditions has been seen as an assertion of institutional, psycho-medical discursive power over people with intersex variations themselves by critics (Davis, 2011). Psychosocial care in mainstream provisions by mental health staff with expertise in DSD is seen as an integral part of 'management' of a DSD to promote 'positive adaptation', and is aimed at facilitating gender assignment/reassignment, timing of surgery, and sex-hormone replacement (Hughes, 2008). A widely endorsed UK care standard document proposed that early psychological input should support people with DSD and their parents to understand their early emotional reactions 'as well as explore present and future worries, adjust to the period of uncertainty during the diagnosis process and facilitate inclusion in informed decision making about themselves or their child' and support for adolescents around medical or surgical attention (Ahmed et al., 2011, pp. 13-14). Research may propose behaviour treatments for disorders of sex development (DSD); which to some extent can pathologise the individual on the basis of biology and assumptions about how one 'should' act. There has been past emphasis on trying to correlate some intersex variations to criminality, particularly males with an additional Y chromosome, with past Australian court cases correlating the condition with the increased psychological propensity for violence (Lyons, 1968). Past research has also proposed people be separated from their communities in special housing/ institutions where they can be observed, studied and experimented with. However, current analyses, although they need to follow stricter guidelines, still work within a framework of intersex issues as largely pathological/ diagnosis-related, despite contemporary debates suggesting other frames of thinking for psychology (Kermode, 2012).

Liberal

The liberal theoretical orientation makes accessible through minor reforms to existing systems the liberties and freedoms of individual identities (Jones, 2011b, 2015). It has been linked to 'human capital theory' and the shift in post-industrial societies where preparation for a single career has been replaced by multifarious 'upskilling' of individuals to allow for a competitive, flexible and insecure workforce and consumerist marketplace engagement (Bauman, 2005; Beck, 1992; Francis, 2006). Research discourses stemming from this orientation construct humans using a 'binary' sex/gender model underpinning most ideas, with some additional room for minor variations and more holistic notions than in the conservative orientation (Jones, 2011a). This can mean that disruptions to the model are experienced as possible and highly rare variations to the available identities and their generally agreed development stages/processes, although they are not seen as ideal and no radical challenging of established notions of sex/gender are proposed. Options for parents in choosing terminations, treatments or other developmentally staged consumer-style care may be privileged over options for actual intersex individuals until they come of age.

Liberal Biological/Medical Sciences (Brain Sex/Endocrinology/Genetics Frames)

In the 1930s endocrinologists and geneticists like Turner, De La Chappelle and others conducted genetic and chromosomal studies of intersex individuals including those exploring XY/XO Mosaics for example or discovering and naming new Syndromes, which generally examined the physical features, chromosomal patterns, or buccal smears of only a few intersex individuals at a time (Appleby et al., 1955; Atkins & Engel, 1962; De La Chapelle & Hortling, 1962; Ferguson-Smith & Johnston, 1960; Jackson et al., 1966; A. Ross, 1960; G. Ross et al., 1965; H. Turner et al., 1963). These sorts of studies were published in academic journals like the *Lancet* or *British Medical Journal*, sometimes with naked black and white pictures of people with particular intersex variations (sometimes with their eyes covered with a black bar for example, in a poor attempt at making them de-identifiable). They recognise the biological diversity within the human species in the combinations of chromosomes (XX/XY/XXY), hormones, androgens and their impacts on brains/bodies. Sex development is understood as staged involving primary traits developed in the womb and present at birth (genitalia/gonads etc.) and secondary sex characteristics triggered through puberty/adolescence (hair, fat and muscle amounts and distributions; maturation of reproductive system, genitalia and erogenous zones; vocal differentiation and so on). However, this liberal more holistic medical perspective does not radically question or challenge the two-sexes model of biological health and normalcy; it simply accepts in addition to it a range of variations within but also beyond 'the healthy norms' accepted for the model. Holistic patient care and choice in treatment is privileged (Brook, 1993), with decisions being relevant to the 'whole person's life' including their own experience of their body, their social experience given the expectations of their parents and community, and so on. Although these works represent knowledge advances from a scientific perspective it can be concerning to peruse the detached recounting of other people's bodies, declarations of necessary treatments and strange depictions of people being prodded, poked or exposed at the genitalia by gloved hands in what may be ethically dubious investigative displays in some of these works or similar. Participants in the research are referred to with words like 'patient', 'human intersex', 'case', and are primarily considered in terms of their variation type and traits which are framed as a 'disorder/syndrome/abnormality' and its symptoms – an aberration from normal or healthy sex development in a Traditional Medical/Clinical Discourse. It is from this perspective that the 'quiet revolution' of medical experts promoting constructions of DSD as being more useful to people with intersex variations than the term 'intersex' was formed – notably with only consultation of two individuals (Topp, 2013). These experts felt being seen as a person with a disorder in sex development/DSD facilitates inclusion in medical schemata and thus supports parents' choices in access to terminations or options for their child's development aids or treatment, or alternately patients with DSDs' rights to choice at an age where any interventions can be to their own preference (Dreger, 2015; Karkazis, 2008; Streuli et al., 2013). However, many critical intersex groups argue this is a pathologising term which presumes the need for correction (e.g. OII, ISNA). DSDs refer to having chromosomal karyotypes including extra or fewer chromosomes beyond the 'normal' for males 46 XY and females 46 XX (e.g., 5-ARD, 47 XXY, 48 XXXY, 49 XXXXY, 47 XXX, 48 XXXX, 49 XXXXX, 45 XO, 45 XX) or mosaicism (e.g., 46XX/45XO, 46XX/46XY, or 46XX/47XXY). They can also include genetic differences or conditions (e.g. De la Chapelle Syndrome); hormonal/androgen insensitivities, excesses or production problems (e.g. CAIS. PAIS), or other physical sex differences (e.g. micropenis etc.). Many people with DSDs are presumed to need treatments to lead 'normal' lives – men with karyotype 47 XYY are seen as simply being a bit taller than usual but (parents of) people who more strongly challenge constructions of healthy male or female physiology are encouraged to seek surgical, hormonal and aesthetic treatments to enhance their social integration and holistic experience. Research involves chromosomal, genetic and hormonal tests (e.g. DNA tests, buccal smears) conducted before birth, in infancy and sometimes later in life, mainly conducted with some permission of the individual, parent or guardian.

Liberal Intersex Activisms

Liberal Intersex Activisms are usually focussed around specific intersex variations (e.g. Turner's Syndrome, Klinefelter's etc.) recognised within Liberal Medical Discourses. They reinforce through minor reforms (within current systems) the human rights and freedoms of people with intersex variations to non-discrimination and psychological supports (Balen, Creighton, Davies, MacDougall, & Stanhope, 2004). They encourage, where the intersex individual is capable of having informed consent, the intersex person to be ensured their bodily autonomy and psychological care as needed (Balen et al., 2004). In order to facilitate this, their access to their own medical histories for understanding and to inform their medical choices is advocated for. Liberal intersex activists and their supporters frame people with intersex variations as part of the range of 'normal' with some biological or medical difference (M. Diamond & Beh, 2008). They have pushed back against the view of people with intersex variations as 'aberrant/needing correction', because it limits their rights. Critical activists note how liberal activists acknowledge that some constructions of people with intersex variations as affected by medical syndromes or disorders may at times be useful from a service access perspective (Chase, 1997). They may accept the framings of people with intersex variations as having disabilities, special needs where seen as relevant. However, the main push is to see people with intersex variations as people first (males or females), to be judged on the content of their character as a whole person, who has an intersex condition which is part of their overall make-up but not wholly defining/determining. Individuals are understood to have very different experiences or intersex status/variations. There is greater acceptance of terms like DSD within this Discourse than within Critical Intersex Discourses, yet less social comfort with high visibility/vocality or declarations of differences requiring large-scale change to institutions. Research of either scientific or sociological significance (for example) is understood to have the potential to enhance knowledge and understanding, which may aid human rights observance. But any intersex individual should have the choice of participation/non-participation, and Milton Diamond is an example of a liberal researcher who has used research-based follow-up on children subjected to enforced interventions to argue for people with 'Differences in their Sex Development' to have more direct personal choices and involvement in their interventions or treatments (M. Diamond & Beh, 2008).

Critical

The *critical* orientation emerged in the 1970s and is linked to wider reform pushes such as class-system reforms, post-colonialism, feminism and gay liberation (Kemmis, Cole, & and Suggett, 1983, p. 129). Examples of linked movements discussed in research include socialist moves in Germany and Soviet Russia (Beckmann, Cooper, & Hill, 2009; Carlson, 1992; Rabinbach, 1973; Sauerteig & Davidson, 2009), civil rights and ethnic revival movements in the US (Mayo, 2005), various feminist reform movements (Elia, 2005; Feltey, Ainslie, & Geib, 1991; Hekman, 1999; Tuttle, 1986), anti-discrimination and inclusion movements (D'Augelli, 1998; Lipkin, 1994; Macgillivray & Jennings, 2008; Magrab, 2003). Within this orientation, holistic reform approaches are seen as necessary for the inclusion of particular non-dominant/'marginalised' social groups, who seek to fight for their right actively through identity-politics based actions (Jones, 2009). Education is understood as having the potential to revolutionise society and even the world (Kemmis et al., 1983); challenging marginalisation and established social orders. Key approaches emphasise affirmation of people with intersex variations and more holistic inclusion of these groups in development of research agendas.

Disability Studies

This academic discipline considers the nature and impacts of the social construction of disability, drawing to an extent on human rights frames to increase individuals with disabilities access to needed resources and support, and overall quality of life. This discourse mainly developed from the 1980s and uses a social model of disability as opposed to a medical model;

the problem of stigma and difficulties for people with disabilities are not attributed to having a disability itself (or physical, intellectual or emotional 'impairment/s') but are attributed to society and how it misunderstands and responds inappropriately to disability (Bickenbacha, Chatterji, Badley, & Üstün, 1999). It is critical of social norms which are maintained through systematic rejection of, erasure of, ignorance of, or undue idealization of (seeking a self-aggrandising and patronising form of 'inspiration' from), disabilities and the people who experience them. Society is construed as having an obligation to provide free access to all healthcare needs, to make key (health/education service) institutions equitable and accessible in a holistic manner, and be inclusive and helpful to these groups (who belong fully to it and should be embraced as such in a practical manner, without idealizing or demeaning them) (Bickenbacha et al., 1999). Financial or pragmatic support should be supplied if needed, but not enforced if not needed. People with disabilities need to be in control, where possible, of any aids/treatments/interventions to the extent they need or desire them and the design of educational studies around their issues (Stout & Schwartz, 2014). However, in recent years, the division between the social and medical models has been challenged and some people with disabilities have noted the usefulness of seeking medical treatments for chronic illnesses whilst also engaging in activisms on the need to promote disability issues in curricula for example (Dewsbury, Karen, Randallb, Rouncefield, & Sommerville, 2010; Stout & Schwartz, 2014). Disability studies/research projects rarely take account of intersexuality outside of intersectional (feminist, Queer) considerations, but where they do the medical presupposition that intersex characteristics are inherently disabling to social viability are challenged, clinicians are discouraged from aggressive interference that does not see intersexed people as humans valid for social recognitions in their own right and of their own choosing, and the termination of intersex babies in utero is challenged (Holmes, 2008).

LGBTIQ Liberation

LGBTIQ Liberation pushes for whole-scale reforms and alternate segregationist spaces in the interests of gay people, and these days the LGBTIQ (gay, lesbian, bisexual, transgender, intersex and queer) umbrella. Most notably in Australia (but less rarely in other countries) people with intersex variations are included as part of the LGBTIQ umbrella of marginalized identities to be advocated for outside of the 'norms' of cisgender heterosexual males and females, celebrated and made visible in the public eye. Gay liberationist discourse can borrow on the political successes of gay activism to push forward other peoples' rights concomitantly (Byne, 2014), but as a small sub-group within the GLBTIQ umbrella the specific needs of people with intersex variations can be overlooked, particularly where hierarchies of power (race/gender/cissexism) exist within GLBTIQ activisms causing them to focus mainly on the interests of white gay men, for example (Stryker, 2008). Where they are included people with intersex variations are seen as people who should be actively protected from experiencing the impacts of widespread social bias on the basis of real or perceived sex/gender/sexual difference through pro-active structural and social change. LGBTIQ research may therefore include people with intersex variations and their issues as a group where possible and should understand people who are intersex may additionally be LGBTQ or not. Attempts to include people with intersex variations can however be difficult due to the LGBTQ publics' misunderstandings of, or attempts to include themselves perhaps incorrectly in, notions of intersex (Jones, 2015; Smith et al., 2014). Other research studies featuring overlaps in LGBTIQ issues include reviews of what is taught to medical practitioners about gender 'anomalies' and 'homosexuality', which have notably included the conflation between people with intersex variations and homosexuality (warnings that girls with large clitorises will become lesbian, and warnings that boys with small penises will become gay) in American reviews during the 1990s (Dreger, 2015).

Critical Intersex Studies

This critical discourse privileges key goals around stopping unnecessary genital surgery in ambiguously sexed infants and making medical histories available to intersex adults (Turner, 1999), along with more whole-scale reforms to thinking on intersex status and variations, sex development and human bodies in general (L.-M. Liao & Simmonds, 2014; Somers xxy et al., 2008). This approach is strongly and vocally critical of traditional and currently dominant (e.g. Psych) approaches to people with intersex variations, particularly enforced/coerced interventions from medical/psychological/educational institutions and parents/guardians/society (e.g. in Liao & Simmonds, 2014; Turner, 1999). Turner (1999) argued that the sex and gender identity rhetoric of members of the Intersex Society of North America – a self-help and advocacy group – exemplified the theoretical and practical problems of identity politics (or, a critical approach). She explains that to overcome the difficulties of community parameters and identification issues ISNA featured an increasing tendency to react against notions of a 'unified subject' and generically consistent models of gender and sex. It sees people with intersex variations as a marginalized group whose rights to non-discriminatory treatment and empowered selfhood are under threat from society's key institutions. Bodily autonomy is valued; this discourse posits that intersex bodies should be accepted, valued and celebrated whilst liberal orthodoxy within both medicine and activism should be challenged (Chase, 1997; Davis, 2015; Holmes, 2009). The discourse values alternate segregationist social and advocacy spaces in the interests of people with intersex variations and intersex rights activism movements, and although there is some acceptance of collaborating with allies where intersections apply (e.g. LGBT, disability), the need for intersex-driven and intersex-delivered activism and parent education is asserted and met by intersex activists, groups and organisations. People with intersex variations are understood to benefit from socializing with other people with intersex variations in terms of getting alternate information about their bodies, identities and opportunities in life, in the face of structural marginalization by hospitals, schools, broader non-intersex only advocacy groups and so on. Whilst this discourse can be strongest in non-government organisations and social groups, the 2014 special issue of *Psychology & Sexuality*, 'Intersex/DSD post-Chicago: New developments and challenges for psychologists', contains calls for critical intersex studies from an academic angle on nomenclature used around intersex issues (L.-M. Liao & Simmonds, 2014). Georgiann Davis' work problematizes DSD as a term which has an 'ab-normalising' impact (Davis, 2015). Inspired by Jeffrey Weeks' seminal interrogation of citizenship in relation to sexuality, Grabham (2007) calls for a holistic inquiry into intersex citizenship and the impact of the corporeal on key social structures. Intersex sociologists have also called for critical conversations with people with intersex variations on the word intersex, researching the term from its early 1917 diagnostic use by biologist Richard Goldschmidt to recent attempts at its overthrow by medical authorities (Davis, 2011; Holmes, 2009). OII Australia suggests research should only be conducted where it serves the direct goals and interests of people with intersex variations as a social group, by intersex researchers, or allies who collaborate with and involve people with intersex variations in their research goals, development and processes (e.g. in its 'nothing about us, without us' motto on its website). Examples include small sets of interviews: a study of nine health care practitioners conducted by intersex and ally researchers on intersex themes (Somers xxy et al., 2008); and a intersex sociologist's study of language use through 36 interviews of adults with intersex traits alongside a few parents and medical experts (Davis, 2015). Liao and Simmonds (2014) emphasise the need to value critical engagement with research literature, theoretically informed question and problem formulation, development of interventions to boost health and wellbeing, honouring of personal agency, equality and diversity, team development facilitation, and research that can contribute to social change.

Post-modern

Post-modernism had a strong emergence in the 1980s, and stems from the critique of French intellectuals around grand narratives[*] during the 1960s and 1970s, which swiftly spread to academics internationally (Carlson, 2005; Leitch et al., 2001). Especially in Foucault's work (1969, 1970, 1976, 1979, 1980), post-modernism makes evident connections with mainstream social science, the sociology of power and the study of sexual and gender identities. The post-modern orientation questions the norms of status quo, grand narratives and identities themselves (Lankshear & Knobel, 2000; Lyotard, 1984). It rejects the notion of a singular grand meta-narrative of sex identity (Lyotard, 1984, p. xxii) and considers its 'truths', along with deconstruction of the vocabularies, grammar and structures of the discursive field in a post-structuralist fashion (Leitch et al., 2001, p. 21). It takes an oppositional relation to the dominant order of the 'real', allowing recognition of all identity positions' partialities, in the spirit of Morton and Zavarzadeh's 'incompleteness and committedness' (1991, p. 12). Thus, intersex identities are not explored as authentic but as cultural constructions with particular uses in affirming or disrupting grand narratives of identity or reality. Research investigates how this occurs, in relation to such areas as gender or disability.

Post-modern/Post-structuralist Intersex Studies

A range of masculinities and femininities, on a range of bodies, have been accepted and pointed out to disrupt norms by feminists, cultural theorists and biologists (Fausto-Sterling, 1992, 1993, 2012; Pease & Pease, 2003). This

---

[*] Overarching stories about history or reality based on universalist notions of truth, which overlook alternative perspectives.

discourse rejects the possibility of asserting universal identity category ‘truths’ in general, and therefore also in relation to sex. This approach would ideally construct many intersex variations and their lived experience as variations of being male, female or otherwise (rather than alternates to these identities, failures of them or non-identities) – or as exceptions which de-bunk the myths of male and female norms (Fausto-Sterling, 2012). A post-modern deconstruction of sex accepts that human biology surpasses easy definition into only two strict categories (thus even an ‘XY male’ has nipples; Pease & Pease, 2003) and the potential for diverse developments exist to some degree within us all (with our gonads able to form into variously testes or ovaries to an extent, for example). Post-modernists thus might alternately view sex as one category with many potential outcomes, a varied and complex spectrum between two extremes (of female or male) or as involving many combinations or possible expressions that are then socially interpreted into biological categories, sometimes falsely (Fausto-Sterling, 2012). Either way, they class the social use of physical sex as a key determinant of social power as misguided (Fausto-Sterling, 2012), and any thinking on intersex identity is seen as a part of discourse/social construction (Morland, 2006). Intersectionality between intersex identities and their theorisation/construction in medical studies, inclusive disability studies, LGBTIQ and queer studies etc. impact the lived experiences of people with intersex variations who enact their identities in invited, alternate or resistant responses to (or in the context of) these dominant tropes. Morland argues that none of the features of post-modernism unequivocally support the reformist agenda of intersex activists around issues of medical health and social inclusion, but that the very ambivalence of post-modernism suits the diversity of views held by people with intersex variations and those they must deal with in a post-modern age (Morland, 2006). This is particularly so in renegotiating intersex ‘management’ with key health, educational, religious and social institutions – which are usually currently stuck in the perspective that people with intersex variations need to be ‘managed’. Research in this perspective has thus far explored grand narratives of biology/sex/intersex/disability in the literature or theology (DeFranza, 2011) or useful understandings of intersex (whether towards preventing or banning interventions as wanted by people with intersex variations, promoting inclusions or promoting distinct spaces) and how these are or can be used or subverted by people with intersex variations as needed (Morland, 2006).

Queer Theory

Intersex issues have not been the main focus of Queer theory, but rather they arise in relation to Queer's dismantling of normative constructions of sex and gender (Butler, 1990; Dreger, 1998; Jagose, 1996; Morland, 2009). In this theory, states of female and male (or any identities) are not recognized as 'truths', but an inauthentic cultural creation, and gender is understood as performatively constructed through iterations and repetitions of culturally established behaviours, mannerisms and so on (Butler, 1990). The illusion of authenticity relies on the stabilising structures of binary oppositions between sex, gender and sexuality. Queer frames can be problematic to a degree in their tendency to over-theorise (other peoples') lived experiences in set vocabularies (Butler, 1990, 2005) which question the authenticity claims of the identities participants (or the groups under discussion) declare. Embodied experiences can therefore be overlooked (Nagoshi & Brzury, 2010), and this is really an anti-identity framework which in its disruptive nature can actually upset those who have long struggled to claim a 'true male core' or other core self for example. Queer accounts (including those by Butler, Hsu and Rubin) are less invested in embodiment of people with intersex variations or people with intersex variations' rights and experiences, as in the theoretical function of 'intersex' as a concept in disrupting sex normativity. Butler (1990) discusses the enforced surgery and gender socialisation of David Reimer as female in an effort to understand gender reappropriation, whom she casts as intersex although he is more accurately a male victim of medical cover-up and experimentation. Hsu (2011) considers how the intersex character Cal (of *Middlesex*) navigates Greek and intersex identities using the fiction of being a hermaphrodite (and associated Greek myths) as a disruption to norms of gender and Greek identities. Rubin (2012) traces a genealogy of intersex issues' historically pivotal role in the development of gender as a concept in twentieth-century American biomedicine, feminism, and their globalising circuits. Using a queer feminist science studies approach, Rubin argues that intersex has been and remains central to the history of gender as a classificatory schema, and that the concept of intersex paradoxically preceded and inaugurated sex/gender distinction. Focussing on John Money's biomedical research, Rubin shows that Money used the concept of gender as being distinct from biological sex in his work to cover the biological instability of the body evident in his research on people with intersex variations, allowing Money to account for how the social normalisation of sex roles can overcome physiological differences. Overall, people with intersex variations are not cast as disordered; Queer Theory (particularly Katrina Roen's work on intersex issues in clinical texts; Roen, 2008) shows the concept of sex itself requires 'others' to affirm its ideals and is therefore in itself a *disordering system* or (in the work of Dreger, 1998) *a discursive invention*. People with intersex variations are simply seen as people, who are interpreted as re-appropriating sex or gender performativity, in ways that are no less or more authentic than people who are not intersex. They show that sex identity is inconsistent, fluid or somehow alternative to established norms. Research shows how intersex bodies erase, reappropriate or overplay traditional notions of sex and development, traditional expectations for gender or desire-based sexual identities.

Crip Theory

Crip theory pushes for more complexified spaces and perspectives (particularly in theory work, but also in activism) in the interests of people with disabilities (sometimes called crippled or crip in a reclaiming of words used as insults against this group) (McRuer, 2006; Schalk, 2013). It embraces physical, mental and emotional diversity in a more actively subversive manner than disability studies that deconstructs able-ist norms and divisions between people who are and are not disabled. Whilst it has a contesting relationship to disability studies and identity, it does not seek to dematerialize disability identity (McRuer, 2006, p. 35). Crip draws on some premises from Queer Theory (Kafer, 2013; McRuer, 2006; Sandahl, 2003; Schalk, 2013). Sandahl (2003) points to how crip (like queer) is not only a noun and adjective, but also a verb: to 'crip' means to spin 'mainstream representations or practices to reveal able-bodied assumptions and exclusionary effects [...to] expose the arbitrary delineation between normal and defective and the negative social ramifications of attempts to homogenize humanity' (p. 37). Crip can therefore also be understood as a specific form of disidentification with the able-bodied world potentially taken up by both disabled and nondisabled people (Sandahl, 2003), as a critique of the hegemonic expectation of able-bodied perspectives and as an expression of the ways their bodies/identities blur the boundaries of social expectations of ability and disability (Schalk, 2013). Crip affiliation can thus include those without a 'medically acceptable, doctor-provided, and insurer-approved' diagnosis for their symptoms and, 'people identifying with disability and lacking not only a diagnosis but any 'symptoms' of impairment' (Kafer, 2013, pp. 12-13). McRuer (2006) emphasises the need to be specific about nondisabled peoples' dis-identification with able-bodied hegemony for theoretical and political purposes (p. 37). This approach may actively question false distinctions between 'normal' and 'crip', finding what is normative about disability and what is disabling about normalcy. It seeks to challenge society to rethink disability as a concept – accepting that disability is not something that defines a small group of outsiders, but something any person can experience whether temporarily or permanently in their lifetime in inconsistent and variable ways (not limited to being a hardship, an inspiration or any of other dominant representations of disability). It may actively embrace or consider alternate cultural models for disability and people with disability in order to subvert or challenge dominant notions of disability. McRuer (2006) understands ability as akin to sexuality; able-bodiedness and heterosexuality are made compulsory in cultural hegemony, yet both can never fully be realised. He critiques mainstream representations of disability in liberal entertainments which purport to celebrate difference (to a degree), but ultimately contribute to its stigmatisation through idealising an individual's 'recovery' from crisis through personal epiphany and effort, and a loss of crip status. People with intersex variations can be constructed as part of the umbrella of marginalized 'crip' identities to be advocated for, celebrated in terms of body acceptance and autonomy and made visible in the public eye. Related research on people with intersex variations might explore how they can erase, reappropriate or overplay traditional understandings of disorder and normalcy in their everyday lives or activism. It may investigate the multifarious identities for people with intersex variations found in various cultures that offer people with intersex variations particular roles (India's Hijra, Native American group's two-spirit, and others), how people with intersex variations are represented in society, or how they construct themselves.

This Study's Framing

Given the contrasting theories around whether intersex identities are linked to brain chemistries or cultural context, and given that people with intersex variations may view themselves or their identities in queer, psychiatric, medical, biological or other terms (in their self-definition as people with intersex variations, sex disorders, conditions, or as fluid for example), the researcher wanted to keep this project 'open' to diversity. In the conservative, liberal and critical views there is tendency to absolutise differences between insiders and outsiders in group memberships (R. Young, 1997). In this study the researcher aimed to mediate this tendency; a relativism was adopted in which each individual's view, or each group's culture is true or valid in its own right but acknowledged as largely incommensurable with the understandings of others and outsiders (Bhabha, 1990; Jones, 2013b; R. Young, 1997). In many ways the project was organised around Critical Intersex Studies goals and methodologies: particularly casting key intersex community representatives as collaborators into the research design and reporting processes in a manner consistent with Critical Intersex thinking about research. Provision of both quantitative and qualitative data on issues reflecting the eight recommendations for nations' treatment of people with intersex variations issued by the Council of Europe (Agius, 2015) were key, and the study considered themes centrally important to intersex advocacy groups and political debates such as intersex Australians' experiences of 'normalising' treatments, counselling, peer support, medical classifications, identity papers, discrimination and services.

However, to ensure that a diverse range of intersex perspectives (beyond Critical visions) could manifest in the data to the level that they are reflected in Australian intersex populations, the project most strongly took a Post-modern/Post-structuralist view. It had a construction of 'intersex' as a fractured and discursively contested/constructed umbrella term at its heart, associated with a range of identities, with multiple meanings to multiple people (who experience or research it according to their particular framework/s of reference, and therefore understand it within their framework). It allowed for the way in which some participants may only have ever been exposed to, or construct themselves within, traditional or liberal medical discourses. Others might be influenced by Queer thinking in terms of rejecting binary sex entirely, and/or by various discourses on disabilities. The perspective taken incorporated a degree of pragmatic pluralism – accepting that whilst there are distinctions in how people with intersex variations view themselves or are viewed, these differences can (and do) speak to and influence each-other in practice to an extent, borrowing from and adjusting other vocabularies with overlapping terms, new concepts or re-signified meanings (particularly around notions of gender identity and transition). Whilst there is no one truth to intersex identities but many frames experienced as truths in a more pluralist manner, relevant intercultural critiques that arise in the data are noted (Young 1996). Post-modern relativism is more useful in dealing with differences within sub-cultures than in comparative work across several different ethnic cultures in this way (R. Young, 1997). Thus, pluralism is used not in the 'vertical' sense (of treating questions as distinct in different domains of science, religion or the social for example), but in the 'horizontal' sense (acknowledging that there can be more than one correct account of how things are in any one given domain – particularly across social identifications), to oppose the type of relativism that eschews hierarchies of domains of knowledge (Baghramian, 2004). Where ordering is necessary, the views of people with intersex variations on intersex issues are always privileged in the hierarchy of conceptualisations, and the reference group team included people with intersex variations with different backgrounds who helped in conceptualisation of the study and all key stages of the study. Because of the interest of these individuals in Critical Intersex Studies and Activisms, critical themes of bodily autonomy and intervention impacts are areas of inquiry in the study; yet it was important to remain open-minded about the diverse views the participants might hold on such topics. For example, it was important to include people who might not identify as intersex despite accepting that they had been born with congenital variations in sex characteristics (perhaps having been told by a doctor they had a disorder/DSD); this had practical implications for how the study's key components were worded. The reference group had informed the researcher that some people might identify with intersex more as a political gender, queering act or even perhaps because they were transgender (some transgender people who see their mind as intersex for example); so indicators were supplied within the survey so the group could be treated as a distinct population without being further marginalised by exclusion.

The main critique of the post-modern position is that it offers no solutions to 'real world' problems (Callewaert, 2006; Frank, 1989).[*] Manfred Frank provides the key neo-structuralist critique of Foucault's assertion that there is nothing outside of discourse,[**] arguing that this critique suggests there is no true reality and offers only chaos (Frank, 1989, pp. 183-184). Frank further contends that assembling orders of discourse (through analysis) is

---

[*] Examples of these problems (given in critique of the paradigm) are class- and sex-based struggles.

[**] Central to critiques reliant on universal structures, for example, Marxist and radical feminist criticisms.

an attack on order that favours disorder, making post-modernists 'against everything' such that their critiques of dominant powers are valueless (Frank, 1989, pp. 184-187). Yet such critique misunderstands that while post-modernism rejects a single 'true reality' beyond discourse, it doesn't theorise *any* exteriority to the discursive orders to constitute Frank's 'chaos'. In addition, while all discourses are indeed partial, some are nevertheless more useful (or less problematic) than others. The existing social orders of the discursive field are not conceived in this study as entirely extinguishable, but certainly changeable and it was important to see what words and perspectives people with intersex variations themselves found useful. Thus, directions for stakeholders around future re-ordering *can* have value and this book includes practical recommendations for a range of institutions and service practitioners, based on people with intersex variations' perspectives and experiences. Critical elements of the project foregrounded the need to consider how the study could be useful to the people with intersex variations at its heart. The research was therefore pitched towards inquiring into areas around the general affirming spirit of recent critical changes in legislation and policy, with a focus on specifying any particular needs of the group, in the fields of health, education, and other social support service areas. The project was also aimed at supporting the social justice interests of research participants, as well as their determination in their own cultural representation. The incorporation of real-world intersex activists onto the study's reference team as advisors with an investment in, but also an appropriate distance from, the actual conducting of the research was an important step in achieving a project that could conceivably support such outcomes at every stage. This project was therefore conducted:

- towards amplifying the visibility, stories and perspectives of diverse people with intersex variations or those born with various congenital differences in sex traits/characteristics (but without the requirement of individual visibility/or 'outing' of individuals who participate);
- towards redressing large-scale quantitative and qualitative research lacks for people with intersex variations or those with congenital sex variations which allow them to define themselves and describe their own experiences of health and services and social conditions in their own terms; and
- towards informing future advocacy for diverse people with intersex variations' needs.

2. Designing a Study on, with and for People with Intersex Variations

> *This research survey was actually the best I have ever filled out. I liked the questions and even though some things were hard to talk about, it meant the world to me that finally there is somewhere I can talk about them and have my voice heard. I hope you do another one.*

Jane, intersex female with Partial Androgen Insensitivity Syndrome, 24yrs

> *I like that this study did not see me as a body first, but as someone with opinions and ideas on my body. Usually researchers are very curious about my body and want to see it and write about it, as if they forget I am in it.*

Peter, male with an intersex variation/DSD/Leydig Cell Hypoplasia/
Micropenis/Cryptorchidism, 41yrs

http://dx.doi.org/10.11647/OBP.0089.02

Key Points

- 272 people with intersex variations participated in the '*Australians born with Congenital Variations in Sex Characteristics (Intersex/DSD/ hormonal, chromosomal or other biological variations/conditions)'* project.
- Participants ranged in age from 16-85+, with the average age 36.
- All Australian states were proportionately represented in the study, and 4% of these participants were Aboriginal or Torres Strait Islander. One fifth of participants lived internationally.
- 52% of the participants were allocated a female sex at birth, 41% male, 2% X, 2% unsure and 4% another option.
- 27% had disabilities.
- 74% of the group had no religious affiliation.

Reference Group

Australians with congenital variations in sex characteristics have historically been a difficult group to reach out to and research, due to issues of visibility and a past lack of widely known social support groups and services for the full diverse range of people with intersex variations. However, the increased networking amongst people with intersex variations in the contemporary context facilitated several opportunities to reach out to people in this demographic, which were essential for developing the field away from its history of medical research done 'to' this group, and towards social research done 'with and for' this group. Such collaborative work may now be essential to progress in Intersex Studies. This has been recognised to a degree in a recommendation for collaborative research on intersex rights issues made by the Council of Europe (Agius, 2015), but could perhaps be more broadly applied to all new research in the field. Opportunities for the researcher Dr Tiffany Jones to make contact with people with intersex variations to discuss her research project work abounded through the increased range of specifically intersex, LGBTI or syndrome/condition focussed social and support groups. However, it was notable that compared to previous studies on transgender and gay groups there were still not many services or group specific media for the researcher to source her reference group members from (magazines and even newspapers for transgender or gay people exist but no such media can be found for people with intersex variations where notices or adverts could be placed). There were also prospects for making contact through new media technologies and social networking sites to individual rights champions. To ensure that these opportunities were used respectfully, the researcher formed a small formal reference group of individual representatives from the intersex community and related organisations, guided by key advocates as to whom to include.

The lead researcher's original vision for this group's role was similar to the roles fulfilled by LGBTIQ and transgender specific reference groups she and various co-researchers had included for previous studies (Hillier et al., 2010; Jones, 2015; Jones et al., 2015; Smith et al., 2014). These reference groups would meet fairly regularly with one or more researchers, and advise the researchers on a broad ranges of matters. These ranged from the name of the study, through to the development of questions, the best and most respectful ways to approach and recruit from the community, and key decisions in reporting. Together we discussed the importance of increasing 'a sense of intersex ownership' of the research, and acknowledging this intersex ownership through allocating the reference group a co-authorship status on the main report of the data. This became something the lead researcher increasingly understood as the ideal for research collaboration with people with intersex variations, as a group whose perspectives on findings and key issues (even how they are 'named as a group') are largely ignored by many key researchers. Thus, to elevate their status in the project and recognise their effort in advising on her first drafts of some key documents, the lead researcher agreed to consider the reference group as community collaborators for the project on the basis of the meetings and emails they had shared. However ethically, the researcher had to ensure that the community members had no access to raw data from the project, and no role at all in collection or analysis of data (the actual 'conducting of research') or its initial writing up beyond advising on the researcher's work. This was appropriate to the ethical approvals the researcher had agreed to under her university's Human Research Ethics Committee, to her protection of and respect for participants' privacy, and to ensuring all findings and conclusions drawn were research-based. Dr Jayne Lucke of ARCSHS and William Leonard of GLHV were also on the researcher's team, and also read over and contributed to the drafts and advised on various aspects of the work in ways equally integral to the success of this project.

Overall Approach

The research project used an emancipatory approach – aiming to conduct research on, with and for the Australians with congenital variations in sex characteristics community. It was aimed at serving social justice goals for the community (rather than simply to generate knowledge for its own sake). The reference group was particularly helpful in discussing the researcher's initial literature review work into what those goals might be. The project was particularly geared towards topics relevant to legislative and policy advocacy that have emerged locally and internationally in recent years, and envisioning service and resource needs for the community.

Data Collection Tool

An online survey was used to collect the data. The survey questionnaire contained both forced-choice (quantitative) and open-ended (qualitative) questions developed by the researcher and advised on by the reference group, through many drafting and redrafting sessions held in late 2014 and early 2015. The choice to use a survey was informed by the lack of large-scale qualitative and quantitative data identified in the literature review, and also to allow a sociological method that contrasted to the pathologising nature of many in-person clinical studies which have historically often involved physical examination of the participants. Participants generally reported their appreciation for this method in the qualitative responses, illustrated by the two example quotes at the start of this chapter, and many others, for example Nora (intersex female with Complete Androgen Insensitivity Syndrome, 31yrs) commented, *'Doing this survey was a pleasant experience. I am glad people conducting research have moved on from clinical methods'*. The survey was mainly used to gather basic descriptive data on the demographics, identities, and experiences of participants in relation to their gender identity. This tool was specifically designed to be used and re-used for longer spaces of time as needed – completion times varied greatly. It was anonymous, and the responses were visible only to the participant and the researchers. The survey was hosted by Survey Monkey, which provides data formatting compatible with analysis programs such as SPSS. It had a Survey Monkey website URL that included the term 'ausvariations'.

There were 10 pages in the survey. It opened with '1. Participant Information and Consent', which allowed participants to consent to the study in full understanding of why the data would be collected and how it was intended to be used. The questions started with the '2. You and Your variation' page supplying more basic demographic questions about the individual, questions on their variation and its impacts, and any impacts experienced by relatives. Pages on '3. Your Early Years', '4. Your Experiences Now', and '5. How People Treat You' all followed, using second-person language to make the participant feel directly addressed and to enhance the sensation of their voice being heard on these primarily social and identification experiences. Sections on institutional engagements followed: '6. How Health, Education and Other Services Treat You' and '7. Your Employment Experiences'. Next came pages asking about more sensitive topics, which the survey built up to in order to increase participants' comfort and sense that they would be taken seriously: '8. Your Health and Mental Health' and '9. Sexuality, Relationships and Reproduction'. Finally, the survey ended on mainly positive topics that allowed the participants a say on key issues affecting them and which might encourage their sense of empowerment from engaging with the survey to some degree, '10. Community, Activism and Research'.

Terminology Use in the Study

Terminology is difficult in Intersex Studies, because some medical terms have historically been imposed on intersex groups without their consent, some social terms might appear 'too confronting' for closeted people with intersex variations to claim or may be misunderstood, or because people who identify as having a condition may not see themselves as intersex at all. The use of the criteria that participants have a 'congenital variation in sex characteristics' was carefully discussed with the reference group and was ultimately broadly conceived – this concept was used by the researcher as an *umbrella term* to cover a range of people who might come under this category (listed in the survey title, which repeatedly appeared on each page).

For example, the aim was to include those born as or who had an intersex variation, those who had been told by medical organisations that they had a Disorder of Sex Development (DSD) or perhaps even preferred that label to other options like intersex, those who had an intersex hormonal/chromosomal/genetic condition who might not normally see themselves as part of an 'intersex' or 'DSD' group but might relate to the idea of having a congenital variation more comfortably. This included a sub-set of people experiencing Poly Cystic Ovarian Syndrome (PCOS), who find that the condition impacts their sex characteristics, as this experience is constructed by some people with the syndrome as an intersex variation and this is particularly relevant where it involves androgen excess. Approximately three quarters of Americans diagnosed with PCOS experienced varying levels of hyperandrogenemia, for example (Huang et al., 2010), and anecdotal evidence suggested there were people online who felt it was certainly an intersex condition in their personal experiences of it (related to their physical androgynous bodily presentation, growth of extra body hair, for example). The survey also allowed for the inclusion of people with intersex variations who later discovered that they were also technically transgender (or vice versa).

The researcher made the carefully considered decision to allow a distinct space within the survey for people who were solely transgender, but understood their transgender nature as having physical origins, by providing them options to identify themselves as transgender in the survey and ensuring that their issues could then be treated as distinct from people with intersex variations', where they did not have a specific congenital variation as such. Having previously studied various transgender groups she was aware of the potential impacts of exclusionary research tools and wished to treat such individuals in a supportive and non-marginalising way (e.g. she avoided 'kicking people off' of the survey as they filled it out through an automated setting, allowing all people to fill it out); however, as purely transgender individuals had different experiences to people with intersex variations on issues such as their physicality, their views on surgeries and other key topics of interest, *only transgender individuals who did have actual congenital variations in their sex characteristics were directly included in the intersex group.* Data from transgender-only participants were separated out from the intersex group to be reported elsewhere and does not feature in this publication.

Within the questionnaire body parts are sometimes denoted interchangeably. For example, the researcher used 'vagina/front hole' in the section on sexuality. This was done in awareness that different individuals might experience a body part in different ways related to gender identity. This sort of language use was achieved on advice of past individual participants of previous studies (Jones et al., 2015). This was done to support the varying framings of bodies accessed by people with congenital variations in sex characteristics, and include both participants who were more, or less, exposed to such terms through supplying alternatives and (at times) definitions when needed.

Ethical considerations

Ethical approval was obtained for this project from the University of New England Human Research Ethics Committee. The first ethical consideration for this research (and perhaps this will be important for some other new works in this field) was around ensuring intersex ownership of intersex research. This consideration was met by the lead researcher initially contacting and meeting with the intersex reference group as one of her very first steps made towards running this project after initial literature review and survey design brainstorming, and then ensuring the reference group were centrally involved in a collaborative dynamic throughout the project's development and the report's final drafting. Various reference group members are Australians with congenital variations in their sex characteristics, and each experiences quite a different variation, and has had a unique journey in that regard. The reference group includes people who are male, female, and have either experienced or not experienced formal gender transitions. Contact was also made with a range of other networks and representatives to aid development stages for the survey, to increase participant ownership of their own representation and ensure data was collected which would be beneficial to the participants' goals more broadly.

Related to this issue of ownership and usefulness, an important ethical consideration was the level of freedom and control participants would have in engaging with the study. All participants had the right not to answer any (or all) questions in the survey, the right to withdraw, and the ability to comment on questions or advise the researchers on their wording and so on. The participants also enjoyed opportunities to suggest alternative lines of questioning or topics they felt should be discussed (at the end of the study, in the final question on future research). Many participants utilised the opportunity to make suggestions about how they should/could be researched in future. All participants were also asked about terms they accepted being used about themselves, in the questions about how they preferred their identity being constructed – the individual's own selected or written-in words were used when they were quoted in this report so that their stories and identities could individually be received in terms with which they were comfortable.

Another key consideration was the protection of all participants from experiencing difficulties in the process of completing the survey, particularly around the mental health questions and the reflections on what could have been difficult life periods. It was essential to be respectful in the wording of questions, and the details of key support services were provided through the survey (including at the start and end). The researcher also protected all participants from abusive responses by ensuring the research data was thoroughly cleansed, and that no participant could see other participants' responses.

The younger participants (aged 16-17) were not required to seek parental approval for their participation in the study. This decision was made in recognition of the lack of support – and sometimes discrimination and abuse – that anecdotal evidence suggested some young people with congenital variations in sex characteristics experience in the home. The researcher felt it would be irresponsible to require young people to have to disclose their wish to participate given that their variation may have been a cause of tension or arguments in their household, for example (perhaps about their willingness to identify as a certain sex, their refusal to engage in a medical procedure or many other possibilities). Therefore, she ensured the design of the study considered these participants' vulnerability and capacity to give consent, and provided clear information about the research. The young people however, are forced in their everyday lives to deal with many issues adults do, and it was therefore essential to include them in the study. This was especially so considering the likelihood they had experienced some interventions in their infancy or recent childhood, or could currently be going through experiences now in their schooling or family life for which the research might indicate some kind of support could be needed. As an expert on youth issues, the lead researcher was careful to include phone numbers and online links to youth-friendly support services and to ensure that young people were well treated by the survey tool.

Sampling

The target group was people with congenital variations in sex characteristics aged 16 and over. Participants needed to self-select to be part of the research. Where in the past research in this field has seen methods of sampling restricted to access to small databases through diagnostic channels (Warne et al., 2005), and this has been regarded as to some extent 'reliable' within that frame's understanding of people/patients, this would be an approach which would bias the survey towards those who were engaged with medical institutions or to those who had a certain set of more positively framed responses to their (ongoing) medical experiences. The intention was to attract these participants but also a broader range of participants (including both those who engage and do not engage with medical institutions, and those who might actively resist medical studies). The researcher actively endeavoured to include people from all states and territories of Australia and those living internationally, and from a range of intersex networks, DSD networks, LGBTIQ networks, disability networks, genetic networks and condition-specific groupings. Both the researcher and the reference group promoted the study with groups with diverse understandings of what the variations mean in relation to identity (e.g. both groups affirming of intersex identity, and groups not modelled around the concept of intersex specifically but considering the variation in terms of a disorder). Furthermore, the study was promoted to groups focussed on diverse goals – political progress, social support, medical or genetic themes, outreach and so on.

Study Title, Concept and Logo

In celebration of the variety of people who might participate in the survey and in consideration of their likely variable uses of the multiple key related identity terms or medical concepts under exploration, the study was named *Australians Born with Congenital Variations in Sex Characteristics (Intersex/hormonal, chromosomal or other biological variations/conditions)*. This name was also used for its inclusivity, its interchangeability of terms, and its descriptive nature. The term DSD was ultimately not included in the title after broader community feedback against the term as offensive. There were several ideas for the logo, but to avoid using the stereotypical medical or gendered imagery often used in relation to intersex themes, eventually the reference group argued that the most appropriate image was simply the UNE university logo which affirmed that this was a university-based study (Figure 2.1).

une
University of
New England

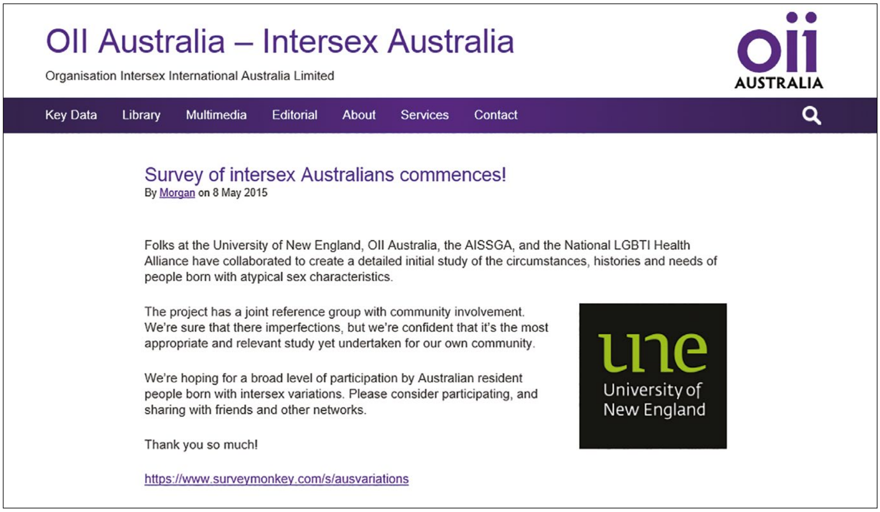
Figure 2.1: The Variations logo

Recruitment and promotion

The survey was opened in May 2015, when active recruitment began. It was closed at the end of June 2015, after a total of two months. A range of media was used to promote the project: intersex Groups/Networks/Services, mainstream/GLBTIQ/transgender media (print, electronic and radio), social networking sites, websites, e-lists, emails, gender clinics, rights groups, individual advocates and rights champions, and word-of-mouth.

Press Release/Media

A press release describing the project was designed by UNE marketing staff and sent out to key mainstream and alternative media, including print and radio. The project was featured in several print news stories, special features in magazines and live radio interviews. OII Australia also released a statement on its website.



OII Australia – Intersex Australia

Organisation Intersex International Australia Limited

Survey of intersex Australians commences!

By Morgan on 8 May 2015

Folks at the University of New England, OII Australia, the AISSGA, and the National LGBTI Health Alliance have collaborated to create a detailed initial study of the circumstances, histories and needs of people born with atypical sex characteristics.

The project has a joint reference group with community involvement. We're sure that there imperfections, but we're confident that it's the most appropriate and relevant study yet undertaken for our own community.

We're hoping for a broad level of participation by Australian resident people born with intersex variations. Please consider participating, and sharing with friends and other networks.

Thank you so much!

https://www.surveymonkey.com/s/ausvariations

Figure 2.2: The survey announced on the OII website

Internet, E-Lists, Networking

Some key Australian genetic and intersex groups (and related transgender, genderqueer and other GLBTIQ groups) organise their contact online through websites and e-lists. It was therefore important that recruitment processes developed new online contacts to increase the potential reach of the survey. The researchers constructed information about the project that could be sent to groups, and then emailed and called people running these groups, sites and lists. This information was widely disseminated throughout the contacts of these groups and networks. For example, OII Australia, AISSGA, National LGBTI Health Alliance, the Turner Syndrome Association of Australia, The Genetic Network of Victoria, YGender, The Freedom Centre, Intersex United and many others gave the project wonderful support.

genetic support network of victoria
*empowering * connecting * supporting*

RESEARCH

Survey for Australians born with congenital variations in sex characteristics

University of New England researchers are conducting a survey of Australians born with congenital variations in sex characteristics (Intersex/DSD/hormonal, chromosomal or other biological variations/conditions).

Some terms with which you might have heard used to describe these variations are: Intersex, DSD/Disorder of Sex Development/Diverse Sex Development, atypical reproductive or sex development condition or variation whether hormonal, chromosomal, or otherwise biological (e.g. CAIS, Klinefelters, Turners, PCOS and many others).

This project has been developed under the advice of a Reference Group including Morgan Carpenter of Organisation Intersex International (OII) Australia; Bonnie Hart of The Androgen Insensitivity Syndrome (AIS) Support Group Australia, and Dr. Gávi Ansara of the National LGBTI Health Alliance.

If you are interested in sharing your experiences of health, education and social supports, please see the survey's first page which goes into detail about the survey and what it involves, and how this data will be used.

See: **www.surveymonkey.com/s/ausvariations** ■

Call for adult participants – Genetic basis of stuttering project

The Murdoch Childrens Research Institute and The Royal Children's Hospital are conducting a project to help understand the relationship between genes and stuttering.

Who can take part?

We are looking for adults aged 18 years and above who have never stuttered. We are interested in people who use English as their primary language and who have not been diagnosed with a neurological disorder.

What is involved?

In order to participate, we will ask you to complete the following:

- Have a five minute conversation with one of our researchers.
- Provide a sample of your saliva so that we can study your DNA to see whether there are common genes that influence the risk of stuttering.

Figure 2.3: The survey advertised through the GSNV newsletter

Social Networking Sites

Due to the popularity of social networking as means for sharing information and facilitating community contact on genetic issues, intersex activism, DSD diagnoses and so on, the researcher circulated posts on the project through online pages, sites and groups. The pages of OII Australia, AISSGA, National LGBTI Health Alliance, the Turner Syndrome Association of Australia, The Genetic Network of Victoria, YGender, The Freedom Centre, Intersex United and many others featured posts on the study. General Facebook advertisements were made to all Australians aged 16+, and this was a dominant recruitment strategy. However, smaller more specific campaigns were targeted at Australians with interests in the following topics in order to ensure people of varying kinds had opportunities to participate: intersex, DSDs, congenital disorders, disability, androgyny, PCOS, androgen insensitivity, Klinefelter's and related interests.

Paid Advertisements

The survey was advertised through paid advertisements on social media such as Facebook, both to the general Australian population aged over 16, and specifically to people who had 'liked' or 'joined' a very select range of topics/groups/pages. This included for example targeting people in Australia who liked the word 'intersex', 'DSD', 'AIS', 'CAH', 'XXY' or similar, for example – showing the advertisement (see Figure 2.4) in the right hand column of their social media page (to their eyes only) and giving them the choice to click on the ad or ignore it. This meant some paid advertising campaigns were quite targeted, whilst others were very broad.

AUSSIE INTERSEX SURVEY
surveymonkey.com
Age 16+ with biological variations in your sex characteristics? Have a say: do the survey!

Figure 2.4: Survey advertisement on the Facebook website

Members-only Online Forums and Groups

Local Australian and international online intersex groups and discussion-boards can be extremely secretive and difficult to enter, based on a strong valuing of privacy and protection from discrimination within these communities. The researchers were able to access these groups either through existing memberships or through joining the groups 'as a researcher' to post the details and links to the survey. These groups included the intersex forum on Laura's Playground, XXY/Klinefelters Groups, PCOS support Groups and many others. The team sought to abide by the rules of such groups and check with any moderators if and where on such sites research-related posting was allowed, before proceeding with any posts about the survey.

Data analysis

Final data were downloaded from the Survey Monkey site and then transposed into quantitative (SPSS v10) and qualitative (Leximancer, Excel) computer programs. The data were screened and cleansed, those participant surveys that did not fit the target group were excluded (the many people who had done the survey by mistake or out of curiosity, abusive attempts and so on). Descriptive and comparative statistical analyses were undertaken for the participants with intersex variations, and grounded thematic analyses of their written responses. Statistical tests are not reported on here but will be available in forthcoming peer-reviewed publications. The journeys of many participants are also displayed within this report.

3. Basic Demographics for People with Intersex Variations

> *I am unsure if family members share my condition. I do not think so, I was called 1 in a million, but perhaps they say it can be the genes. I live with my partner, I married a man. Over 50 years together, we always have dinner together at the table and we never go to sleep without saying I love you. I am sterile, with osteoporosis. I lost my teeth young and they were replaced with dentures. We adopted children. We told them when they were old enough to know about being adopted and how bodies work, and how my body worked. I was nervous. They took it all in their stride and did not worry as much as I thought they would. We are now grandparents, and some of our grandkids know and ask questions, they think it makes me special. There were stories (on intersex people) in the newspapers in the last few years, our sons showed us. It was hard to believe how things have changed for the better. There was nothing like that when I was going through it and I would have treasured that opportunity, now I have my own family so I am not alone.*

Anne, intersex woman with Ovo-testes and XXY/47 karyotype, 87yrs

> *I was initially raised as male despite having lower than normal 5.5 free testosterone level and XXY chromosomes, and my parents tried to masculine me. I had hormone replacement therapy during adolescence and adulthood. However, I could not reliably live as a man the further I progressed into adulthood, and since transitioned to female. After being forced to divorce, I lost my mortgaged home and have spent months being homeless. I am estranged from family. I couch surf.*

Elaine, trans intersex woman with Klinefelter's Syndrome, 31yrs

http://dx.doi.org/10.11647/OBP.0089.03

Key Findings

- 272 people with intersex variations participated in the '*Australians born with Congenital Variations in Sex Characteristics (Intersex/DSD/ hormonal, chromosomal or other biological variations/conditions)*' project.
- Participants ranged in age from 16-85+, with the average age 36.
- All Australian states were proportionately represented in the study, and 4% of these participants were Aboriginal or Torres Strait Islander. One fifth of participants lived internationally.
- 52% of the participants were allocated a female sex at birth, 41% male, 2% X, 2% unsure and 4% another option.
- 27% had disabilities.
- 74% of the group had no religious affiliation.

Number of Participants

While many people (over 300) responded to this first national survey of Australians with intersex variations, those who did not fit the criteria were removed from the study. The criteria included age (16+), and having congenital variations in sex characteristics. A group of 16 transgender people who did not have an intersex variation were necessarily treated as a distinct group in terms of physical status and social experiences and views, and so have been reported on in other community disseminations outside of this book to allow their stories to be told and their identifications to be better understood. This left us with 272 participants who did report having intersex variations;[*] the largest group in a Southern Hemisphere study to date.

Age

The 272 survey participants with intersex variations represented a diverse range of age groups. The youngest were 16, the oldest was 87. Whilst the majority of participants were under 40, the average age was 36. This is older than the few participants with intersex variations in the Australian

---

[*] These participants' responses (how they described their bodies and so on) were considered 'consistent with' having the intersex variations reported. Some had intersex variations *and* were transgender.

diverse youth study *Writing Themselves in 3* (Hillier et al., 2010; Jones & Hillier, 2013) and just slightly older on average than the 3% of participants who were intersex in a study of FtM transgender people (Jones et al., 2015). It is noteworthy that there were no 'statistically significant' comparative findings when the group was divided into various age-based groupings.

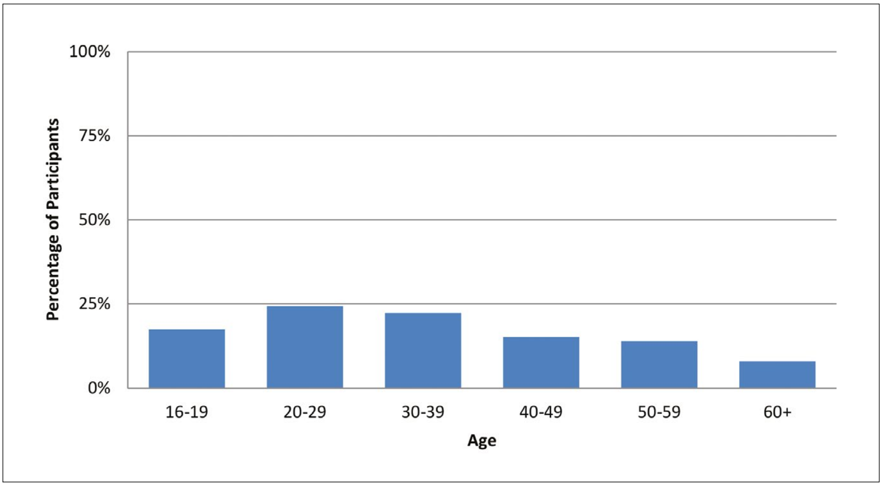


Figure 3.1: Age of participants (n=272)

State/Territory

The participants were asked their location. The majority (79%) were based in Australia. These participants came from every state and territory in Australia, which was an achievement for the study given that it was widely accessing a group usually considered hard to access to the point where it has been difficult to include them in past research (Smith et al., 2014). Efforts were made to recruit Australian respondents in proportion to the general population of each Australian state and territory, and Figure 3.2 shows that this was generally achieved in proportion to the broader Australian population (Australian Bureau of Statistics, 2012c), with slightly lower representation from Western Australia and slightly higher from the two territories. Of the Australian participants most came from the three most populated states New South Wales (32%), Victoria (21%) and Queensland (18%). There were also participants from Western Australia (6%), South Australia (10%), Tasmania (2%), the Australian Capital Territory (5%) and Northern Territory (4%). The proportionate distribution of people with intersex variations is similar to that of same sex attracted and gender diverse young people (Hillier et al., 2010; Jones & Hillier, 2013); however, it differs from transgender adults who tend to move in greater numbers to states like Victoria and New South Wales due to their superior provision of services to transgender people (Jones et al., 2015). The data for people with intersex variations thus showed no trend towards 'moving for services', including as adults.

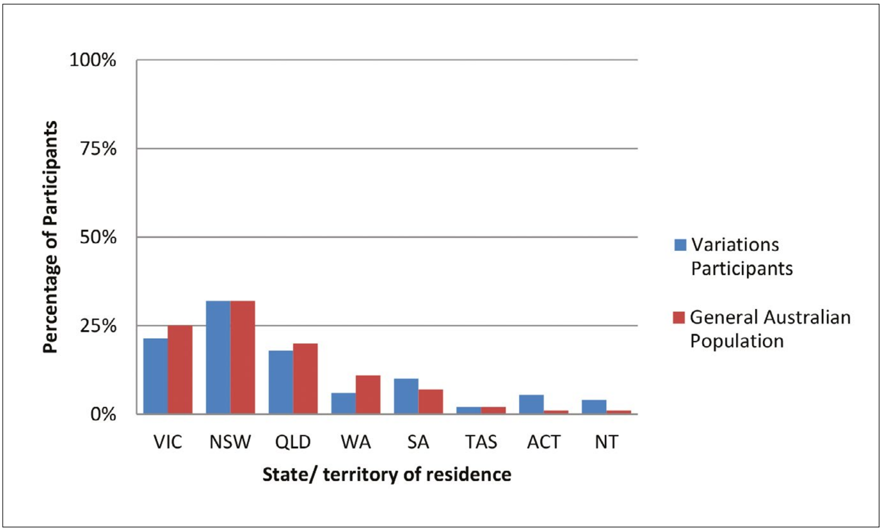


Figure 3.2: Residence of *Variations* participants (n=272) compared to the general Australian population (n=22,906,400)*

In addition to the Australian survey participants, around one fifth of the participants overall were living in another location outside of Australia. Most commonly these internationally-based participants came from the United States of America (including 31 people from a range of states for example California, Colorado, Florida, Indiana, Kentucky, New Jersey, Oregon, Virginia and Washington), England (7), Canada (3) and New Zealand (2). There were also individual participants based in a range of nations including Austria, China, France, Germany, Greece, Italy, the Maldives, Scotland and Sweden. It is noteworthy that there were no 'statistically significant' comparative findings when the group was divided into Australian and international groupings.

---

* As reported by the ABS (2012).

Aboriginal and Torres Strait Islander Descent

The survey was promoted through Aboriginal and Torres Strait Islander networks, including for example Sistergirls & Brotherboys Australia. Overall, 4% of people with intersex variations in the study were of Australian Aboriginal and Torres Strait Islander descent. These participants ranged in age from 17 to over 85, and there were no distinct trends in the data for these participants as a sub-group that distinguished them otherwise from the other participants.

Sex Marker Assigned at Birth

The majority of the respondents were assigned a female/'F' sex (52%) or male/M' sex (41%) at birth. Thus, the majority of people with intersex variations do not class themselves as a kind of 'third sex'. However, 2% of participants responded that they were allocated 'X', 2% were unsure, and 4% were allocated another option. Amongst the latter group, some people were assigned a sex or a substitute marker of some kind only after a period of delay. For example, Ashley (intersex individual, with bladder exstrophy/Klinefelter's/ovo-testes, 53yrs) was ultimately given an 'undetermined sex' and Duane (male with a micropenis and bladder exstrophy, 32yrs) said 'I was gender tested at birth before I was announced as male'. Kelly (intersex individual with Classic CAH, 63yrs) said their sex was 'not assigned because of a mix up and living in a small rural community; I was assigned M several years later'.

There were also people who explained that their assignations had been changed from one sex to another whilst they were still babies, such as Peter (male with an intersex variation/DSD/Leydig Cell Hypoplasia/Micropenis/Cryptorchidism, 41yrs) who was assigned 'female, and shortly after male' and Frank (male with intersex variation micropenis from Progestin Induced Virilisation, 34yrs) who was 'initially assigned male, revised to female'. A few individuals explained that they had experienced difficulties in uncovering the documentation around their sex allocation at birth. Tessa (intersex woman with clitoromegaly and ovo-testes, 19yrs) said 'I was adopted, so I have no birth certificate. I'd assume I'd be X'. Dana (woman with XXXY chromosomes, 45yrs) had a particularly rare karyotype, which may have been a result of absorbing 'a small percentage of my fraternal twin that didn't make it'. She reported her suspicions that medical practitioners had actively hidden her allocated birth sex in attempts to subsequently cast her as male had been confirmed, saying: 'I was unable to unseal the record until recently; initially, I was gendered female, then they sealed that and made it look as if no previous record had existed. I have now been able to get the original with the original registration date reinstated'.

Sex Marker Used Now

The participants were asked which sex/sex marker they applied now. The majority of the respondents were female/'F' (52%) or male/'M' (23%). Many of the people in the female or male sex marker group generally lived their lives as women or men with relatively little attention to/mention of their intersex variation. Bianca (female with 47/XXY/micropenis/cryptochidism, 52yrs) was typical of this group in that she was assigned and lived comfortably in all aspects of her life as female, saying, 'for all my needs I am female, except my gyno, she knows the condition, but there is no need to talk about it otherwise'. However, there were also people in the female or male sex marker group who saw themselves more clearly as 'an intersex man/an intersex woman' and for whom having a variation was perhaps a bigger part of their daily experience of being male or female. For example, Kennedy (non-binary intersex female with Classic CAH, 17yrs) used a female sex marker/pronouns but felt being intersex made her daily experience of being a girl different, 'My body does not produce cortisol and aldosterone, but overproduces male sex hormone. This means, as a girl, I have masculinised genitals. And really I feel sort of not completely female'.

It was noteworthy that a higher portion of people with intersex variations were/used sex markers outside the male-female binary than had been assigned these at birth; 7% of participants responded that they were 'X', 6% were unsure, and 12% used another option. Figure 3.3 shows the variance between sex markers assigned at birth and used now, and the distinct drop in a use of male/'M' compared to these alternative options. There was no 'typical story' for individuals who had moved from a male assignation or who used one or more of the other options. In one example Alex (intersex individual with Hypospadias/Cryptorchidism, 58yrs) used 'intersex' having been raised female and having used male terms for a time, saying, 'I used to use Male/man/Mr, but didn't like it'. In another example Jamie (X intersex individual with CAH/21 hydroxalase deficiency, 39yrs) recalled how they were raised male but came to frame themselves as 'X' and intersex due to both their anatomical difference and inconsistent gender identity:

> *I always knew my genitals were different, my family knew something was different about me as well, I recall them talking about me saying I was a girl around my mother and a boy around my father, at age five I was beaten by my stepmom with a cat food can as she screamed at me asking if I wanted to be a boy or a girl, there were other instances as well. At age 19, I discovered during a self-exploration what I now know to be my vagina, which is virilised. Until my adrenal crisis, I figured it was a fluke, like double-jointedness. I didn't know what it was until I had adrenal fatigue a few years back which almost killed me, and still endangers me greatly. The disease has affected me in every area of my life, making socializing so awkward and uncomfortable I avoid contact with people as much as I can. After my adrenal crisis, my testosterone levels dropped and my ovaries began to 'wake up' and I realized after some time the implications of this.*

More rarely, a few individuals said they did not select or use a sex marker at all, and a few individuals selected multiple sex markers as the preferred sex marker they used now (such as both 'F' and 'X', for example). This showed that medical assumptions of a simplistic sex allocation by intersex variation (the assumption that a person with CAH is usually female, a person with Klinefelter's male) or the belief that sex allocation is always necessarily stable, do need to be questioned, perhaps even further than seen in previous studies (such as the more tentative challenges to sex allocation by variation offered by Herlihy & Gillam, 2011).

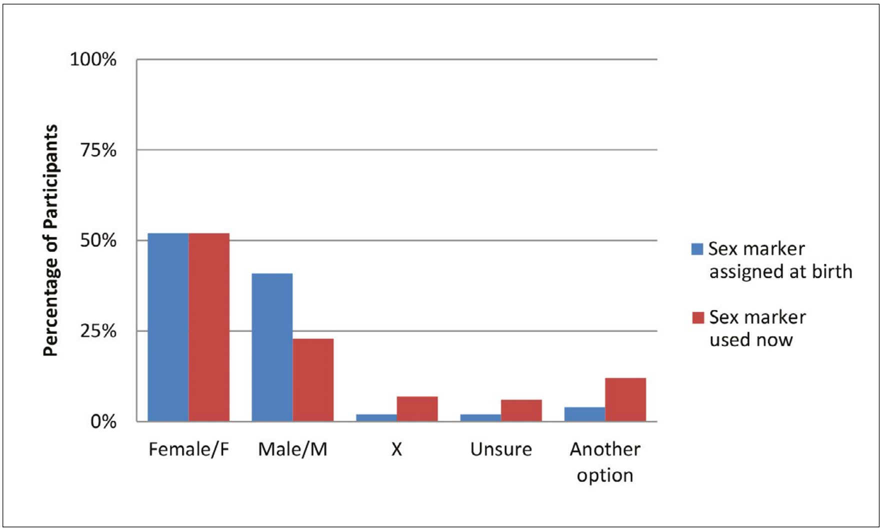


Figure 3.3: Comparison of people with intersex variations' sex marker assigned at birth and used now

Transgender Status

The large majority of participants with intersex variations were not transgender. There were however 23 people with intersex variations (8%) who had identified themselves as being transgender, which would appear to be around the lower end of the range found in other research (Sampaio Furtado et al., 2012). However, there were differences in the way questions were asked in this study which did not frame transgender status as inherently a pathology. Most of these individuals had transitioned from male to female or non-binary/genderqueer, and some from female to male or non-binary/genderqueer identities. Evelyn (trans woman with PAIS, 59yrs) had been assigned male at birth and said that she had transitioned to female at 23yrs of age through hormone therapy:

> *I was born in 1956 and assigned as male on birth certificate. I have a small penis/ enlarged clitoris, urethra at female position, vagina behind fused labia that appear as an empty scrotum, intra-abdominal gonads. Breast nipples have always been more feminine since childhood. I was very hairy as a boy. I did not go through puberty (at least to say, puberty came late): I had no Adam's apply, my voice was feminine, I have feminine facial features, and I had no male musculature. I started oestrogen in 1979; my body hair feminised within a few years – all body hair is gone. Breast size is now 'C'. Oestrogen came too late to stop facial hair; that is gone via electrolysis. Endocrinologist originally doubted any possible feminisation, then commented how my body changed to the female body it would have been had I been 'born' female.*

Darren (trans man with intersex variations Clitoromegaly/Cryptorchidism/ Mosaicism and PCOS Hyperandrogenism, 49yrs) said counselling empowered him to live as male, and he did not feel he needed to engage in the many transition options available to most transgender people as people sometimes already see him as male when he grows his beard. He commented, 'outwardly I have a female looking body apart from facial hair which as a transman I now allow to be prominent'. It is also important to note that *some individuals with intersex variations had changed their sex markers over time or used multiple sex markers but did not identify themselves as being transgender*. As they did not use that frame, it would be inappropriate for the report to impose this upon their experiences; these people do to some extent contribute to the difference between the percentages of sex markers allocated to participants at birth and those they preferred to use now and may make this research in some ways more similar to international work. These people understood their change in sex marker more in terms of their story of having an intersex variation – as being about changing a mistakenly or intentionally allocated sex that *did not fit their biology and gender identity* (not just their gender identity, in the sense of being transgender).

Disability

The large majority of participants did not identify as having a disability – an important point to emphasise given the fact that people with intersex variations have been construed by some medical bodies as disabled/disordered on the basis of their bodily difference alone, and have sometimes more recently had to use disorder framings to access services. In total, 27% of the group identified themselves as having one or more disabilities. This was higher than the 17% of transgender people who reported having disabilities in a recent Australian study (Jones et al., 2015) and the 18.5% of the broader Australian population who have disabilities (Australian Bureau of Statistics, 2012d).

Approximately half of the disabilities described were physical in nature. These included, for example, being legally blind or colour blind, being mainly wheelchair-bound, bone degeneration, central diabetes insipidus or type 1 diabetes, epilepsy, fibromyalgia, glaucoma, hypothyroid, lupus, malformed kidney, motor skill development delay, movement impairments, osteoporosis-related bone density loss, scoliosis, Schurmann's disease and so on. Participants with Turner's Syndrome were particularly likely to discuss related issues with their legs and heart valve development malformation, participants with Kallman's Syndrome experienced anosmia (lack of a sense of smell and related to this, taste) and dental health issues, and a few individuals with 47/XXY discussed losing their teeth or poor dental health. Several individuals saw infertility related to their variation as a disability. A few individual participants with osteoporosis and bone degeneration suspected this was related to hormone therapies.

The remainder of the disabilities were mental/emotional/cognitive in nature. These included for example ADHD, anxiety, Asperger's syndrome, autism, bipolar disorder, borderline personality disorder, depression, gender dysphoria, PTSD, reactive detachment disorder and a range of learning disorders. Seven individuals diagnosed with disabilities said (or had been previously told) their intersex variation was a physical disability in itself (including 47XXY, CAH, CAIS Grade 7, Kallman's, Klinefelter's, PAIS and Turner's Syndrome XO) – whether they did so in a manner in keeping with Conservative notions of intersex status as a disability, or as more intentionally Post-modern subversions of 'able-bodied' identification and glorification, was unclear (due to the short answer nature of responses).

The overall resistance of people with intersex variations to doing so however perhaps explains the tensions around classifications of intersex diagnoses as disorders of sex development or otherwise, discussed in chapter one and referenced in the literature elsewhere (Ahmed et al., 2011; Davis, 2015; Hughes, 2008; L.-M. Liao & Simmonds, 2014). It suggests that the study's participants may have taken a largely Critical perspective on their framing of intersex status.

Living Arrangements

The participants were mostly living in relatively stable situations with their loved ones: 34% were living with their partner, 23% with their parents, and 17% with friends – figures comparable to transgender people (Jones et al., 2015). Around 17% were living alone, which was also a similar figure to studies of transgender people. Around 6% reported that they were in more precarious contexts or homeless, couch surfing or living on the street – this was similar to the high incidence of homeless gender questioning youth in *Writing Themselves in 3* (Hillier et al., 2010). Also, 2% were living at college and a further 6% described other living arrangements, including living at a military base, in a hospital, with grandparents, with an employer or across several locations for example. Around a third of participants had a pet/s.

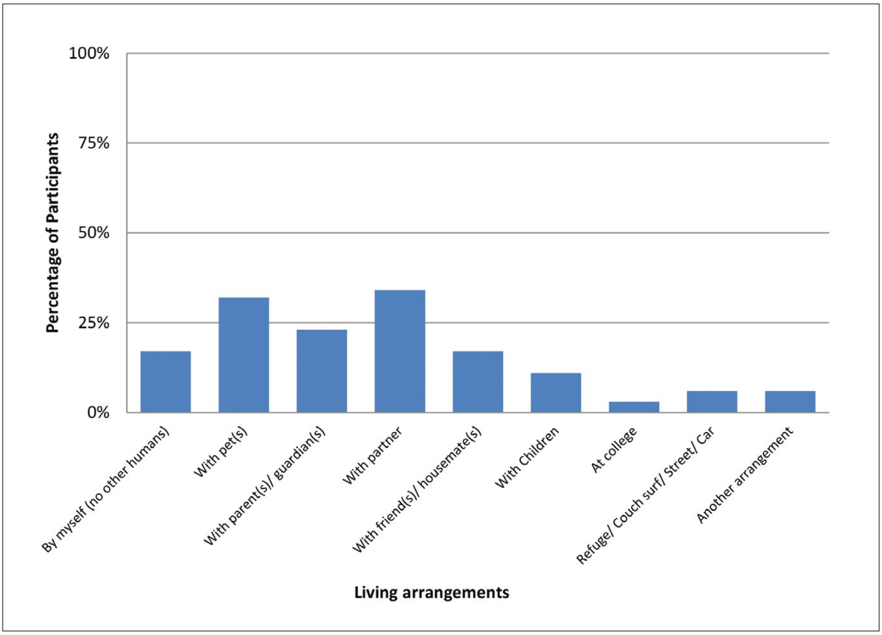


Figure 3.4: Living arrangements of people with intersex variations (n=255)

Religion

In terms of religion, 73% of the respondents reported that they did not have an affiliation to a religious denomination. This is a strikingly high portion in comparison to the 22% of Australians with no religious affiliation more broadly (Australian Bureau of Statistics, 2012b), and almost as high as the (86% of) FtM transgender Australians who have no religious affiliation (Jones et al., 2015). There is evidently a message in this statistic – that the mainstream Christian faiths usually so common in Australian society (and the Western contexts more strongly represented in the study) are less embraced by, and/or likely less embracing of, the intersex community. The lack of support for people with intersex variations in Christian theologies does indeed seem to be interpreted as condemnation in practice, as the literature reviewed theorised (DeFranza, 2011; Fonrobert, 2009). Amongst the 27% of participants who did have a religious affiliation, the most common denominations were Christian (50%, including Anglican, Catholic, Lutheran, Pentecostal and Uniting Churches), Buddhism (11%), Judaism (10%), Pagan (9%) and other beliefs (20%). Of the beliefs nominated by the latter group, these included for example Hinduism, Islam, Taoism, Agnosticism and general spirituality, for example. The relative popularity of a range of religions with people with intersex variations in comparison to the broader dominance of Christian faiths in Australian society, reflects a broader interest amongst the LGBTI community in non-Christian creeds (Gahan & Jones, 2013; Gahan et al., 2014).

4. Discovering, Experiencing and Discussing Intersex Variations

> *I was christened male, but reassigned female at day 5, and then realigned back to my male self at age 29. I dislike that my testes were removed and the fact that I still have the makings of female genitalia which is embarrassing. I've always been positive, my main reason why I answer 'good' is because despite the incorrect surgeries and the pain and mental anguish this could cause if I thought about it for too long, my biggest sex organ I have is my brain.*

Mark, male with XY/XO Mosaics and Cloacal Exstrophy, 35yrs

> *My first endo said if I have a Y chromosome I must be male and treated me accordingly, but I never agreed to that. My new endo believes I am female and we get along famously. My GP is confused! 'X' and 'Y' are simply the apparent shape of the chromosomes and have little, if anything, to do with gender and sexuality. One friend told me that when she was little everyone thought she was a tom-boy... in other words she missed the point entirely. (Intersex groups were) mostly positive, but even within intersex communities there is great opposition to including transgender people like me.*

Melissa, trans intersex male-to-female with 48XXXY chromosomes, 63yrs

http://dx.doi.org/10.11647/OBP.0089.04

Key Findings

- Participants had over 40 specific intersex variations, ranging from 5-ARDS to XY Turner's Syndrome Mosaics.
- Most (64%) learned about their variation at under 18yrs, a third as adults.
- Learning about a variation usually involved being told by doctors or parents.
- 22% knew they had relatives with their variation, usually more than one. These relatives were most often siblings.
- Experiences of the variation could differ between relatives.

Participants' Variations

Participants were asked to select any variation/s that they were born with from an alphabetised list of over 30 options from 5-alpha reductase deficiency (5-ARD) to XY-Turner's Syndrome, including 'unknown' and 'another option'. In total, the 272 participants reported having variations. On average, participants reported having two of the options listed. Participants experiencing multiple intersex variations is not surprising; some of the variations can also be features of/related to another variation – some people may experience micropenis without a specific diagnoses or other intersex features/variations, whilst others experience micropenis specifically within the context of having XXY chromosomes and a diagnosis of Klinefelter's Syndrome for example. All 23 of the participants who saw being transgender as part of their experience of an intersex variation, had at least one other intersex variation listed (those who were solely transgender had been removed from the group).

Table 4.1: Variations experienced by participants (n=272)

Answer Choices Responses	Responses
5-alpha reductase deficiency (5-ARD)	2
17-beta-hydroxysteroid dehydrogenase deficiency	3
Aphallia	1
Bladder exstrophy	4
Clitoromegaly (large clitoris)	14
Classic Congenital Adrenal Hyperplasia (Classic CAH)	10

Answer Choices Responses	Responses
Complete Androgen Insensitivity Syndrome (CAIS)	20
Cryptorchidism (undescended testicle/s)	17
De la Chapelle (XX Male Syndrome)	4
Epispadias	1
Fraser Syndrome	2
Gonadal dysgenesis (partial or complete)	8
Hypospadias	12
I am a transgender person who sees my brain, gender or body as intersex	23
Jacobs/XYY Syndrome	2
Kallmann Syndrome	4
Klinefelter Syndrome	25
Late Onset Congenital Adrenal Hyperplasia (late onset CAH)	2
Leydig Cell Hypoplasia	1
Micropenis	21
Mosaicism involving ‘sex’ chromosomes	7
MRKH (Mullerian agenesis; vaginal agenesis; congenital absence of vagina)	6
Mullerian (Duct) Aplasia	1
Ovo-testes (formerly ‘true hermaphroditism’)	16
Partial Androgen Insensitivity Syndrome (PAIS)	24
Persistent Mullerian Duct Syndrome	0
Polycystic Ovary Syndrome (PCOS)/Hyperandrogenism	38
Progestin Induced Virilisation	1
Swyer Syndrome	4
Turner’s Syndrome (TS, one X chromosome)	10
Triple-X Syndrome (XXX)	1
XXY/47	31
XY/XO Mosaics	8
XY-Turner’s Syndrome	2
Unknown	22
Another variation	29

The most strongly represented variations included Androgen Insensitivities (whether Complete or Partial); Hyperandrogenism from Poly-Cystic Ovary Syndrome (a more extreme experience of hormonal and anatomical variations most commonly associated with PCOS); XXY/47 and Klinefelter's Syndrome (the latter two usually appearing in combination). The greater numbers for these variations can be explained both by their greater estimated frequency of appearance in humans broadly compared to some variations listed, and the availability of variation-specific support groups through which participants could be recruited. The willingness of people with PCOS to participate in this study and in many cases use the term intersex in relation to their variation confirmed the suggestion by Huang et al. that hyperandrogenism in this population has perhaps been underestimated (Huang et al., 2010). Participants with these more strongly represented variations experienced them differently to some degree. For example on one hand Zoe (intersex woman with CAIS, 53yrs) described her androgen insensitivity as impacting her body in multiple ways, 'I had internal testes that were removed at 17. I have ongoing oestrogen HRT since then. I have a shorter vagina and have used dilators to assist in improving length'. On the other hand Tori (woman with intersex variation CAIS, 58yrs) described her androgen insensitivity as making her body infertile, but noted that all other bodily features she experienced in relation to her CAIS were 'caused by [...] the unconsented surgeries I had as an infant (double orchiectomy)'.

Karma (transgender non-binary intersex person with PCOS/Hyperandrogenism, 25yrs) experienced impacts on their body of 'virilisation at puberty [...] deep voice, visible 'Adam's Apple', clitoromegaly, elevated testosterone levels'. Debbie (woman with intersex variation PCOS/Hyperandrogenism, 34yrs) instead discussed how facial hair strongly featured in her experience of Hyperandrogenism:

> *I have an imbalance in hormones due to PCOS affecting my ovaries and so many areas, this has led me to have more male hormones then female ones, and I have chest hair, back hair and a beard amongst other features which are masculinised for a woman. I used to get it all waxed several times a week, hurt like hell. Other days I tried to shave, started to get the afternoon shadow as it grew back. For a long time I'd question norms of sex... was my sex what is on my face, what is between my legs, what is on my back, my chromosomes, my hormones? Now, I just LIVE MY LIFE. Yep, with a beard.*

Celine (female with XXY/47, 50yrs) resisted the concept that most people with XXY/47 relate to a male sex; she identified and lived as female and yet on occasion was referred to with male pronouns against her wishes;

noting ‘my GP lists me as having Klinefelter’s Syndrome which is synonymous with low testosterone and hypogonadism both of which are only of concern for MALE identifying XXY’. Celine does not list herself as having the syndrome. This contrasts with Cameron (male with XXY/47 and Klinefelter’s, 66yrs), who identified and lived as male and said ‘I am sterile. I have to use testosterone therapy’.

The researcher was unable to recruit any participants with Persistent Mullerian Duct Syndrome, and recruited fewer participants with Aphallia and some other rarer intersex variations around which fewer variation-specific support groups had developed by 2015 when the survey was run. James (intersex man with aphallia, cryptochidism and another variation, 53yrs) provided insight into his experience of the quite rare experience of having aphallia; as an absence of genitalia:

> *This is very hard to put down here, I still suffer a lot of triggers on this. I have always been a male, but I did not know this for a long time. I was born without a penis and with only one of my testes formed, it had not descended. At first they thought I was a baby girl. Then they were not sure and my mother recalls several doctors examining me and taking measurements. Then later on my records they wrote that I had aphallia, well it was instead written up as several more precise terms ‘penile agenesis’ and ‘partial testicular agenesis.*

Those who selected the option ‘Another variation’ often supplied information about alternate variations such as 48XXXY, chimerism, 21 hydroxalase deficiency and other rare variations. These included for example Nina (intersex female with 3beta hydroxysteroid dehydrogenase deficiency, 32yrs) who described the impacts of her rare variation:

> *My body is deficient in 3Î^{2}-HSD II, which causes my particular type of congenital adrenal hyperplasia (CAH). As a baby everyone thought I was a boy, but my body was not quite a boy’s. My testes were in my abdomen and my penis did not grow much, this got more obvious as I grew as a person but not as a boy.*

Some participants also used ‘another variation’ to cover symptoms of having had intersex variations or treatments/interventions without over-arching titles or explanations. For example, Warren (intersex man with unexplained scarring, 38yrs) used ‘another variation’ to cover the fact that ‘I have scarring from medical procedures about which I was not informed. I was given hormones without informed consent during my childhood to induce ‘normal’ puberty’.

Those who selected the option 'Unknown' mostly commented that they were currently in the process of gaining more information about their variation/s. Mia (intersex woman with clitoromegaly and unknown variation, 24yrs) said:

> *I was very short when I was a young girl and now I am very tall with a muscular body and masculine energy. I have a large clit that can actually move and harden during sexual activity, and recently was told I have abnormally high amounts of testosterone that may put me in a general intersex category but they need to do further testing to find out more. I am not sure how much I need to find out. I had severe acne as a teen and into my twenties, so the testosterone may explain that. I did not get my period until I was 20.*

A smaller group of those who selected 'Unknown' discussed being unable to uncover the precise nature of their variation. An example of this was seen in a response from Ray (intersex man with unknown variation, 24yrs):

> *I am XX with internal female reproductive organs, a clitoris that has grown into a flaccid 2 inch penis (due to testosterone therapy) and a prostate. I have no idea what my condition is called. My endocrinologist hasn't been able to figure out my condition. I feel lost and unsure of my medical history. I feel like I am alone and I am often misunderstood by doctors. I want to discover and understand my condition so I can be better prepared for the future.*

The above quotes expressed the kind of confusion and uncertainty typically experienced in the sub-group of participants who had selected 'Unknown' in their ongoing search for information.

Variations in Family Background

Because of the largely congenital nature of intersex variations, the survey investigated the participants' knowledge of whether their variations or similar had been experienced by others in their family backgrounds. Overall, the largest portion of participants (48%) knew they did not have a relative who shared their variation/s or similar. In addition, a group of 30% were unsure whether any of their relatives shared their variation/s. However, 22% of people with intersex variations in the study did have relatives with their variation/s or similar. The participants in this group usually had more than one relative with their variation/s – including siblings (10%), parents (6%), parents' siblings (6%), grandparents (2%) and/or another biological relative (8%).

Inter-family secrecy around whether or not relatives had variations and how they experienced them if they did, was a strong theme that emerged in the qualitative data from the majority of participants (including both those who were unsure whether their relatives shared their variation/s and those who knew that they did). In a comment typical of most responses from those who were unsure when asked about the incidence of their variation/s in their family backgrounds, Lara (female with intersex variations Gonadal dysgenesis/mosaicism/ovo-testes, 27yrs) said 'I have no idea'. There were also instances where a participant who had selected 'Unsure' strongly suspected a specific family member shared their variation/s, but this could not be verified. This was illustrated in Simon's (male with intersex conditions Kallman Syndrome and micropenis, 36yrs) experience: 'one of grandma's brothers may have had this, she thinks, but nothing was diagnosed in those days'.

Those who did know relatives with their variation/s often found out too late to discuss their experiences, or struggled to share information given an established context of silence. For example, Sienna (female with Polycystic Ovary Syndrome (PCOS)/Hyperandrogenism, 30yrs) experienced strong facial and bodily hair, a receding hairline, infertility and a variety of features which she learned her grandmother had also experienced before dying of bursting cysts and complications related to the variation. Inga (intersex woman with XXY/47 and Cryptochidism, 43yrs) was always a 'girly boy, into girly games', who loved having long hair as she grew up. However, there was an atmosphere of tension around this and she explained that it prevented her finding out if there were others in her family background with the same chromosomes, 'my family was so uncomfortable with me being different that there was no way I could ever even ask them'. Patti (intersex female with CAIS, 37yrs) had one sister with CAIS and another who was a carrier of the gene. Her mother was also a carrier of the gene, and she had many Aunts on her maternal side with CAIS. In addition, her grandmother was a carrier of the gene. She commented, 'I assume this pattern continues back throughout my maternal ancestral line, however, we will never know as nearly all the people mentioned here have been extremely secretive about it and hence it is not really documented'.

Nevertheless, some of the participants who knew relatives shared their variations were able to discuss and compare their experiences with them to some extent. They found that whilst there was some overlap in their experiences, their relatives' experience of the variation often differed in some ways. Like Patti who had noted that some relatives had

CAIS whilst others carried the gene, there were other participants with androgen insensitivities who found some relatives were gene carriers or experienced androgen insensitivity to a greater or lesser degree (or 'grade' in medical terminology), and participants with a range of variations who noted differences in height between themselves and the relative sharing their variation, differences in development during puberty or differences in intensity of other features particular to their specific variation (such as impacts on the senses for Kallman's Syndrome or impacts on the organs for Turner's Syndrome). For example, Kyle (intersex male with Kallman's, 28yrs) said he 'went through childhood fine and my body seemed like any other boy's'. But he did not start puberty due to his experience of Kallman's, 'so being a teenager was a very different story'. He could not smell, which affected his ability to detect smoke in the case of a fire, for example, or experience the taste of food, he had problems with his jaw and teeth and had 'a high voice for a man, no real face hair growing up, and I look younger than I am'. Whilst his brother had some similar experiences of Kallman's, his differences in experience included having 'a better sense of taste than I do, and better sense of smell'. Because his brother had some sense of taste (with spicy or strong smelling foods) he felt that their daily lives were quite different as his brother participated in social groups based around seeking out highly stimulating food, whilst he still preferred activities he did when he was a bit younger like gaming.

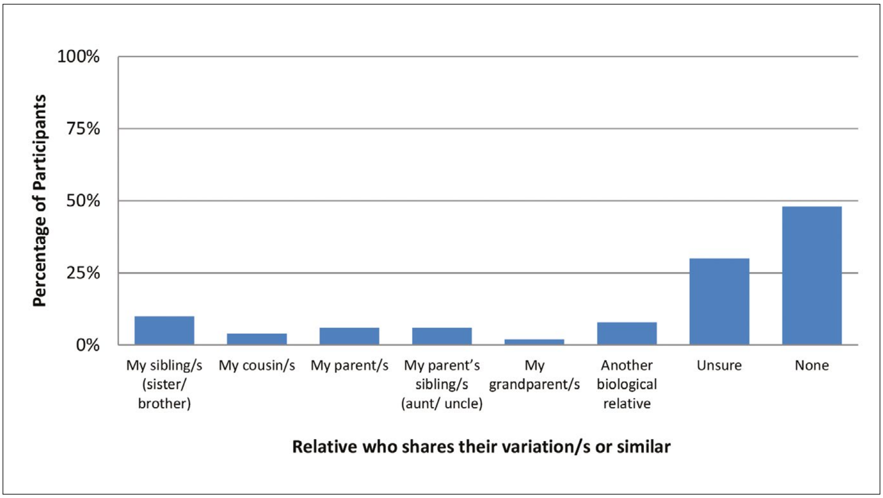


Figure 4.1: Participants who had relatives who shared their variation/s or similar (n=250)

Age of Discovery

The survey asked the participants at what age they started to learn of their intersex variations. Most (64%) learned of their variation for the first time at under 18yrs, a third as adults, and a small number were still unsure of the full details of their variation when completing the survey (see Figure 4.2). The survey then asked participants to share how they found out (from whom, why and how) in a short-answer response. The largest portion of responses (87 responses) involved a participant being told about their intersex variation/s by one or more parent/s, most commonly just their mother (39 responses) or both parents (37 responses); less commonly just their father (11 responses). These discussions usually occurred at the home or in the car, and were often stimulated in relation to appointments at the doctor's or a hospital (such as before, after, or because the participant asked a question about these appointments). Typically, they involved inadequate information for the participant and little follow-up. Briony (female with Turner's Syndrome/One X Chromosome, 30yrs) was nine when she asked her mother why she had to keep going to hospital and doctors' appointments when nobody else she knew did. 'I was very surprised to get a real answer', she recalled, 'I was actually just having a tantrum as I really did just think it was a leg problem, not an XO problem, hard to get your head around that as a kid and I wish it did not come up during a fight like that'.

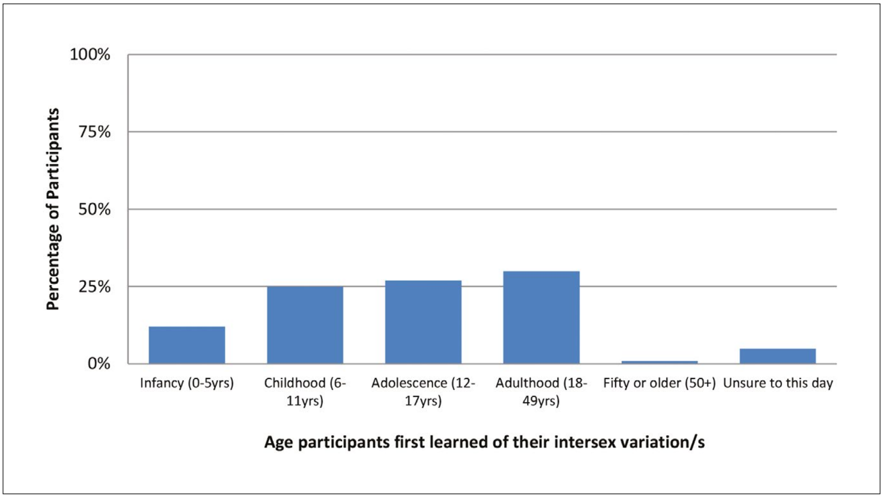


Figure 4.2: Age participants first learned of their intersex variation/s (n=212)

Louise (woman with CAIS, 38yrs) was told by her parents after she had attended a sex education lesson at school at nine years old, two years after they found out. They had received her diagnosis from Louise's weeping doctor without Louise present, after he performed abdominal surgery on her at age seven. Her parents had also wept. Louise remembered, 'They told me I had 'testicular feminization' but were unable to explain the condition beyond asserting that I had no uterus, would not menstruate and could not have children'. Apart from taking her to the family GP to commence hormone replacement therapy at the start of high school, her parents never provided Louise with any further information or discussed the condition with her again. 'To this day, my parents don't understand the condition' she reflected. Left to her own devices, Louise stumbled across outdated information about 'hermaphrodites' in her school biology text book and began to suspect that there was much more to her own condition than what she knew of it. Finally gaining internet access at university, by her early-mid 20s she had accumulated enough information online to realise the potential long term health consequences of her HRT. She insisted her GP refer her for bone density testing, endocrinology and gynaecology reviews. 'Despite evidence of osteopenia, no education or adjustment to routine HRT was provideded' she stated. 'In my early 30s I eventually commenced consulting a holistic GP who was willing to consider bio-identical hormone therapy and additional nutrition supplements which helped remediate osteopenia'.

The second largest proportion of responses (77 responses) involved a participant being told about their intersex variation/s by a doctor, endocrinologist, gastroenterologist, urologist or gynaecologist (or some combination of these medical practitioners). These discussions usually occurred at the doctor's office or hospital, and were often stimulated in relation to a particular test result that was being sought or had arrived, or a procedure that the participant was about to undergo. Typically, these experiences involved embarrassment for the participant or some kind of negative factor such as the doctor making blanket pre-emptive claims about fertility or the treatments the patient 'should' undergo rather than affirming their patients' diversity or diverse options. For example, Olivia (intersex woman with CAIS, 28yrs) had no menstrual cycle at age 14 and went to her doctor to undergo tests to explore why. 'Two months later, my doctor told me that lab-work, x-rays and an ultrasound determined I had CAIS', she recounted. 'The doctor said I could not have kids and handed me a booklet to read'. Mary (woman with intersex variation non-classic congenital adrenal hyperplasia, 19yrs) was 16 and had no period, 'crazy acne and hair growth on her body, when her mother became concerned over her hormone levels and took her to the doctor's office. The doctor did a physical examination of Mary and took some x-rays and blood samples. Mary found the process uncomfortable, explaining 'I also had to give them my pee, all pretty embarrassing, as if the exam was not enough'. The doctors found that she did not have a full uterus, and 'had all these hormone level symptoms of some kind of lower level CAH'. Francis (transgender woman with intersex variation PAIS, 32yrs) had 'mixed attributes' growing up which led to her being read 'unpredictably as male or female'. Although her parents had raised her as a boy, when she had a doctor suggest she had PAIS, and discussed this with her parents, they finally disclosed 'childhood medical details that confirmed this' that they had previously withheld. This included that they were advised by doctors to give her testosterone as a teen but did not comply; a decision Francis was grateful for, although she wished her parents had been more forthcoming about her variation so that she did not have to find out about her PAIS from a doctor years after a difficult and confusing adolescence.

There was also a third and slightly less common theme in other participants' responses to this question which involved exposure to documentation that revealed key information, whether by accident or on purpose. Examples from this group included when Bailey (intersex non-binary individual with Klinefelter's and ovo-testes, 25yrs) looked at their birth certificate as a child and saw that they were recorded as 'XXY'. They wanted to know what it meant, so they started looking into the 'Charlie Brown' book they had been given about where babies come from, and the basics of genetics and reproduction, saying that because so little information was provided 'it wasn't until I was about 18 that I learned about Klinefelter's'. Georgina (trans intersex woman with Cryptochidism/Hypospadias, 71yrs) had been told by her mother that she was born with undescended testes when she was a 10 year old, recalling 'I saw the line on the scrotum and assumed this was a surgical scar. I was also aware that my urethra exited a fraction short of the end of the glands and that there appeared to be a short scar line there, too'. However, she only found her mother's full diary references to her being intersex and undergoing childhood interventions after her mother passed away several years ago. Tori (woman with intersex variation CAIS, 58yrs) was given no information about the various interventions she had experienced in relation to her intersex variation since infancy. She only found out that she had CAIS at 32yrs of age after being put through the removal of her gonads in infancy and hormone therapy in childhood, because she actively pursued the information she suspected had been secretly collected on her intersex variation by medical practitioners. She bluntly recounts: 'I stole my medical records from my endocrinologist's office. Yes, that's right, I STOLE them'.

Feelings about Intersex Variations

To investigate participants' feelings about their intersex variations over time, the survey asked participants how they felt about their intersex variations when they first found out they had them; from the range of options provided 7% selected 'Very Good', 12% 'Good', 33% 'Neutral', 20% 'Bad' and 28% 'Very Bad'. More than twice the portion of participants felt negatively than positively about their variation when they first learned they had it. However, the survey also asked participants how they felt about their intersex variations at the time of taking the survey and contrastingly 23% selected 'Very Good', 33% 'Good', 22% 'Neutral', 15% 'Bad' and 7% 'Very Bad'. Thus, most (56%) felt positively about their intersex variation/its impacts on their body at the time of taking the survey; well over twice as many as when they had first learned about their variation.

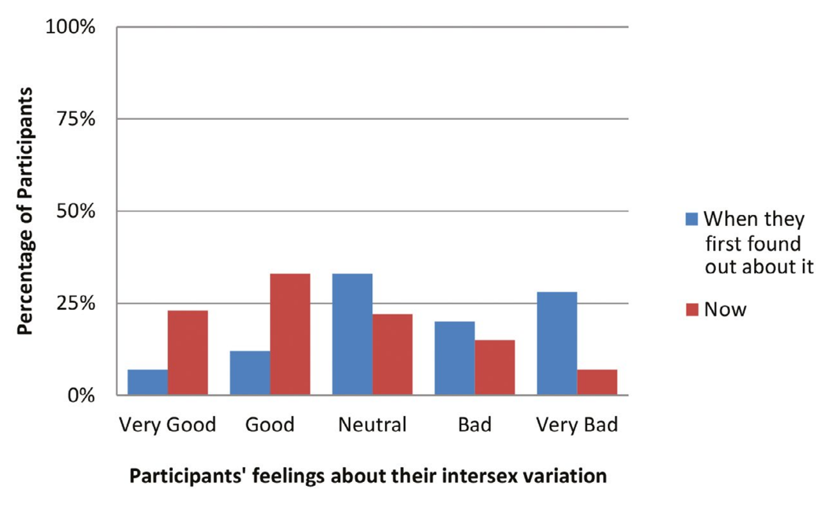


Figure 4.3: Comparison of how participants felt about their intersex variation/s when they first learned of them, compared to how they felt about their intersex variation/s now

Thus, the quantitative data showed that whilst participants felt mostly negatively about their variations initially: they felt better about their variations over time and ultimately appeared to become mostly positive about them. The qualitative data also supported this finding. For example, Marcia (intersex woman with Turner's Syndrome, 27yrs) commented that she got 'happier as I get older'. Similarly, Selma (intersex woman with 47XXY, 24yrs) stated 'I was forced on Testosterone at 15yrs. They tried to correct my body and my behaviour. Now I'm embracing it'.

It was important to explore why participants initially felt so much worse about their intersex variations than they did later on, and the comments by participants shed some light on this. Many people who initially felt bad about their intersex variations found out about them in traumatising circumstances; such as immediately before or during, or even a long time after, they had undergone tests or treatments to 'correct' their bodies in some way (including quite serious surgeries and hormone replacement therapy treatments). This could create a context in which participants felt like their bodily autonomy or life choices were taken away from them, like their body needed to be 'fixed' and/or was not classed within the broad spectrum of healthy (if not necessarily common) bodies, or like people could touch and judge their bodies with little to no permission. For example, Eunice (woman with intersex variation PAIS, 52yrs) found out around age six that she had undescended testes. 'I found out about it in the context of 'so you are having an operation',' she explained. 'So I was extremely scared. Very frightened of being cut open'. She was given no alternative choices about how she could react to her body and was not told that she had the right to avoid the surgery or subsequent interventions such as hormone therapies and genital reconstruction surgeries she experienced. She said she was told 'no detail; just that I had testicles like my brother and they were going to be taken out because unlike my brother I was a girl'. She now feels 'Neutral' about her variation because she felt bitter about what was done to her, yet 'on the other hand, I feel much more open and accepting about being intersex and having AIS, I see that the body would naturally have coped with this if I had not been interfered with by the medical institution'. Louise (woman with CAIS, 38yrs) had been told a little about her variation after being placed on hormonal therapies in childhood and was later asked to use dilation therapies to expand her vagina in her teens. She recalled my parents and doctors distress but 'didn't understand the diagnosis and reasons for the adults around me to be so upset'. Her experience was defined by the negative emotional setting established in conversations with adults about her variation, and she mirrored their responses. Particularly, she learned their reservations about possibilities for her life and their general silence on the topic as a strategy in her own life:

> *My parents' discouragement of relationships in favour of career made me feel that I would never be wanted by an intimate partner as a result of the condition, and that my inability to have children was reason for intense grief. Others' avoidance of talking about the condition made me feel that it was shameful. I have never disclosed the diagnosis to anyone in my personal life, nor discussed it with anyone except my parents/siblings and medical practitioners.*

There was a strong message across the qualitative data that participants felt themselves to be impacted (particularly when aged under 18, and particularly before they had access to other sources of messaging around their variation such as support groups) by any negative emotions and attitudes about their variations conveyed by the people (mainly doctors and parents) who first told them about their variation.

In addition, many participants who initially had negative feelings about their variation were given little to no information about the experience of having their variation/s, and there was no real affirmation from parents or doctors about having variation/s that would help them to frame their variation/s positively in their minds. For example, Andy (intersex man with Jacobs/XYY Syndrome, 34yrs) felt 'Very Bad' when he first was told about his variation as a teenager, because he said he did not know exactly 'what' he was. He was subjected to negative treatment from parents about his gender expression and pressure to be 'manly', and became suicidal without any real supportive assistance around his variation from medical bodies, Islamic faith groups or at home. In later years, it significantly aided Andy to look up support groups for people with intersex variations online. He reflected that after this exposure he now feels 'Very Good' about his variation and its impacts on his body and has more information; 'When you know what you are, you can learn to live with it'. Similarly, Chris (intersex individual with 47/XXY, 44yrs) felt 'Very Bad' about the initial experience of receiving minimal information about their diagnosis as a teen, but had more recently received full access to their medical records and information about their chromosomes from a more supportive doctor, and now felt 'Very Good' about their variation.

These findings disrupt the presumption that intersex status is something people will necessarily feel *intrinsically* bad about *in itself*, as seen in historic psychological and medical theorisation (Jones and Lasser, 2015). Instead, the data suggest social and medical constructions of intersex status certainly have an important role to play in how people feel about their intersex status.

Preferred Language for Intersex Variations

The literature review had showed the need to investigate the use of language around peoples' intersex variation, to better understand their preference in relation to labels. Overall, more participants preferred to use the word intersex to discuss their own variation (48% used intersex, 20% intersex variation, 18% intersex condition) than other terms (25% diagnosis, 17% my chromosomes, 7% difference of sex development, 3% disorder of sex development). In total 60% of participants who answered preferred to use one or more of the terms related to the word intersex. The gap between the popularity of the words 'intersex' and 'DSD' was so large that the research suggested that any imposition of the DSD label on this community in Australia would clearly be inappropriate, despite attempts to impose it elsewhere (Hughes, 2008; P. Lee et al., 2006). The comments largely suggested that the main reason that intersex-related language was preferred, was because non-disordering language was more affirming. This was illustrated by comments by participants like Lara (female with intersex variations Gonadal dysgenesis/mosaicism/ovo-testes, 27yrs) who preferred 'intersex variation', explaining she 'used to use intersex condition a lot before I heard the term intersex variation used, and now I prefer to use that to describe my circumstances; it feels a lot less pathologising'. Kelly (intersex individual with Classic CAH, 63yrs) similarly preferred intersex to 'any other word that makes me a sickness... like disorder, difference'. Those who preferred using diagnosis-related terms as well as or instead of intersex-related terms, often used acronyms or internally specific slang terms for the diagnosis. For example, both Kallman's Syndrome and Klinefelter's Syndrome were occasionally referred to as 'KS'. In addition, several individuals with Turner's Syndrome particularly expressed preferences for using a range of slang terms for the syndrome like 'butterfly', such as Cassie (female with Turner's Syndrome, 19yrs) who found terms like intersex variation acceptable but preferred terms specifically related to Turner's Syndrome more and particularly those which referenced the 'x' shape of her chromosome karyotype, said 'I like to say butterfly best of all as it sounds pretty and happy! I like TS, TS sister, TS butterfly. X like a kiss, XO a kiss hug. Disorder is not nice, syndrome is better'.

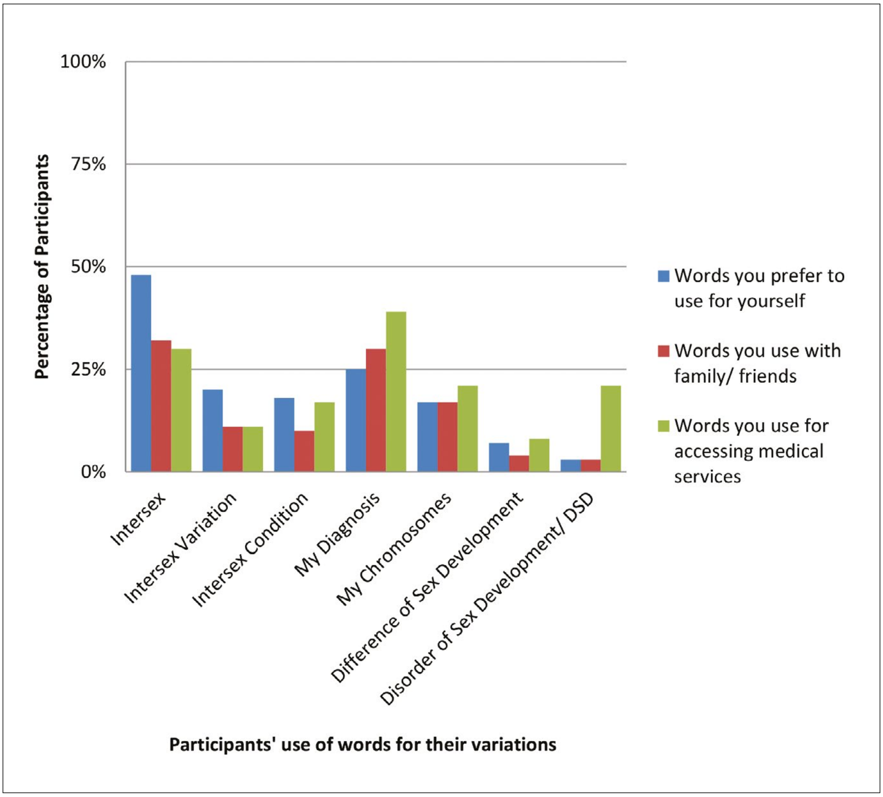


Figure 4.4: Comparison of participants' preferred use of words for their variations to those they use with family/friend and for accessing medical services (n=203)

The data showed that the participants' language use about their variations changed slightly overall in relation to the words they used for family and friends, and for accessing medical services (see Figure 4.4). In both of these contexts, they were more likely to use their diagnoses than would otherwise be their preference. For example, Stewart (male with intersex variation Klinefelter's/XXY, 39yrs) said he would mainly say he had 'Klinefelter's or KS' to friends and would 'not go into the X (his additional chromosome) too much' or use the word intersex, to prevent them from seeing him in a feminising light. Danielle (female with intersex variation CAIS, 41yrs) also explained that where necessary with friends, family members or other audiences she would shift her language from the preferred term of intersex variation to other options such as her diagnosis or even the inaccurate term hermaphrodite: 'I have to often describe myself as having a form of human hermaphroditism, which is a little stigmatising but I do some public speaking and find for people who know absolutely nothing about AIS and intersex it is the quickest way to give them an idea of what I am talking about'. Clyde (trans intersex man with 47/XXY, 44yrs) commented that using his diagnosis could be a useful way of helping people to understand him better or at least be more sympathetic to his recent gender transition: 'with my family and friends I have sometimes had to really emphasise my diagnosis to help them understand me becoming male'.

However most notably, despite people with intersex variations' clear lack of preference for the term 'disorder of sex development' outside medical contexts (only 3% preferred it, and only 3% used it with family and friends), 21% reported using it in accessing medical services. Tori (woman with intersex variation CAIS, 58yrs) discussed the pressure to use DSD in such contexts:

> *DSD (disorder of sex development) is often what doctors still use. For example, they say, 'oh, you mean DSD. Well let me just write that in your record since that's its proper name', to which I say, 'bullshit! Write down intersex. I refuse to have either DSD or male pseudo-hermaphrodite in my medical records, thank you'.*

Edwina (woman with intersex variation Mayer Rokintanky Kuster Hauser Syndrome, 27yrs) said she did not feel safe enough to use her preferred word intersex with doctors, as they 'see me as a woman with a disorder, an un-whole or an incomplete woman'. Rowena (intersex female with PAIS, 32yrs) used 'intersex' at home and said 'it is not something that changes how I am seen as a person, it is just part of me'. However, she used DSD in medical contexts, but said that she doesn't like the way doctors acted like there is something wrong with her in its use, 'like I have a disorder (DSD) or look 'wrong'... I have lived a whole life this way, I will be okay! There are issues I am affected by (hormones, fertility and so on) but it is not this big 'freak show' they turn it into'. Vincent (male with intersex variation XXY/47, 49yrs) saw himself as a man with an intersex variation but occasionally had to use other terms to explain that variation to others or access services. He said:

> *I do not call myself intersex like someone who is halfway for example. I do not see myself as intersex in terms of an identity as a third sex to tell friends or neighbours, I am a man with an intersex variation. I am not my chromosomes, I have chromosomes or a variation. I have heard doctors say DSD recently. I am glad I did not grow up thinking I had a disorder.*

Nadine (female with intersex variations Clitoromegaly/Classic CAH, 53yrs) reported that whilst she preferred to frame herself as having intersex variations, she used other words when she 'had to', because 'doctors understand DSD or my diagnosis details, or hermaphrodite'. Even though she found these words offensive, she said she got 'tired of explaining that humans are never hermaphrodites or that I am not sick, just intersex'. She, like many others in the study, held out hope for a future where people would use more affirming and accurate language in both social and medical settings.

5. People with Intersex Variations, Health and Medical Services

> *I am a fairly ordinary woman in most respects. The difference is I developed testes instead of ovaries. I also take a large shoe size. I had constant messages and pressure to be feminine as a kid and as a young woman from parents and doctors. Really messed me up. I was given the very loosest process information about my treatments, no messages at all on the risks to my life. I nearly died of septicaemia as a teenager, due to my genital surgery, I missed so much school I actually had to drop out entirely. It changed my whole life. Immense emotional impact to this day. I suffered PTSD and depression, and attempted suicide. I have struggled to get or keep jobs and felt trapped in a cycle of being outside of the normal social systems. I feel good about the way my body was naturally now that I have read more and talked to more people. I will never feel good about the surgical changes I was made to endure at an age too young to know better.*

Sarah, woman with intersex condition PAIS, 44yrs

> *I have trisome x. I look like a tall and girly girl, you would not be able to tell by looking at me, you would think 'oh she is tall'. Although, I have speech disabilities related to being Triple X, and had delayed motor skill development (took longer to walk than most babies). The other symptoms are not obvious, in me anyway. They were checking my blood when I was in my early teens and doing all sorts of tests because I was so tall and having back problems and the doctors were worried I was having problems stopping growing. That was not it though, it was xxx. I felt neutral when I was told, I did not know what to think. I needed several surgery treatments for scoliosis, related to my trisomy, which were extremely painful, helping to straighten me up. I was given information on the processes, ideal outcomes and risks. We knew it was dangerous, but scoliosis is also dangerous and can impact my breathing, so we decided to do the surgeries.*

Xanthe, woman with intersex variation Triple-X Syndrome/XXX, 18yrs

http://dx.doi.org/10.11647/OBP.0089.05

Key Findings

- 79% of people with intersex variations considered themselves moderately to extremely healthy when filling out the survey.
- 60% reported having had medical treatment interventions related to their intersex variation.
- Over half of the reported treatments occurred when the participants were under 18yrs, most commonly genital surgeries (many of which occurred in infancy) and hormone treatments.
- Most participants were given no information on the option of declining or deferring treatments; a fifth were given no information at all about any of treatments they received.
- The majority of participants listed at least one negative impact from their treatments, for some these were life-threatening.

Physical Health Now

When asked how they would describe their physical health at the time of taking the survey, a strong majority (79%) of people with intersex variations described their health in an affirming way from the options provided: 9% were extremely healthy, 22% were very healthy, and 48% were moderately healthy. However, 14% said they were less healthy and 7% were not healthy at all. The portion of people with intersex variations who assessed their physical health negatively was higher than in various recent Australian studies of transgender people (Couch et al., 2007; Jones et al., 2015; Smith et al., 2014). A group of 86 respondents had written additional explanations or lists of the physical health conditions they had been diagnosed with, and most of these responses included multiple conditions rather than just one. Of these responses 20 mentioned bone issues (decreased density, osteoarthritis and osteoporosis); some participants reported these issues were linked to their variation (such as people with Turner's Syndrome) and others reported these issues were linked with undergoing long-term hormone therapies (particularly from their early teen years). A further 20 mentioned being overweight and several reported this was related to their variation or related hormone therapies. For example, Jordan (intersex individual with intersex variation 47/XXY/Klinefelter Syndrome, 56yrs) said 'I have to attend the gym 3x a week in order to maintain muscle strength and flexibility. I am obese, but that fluctuates according to how my body is responding to hormone therapy'. A dozen mentioned heart problems, and as many again reported having diabetes. Smaller groups mentioned joint problems particularly related to Turner's Syndrome, kidney issues, scoliosis or chronic eczema. Participants also listed having adrenal fatigue, albinism, anorexia, asthma, Bradycardia CAIS, cancer, bow legs, fibromyalgia, high cholesterol, injuries from car crashes or other incidents, gut problems, reflux, scoliosis, visual issues ranging through from minor occlusions to being legally blind, and a range of other physical health diagnoses.

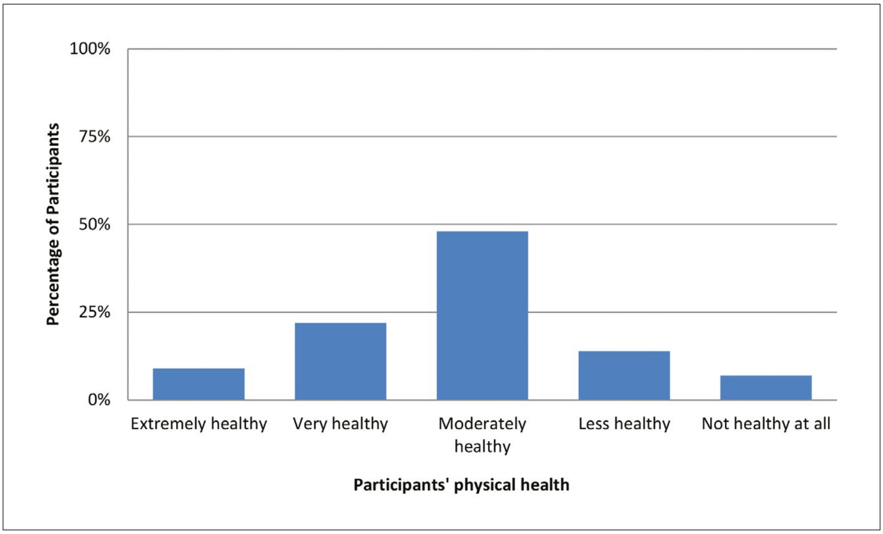


Figure 5.1: Health of people with intersex variations when surveyed (n=182)

Experience of Surgical and Hormonal Interventions

The background literature for this study had highlighted that surgical and hormonal interventions for people with intersex variations are currently under heated debate, with the United Nations decrying 'normalising' interventions in reports on torture and the right of the child (Davis, 2015; United Nations, 2012), and some medical researchers supporting their use (Warne et al., 2005). There was clearly a need to better understand interventions, and whilst the views of medical practitioners can be found in various media there were clear gaps in the literature around research on the perspectives of people with intersex variations. To establish the incidence of interventions participants were asked to indicate from a supplied list of surgeries and treatments they had been given and the life stage at which this occurred, which included a write-in option where any interventions not listed could be added.

Table 5.1: Participants' reported medical treatment interventions related to their intersex variation (n=272)

Interventions	**Infancy (0-5yrs)**	**Childhood (6-11yrs)**	**Adolescence (12-17yrs)**	**Adulthood (18-49yrs)**	**Fifty or older (50+)**
Removal of Gonad/s	14	10	15	12	2
Genital Construction (vaginal/penal/ labial or scrotal construction, shaping or changes)	26	9	17	15	2
Mastectomy (breast removal/ reduction)	1	1	5	14	1
Chest Reconstruction/ shaping	1	0	3	18	1
Hormonal Treatments (pills/ injections/creams)	4	16	66	90	14
Dilation Treatments (being made to insert objects into your vagina or frontal opening)	2	4	13	15	1
Orchiopexy/ orchidopexy (surgery to move undescended testicle/s into the scrotum)	5	2	4	2	0
Another Surgery/ Treatment*	15	9	12	22	3

*Note. *Other surgeries and treatments included for example electrolysis/hair removal, removal of neck webbing, and a range of other interventions used for people with intersex variations.*

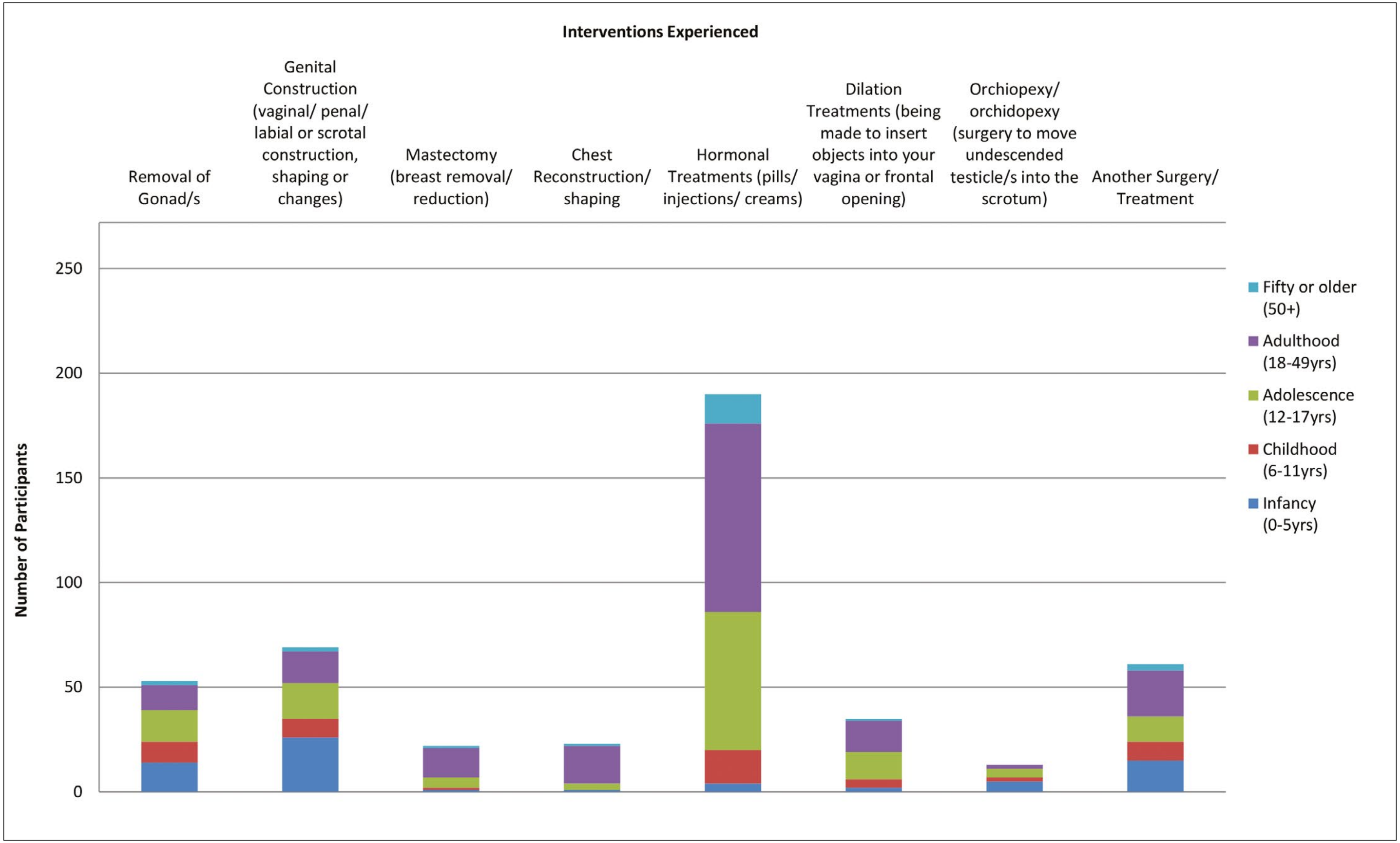


Figure 5.2: Interventions experienced by people with intersex variations (n=272)

Of the 272 people with intersex variations in the study, 60% of the group (163 people) reported that they had experienced a medical treatment intervention related to their intersex variation. On average they had experienced at least two interventions. The most commonly reported interventions were hormonal treatments; with 136 reports of use of pills/injections/creams. The second most common type were genital surgeries of varying kinds; with 115 reports cumulatively including 52 reports of genital construction surgeries (vaginal/penal/labial or scrotal construction, shaping or changes), 50 reports of gonad removal surgeries and 13 reports of orchiopexies (surgery to move undescended testicle/s into the scrotum). There were also 40 reports of chest surgeries (including 21 reports of chest reconstruction/shaping and 19 reports of mastectomies), and 28 reports of dilation treatments (being made to insert objects into the vagina or frontal opening to expand it).

In addition, there were 43 reports of another type of surgery or treatment. Of the participants who indicated that they had experienced another type of intervention related to their intersex variation, most had experienced a unique type of treatment specific to their own medical practitioners' continuing overall treatment plans for their variations. For example, several participants with Turner's Syndrome reported having different types of operations on different parts of their legs and joints to aid development and movement, such as Una (female with intersex variation Turner's Syndrome, 21yrs) whose surgeries were particularly focussed on her knees:

> *I had some surgery on my legs in my first few years to help with development problems. I have had tissue removed from both knees and one of my elbows when I was about 14-16. I also started some HRT which did apparently help me grow (not really I am only like five foot still) and now we are trying other treatments because I don't feel quite right (on current hormones) and have heard other types worked for other girls.*

Some participants had reported having additional exploratory surgeries on various areas of the body including their chest, stomach and bowel. For example, Clementine (woman with Polycystic Ovary Syndrome/Hyperandrogenism, 26yrs) reported having had hormonal treatments during her adolescence and later an exploratory laparoscopic surgery that left her with stomach scarring and discomfort, as part of a plan aimed towards further treatments. Mary (woman with intersex variation non-classic congenital adrenal hyperplasia, 19yrs) reported having electrolysis treatments to remove facial and bodily hair on her doctor's advice, commenting that it 'was a bit painful, more than the tingling they said, but it did work a bit. I was told I will need more sessions as I get older'.

Interventions and Informed Consent

In total, over half of all treatments (254 of the treatments reported or 55% of all treatments) were delivered to participants when they were aged under 18yrs, before they were adults. The youth of these participants at the time of treatment is especially important to consider, given that issues of consent for people aged under 18 can be highly problematic where these individuals are unsure of their position on a treatment or are more susceptible to the influence of a range of adults (such as parents and medical practitioners). In addition, since the data on how participants felt about their intersex variations had clearly shown that they were more likely to feel better about the variations and the impacts they had on their bodies as they got older, there was also the possibility that any decision to undergo treatment might be considered differently as an adult. It was particularly notable that there were 101 reports of genital surgeries under 18 (including 52 reports of genital constructions, 39 reports of gonads removals, and 10 reports of orchiopexies), alongside the 86 reports of people starting hormone treatment under 18 (usually at or after the beginning of adolescence to coincide with the ages at which puberty is frequently expected to begin). Genital surgeries were therefore even more commonly experienced than hormone therapies by people with intersex variations when they were aged under 18, and it is particularly poignant that there 45 reports of genital surgeries conducted when participants were in their infancy (aged 0-5yrs) – a life stage at which if consent were sought, it would need to be sought from parents/guardians rather than the individual affected. It is also concerning that all surgeries of this nature have other inherent risks (from fatalities to infections, mistakes and so forth) that must be carefully weighed by individuals considering them.

The controversy surrounding matters of informed consent and bodily autonomy in treatment of people with intersex variations in the literature reviewed for this study (Creighton et al., 2013; DPA Local Editorial, 2015; Ford, 2001) suggested it was important to ascertain the extent to which participants who had experienced treatments had been given appropriate information and choices about their variation (and their options regarding it). Firstly, participants were asked if they had been given access to their medical records and history regarding their congenital variation/s; only one fifth had been given full access to this information. Secondly, participants were asked to select from a list of options the clinical information they had been given about (any of the) specific treatments/surgeries they had experienced. Of the 192 participants who answered the question, one fifth had been given no information at all about any surgical or hormonal treatments they had received. Only 46% received information on the ideal outcome of their treatments, 43% on the processes involved, and 32% on the risks/problems associated. This data appears to hint at how little people with intersex variations' own understanding of the (often quite significant) treatments happening to their own bodies was actively supported by medical practitioners and institutions providing treatments.

Further, only 16% of the participants were provided with any information on the option of not having their treatments, 14% on the option of alternative (other) treatments and 10% on the option of deferring treatments until they were ready or willing to undergo them. This suggested that not only were many participants made to believe they had 'no choice' but to engage in various treatments, but that there exists an institutionalised disregard for the bodily autonomy of people with intersex variations, where their decision-making rights and options are simply not adequately structurally supported by medical practitioners or institutions to an acceptable degree. On top of this, only 9% of participants were provided information on the social history of their treatments (other peoples' good/bad experiences), 7% on a community-led support group, 3% on a clinician-led support group, and 2% on a parent-led support group. It was clear that social information and referrals to social support provision were only very rarely used, and that the value of community knowledge and contact about treatment was not yet being widely affirmed by medical practitioners and institutions. Edwina (woman with intersex variation Mayer Rokintanky Kuster Hauser Syndrome, 27yrs) was one of many participants given inadequate information about a genital surgery she underwent in her youth:

> *I was given no information about what had happened and was treated very coldly by nursing staff and doctors. It turned out much of my vagina was missing, but I was not made aware of this until later, and not by staff but by mum whom they told instead of me. I was very angry that they told her over me. I had had so much bleeding from the imperforate hymen surgery that made me confused about what they even did, I felt they had dabbled without my permission and am very distrustful of doctors to this day.*

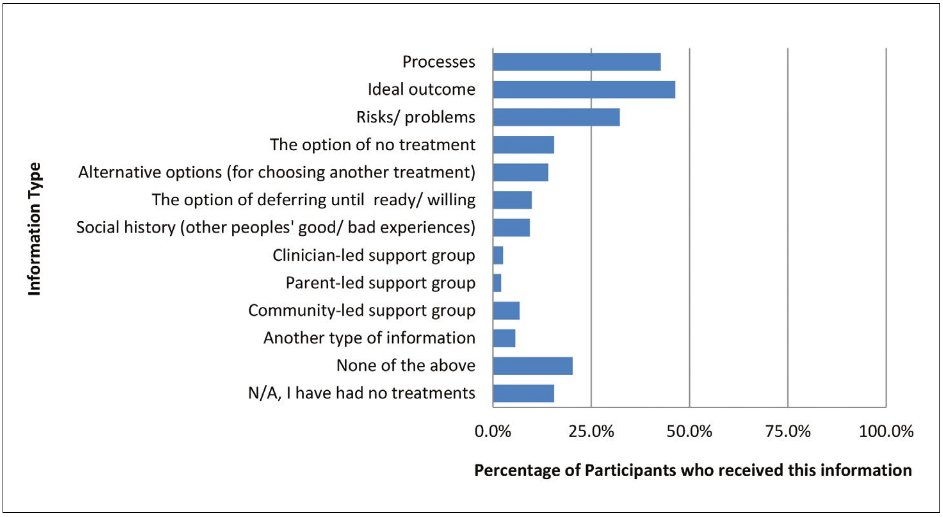


Figure 5.3: Information provided to people with intersex variations about the treatments/surgeries they were given (n=192)

Finally, the data revealed that 6% of participants were given ‘another type of information’. Analysis of the explanatory responses participants provided to contextualise this answer showed that they selected ‘another type of information’ almost exclusively to refer to misinformation. In one example, Dylan (man with intersex variations PAIS and Hypospadias, 24yrs), explained he was given no information about the risks involved in an operation ‘to stop the penis being open to the surface that left me with little to no control over my penis during sex’, infections and painful sensations; he was also given misinformation about the social supports available to people with intersex variations. ‘I wish I had been told about the control problem, I wish I had been able to meet other people like me first to know what to do’, he reflected. ‘But they said there were no groups, which I now know is a lie from the internet and this study’. In another example, James (intersex man with aphallia, cryptochidism and another variation, 53yrs) had been allocated a female sex and raised as a girl, and did not actually get told by the many medical professionals treating him throughout his childhood and adolescence that he had elements of male genitalia or that they were removing them. He explained that before both his first genital surgery medical staff ‘told me I was going to go to sleep because I was sick and the doctor would fix me’ and before his second ‘they said I had a tummy tear and they would sew it up (they were removing my testicle)'. The procedures left him completely sterilised and effectively gave him an anatomical sex change without any consultation as to his own feelings about his sex characteristics or gender identity, and certainly without his informed consent. James said that even with the removal of his genitals he still felt male on the inside, and the misinformation he was given prevented any opportunity for him to assert his bodily autonomy and avoid the procedures; 'I had felt insane because I dreamed I was a boy for so long and it was actually real and I went through it all for no reason'. In sum, James was one of several individuals who characterised the other information they were given about their treatment/s (particularly under 18) as 'lies and stories that gave me no say in what was happening', which ultimately resulted in the application of devastatingly inappropriate treatments and much subsequent trauma for those particular participants. It is noteworthy that what participants here perceived as intentional misinformation may instead have been a matter of doctors having inadequate information themselves.

Considering the 82 comments participants had written about the adequacy of information provided for treatments/surgeries overall, the majority (54 comments) argued that information provision was inappropriate; overlooking details or choices in ways which hindered the possibility of their informed consent. This particularly applied for treatments participants had experienced aged under 18yrs; many described being completely excluded from discussions about their bodies between doctors and their parents/carers because the possibility of their input either then or at an age where consent was possible was not even considered. For Monique (female with intersex variations Classic CAH and Clitoromegaly, 58yrs), the possibility of her informed consent was circumvented entirely:

> *At 2 years old they discovered a hole beneath my clitoris which they had considered a willy, and discovered I had female internal organs and could potentially carry a child one day. So they removed anything that conflicted with their idea of a girl. That included my clit, as they thought it made me look like a boy. I was a baby. I was not consulted in any way, I never even knew it happened until I investigated as an adult in my twenties.*

Merryn (intersex woman with PAIS and Cryptorchidism, 18yrs) and several others described being coerced into genital constructions and hormone treatments by selective information provision; 'I was pushed into it, and the information (only covered) bad aspects if I didn't do it'. The second most common theme (in 15 comments) described participants' experiences of proactively gaining the information they needed by themselves or with their loved ones; by demanding its supply, researching it online or leveraging medical connections to access information. Nina (intersex female with 3beta hydroxysteroid dehydrogenase deficiency, 32yrs) said her parents insisted on the information provision around her genital surgery; 'You really have to have advocates or you get nothing'. Briony (female with Turner's Syndrome/One X Chromosome, 30yrs) demanded information about her hormone treatments, saying 'now I am older I demand to know risks because of bad experiences'. Cary (intersex woman with Classic CAH and Clitoromegaly, 19yrs) said her doctor had recently recommended reducing the size of her clitoris; after researching the risks with her girlfriend on the internet Cary rejected it: 'if anything I feel a bigger clit would be more fun'. The third and smallest theme (in 13 comments) described positive information provision about treatments, mostly supplied to the participants as adults. Noreen (transgender intersex woman with Cryptochidism, 61yrs) received no information for her orchidectomy as a child, but said the clinical information on HRT she received before proceeding with it in her forties 'was a definite improvement over nothing at all'. Whilst Lily (intersex female with MRKH/congenital absence of vagina, 31yrs) had experienced traumatic interactions with many doctors as a teenager, she had later met with a surgeon as an adult to discuss surgical expansion of her vagina, but then decided to learn about dilation instead when given the option; 'This doctor was kind and gentle' she said. 'He did ask me if I had questions and offered to connect me with someone else with MRKH. I was given dilators and was shown how to use them'.

Impacts of Interventions

Given the controversy surrounding interventions for people with intersex variations, the literature suggested the importance of being better able to understand the impacts they had on those who experienced them. Participants were asked to comment on the impacts they had experienced from their surgeries/treatments. Of the 117 responses, a strong majority of 97 responses described one or more negative impacts (including 74 responses which described *only* negative impacts from interventions). Scarring was the most recurrent theme for those who had genital or chest surgeries (described in over a third of responses), followed by decreased or loss of sensation/pleasure/climax, and infections. Some people reported being spoken to or treated in a way that suggested their natural genitals were dirty or shameful by medical staff during surgery pre-care or after-care, or being outright ignored. Several individuals had experienced extreme trauma and anxiety in medical settings due to receiving these interventions without consent. A few people had either experienced the treatment processes as sexual abuse or reported additional incidents of sexual abuse by doctors during so-called 'treatment sessions', or explained that their shame about their genitals made them more susceptible to sexually abusive dynamics subsequent to the surgery. Patti (intersex female with CAIS, 37yrs) described being called 'abnormal' as an adolescent by doctors and said that the removal of her gonads:

> *…exists in my memory as some type of clinical rape; 10 student doctors standing around staring up my vagina as the doctor put his fingers in me and spoke about me like I wasn't there. Everyone was complicit in this, my parents, extended family, the doctors, the state as far as I knew, the whole world.*

Several people said surgeries had driven a wedge between themselves and their families, or themselves and the person they were 'supposed to be'. Noreen (transgender intersex woman with Cryptorchidism, 61yrs) said undergoing genital surgery at age 12 without proper explanation still upsets her now: 'I can't help but feel that I was mutilated and forced to become something I didn't believe myself to be; male. The scars on my body have faded, but not the ones on my mind'. Further, some individuals had complications so severe they nearly died during or after surgeries.

For hormonal therapies, negative impacts included decreased bone density/osteoporosis, moodiness and the difficulties of getting the hormones in balance such as weight gain, fogginess, aggression, de-contextualised sexual stimulation and depression. More rarely people had experienced difficulties walking due to a reduction in bone density, life threatening blood clots, and homicidal and suicidal ideation. For example, Ralph (man with intersex variation 47/XXY/Klinefelter's, 42yrs) had low testosterone and was put on T injections which made him feel more alive and energetic, but were also 'related to my rage problem and strange feelings of wanting to really hurt someone'. He said 'lots of people with KS seem to say they did feel that way' in the groups he engaged with. Celine (female with XXY/47, 50yrs) said being on her hormone therapy 'brought me to the brink of ending my life', and this was particularly aided by the fact that her doctor had said her life would 'not be worth living' if she stopped the treatment, even though it made her feel suicidal. Eunice (woman with intersex variation PAIS, 52yrs) had experienced 'blood clotting issues' from hormone therapy, and then decreased later osteoporosis:

> *I use a wheelchair increasingly, which is its own difficulty as many people ask why I am in a chair when I can walk or used to be able to walk, and I have to explain my pain and difficulty. It is another form of social isolation on top of all the lies I had to tell about my condition growing up. I feel angry and like I have been forced to be an outsider.*

Other therapies had also caused participants negative impacts such as dilation therapies particularly when engaged in by young people who were not sexually active; which many described as painful, emotionally fraught, and nothing like the sexual acts they engaged in later on in life. There were several descriptions of participants' dramatic abandonments of dilation tools that they 'threw out', 'shoved into the back of the cupboard' or kicked 'under the bed' in disdain. Frida (woman with intersex variation PAIS, 39yrs) persisted with dilation, generating further feelings of futility:

> *I have spent so much of my life and at different ages dilating this thing that nobody would want to have sex with (or could easily, at that angle). Used perspex and glass dilators for 10 minutes every other day or more. If I stop it mainly shrinks back. But I feel pointless doing it.*

Where dilation was decontextualized from any positive sexual experiences, it pre-empted sex as being dutiful, painful and penetrative; erasing potential for non-penetrative focussed pleasure/play.

Only eleven participants (9%) commented on having had solely positive impacts from experiencing interventions. Of those participants, all were either adults at the time of the interventions related to sex presentation (which included hormonal treatments, gonad removal and getting breast implants) or had experienced necessary interventions around specific difficulties associated with their variation (including surgeries for Turner's-related leg problems and trisomy-related scoliosis) or interventions they had individually wanted. Francis (transgender woman with intersex variation PAIS, 32yrs) said her parents refused to allow the hormonal treatment doctors had advised she undergo as a teen 'to my relief'. She went on to be happy with the hormone therapy and surgical treatments she sought 'as an adult, all were with consent'. Roselyn (XY female with Swyer Syndrome, 58yrs) chose hormonal treatments in her late 30s when she discovered her variation, and they aided her in 'feminising my look'. A few individuals found hormones helpful in stimulating sexual feeling and development in their late teens. Finally, Ashton (pan-gender intersex woman with PAIS and ovo-testes, 58yrs) framed only being permitted to adopt a child after having her ova/testes removed at age 30 as a positive impact; 'they (the adoption committee) considered it too risky to leave them in situ, in case I developed cancer'. This positive impact was more a case of improved social reception of the participant (rather than actual physical benefits to the participant), within what was a discriminatory context at the time, which enabled the participant to then achieve a parenting goal.

A further nine participants commented on having had no interventions, and all nine argued they had experienced positive impacts from not having had interventions. Ian (intersex male with PAIS and micropenis, 16yrs) commented he had not engaged with medical professionals on the advice of his parent 'who had terrible scarring, traumatic experiences and lots of emotional difficulties from medical treatments', and felt better about himself for this reason. Nadine (female with intersex variations Clitoromegaly/Classic CAH, 53yrs) said she was pleased she had avoided genital surgery on the basis that it was purely aesthetic, as advised by her doctor father. She had also declined hormone pills; 'I loved my lean body while lots of my girlfriends were fatter and had big baggy breasts slowing them down. Mine were cute and perky'. Rowena (intersex female with PAIS, 32yrs) felt no regret over refusing the genital surgery suggested by her doctor during her twenties:

> *I laughed when the doctor proposed it. So I am a little different, so he hasn't seen genitals like mine before... so? I lived over twenty years without feeling broken, why should I be fixed?… Whose genitals don't look a little bit funny? Genitals are always kind of 'their own fish'. Nobody looks like the ideal, we're all a bit hairy, a bit pokey; at least I can enjoy what I have.*

Overall, there was evidence in this study that some treatments were experienced as useful by some participants, particularly where they were either medically useful/necessary rather than aesthetic, or where they were delivered with the fully informed consent of the participant as part of an overall plan that enabled that participant's bodily autonomy and affirmed their own choices. Some parents and medical practitioners had really made an effort to empower, enable and support individuals with intersex variations to determine and receive the treatments they personally determined as appropriate around their sex characteristics (which was in some case cases none at all). However, there was strong evidence suggesting a pattern of institutionalised shaming and coercive treatment of people with intersex variations had existed more broadly.

Alcohol and Drug Use

The participants were asked about their use of alcohol, cigarettes and a range of drugs (from marijuana to heroin). Most of the participants mentioned that they consumed alcohol rarely (33%), monthly (12%), fortnightly (12%), weekly (29%) or daily (6%). Almost one fifth never drank. Over half of the respondents never smoked, whilst 16% of the group smoked daily. The majority of participants never used any other drugs, and only a few individual participants used any of the drugs listed daily. About one fifth of the group smoked marijuana rarely. There was almost negligible regular use of all other drugs, with some participants using sedatives and ecstasy rarely for example. These were similar figures to transgender populations (Jones et al., 2015).

Of the few participants who discussed having addiction issues, Ralph (man with intersex variation 47/XXY/Klinefelter's, 42yrs) explained how these issues were intertwined with his difficulty in having low testosterone, having been bullied and other factors related to coping with accepting his variation:

> *Until about two years ago I was drinking excessively; some evenings half a bottle of Vodka (700ml) and yes combined with smoking 10+ Marijuana joints per day, maybe cocaine 2-3 times in a year this was a mixture of avoidance of pain and emotions and for fun. I managed to get off the Marijuana, cold turkey, almost 3 years ago when I auditioned for a live theatre play. To remember so many lines, and full fill my dream of acting, this was the best thing to do. It has worked well for me now as I am focused, motivated on living the dream with my successful business and life. I very rarely smoke marijuana these days and this is only 2-3 times a year. I no longer rely on it.*

Other individuals related their addiction issues to both the emotional trauma and the access opportunity they are exposed to during surgical treatment when they were younger. For example, Marvin (intersex man with 5-ARD, 42yrs) discussed starting his drug use after his first genital construction surgery, and finding it difficult to get off them after any of his subsequent surgeries:

> *I've had struggles with addiction to scripted pain relief. I started when young and post-surgery, and found they made me feel better. Generally I can stay clean but having surgery usually results in an addiction for a few months until I can get off them.*

Inga (intersex woman with XXY/47 and Cryptochidism, 43yrs) said she barely touched most substances now beyond a drink on weekends, but had 'gone through many addictive cycles in my life with different substances when I was lost and unable to accept my lot. I am living a much cleaner, happier life these days'.

Overall Experiences with Health Services

Of 181 participants who responded to a question asking them to rate their overall experiences of health care providers' treatment of their variation, over a third (35%) of people with intersex variations rated the treatment negatively, and a smaller portion (24%) rated it positively (7% selected 'very good'; 17% 'good', 34% 'neutral or mixed', 16% 'bad' and 19% 'very bad', 7% selected N/a). Participants gave 115 comments about their overall experiences of health care services. Almost all comments save ten included mention of at least one or more negative experiences. The strongest theme around negative service delivery which emerged in the sample comments (53) was an emphasis on the lack of information supplied to the participant about their variation. Helena (woman with intersex variation Swyer Syndrome, 29yrs) said,

> *I have grown a few inches from HRT and have a more ladylike figure, a bit more weight. So I am happy about the HRT. I am not happy about the control the doctors had or the gatekeeping of my information from me. The bureaucracy of the health sector for someone with SS is one hurdle after another.*

A second strong theme in the examples of negative service discussed the need for the participants to educate their own health care practitioners to manage their lack of knowledge (38 comments). Zoe, (intersex woman with CAIS, 53yrs) commented,

> *Most specialists are not trained in intersex so they don't know how to give appropriate treatment. Many endocrinologists are good with hormones for other populations but*

> *not so experienced with intersex. Most GPs are also not very familiar with it. They are usually understanding and try to do their best but it is frustrating to have to educate them about it all the time.*

Several of these comments described participants' frustration in having to educate not just one practitioner, but many practitioners many times.

The strongest theme around positive service delivery which emerged in the sample comments was around finding a good individual or set of health practitioners/doctors (25 comments). Most commonly these comments described individual GPs who made attempts to educate themselves or to support the participant's control of their own health management plan. Jacky, (intersex individual with unknown variation, 31yrs) had their gonads removed at birth and a vagina created at age 7yrs. They describe experiencing a range of doctors over time and how dynamics with doctors were sometimes influenced by Jacky's parents:

> *My long term specialist (for renal/kidney care) has been supportive, and he told me last year (2014) that in fact the doctors wanted to tell me at age 13 that I had intersex, so I could make a decision at that age on which way I wanted to go, however this was blocked by my parents, who then also forced the doctors to put me on oestrogen. My parents have been in denial of this since, despite it being recorded by my doctors and explained to a long term specialist of mine. At age 13, I didn't want to be on oestrogen after taking it for about six months, and once I stopped taking it, I then got lectured by my Endocrinologists at the time for failing to take it. My current GP however is a lot better and is extremely supportive and is in fact a registered LGBTIQ Ally where he works on the university campus.*

Some individuals faced unique challenges in their health service experiences. For example, Marvin (intersex man with 5-ARD, 42yrs) had mostly good experiences, but found his work background impacted his privacy; *'given both me and my partner have senior roles in health it's always scary seeking help for anything genital related as we know so many doctors'*. He acknowledged that even with his high-end health career he could not 'call' doctors on their prejudice when faced with inappropriate questions, invasive unnecessary examinations and other disrespectful treatment. Clearly, if a former hospital director finds it difficult to complain about poor treatment on the basis of his intersex variation, young people and those lacking a knowledge of patient rights or medical standards likely also struggle to alert health services of such incidents.

Improving Health Services

Previous research has not yet offered clear cut methods for improving health services, and in many cases was not strongly critical of existing methods (P. Lee et al., 2014; Lux et al., 2009; Schnitzer & Donahoe, 2001; Warne et al., 2005). Participants were asked how health care services could be improved for people with intersex variations. There were 137 responses, suggesting a range of strategies for health care services or practitioners in their work with people with intersex variations. The most common suggestions included supporting people with intersex variations to choose their own treatment paths, if any (45 comments); providing training/ education for staff on intersex variations (34); providing more information on intersex variations to patients (28); and providing referrals to intersex support groups (20 comments). For example, Scarlet, female with 3BHSD Late Onset Congenital Adrenal Hyperplasia, 40yrs, called for: 'Education, education, education. I've been called in by professors of medicine and psychology to give remedial training [...] many of the texts are worse than useless'.

There were other smaller themes; fifteen participants wanted health care practitioners/doctors to stop inappropriate practices (particularly pushing or influencing people and especially children to make quick decisions about treatment); eleven wanted them to listen more; ten wanted them to avoid making assumptions (about their bodies/consent/identities). There were also comments about the need for more sensitive treatment and appropriate language use, for example Ronaldo (male with PAIS/ Cryptochidism, 49yrs) wanted health care practitioners to be aware of how their prejudices influence patients; 'I once overheard someone call me a man-woman which wasn't great for my confidence'. A few individuals described their experiences as needing no improvements.

Jane (intersex female with Partial Androgen Insensitivity Syndrome, 24yrs) contributed a comment which referred to several of the most common topics and some unique ones:

> *Don't expect kids (or adults!) to be okay with having any unnecessary pelvic exams, especially not public ones, without their permission. Don't stick your fingers near, on, in or around our genitals without permission. That is sexual abuse, not an examination. Don't force surgeries or treatments onto healthy people; you can explain that those and other options are available if we want them. Once. If we want them after that point, trust me, we will be the one to bring it up. Or even better,*

> *provide some reading material about all the different options (including not doing anything) that we can take home and take our time with, and come back to later in life if we choose to on our own terms. Don't act alarmed, frightened, concerned, or in over the top ways when you first see our bodies. You can let us know if we do not know, that our bodies are different, so that we do not find out from someone else, but do it in a sensitive way and check if we are already aware (if we did not bring it up first).*

Jane's extensive list illustrated both how detailed some of these answers were, and the protectiveness often extended to younger community members with intersex variations in the comments. Whilst the many improvements were suggested, participants generally promoted improvements which would contribute to an overall approach in which patient-rights, information-sharing and sensitive treatment featured more strongly.

6. People with Intersex Variations, Wellbeing and Mental Health Services

---

> *Going through a period of suicidal thoughts and nothing around to help; all the services are for youth or for men or for post-natal, menopausal... whatever mainstream folk have. Assistance for an intersex person who has had an extremely traumatized life and is experiencing a reaction to that and more trauma? 'Toughen up princess'.*

Kelly, intersex individual with Classic CAH, 63yrs

> *Because I struggled with exogenous testosterone, the endocrinologist who made the initial diagnoses referred me to a psychologist who said 'I didn't come across as being a typical transgendered person' …FAIL. Upon getting my life back on track and seeking out an alternative medical team, the second psychiatrist also said I wasn't typical Trans, and tentatively recommended oestrogen as an antidote to testosterone, but only for a short time. My Endo said to take no heed of what the psychiatrist wrote and has been treating me with oestrogen for the past ten years. Over that time period the psychiatrist has been in touch with me on two occasions and has written two papers inclusive of my experience of gender difference, perhaps I was the subject matter he had long waited for.*

Celine, female with XXY/47, 50yrs

http://dx.doi.org/10.11647/OBP.0089.06

Key Findings

- 59% of participants rated their mental health as good or better.
- The most commonly reported mental health diagnoses for people with intersex variations were depression, anxiety and PTSD.
- 60% of the participants had thought about suicide, and 19% had attempted it, on the basis of issues related to having a congenital sex variation.
- 44% of the group reported receiving counselling/training/pressure from institutional practitioners (doctors, psychologists etc.) on gendered behaviour; 43% reported it from parents.
- Experiences of mental health services were mostly mixed.
- Participants listed a range of ways to improve mental health services including training.

Mental Health Now

When asked how they would describe their mental or emotional health at the time of taking the survey, the largest portion (59%) of people with intersex variations described their mental health as good or better from the options provided (9% reported their mental health was excellent, 21% very good, 29% good, 29% fair and 12% poor). A group of 96 respondents had written additional explanations or lists of the mental health conditions they had been diagnosed with, and many of these responses included multiple diagnoses. Within these responses three diagnoses were the most common: 58 participants reported a diagnosis of depression; 35 a diagnosis of anxiety; and 21 a diagnosis of PTSD. There were other diagnoses including six diagnoses of bipolar, and six of autism spectrum or Asperger's. Some individuals also mentioned acrophobia, adrenalin, agoraphobia, anger, arthropodiphobia, borderline personality disorder, bulimia, gender dysphoria, schizophrenia, Tourette's syndrome, or reactive detachment disorders diagnoses for example. Some of the diagnoses related to how intersex variations were experienced or treated. For example, Briony (female with Turner's Syndrome/One X Chromosome, 30yrs) experienced her diagnosed depression and anxiety in relation to infertility from her variation, 'I do better now, however the lows when they come are lower, as this is the age my friends are all having kids'. Zeena (intersex female with Turner's Syndrome, 40yrs) suffered 'PTSD from my abusive and unsupportive childhood, including lack of body integrity and lack of understanding about my issues'.

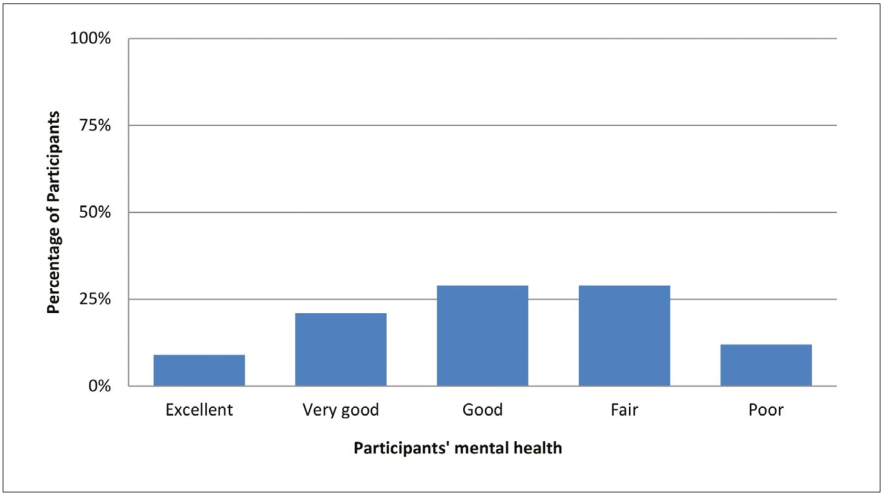


Figure 6.1: Mental health of people with intersex variations when surveyed (n=181)

Self-harm and Suicide

Of the 176 participants who answered the question about wellbeing, 42% had thought about self-harm on the basis of issues related to having a congenital sex variation, and 26% had engaged in self-harm on the basis of issues related to having a congenital sex variation. In addition, 60% had thought about suicide on the basis of issues related to having a congenital sex variation, and 19% had attempted suicide on the basis of issues related to having a congenital sex variation. These concerning statistics are higher than those for the broader Australian population (under 3% of Australians surveyed considered or had attempted suicide, Response Ability, 2013). There were 80 comments about participants experiences of self-harm and suicide. There were 31 comments directly linking negative wellbeing impacts to other peoples' negative responses to the participants' intersex variation. These comments considered the effects of being unable to connect to people with the same or similar variations, feeling isolated by stigma or discrimination, family rejection, school bullying from peers and teachers, loss of romantic relationships or tension in relationships on the basis of the variation or related fertility issues, lacking positive social reinforcement, being unable to trust others or disclose to them, and anger or depression over broader socio-cultural rejection. Marcia (intersex woman with Turner's Syndrome, 27yrs) reported that she had engaged in self-harm and considered suicide because she 'was less connected to people with TS back then and felt very, very alone'. Scarlet (female with 3BHSD Late Onset Congenital Adrenal Hyperplasia, 40yrs) experienced suicidal ideation 'after being told by a mental health professional that my existence was hurting my son'. There were also 21 comments directly linking negative wellbeing impacts to the impact of having undergone medical interventions including having undergone a traumatising or unwanted surgery and grieving the physical parts or sense of autonomy that were lost, beginning hormone therapies and feeling emotionally impacted or unlike themselves; or responding to negative experiences of having engaged in dilation therapies for example. For example, Frida (woman with intersex variation PAIS, 39yrs) had harmed herself when she discovered the cover-up of past genital surgeries that she had unknowingly undergone, and also when she 'was doing dilation a lot but getting nowhere'. Jordan (intersex individual with intersex variation 47/XXY/Klinefelter Syndrome, 56yrs) attempted suicide in the first year of hormone therapy because it 'generated feelings and desires in me that were alien' including a 'significant sex drive' despite being incapable of experiencing release (orgasm).

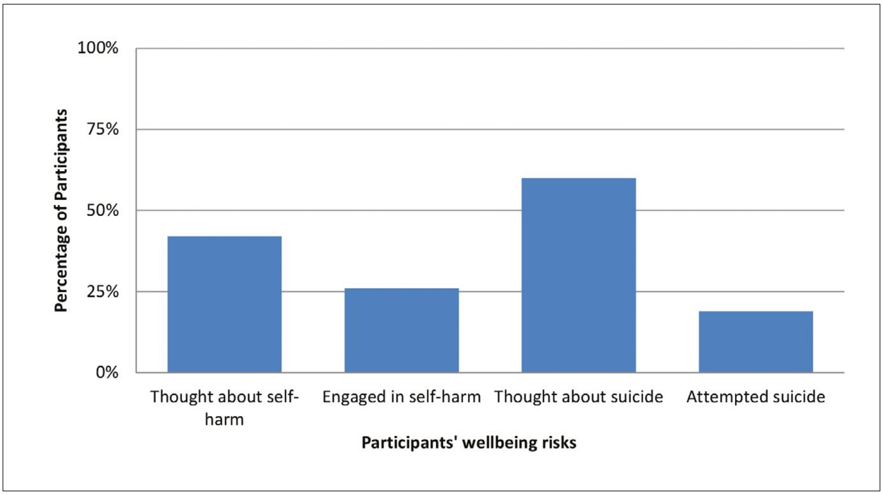


Figure 6.2: People with intersex variations' reported experiences of wellbeing risks (n=176)

There were further 16 comments linking negative wellbeing impacts to issues around gender related to having an intersex variation. These comments considered the effects of being unable to express or understand one's gender identity, recklessness during gender dysphoric periods, and attempts at trying to relieve the disparity between gender identity and body which created inadvertent bodily harm. Dylan, (man with intersex variations PAIS and Hypospadias, 24yrs) discussed his suicidal ideation in relation to confusion about his gender and sex characteristics; 'I have had difficulties with knowing who I am; knowing I am intersex was a big break through'. Jamie (X intersex individual with CAH/21 hydroxalase deficiency, 39yrs), said regarding their self-harm, 'I've cut myself to afford access to my vagina' multiple times. There were finally 11 comments discussed factors contributing to the ways participants overcame thinking about self-harm or suicide. These comments considered the value for particular individuals (who had overcome such thoughts) of drawing on relationships or not wanting to hurt family, considering how things could be worse and the good things they had in their life, recognising the signs and seeking counselling, drawing on their faith, focussing on what would they would miss out on if they died, having a friend sit with them, or receiving the message from others that they would have a positive future. Jannali (intersex female with CAIS, 25yrs) had made a 'serious plan' to end her life in the period after learning about her variation in quite negative terms from her doctor, and explained that her family's support was crucial:

> *My parents hovered about me a lot during that time and looking back, again I think I need to thank them, as I think they knew I needed to be watched and told how loved I was. They tried everything and made me my favourite foods and tried to help. It did actually help, having them there, and having them tell me I was okay and I would have a great life.*

Overall Experiences with Mental Health Services

Therapy can potentially provide a space for people with an intersex variation to come to accept any physical differences they may have, work through confusion about their sex or gender identity (if any is apparent), or issues related to any enforced surgeries if relevant (Jones & Lasser, 2015). Of 117 participants who rated their experiences of mental health service providers' treatment of their variation, the largest portion (30%) rated the treatment as neutral or mixed (10% selected 'very good'; 9% 'good', 30% 'neutral or mixed', 13% 'bad' and 10% 'very bad', 28% selected N/a). Participants gave 96 comments about their overall experiences of mental health care services. 38 comments discussed ways in which mental health providers and workers were problematic; 21 comments discussed mixed experiences of both good and bad mental health workers; 18 described good experiences of mental health workers and 18 described how the respondents were offered/referred to no mental health services at all. Experiences described in negative terms mainly included using mental health services where there was a lack of training or unwillingness to become educated. Ahmed (intersex man with micropenis, 29yrs) even felt his psychologist didn't believe in intersex variations or that Ahmed actually had a micropenis; 'and I'm not whipping it out'. Other problems included when the mental health workers/psychologists misunderstood having an intersex intervention as a sexual disorder or fetish of some kind or became overly interested in sexual details. Finally, there were problems with mental health workers not appreciating the particular links to both experience of social bias and wellbeing risks that having an intersex variation can have and therefore not being open to discussing themes which were important to particular participants. A few individual comments in this group related problems with the sense that a particular psychologist or mental health worker took 'the parent's side' or the doctors' perspective on treatment or other issues rather than supporting their client, or only saw the client for money and gave little actual aid. Wendell (male with 47/XXY/Klinefelter's) said his counsellor did not even ask how he was doing, and just 'took the money and ran'.

Conversely, elements of mental health services which were affirmed in the comments mainly included mental health services and workers which were not 'put off' by intersex people and actively interested in serving them; those that made the effort to educate themselves and even the participant on new information about their variation (including on sex issues or fertility issues, for example); those that aimed to empower and enable the participants in seeking the treatments or tests that they specifically wanted. Frida (woman with intersex variation PAIS, 39yrs) had positive experiences of mental health services, and commented; 'I have taken much out of my therapy sessions, it was great to talk to someone. Gestalt therapy helped me to see my body was my own and carried with it the memory of all the things done to it'. Veronica (female with intersex variation CAIS, 26yrs) said, 'I have spoken to two counsellors about my variations. They have not known anything about it to begin with but have been happy to learn and do their own research'. Of the individuals who said they had not been offered mental health services, many said this was support they might have valued. For example, Danielle (female with intersex variation CAIS, 41yrs) said:

> *I have never been recommended mental health services nor received any counselling as a result of coming in contact with any other treating physician for my variation, even though I've been depressed and suicidal a few times in my life.*

Patti, intersex female with CAIS, 37yrs similarly wondered, 'no support was offered to me as a child/adolescent or to my parents/sibling. I wonder if it was what would be different'.

Counselling/Training on Gendered Behaviour

People with intersex variations were asked if they had experienced any counselling, training, or pressure to act in a more feminine or more masculine manner from any one in their life. Of the 211 participants who responded, 44% of the group reported experiencing this counselling/training/pressure from institutional practitioners (doctors, psychologists etc.), and 43% reported experiencing it from parents. In total 103 comments on these experiences were provided by respondents; 44 focussed on counselling/pressures to be feminine, 28 on counselling/pressures to be masculine and the remainder on a range of other smaller themes most notably including the pressure to mature. The comments that focussed on femininity often discussed clinical or familial pressure towards becoming a 'normal woman'; often conceptualised within the comments as pressure to wear dresses and long hair, remove any bodily or facial hair, play with girls, learn and do domestic duties and hobbies, become physically capable of penetrative sex, and marry a man, for example. Giana (female with intersex variation PAIS, 17yrs) faced both counselling around her femininity and 'medical pressure about making myself more fully a woman and removing the remainder of the testes'. Marina (woman with Swyer Syndrome, 18yrs) had experienced pressure from her doctor on how to act and what interventions she needed to be feminine, and reflected he 'said I would need to be more womanly look to catch the boys. That meant like a curvier body. I hate him. Idiot'. Tori (woman with intersex variation CAIS, 58yrs) recalled how she had been 'counselled' by a professional to spend more time with other females, towards fitting in.

The comments that focussed on counselling/pressures around masculinity often discussed pressure to be strong, to go to the gym or build muscle, to be unemotional, to avoid clothing or behaviours seen as feminine, to engage in HRT or 'corrective' work on genitalia, to fit fathers' or other males' conceptualisations of maleness. Raj (male with 17-beta-hydroxysteroid dehydrogenase deficiency, 26yrs) said his psychologist had pressured him to be more masculine and 'told me to go to the gym to build my body up'. He had since found that working in the field of IT, the presentation of his body mattered less and his psychologist's assumptions about the need for a masculine presentation were less relevant because in his less physical working environment he had been pleased to discover 'no one cares'. Jordan (intersex individual with intersex variation 47/XXY/ Klinefelter Syndrome, 56yrs) said 'I resisted hormone therapy for many years', but became 'worn down by doctors whose view was that to remain androgynous was not an option'. Angus (male with hypospadias, 51yrs) discussed the difficulty of urinating in-front of his father or other males growing up and how the presentation of his penis had been a major focus of discussion of his masculinity. Bailey (intersex non-binary individual with Klinefelter's and ovo-testes, 25yrs) found pressure from professionals and parents to be more masculine, including being told not to use certain bags or act in certain ways, shaped who they became:

> *I was ridiculed for not liking sports, and for preferring poetry and playing with dolls. My lack of physical strength was also a target for teasing and ridicule. In a lot of ways I came to resent being seen as weak, and like to both outsmart people as well as to be tough and scrappy; to beat people in physical fights by being able to take harder hits than them rather than to hit hard myself. I also liked to show off the skills I do have and make fun of guys for not being able to do things that are easy for me.*

Unfortunately, a few individuals reported being hit by a parent within contexts of being shamed for perceived femininity or encouraged to increase their masculinity/strength.

The comments that focussed on counselling/pressures to be more mature discussed the pressure to 'grow up', to engage in adolescent or adult interests and activities and forego those considered 'childish', and to engage in or show interest in dating. There were several participants who discussed this pressure which particularly came from parents and family members, including people with Kallman's and Turner's Syndromes which may impact puberty and development. Gabriel (male with intersex variation XY/XO Mosaics, 19yrs) felt pressure ‘to grow up. Not my fault I couldn’t! That is part of Turners’. Vita (intersex female with Kallman’s Syndrome, 18yrs) commented:

> *I was always growing up without growing up, getting a bit taller but like a taller child, with a young body and interests. So my family did encourage me to date boys and try things teenaged girls did and I was more interested in quiet games at home or doing schoolwork. You’d think they’d like that but they wanted me to meet boys and do things like my sister. My sister did too, she tried to get me to dress sexier but I was not having those feelings and did not want to be seen that way. Doctors would say I’m a late bloomer, a late developer, that once I got interested in the boys it would all start happening and I should try to get out more. But they were wrong! I was very normal for a KS teen apparently.*

Kyle (intersex male with Kallman’s, 28yrs), similarly noted ‘when you are little people say they want you to be a kid forever. But that is a lie’, explaining that when someone does not experience a puberty ‘they say he is short for a boy his age. Or he doesn’t like the girls. Or he is too scared for his age’.

Improving Mental Health Services

The data from this study around suicidal ideation and other mental health outcomes appeared to have contradicted Warne et al.’s (2005) assessment of ‘psychological outcomes’ for ‘patients with intersex conditions’ for medical intervention, which perhaps downplayed psychological risks to this population. Notably, Warne et al. did not ask the people with intersex variations themselves how they had felt about the interventions they were subjected to or their need for them. Participants in this study were thus directly asked how mental health care services could be improved for people with intersex variations. There were 108 responses, suggesting a range of strategies for mental health care services or practitioners in their work with people with intersex variations. The most common suggestion advised mental health practitioners and organisations to seek training/education on intersex variations (33 comments). For example, Briony (female with Turner’s Syndrome/One X Chromosome, 30yrs) advised mental health practitioners to learn about the variations experienced their clients; ‘I should not be paying you to listen to me to talk about the variation, you should do that groundwork on your own time and not charge me or waste my sessions with explaining information that can be googled’.

Another popular theme (in 29 comments) advised mental health services to be supplied specifically for younger people/children/adolescents with intersex variations which could empower and support them to have a say in their medical treatments and interactions around their body with doctors and/or family. Ruth (female with intersex variation 21 hydroxylase deficiency, 18yrs) explained further how she felt mental health services could be supportive of mental health for young people:

> *This would mean acknowledging their confusion or supporting their gender identity even if the parents want you to make those things go away. How about supporting the kid to deal with the parents being difficult, or offering time to the parents to deal with why they find it all so difficult.*

Other participants talked about the importance of allowing young people the space away from their parents to understand their own perspectives, as well as counselling with their parents/carers so that they are supported to have these perspectives voiced and listened to by key adults in their lives.

There was a long list of other improvement recommendations for mental health services including promoting decreased bias against people with intersex variations, encouraging staff to use increased sensitivity in dealing with intersex variations, not dismissing the person with the intersex variations' own perspectives on their own bodies, and a range of other points. Ahmed (intersex man with micropenis, 29yrs) offered the following poignant reflection:

> *A lot of things happen to intersex people that sound paranoid and outlandish; some of them we remember and some of them we don't; the records destroyed in a fire story is very common (hopefully now that there are electronic records in many places, 'lost' records won't happen so much). Don't assume that experiencing trauma necessarily leads to mental health problems, sometimes people just need help figuring out specific issues like career moves, financial stress, relationship problems etc., and revisiting procedures that happened 15-65 years ago can be very damaging.*

There were also suggestions for developing specific mental health supports or experts for people with intersex variations, or offering referrals to support groups for people with intersex variations.

7. People with Intersex Variations and Education

> *I found out (about having Turner's) at 9, but my parents knew before then because of the problems with my legs and some other signs (slow to learn some things like crawling) when I was a kid. They really could have said something earlier. I liked knowing why I was small and why I had some (back then smaller) problems with my elbow and knees, for example. It helped to understand why I had such a hard time at school, too. But I did not like that my parents and doctor had known ALL ALONG and told me only then, when (a related learning disorder) was affecting my school work. And I was told in a meeting with school staff, so I was not just being talked to alone or anything. That was hard because it was confusing, embarrassing and I did not feel I could ask questions really until much later. (Having information on intersex variations supplied by school) would have helped people to understand me and what I was going through, and even now I wish my friends knew more so they could understand, and the place to get that is school.*

Una, female with intersex variation Turner's Syndrome, 21yrs

> *My teacher had us browse the web to find out something about DSD. It was weird, because when she asked us if she should invite a member of the LGBTQI+group in Austria and told us about DSD, in this moment I thought: Oh my god, she's talking about me. I am the only student in my class who knows of the existence of DSD. I was feeling a bit unwell, when the person was in our school to talk to us. I didn't say anything about it to my parents, because I think it is my condition and they don't have to know that I spend time with this issue of my life. This year, when the eleventh form was confronted with this issue, in the break, I thanked my teacher that she taught teenagers about it and that I was really feeling awkward last year because I knew what she was talking about, better than she knew. (The last part I skipped though, because I didn't want her to know that I am intersex). My three friends don't know that I have DSD, but two of them said that whatever I had, I would still be their friend. I wouldn't change because of this. I was so relieved and am planning to tell them in the summer. The first two people that would know that I have DSD because I willingly told them. I'm looking forward to it. The other person wasn't so amused about it and I really don't know what to do. I don't want to lose her but on the other side can't I give her the same as somebody different could.*

Merryn, intersex woman with PAIS and Cryptorchidism, 18yrs

http://dx.doi.org/10.11647/OBP.0089.07

Key Findings

- Most (62%) people with intersex variations had a post-secondary qualification, however a much higher portion (18%) had not completed secondary school compared to the general Australian population.
- Despite national legal protections for students with intersex variations, education policies and guidelines detailing how to support their education access were mostly lacking.
- Almost all (92%) participants attended a school lacking inclusive puberty/sex education provisions.
- Almost all (95%) participants attended a school lacking inclusive counselling/referral links.
- Only a quarter of participants rated their overall experiences with education/school positively. Participants suggested improvements to education focussed on information provision and specific support features for people with intersex variations.

Education Level

Some aspects of the education levels attained by people with intersex variations were similar to average – the majority of participants had a post-secondary schooling qualification of some kind (62%), a similar portion to the general Australian population (57%, Australian Bureau of Statistics, 2012a). These participants were relatively divided between having post-graduate degrees (14%) and undergraduate degrees (22%), and TAFE qualifications (24%). In addition 20% of participants had achieved their High School Certificate as their highest level of educational attainment. On the other hand, a notable portion of participants had only completed primary school or lower and not gone on to ultimately complete secondary school (18%), and this portion was much higher than the portion of the general Australian population who had not attained their high school certificate (2%, Australian Bureau of Statistics, 2012a). It was also higher than transgender populations who had not attained their higher school certificate in recent studies (Couch et al., 2007; Jones et al., 2015).

Given that by law Australian young people are required to stay in schools until 15-17 years of age (depending on state and territory laws), this educational disruption suggested that there have been difficulties for people with intersex variations either in school contexts themselves, and/or in relation to their general experiences at schooling age, in ways which affected schooling success and meant they dropped out of/left schools without being able to take advantage of the full qualifications available to them there, and increasingly necessary for opening up job opportunities in modern times.

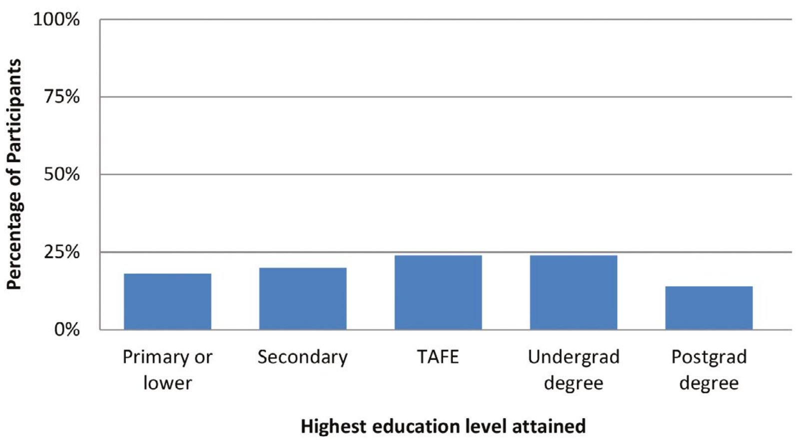


Figure 7.1: Highest education level completed by people with intersex variations (n=251)

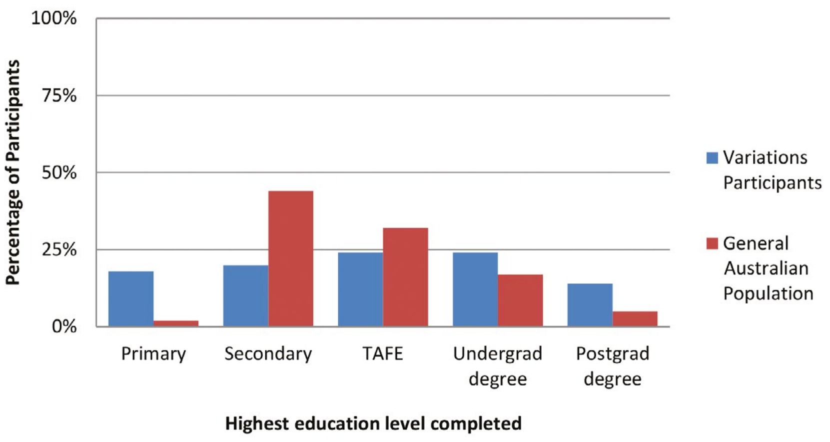


Figure 7.2: Highest education level completed by *Variations* participants (n=251), compared to the general Australian population (n=22,906,400)*

---

* As reported by the ABS (2012).

Whilst previous literature has highlighted the difficulties for both same sex attracted and gender questioning young people in schooling environments (Hillier et al., 2010; Jones & Hillier, 2012), the specific experiences of young people with intersex variations in educational environments had not been explored; this educational attainment data showed the urgent need for further investigation.

Examining the data on people with intersex variations who had left school early, all went to schools with no inclusion of intersex variations in curricula or in terms of the school counsellor's provisions, almost all were Australian, and most left school around the eighth-ninth grade (so during the years most associated with expectations around puberty developments and hormone therapy interventions). Lily (intersex female with MRKH/congenital absence of vagina, 31yrs) said she had 'very bad' experiences at school, which she did not detail further. Surrounding and possibly contributing to the school experience, she had also gone through 'traumatic' medical treatment incidents after having her variation diagnosed in eighth grade; her genitalia were examined in-front of groups of medical students for example. She had thought about and attempted both self-harm and suicide, and was ultimately diagnosed with PTSD and depression. She explained, 'I was a teenager. I felt like a freak. I didn't know this was possible. I felt like I was very alone and that something was really wrong'. Given her emotional state, ultimately that same year she 'dropped out of school early'. Her view on what would have helped her in school was 'teach about it (variations)' as a normalising message. Zachary (male with intersex variation, Klinefelter syndrome 47/XXY/micropenis, 20yrs) said his intersex variation 'may be why I left school early and found it hard'; without testosterone treatment he had felt low energy and found it hard to concentrate, whereas with it he experienced a lot of anger. He recalled that at school 'I was always called lazy, had no energy. Probably from low testosterone I reckon, they were pretty mean teachers'. His view on what would have helped him in school was staff training on variations; 'learn about the variations, help kids through, don't assume low energy = lazy it could be a health issue'. Inga (intersex woman with XXY/47 and Cryptochidism, 43yrs) dropped out in grade nine, after intense bullying and a general sense of 'being so lost' and looking for the school to 'find' her or reach out in some way. She offered that schools should find places in their curricula 'to discuss intersex bodies, chromosomes, and the many varied elements of sex as early as possible. Repeat this over the different grades. It will be the ray of light kids like me were looking for, and it is after-all, true'.

There were other experiences of educational disengagement which were directly related to poor experiences of medical treatment and related mental health complications, where students spent a lot of time in hospitals or became so distressed they were unable to engage in a regular manner in schooling requirements, fell behind and finally left. In addition, some of these participants also did not go into detail around leaving school early, so from them what we mainly learn is that students with intersex variations may be at increased risk of early drop out for a combination of reasons (including some that we don't yet know). Educational disengagements on the basis of issues surrounding intersex variations were also not exclusive to junior and secondary schooling. Several people discussed starting study programs when they were older or wanting to begin study to upskill for a new field, but then dropping out due to depression or other issues related to psycho-social experiences of having an intersex variation. For example, Lara, female with intersex variations (Gonadal dysgenesis/mosaicism/ovo-testes, 27yrs) explained that she had dropped out of university after going through a period of depression based on past medical treatments and anxiety attacks around even 'stepping foot in' hospitals. In all these situations counselling that was inclusive of people with intersex variations was lacking in the educational institution, and this in combination with schools offering general affirming messaging around diverse bodies and development variations prior to and during the years associated with puberty (so starting well before eighth grade) potentially could have been a first point of assistance or contact that could reach students (including those who had not yet disclosed their variations to the school) towards managing the difficulties they faced and facilitating supports around maintaining engagement or offering re-engagement with education systems at a later date, as needed.

Policies and Programs

In 2013 the SDA Amendment Act (Sexual Orientation, Gender Identity and Intersex Status) made discrimination on the basis of intersex status in the provision of education unlawful. Concerted efforts by the lead researcher and activists behind this report, and many other groups, ensured that no exemptions for religious schools were supplied in the new law – at least regarding intersex status (The Senate Legal and Constitutional Affairs Legislation Committee, 2013). This means that religious schools *cannot* claim doctrinal exemptions from their obligations to respect students with intersex variations' rights to access their education, although these legal provisions have yet to be tested. However, as yet the Australian Government has not created a national education policy on supporting the access or experience of students with intersex variations in school, there are as yet no clear guidelines on how non-discriminatory schools can be achieved nation-wide. In 2015, Victoria's previous 'Gender identity and students with a transgender or intersex status' policy in the *Victorian Schools Reference Guide* (VIC Government, 2007, 4.5.10.11) was no longer available. The old policy had supplied the most (and only) guidelines on supporting people with intersex variations in schools at the state level; with a focus on maintaining their privacy and encouraging their own/their advocate's involvement in any individual management plans created for the school. A policy officer had previously explained that this policy was developed by the Victorian Department of Education and Early Childhood and Development on the basis of requests for guidelines from various schools who had students with related concerns in their care (Jones, 2015). The existence of policies has been previously shown to be useful for other key student groups in schools (Jones, 2015); as it currently stands, Australian schools lack guidance on how best to provide the non-discriminatory access and environments for students with intersex variations now required in law.

Puberty/Sex Education Provision

Specific education guidelines supporting people with intersex variations is currently lacking in Australia and overseas (Jones, 2015). Proposed national curricula inclusion of GLBTIQ issues in sex education and health had been deleted from the most recent draft of the forthcoming *Australian National Curriculum* at time of print, to the outcry of many advocates and researchers – including ourselves (McNeilage, 2013). Participants were asked whether any of their schooling (primary/secondary) offered inclusive puberty/sex education information about congenital sex variations in a positive manner. Overwhelmingly (for 92% of the 182 participants who answered the question), the response was 'no'. Therefore, these students experienced less inclusive puberty/sex education at school than the two thirds of transgender students who found it mostly inappropriate in other research (Jones et al., 2016). Participants gave 80 comments about their puberty/sex education. The strongest theme emerging in 58 comments was that information on intersex variations was prevented by more dominant messages on abstinence, restrictive notions of body normativity, binary sex/gender constructions, and focuses on reproductive penetrative 'penis in vagina' sex or religion-based morality and censorship. Various participants described how in their schools' lessons normal boys and girls were described or pictured with no sign that kids with intersex variations were normal too, that sex was described as a binary of 'XX vs. XY' to the exclusion of other possibilities, that only able-bodied people were represented or even that no bodies were really discussed in detail. These comments also sometimes discussed the absences of intersex variations 'from' biology, sex education, physical education and other areas where they may have potentially emerged. For example, Edwina (woman with intersex variation Mayer Rokintanky Kuster Hauser Syndrome, 27yrs) argued, 'schools are in on this big conspiracy of silence about [...] bodies that were anything other than fully functioning reproductive systems in generic male and female patterns'. Jane (intersex female with Partial Androgen Insensitivity Syndrome, 24yrs) said there was 'nothing in science about it. Nothing in sex ed. Nothing in PE. I kept expecting it to come up when they talked about bodies, like it would have been logical, but it never did'.

A second strong theme in 14 comments outlined ways which information in schools could become inclusive of intersex variations in future. The participants imagined the information fitting into education around not only puberty/sex education, but also science, discussion of the variety of bodies people have (at increasing levels of complexity from the very basic to discussion of chromosomes and so on in a spiral curriculum) in the context of biology, physical education, and developmental stages and what to do if 'you don't reach them'. Some participants had envisioned the potential for discussion of ethical issues around having kids with intersex variations and how to raise them, discussion of how the range of human bodies are not accurately represented in movies or pornography, or the kind of information a student with an intersex variation might not be otherwise getting elsewhere. For example, Dylan (man with intersex variations PAIS and Hypospadias, 24yrs) commented that in the age of the internet, 'it would make a big difference for all kids if they could understand that real bodies come in lots of sizes and can look very different to porn and movies'. James (intersex man with aphallia, cryptochidism and another variation, 53yrs) commented on a range of information useful to kids with intersex variations and their peers, saying 'if this were more widely talked about I may have had a chance of knowing what was happening to me. I think schools these days are much more able to do this, with the right help'.

A small set of six comments discussed negative constructions of people with intersex variations which *did* emerge in participants' classrooms. These constructions included visions of people with intersex variations as: having disorders, weird, rejected, negatively construed, or an awkward topic socially. Warren (intersex man with unexplained scarring, 38yrs) reported that the puberty/sex education information his school provided on intersex variations included 'only negative messages about disorders and weirdos'. Merryn, (intersex woman with PAIS and Cryptorchidism, 18yrs), said 'It wasn't mentioned until high school and in high school it was negative'. Finally, two comments were offered by people who *had* reported attending schools providing affirming messages on specific variations in puberty/sex education. Vita (intersex female with Kallman's Syndrome, 18yrs) reported that staff disseminated information on Kallman's Syndrome on her request; 'when they found out they helped me explain to the people who I wanted to know and they just basically supported me'. Olivia (intersex woman with CAIS, 28yrs) directly disseminated information at her school; 'high school health class was my first time sharing about my CAIS. I DIDNT share about the intersex aspect, but it was a start'. Whilst these individuals felt supported to discuss or have staff discuss at least some information on their own specific variations, the lack of a systematic and broad approach to general inclusion of the existence of intersex variations in schools due to the dominance of strong 'normativity' messaging certainly remained the strongest theme in the comments overall.

Responses to Disclosures

Participants were asked how not only people at educational institutions, but a range of people treated them regarding their intersex variation, and the comparative results can be found in more detail in Chapter 9 of this book. A key finding of this study was that most people with intersex variations had not told school staff about their variation, whilst just over half had told their classmates. Principals were the least likely people in a student's life to be told about their intersex variation overall; further, they were the least likely of all key people for the participant to be supportive and the most likely to be unsupportive. Of 161 participants who answered the question on how their principal treated them in relation to their intersex variation, only 4% had reported that they told their principal about their variation and found they were supportive. Further, 11% told their principal and found they had a neutral/mixed response and 22% told their principal and found they were unsupportive – 63% did not tell their principal about their variation. Shannon (intersex person with ovo-testes, 17yrs) found it difficult that their principal insisted that 'I had to be enrolled as either male or female'.

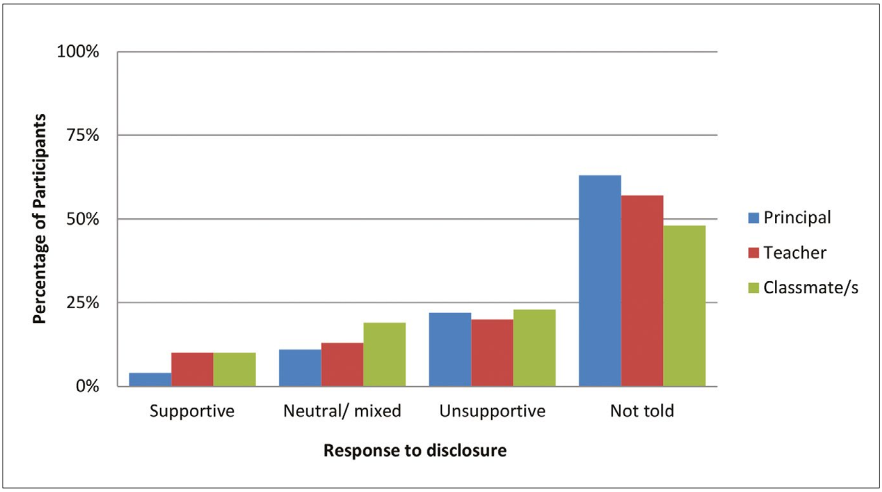


Figure 7.3: Comparison of principals, teachers and classmates' responses to students' disclosures about their intersex variations

Of 164 participants who answered the question on how their teacher treated them, only 10% had reported that they told their teacher about their variation and found they were supportive. Further, 13% told their teacher and found they had a neutral/mixed response and 20% told their teacher and found they were unsupportive – 57% did not tell their teacher about their variation. Antoinette (female with intersex variation Swyer Syndrome and gonadal dysgenesis, 29yrs) experienced unexpected difficulties when teachers did not know of her variation:

> *My High School PE Teacher was unaware and my diagnosis was fairly new. She didn't realise my physical inability and lack of desire for physical activity stemmed from an inability to do it due to being way behind my peers, physically. She should have clued in from my sheer extreme tiny size that something wasn't quite right. She then proceeded to bully and harass and even accused me of being a drug addict.*

> *I duly informed her it was medical treatment... told her it was none of her business and told her the Principal was aware of my new diagnosis, told her what it was. She had accidentally seen some needle bruise marks... so her confusion was partially justified but the attack without further investigation wasn't! The epi-pen was yet to be available for Human Growth Hormone so I was pretty bad (at self-injecting) and marking myself […] alerting her to attack and poke her nose into my personal business.*

Of 162 participants who answered the question on how their classmate/s treated them, only 10% had reported that they told their classmates about their variation and found they were supportive. Further, 19% told their classmates and found they had a neutral/mixed response and 23% told their classmates and found they were unsupportive – 48% did not tell their classmates about their variation. Cassie (female with Turner's Syndrome, 19yrs) also reported that her teachers were not informed enough about her variation and this impacted their ability to perceive or respond to how Cassie was treated by peers: 'My principal and teachers could have learned more too. Some people in the class and some friends bullied me for how I look or what I find harder than them'. Edwina (woman with intersex variation Mayer Rokintanky Kuster Hauser Syndrome, 27yrs) found being unable to discuss her variation with her classmates led to misunderstanding and judgement during the period of time that she underwent genital surgeries:

> *My school principal, teacher and counsellor made it hard for me to get the time off school I needed and did not understand the need to deal with the situation in the time it took. My classmates either thought I was a freak or did not understand what was going on and saw me as a bludger trying to get out of class (I was bleeding like a stream from my vagina for god's sake, it is not something you want to say is happening or go to school with).*

School Counselling/Referrals

Participants were asked whether any of their schooling (primary/secondary) offered or provided links to counselling that affirmed people with an intersex variation. Overwhelmingly (for 95% of the 178 participants who answered this question), the response was 'no' as this simply was not available through their schools. Therefore, these students experienced less inclusive counselling at school than transgender students for example, who have reported affirming changes in attitudes amongst school counsellors in recent years (Jones et al., 2016). There were 49 comments on the issue of counselling offered by participants. The comments on school counselling and referrals for students with intersex variations fell into four themes. Firstly there were 27 comments on the way in which the participants' counsellors had never heard of or mentioned variations. For example, Vincent (male with intersex variation XXY/47, 49yrs) said 'they were clueless about all this'. Secondly, there were 13 comments on what participants considered poor practices by school counsellors, such as neglecting to learn about or show interest in a student's variation, not perceiving the student's need for someone to talk to an advocate concerning their variation, dismissing bullying, for example, or promoting engagement in gender norms as a way to 'fit in' and resolve social problems. In one example, Ruth (female with intersex variation 21 hydroxylase deficiency, 18yrs) went to her school counsellor about bullying she experienced, and was unsatisfied with his dismissive response:

> *'Boys are boys, what did I expect, everyone has a hard time'. So somewhat dismissed it to get me out of the office, did not pass on my complaints, and left me alone with nobody but my brother to protect me. Offered me no help or sympathy about CAH when I went to them about this, just said it was not his area.*

Thirdly, there were six comments by participants saying they wished inclusive counselling or referrals had been available, which were illustrated by Toni's (female with intersex variations Turner's Syndrome and XY/XO Mosaics, 23yrs) comment: 'This would have really helped me'. Finally, there were three comments about good counselling experiences, where formal or informal school counsellors took an interest in and actively tried to learn about and help the student. For example, Giana (female with intersex variation PAIS, 17yrs) commented that the 'current counsellor tries really hard to help, she was not trained to know about CAIS, but she looks things up and shares them with me'.

Overall Experiences with Education/School Services

Of the 178 participants who responded to a question about their overall rating of their education/school service experiences in general, approx. a third (34%) of people with intersex variations rated their overall experiences with education/school services negatively, and a smaller portion (24%) rated them positively (11% selected 'very good'; 13% 'good', 31% 'neutral or mixed', 24% 'bad' and 14% 'very bad', 11% selected N/a). Participants offered 102 comments about their school experiences overall. In total, 77 of the participants made comments about being bullied, ranging from daily to occasional incidents. The bullying ranged from occasional rude questions which the participant tried to dismiss or could distract themselves from with study or engagement in sports, through to regular insults (like dyke or boy-girl) or physical violence requiring staff or family interventions, which participants sometimes reported as linked to negative wellbeing outcomes such as dropping out or engaging in suicidal ideation. Perpetrators were mainly students and occasionally staff. Sometimes the bullying was directly on the basis of a known variation, more often it was on the basis of unusual traits (such as tallness or shortness, lack of energy, lack of development, learning disorders or various sex characteristics) or engagement in treatments (and subsequent time off school) related to participants' particular variations or treatment plans. For example, Olivia, intersex woman with CAIS, 28yrs said, 'Indirectly, I did get made fun of for being tall, having big hands and feet' related to her CAIS. Briony (female with Turner's Syndrome/One X Chromosome, 30yrs) reported:

> *I had a hard time as I looked different and was called names from primary to high school. I was called retard or downs' syndrome, lots of nasty names. I was physically less mature and that became so tough in high school. I wanted more help from staff than I got, definitely.*

Sheldon (intersex male with De la Chapelle/XX Male Syndrome, 31yrs) said when teachers discussed his variation most of the time the wording they chose sounded 'as if it were wrong. A disorder. This is very frustrating for an intersex person'. Ruth (female with intersex variation 21 hydroxylase deficiency, 18yrs) said her 'hair was pulled, I was pushed into walls, and I was hit a few times before my brother started walking me in, which I know he resented having to do'.

Secondly, 14 participants made comments about their variation not being known at school, whether because it had not yet been discovered or because they were keeping their variation secret (on family advice or their own plan). This worked for some people who wished to maintain their privacy. However, some of these comments showed that this could lead to its own problems, such as for some a sense of shame attached to lying and secrecy, for some difficulties in getting their needs met or the sense that they 'slipped through the net'. For others, there was some misunderstanding about their situation which they didn't feel they could rectify given the lack of information available to pass on that could help making disclosure 'worthwhile'. Eunice (woman with intersex variation PAIS, 52yrs) said that whilst she felt her parents may have been right to keep her variation private in some ways given the lack of knowledge of what it meant, in other ways she struggled because she 'had to lie to my teachers and could not answer the kids properly. It was so stressful. I needed someone to help me with how to handle the situation and no one was there'.

Thirdly, 11 participants made comments about good experiences they had in their education, including the ability to be open, social support, a lack of discrimination, and teachers encouraging the students to do further projects on their variation (such as a film in one case, written project and web research). Over half the participant comments discussing positive experiences mentioned that these experiences occurred in university or TAFE environments rather than in schools. Ling (intersex woman with CAIS, 18yrs) reported, 'I am very open about my condition, and I will talk about it freely. Everyone is kind and supportive'. Jacky (intersex individual with unknown variation, 31yrs) said that being set a special project by a lecturer and working on the topic of exploring intersex variations with a team of other students,

> *…allowed me to properly open up in my own way separate from the class which kept me feeling safe, and since then I've managed to become more comfortable in speaking to others beyond simply some close friends and obviously family being aware of being intersexed. Overall though, I haven't had any other major issues with university, TAFE or school, and myself being intersex rarely comes up, and only comes up if there is a context to it.*

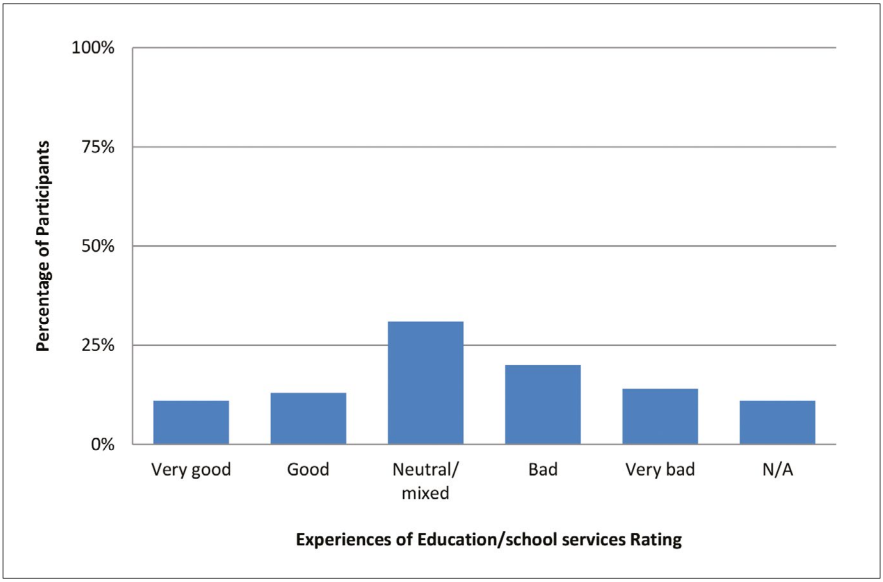


Figure 7.4: People with intersex variations' rating of their overall experiences of education/school services (n=178)

Improving Education Services

Participants were asked to describe any ideas, features or action they recommended regarding how schools/education services could have improved their services in regards to their variation. There were 111 short answer comments supplied by participants in response. The most common suggestion (in 68 comments) advised providing information on intersex variations both to staff and students. This included around puberty/sex education, description of genitals' formation and those between penis and vagina, describing a range of intersex variations and their features, and similar topics. For example, Edwina (woman with intersex variation Mayer Rokintanky Kuster Hauser Syndrome, 27yrs) suggested:

> - *Information on lots of body types,*
> - *information on lots of various genital developments,*
> - *name the many chromosome types people have,*
> - *revise human biology in school science as it is over-simplified to the point of being incorrect,*
> - *information on the many sexual acts between two people of whatever type, intercourse is not all it is,*
> - *information on lots of reproductive options including not having kids,*
> - *information not judgement.*

Some responses argued that it would be important, in provision of information about having intersex variations, for teachers to understand that many students with these variations do not disclose their identities at school but that information sessions may create opportunities for them to do so. Teachers would need to understand the need to create a safe space for the possibility of disclosures or to note for students that nobody was under any pressure to disclose any variations they did have.

In addition, 27 comments advised ensuring provisions specifically useful for individuals with intersex variations including: supplying counsellors trained on people with intersex variations, support for networking of students with intersex variations, social assistance from teachers in ensuring people with intersex variations make friends if needed, and allowing students with intersex variations some involvement in planning the management of disclosures and other supports (such as allowances around not having to share change rooms if needed, for example) that they may feel they individually would need at school to enhance their education access. For example, Gordon (male with intersex variation Klinefelter's

Syndrome/47 XXY and micropenis, 21yrs) recommended schools 'have a plan and let us discuss it and what we need, in a meeting in a relaxed way'. Also, 12 comments advised schools on addressing bullying against people with intersex variations; whether through prevention policies, protection in the form of greater staff attention to bullying on the basis of sex characteristics and intervention in the issue, and defending people with intersex variations in the event of attack. Ruth (female with intersex variation 21 hydroxylase deficiency, 18yrs) said, 'it should not be up to the students to have the support, all the teachers should be aware of bullying'. Further, four comments advised systemic changes overall to how gender and sex are treated in schools. James (intersex man with aphallia, cryptochidism and another variation, 53yrs) said 'there need to be system-wide changes in schools to make these spaces friendly to people outside the traditional male and female body types, and to stop their over-reliance on gender as the basis of absolutely everything that happens there'. This included offering allowance in single sex schools for lenience around uniforms if needed for various reasons. Finally, other comments suggested improvements that included promoting protection for teachers with intersex variations becoming visible role models for students and training school counsellors to be able to help determine if someone needs to be tested for intersex variations.

8. People with Intersex Variations and Employment

> *… I felt they were more interested in my appearance and identity than my skills and experience. I strongly believe that gaps in my resume related to medical issues, and intersex activism, have an impact on my perceived employability. As a result, I tend to look for work in the Non-Government Organisation (NGO) sector. I have experienced unnecessary questioning about aspects of my physical appearance in the workplace.*

Neil, male with intersex variations testicular impairment 'disorder' and gynaecomastia, 48yrs

> *I left my employment in (a country town) as being a government teacher I couldn't get a transfer to the city to access medical treatment. When I left my boss wrote a two line shocking reference after finding out my reason for needing to move from the country town to the city. I was also attacked by a student with a knife in the school yard when I was living in a female gender role. There was no support from my employer to affirm a male identity in the workplace.*

Guido, male with intersex conditions Ovo-testes and PCOS/Hyperandrogenism, 48yrs

http://dx.doi.org/10.11647/OBP.0089.08

Key Findings

- The majority of participants (65%) were working (full-time, part-time or casually).
- 12% were unemployed and looking for work.
- The majority of participants (63%) earned an income under $41K per year.
- More than half the people with intersex variations surveyed had not told their employer/boss about their variation, and a similar amount had not told co-workers. The responses to participants' disclosures from both employers and co-workers were mostly neutral/mixed.
- When asked whether having a congenital sex variation had impacted their work experiences, 48% said yes and 24% were unsure. Impacts included: obstacles to gaining or maintaining work, and effects on some participants' comfort in particular working arrangements or industries.

Main Occupation

Most people with intersex variations surveyed were employed (65%): full-time (40%), part-time (13%), or casually (12%). In addition, there were participants who were unemployed and looking for work (12%) – a higher portion in comparison to the general Australian population, although comparable to and falling between the 9-15% portions of transgender people unemployed in various recent studies (Couch et al., 2007; Jones et al., 2015; Pitts, Smith, Mitchell, & Patel, 2006). There were also participants who reported they were on a disability pension (12%) or retired (8%). An additional portion of the people surveyed reported that they were also engaged in 'another option' (21%, mainly in conjunction with maintaining their employment) – largely study. Specifically, of these 39 people 25 were engaged in study at school, TAFE or university; four were self-employed; two were at-home parents; two were carers; and two were volunteers. There were also individuals who reported unique responses such as that they were applying for disability support, forced to resign due to bullying/harassment, being made redundant or suffering from an illness.

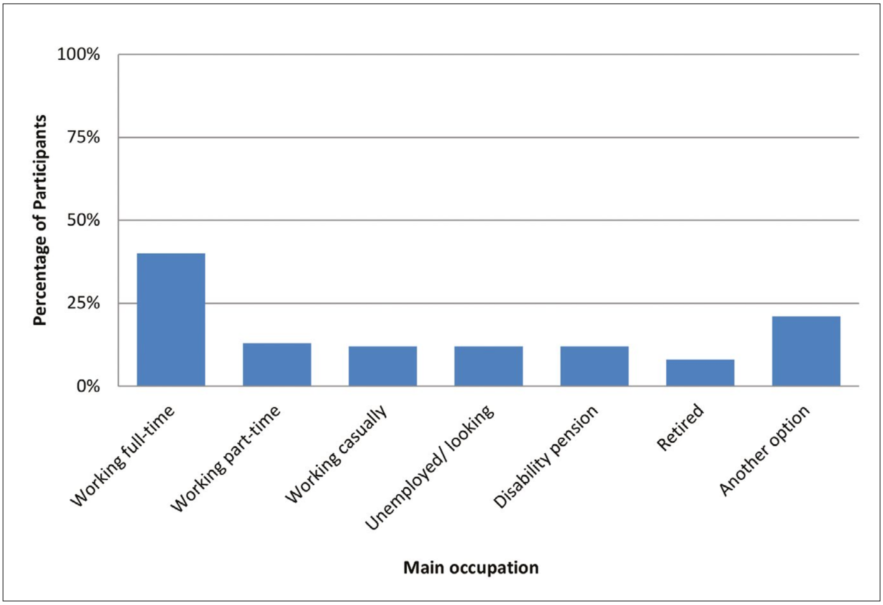


Figure 8.1: Main occupation of people with intersex variations (n=182)

Income

People with intersex variations had a range of annual incomes. At first glance the income earned by the group seemed relatively low, with the majority (63%) under $41K per year. Moreover, 41% were earning less than $20K, and this is a significantly larger portion than the 35% of transgender people in *Tranznation* (Couch et al., 2007) and the 22% in *Private Lives* (Pitts et al., 2006). Perhaps this could be partially explained by the fact that a larger portion were on disability pensions. There were also however participants earning a range of salaries: 21% earned $41K-$60K, 7% earned $61K-$80K, 4% earned $81K-$100K, and 5% earned over $100K. So, whilst a smaller portion of the participants were earning the higher wages than across Australian populations more broadly, and they seemed to be earning less than expected for such a well-educated group, the data showed it was certainly achievable for this population to be gainfully employed. The researcher surmised that there were likely factors (such as issues related to treatments or perhaps particular issues in gaining work) which might be impacting the group's work opportunities.

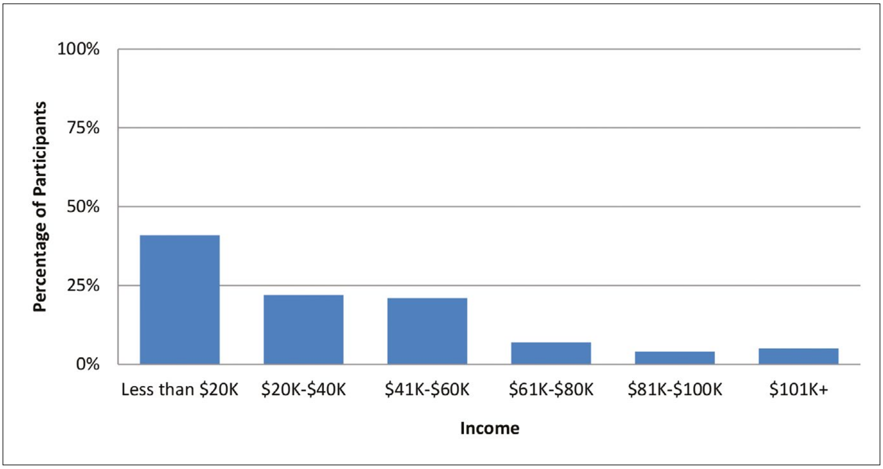


Figure 8.2: Income of people with intersex variations (n=180)

Responses to Disclosures

The 2013 SDA Amendment Act (Sexual Orientation, Gender Identity and Intersex Status) made discrimination on the basis of intersex status in employment unlawful, with no exemptions for religious organisations. Until now there has been no national data on whether or not people disclose that they have intersex variations to their employers or co-workers, and how they are treated in response to their disclosures. Participants were asked how not only people at work but a range of people treated them regarding their intersex variation, and the comparative results can be found in more detail in Chapter 9 of this book. However, it is important to note here that more than half the people with intersex variations surveyed had not told their employer/boss about their variation, and a similar number had not told co-workers. The responses to participants' disclosures from both employers and co-workers were mostly neutral/mixed. Of 160 participants who answered the question on how their employer treated them in relation to their intersex variation, only 12% had reported that they told their employer about their variation and found they were supportive. Further, 19% told their employer and found they had a neutral/mixed response and 10% told their employer and found they were unsupportive – 59% did not tell their employer about their variation. Like the majority of participants, Peter (male with an intersex variation/DSD/Leydig Cell Hypoplasia/

Micropenis/Cryptorchidism, 41yrs) had not disclosed to anyone at work. He said he 'hid everything' from his employer. Guido (male with intersex conditions Ovo-testes and PCOS/Hyperandrogenism, 48yrs) was among the tenth of respondents whose employers had reacted negatively to disclosures about his intersex variation, and for Guido this impacted his ability to express himself within his (teaching) role and also his ability to get a decent reference when he left the job. Veronica (female with intersex variation CAIS, 26yrs) contrastingly was supported by her bosses, and said 'I work in an LGBTIQ organisation so work has been very supportive'.

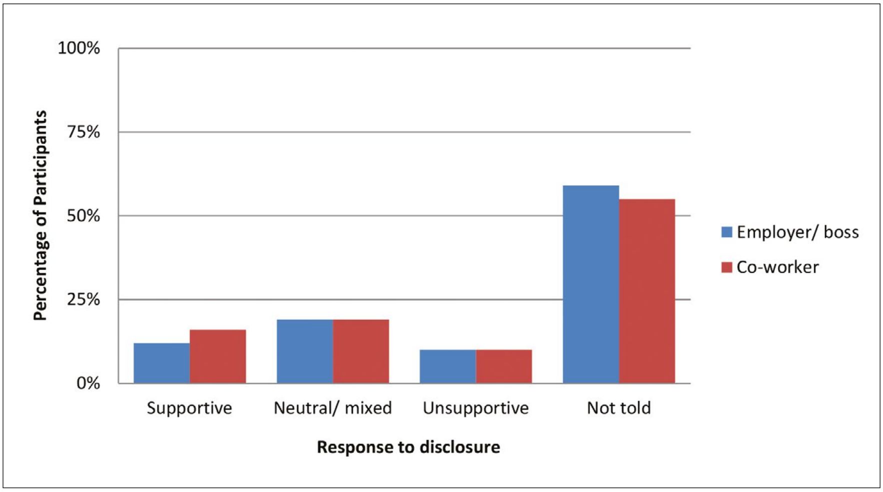


Figure 8.3: Comparison of employers and co-workers' responses to employees' disclosures about their intersex variations

Of 159 participants who answered the question on how their co-workers treated them, only 16% had reported that they told their co-workers about their variation and found they were supportive. Further, 19% told their co-workers and found they had a neutral/mixed response and 10% told their co-workers and found they were unsupportive – 55% did not tell co-workers about their variation. Like most people in the study Blake (male with XXY/47, 49yrs) did not disclose his intersex variation to co-workers. He reported that he had difficulty in disclosing 'in all relationships including at work'. A few participants found relations with co-workers fraught enough to warrant choosing alternative working arrangements. For example, Ashley (intersex individual, with bladder exstrophy/ Klinefelter's/ovo-testes, 53yrs) commented, 'When I was not self-employed

I was a victim to workplace incidents'. Jamie (X intersex individual with CAH/21 hydroxalase deficiency, 39yrs) rarely told people at work about their intersex variation, and reported that co-workers often became overly-fascinated with them if discussions of their variation arose:

> *Mostly with official type people, employers and whatnot, it's not appropriate to discuss (my variation), and if it comes up with co-workers it is met with disbelief. It's very awkward because a lot of times there is some kind of playful attraction they feel toward me and are unsure how to deal with, and eventually it becomes a very big problem and interferes with our professional relationship. As a result, I have learned the skills and bought my own tools and equipment so that I can contract jobs independently, but now, I'm basically a cripple because my adrenals have left me so weak.*

Raj (male with 17-beta-hydroxysteroid dehydrogenase deficiency, 26yrs) worked in IT and was of the small group who had both disclosed to, and been supported by, some colleagues. He commented that compared to other people in his life, 'colleagues were better as they did not have anything invested in how I am, they just like to hang out. [...] That kind of acceptance feels good and I like being able to talk to them about it'. Overall, it is quite understandable that employees were more likely not to disclose that they had intersex variations to employers or co-workers, given the largely mixed nature of responses experienced for disclosures, so employers and industry leadership need to understand that people with intersex variations may work in their organisations/sectors whether or not they discuss this. However, the new anti-discrimination legal protections in place reinforce that those who do disclose in the workplace should be more strongly supported than is currently the case, and some of the incidents discussed suggest that general workplace policies and guides around appropriate professional responses to employees with intersex variations broadly could be useful.

Overall Impacts on Employment

To further understand the distinct nature of the issues that arose for people with intersex variations around employment according to the quantitative survey data, participants were asked whether having a variation impacted their work experiences overall. Of the 178 participants who responded to this question, 48% said having a variation impacted their work experiences and 24% were unsure. Around a third (35%) said it did not. Participants supplied 96 comments on the ways having intersex variations impacted on their work experiences. The largest theme that emerged (in 58 comments) was around negative impacts which were obstacles that people with intersex variations experienced to their careers; whether the obstacles were to getting a job, time spent on the job, keeping or wanting to remain in a job, or overall support at the job. Some obstacles were related to prejudice based on employers' responses to physical impacts of variations. For example, Debbie (woman with intersex variation PCOS/Hyperandrogenism, 34yrs), whose variation made a noticeable impact on her body particularly in terms of facial and bodily hair for example, felt 'sure I did not get some jobs because of prejudice'.

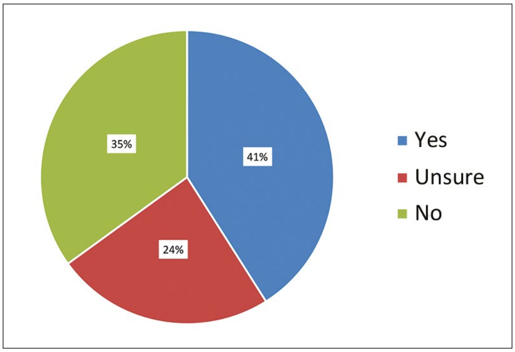


Figure 8.4: Were participants' work experiences impacted by having intersex variations (n=178)

Other participants felt they were held back by the complications of direct and indirect mental health impacts related to having a variation. Take Monique (female with intersex variations Classic CAH and Clitoromegaly, 58yrs), who commented that she 'needed time off for depression over the surgery'. Or for example Patti (intersex female with CAIS, 37yrs), whose depression and self-loathing around her experiences both made it difficult to gain full-time work and were further fed by not gaining full-time work – which therefore 'made engaging with the workforce and market place extremely difficult'. There were also participants for whom the physical impacts of some of their variations or their treatment interventions were themselves prohibitive, such as Eunice (woman with intersex variation PAIS, 52yrs):

> *Because I am now wheel-chair bound related to the osteoporosis, related to having my testes removed, I see this as an indirect impact of having a variation, or a direct*

> *impact from the surgeries. This affects me every day and it made the work I used to do (which was physical) impossible to continue, and I had to retrain in administrative skills.*

Multiple individuals experienced this sense of being trapped outside of employment opportunities at some or several stages in their lives, or in an ongoing manner.

The second largest theme that emerged (in 24 comments) was around the practical ways in which having intersex variations impacted the type of work or industry/field that the participants engaged in, which was usually seen as a positive impact and less commonly as a negative one. This impact was sometimes characterised by gaining an enhanced interest in a field through their exposure to it through the experience of having an intersex variation (such as science, biology, medicine, nursing, social work); sometimes this impact was more characterised by being unable to do certain jobs or aspects of jobs (such as phone-based roles which could be impacted by a hearing impairment, or driving which some participants found stressful due to other impairments or their short height). In addition, sometimes this impact was characterised by wanting to work amongst certain types of people (such as artists, activists, NGOs, LGBTIQ groups) or in fields where it was possible to be more hidden or retiring from human interaction (self-employment, librarian work, IT work, non-service roles) or going where participants believed they could explore or affirm a certain element of their gender expression (hairdressing, truck driving, and so on). For example, Marnie (intersex woman with gonadal dysgenesis, 58yrs) said she changed profession in relation to her intersex variation; 'I had a very high profile and visible job in an organisation and felt like it was a vulnerable point and that I could be 'exposed' and marginalised in the political nature of the role as intersex'. Nora (intersex female with Complete Androgen Insensitivity Syndrome, 31yrs) said:

> *It gave me my interest in medical work, I do not think the idea would have occurred to me if I had not been exposed to it in such a powerful way. I wanted to be on the other side of the stethoscope too, to not be the one being looked at. It makes me look at patients in a different way too, having been in their shoes.*

Eight comments discussed the lack of any impact which having intersex variations had on employment for some people; this was usually explained in terms of their variation not being visible or not impacting their abilities in anyway, and the participants' preference or decision not to disclose it. For example, in a comment typical for this sub-grouping, Bailey (intersex non-binary individual with Klinefelter's and ovo-testes, 25yrs) said that having a variation 'doesn't change a thing; other than that I don't talk about it'. Five comments discussed generalised skills, not specific to any one industry, that participants reported that they had gained from having intersex variations. These included greater social skills for several of them (who for various reasons were able to connect on a deeper level with colleagues after disclosing their intersex variations), greater career ambition and greater empathy. For example, Georgina (trans intersex woman with Cryptochidism/Hypospadias, 71yrs) said 'I am more empathetic in my dealings with others who are vulnerable for whatever reason'. Louise (woman with CAIS, 38yrs) discussed engaging in 'increased career striving' related to how she had been told from a young age that she would be infertile and might need other types of fulfilment to draw on besides child-bearing. Whilst these days there are many options around having children if one is infertile, Louise reported that it made her see her career as having the potential to be a more fulfilling part of her life than she might otherwise have realised. She worked full-time and had progressed significantly and enjoyed a high income.

9. Social Support for People with Intersex Variations

> *I went through a twenty month legal fight to get an Australian passport; they couldn't figure out what sex I was. [...] I was offered a travel document that would enable me to leave the country for specialist treatment, but not return. While DFAT was hostile, Immigration was supportive, the people were aghast after they'd verified the way I'd been treated, and they worked extra unpaid hours to help me. When I left to standing applause for my courage and patience, I shed a few tears at their kindness. I have also experienced one minor arson attack from religious nutters who think I'm the spawn of Satan, and two dousings with holy water.*

Scarlet, female with 3BHSD Late Onset Congenital
Adrenal Hyperplasia, 40yrs

> *Meeting happy, healthy intersex people online caused a complete and radical shift in my thinking and wellbeing. Seeing that they had come out about being intersex, and that they liked themselves, that some had partners, and that they sometimes even talked about having had and enjoyed various kinds of sex, that they had found all these ways to have children and jobs and lives... BEST. THING. EVER!*

Jannali, intersex female with CAIS, 25yrs

http://dx.doi.org/10.11647/OBP.0089.09

Key Findings

- Of the key people in their lives, participants' doctors, mothers and friends were most likely to know about their intersex variations; principals and priests/spiritual advisors were least likely to know.
- Participants were most likely to have experienced supportive responses from a friend, partner, sister or mother; and least likely to have had a supportive response from people at school.
- Whilst most participants assessed their variations as mainly rarely to not at all obvious, a smaller portion of participants felt their variations were mostly or completely obvious to strangers.
- 66% of participants had experienced discrimination on the basis of their intersex variation from strangers.
- Most (70%) never or rarely discussed their variations with strangers, and could risk being exposed to common myths about their identities in discussing the topic. Conversely, most (65%) said engaging with others with their variation or similar improved their wellbeing.

Responses from Key People in Participants' Lives

Participants in the study were asked about how a range of key people in their lives treated them regarding their intersex variations; including family members and other loved ones, friends, health and mental health service providers, people at work, people at school and religious/spiritual advisors. Their responses firstly distinct showed trends in who actually knew about their variation and how they responded. The participants' doctors (92%), mothers (90%) and friends (88%) were the most likely people in their lives to know about their variations. In addition, fathers (79%), partners (74%), sisters (64%) counsellors (60%), brothers (57%) and classmates (52%) were more likely to have been told than not. Fewer participants had told their co-workers (45%), teachers (43%) and employers (41%). Finally, priests/spiritual advisors (30%) and principals (27%) were least likely to know of participants' variations of those discussed.

Participants reported that the key people in their lives who knew about their variations had responded in a variety of ways. Participants were most likely to have experienced supportive responses from a friend, partner, sister or mother. Unfortunately, participants were least likely to have experienced a supportive response from the people in their schools – their principals, classmates and teachers; and from their priest/spiritual advisor.

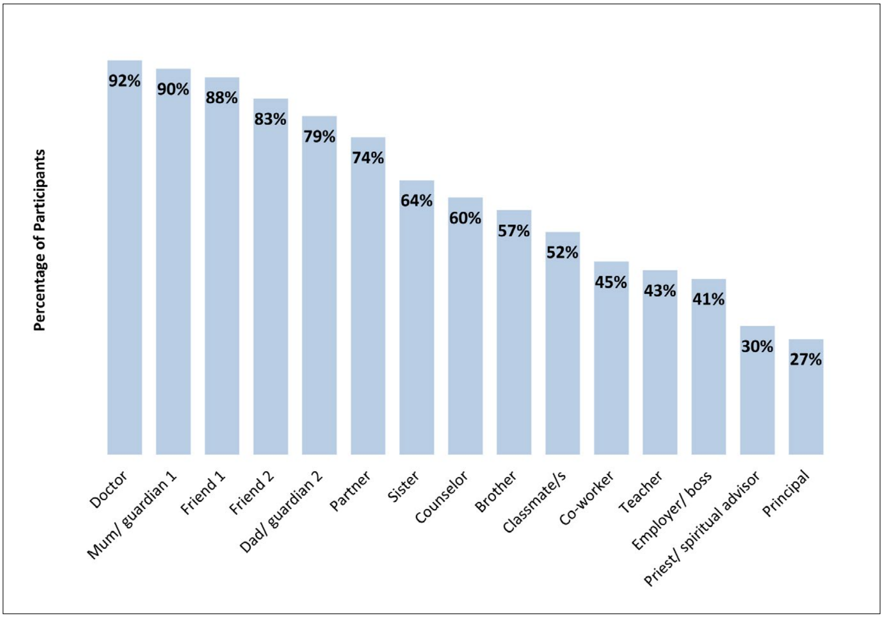


Figure 9.1: Percentage of participants who had key people in their lives know about their intersex variations

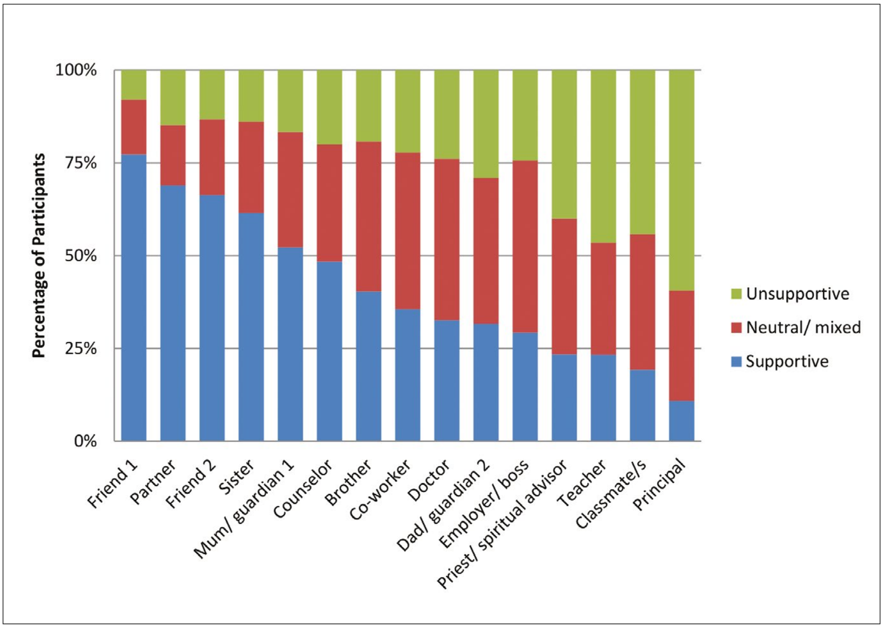


Figure 9.2: Responses participants experienced from key people in their lives about their intersex variations

Given that most participants were under 18 at their time of finding out about their intersex variation and at that time they tended to experience psychological vulnerability; school staff and (if relevant) religious/spiritual leaders could have potentially been a very important influence in their lives at their point of greatest sensitivity – yet the data suggest that participants did not receive appropriate support from these people. Further, principals stood out as a group for having been the most likely to actively respond in an unsupportive manner according to participants' reports. Further difficulties for people with intersex variations at schools and at work, tied to these findings, were discussed in earlier chapters.

Participants gave 125 comments about their disclosures and experiences of support from people in their lives. Examples of discrimination in the comments (featured in over half of the comments overall) particularly focussed on themes of the emotional difficulty of these experiences. Barbara (trans intersex female with PAIS, 40yrs) reported having particular experiences of discrimination for which she was considering making a formal claim with the backing of her social workers in lieu of family support, which really 'took a toll' on her. Fernanda (female/X with PAIS, 25yrs) said:

> *I have had a few incidents, one was with a male GP who replied that I looked so 'normal' for an intersex person. Also growing up in the church has also been difficult, not so much on a personal level but on an institutional level; normative gender roles are very much advertised. I also sought counsel from one of my pastors and they brought my sexuality into the mix which I thought was very unnecessary, and quite beside the point.*

Kelly (intersex individual with Classic CAH, 63yrs) said 'previous partners treated me as if I was a pervert, priest warned me I would end up in permanent psych care, my father sexually abused me on the basis that I was an 'Hermaphrodite''. She found it difficult to get the right counsellor to deal with the abuse she had experienced because people were distracted by her being intersex and 'folk want to hear about Intersex not trauma'. Angus (male with hypospadias, 51yrs) discussed the difficulty of facing rejection from sexual partners who would 'freak out thinking it's contagious'. Sometimes peoples' biases against people with intersex variations manifested more subtly; 'my doctor, priest and principal try to make it like I am fit into a box, they look uncomfortable when I say I don't know how I feel, or I don't think I want to be a mum or whatever' (Kennedy, non-binary intersex female with Classic CAH, 17yrs). Many individuals discussed having key people in their life who simply refused to discuss their intersex variation and tried to encourage normative sex expressions (in terms of parents, this was more often fathers).

Examples of support in the comments (featured in just under half the comments) particularly focussed on themes of the refuge provided by friendship, and to a lesser extent some participants' appreciation of family protectiveness. Firstly, friendships were seen as refuges from the tensions of other relationships because friendships did not have the same implications other relationships did. For example, Ashley (intersex individual, with bladder exstrophy/Klinefelter's/ovo-testes, 53yrs) had supportive friends who provided a refuge away from tensions with their father and his religious views, and expressed a common view that 'friends should always be supportive, that's why we pick them' whereas parents may want a child to be more directly reflective of their own selves. Marnie (intersex woman with gonadal dysgenesis, 58yrs) said that whilst 'my mum felt like it was her fault and maybe it was something she did while she was pregnant, and so was always upset about discussing it', she had one close friend who was 'the only person who is interested and wants to know more and support me'. Reese (intersex female with CAIS, 40yrs) said some of her partners in the past had not fully understood and were unable to continue their relationships with her, as her intersex status made them question their own sexuality. Compared to this, disclosure to friends felt less fraught and was how she gained her social support; at work she would also ensure 'only close friends are aware; disclosure to everyone at work would make working life difficult'. Further, there were participants who experienced support more as expressions of protection, whether from abuse or from medical interventions or other things. Xanthe (woman with intersex variation Triple-X Syndrome/XXX, 18yrs) illustrated the theme of people looking to their families for protection, saying, 'my family are really good and very defensive of me, if anyone says anything about my height'. Jannali (intersex female with CAIS, 25yrs) said the 'biggest thing' her parents had done for her was to be open with her from early childhood and to prevent her being forced into any interventions. Debbie (woman with intersex variation PCOS/Hyperandrogenism, 34yrs) said 'family always told me I was natural, nothing wrong with me' despite what others including medical professionals said to her. Angelina (intersex female with PAIS, 35yrs) said most family, including her grandmother who is quite religious, 'accepted it without question'. Briony (female with Turner's Syndrome/One X Chromosome, 30yrs) explained her brothers were 'very protective and supportive [...] if anyone said anything about me looking different or being small, they would back me up in a second. They help me with anything I need, like fixing my car to suit my height'.

Visibility of Participants' Variations to Strangers

In order to understand the social experiences participants with intersex variations had in relation to strangers, it was necessary to first establish the level of visibility participants assessed their own intersex variations as having. Overall, the participants assessed their variations more often as being on the 'rarely to not at all obvious' end of the scale rather than obvious to strangers. Specifically, 41% reported that their variations were 'Not at all obvious, people never notice'; 20% reported that their variations were 'Rarely obvious, few people notice'; 23% reported that their variations were 'Sometimes obvious, it varies/some people notice'. Only 7% reported that their variations were 'Mostly obvious, most people notice' and only 9% reported that their variations were 'Completely obvious – people always notice'. This suggested that in the main, one cannot tell who in society has intersex variations simply by looking at people; although a small portion of people with intersex variations are more noticeably visible in one way or another.

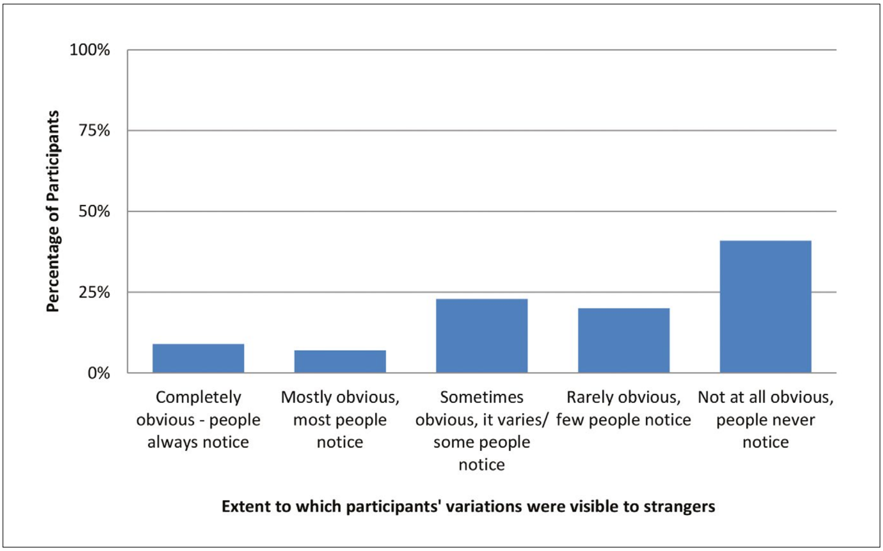


Figure 9.3: Extent to which participants' intersex variations were obvious to strangers by their own estimations (n=190)

Participants wrote 112 comments on the visibility of their congenital variations. The largest theme that arose in 53 responses described many participants' experience of not being visible to strangers as having an intersex variation, unless they chose to tell someone, were naked or having sexual intercourse. For example, Veronica (female with intersex variation CAIS, 26yrs) found that her androgen insensitivity made her present very directly as female and given that her XY chromosomes were not visible to the eye, said 'I feel that I pass in society as female and there would be no question about it unless I mentioned it'. Stewart (male with intersex variation Klinefelter's/XXY, 39yrs) said HRT helped him to look masculine; '…on T especially I am like most guys most of the time'. Ariel (intersex female with cryptorchidism, 54yrs) reflected on how people not only do not read her as having a variation but always assume she has fully functioning female parts: 'first time I went to a free clinic about three years ago for an intake assessment, the nurse asked when I last had my cycle and was totally shocked when I told her that I have never had one'. Rowena (intersex female with PAIS, 32yrs) similarly commented that her variation was not obvious 'unless my pants are off, and even then doctors have missed it completely because they were distracted by other concerns... but once you look directly yes, there is a difference in size and shape. I guess that all shows how unimportant it is, most of the time'. Invisibility could have some drawbacks in connecting with other people with intersex variations in community contexts; Blake (male with XXY/47, 49yrs) commented 'Apparently nothing is visible of my condition. The biggest problem is not the disclosure of the symptom but the ignorance of people who do not know the differences that unite us'.

Contrastingly, 24 responses described some participants' experience of being 'visible' to strangers and directly identifiable as having some kind of intersex or otherwise congenital variation. Taylor (intersex X/male/female individual with gonadal dysgenesis/hypospadias/micropenis, 42yrs) commented that strangers often perceived their intersex variations as 'my shape seems wrong to people'. Kelly (intersex individual with Classic CAH, 63yrs) was frequently made aware of how they stood out, saying; 'I get reminded twice a day on average that I am sir... err madam... err'. Warren (intersex man with unexplained scarring, 38yrs) explained his intersex variation 'mainly affects my height, voice, and body composition [...] others harass or discriminate against me for it'. Siobhan (girl with intersex variation TS or 'TS butterfly', 16yrs) said:

> *I look very young and short and have a small voice. My ears stick out, my jaw is small. Some people think I am extra cute, some do not like or understand people who look a bit different. But people do see it, I know that. Having the neck surgery (to reduce neck webbing) did help.*

Sienna (female with Polycystic Ovary Syndrome (PCOS)/Hyperandrogenism, 30yrs) was unable to hide her facial hair and general androgynous appearance even with great personal effort, 'even when I have fully plucked my 'beard' (a nightly occurrence), I have very irritated rough skin that stands out' and she was 'also very frequently judged because of my size'.

A further 20 responses mainly described some participants' experience of being not clearly identifiable as intersex necessarily, but often misread in some way whether mis-gendered or mistaken for having a sexuality they do not have, or not being consistently 'read' as the sex they were. For example, Ruth (female with intersex variation 21 hydroxylase deficiency, 18yrs) reported that she had a mixture of feminine and masculine features and a particularly deep voice, thus she reflected, 'my body can be unexpectedly girly if you only met me on the phone, or my voice can be a shock if you only saw me first'. Bailey (intersex non-binary individual with Klinefelter's and ovo-testes, 25yrs) commented 'I hate that I get automatically assumed male just because of my facial and body hair the structure of my jaw'. Olivia (intersex woman with CAIS, 28yrs) said 'I have some people look at my height and facial features (angular) and call me a man or sir. Then they apologize and realise I'm a woman. Awkward!' Lastly, 15 responses mainly described some participants' experience of inconsistency in how people perceived them at different points in their life when their variation had become more or less obvious over time with age, or the way they had responded to it (whether hiding it less in their physical presentation, or the extent to which they had sought treatments) had changed. Sasha (intersex individual with 5-ARD and PAIS, 45yrs) said that after years of trying hard to fit in and more recently feeling comfortable enough to be themselves, 'it's probably more obvious now, but it wasn't obvious at all until a few years ago'. Nina (intersex female with 3beta hydroxysteroid dehydrogenase deficiency, 32yrs) explained, 'since I have had some treatments it is less obvious to strangers, but more obvious to old friends for example'.

Responses from Strangers

Participants were asked how often they experienced discrimination related to their variation when interacting with strangers. Overall, 66% of participants had experienced discrimination on the basis of their intersex variation from strangers. Specifically, 34% reported that they experienced discrimination from strangers 'Never'; 35% 'Rarely'; 21% 'Sometimes'; 6% 'Most of the time' and 4% 'Always'. Participants were asked to give examples of support or discrimination they had experienced from strangers. Participants gave 86 responses. In total, 70 responses detailed examples of discrimination participants had experienced. A few individuals mentioned indirect discrimination. For example, Edwina (woman with intersex variation Mayer Rokintanky Kuster Hauser Syndrome, 27yrs) reported that without being aware of her variation, people often said:

> *…derogatory stuff about hermaphrodites or people who did not fit sex norms, about women who choose not to have or cannot have babies, about people who don't have 'real female bodies'… these rules on who can be what impact me so much. Most of all, I hate it when people make rules about what intersex people should do with their bodies.*

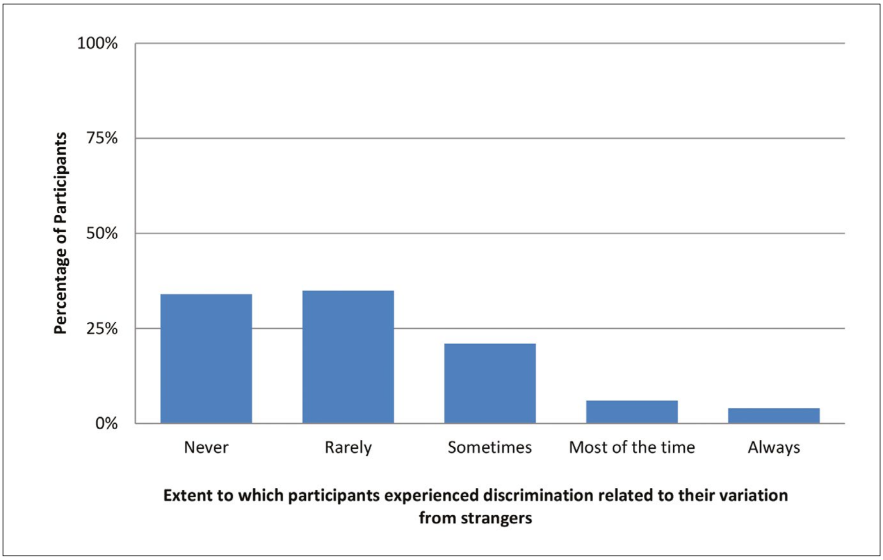


Figure 9.4: Extent to which participants experienced discrimination related to their variation from strangers (n=189)

More frequently the examples included direct experiences of rudeness and personal insults (most commonly dyke, gay, tranny, boy-girl, hermaphrodite, giant or shorty, retarded etc.), being laughed at, being looked down on and so on. For example, Barry (intersex male with Klinefelter's/47/XXY, 17yrs) said he was often 'laughed at and insulted with his shirt off, like at the pool or beach'. In specific contexts (such as shopping centres) discrimination examples sometimes involved being denied documents in processing situations, being mis-gendered and then escorted out of bathrooms, being actively overlooked in service situations, or being over-charged or over-examined (amongst many other examples) in medical contexts. Mickie (X individual with intersex variations including PAIS and mosaicism, 33yrs) recounted practical daily experiences of discrimination in many specific contexts, listing incidents including being 'refused service in restaurants' or when 'A taxi driver refused to return my change'; adding 'Sometimes people don't want to talk to me and I am unsure why'. There were also experiences of violence. Peter (male with an intersex variation/DSD/Leydig Cell Hypoplasia/Micropenis/Cryptorchidism, 41yrs) said other males would 'try to give you a wedgie or a few hits during a tackle'. Debbie (woman with intersex variation PCOS/Hyperandrogenism, 34yrs) said that strangers had at times been both verbally and physically abusive with her; 'they would get confused, call me tranny, ladyboy, butch, transman, gay. All the names. I have been hit and shoved. I have been tripped over. Paper cups, balls, various items thrown at me'.

Nine responses detailed participants' explanations of why they felt they did not experience either discrimination or support; mainly because they have been using silence and privacy maintenance as a means of self-protection, their difference was not noticeable or they had provided some education in their key social contexts about their variations. For example, Merryn (intersex woman with PAIS and Cryptorchidism, 18yrs) said, 'I never tell strangers about DSD, so it is not possible' (for people to discriminate against her). Vita (intersex female with Kallman's Syndrome, 18yrs) said, 'Some kids my age have called me anorexic or pointed out how I had no boobs. When they found out about the KS it stopped'. Seven responses detailed mixed examples of both support and discrimination participants had experienced. Marina (woman with Swyer Syndrome, 18yrs) was 'called flat by two boys on the bus, but they are mean to everyone'. Conversely, she found that 'girls like how skinny I am'. Anne (intersex woman with Ovo-testes and XXY/47 karyotype, 87yrs) commented, 'It was much worse when I was younger and finding my way. Now I stand tall and brook no rudeness, people are more respectful to me, they will follow your lead so you must stand proud in this life'.

Strangers, Explanations and Myths

Participants were asked the extent to which they discussed their variations with people they'd just met in their everyday life. Most (70%) never or rarely discussed their variations with strangers. Perhaps contributing factors for this included not only the risk of discrimination (discussed earlier) but also the likelihood of being exposed to false beliefs or myths about people with intersex variations which have filled in the space left by the lack of education identified for the topic in schools. In total, 136 participants named myths or misconceptions that other people seemed to believe about people with their variation. The most commonly cited myth (in 62 responses) were that people with intersex variations were not 'really' the sex that they lived as but actually another sex – that they were either lying, hiding parts or somehow had parts they actually did not have that would somehow more accurately pinpoint them as that alternate sex (whether male, female, X or otherwise) beyond the one *they were*. For example, Sarah, (woman with intersex condition PAIS, 44yrs) said the myth that 'if I am XY, I am a man, is the big misconception'. James (intersex man with aphallia, cryptochidism and another variation, 53yrs) commented that this myth had been expressed in the form 'that someone born without a penis' (such as himself) 'is female'. He reflected that, 'a man is more than what is between his legs, and a woman is more than just 'not' a man'.

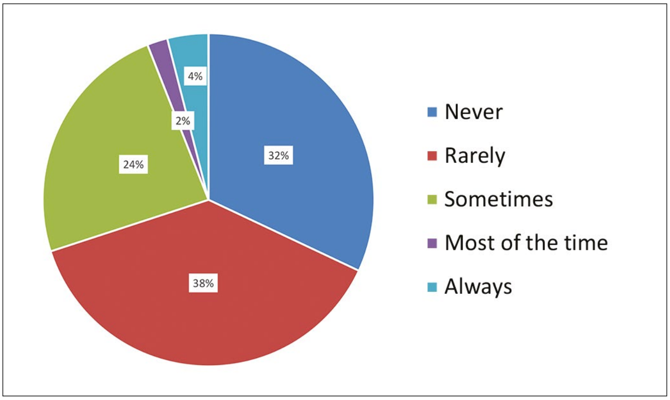


Figure 9.5: Extent to which participants explained their variation to people they'd just met in their everyday life (n=187)

Other common myths repeatedly listed by participants were that people with intersex variations were always transgender or simply the same as transgender people (28 responses); were necessarily gay or bisexual (18 responses); or were hermaphrodites with two fully functioning sets of genitals and/or the ability to get themselves pregnant (17 responses). For example, Helena (woman with intersex variation Swyer Syndrome, 29yrs) said 'People assume I must feel like a boy if I am an intersex person, like a transgender person; I do not'; and Zachary (male with intersex variation, Klinefelter syndrome 47/XXY/micropenis, 20yrs) highlighted the misunderstanding 'that intersex people are all between the sexes or gay or trans, I am not, I am a boring hetero guy'. A few individuals talked about myths that people with intersex variations should be 'fixed' (4 responses). This myth was expressed by Jannali (intersex female with CAIS, 25yrs) as the assumption 'that we are abnormal or need to be fixed'. Some people gave other unique responses around assumptions made about other themes including their fertility (that they would or would not be fertile), intellect (that they would necessarily have cognitive disabilities) or need for privacy. For example, Warren (intersex man with unexplained scarring, 38yrs) said other people assumed that people with intersex variations 'are not human beings who deserve privacy and courtesy (but) should be walking genital display cases for the titillation of others'.

Religious/Spiritual Services

People with intersex variations were asked to describe how religious/spiritual institutional services (churches, mosques, synagogues, religious or spiritual outreach programs) treated them in relation to your variation. A total of 92 participants responded to this question. Overwhelmingly, the participants who responded (71) explained that due to their negativity (whether directly about intersex variations or simply in terms of sex and gender normativity) religious/spiritual views on their variation were not useful to them or affirming. Carson (male with Klinefelter's/XXY/47, 53yrs) said, 'In Christianity, the only people that exist are Men and Women. There are no grey areas'. Mary (woman with intersex variation non-classic congenital adrenal hyperplasia, 19yrs) said she did not bring up her variation, 'because as a Jewish girl the expectation is marriage and lots of Jewish babies of course, handing on the faith. I worry what my future in-laws would think about my infertility'. Zeena (intersex female with Turner's Syndrome, 40yrs) said her mother's church actually refused to recognise any variations; 'they believe, and it was stated by the main pastor in the church, that only XX and XY come together to make children and are morally acceptable. Sorry, I do exist you can't magic me away!'

However, there were exceptions to this finding; 11 participants discussed experiencing a mixture of affirming and negative responses from religious/spiritual contexts. For example, Georgina (trans intersex woman with Cryptochidism/Hypospadias, 71yrs) said she experienced a 'very mixed response from Catholic Church; local priest was appalling, another was truly wonderful and non-judgmental'. Finally, ten participants discussed experiencing nothing but support from religious/spiritual contexts and services. Buddhists were particularly represented in this sub-group, but there were also participants who were pagan, or Christian. Jordan (intersex individual with intersex variation 47/XXY/Klinefelter Syndrome, 56yrs) said they 'practice non-religious Buddhism and most people in my centre are aware of my variation, but it's not an issue'. Other Buddhists in this subgroup discussed how the focus on people being of equal worth was relevant to the support they received. Darren (trans man with intersex variations Clitoromegaly/Cryptorchidism/Mosaicism involving 'sex' chromosomes and PCOS Hyperandrogenism, 49yrs) said that as a solitary Pagan his 'practices are personal' and so not reflective of organisational biases of any kind.

Engaging with Community Social Groups

Participants were asked if they had ever engaged with any community organisations or social groups related to their intersex variation; most participants (73%) selected 'Yes', and the remainder (27%) selected 'No'. That the majority of people with intersex variations in this study were in some way engaged with community makes sense given that the study (run over only a few months) used various community networks as one of the key recruitment methods; so this finding may not be reflected for the broader group as a whole (it is likely there are more people with intersex variations who have not yet engaged with community groups). Of the participants in this study however, most (60%) had found the organisations/groups they engaged with via the internet. Other means through which contact was made included being referred by friend/word of mouth (24%), family (10%), medical institution/staff (6%), another service (5%), psychological or counselling institution/staff (4%). An almost negligible portion of the group were referred by school/staff (1%) or used the phone book (1%).

Some had made contact with various groups via various means. The overall picture strongly suggested that the internet has played an important part in enabling people with intersex variations to reach out to each-other.

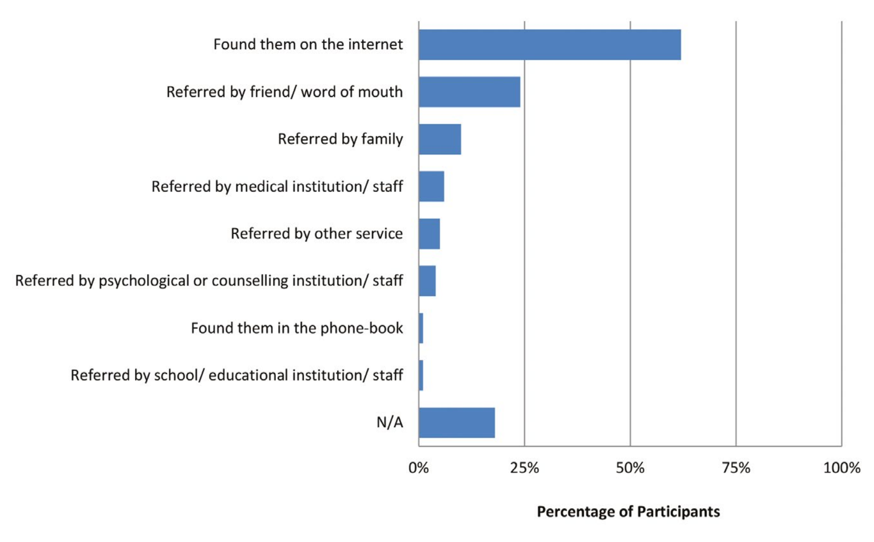


Figure 9.6: How participants found out about organisations/groups for people with intersex variations with which they engaged (n=167)

Wellbeing Impacts of Community Engagement

Participants were asked whether engaging with others with their variation or similar improved their wellbeing; most participants (65%) selected ‘Yes’, some (23%) were ‘Unsure’ and the remainder (12%) selected ‘No’. They were invited to comment on this, and 87 participants wrote in short answer responses. The largest theme that emerged (in 72 of the comments) was participants’ explanations of why they found their wellbeing improved. Answers included that being with others improved body image and self-esteem, challenged the isolating myth that people with intersex variations were ‘one in a million’ and combated loneliness by creating a sense of belonging. For example, Sarah (woman with intersex condition PAIS, 44yrs) had found an online group through an internet search and participated in their blog posts. She said her ‘body acceptance improved’ from the experience. Peter (male with an intersex variation/DSD/Leydig Cell Hypoplasia/Micropenis/Cryptorchidism, 41yrs) said he had been much happier since he found and read a group discussion-board online; saying it was ‘encouraging to be able to talk to people on the other side of the world about a problem that had always felt so personal to me'. Mia (intersex woman with clitoromegaly and unknown variation, 24yrs) was lesbian, and said she had been to LGBTI events including Mardi Gras where there were intersex people before receiving her diagnosis, and this exposure to community later became very important:

> *I did not know it at the time, but seeing those intersex people at Mardi Gras meant a lot to me when I was first getting the results and starting to look into this. It was something my girlfriend and I talked about, those people and how happy they were. The fact they did that, meant I did not feel alone when I found out.*

There were also answers emphasising that meeting others exposed participants to circumstances in which their experiences/bodies/identifications were acceptable and exposed participants to alternative notions about treatments and bodies to those dominant in medical arenas. For example, Stewart (male with intersex variation Klinefelter's/XXY, 39yrs) had found an online social networking site for people with his variation 'SO much help, just seeing what other men do and what they use [...]. Cannot imagine going it alone'. Kyle (intersex male with Kallman's, 28yrs) said he met 'some friends with KS online', and then met with the people they knew. 'They know what it is like. They can have more information than the doctors'. Other participants emphasised how meeting others supplied them with emotional and psychological support, and helped them to prevent hopelessness, depression or suicide attempts. Toni (female with intersex variations Turner's Syndrome and XY/XO Mosaics, 23yrs) said 'I felt less suicidal and like I had people I could go to with questions about TS or who would not judge me'.

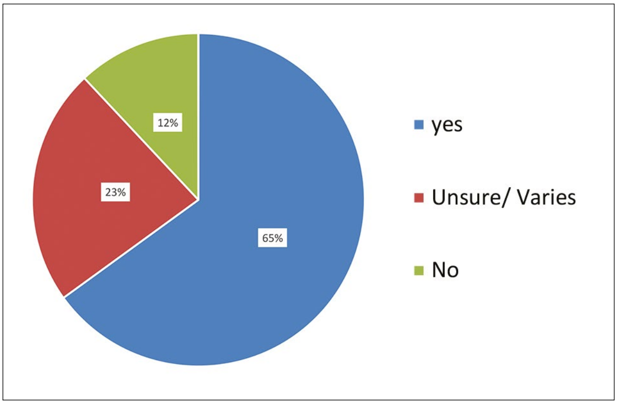


Figure 9.7: Whether engagement with organisations/groups for people with intersex variations improved participants' wellbeing (n=164)

There were additionally smaller sets of responses with different themes. Six comments offered information on mixed experiences participants had had in engaging with community; mainly highlighting that there can be occasional issues of the difficulties in being exposed to other peoples' difficult experiences, and lateral tensions around the policing of community boundaries, although all the comments argued that community engagement was nevertheless valuable. For example, Una (female with intersex variation Turner's Syndrome, 21yrs) said it helped her wellbeing to meet others, but acknowledged that there are some emotional complexities involved in supporting others:

> *YES!!! I love my butterfly and other syndrome friends <3. It can be sad to see people with your variation or similar if they are sick, or not doing well. It can sometimes bring up your own worries, I will not lie, and some of our friends have been very ill, and some people come because their loved one has died and they talk about it and it is sad and hard. There is even then, something to being in a group where you and they can share problems, experiences, and hard times. I find it very rewarding and it got me through the worst times in my own life. Even going to uni, I could ask people how that was for them living on a campus, and have friends off campus to talk to on bad days. I know so much about HRT and dating from these friends.*

A further six comments were by participants who had not engaged with community at all but would like to. Nora (intersex female with Complete Androgen Insensitivity Syndrome, 31yrs) said 'I know I would like to have a friend with AIS. I think what holds me back is that the idea of joining a group is confronting for me, it could make it all a bit real'. Finally, three comments described difficulties in communities of people with intersex variations, including individuals' senses of not fitting in with people who had fewer or more impacts. In addition, Guido (male with intersex conditions Ovo-testes and PCOS/Hyperandrogenism, 48yrs) explained 'I prefer to live as a general member of society than wallow in self-pity'. Overall though, most people who responded to the question described meeting other people like themselves as an affirming experience which contributed in positive ways to their mental health.

10. Sexuality, Romance and Relationships

> *I'm in a long-term monogamous marriage currently legally recognised in Australia. I believe anyone should be able to marry, nobody should divorce someone just because they have a variation. People should be more understanding, it could have happened to any of us. Mostly testosterone helped with sexual passion. Yet as my wife and I get older we decided that is less important. The sexual protective devices available are adequate for my body; although now we are married do not use any condoms.*

Vincent, male with intersex variation XXY/47, 49yrs

> *I have vaguely female bits, and I'm attracted to women. I'm always open to my partners about my sex and gender, but for sake of ease I identify as a lesbian. It's really just a compatibility thing. I have been attracted to a couple of men, but nothing eventuated from those attractions. Anxiety (about sexual acts) is a difficult thing to overcome, but once I'm past that, I am able to experience orgasms. From observation, I think I'm less sensitive than a lot of other women, but it hasn't been too much of a problem.*

Lara, female with intersex variations Gonadal dysgenesis/
mosaicism/ovo-testes, 27yrs

http://dx.doi.org/10.11647/OBP.0089.10

Key Findings

- Most of the participants were currently involved with one or more partners or dates (62%).
- The majority of participants had never formally or legally married.
- Whilst the most popular single sexuality term applied by participants to themselves was 'Heterosexual' (48% of the group selected it), most participants were not (or were not only) heterosexual, and the group defined sexuality labels in varying ways.
- Most participants (65%) said their variation (or related treatments) impacted on their sexual activities.
- Whilst most found current sexual protective devices adequate, some did not, and 14% had contracted STIs.
- Just over half said people with intersex variations needed specific sexual information packs.

Relationship Status

Until now, little has been known about the relationships of people with intersex variations, and the data on participants' experiences of being told about their variation showed that questions about the possibility of relationship often arise or are discussed in relation to learning one has an intersex variation particularly at a younger age. Of the 172 participants who answered the question about relationship status, most were currently involved with one or more partners or dates (62%), whilst just over a third were not (38%). So the data suggests that it is indeed common for people with intersex variations with a range of body types to date and have partners (despite whatever social myths or medical warnings may sometimes obscure this fact). Participants were asked to tell us more about how they describe their relationship/relating style, and the extent to which this style was impacted by their variation. There were 97 comments in response which illustrated a definite diversity across participants' relating styles and experiences of their variation around dating. In half of the comments (49 comments) participants described being in long-term monogamous relationships sometimes for many years (whether with a male, female or non-binary individual), and mainly discussed how these relationships were not strongly impacted by their variation. Where there were impacts on the relationship for this group, the impact was around partners supplying participants with much support about their variation or helping participants to overcome some of the shame about their bodies which they had experienced. Lara (female with intersex variations Gonadal dysgenesis/mosaicism/ovo-testes, 27yrs) commented:

> *I'm in a very loving, emotionally stable, and supportive relationship with another woman. We're currently living together and under an understanding that when we are able to get married, we will. Though we're not in any kind of formal engagement. I wouldn't say our relationship is impacted by my variation. But she has done a lot to make me feel accepted and normal, which has helped me come to terms with myself.*

Kelly (intersex individual with Classic CAH, 63yrs) said that they had a long-term monogamous partner 'who couldn't care less about my physical differences save that people judge me because of them'. There were also an additional ten individuals who were currently dating (but not fully in a relationship with) one person in the main, who also reported no impacts from their variations beyond supportiveness from their dates. This included Una (female with intersex variation Turner's Syndrome, 21yrs) who had 'been on a few dates with a boy. Just to the movies and things. I am not sure but I think I like him! I also like that he likes me being short'. There were also a further ten individuals who were in long-term polyamorous relationships, who similarly had experienced nothing but support about their variation from their partners. For example, Francis (transgender woman with intersex variation PAIS, 32yrs) was involved with a partner in an open relationship, and reported that they had experienced 'no impact from variations'.

There was a smaller group of 14 comments made by people who were currently single, who had experienced a mixture of impacts around their variation when dating – ranging from confidence problems to issues around social expectations or trust. Reese (intersex female with CAIS, 40yrs) explained that self-confidence issues had impacted her sexual relationships, but that she was excited over how going on testosterone was 'now providing a sexual drive for the first time in my life'. Neil (male with intersex variations testicular impairment 'disorder' and gynaecomastia, 48yrs) said:

> *I tend not to date. My physical differences are far more obvious unclothed, and so social expectations based on my appearance don't fit the reality. Also, my body doesn't respond physically in ways that I experienced prior to surgical interventions. I also have trust issues arising from diagnosis during a long term relationship due to pressure from my then partner.*

Elaine (trans intersex woman with Klinefelter's Syndrome, 31yrs) said whilst she desperately wanted a male partner 'before I get too old', she was 'in a terrible situation where I can't have sex with them'. A few participants in the single subgroup were looking for partners for whom penetrative sex was less of a focal point due to their own disinterest either on the basis of their bodily variation or the impacts of treatments they had received. Others had actively sought single lives to focus on their own happiness unhindered by partners. Finally, there were an additional 14 comments by people who were dating or in relationships and had experienced distinct impacts on their partnering experiences around having a variation. These impacts mainly concerned the effects of both 'normative' social and sexual expectations for relationships which were challenged by the participant's variation. Duane (male with a micropenis and bladder exstrophy, 32yrs) said that 'Dating is hard. Sex is the hard bit... I can receive pleasure and give it so it should be all good. All the messy rest is socialised fucked-up-ness'. Merryn (intersex woman with PAIS and Cryptorchidism, 18yrs) feared 'normal' lesbian sex might not be possible with her body, so when her girlfriend tried to give her pleasure she 'made her stop' and this had affected how they related. Other complications included the way in which entering a live-in relationship reduced disability pensions – making some participants financially reliant on any domestic partners they had (who sometimes later became resentful of their reliance/and thus their variation when it was a factor in a disability). A few individual participants dealt with the way their variations disrupted traditional relationship expectations through adopting uniquely creative alternative partnerships which satisfied their romantic needs. Scarlet (female with 3BHSD Late Onset Congenital Adrenal Hyperplasia, 40yrs), for example, was 'straight' yet in a creative partnership with a 'straight' female where each had her romantic needs met without any concern over either partners' desires. They were 'completely celibate' yet 'very much in love'.

Marital Status

When this study took place in 2015, Australia did not have equal marriage laws in place for GLBTIQ people broadly, although marriage activism and marriage equality debates had reached an unprecedented level of intensity. So in inquiring into marital status, the survey provided options whereby participants could express whether or not they were in formal marriage relationships, and whether or not these were legally recognised in Australia. Of the 175 participants who described their marital status in the survey, the majority had never formally or legally married (65%). In addition, 12% were currently recognised as legally married in Australia, 8% had formally married overseas or in Australia but the relationship was not legally recognised as a marriage in Australia, 1% were widowed and 14% were now separated/divorced.

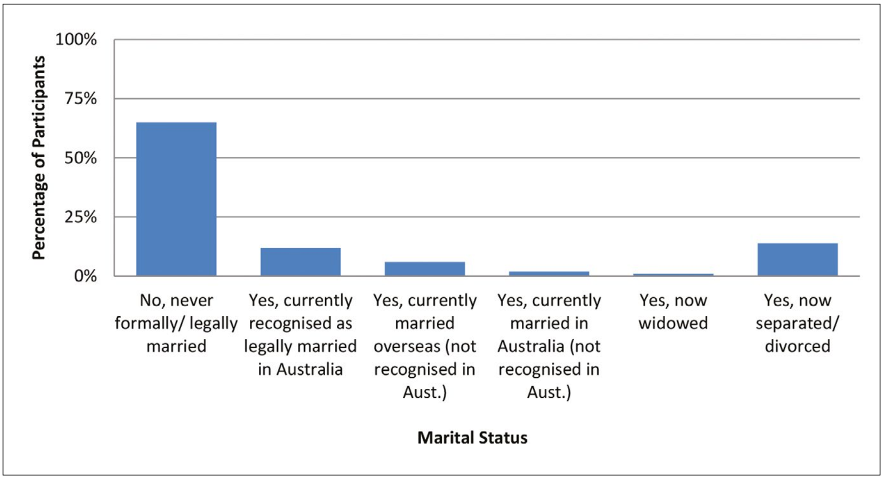


Figure 10.1: Marital status of participants (n=175)

Participants were asked to add any comment on their marriage or ability to marry; 69 participants responded. Amongst the comments, 50 referred in some way to participants' concerns around inequalities in current Australian marriage legislation. Some of these concerns related to how divorce laws in Australia facilitated discrimination against people with intersex variations. One example came from Rowena (intersex female with PAIS, 32yrs), who said 'I have heard that being intersex is grounds for divorce... I can only imagine the shame and loneliness that must create for some people'. Some concerns related to how the laws in Australia facilitated discrimination against people who did not have a male or female sex marker. For example, Taylor (intersex X/male/female individual with gonadal dysgenesis hypospadias/micropenis, 42yrs) was concerned that because Australian law only allowed marriage between a man and a woman, getting an X on their birth certificate meant they couldn't marry. They explained that 'this is a distressing and unjust situation'. Other concerns related to how the laws in Australia facilitated discrimination against people in same sex relationships. Cary (intersex woman with Classic CAH and Clitoromegaly, 19yrs) provided an example of such concerns when she explained she had a 'serious girlfriend' with whom she was in love, and argued 'it should be legal for me to marry her. Hurry up! Australia looks so dumb compared to overseas'.

Ten comments referred to other more personally specific barriers around marriage related to individual participants' own experiences in their personal lives or past marriages. For example, Ashton (pan-gender intersex woman with PAIS and ovo-testes, 58yrs) explained that 'a big part of me getting married was to make my life look like everyone else's' and that this was definitely no longer a personal motivation. Noreen (transgender intersex woman with Cryptorchidism, 61yrs) had divorced and reflected on the difficulties of marriage for her personally when she was male due to her intersex variation:

> *My wife accused me of being a flatmate rather than a husband and being like a woman in bed. And I suffered every kind of sexual dysfunction male genitalia could be afflicted with. Somehow I did end up with two children whom I love dearly, but apart from that being married was nothing short of daily torment.*

Finally, nine comments referred to positive experiences of being married which had been legally recognised, even including for some marriages which had later ended. Lucas (intersex man with Kallman's Syndrome/Cryptorchidism/Micropenis, 77yrs) gave a comment illustrating this small sub-theme, saying 'marrying my wife was the happiest moment in my life. I would wish that for all people'. Izzy (female with Cryptorchidism, 59yrs) said she was 'open and honest with my partner before marriage and he accepted me for how I was. Even though I wasn't able to have children, he accepted this'. The couple then enjoyed volunteering together overseas for eight years 'as our contribution to raising kids'.

Sexuality Terms and Definitions

Participants were able to select any terms (and as many as they found relevant) from a list of terms which best described how they viewed their own sexuality. Of 176 participants answering the question, just under half (48%) selected 'Heterosexual' – making this the most popular single label amongst the group. However, the majority of participants did not view themselves as heterosexual or as solely heterosexual; 22% selected

'Bisexual, 18% selected either 'Gay' or 'Lesbian', 15% selected 'Queer', 11% selected 'Questioning', and 10% selected 'Pansexual'. In addition, 10% selected 'Asexual', 10% selected 'Prefer no label' and 4% selected 'Another label' – most commonly fluid, although other terms (a-romantic, bi-curious and others) were offered. As this data shows, over a third of the group actually ticked multiple labels, and labels often used in conjunction with other labels included heterosexual and asexual, amongst others. So overall, the data showed that whilst 'Heterosexual' was the most popular term for these participants, most participants were not (or were *not solely*) heterosexual.

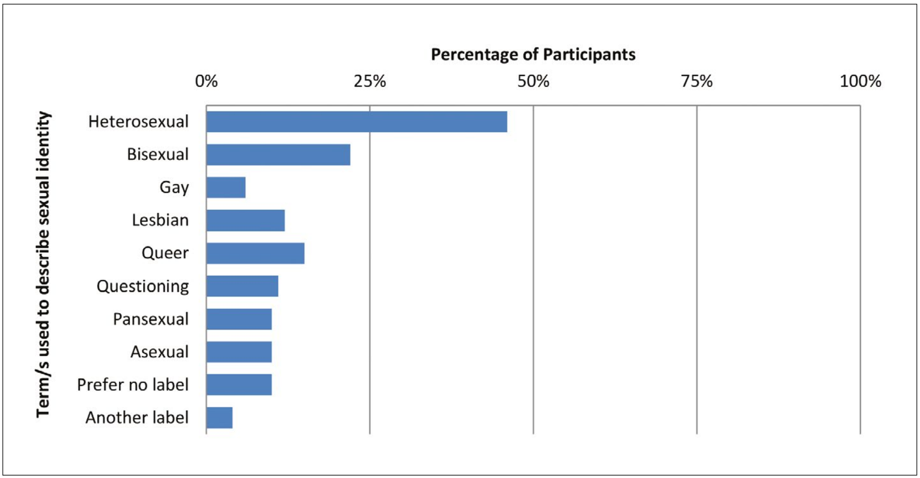


Figure 10.2: Sexual orientation term(s) used by people with intersex variations (n=176)

The survey asked participants to define the sexual identity terms they had selected using their own words. The definitions offered by participants in response only further complicated understanding of their sexualities in interesting ways. Participants defined 'heterosexual' in a wide variety of ways ranging from traditional to non-heteronormative, and sometimes in conjunction with other sexuality labels they were using. For example, Olivia, intersex woman with CAIS, 28yrs defined herself solely as heterosexual and said 'I am a woman who likes men'; similarly Barry (intersex male with Klinefelter's/47/XXY, 17yrs) defined himself solely as heterosexual and said 'I like girls'. Conversely, Duane (male with a micropenis and bladder exstrophy, 32yrs) said he was heterosexual and queer, defining this by saying, 'I like women and trans women, I'm kinda into anal sex but basically pretty hetero'. Francis (transgender woman with intersex variation PAIS, 32yrs) used 'heterosexual' and also offered another term 'bi-romantic', defining her sexuality thus; 'prior to hormonal treatment I was asexual bi-romantic, hormones triggered my development of sexuality'. Evelyn (trans woman with PAIS, 59yrs) identified as a heterosexual female and bisexual and lesbian, saying she 'would have no reluctance to explore as homosexual female'. Such contrasting definitions pervaded the use of all the sexuality terms participants used. For example participants also defined 'bisexual' in a diverse manner. Guido (male with intersex conditions Ovo-testes and PCOS/Hyperandrogenism, 48yrs) defined himself, as a bisexual, as 'a person who is attracted to more than one sex'; whilst Nina (intersex female with 3beta hydroxysteroid dehydrogenase deficiency, 32yrs) defined it as describing how she officially lived a heterosexual life and repressed her secret attractions to women because 'it's easier for me in my family'. Jacky, (intersex individual with unknown variation, 31yrs) defined bisexual as referring to their past relationships with both women and men, but noted they had an overall preference for women. Ray (intersex man with unknown variation, 24yrs) described used both bisexual and gay to explain how he was mainly sexually attracted to men and slightly sexually attracted to women, and noted that 'because I am in a relationship with a man, people often call me gay'. Cary (intersex woman with Classic CAH and Clitoromegaly, 19yrs) also used gay but in relation to liking women, saying 'lesbian or gay work for me, I like girls. Sometimes queer when I feel like I am genderqueer or feeling more like a boy. Baby butch is ok too'.

Sian (female with Polycystic Ovary Syndrome (PCOS)/Hyperandrogenism, 22yrs) used the terms 'Bisexual', 'Queer', 'Questioning', and 'Pansexual', explaining 'I definitely identify as Queer, but I am unsure on whether 'bisexual' or 'pansexual' best reflect my sexuality overall'. Jordan (intersex individual with intersex variation 47/XXY/Klinefelter Syndrome, 56yrs) felt that 'Gay' did not entirely fit, but that 'Asexual' was only partially accurate, and also offered 'Another label' (homo-erotic) which was perhaps the best term they'd found for being not quite completely male and not quite completely sexually available to men, but somewhat both those things. Patti (intersex female with CAIS, 37yrs) combined 'Bisexual' and 'Another label' (fluid) with heterosexual, explaining she had previously 'had sexual experiences with both men and women but tend towards relationships with men'. Finally, those participants who had selected 'Prefer no label' had mainly done so in conjunction with labels like bisexual, or asexual, or questioning. Bette (intersex woman with 'another variation' related to chemical exposure in-utero, 58yrs) used 'Prefer no label', and argued that 'applying a sexuality label to intersex is frankly utterly ridiculous'. Whether label use for this group can best be understood as ridiculous, complicated and inconsistent, or useful overall, probably needs to be determined by each individual with intersex variations for themselves. However, from a research perspective the discussion of terms used around sexuality by this group at the very least allowed us to offer a broader picture of the notions and range of sexualities experienced and to see that the sexuality terms this group uses cannot be assumed to have simplistic meanings or obvious meanings. This finding may be important in informing potential approaches to any further social research for this group, and may also be useful in a practical sense for any sexual health provision efforts.

Impacts on Sexual Ability and Desire

In the literature review for this study, it was noted that Warne et al.'s (2005) assessment of medical intervention for this population acknowledged that people with intersex variations who had been treated sometimes struggled to experience orgasm, experienced pain during intercourse and were less likely to have sexual activity several times or more a week than control groups. Reporting of the study in some ways minimised problems with sexual activity however, so it was important for this study to explore sexual ability and desire in greater detail. Participants supplied 116 comments on the ways having intersex variations impacted on their sexual ability and desire. There were five main themes to the comments.

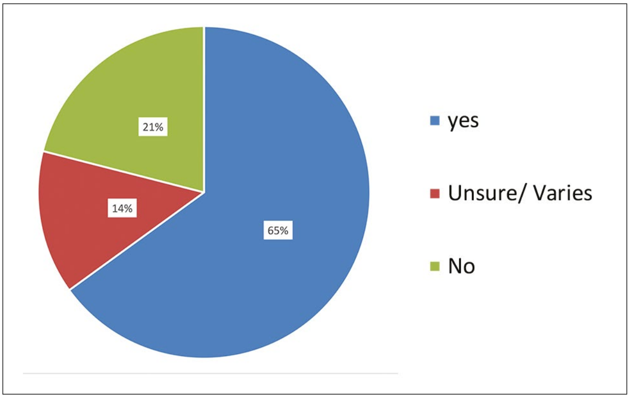


Figure 10.3: Whether participants' variations (and/or related treatments) impacted their ability or desire to engage in sexual activities (n=175)

The largest theme that emerged (in 39 comments) was on the physical ways having intersex variations or treatment interventions negatively impacted on some participants' physical sexual ability and desire. Impacts included loss of control over genitals, lowered libido, vaginal dryness, an inability to get or maintain erections, lowered sensitivity and so forth. Warren (intersex man with unexplained scarring, 38yrs) explained his intervention had led to decreased sexual activity; 'my genitals don't always do what I want, so I probably have less sexual activity'. Ronaldo (male with PAIS/ Cryptochidism, 49yrs) was 'unable to get and keep strong erections'. Monique (female with intersex variations Classic CAH and Clitoromegaly, 58yrs) said 'I find sex brings little pleasure, my lack of a sex drive is related to the interventions and lack of sensitivity without my clit, trauma over the way it happened, and scarring'. Merryn (intersex woman with PAIS and Cryptorchidism, 18yrs) said 'petting is involved but not more. I feel that I get aroused but not to the climax. In some ways it is frustrating'. Antoinette (female with intersex variation Swyer Syndrome and gonadal dysgenesis, 29yrs) commented that her variations 'may be the cause of my Asexuality, but that is just a guess'. The second largest theme that emerged (in 29 comments) was on the psychological and emotional ways having intersex variations negatively impacted on some participants' sexual ability and desire. In this subgroup participants discussed how they worried about, delayed, or actively avoid sexual activities due to their feelings of shame, low confidence, low self-esteem or even fear around their bodily variation in relation to sex. For example, Andy (intersex man with Jacobs/XYY Syndrome, 34yrs) said he 'would feel really weird about (having sex)'. Bailey (intersex non-binary individual with Klinefelter's and ovo-testes, 25yrs) said his variation 'has made me nervous and uncertain about sex for a long time. I have been very self-conscious'. Mary (woman with intersex variation non-classic congenital adrenal hyperplasia, 19yrs) commented, 'I'm scared for lots of reasons. The doctor said I might have pain'. Fernanda's (female/X with PAIS, 25yrs) comment showcased the sense of humour some of this subgroup had when discussing their fears, when she said that her variation and subsequent surgery had 'been a huge stumbling block' in her sexual life, due to her sense of 'the unknown; is my handcrafted vagina a black hole to another dimension, I have no clue'.

Another theme arose (in 20 comments) on how hormonal treatments had improved some individuals' sexual ability and desire, mainly for the better.

This variously happened for different participants in this subgroup either quite immediately or after a long time, on the first attempt at hormonal therapy or after many different modifications to treatment plans over time, and in intermittent or ongoing ways. For example, Zachary (male with intersex variation, Klinefelter syndrome 47/XXY/micropenis, 20yrs) naturally had testosterone, and reported he immediately discovered after starting treatment that 'T makes me much more randy'. Carson (male with Klinefelter's/XXY/47, 53yrs) found the effects of hormones so immediate that he reported, 'it's like I can turn my sex drive off if I don't take my testosterone injections'. Contrastingly, Danielle (female with intersex variation CAIS, 41yrs) lost her libido 'when my testes were removed at age 17 and I went on estrogenic hormone replacement therapy', however, after changing the treatment plans and taken testosterone, it took a longer period of time before she slowly said she 'greatly recovered my libido'. Zeena (intersex female with Turner's Syndrome, 40yrs) found the impacts of HRT were complicated. On the one hand, she felt no 'desire to engage' sexually without HRT, whilst on it 'it caused almost the opposite impact; almost a desire to engage as much as possible to validate my own self... really bad idea actually'. She said with this increased sex drive 'you can often feel used or only 'good enough for one thing' etc. Not always the partner's fault that you feel this way'. She had enjoyed some of the sexual sensations of being on HRT but had more recently decided to have a break from it and also to try to lessen its 'damaging impacts' on her body more broadly.

A smaller theme arose (in 14 comments) on the social ways having intersex variations negatively impacted on some participants' sexual ability and desire. A few of the social impacts were about sexual rejection, which limited social opportunities for sexual activities, whilst other times the social impacts were about the ways people navigated rejection and acceptance (and their own role in protecting or exposing themselves to it). For example, Lee (intersex individual with Klinefelter's Syndrome, 44yrs) commented that having large breasts on a mostly masculine frame meant a lot of social rejection, 'Women don't want someone who is ambiguous'. Similarly, Debbie (woman with intersex variation PCOS/Hyperandrogenism, 34yrs) reported that the physical presentation of her variation was sometimes off-putting to men she had liked but was in one sense a filter, reflecting 'It was much harder to find the right guy, much easier to know when I met him'. Patti (intersex female with CAIS, 37yrs) went through a phase of being celibate and feeling 'like a freak' in her adolescence due to the social implications of her variation and the treatment she'd had;

> *The scars on my body would lead to questions that I did not have the words to answer. If I wasn't accepting of my own body how could I ask anyone else to accept it? [...] I also felt I needed to disclose my intersex variation to any potential suitors, less they get the wrong idea... that's total bullshit and I only do that now if I want to, otherwise it's not really relevant.*

Patti's comment showed how she had changed her position on the extent to which she would give people the opportunity to reject her on the basis of having a variation. Marina (woman with Swyer Syndrome, 18yrs) found a key social impact on her sexual opportunities and whom she personally attracted came from how she looked younger than her age; 'I am not sure if boys like that. Old men do but that is disgusting'. She was increasingly careful not to expose herself socially to those particular older men who sometimes fetishized her younger looks in ways that made her uncomfortable.

Finally, one last key theme arose (in 14 comments) on individuals finding that their intersex variations increased their sexual desire and pleasure and influenced their various strategies towards pleasure. For example, a few individuals felt their sex drive was naturally greater due to their intersex variations, such as Hunter (intersex man with ovo-testes and PAIS, 23yrs) whose drive was 'unusually high', and Nadine (female with intersex variations Clitoromegaly/Classic CAH, 53yrs) who reported 'I think I enjoy sex more! My body can handle more sex than women I have been with, and some of my intersex friends have said that too'. Mia (intersex woman with clitoromegaly and unknown variation, 24yrs) said her variation impacted both the amount of sex she craved and the particular ways she physically achieved and enjoyed sexual pleasure;

> *…my clit is so different to women's' clits, it is bigger and stronger, it can get hard and I feel very excited about rubbing up against my girlfriend. I think this is an impact at least for me, I like to fuck her rather than be fucked by her, my body wants me to do it a certain way and I really am happiest that way.*

Cary (intersex woman with Classic CAH and Clitoromegaly, 19yrs) similarly said 'I don't like anything going inside me. But I love sex, I love giving in sex'. Inga (intersex woman with XXY/47 and Cryptochidism, 43yrs) said she had been exposed to more sexual activities and pleasures because she had 'tried more in the search to find myself'. James (intersex man with aphallia, cryptochidism and another variation, 53yrs) used a strap on to further enable his sexual engagements. Jamie (X intersex individual with CAH/21 hydroxalase deficiency, 39yrs) described being extremely horny all the time due to 'excess' androgens and hormones; 'it is common with my condition, it is very difficult to gratify these desires with another partner due to the complications of my anatomy [...] all this being said I manage to fulfil my needs'.

Sexual Activities Engaged In

To redress the ways in which these experiences for people with intersex variations are underrepresented in the literature, the participants were asked to select from a list the sexual activities they had engaged in (willingly) in their life-time. The most common sexual activities engaged in by more than half the group were kissing (94%), fondling others (86%), touching others' genitals with fingers (83%), giving oral sex to others (79%), masturbation (78%), receiving fondling (78%), receiving touching on genitals (76%), and receiving oral sex (63%). Less common sexual activities engaged in by less than half the group included receiving penetrative sex with genitals, hands or toys (in the vaginal/front hole – 42%, or anus – 40%); and anal sex (receiving – 40%, or giving – 26%). Just under a quarter of the group described other sexual activities they engaged in (23%). The additional sexual activities listed by participants included bondage, domination and sado-masochism (BDSM); breast play (alone or with others); being bitten or biting; costume play; cuffs-play; docking; erotic fiction (reading or writing of); food play; frottage (rubbing genitals together); hand-holding; hiring a sex worker; hugs/cuddles; humping; kink; grinding; lingerie wearing and play; naked cuddles; rimming/butt play; role play; sexy massages (giving and receiving); scissoring (rubbing genitals together in a manner which resembles two sets of scissors coming together); sexting (sexual texting); sexy photos and 'selfies' (taking, featuring in or sharing); Shibari (rope bondage); Skype or other video-supported online sex play; spanking; and water sports (urinating on or in view of another or being urinated on/ watching urination for sexual stimulation).

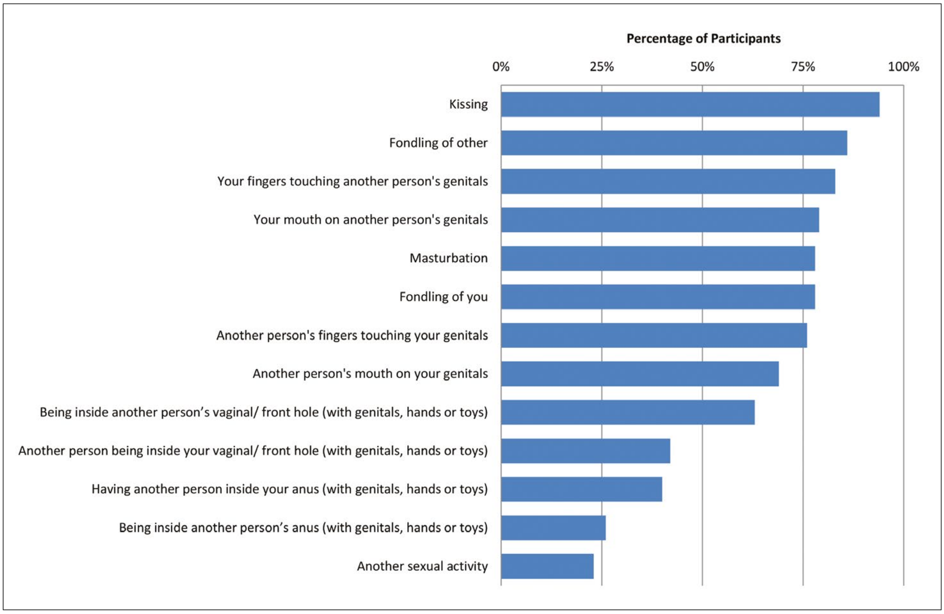


Figure 10.4: Sexual activities willingly engaged in by people with intersex variations (n=166)

Whether the participants were heterosexual, asexual or another sexuality had no bearing on the sexual activities they had engaged in. There were individuals of all sexual identities who had engaged in almost none of the sexual activities listed or almost all of them. The sexual stories of the group in terms of activities they had experienced and how they responded to and reflected on them therefore tended to be quite unique. For example, Dylan (man with intersex variations PAIS and Hypospadias, 24yrs) described himself as bisexual, and had been with guys and girls and participated in all the sexual activities listed and some additional ones. He had commented that 'spanking was fun, it would not be the meal but it would be a good side dish'. He now was starting to question the type of people he wanted to date; 'I dated a lot in my teens and after school. But not knowing who I am has put me off it. I only want to be with good people now who will support all I am'. Sloan (individual with PCOS/hyperandrogenism, 45yrs) had tried a few activities from the list with both males and females, and in addition had tried a little 'role play and BDSM' but had since given up. Sloan explained; 'sex seems rather pointless. I have experimented a bit to see if it could hold my interest, but it doesn't'. Sloan felt they had 'another sexuality label', yet to be determined, and that a contributing element to their sexuality was the way in which whenever they finally had sexual contact with a person (of any sex) they were interested in, their interest ended immediately afterwards. Danielle (female with intersex variation CAIS, 41yrs) had married and divorced a man and was now seeing herself as somewhere between heterosexual and bisexual. She said she would consider being with a woman, and had tried all the listed activities, commenting 'I've tried it all, willingly'. Linden (male with De la Chapelle/XX Male Syndrome, 45yrs) reported he was gay and had separated from his previous partner. He had engaged in various oral and anal sex acts as well as other activities. Rowena (intersex female with PAIS, 32yrs) described herself as heterosexual and recognised as legally married in Australia. She had engaged in most of the sexual activities listed also including anal sex and had tried many additional activities with her husband too. She had added the comment 'Cuddling can be sexy! Massages! Tickling each other with feathers, with ice cubes. It is all just bodies coming together in their own ways, it doesn't matter what you do, if you both enjoy it and feel respected'.

Sexual Protection

Most participants in the study (67%) found the STD/contraceptive protections generally available adequate for their bodily needs, whilst 19% said this varies and 14% said they were not adequate. Of all the protective devices listed in the survey, most participants had tried condoms on themselves or their partner (71%), and often had in addition tried one other protective device. However, around a quarter had never used any kind of protection. The participants supplied 29 comments on this theme; the strongest theme in those responses was that some of the participants' felt there needed to be improvements to condom sizing or latex genital protective devices generally to fit the range of genitalia humans have (16 comments). For example, Taylor (intersex X/male/female individual with gonadal dysgenesis/hypospadias/micropenis, 42yrs) reported, 'there are no condoms for micropenises'. Ray (intersex man with unknown variation, 24yrs) responded, 'I can penetrate with my penis (testosterone enlarged clitoris) and I feel very unprotected and unsafe because I can't use a condom when I penetrate my boyfriend'. Guido (male with intersex conditions Ovo-testes and PCOS/Hyperandrogenism, 48yrs) responded that he wanted 'a condom that fits my small cock and will not leak. A dental dam doesn't do the job and ordinary condoms are too big'. Eight comments focussed on the reported irrelevance of sexual protection in certain participants' sex lives; these participants argued that because they were infertile or in a long-term relationship they did not require sexual protection. For example, Merryn (intersex woman with PAIS and Cryptorchidism, 18yrs) commented that she was infertile, and so therefore she believed 'I won't ever need any'; Ronaldo (male with PAIS/Cryptochidism, 49yrs) also commented 'I am infertile'. Whilst it is difficult to interpret the sexual risks any individuals are exposed to from the information available in the survey, it could be useful for participants to access sexual health information on how protective devices can additionally be useful for mediating STI risks for people involved in a range of sexual activities rather than to see frame them only in contraceptive terms. There were, finally, five comments from individuals who affirmed that they personally had found currently the available sexual protective devices had been useful and adequate.

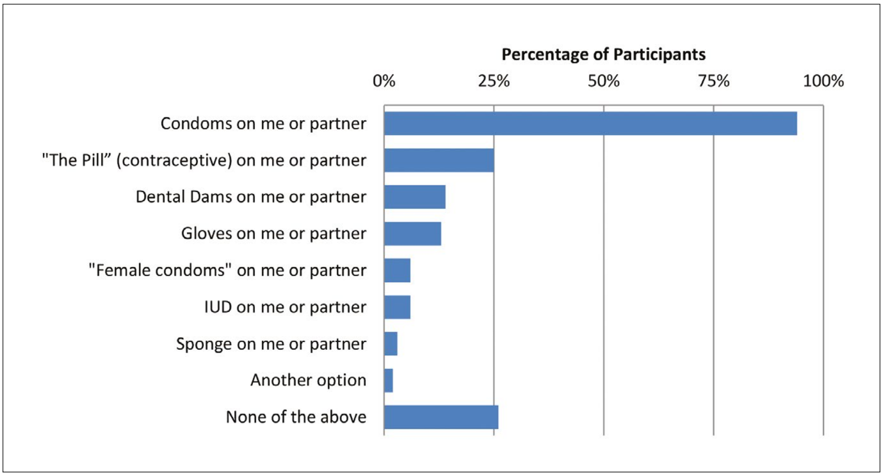


Figure 10.5: Sexual protective devices used by people with intersex variations (n=164)

The majority of participants had never contracted a sexually transmitted infection/STI (86%); however 14% of the group had. There were 21 responses from participants about the STIs they had contracted. These included: herpes (7 responses), chlamydia (5 responses), and HIV/AIDS (4 responses). There were also responses about crabs, HPV, syphilis, thrush, warts and yeast infections. In considering the sexual information available to this population outside of school-based sexual education efforts, just over half the participants (56%) felt sexual information packs were needed for people with their intersex variations. Participants offered 64 comments on what these packs should contain to meet their needs. The majority (33 comments) called for sexual information packs providing body-positive and community-led story-based information for people with intersex variations. Suggestions offered included descriptions or pictures of the range of bodies, descriptions or 'cartoon ideas' for sexual activities with different body types, affirming messages about difference, and affirming stories from community members who had experienced different sexual lives. Some of the comments envisioned this information as largely 'sex positive', for example, Jane (intersex female with Partial Androgen Insensitivity Syndrome, 24yrs) wanted packs to include 'the many ways to enjoy lots of different types of bodies with other people or alone. Information that says that sex is possible. Information that says that sex is many different things, not just penetrative'. Other comments in this subgroup envisioned this information as also including affirming framings of people with a disinterest in sex, for example, Lara (female with intersex variations Gonadal dysgenesis/mosaicism/ovo-testes, 27yrs) said: 'More information, even just the message of 'some stuff might not work for you and that's okay, there's other stuff you can try' would be a very positive one to someone like me'. The second largest theme (13 comments) called for STI risks to be communicated to people with intersex variations, particularly the message that infertility was not a sexual protection against STIs. A comment by Reese (intersex female with CAIS, 40yrs) was typical for this sub-group of responses: 'children with variations need to understand if they are infertile this does not mean they are immune to STIs'. Nine comments argued for the inclusion of sexual information for people with intersex variations in more general, mainstream locations such as school textbooks and other sexual information kits. Seven comments argued that this sexual information was most urgently needed for young people. Finally, two comments called for information on the variety of reproductive and child-rearing options available to people with intersex variations.

11. Fertility, Parenting and Views on Parenting

> *I am perfectly healthy and I don't have to deal with a lot of women's issues which sound painful. I've never wanted to have children so the fact I can't just makes sense to me. I'm glad I am the way I am, I just wish that everyone understood.*

Juliet, female with intersex variation MRKH – Mullerian agenesis; vaginal agenesis; congenital absence of vagina; 22yrs

> *I am XXY with a female exterior and breasts and I had normal menstruation until menopause. However, I am very tall and large in stature. Have always had an extremely healthy sex life. I have given birth. [...] I was told I should have been sterile. But easily got pregnant.*

Jules, intersex female with XXY/47 chromosomes, 48yrs

http://dx.doi.org/10.11647/OBP.0089.11

Key Findings

- Most participants had experienced impacts on their fertility: whether directly due to their intersex variation or due to treatments/surgeries around their intersex variation.
- Some participants did not see barriers to fertility as a major issue in their lives. Others had emotional responses to, or worked to overcome, obstacles through various means including adoption and fertility treatments.
- Of the 42 parents with intersex variations in the study, 23 had discussed their intersex variation with their children and 19 had not.
- Most of the parents who had made disclosures about their intersex variation to their children experienced affirming or accepting responses from their children.
- Participants said their own parents had been given inadequate information about their intersex variations when they were first discovered, and saw health care decisions for children with intersex variations as belonging to those children/themselves.

Fertility and Reproductive Capability

The survey explored issues of fertility, to understand the social experiences of both fertility barriers and parenting for people with intersex variations. The survey included a question on whether participants' variation affected their fertility/reproductive capability. Overall, the majority of participants had impacts on their fertility: 48% could not reproduce directly due to their intersex variation; 17% could reproduce only with difficulties; and 15% could not reproduce due to treatments/surgeries around their intersex variation. In addition, 14% were unsure and only 7% knew their intersex variation did not affect their fertility at all.

Participants offered 62 comments related to the topic of fertility/reproductive capability. The most common theme arising from the comments (25 comments) focussed on the emotional experience of infertility, from participants who faced fertility barriers and currently had no children through any means. Most of these comments discussed how these participants were not particularly emotional about this for one reason or another, including a disinterest in having children, having been well prepared to not have children for a long time, having other things that filled their lives such as work and relationships, or not seeing themselves as the kind of person who would carry or rear a child.

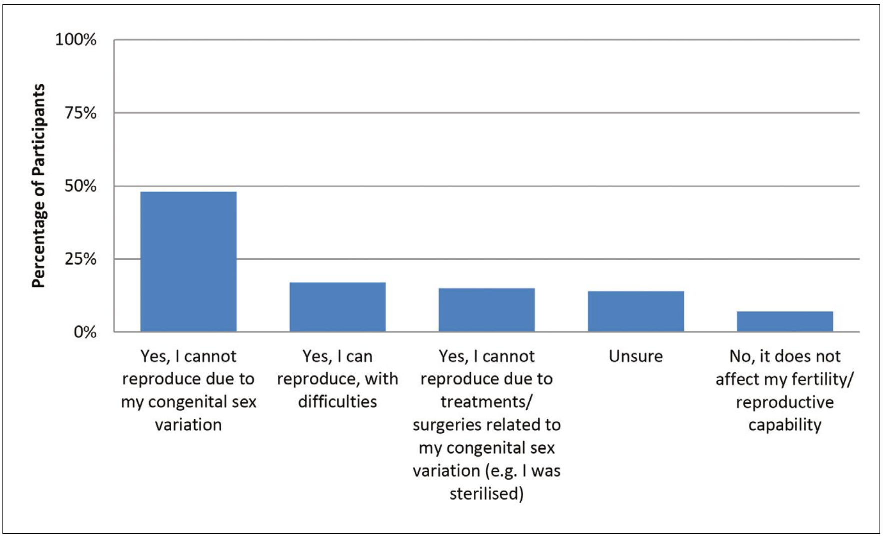


Figure 11.1: Whether participants' variations (and/or related treatments) impacted their fertility/reproductive capability (n=170)

For example, Ashton (pan-gender intersex woman with PAIS and ovo-testes, 58yrs) commented 'I'm pleased that I've always known I was infertile. Better to be told as a small child'. Cary (intersex woman with Classic CAH and Clitoromegaly, 19yrs) said she had fertility barriers, however 'I am NOT EVER having a baby from me so it does not matter. I would hate to be pregnant, too girly. It's not me'. Izzy (female with Cryptorchidism, 59yrs) commented:

> *Not sure if my condition triggered this response, but I was never interested in having children. I never had that maternal instinct. Or maybe it was too much babysitting as a teenager! I did feel awkward about this in my twenties when everyone had family on their mind. I didn't openly tell my friends I wasn't able to have children.*

There were however some participants in the group who were very sad or angry about their fertility barriers. Zoe (intersex woman with CAIS, 53yrs) reflected, 'this was the most difficult aspect of my intersex variation to cope with. It has been very traumatic and has impacted a lot on my life'. Reese (intersex female with CAIS, 40yrs) had periods of sadness due to being unable to have children, which increased when 'watching friends alter due to being a mother, I am sad I will never experience that and grieving that I am never able to produce grandchildren for my parents'.

The second most common theme (12 comments) focussed on experiences and plans of adoption of and fostering of children. Jane (intersex female with Partial Androgen Insensitivity Syndrome, 24yrs) for example said, 'I can adopt, or I may end up with a partner who has kids already, or I can foster... being infertile is not the end of the world these days'. Stewart (male with intersex variation Klinefelter's/XXY, 39yrs) said, 'we are on the wait list' for the adoption. Anne (intersex woman with Ovo-testes and XXY/47 karyotype, 87yrs) said that with her husband she 'adopted two boys' who went on to have their own kids too. Eleven comments focussed on participants' past or ongoing experiences of seeking fertility treatments such as IVF and various other types, which were mainly frustrating experiences for them. For example, Sloan (individual with PCOS/hyperandrogenism, 45yrs) said 'I had laser surgery to see if it could help. I developed thick scarring all over my ovaries from the surgery and monthly pain became unbearable till eventually I had a Mirena implant fitted to stop my cycles'. Zeena (intersex female with Turner's Syndrome, 40yrs) expressed frustration that although she was technically able to reproduce with IVF, 'I cannot afford it'. Lisa (female with PCOS/Hyperandrogenism, 31yrs) said her fertility treatment 'will be difficult and take a while'. Eight comments focussed on the disappointment of participants who had, or suspected they had, been sterilised in childhood medical interventions to which they had not consented. Merryn (intersex woman with PAIS and Cryptorchidism, 18yrs) said it would have been possible for her to have children, 'with difficulties, if my undescended testes were not removed'. Dana (woman with XXXY chromosomes, 45yrs) said, 'If they had left me alone I could have reproduced'. Lastly, six comments related to participants' experiences of becoming biological parents. For example, Sinead (intersex female with classic CAH, 32yrs) said she had a child 'through surrogacy and the use of my own eggs, but now I am sterile'. Scarlet (female with 3BHSD Late Onset Congenital Adrenal Hyperplasia, 40yrs) said, 'there was a four year period I wasn't completely sterile, so with technical help managed to become a biological parent'.

Disclosure to Children

Participants who had children were asked whether they discussed their intersex variation with them. Of the 42 parents with intersex variations in the study who answered the question, 23 had discussed their intersex variation with their children and 19 had not. The respondents who had shared disclosures with their children were asked to explain how the disclosures they made to their children were received. Only a few individuals had experienced directly negative responses. For example, Georgina (trans intersex woman with Cryptochidism/Hypospadias, 71yrs) said her children responded 'badly' to her various disclosures about herself. However, the majority of the comments (17 comments) described children responding in an affirming or accepting manner. In one example, Simon (male with intersex conditions Kallman Syndrome and micropenis, 36yrs) reported having told his kids 'an overview of why they were adopted, some things about my story, and they knew about some of my difficulties with smelling and other things already'. He said the exposure to parts of his story over time helped them to understand 'so they took it all in easily enough'. However, he felt that kids generally are less concerned about a parent's story and more worried about 'their own story and (knowing) that they were wanted'. In another example, Anne (intersex woman with Ovo-testes and XXY/47 karyotype, 87yrs) and her husband told their two sons about Anne's variation 'when they were old enough to know about being adopted and how bodies work, and how my body worked'. It was an easier conversation for the boys than for Anne. 'I was nervous', she commented, 'but they took it all in their stride and did not worry as much as I thought they would'. Anne later went on to become a grandparent, and said that 'some of our grandkids know and ask questions, they think it makes me special'. Celine, (female with XXY/47, 50yrs) similarly said her children 'understand and are very supportive'. Noreen (transgender intersex woman with Cryptorchidism, 61yrs) said that her various disclosures about her body and other aspects of her life to her children 'went well and continue to go well', and that of all the people in her life, 'they are my biggest supporters'.

Views on Parenting

It was important to understand the participants' views on key debates on children with intersex variations (see Table 11.1), which had not yet been researched before, and related in some way to how parents' might consider their roles in relation to these children. Ideally, the participants' views could then be useful for informing advice to future parents of children with intersex variations who may be faced with tough decisions to make around health and rights issues, or towards advocacy around related legislation. Though there was some variance, the participants' views were overall against children with intersex variations being treated in ways which did not privilege the child's equality with other children in their natural form, and bodily autonomy. For example, 81% of participants disagreed (or strongly disagreed) with the proposition that 'people should select against having intersex offspring (e.g. using IVF selection techniques)'. Moreover, the participants' views suggested a protective role for parents around interventions aimed at aesthetically 'correcting' their children's' variations: 75% of participants disagreed with the proposition that 'children should have genitals that precisely match the sex they are reared as'; 88% of participants disagreed with the proposition that 'genitals (e.g. clitorises/penises) that do not fit a size 'norm' should be surgically altered in size' and 92% disagreed with doctors engaging in surgical interventions without knowing the long term outcomes. Where parents are placed in the position of potentially being the person to consent (or withhold consent) to such surgical interventions to the child on the child's behalf, it is clear that most participants would not want them to automatically consent to medical interventions (if the opportunity to consent were indeed offered). In addition, 92% of participants disagreed with the proposition that 'health providers should be able to apply interventions to their sex characteristics (such as surgeries, sterilisation or hormonal treatments) without their informed consent' – as this study has shown can happen for children with intersex variations. Finally, just under one tenth (9%) of the group agreed that their parents were given adequate choices and information about their intersex variation when it was first diagnosed. It is therefore important for parents of children with intersex variations to understand that in the initial period around diagnosis, the participants suggest they may not have all the information they need to either understand their child's diagnosis or the health care/ treatments the child themselves would one day wish for them to consent to on their behalf – suggesting a need for greater caution at that time.

Table 11.1: Participants' reported views on parenting debate topics related to their intersex variation (n=170)

Parenting Debate Topic	Strongly Agree	Agree	Neutral/ Unsure	Disagree	Strongly Disagree
Children should have genitals that precisely match the sex they are reared as.	5	9	28	34	94
Genitals (e.g. clitorises/ penises) that do not fit a size 'norm', should be surgically altered in size.	4	3	14	25	124
Doctors should engage in surgical interventions on intersex kids, without knowing long term outcomes.	3	1	9	21	136
People should select against having intersex offspring (e.g. using IVF selection techniques).	3	5	25	24	113
Health providers should be able to apply interventions to my sex characteristics (such as surgeries, sterilisation or hormonal treatments) without my informed consent.	4	1	9	15	141
Adequate choices and information were given to my parents about my congenital sex variation when it was first diagnosed.	8	8	38	24	92

12. Representation in Media, Activism and Research

> *The film 'Intersexion' had a lovely quote that stuck in my mind, about 'not being your genitals but having some genitals'. It was very comforting and I have to remind myself of this film's message a lot as I have felt very ruled by other peoples' problems with my genitals, for my whole life.*

Frida, woman with intersex variation PAIS, 39yrs

> *No (I have not done any activism). I do not know how to begin. I have been just surviving it all for so long I can't actually imagine doing something like that alone anyway. I do not know that it should be up to me, I think we need people with more power to help us out like how rich famous gay people come out. I do not know any celebrity intersex people who I could have looked up to as a kid, and the people I saw in the media were treated so bad like that athlete.*

Gabriel, male with intersex variation XY/XO Mosaics, 19yrs

http://dx.doi.org/10.11647/OBP.0089.12

Key Findings

- Over half (58%) of the participants had seen 'real people' with intersex variations represented in the media (documentaries/books). Participants assessed most of these representations of real people positively.
- Less than half (41%) of the participants had seen 'fictional characters' with intersex variations represented in the media (TV/film/books). Participants assessed these representations of fictional characters as largely mixed.
- The overwhelming majority of participants were against people with intersex variations being treated in ways which did not privilege their access to key information, services or citizenship rights.
- Some participants had engaged in activism of varying kinds ranging from anonymous activities to tasks requiring a public profile.
- Participants called for more research in the field generally, particularly on health care and social themes.

Representation of 'Real People' in the Media

The survey investigated whether the survey participants had come across people with intersex variations in various media, and what their response to those constructions were, with a view to being able to report their own ideals for ways people with intersex variations could be constructed in future. Participants were asked if they had ever seen 'real people' with intersex variations represented in the media (documentaries/books etc.) – more than half (58%) had, 10% were unsure and 32% said no. Participants were asked to comment on how positively/negatively real people with intersex variations were represented. There were 78 comments in response. Firstly, 45 comments discussed (what participants assessed to be) positive media representations. Receiving particular praise amongst the comments were the documentary *Orchids* by Phoebe Hart, the film *Intersexion*, a 2015 Buzzfeed video featuring members of the American youth group Inter/Act, a beyondblue video on Youtube featuring Gina Wilson, newspaper articles on Tony Briffa or members of OII around political themes, the text *The Missing Vagina Monologue* by Esther Morris, an Oprah episode featuring Hida Viloria, and a range of radio interviews and internet videos featuring people with specific variations. The comments sometimes praised their focus on how intersex variations were experienced in real lives, their accuracy of information about variations or experiences, their non-sensationalist and non-pathologising lens, or simply their affirming nature. A few individuals used these representations as catalysts to stimulate more dialogue about their variations with family or partners. Ahmed (intersex man with micropenis, 29yrs) reflected on how the representations he had seen affected him; 'Intersexions – positively; Tony Briffa as a public figure, positively'. Lucas (intersex man with Kallman's Syndrome/Cryptorchidism/Micropenis, 77yrs) recalled, 'there was an Oprah show with an intersex woman. The woman was very well spoken, they asked her to talk on quite private matters in front of the audience. She held together and I took from her strength'. Mia (intersex woman with clitoromegaly and unknown variation, 24yrs) said she had seen a 'short meme video on Buzzfeed, it was unexpected as they all looked happy and healthy. It was great and I shared it online'.

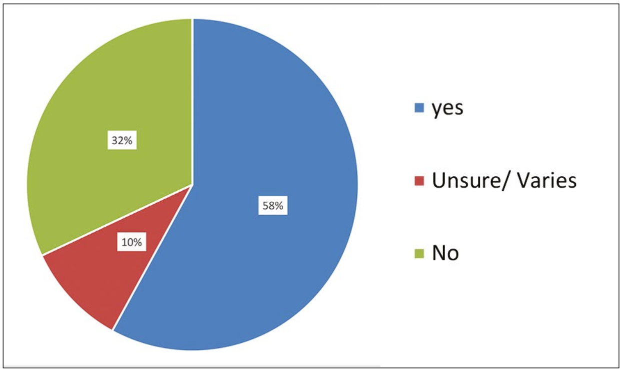


Figure 12.1: Whether participants had seen 'real people' with intersex variations in the media (n=172)

Secondly, 23 comments discussed (what participants assessed to be) mixed experiences of representations in the media, mainly basing their discussion on how positive representations were difficult to find and more obscure than the negative news coverage of athletes with intersex variations in mainstream media, or how representations were so rare that they could not accurately depict the full range of people with intersex variations (focussing mostly on white women) or might focus on symptoms the subject had but not all people with a specific variation would have had. Gabriel (male with intersex variation XY/XO Mosaics, 19yrs) reflected:

> *If you count the web as media, I have looked up some people and it has been good. They represent themselves rather than be represented. So, they have their own channels and videos, I have not seen them interviewed or helped by anyone else. That says something. The athlete in the recent Olympics who was intersex, from Africa, is the only person people talked about on the news and that was really, really bad because she was being treated as a liar or a fake woman.*

Lisa (female with PCOS/Hyperandrogenism, 31yrs) said that whilst 'nearly everything I have seen/read has been positive or at least neutral' for people with intersex variations, 'specifically for PCOS there was one medical show that completely got PCOS wrong and kind of hyped up this woman's one symptom without even explaining that it affects people differently'. Lisa said she 'did not want to tell people I had PCOS' after that show aired. Thirdly, ten comments discussed (what participants assessed to be) negative media representations. Several participants reported that they were annoyed at how negatively Caster Semenya (who had been publicly 'accused' of potentially having some unknown intersex variations) was treated in previous Olympic Games media coverage –reflecting analyses provided in the literature review of the likely distress the coverage could cause to people with intersex variations (Sawer & Berger, 2009). Jordan (intersex individual with intersex variation 47/XXY/Klinefelter Syndrome, 56yrs) argued that people with intersex variations were 'Treated like titillating side-show entertainment. Also, Intersex people often represented in media as transsexuals'. Guido (male with intersex conditions Ovo-testes and PCOS/Hyperandrogenism, 48yrs) simply assessed representations he had seen as 'negative experiences on the whole'.

Fictional Representations in the Media

Participants were also asked if they had ever seen 'fictional characters' with intersex variations represented in the media (TV/film/books etc.) – less than half (41%) had, 12% were unsure and 47% said no. Participants were asked to comment on how positively/negatively fictional characters with intersex variations were represented. There were 50 comments in response. Firstly, 20 comments discussed (what participants assessed to be) mixed experiences of fictional representations, mainly basing their discussion on how representations in fiction had tended to improve over time or their opinion that there needed to be more fictional representations. Ian (intersex male with PAIS and micropenis, 16yrs) reported that in his view, most were negative, whilst a few 'got it right' and he wanted to see more. Georgina (trans intersex woman with Cryptochidism/Hypospadias, 71yrs) felt that whilst in the past representations were poor this 'is changing'. Danielle (female with intersex variation CAIS, 41yrs) called past representations 'quite negative', and more recent fictional characters she had come across 'nuanced and interesting'.

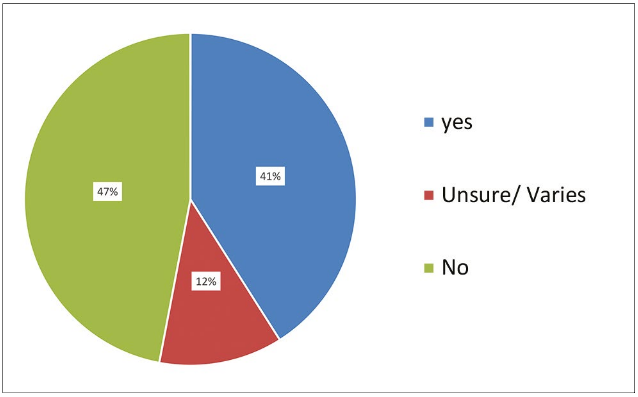


Figure 12.2: Whether participants had seen 'fictional people' with intersex variations in the media (n=171)

An additional 16 comments discussed (what participants assessed to be) negative fictional representations. Respondents reported that negative representations sometimes tended towards the exploitation style by using unnecessary nudity, a 'freak factor' lens or sexual titillation. Fictional texts receiving such critique included an episode of the television show *House* where a patient found out she had CAIS and 'went crazy, taking off her clothes to 'prove she was female' in the middle of the hospital!' (Olivia, intersex woman with CAIS, 28yrs); 'hentai/Japanese anime porn' videos which represented bodies with intersex features in an inaccurate and hermaphroditic manner (Hunter, intersex man with ovo-testes and PAIS, 23yrs), and texts where 'they were presented as perverts so that any negative fate was deemed acceptable' (Bianca, female with 47/XXY/micropenis/cryptochidism, 52yrs). There were also several comments which denounced the way in which *Middlesex* associated people with intersex variations with generations of incest; Xanthe (woman with intersex variation Triple-X Syndrome/XXX, 18yrs) explained, 'my variation is just luck. I think that book would give people the wrong idea'. This representation was thus seen to recall the correlation of incest and aberration found in early literature privileging Biological Essentialist approaches to intersex themes. Finally, only 14 comments discussed (what participants assessed to be) positive fictional representations. Receiving particular praise amongst the comments were the character 'Lauren' on the show *Faking It*, the films *Spork!* and *XXY*, and a science fiction novel series *The Wraeththu* (about a post-apocalyptic hermaphroditic species, so not exactly realistic in depiction but apparently affirming in the context of science fiction according to their fans in the survey). Cassie (female with Turner's Syndrome, 19yrs) commented 'Mum read a book 'The Condition' that she talks about with a TS girl in it, she is the daughter. I have not read it but she loves it and gives it to other parents'.

Representation in Activism

It was important to understand both the survey participants' views on additional key themes discussed in the context of contemporary activism in Australia and internationally (see Table 12.1). Ideally, the participants' views could then be useful for informing advice and recommendations around issues of equity and access. Though there was some variance, the participants' views were overall against people with intersex variations being treated in ways which did not privilege their access to key information, services or citizenship rights – in ways that largely supported the goals of both the Liberal and Critical Intersex Activism approaches described at the beginning of this book. For example, 92% of participants disagreed (or strongly disagreed) with the proposition that 'it is acceptable to prevent people with congenital sex variations from accessing their own medical records and history'. This study has shown that many participants did not have full access to their own medical information or did not feel they had adequate information on their variations, despite their position on the matter as a group. In addition, 92% of participants disagreed with the proposition that 'it is acceptable for people with congenital sex variations to not be given referrals from health providers to supportive environments for people with (their) congenital sex variation/s'. This study has shown how making some kind of contact with people with their variation or similar had improved the wellbeing of people with intersex variations, according to their own reports. Finally, 92% disagreed with the proposition that 'it is acceptable to prevent people with congenital sex variations from marrying whomever they choose'. This study has shown that just under a tenth of people with intersex variations were formally married in relationships not recognised in Australian legislation, and many had sexualities which would be outside those recognised within current marriage law should those individuals wish to marry. There were participants who were concerned about current

Australian provisions for divorce on the grounds that an individual has an intersex variation (or that a marriage was not technically between a male and a female). Other issues the participants felt strongly about in relation to current legislative pushes included doctors engaging in surgical interventions without their consent and related bodily autonomy themes (see the statistics provided at the end of Chapter 11). Participants' views as expressed in the survey may be useful for community representatives in formulating any future recommendations in community consultation work with key bodies related to medical institutions and policy-makers.

Table 12.1: Participants' reported views on general topics under debate related to intersex variations (n=170)

Parenting Debate Topic	Strongly Agree	Agree	Neutral/ Unsure	Disagree	Strongly Disagree
It is acceptable to prevent people with congenital sex variations from accessing their own medical records and history.	6	0	8	15	141
It is acceptable for people with congenital sex variations to not be given referrals from health providers to supportive environments for people with (their) congenital sex variation/s.	5	1	8	23	133
It is acceptable to prevent people with congenital sex variations from marrying whomever they choose.	5	1	8	12	144

Participants were asked if they had ever engaged in any kind of activism for people with intersex variations or on their own behalf. There were 110 responses. Just over half of them (62 comments) were from participants who had engaged in activism of some kind. Some types of activism engaged in by this group involved less public exposure of the individual who engaged in the activity, and could be conducted on computers or in one's own personal life. For example, these types of activities included 'liking' Facebook pages around intersex variations, anonymously commenting on public Youtube videos or discussion-boards, anonymously sharing personal stories online, completing surveys, posting inspirational images on Tumblr, talking to personal acquaintances about an intersex variation and so on. For example, Una (female with intersex variation Turner's Syndrome, 21yrs) said she 'stuck up for a friend who was being bullied online' and 'reported bullying on social media'. Clyde (trans intersex man with 47/XXY, 44yrs) said he engaged in activism:

> *In my own social life in a small way, just talking to people and trying to get them to read things. But sometimes activism is knowing you need to look after yourself and limit your contact with certain people, whether the church or your family. Sometimes not saying anything to people can be your message.*

Other types of activism which participants engaged in were slightly more exposing, and sometimes required participants to do something out of their usual social circle or activities, without necessarily requiring them to be widely or publicly known. These included attending marches and rallies, attending groups and helping peers within them, giving a one-off speech about an intersex variation for a school assignment, and other efforts. For example, Siobhan (girl with intersex variation TS or 'TS butterfly', 16yrs) said she 'Gave a speech on TS at school. Got a standing ovation!' Bianca (female with 47/XXY/micropenis/cryptochidism, 52yrs) said that when she was teaching she sometimes would 'mention people with congenital variations and initiate students to understand their difficulties'. Vincent (male with intersex variation XXY/47, 49yrs) had spent some years actively engaging in 'meeting and supporting other men'. A third set of types of activism conducted were more labour intensive or more exposing of the individuals who engaged in the activity. This included engaging in various advocacy campaigns, creating public submissions into legal inquiries or lobbying towards potential legislative change, creating documentaries, doing various types of interviews, conducting petitions, trying to increase public awareness, reviewing organisations' policies or guidelines, attending international forums, starting or running support groups, giving education-based seminars and workshops, representing intersex people on public boards and so on. There were also individuals like Barbara (trans intersex female with PAIS, 40yrs) who had engaged in activism 'at all levels'.

The second strongest theme in the group (in 35 comments) came from participants who had not engaged in activism; further, they were not personally interested in doing so. Some found activism personally too challenging or confronting, some felt too much shame about themselves, others were shy. For example, Peter (male with an intersex variation/DSD/Leydig Cell Hypoplasia/Micropenis/Cryptorchidism, 41yrs) did not engage in activism not because he was opposed to it, but due to the feeling it was too emotionally challenging, 'I know there are people who do this and I hope they do more, there are those of us for whom it would feel too hard a step'. Roselyn (XY female with Swyer Syndrome, 58yrs) never engaged in activism around her variation because for her 'there was too much shame'. In other comments people talked about it not fitting within the scope of their personality, for example, Stewart (male with intersex variation Klinefelter's/XXY, 39yrs) had commented 'Nah. Bit shy'. There was also, finally, a group of participants who expressed a desire to one day engage in activism (in 12 comments), and who had however not yet done so. They also gave various reasons as to why they had not engaged in activism, and also in some cases why they wanted to. Mia (intersex woman with clitoromegaly and unknown variation, 24yrs) said:

> *Thinking about what it meant to me to see intersex people marching at Mardi Gras, makes me think it would be important to get to the place where I too can do that and be that person for somebody else. I need to work through this with my family and take my time first. But the idea has now been planted and I know it would be a milestone in this journey.*

Some participants in this group had specific plans to engage in some activism one day, some did not know where to begin or what steps to take to engage in activism, some felt too young or uninformed to engage in it, and there were various other reasons. Merryn (intersex woman with PAIS and Cryptorchidism, 18yrs) said she had 'not really' engaged with any activism yet, 'I am a bit young I don't know how. Well, I told some people about it, but that was it'. Others had no time in which to do activism or were too ill; such as Jules (intersex female with XXY/47 chromosomes, 48yrs) who said she had 'not been well enough unfortunately'.

Representation in Research

There has historically been a lack of collaborative involvement with people with intersex variations in setting research agendas for various types of academic and scientific investigation concerning or relevant to this group. The literature review for this book showed there has also been a sometimes quite concerning history of their treatment in research, and a bias overall towards certain types of investigations (mainly clinical) over others. It was important to collate and understand survey participants' own views on what research needed to be conducted on and/or for people with intersex variations in the future, towards setting various agendas for the field of Intersex Studies. Participants offered 101 responses to a question asking what further research they would like to see conducted for people with intersex variations. The strongest theme that arose in 45 comments called for research focussed on a range of health care topics related to having a variation. These comments particularly focussed on research exploring the group's health care needs (generally which treatments they really argued were and were not necessary), investigating barriers to appropriate health care in the medical system for people with intersex variations and inquiring into health care techniques that were useful and not useful for the participants. Other topics included considering long-term follow-up in health care, inquiring into the outcomes of intervention treatments and not having intervention treatments, considering mental health themes, examining the outcomes of a range of experimental fertility treatments and developing new fertility treatments, generating better understanding a range of specific variations that were particularly rare, and more research into the relationship between variations and gender identities. Examples of these health-focussed responses included Marvin's (intersex man with 5-ARD, 42yrs) comment reporting that he wanted research to examine:

> *The appropriateness of care and examinations; I was fortunate I was given the choice to get surgery if I wanted it. I did and recently finished with everything. I could easily have been raised a girl as many have with my condition and I'm clearly male – I can't imagine how that would have affected me.*

Karma (transgender non-binary person with PCOS/Hyperandrogenism, 25yrs) wanted research to explore the 'legal and medical hindrances currently faced by Australians born with congenital sex variations' when they were attempting to gain appropriate health care. Una (female with intersex variation Turner's Syndrome, 21yrs) wanted research 'about the options for surgeries and HRT, or people who don't have them and what life is like for them'.

A theme that arose in 18 comments called for more inclusion of people with intersex variations in studies on general social research topics. Some of these comments specifically called for people with intersex variations to be included directly as a subgroup within broader social research studies, some specified that they wanted the inclusion to occur in an affirming manner, and some specified particular topics of interest such as gathering more information on social treatment. For example, Louise (woman with CAIS, 38yrs) commented that more research inclusion of people with intersex variations 'in all areas is needed, but especially psychosocial treatment/support'. Jannali (intersex female with CAIS, 25yrs) wanted 'stories from intersex people about their own lives, stories about sexuality and how people come to accept their identity. Positive stuff to counter all the disordering messaging'. Lee (intersex individual with Klinefelter's Syndrome, 44yrs) wanted to see 'more research into how discrimination impacts us financially. E.g. lack of jobs and/or promotions due to employment discrimination. Everyday experiences of discrimination'.

A theme in 13 comments considered dissemination of research. These comments discussed the scarcity of accessible research reporting, the lack of reports or resources made directly to or for community members, and the need to use research to educate people in a range of professions and services. For example, Zachary (male with intersex variation, Klinefelter syndrome 47/XXY/micropenis, 20yrs) wanted various researchers to create 'one big book with all the information in one place, it's too hard to find things'. Nadine (female with intersex variations Clitoromegaly/Classic CAH, 53yrs) offered the comment, 'I want to see some kind of intervention tested for doctors and parents, not for intersex people. A re-education model of some kind, to change their thinking'. Jamie (X intersex individual with CAH/21 hydroxalase deficiency, 39yrs) said 'awareness should be spread, people should have some resource where they can answer questions and get an idea of what their particular variation is'. Carson (male with Klinefelter's/XXY/47, 53yrs) said 'I would just like to hear about it more. I still don’t hear about Sex Variations anywhere. I had to search online for most of what I’ve learned’.

Eleven comments were made by participants in direct praise of the survey used in this study. These comments considered its focus on the participants’ own perspectives on their experiences (which they felt had been overlooked previously), the way the study considered their social experiences rather than solely their bodies, the way its key themes were of concern to the participants themselves in their own lives, and the affirming experience of being part of a research sample sharing stories with other community members. For example, Dylan (man with intersex variations PAIS and Hypospadias, 24yrs) commented:

> *Thank you so much for this chance to tell my story, it was energising and I am sure this discovery has started a new chapter in my life. I hope my story helps other people like me in the way other people have helped me too. I hope one day I can read about this survey somewhere and know that I made a difference.*

Clyde (trans intersex man with 47/XXY, 44yrs) said he’d like to see the results of this study, and wanted to see more studies ‘from our perspective like this’. He said he was most interested in hearing ‘other peoples’ stories as it has been a very important thing in my life to know there are many others like me and to feel part of a community’. Rowena, intersex female with PAIS, 32yrs similarly called for ‘studies like this one that give us a chance to comment on the issues that concern us’. Nine comments were by participants who were not disinterested in research but were simply unsure of the type that would be useful; Danielle’s comment (female with intersex variation CAIS, 41yrs) ‘I don’t know. I’ll think about it…’ was typical for this subgroup. Finally, five comments focussed on the need for research into education contexts, specifically exploring the development of sexuality education resources, anti-bias training efforts or trialling other support features in those environments. Penelope (intersex female with Turner’s Syndrome, 18yrs) wanted researchers to explore ‘how to make school easier for kids with the same difficulties I had’.

13. Conclusion and Recommendations

> *Doing this survey feels like doing activism. I do not have the best words to use or the best ears to listen to me. I hope you take my story, tell people who can help us.*

Sarah, woman with intersex condition PAIS, 44yrs

> *Research is fine but we need legislation to protect unconsenting infants from indiscriminate knives. Certainly more research in the area of effective HRT, the long term effects and better delivery systems, I am taking the pill for my hormone needs and have no wish to be on it for the rest of my life. Also a long term health plan for intersex individuals as to risks to disease etc. I truly believe that being intersex is amazing and it is completely normal in the sweeping expanse of the human narrative, but I think it is time to take the pen from whoever has been writing the story. Also, extended research into the long term mental health barriers that intersex people face. Also, better informed health care professionals across all areas involvement with intersex individuals.*

Fernanda, female/X with PAIS, 25yrs

http://dx.doi.org/10.11647/OBP.0089.13

Trends and Individuals

As intersex variations vary greatly; and the people who have them range in age, sex and variation type; there really was no single 'truth' to what it meant to have an intersex variation or the impacts this may have on the body beyond that this involved having (at least one or more) atypical sex characteristics (whether this involved chromosomes, hormones, internal or external anatomy, primary or secondary characteristics). There were certainly trends in some areas of preferred language and general experience. Many people saw themselves as male or female, debunking any notion that all people with intersex variations are somehow a third sex or clear-cut category. Most used a word related to 'intersex' to frame their variation in a Critical manner for themselves, with some variance in how they discussed it depending on context and what was possible with certain people in their lives (including experts, loved ones and strangers). Most were not transgender or at least did not classify their experiences (even including in some cases going through changes in sex markers) as coming under the transgender umbrella of experiences, although some did. Most people had no religious affiliation, reflecting a social resistance to indirect and direct condemnations of people with intersex variations the literature reviewed recognised in dominant Christian faiths (DeFranza, 2011; Fonrobert, 2009). Many lived in stable situations with loved ones. Most did not have disabilities (or identify themselves as having one), however a higher portion than both the general and the transgender population had disabilities (Australian Bureau of Statistics, 2012d; Jones et al., 2015), and for some their variation or related treatment outcomes were considered a disability or a direct contributing factor to having a disability. Most people felt good or very good about their intersex variation at the time of the study, but many had really struggled with it initially or considered suicide at some point in their lives; and some experienced depression, anxiety or PTSD, for example. Intersex status appeared not to be something people feel *intrinsically* bad about *in itself*, as in the historic psychological and medical theorisation supporting early intervention (Jones and Lasser, 2015); instead, most participants found their exposures to social and medical constructions of their intersex status played important roles in how they felt about their intersex variations. There were very clear cut issues around medical intervention, the lack of structural support features in schools and impacts on employment for some. People with intersex variations also seemed to have mainly uniform positions on a few matters currently being debated around their inclusion in society (such as on surgical intervention and other themes). Most did not widely discuss their variation with other people in their own lives, yet most benefitted from reaching outside their social circles to engage in social interactions of some kind (whether in groups, online or otherwise) with people with their own intersex variations or similar.

However, there were also subgroups and individuals with differing identification and experiences – people who classified their sex marker as X or another sex, who did not in any way relate to sex binaries or who were both intersex and transgender. This showed that medical assumptions a simplistic sex allocation by intersex variation (the assumption that a person with CAH is usually female, a person with Klinefelter's male) or that sex allocation is always necessarily stable do indeed need to be questioned, further than seen in previous studies (beyond the challenges to the assumption that people with Klinefelter's are male offered by Herlihy & Gillam, 2011). Some people were homeless or lived less stable lives at the time of doing the survey, in rates similar same sex attracted youth (Hillier et al., 2010). Some were Christians, Buddhists, Muslim or had other beliefs reflecting a relatively broader interest amongst the LGBTI community in non-Christian creeds than that seen in the general Australian community (Gahan & Jones, 2013; Gahan et al., 2014). There were people who had very positive experiences of health care, and a very minor portion of the group who preferred the use of the term DSD and understood themselves in quite clinical terms. A few had been raised by people who were open with them about their variation from a young age and who never faced any pressure to engage in treatments for their variation, or who had adult advocates who represented their rights in clinical contexts. There were a few people who had been exposed to quite affirming experiences or structural supports around having an intersex variation during their studies or at work. There were people who lived their lives as 'out and proud' advocates for those with intersex variations and often engaged with complete strangers around related topics, and people who had almost nothing to do with intersex topics beyond completing a few doctor's appointments and participation in this study. There were people who engaged in heterosexual marriages, religious lives, procreative sex and child-rearing; right through to people who had multiple partners of multiple sexes, or were divorced, or enjoyed a range of sexual play outside of traditional notions of penetrative sex, or had abstained from relationships and sexual activities almost entirely. Some participants had never met anyone else with an intersex variation and were excited to discover the social groups listed on the survey itself, some had regular contact with other people with intersex variations. Whilst this study showed themes and commonalities in a mainly Australian context, it is important to remember that all people with intersex variations are individuals and should not be stereotyped, and further they may think about their variation and the level to which it should be discussed or treated (if ever) in wildly different ways. It would almost be quite naïve to assume anything at all, for example, about which treatments or specific schooling management plan would be useful for any given individual with an intersex variation before actually talking to that individual about their unique perspective on the matter; therefore, the recommendations that follow have been honed to cater for a diverse range of possibilities for improvements that can be offered in institutional and social contexts towards better overall social outcomes for this group.

Recommendations

The issues and implications emerging from this research covered a range of fields, and involved a number of stakeholders from governments through to service workers and everyday citizens. These recommendations include consideration of parents/guardians of people with intersex variations; health services and policy and training; mental health services and training; education policy and practices; employment policy; social contexts; and media representation, advocacy and further research.

Social contexts

Friends, partners, sisters and mothers were key sources of social support for people with intersex variations, and further support across a range of relationship types is to be encouraged. Everyday people in the lives of those with intersex variations have the potential to offer support simply through taking an affirming attitude; this particularly needs to happen in schooling contexts and religious/spiritual contexts where a range of people have more frequently responded in mixed or unsupportive ways. Given most participants had experienced discrimination, many myths about people with intersex variations abounded and most people with these variations never or rarely discussed the reality of their variations with strangers (and nor should they have to). Broader social campaigns educating the general public (without requiring unwilling individuals to come out or explain themselves) might perhaps be of great value to ensuring wider affirmation of this group. A game-changing finding of this study was that most participants found engaging with others with their variation or similar improved their wellbeing. This finding suggests that more Government and philanthropic grant support for these groups – if used wisely – could represent a strong long-term investment in contributing to the social factors that can improve the groups' overall mental health risks.

Health Services, Policy and Training

Whilst most people with intersex variations considered themselves to be moderately to extremely healthy at the time of the survey, this group had several key concerns about health/medical service provisions. These concerns particularly focussed on the period in which their variations are first discovered and where treatment plans are initiated and carried out. The background literature for this study had highlighted that surgical and hormonal interventions for people with intersex variations are currently under heated debate, with the United Nations decrying 'normalising' interventions in reports on torture and the right of the child (Davis, 2015; United Nations, 2012), and some medical researchers supporting their use (Warne et al., 2005). Most participants in this study had experienced around two treatment interventions, most commonly hormonal treatments and genital surgeries of varying kinds, and many of the key issues around these treatments arose around the fact that over half were delivered when they were aged under 18yrs – at a time when, and in ways where, their right to be able to make fully informed decisions about treatments were often overlooked. With the majority of participants receiving no information about risks related to the interventions and one fifth receiving no information at all, people with intersex variations were often uninformed about their rights as patients and in some cases class themselves as being coerced or outright abused by individuals and processes in medical institutions. This has created, for a noteworthy portion of this population, feelings of anger and trauma around medical services, and in some cases people now actively avoided them – which is worrying in light of the fact that people with intersex variations, like anyone else, may have physical health needs or illnesses for which medical help can be useful. The data clearly showed that there were physical, mental and psychological impacts to treatments used for people with intersex variations around their sex characteristics, which must not be ignored – even in most of the cases where treatments were seen as useful by an individual overall there was also at least one negative impact they had not been warned about. Whether health services framed intersex variations in supportive or negative ways also held ramifications for how people felt about their intersex variations, with negative health service constructions of intersex variations associated with negative feelings and periods of suicidal ideation for many participants.

Whilst medical practices and attitudes may be changing from those experienced by participants in this study (who were all 16 or over), recommendations are clearly needed to help ensure the negative experiences associated with older approaches are not shared by future generations of people with intersex variations. This is especially important since other recent studies have not clearly pointed out issues with early intervention paths – despite findings which confirmed, as with this study, the likelihood that intervention can lead to sexual difficulties and complications (Lux et al., 2009; Warne et al., 2005). Recommendations by civil society organisations such as the United Nations and World Health Organisation (as well as their regional and state members) should include that people with intersex variations should be given adequate information about their variation, and should become not only a partner with medical practitioners in formulating any treatment plan but indeed, the driver of any such plans. Risks of treatment should be actively communicated to all potential patients. All people with intersex variations (especially those under 18) need information and counselling about their right to not engage in or defer treatments – if they are truly to give fully informed consent to life-changing surgeries or treatments. Moreover, the bias towards automatically 'treating/correcting' variations in sex presentation needs to be challenged in itself.

Another key recommendation based on this study is that medical practitioners of all kinds be trained (both in undergraduate and professional development programs) to understand that sex presentation is and should be variable; intersex variations are to be expected in the human population. It would be useful for training to cover intersex variations of many kinds, and that most people with these variations have healthy bodies but some may or may not choose to seek assistance (as needed/desired) in areas including stimulating a puberty; aesthetic appearance of sex characteristics; and/or fertility treatments for example. Anger and trauma particularly surrounded certain practices which all medical practitioners need to be *trained to avoid*, and which institutional policies should prohibit, including:

- responding to patients' bodies negatively (expressions of shock, horror, curiosity should be avoided);
- proceeding with physical (particularly genital) exams or tests for which no patient permission was sought (whether they are a child, teen or adult);
- sharing information on the patient's body or the viewing of the patient's body with no patient permission (whether with a colleague/ supervisor or group of medical students for example);
- proceeding with 'correction treatments' of atypical sex characteristics for which no patient permission was sought or information/ counselling provided; and
- asserting (inaccurate) social biases against the life people with intersex variations might lead without treatments.

Based on that data both on what people with intersex variations most wanted, and on what increased wellbeing for this group, medical services should have policies organised around goals to:

- increase support for the autonomy and choices of people with intersex variations around their own treatment paths,
- provide staff training/education on intersex variations;
- provide people with intersex variations with information on their specific variations on and after diagnosis; and
- provide people with intersex variations with referrals to intersex support groups and online communities, where positive constructions of intersex status can be experienced, and information and support can be shared.

It is important to note that some people with intersex variations participating in this project may have been subjected to medical approaches no longer considered optimal or in wide use, and that some modern Australian medical services may indeed already be applying more critical approaches. However, to ensure these processes do indeed occur, governments of countries including Australia should take legislative, administrative and other measures to guarantee that non-urgent, irreversible medical interventions for people with intersex variations are postponed until and unless they are sufficiently mature to participate in decision-making and additionally give their informed consent.

Roles for Parents/Guardians in Healthcare

Families, parents and other guardians of people with intersex variations were often given inadequate information about their intersex variations according to the participant themselves, including the full range of treatment options and future possibilities open to someone with an intersex variation. Where they made treatment decisions on their child's behalf, some participants explained that having their health care decisions taken out of their hands caused them personal difficulties and wellbeing complications, and for those who would have made alternate decisions there were sometimes lifelong complications around their sex presentation and fertility (and both immediate and long-term health complications as well). It is important to note that this was not always the case. Tina (woman with intersex condition 17-beta-hydroxysteroid dehydrogenase deficiency, 33yrs) had outlined her individual concerns that those few activists with intersex variations who aimed at representing the group more broadly were mostly 'a very vocal minority' set against medical interventions;

> *I believe the majority of people with intersex conditions are living happily, with loving families and good medical support. I was operated on at 8 years old, and given hormone replacement therapy at 12. Of course, I could not 'consent' – my parents did that on my behalf and I'm very glad that they did.*

Nevertheless, the findings of this study suggested that undergoing treatments to one's sex characteristics without one's consent was perhaps a more common experience for people with intersex variations than may have ever been previously recognised in research, and that a strong majority of participants disagreed with any kind of health care approach in which they were unable to have their own perspectives on their own bodies foregrounded.

Given the health and mental health risks experienced by people with intersex variations, their overall opinions as a group, and the lack of information we have on the overlap between parents' visions and people with intersex variations' visions for their 'ideal health care' and what exactly that should entail, it is recommended that parents and guardians take a cautious approach and actively resist engaging interventions for their child before they are of an age to themselves give their consent – which could vary from individual to individual, and may be impacted by a range of physical, psychological and social factors. Whilst the broader literature may give some conflicting advice on this matter, new literature produced by the United Nations and individuals with intersex variations themselves argue for the right to bodily autonomy (Davis, 2015; United Nations, 2012). Furthermore, in this study, participants many times expressed a desire for their parents to be a more protective force for their personal rights in navigating health care services. Because the study highlighted perceived gaps in parents' knowledge of people with intersex variations' needs, it is important that governments including the Australian government consider mandating the provision of some basic counselling services for all parents and guardians of people with intersex variations, to inform them of the consequences of unnecessary surgery and other medical treatment and to ensure a context in which expertise around intersex variations could be shared. It may be necessary for a general resource around this matter to be developed, such as a booklet for parents and guardians, which could be provided by a range of counselling services with varying levels of expertise on the matter, to help educate all parties about key issues.

Mental Health Services and Training

The data from this study around mental health outcomes contrasted with Warne et al.'s (2005) more positive assessment of 'psychological outcomes' for the population surrounding medical intervention. Notably, Warne et al. did not ask the people with intersex variations themselves how they had felt about the interventions they were subjected to. In this study, whilst most participants reported that they had good or better mental health at the time of the survey, most reported that they had also been through periods of suicidal ideation in their lives and many had experienced depression, anxiety and PTSD. Mental health risks – particularly suicidal ideation – appeared to be notably high around the time period in which people with intersex variations were first told of their variation. Factors contributing to risks as cited by participants included negative social responses from others, difficulties around having undergone interventions or issues around gender/identity (which could be exacerbated by professional care which involved pressure around producing a certain type of gendered behaviour and/or identity). This appears to reflect both the history of silence and stigma around people with intersex variations outlined in the literature, and the complex context around medical interventions and negative messaging around the 'ab/normalcy' of intersex variations. Participants in this study called for improvements in training for mental health services/workers, and it would be useful for general information to be available in undergraduate training and professional development opportunities for psychologists, counsellors and other mental health workers. In addition, mental health practitioners are advised to try (and indeed, be seen to try) to learn about the variations experienced their clients and take interests in their concerns. Some participants wanted to see mental health services to be supplied specifically for younger people/children/adolescents with intersex variations which could empower and support them to have a say in their medical treatments and interactions around their body with doctors and/or family; this is a sensitive area that could benefit from further inquiry and development.

Finally, it is undeniable that a few individuals in this study had suffered a unique and extreme form of trauma from the multifarious impacts of being subjected to unnecessary and damaging medical interventions without their consent. This is not to characterise people with intersex variations as inherently victims, or intervention as inherently victimising. It is important to note the resilience of many people with intersex variations broadly and in relation to interventions whether they actively sought them out or not. Some individuals experienced positive impacts from interventions, particularly from chosen interventions or from interventions in-keeping with their own personal ideal visions for their bodies. However, there *were* individuals who experienced significant negative impacts from medical interventions they had not consented to including for example negative health impacts, negative mental health impacts, negative sexual health impacts, and/or negative employment impacts. For some individuals, these experiences combined to position them outside of the educational, industrial and social systems necessary to leading a dignified, fulfilled and socially connected existence. It is recommended that, for such individuals, governments provide adequate redress for their physical and psychological suffering to help mediate long term impacts on their quality of life, to truly affirm their individual value and to show an active intention to create a ready place for all people with intersex variations in our communities.

Education Policy and Practice

Specific education guidelines supporting people with intersex variations is currently lack in Australia and overseas (Jones, 2015). Whilst many people surveyed had a post-secondary qualification, the portion who had only had a primary school education (18%) was significant in comparison to the broader Australian population. School staff and students were not largely responding to disclosures about intersex variations in a supportive manner, there was a lack of guidelines for how to serve students with intersex variations across the country and school sector types, and appropriate school counselling services/referrals were widely lacking. There were many reports of bullying based on physical or other aspects of having a variation. Participants suggested improvements to schools' information provision and support features. Schools particularly lacked inclusion of people with intersex variations in their puberty and sexuality curricula provisions. There were also broader calls in other survey data on sexuality in the study for sexual health information specific to people with intersex variations, whether included in broader sexual health coverage or on its own, which highlighted body positive messages and community experiences in an inclusive manner, and distinguished clearly between issues of fertility and issues of infection risk (particularly to young people). Schools could be an ideal location for such messaging in their own puberty and sexuality provisions, and this could be a very important first step for the education systems moving forward. Based on the findings of this study, it is therefore recommended that education providers:

- provide policy protection against discrimination and bullying for people with intersex variations in their staff and student bodies;
- promote, in general diversity messaging to educational communities, a welcoming attitude to people with intersex variations as part of the broad spectrum of community members valued by the institution;
- provide guidelines and training to staff about responding in a supportive manner to disclosures about intersex variations;
- provide opportunities for people with intersex variations/their parents and guardians to safely and privately disclose any special/medical needs to the school where relevant, and to contribute to plans around any relevant management or suitable support provisions;

- broadly offer (or offer links to) appropriately supportive counselling services/referrals for individuals with intersex variations in general so such opportunities can be privately accessed as needed; and
- acknowledge the existence of people with diverse intersex variations and the general variability of sex in puberty and sexuality/science/health curricula provisions.

Employment Policy and Practice

Unemployment was notably high in this population, falling between the 9-15% portions of transgender people unemployed in various recent studies (Couch et al., 2007; Jones et al., 2015; Pitts et al., 2006) – with both similar factors of early school drop-out and fear of discrimination, and unique concerns around disabilities and health complications, influencing unemployment. More than half the people with intersex variations surveyed had not told their employer/boss about their variation, and a similar amount had not told co-workers. The responses to participants' disclosures from both employers and co-workers were mostly neutral/mixed. Impacts of having a variation (and surrounding influences) in the workplace included obstacles to gaining or maintaining work due to workplace discrimination or the complications of wellbeing issues, and reported effects on some participants' comfort in engaging in particular working arrangements or industries. The data suggest the need for special social or employment service consideration of this group in times of crisis, in terms of ensuring people are not left alone to fall so far out of employment systems that they cannot get back in. It would be good to see more guidelines for industries around inclusion of this group in the workforce; perhaps representatives from key unions might be able to work with people with intersex variations in formulating visions of how practical guidelines might look in the first instance.

Media representation, advocacy and further research.

Participants had generally seen more, and better (by their own assessments) representations of 'real' people with intersex variations in the media than fictional ones. However, there was an appetite for more media representations of both kinds, and some of the comments suggested that non-sensationalised, non-pathologising representations contributed to people with intersex variations feeling good about themselves, feeling strong and being able to discuss their variations more freely. Critical intersex representations informed by or incorporating actual people with intersex variations were particularly valued, alongside Post-modern disruptions of normative sex narratives. Negative representations – particularly those reminiscent of old Socio-Cultural Sex Conservatism tropes of monstrosity or evil, or early Biological Essentialist Discourse's correlation of incest and intersex bodies – were disappointing to the group on the whole. They made some individuals feel they did not want people knowing they had specific variations they felt were misrepresented. Several participants reported that they experienced distress at the negative media portrayal of Olympic athlete Caster Semenya – reflecting analyses provided in the literature review of the likely distress the coverage could cause to people with intersex variations (Sawer & Berger, 2009). The chapter on media names some of the most popular media texts which those people with intersex variations who are looking for further texts of interest might wish to explore (such as the films *Orchids* and *Intersexion*), and which might provide documentary-makers and other text-producers with inspiration around the kind of texts that have been well-received by this population. Participants' comments also offered insights into the kinds of exploitation-style approaches that were not welcomed by the community.

The study also found that people with intersex variations ranged from those who were highly engaged in and organised much of their lives around activism to ensure affirming representation of the group in legislation and other areas, through to people who did not engage in it and did not have any desire to personally engage in it. There was, however, a small group who did not engage in activism currently – sometimes because they were unsure how, yet would like to. This book provided some of the activism techniques people used which may serve as ideas, many of which were in the main anonymous or did not require an ongoing public profile, and did not require an excess of labour. Regardless of whether individuals were largely in keeping with the goals of both the Liberal and Critical Intersex Activism approaches described at the beginning of this book which sit behind current activism-based organisations run by intersex advocates. The participants' views regarding key activism themes were overall against people with intersex variations being treated in ways which did not privilege their access to key information, services or citizenship rights. Other key activism themes privileged by this group which Australian and other governments should prioritise included:

- ensuring people with intersex variations have access to their medical records and history;
- ensuring health providers offered referrals to supportive social groups; and
- marriage equality for people with intersex variations (including equal access to marriage rights with the partner of their choosing, and protection from punitive divorce provisions on the basis of intersex status).

Regarding the latter point, debates in Australia and other countries on marriage equality particularly need to include stronger representation of the needs and concerns of people with intersex variations, and this is an area for collaboration with LGBT and other groups. Further, the point that divorce provisions on the basis of intersex status send the clearly discriminatory message that people with intersex variations are somehow 'less worthy' of love and companionship, or should be more readily abandoned than other community members, needs to be made in these debates so that when legislation around marriage equality is amended this provisions can be concomitantly redressed. This showed that people with intersex variations were concerned not only with their media representation expanding and improving, but also their political representation.

Regarding future research, this study offered implications for how to capture people with intersex variations in a questionnaire. The participants with intersex variations in this study were more easily recognised as a group by their declaration of having a specific intersex variation – rather than whether they answered yes or no to a question on whether they had congenital sex variations/atypical sex characteristics; which was not in itself indicative as transgender people who did not have a variation still answered 'yes' to that question. Further, to ask whether participants are intersex would also be a more problematic question as people who are not intersex may believe their can 'identify' as intersex without having a variation, in addition it would be incorrect to include the term intersex in a list of sex or gender options purely as some kind sex marker or gender identity (as there is no 'intersex' sex marker other than 'X' which may not in itself indicate being intersex, and intersex is only rarely used by people with intersex variations as a gender identity). Therefore, researchers looking to include people with intersex variations in their surveys or other projects on other themes are advised that it is most useful to ask a question along the lines of: 'Please list any intersex variations you have been diagnosed with ___________'. Those participants for whom that question is relevant will then be able to name or describe their variation/s to the extent they are willing, so that this information can be acknowledged in any reporting on the study. It would be essential for researchers to check that the diagnoses are actual intersex variations; this report supplies some useful information in its glossary. The willingness of people with PCOS to participate in this study and in many cases use the term intersex in relation to their variation confirmed the suggestion by Huang et al. that hyperandrogenism in this population has perhaps been underestimated (Huang et al., 2010); researchers can indeed include such people with PCOS-related hyperandrogenism in their data.

Amongst the participants' ideas for future research specifically about people with intersex variations, the key themes of most interest to the group included:

- investigation into varying constructions of health care and practical aspects of health care for people with intersex variations broadly and for diverse groups within that umbrella; and
- further investigation into the social experiences of people with intersex variations.

The data itself also suggested the likely importance of studies on other topics including:

- the overlap between parents, doctors and people with intersex variations' visions of what health care for people with intersex variations could look like;
- trials of particular approaches to improving mental health provisions for people with intersex variations both broadly and particularly for young people; and
- trials of particular approaches to inclusion of intersex issues in puberty or sex education, science and health program and/or resource provisions in schools.

These research themes constitute a useful research agenda for those wishing to contribute to Intersex Studies.

These study areas particularly fit within Critical framings which value the stated research goals of people with intersex variations, and

Post-modern framings which question the norms of existing systems and grand narratives in complex institutional settings impacted by competing health and educational discourses. With almost a third of the participants reporting that they had disabilities, although it was rare that they framed their intersex variation itself as a disability, both Critical Disability Studies and Post-modern Crip Theory lenses might also offer some very interesting lenses for creative examination of how and when disability labels and concepts are used and challenged by this community. However, in reporting on such studies, it is important for researchers to understand (and be forewarned) that Critical and Post-modern studies do not 'speak the (largely Conservative and Liberal) language' of established medical and psychological organisations, nor the many research journals through which their knowledge is communicated. There have been documented efforts to control language use around this group in academic conferences and debates, which have thus far privileged DSD conceptualisations (Davis, 2011; Hughes, 2008; P. Lee et al., 2006). Academic journals such as the *Archives of Sexuality* even have policies of actively refusing post-modern and critical work, solely on the basis of its frame. Researchers are encouraged to push directly back against the biases of such medical and psychological publishers, and to actively seek alternate (particularly open access) routes of publishing new work in this area, so that the voices of people with intersex variations can form the basis of an emergent Intersex Studies field and directly challenge the current proliferation of Conservative DSD-focussed work in exciting and useful ways.

Conclusion

It has been an honour to do this study, and at times a very humbling learning experience. This book is dedicated to the people with intersex variations – of all age groups, lifestyles and experiences – who form this rich and diverse community in Australia and overseas. Their enthusiasm in engaging in a study that for many would have stirred up raw emotions about sensitive issues is admirable, and they were asked many personal questions on topics that can generally be taken as taboo in daily life but which were necessary for the sake of knowledge generation in this field and informing recommendations to key bodies. All stakeholders are encouraged to understand the rarity of this research and appreciate the effort that participants went to in contributing to it, and to act on these recommendations in support for their future, as Australia starts to honour the equality protections for this group now written directly into law. There is still much to learn from community members with intersex variations, and about the complexity of sex itself, in moving forward.

References

Anti-Discrimination Act 1991, ACT Parliamentary Counsel, 35 Cong. Rec. (2010).

Agius, S. (2015). *Human Rights and Intersex People*. Strasbourg: Cedex. http://fra.europa.eu/en/publication/2015/fundamental-rights-situation-intersex-people

Ahmed, S., Achermann, J., Arlt, W., Balen, A., Conway, G., Edwards, Z., & Willis, D. (2011). UK Guidance on the Initial Evaluation of an Infant or an Adolescent with a Suspected Disorder of Sex Development. *Clinical Endocrinology, 75*(1), 12-26. http://dx.doi.org/10.1111/j.1365-2265.2011.04076.x

Ainsworth, C. (2015). Sex Redefined. *Nature, 518*(1), 288-291. http://dx.doi.org/10.1038/518288a

Amdur, N. (1977). Renée Richards Ruled Eligible for U.S. Open; Ruling Makes Renée Richards Eligible to Qualify for U.S. OpenTimes. *The New York Times*.

Appleby, J., Gibson, G., Norymberski, J., & Stubbs, R. (1955). Indirect Analysis of Corticosteroids. I. The Determination of 17-Hydroxycorticosteroids. *Biochem J., 60*(3), 453-460. http://dx.doi.org/10.1042/bj0600453

Atkins, L., & Engel, E. (1962). Absence of the Y Chromosome (XO Sex-Chromosome Constitution) in a Human Intersex with an Extra-Abdominal Testis. *Lancet, 7*(3), 20-23. http://dx.doi.org/10.1016/s0140-6736(62)92934-3

Australian Bureau of Statistics. (2012a). 1301.0 – Year Book Australia: Educational Attainment. http://www.abs.gov.au/ausstats/abs@.nsf/Lookup/by Subject/1301.0~2012~Main Features~Educational attainment~110

Australian Bureau of Statistics. (2012b). 2071.0 – Reflecting a Nation: Stories from the 2011 Census, 2012-2013 – Cultural Diversity in Australia. http://www.abs.gov.au/ausstats/abs@.nsf/Latestproducts/2071.0Main Features902012-2013

Australian Bureau of Statistics. (2012c). 3101.0 – Australian Demographic Statistics. http://www.abs.gov.au/ausstats/abs@.nsf/mf/3101.0

Australian Bureau of Statistics. (2012d). 4430.0 – Disability, Ageing and Carers, Australia: Summary of Findings, 2012. Canberra: Australian Bureau of Statistics. http://www.abs.gov.au/ausstats/abs@.nsf/mf/4430.0

Australian Government. (2013). Guidelines on the Recognition of Sex and Gender. Barton: Commonwealth of Australia. https://www.ag.gov.au/Publications/Documents/AustralianGovernmentGuidelinesontheRecognitionofSexandGender/AustralianGovernmentGuidelinesontheRecognitionofSexandGender.PDF

Baghramian, M. (2004). *Relativism*. London and New York: Routledge. http://dx.doi.org/10.4324/9780203645895

Balen, A. (2007). Sexual Differentiation: Intersex Disorders. In A. Balen (Ed.), *Reproductive Endocrinology for the MRCOG and Beyond* (pp. 1-16). London: Cambridge University Press. http://dx.doi.org/10.1017/cbo9781139696920.003

Balen, A., Creighton, S., Davies, M., MacDougall, J., & Stanhope, R. (2004). *Paediatric and Adolescent Gynaecology: A Multidisciplinary Approach*. London: Cambridge University Press. http://dx.doi.org/10.1017/cbo9780511527036

Bazzul, J., & Sykes, H. (2011). The Secret Identity of a Biology Textbook: Straight and Naturally Sexed. *Cultural Studies of Science Education, 6*(2), 265-286. http://dx.doi.org/10.1007/s11422-010-9297-z

Beckmann, A., Cooper, C., & Hill, D. (2009). Neoliberalization and Managerialization of 'Education' in England and Wales – A Case for Reconstructing Education. *Journal for Critical Education Policy Studies, 7*(2), 311-345. http://www.jceps.com/?pageID=article&articleID=170.

Bezhanova, O. (2014). Intersex, Monstrosity and the Civil War in Alicia Gimenez Bartlett's Donde Nadie te Eencuentre. *Hispanofila, 170*(1), 57-59. http://dx.doi.org/10.1353/hsf.2014.0013

Bhabha, H. (1990). *Nation and Narration*. London: Routledge. http://dx.doi.org/10.4324/9780203823064

Bickenbacha, J. E., Chatterji, S., Badley, E. M., & Üstün, T. B. (1999). Models of Disablement, Universalism and the International Classification of Impairments, Disabilities and Handicaps. *Social Science & Medicine, 48*(9), 1173-1187. http://dx.doi.org/10.1016/s0277-9536(98)00441-9

Blair, A., & Monk, D. (2009). Sex Education and the Law in England and Wales: The Importance of Legal Narratives. In L. D. H. Sauerteig & R. Davidson (Eds.), *Shaping Sexual Knowledge: A Cultural History of Sex Education in Twentieth Century Europe* (pp. 37-54). London and New York: Routledge.

Brook, C. (1993). *A Guide to the Practice of Paediatric Endocrinology*. London: Cambridge University Press. http://dx.doi.org/10.1017/cbo9780511526862

Butler, J. (1990). *Gender Trouble: Feminism and the Subversion of Identity*. London: Routledge. http://dx.doi.org/10.2307/1395391

Butler, J. (2004). *Undoing Gender*. New York: Routledge. http://dx.doi.org/10.4324/9780203499627

Butler, J. (2005). *Giving an Account of Oneself*. New York: Fordham University Press. http://dx.doi.org/10.1353/dia.2004.0002

Byne, W. (2014). Forty Years after the Removal of Homosexuality from the DSM: Well on the Way but Not There Yet. *LGBT Health*. http://dx.doi.org/10.1089/lgbt.2014.1504

Callewaert, S. (2006). Bourdieu, Critic of Foucault: The Case of Empirical Social Science Against Double-Game-Philosophy. *Theory, Culture & Society, 23*(6), 73-98. http://dx.doi.org/10.1177/0263276406069776

Carlson, D. L. (1992). Identity Conflict and Change. In J. T. Sears (Ed.), *Sexuality and the Curriculum: The Politics and Practices of Sexuality Education* (pp. 34-58). New York: Teachers College Press. http://dx.doi.org/10.5860/choice.30-1069

Carlson, D. L. (2005). Poststructuralism. In J. T. Sears (Ed.), *Youth, Education, and Sexualities: An International Encyclopedia* (pp. 635-638). London: Greenwood Press. http://dx.doi.org/10.5860/choice.43-5046

Carroll, L. (2005). Intersex. In J. T. Sears (Ed.), *Youth, Education and Sexualities: An International Encyclopedia (Vol. One: A–J).* (pp. 440-444). Westport, Connecticut: Greenwood Press.

Chase, C. (1997). Special Issue on Intersexuality. *Chrysalis: The Journal of Transgressive Gender Identities*, Fall/Winter.

Couch, M., Pitts, M., Muclcare, H., Croy, S., Mitchell, A., & Patel, S. (2007). *Tranznation: A Report on the Health and Wellbeing of Transgendered People in Australia and New Zealand*. Melbourne: Australian Research Centre in Sex Health and Society.

Court Brown, W., Price, W., & Jacobs, P. (1968). The XYY Male. *BMJ, 4*(5629), 513. http://dx.doi.org/10.1136/bmj.4.5629.513-a

Creighton, S., Michala, L., Mushtaq, I., & Yaron, M. (2013). Childhood Surgery for Ambiguous Genitalia: Glimpses of Practice Changes or More of the Same? *Psychology & Sexuality, 5*(1), 34-43. http://dx.doi.org/10.1080/19419899.2013.831214

D'Augelli, A. R. (1998). Developmental Implications of Victimization of Lesbian, Gay, and Bisexual Youths. In G. M. Harek (Ed.), *Stigma and Sexual Orientation: Understanding Prejudice Against Lesbians, Gay Men, and Bisexuals* (pp. 187-210). Thousand Oaks, CA: Sage Publications. http://dx.doi.org/10.4135/9781452243818.n9

Davis, G. (2011). 'DSD is a Perfectly Fine Term': Reasserting Medical Authority Through a Shift in Intersex Terminology. *Advances in Medical Sociology, 12*(1), 178. http://dx.doi.org/10.1108/s1057-6290(2011)0000012012

Davis, G. (2015). *Contesting Intersex: The Dubious Diagnosis*. New York: NYU Press. http://dx.doi.org/10.5860/choice.194112

De La Chapelle, A. (1986). The Use and Misuse of Sex Chromatin Screening for 'Gender Identification' of Female Athletes. *Journal of the American Medical Association, 256*(1), 1920-1930. http://dx.doi.org/10.1001/jama.256.14.1920

De La Chapelle, A., & Hortling, H. (1962). XY/XO Mosaicism. *Lancet, 13*(2), 783-784. http://dx.doi.org/10.1016/s0140-6736(62)90611-6

De Schweinitz, K. (1939). *Growing Up. The Story of How a Baby is Born*. Sydney: Angus and Robertson.

DeFranza, M. (2011). *Intersex and Imago: Sex, Gender, and Sexuality in Postmodern Theological Anthropology.* (PhD), Marquette University, Milwaukee, Wisconsin Retrieved from http://epublications.marquette.edu/dissertations_mu/117/

DeFranza, M. (2015). *Sex Difference in Christian Theology: Male, Female, and Intersex in the Image of God*. Grand Rapids, MI: Eerdmans Publishing Co.

Dewsbury, G., Karen, C., Randallb, D., Rouncefield, M., & Sommerville, I. (2010). The Anti-Social Model of Disability. *Disability & Society, 19*(2), 145-158. http://dx.doi.org/10.1080/0968759042000181776

Diamond, D., Sytsma, S., Dreger, A., & Wilson, B. (2003). Culture Clash Involving Intersex. *The Hastings Center Report, 33*(4), 12. http://dx.doi.org/10.2307/3528374

Diamond, M., & Beh, H. (2008). Changes in Management of Children With Differences Of Sex Development. *Nature Clinical Practice Endocrinology & Metabolism, 4*(1), 4-5.

Diamond, M., & Sigmundson, H. K. (1998). Sex Reassignment at Birth: Long-Term Review and Clinical Implications. *Archives of Pediatrics and Adolescent Medicine, 15*(1), 298-304. http://dx.doi.org/10.1001/archpedi.1997.02170400084015

Donahoe, P. K. (1987). The Diagnosis and Treatment of Infants with Intersex Abnormalities. *Pediatric Clinics of North America, 34*(1), 1333-1348.

DPA Local Editorial. (2015). Intersex Person Sues Clinic for Unnecessary Op. *The Local.* http://www.thelocal.de/20150227/intersex-person-sues-doctors-for-unwanted-op

Dreger, A. (1998). *Hermaphrodites and the Medical Invention of Sex*. Cambridge: Harvard University Press. http://dx.doi.org/10.2307/2649586

Dreger, A. (2015). *Galileo's Middle Finger: Heretics, Activists, and the Search for Justice in Science*. New York: Penguin.

Elia, J. P. (2005). Sexuality Education. In J. T. Sears (Ed.), *Youth, Education, Sexualities: An International Encyclopedia* (pp. 785-789). London: Greenwood Press.

Fausto-Sterling, A. (1992). *Myths of Gender: Biological Theories About Women And Men*. New York: BasicBooks.

Fausto-Sterling, A. (1993). The Five Sexes: Why Male and Female Are Not Enough. *The Sciences*, March/April, pp. 20-24. http://dx.doi.org/10.1002/j.2326-1951.1993.tb03081.x

Fausto-Sterling, A. (2012). *Sex/Gender: Biology in a Social World*. New York: Routledge.

FAZ & DPA Editorial. (2015). Intersexualität: Chirurg muss für Entfernung von Geschlechtsorganen zahlen. *Frankfurter Allegemeine Gesellschaft.* http://www.faz.net/aktuell/gesellschaft/gesundheit/intersexualitaet-chirurg-muss-fuer-entfernung-von-geschlechtsorganen-zahlen-1515845.html

Feltey, K. M., Ainslie, J. J., & Geib, A. (1991). Sexual Coercion Attitudes Among High School Students: The Influence of Gender and Rape Education. *Youth & Society, 23*(2), 229-250. http://dx.doi.org/10.1177/0044118x91023002004

Ferguson-Smith, M., & Johnston, N. (1960). Chromosome Abnormalities in Certain Diseases of Man. *Ann Intern Med, 53*(1), 359-371. http://dx.doi.org/10.7326/0003-4819-53-2-359

Findlay, D. (1995). Discovering Sex: Medical Science, Feminism, and Intersexuality. *The Canadian Review of Sociology and Anthropology, 32*(1), 25-52. http://dx.doi.org/10.1111/j.1755-618x.1995.tb00833.x

Floyd, D. (2010). *The Captain and Thomasine*. Raleigh, NC: Lulu Enterprises.

Fonrobert, C. E. (2009). Gender Identity in Halakhic Discourse. *Jewish Women: A Comprehensive Historical Encyclopedia*. http://jwa.org/encyclopedia/article/gender-identity-in-halakhic-discourse

Ford, K. (2001). 'First, Do No Harm' – The Fiction of Legal Parental Consent to Genital-Normalizing Surgery on Intersexed Infants. *Yale Law and Policy Review, 19*(1), 469.

Foucault, M. (1969). *The Archeology of Knowledge and the Discourse on Language*. New York: Pantheon Books.

Foucault, M. (1970). *The Order of Things*. New York: Pantheon.

Foucault, M. (1976). *The History of Sexuality: Volume One, the Will to Knowledge*. Harmondsworth: Penguin Books.

Foucault, M. (1979). *Discipline and Punish: The Birth of the Prison*. Harmondsworth: Penguin Books.

Foucault, M. (1980). *Power/Knowledge*. New York: Pantheon

Frank, M. (1989). *What is Neostructuralism?* (Vol. 45). Minneapolis: University of Minnesota Press.

Futterweit, W., & Deligdisch, L. (1986). Histopathological Effects of Exogenously Administered Testosterone in 19 Female to Male Transsexuals. *Journal of Clinical Endocrinology and Metabolism, 62*(1), 16-21. http://dx.doi.org/10.1097/00006254-198609000-00017

Gahan, L., & Jones, T. (2013). *Heaven Bent: Australian Lesbian, Gay, Bisexual, Transgender and Intersex Experiences of Faith, Religion and Spirituality.* Melbourne: Clouds of Magellan.

Gahan, L., Jones, T., & Hillier, L. (2014). An Unresolved Journey: Religious Discourse and Same-Sex Attracted and Gender Questioning Young People. *The Social Scientific Study of Religion, 25*(1), 202-229. http://dx.doi.org/10.1163/9789004272385_012

Genel, M. (2000). Gender Verification No More? *Medscape General Medicine, 2*(3). http://www.medscape.com/viewarticle/408918

Grabham, E. (2007). Citizen Bodies, Intersex Citizenship. *Sexualities, 10*(1), 29-48. http://dx.doi.org/10.1177/1363460707072951

Green, M. H. (2013). Caring for Gendered Bodies. In J. M. Bennett & R. M. Karras (Eds.), *The Oxford Handbook of Women and Gender in Medieval Europe* (pp. 345-361). Oxford: Oxford University Press. http://dx.doi.org/10.1093/oxfordhb/9780199582174.013.003

Hegarty, P., & Chase, C. (2004). Intersex Activism, Feminism and Psychology. In I. Morland & A. Willox (Eds.), *Queer Theory* (pp. 70-80). Basingstoke: Palgrave Macmillan. http://dx.doi.org/10.1177/0959353500010001014

Heggie, V. (2010). Testing Sex and Gender in Sports; Reinventing, Reimagining and Reconstructing Histories. *Endeavour, 34*(4), 157-163. http://dx.doi.org/10.1016/j.endeavour.2010.09.005

Hekman, S. (1999). Identity Crises: Identity, Identity Politics, and Beyond. *Critical Review of International Social and Political Philosophy, 2*(1), 3-26. http://dx.doi.org/10.1177/14647000022229245

Herlihy, A., & Gillam, L. (2011). Thinking Outside the Square: Considering Gender in Klinefelter Syndrome and 47 XXY. *International Journal of Andrology, 34*(5), 348-349. http://dx.doi.org/10.1111/j.1365-2605.2010.01132.x

Hillier, L., Jones, T., Monagle, M., Overton, N., Gahan, L., Blackman, J., & Mitchell, A. (2010). *Writing Themselves In 3: The Third National Study on the Sexual Health and Wellbeing of Same-sex Attracted and Gender Questioning Young People*, Melbourne: http://www.latrobe.edu.au/arcshs/downloads/arcshs-research-publications/WTi3.pdf

Holmes, M. (2008). Mind the Gaps: Intersex and (Re-productive) Spaces in Disability Studies and Bioethics. *Journal of Bioethical Inquiry, 5*(2-3), 169-181. http://dx.doi.org/10.1007/s11673-007-9073-2

Holmes, M. (2009). *Critical Intersex*. Ontario: Ashgate.

Hsu, S. (2011). Ethnicity and the Biopolitics of Intersex in Jeffrey Eugenides's Middlesex. *MELUS, 36*(3), 87-89. http://dx.doi.org/10.1353/mel.2011.0045

Huang, A., Brennan, K., & Azziz, R. (2010). Prevalence of Hyperandrogenemia in the Polycystic Ovary Syndrome Diagnosed by the National Institutes of Health 1990 Criteria. *Fertility and Sterility, 93*(6), 1938-1941. http://dx.doi.org/10.1016/j.fertnstert.2008.12.138

Hughes, A. (2008). Disorders of Sex Development: A New Definition and Classification. *Best Practice & Research Clinical Endocrinology & Metabolism, 22*(1), 119-134. http://dx.doi.org/10.1016/j.beem.2007.11.001

Hutson, J. (2012). The Neonate with Ambiguous Genitalia. In J. Hutson, G. Warne, & S. Grover (Eds.), *Disorders of Sex Development: An Integrated Approach to Management* (pp. 103). Berlin: Springer. http://dx.doi.org/10.1007/978-3-642-22964-0_11

Huỳnh, M. (2006). *Gia Định Xưa*. Ho Chi Minh City: Văn Hóa-Thông Tin Publishing House.

Ike, N. (2000). Current Thinking of XYY syndrome. *Psychiatric Annals, 30*(2), 91-95. http://dx.doi.org/10.3928/0048-5713-20000201-03

Jackson, W., Hoffman, M., & Makda, H. (1966). The 45XO/46XY Mosaic Intersex Syndrome. *J Med Genet, 3*(1), 23-32. http://dx.doi.org/10.1136/jmg.3.1.23

Jagose, A. (1996). *Queer Theory: An Introduction*. New York: New York University Press.

Jones, T. (2009). Framing the Framework: Discourses in Australia's National Values Education Policy. *Educational Research for Policy and Practice, 8*(1), 35-57. http://dx.doi.org/10.1007/s10671-008-9058-x

Jones, T. (2011a). Saving Rhetorical Children: Sexuality Education Discourses from Conservative to Post-Modern. *Sex Education, 11*(4), 369-387. http://dx.doi.org/10.1080/14681811.2011.595229

Jones, T. (2011b). A Sexuality Education Discourses Framework: Conservative, Liberal, Critical and Post-Modern. *American Journal of Sexuality Education, 6*(2), 133-175. http://dx.doi.org/10.1080/15546128.2011.571935

Jones, T. (2012). *Minding Our GLBs & TIQs. A Submission to the Inquiry by the Senate Legal and Constitutional Affairs Committee on the Exposure Draft of the Human Rights and Anti-discrimination Bill 2012*. https://www.academia.edu/2485071/Jones_T._2012_._Minding_Our_GLBs_and_TIQs_A_Submission_to_the_Inquiry_by_the_Senate_Legal_and_Constitutional_Affairs_Committee_on_the_Exposure_Draft_of_the_Human_Rights_and_Anti-discrimination_Bill_2012._Australian_Parliament_Canberra

Jones, T. (2013a). How Sex Education Research Methodologies Frame GLBTIQ Students. *Sex Education: Sexuality, Society and Learning, 13*(6), 687-701. http://dx.doi.org/10.1080/14681811.2013.806262

Jones, T. (2013b). *Understanding Education Policy: The 'Four Education Orientations' Framework*. Dordrecht Netherlands: Springer. http://dx.doi.org/10.1007/978-94-007-6265-7

Jones, T. (2015). *Policy and Gay, Lesbian, Bisexual, Transgender and Intersex Students*. Cham, Heidelberg, New York, Dordrecht and London: Springer. http://dx.doi.org/10.1007/978-3-319-11991-5

Jones, T., Smith, E., Ward, R., Dixon, J., Hillier, L., & Mitchell, A. (2016). School Experiences of Transgender and Gender Diverse Students in Australia. Sex Education, *16*(2), 156-171. http://www.tandfonline.com/doi/pdf/10.1080/14681811.2015.1080678

Jones, T., del Pozo de Bolger, A., Dunne, T., Lykins, A., & Hawkes, G. (2015). *Female-to-Male (FtM) Transgender People's Experiences in Australia*. Cham, Heidelberg, New York, Dordrecht and London: Springer. http://dx.doi.org/10.1007/978-3-319-13829-9

Jones, T., & Hillier, L. (2012). Sexuality Education School Policy for GLBTIQ Students. *Sex Education, 12*(4), 437-454. http://dx.doi.org/10.1080/14681811.2012.677211

Jones, T., & Hillier, L. (2013). Comparing Trans-Spectrum and Same-Sex Attracted Youth: Increased Risks, Increased Activisms. *LGBT Youth, 10*(4), 287-307. http://dx.doi.org/10.1080/19361653.2013.825197

Jones, T., & Lasser, J. (2015). School Psychology with Gay, Lesbian, Bisexual, Transgender, Intersex and Questioning (GLBTIQ) Youth. In M. Thielking & M. Terjesen (Eds.), *Handbook of Australian School Psychology*. Cham: Springer.

Jordan-Young, R. (2011). Hormones, Context and 'Brain Gender': A Review of Evidence from Congenital Adrenal Hyperplasia. *Social Science & Medicine, 74*(11), 1738-1744. http://dx.doi.org/10.1016/j.socscimed.2011.08.026

Kafer, A. (2013). *Feminist, Crip, Queer*. Bloomington, IN: Indiana University Press.

Karkazis, K. (2008). *Fixing Sex: Intersex, Medical Authority, and Lived Experience*. New York: Duke University Press. http://dx.doi.org/10.1215/9780822389217

Kemmis, S., Cole, P., & and Suggett, D. (1983). *Orientations to Curriculum and Transition: Towards the Socially Critical School*. Melbourne: Victorian Institute of Secondary Education.

Kermode, J. (2012). Debate Surrounds Intersex Inclusion in the DSM V. *Pink News*. http://www.pinknews.co.uk/2012/06/13/debate-surrounds-intersex-inclusion-in-the-dsm-v

Laflamme, N., Leblanc, J., Mailloux, J., Faure, N., Labrie, F., & Simard, J. (1996). Mutation r96w in Cytochrome p450c17 Gene Causes Combined 17a-hydroxylase/17-20-lyase Deficiency in Two French Canadian Patients. *Journal of Clinical Endocrinology and Metabolism, 81*(1), 264-268. http://dx.doi.org/10.1210/jcem.81.1.8550762

Lankshear, C., & Knobel, M. (2000). Mapping Postmodern Literacies: A Preliminary Chart. In M. Yla-Kotola, J. Suoranta, & M. Kangas (Eds.), *The Intergrated Media Machine* (Vol. 2). Edita: Hameenlinna.

Larned, D. (1976). The Femininity Test: A Woman's First Olympic Hurdle. *Womensports, 3*(1), 8-11.

Lee, P., Houk, C., & al., e. (2006). Consensus Statement on Management of Intersex Disorders. *Pediatrics, 118*(2), e488-e500. http://dx.doi.org/10.1016/j.jpurol.2006.03.004

Lee, P., Wisniewski, A., Baskin, L., Vogiatzi, M., Vilain, E., Rosenthal, S., & Houk, C. (2014). Advances in Diagnosis and Care of Persons with DSD over the Last Decade. *International Journal of Pediatric Endocrinology, 19*(1). http://dx.doi.org/10.1186/1687-9856-2014-19

Leitch, V., Cain, W., Finke, L., Johnson, B., McGowan, J., & Williams, J. (2001). *The Norton Anthology of Theory and Criticism.* New York: Norton. http://dx.doi.org/10.2307/1315311

Liao, L.-M., & Simmonds, M. (2014). A Values-Driven and Evidence-Based Health Care Psychology for Diverse Sex Development. *Psychology & Sexuality, 6*(1), 83-101. http://dx.doi.org/10.1080/19419899.2013.831217

Liao, L., & Boyle, M. (2004). The Psychologist (Intersex Special Issue). *Journal of the British Psychological Society, 17*(8), 446-462.

Lipkin, A. (1994). The Case for a Gay and Lesbian Curriculum. *High School Journal, 77*(1), 95-107.

Lux, A., Kropf, S., Kleinemeier, E., Jürgensen, M., Thyen, U., & The DSD Network Working Group. (2009). Clinical Evaluation Study of the German Network of Disorders of Sex Development (DSD)/Intersexuality: Study Design, Description of the Study Population, and Data Quality. *BMC Public Health, 9*, 110. http://dx.doi.org/10.1186/1471-2458-9-110

Lynch, S. (2004). When Men were Men… and so Were the Women. *Guardian*, August(7), 82.

Lyons, R. (1968). Genetic Abnormality is Linked to Crime; Genetics Linked to Violent Crimes. *The New York Times,* 1.

Lyotard, J.-F. (1984). *The Postmodern Condition: A Report on Knowledge* (G. Bennington & B. Massumi, Trans.). Minneapolis: University of Minnesota Press. http://dx.doi.org/10.2307/1772278

Macgillivray, I. K., & Jennings, T. (2008). A Content Analysis Exploring Lesbian, Gay, Bisexual, and Transgender Topics in Foundations of Education Textbooks. *Journal of Teacher Education, 59*(2), 170-188. http://dx.doi.org/10.1177/0022487107313160

Magaldi, K. (2015). Gender Reassignment Surgery: Parents Sue Doctors for Making their Child a Girl, Claiming Genital Mutilation. *Medical Daily*. http://www.medicaldaily.com/gender-reassignment-surgery-parents-sue-doctors-making-their-intersex-child-girl-347804

Magrab, P. (2003). *UNESCO Open File on Inclusive Education: Support Materials for Managers and Administrators*. Paris: UNESCO.

Martin, E. (1990). Science and Women's Bodies: Forms of Anthropological Knowledge. In M. Jacobus, E. F. Keller, & S. Shuttleworth (Eds.), *Body/Politics: Women and the Discourses of Science* (pp. 69-82). New York: Routledge.

Mayo, C. (2005). Multicultural Education. In J. T. Sears (Ed.), *Youth, Education and Sexualities: An International Encyclopedia* (pp. 561-565). London: Greenwood Press.

Mazur, T., & Clopper, R. (1991). Pubertal Disorders: Psychology and Clinical Management. *Endocrinology and Metabolism Clinics of North America, 20*(1), 211-231.

McNeilage, A. (2013, 07.08.13). Sex Education Draft 'Dreadful'. *The Sydney Morning Herald*. http://www.smh.com.au/national/education/sex-education-draft-dreadful-20130806-2rdjd.html

McRuer, R. (2006). *Crip Theory: Cultural Signs of Queerness and Disability*. New York: New York University Press. http://dx.doi.org/10.1080/15017410701880122

Metzler, I. (2006). *Disability in Medieval Europe: Thinking About Physical Impairment During the High Middle Ages c. 1100-1400*. London: Routledge. http://dx.doi.org/10.1093/shm/hkl049

Metzler, I. (2010). Hermaphroditism in the Western Middle Ages: Physicians, Lawyers and the Intersexed Person. In S. Crawford & C. Lee (Eds.), *Bodies of Knowledge: Cultural Interpretations of Illness and Medicine in Medieval Europe.* Sally Crawford & Christina Lee (Eds.) (pp. 27-39). Oxford: Archaeopress.

Meyer-Bahlburg, H. (1990). Will Prenatal Hormone Treatment Prevent Homosexuality? *Journal of Child and Adolescent Psychopharmacology, 1*(4), 279-283. http://dx.doi.org/10.1089/cap.1990.1.279

Miller, L., Kanter, M., & Wolfort, F. (1990). Treatment of Webbed Neck in Turner's Syndrome with Tissue Expansion. *Annals of Plastic Surgery, 24*(5), 447-450. http://dx.doi.org/10.1097/00000637-199005000-00009

Money, J., & Ehrhardt, A. (1996). *Man & Woman, Boy & Girl: Gender Identity from Conception to Maturity*. Northvale, N.J.: Jason Aronson. http://dx.doi.org/10.2307/2061919

Moran, J. P. (2000). *Teaching Sex: The Shaping of Adolescence in the 20th Century*. London Harvard University Press. http://dx.doi.org/10.2307/2692842

Morland, I. (2006). Postmodern Intersex. *International Library of Ethics, Law and the New Medicine, 29*(Ethics and Intersex), 319-332 http://dx.doi.org/10.1007/1-4220-4314-7_20

Morland, I. (2009). Intersex and After: What Can Queer Theory Do for Intersex? *GLQ: A Journal of Lesbian and Gay Studies, 15*(2), 285-312. http://dx.doi.org/10.1215/10642684-2008-139

Morton, D., & Zavarzadeh, M. (1991). Theory Pedagogy Politics: The Crisis of 'the Subject' in the Humanities. In D. Morton & M. Zavarzadeh (Eds.), *Theory/Pedagogy/Politics: Texts for Change* (pp. 1-32). Urbana and Chicago: University of Illinois Press.

Nagoshi, J. L., & Brzury, S. i. (2010). Transgender Theory: Embodying Research and Practice. *Affilia, 25*(4), 431-443. http://dx.doi.org/10.1177/0886109910384068

Anti-Discrimination Act 1997, NSW Parliamentary Counsel, 48 Cong. Rec. (2010).

Anti-Discrimination Act 1992, NT Department of Justice, REPA027 Cong. Rec. (2010).

OII Australia. (2012a). An Annulment of Marriage Due to Being Intersex – In the Marriage of C and D (falsely called C). https://oii.org.au/16808/annulment-marriage-due-intersex-marriage-falsely-called

OII Australia. (2012b). *Intersex for Allies*. http://oii.org.au/21336/intersex-for-allies

OII Australia. (2013). Third Submission on the Involuntary or Coerced Sterilisation of People with Disabilities in Australia. http://oii.org.au/22613/third-submission-senate-inquiry-sterilisation

Pasterski, V., Mastroyannopoulou, K., Wright, D., Zucker, K., & Hughes, I. (2014). Predictors of Posttraumatic Stress in Parents of Children Diagnosed with a Disorder of Sex Development. *Archives of Sexual Behavior, 43*(2), 369-375. http://dx.doi.org/10.1007/s10508-013-0196-8

Pease, B., & Pease, A. (2003). *Why Men Don't Listen and Women Can't Read Maps*. London: Orion Publishing Group.

Pitts, M., Smith, A., Mitchell, A., & Patel, S. (2006). *Private Lives: A Report on the Health and Wellbeing of GLBTI Australians*. Melbourne: Australian Research Centre in Sex Health and Society.

Anti-Discrimination Act 1991, QLD Parliamentary Counsel, Reprint No. 9B Cong. Rec. (2010).

Rabinbach, A. G. (1973). The Politicization of Wilhelm Reich: An Introduction to 'The Sexual Misery of the Working Masses and the Difficulties of Sexual Reform'. *New German Critique, 1*(1), 90-97. http://dx.doi.org/10.2307/487631

Response Ability. (2013). Overview of Suicide in Australia. http://www.responseability.org/home/fact-sheets-and-podcasts/promotion-and-prevention?a=7991

Roen, K. (2008). 'But We Have to Do Something': Surgical 'Correction' of Atypical Genitalia. *Body & Society, 14*(1), 47-88. http://dx.doi.org/10.1177/1357034x07087530

Ross, A. (1960). The Demonstration of Sex Chromatin in Buccal Smears. *J Med Lab Technol., 17*(1), 178-179.

Ross, G., Holland, J., Kiser, W., & Douglas, G. (1965). XO-XY Chromosomal Mosaicism and Extragenital Stigmata of Turner's Syndrome in a Phenotypic Male. *J Clin Endocrinol Metab., 25*(1), 141-145.

Rubin, D. (2012). An Unnamed Blank That Craved a Name: A Genealogy of Intersex as Gender. *Signs: Journal of Women in Culture & Society, 37*(4), 883.

Equal Opportunity Act 1984 SA Parliamentary Council, 1.2.2010 Cong. Rec. (2010).

Sampaio Furtado, P., Moraes, F., Lago, R., Oliveira Barros, L., Betânia Toralles, M., & Barroso J, U. (2012). Gender Dysphoria Associated with Disorders of Sex Development. *Nature, 9*(November), 620-627. http://dx.doi.org/10.1038/nrurol.2012.182

Sandahl, C. (2003). Queering the Crip or Cripping the Queer?: Intersections of Queer and Crip Identities in Solo Autobiographical Performance. *GLQ: A Journal of Lesbian and Gay Studies, 9*(1-2), 25-56. http://dx.doi.org/10.1215/10642684-9-1-2-25

Sauerteig, L. D. H., & Davidson, R. (Eds.). (2009). *Shaping Sexual Knowledge: A Cultural History of Sex Education in Twentieth Century Europe*. London and New York: Routledge.

Sawer, P., & Berger, S. (2009, 27.08.09). Gender Row over Caster Semenya makes Athlete into a South African Cause Celebre. *The Daily Telegraph*.

Schalk, S. (2013). Coming to Claim Crip: Disidentification with/in Disability Studies. *Disability Studies Quarterly, 33*(2).

Schnitzer, J. J., & Donahoe, P. K. (2001). Surgical Treatment of Congenital Adrenal Hyperplasia. *Endocrinol Metab Clin N Am, 30*(1), 137-154. http://dx.doi.org/10.1016/s0889-8529(08)70023-9

Shah, R., Woolley, M. M., & Costin, G. (1992). Testicular Feminization: The Androgen Insensitivity Syndrome. *Journal of Pediatric Surgery, 27*(1), 757-760. http://dx.doi.org/10.1016/s0022-3468(05)80110-1

Shryock, H. (1951a). *On Becoming a Man. A Book for Teen-age Boys*. Warburton: Signs Publishing Company.

Shryock, H. (1951b). *On Becoming a Woman. A Book for Teen-age Girls.* Warburton: Signs Publishing Company.

Siculus, D. (1935). *Library of History Book IV*. Cambridge: Harvard University Press.

Slot, O. (2009, 19.08.09). Caster Semenya Faces Sex Test Before She Can Claim Victory. *The Times*.

Smith, E., Jones, T., Ward, R., Dixon, J., Mitchell, A., & Hillier, L. (2014). *From Blues to Rainbows: The Mental Health and Well-Being of Gender Diverse and Transgender Young People in Australia*. Melbourne: Australian Research Centre in Sex Health and Society.

Somers xxy, C., Reibel, T., & Whyatt, D. (2008). *Intersex and Androgyny and Implications for Provision of Primary Health Care*. Geraldton WA: Combined Universities Centre for Rural Health.

Stout, A., & Schwartz, A. (2014). 'It'll Grow Organically and Naturally': The Reciprocal Relationship between Student Groups and Disability Studies on College Campuses. *Disability Studies Quarterly, 34*(2).

Streuli, J., Vayena, E., Cavicchia-Balmer, Y., & Huber, J. (2013). Shaping Parents: Impact of Contrasting Professional Counselling on Parents' Decision Making for Children with Disorders of Sex Development. *The Journal of Sexual Medicine, 10*(8), 1953-1960. http://dx.doi.org/10.1111/jsm.12214

Stryker, S. (2008). *Transgender History*. Berkeley: Seal Press.

Swiss National Advisory Commission on Biomedical Ethics. (2012). *On the Management of Differences of Sex Development: Ethical Issues Relating to 'Intersexuality'*. Zurich: Swiss National Advisory Commission on Biomedical Ethics.

The Anti-Discrimination Act 1998, TAS Parliamentary Counsel, 46 Cong. Rec. (2010).

The ETCSL Team. (2003). Enki and Ninmaḫ. *The Electronic Text Corpus of Sumerian Literature*. http://etcsl.orinst.ox.ac.uk/cgi-bin/etcsl.cgi?text=t.1.1.2#

The Senate Legal and Constitutional Affairs Legislation Committee. (2013). *Report on the Sex Discrimination Amendment (Sexual Orientation, Gender Identity and Intersex Status) Bill 2013 [Provisions]*. http://www.aph.gov.au/Parliamentary_Business/Committees/Senate_Committees?url=legcon_ctte%2Fcompleted_inquiries%2F2010-13%2Fsex_discrim_sexual_orientation%2Freport%2Findex.htm

Topp, S. (2013). Against the Quiet Revolution: The Rhetorical Construction of Intersex Individuals as Disordered. *Sexualities, 16*(1-2), 180-194. http://dx.doi.org/10.1177/1363460712471113

Turner, H., Greenblatt, R., & Dominguez, H. (1963). Syndrome of Gonadal Dysgenesis and Abdominal Testis with an XO/XY Chromosome Mosaicism. *J Clin Endocrinol Metab, 23*(1), 709-716. http://dx.doi.org/10.1210/jcem-23-7-709

Turner, S. (1999). Intersex Identities: Locating New Intersections of Sex and Gender. *Gender and Society, 13*(4), 457-479. http://dx.doi.org/10.1177/089124399013004003

Tuttle, L. (1986). *Encylopedia of Feminism*. London: Arrow Books.

United Nations. (2012). Born Free and Equal: Sexual Orientation and Gender Identity in International Human Rights Law. New York and Geneva: United Nations Human Rights Office of the High Commissioner, http://www.ohchr.org/Documents/Publications/BornFreeAndEqualLowRes.pdf

VIC Government. (2007). *Victorian Government Schools Reference Guide*. Melbourne: VIC Department of Education and Early Childhood Development Retrieved from http://www.education.vic.gov.au/management/governance/referenceguide/default.htm

Equal Opportunity Act 1995, VIC Parliamentary Counsel, 16/2010 Cong. Rec. (2010).

Equal Opportunity Act 1984, Western Australia Parliamentary Counsel, 083 Cong. Rec. (2010).

Warne, G., Grover, S., J, H., Sinclair, A., Metcalfe, S., Northam, E.,... Murdoch Childrens Research Institute Sex Study Group. (2005). A Long-Term Outcome Study of Intersex Conditions. *J Pediatr Endocrinol Metab, 18*(6), 555-567. http://dx.doi.org/10.1515/jpem.2005.18.6.555

Wilson, G. (2013). Intersex and Religion. In L. Gahan & T. Jones (Eds.), *Heaven Bent: Australian Lesbian, Gay, Bisexual, Transgender and Intersex Experiences of Faith, Religion and Spirituality* (pp. 42-46). Melbourne: Clouds of Magellan.

Young, H. H. (1937). *Genital Abnormalities, Hermaphroditism, and Related Adrenal Diseases*. Baltimore: The Williams & Wilkins Co.

Young, R. (1997). Comparative Methodology and Postmodern Relativism. *International Review of Education, 43*(5), 497-505. http://dx.doi.org/10.1007/978-94-011-5202-0_8

Appendix: Glossary

This glossary was compiled in relation to people with intersex variations, so related meanings are privileged here. Some of the definitions first featured elsewhere (Jones, 2012; Jones & Hillier, 2012). Some medical notions of intersex variations are used; the authors do not share any assumption in the language surrounding diagnoses that atypical sex characteristics are inherently problematic. Infertility is possible for most intersex variations listed.

17-beta-hydroxysteroid dehydrogenase deficiency/17β-Hydroxysteroid dehydrogenase III deficiency: An autosomal difference including two carrier genes, one from each biological parent, which affects testosterone biosynthesis (by 17β-HSD III) in people of any sex, such that sexual development is impacted. Individuals with these variations tend to be born with ambiguous external genitalia or typical female external genitalia. An individual with this variation may also have impacts on their puberty; they may feature ambiguous secondary sex characteristics.

47 XXY/Klinefelter Syndrome (and more rare variations such as 48 XXXY or 49 XXXXY): This variation involves 'aneuploidy', an extra 'X' chromosome added to a more common two sex chromosomes, such that the individual has a karyotype 47 XXY (in rarer cases karyotypes have included 48 XXXY or 49 XXXXY). An individual with this variation may have testes with reduced size, increased firmness and no sperm production or other impacts to their primary sex characteristics. An individual with this variation may also have impacts on their puberty (include delays or absence of puberty); they may develop ambiguous secondary sex characteristics. Some individuals may experience cognitive, developmental or health issues.

48 XXXX/XXXX syndrome/Tetrasomy X/Quadruple X (and more rare variations such as 49 XXXXX/XXXXX Syndrome/Pentasomy X: The presence of extra X chromosomes. Individuals with this variation experience impacts similar to those with Triple-X Syndrome/XXX, including increased height but also joint issues and other features that may be unnoticeable in the main or may require that the individual has care for their lifetime depending on severity. The individual may or may not experience a puberty, or cognitive difficulties. Perhaps 30 people have been found to have Pentasomy X. Individuals with this variation experience severe cognitive difficulties, and are short with different facial features which may suggest misdiagnosis as Down syndrome. As with XXX and XXXX, heart issues, joint issues and so on may be present and more exaggerated.

5-alpha reductase deficiency/5-ARD: An autosomal difference (on a chromosome other than the X or Y chromosomes) including two altered genes, one from each biological parent. It affects people with a Y chromosome only, impacting their androgen ratios (testosterone and DHT) and development in utero. An individual with 5-ARD has testes but they may have typically male, ambiguous or typically female external genitalia. The hormones of puberty may trigger the development of masculine traits (descending testes or enlarged clitoris, deepening voice, increased facial/body hair). Some individuals may produce sperm; none can carry pregnancies.

Amenorrhea: An impact of some variations; the absence of a menstrual cycle in those with a uterus.

Androgynous: Can mean having both masculine and feminine characteristics, or having neither specifically masculine nor feminine characteristics. People with intersex variations may sometimes be androgynous. Some people who are androgynous may identify as genderqueer, trans or androgynous.

Aphallia: Being born without external genitalia (generally a term applied to being without a penis), this variation impacts people with any type of genitals, who experience a halted development of the genital tubercle a few weeks after conception, such that their urethra opens on the perineum.

Bilateral salpingo-oophorectomy/BSO: The removal of both ovaries and fallopian tubes.

Bisexual or Bi: People whose sexual or romantic feelings can be for men and women.

Bladder exstrophy/Ectopia vesicae: This variation or impact, involves some features similar to epispadias, and particularly the protrusion of the urinary bladder through the abdominal wall. Individuals with this variation may experience related impacts in the pelvic floor, rotation of the pelvis and/or in the presentation of their genitalia. Medical procedures to reconstruct the bladder can be complete (which can have known complications around loss of penile tissue) or staged across early years; sometimes these are teamed with other genital interventions and there can be complications.

Buccal Smear: A process used in sex testing which involves screening cells taken from the inside of the cheek.

Chest Surgery/ies or Mastectomy: Can involve breast implants, chest reduction (the surgical reduction in size/amount of the chest tissue), mastectomy (surgical removal of one or both breasts/chest tissue, partially or completely), chest contouring/reconstruction (giving the chest a masculine aesthetic through implants, sculpturing of tissue, tattooing etc.) or related surgeries.

Chromosome: A tightly wound string-like package of DNA/genetic information and proteins of which humans are comprised; impacts our biological diversity.

Cisgender/ed: Refers to people whose internal sense of gender and/or sex matches the sex they were assigned at birth.

Clitoromegaly/large clitoris: A clitoris that is larger than socially or medically ‘expected’ for the body part, whether it is slightly larger or larger to the point where it more strongly resembles a phallus. This is a cosmetic issue; there is nothing inherently wrong with the clitoris. It generally impacts people considered girls or women; the corollary is ‘micropenis’ in men. It can impact other body types, and it can be related to CAH or Fraser Syndrome for example. People who are not intersex sometimes induce clitoromegaly through use of hormones for sports or other reasons.

Congenital Adrenal Hyperplasia/CAH: Various autosomal recessive differences resulting from particular expressions of genes for enzymes mediating production of cortisol by an individual’s adrenal glands (steroidogenesis). This can involve greater or lesser production of sex steroids, altering the development of primary or secondary sex characteristics in people of various sexes/body types at different ages (milder versions may only impact fertility, stronger versions may produce impacts much earlier). CAH is most extreme (potentially fatal) when the individual has inadequate mineralocorticoids, involving vomiting leading to dehydration. An individual described as having excess androgens may experience no sperm production, ambiguous genitalia, an absent/delayed or advanced puberty, excessive facial hair, adolescent menstrual irregularity, and/or an enlarged clitoris and shallow vagina. CAH is commonly screened prior to birth in many countries around the world.

Complete Androgen Insensitivity Syndrome/CAIS: A complete inability of cells to respond typically to androgenic hormones, meaning that a person with XY chromosomes will develop along primarily female lines, including secondary sexual characteristics at puberty. People diagnosed with CAIS are almost invariably women and will experience typically female maturation except for the onset of menses, as the individual has internal testes rather than ovaries. People with this variation may have longer limbs/hands/feet, proportionally greater stature, larger teeth, minimal or no acne, dry eye syndromes, light sensitivity, and/or decreased bone mineral density.

Cryptorchidism: Usually understood to involve having one or more undescended testicle/s. One or both testicles are considered 'absent' from the scrotum, whether they are entirely absent, undeveloped, differently developed, or located elsewhere in the abdomen or thigh for example.

De la Chapelle/XX Male Syndrome: An unequal 'crossing over' between X and Y chromosomes during meiosis in the individual's father, which results in the individual's X chromosome containing the genetically-male SRY gene. An individual with this variation has an X chromosome with SRY from the sperm gamete which teams with the X from the egg during fertilisation, so that they present as typically male but are chromosomally XX. The individual may or may not have small testes, feminine characteristics, extra breast tissue, decreased facial hair or experience decreased libido.

DES: Diethylstilbestrol was a drug formerly prescribed during pregnancy to prevent miscarriages in Australia, which is now linked to various health concerns for the child.

Dex: Prenatal dexamethasone has been recommended by some physicians to pregnant women who were believed to be 'at risk' for having a foetus with 21-Hydroxylase Deficiency Congenital Adrenal Hyperplasia (CAH); research associates it with a wide range of adverse complications for the child.

Dilation Treatments: A treatment in which some individuals are encouraged to insert glass or plastic phallic objects into their vagina or frontal opening, to dilate it, in anticipation of penetrative sex.

Disorders of Sex Development/DSD: a pathologising term used in medical discourse to replace intersex without much consultation with intersex communities. Alternatives (less widely known) have been proposed such as Diverse Sex Development.

Epispadias/Hypospadias: Intersex variations involving formation of the genital tubercle and/or pelvic fusion in the first months in the womb, experienced by a range of individuals (male, female and genderqueer/non-binary). Impacts often include issues with the bladder neck and a shortened urethra. This can lead to an 'early' opening on the upper aspect of the individual's penis and/or potential difficulties in fertility for some; there can be more extreme variations where the external genitals are not attached strongly. It can alternately lead to 'early/forward' vaginal genitalia, an unfused clitoris and/or possible 'stress leaks' (urinating when one coughs or laughs).

Enforced/coerced surgery: When medical professionals/surgeons conduct (unnecessary) 'corrective', 'normalising' or aesthetic surgery on an intersex individual's body without their full and informed consent (requiring the individual being of an age and mentality where they understand all available information about their body and all key options for action, including the option not to act).

Follicle-stimulating hormone insensitivity/FSH: An intersex variation where individuals do not respond to follicle-stimulating hormones (FSH), necessary for stimulation of typically female sex hormones. Impacts include hypogonadism, reduced or absent puberty (lack of development of secondary sexual characteristics), and/or infertility.

Fraser Syndrome/Meyer-Schwickerath's Syndrome/Fraser-François Syndrome/Ullrich-Feichtiger Syndrome: An intersex variation involving an autosomal recessive congenital condition and particular genes. An individual with this variation may have eyelids which do not separate in each eye and other impacts (in formation of the nose, fingers/toes, ears, larynx, renal system, or sometimes the mind), ambiguous genitals (e.g. micropenis or clitoromegaly) or urinary tract differences.

Gay/lesbian/homosexual: People whose sexual and romantic feelings are primarily for the same sex.

Gender Dysphoria: A medical diagnosis related to transgender people in the DSM-V, which refers to extreme discontent with the assigned sex allocated to an individual at birth.

Gender Identity: The gender-related identity, appearance or mannerisms or other gender-related characteristics of an individual (whether by way of medical intervention or not, socialisation or alternative expression), with or without regard to the individual's designated sex at birth.

Gender test in sports/gender verification/sex verification/gender determination/sex test: Processes used to verify the eligibility of an athlete to compete in a sporting event that is limited to a single sex in sport, involving some combination of chromosomal, genetic, hormonal, physiological and psychological examination. May not be compulsory depending on the context. Notably, there is no single test by which sex can be determined, tests can only consider one or more of the various markers; medical conclusions should not be seen as exact or definitive.

Genderqueer: People who do not socially comply with traditional male or female gender expectations through their dress, hair, mannerisms, appearance and values.

Genitoplasty/Genital Construction: Surgical alteration of one's external genitals, whether by the individual's choice (as in a sex affirmation or reassignment, or minor procedure chosen by an adult), or against/or without the individual's choice (as in neonatal sex reassignment). Intersex groups often advocate against enforced/coerced genitoplasty. It can involve for example sterilisation, hysterectomy, genital reconstructive procedures/GRT and so on.

GLBTIQ/LGBTIQ: Gay, lesbian, bisexual, transgender, intersex and otherwise queer/questioning (people).

Gonadal dysgenesis (partial and complete): Intersex variations and impacts of the reproductive system which can impact people of any sex, involving progressive loss of germ cells on the developing gonads of an embryo. Individuals with these variations/impacts have gonads or ovaries mainly composed of fibrous, functionless tissue (sometimes called 'streak gonads') – they thus can experience arrested hormones, develop no secondary sex characteristics, infertility and an infantile typically female presentation. Associated with for example Turner syndrome/mosaicism; XX gonadal dysgenesis/pure gonadal dysgenesis/46 XX; Swyer syndrome/pure gonadal dysgenesis/46 XY; Perrault syndrome, Mixed gonadal dysgenesis; and exposure to environmental endocrine disruptors.

Hermaphrodite/ism: No intersex humans are hermaphrodites; this term is inaccurate and largely seen as offensive in intersex activism (only a few individuals embrace it as a subversive 'pride' term in the face of its use as an insult, it would be inappropriate for people outside the community to use it). It only applies to plant and (mostly invertebrate e.g. slug and snail) animal species that have both fully functioning male and female reproductive systems.

Hormone Therapy/Hormone Replacement Therapy/HRT/Puberty Blockers: These treatments can be used by people with intersex variations to impact hormonal development through triggering, changing or blocking it. These treatments can impact secondary sex characteristics, although impacts vary (e.g. hair growth on face and body, voice timbre, change in appearance in terms of facial features and muscle/fat distributions on the body, development of genitalia, changes in energy levels/mood/appetite/emotions and so on). Hormones, androgens, pro-hormones or supplements may be delivered via injections, transdermal applications (patches, creams, gels), subcutaneous pellets (inserted under the skin every few months), orally (as tablets), or sublingual/buccal form (absorbed in mouth mucus).

Hypogonadism: Impacts of some intersex variations comprising of low levels of androgens/hormones. Individuals who are genetically female are may not: menstruate, develop breasts, gain height, or have much libido or body hair. They may experience hot flashes if onset is late. Individuals who are genetically male may not: develop or retain muscles, gain height, retain erections easily or have much facial or body hair. They may develop breast tissue.

Intersex status: The status of having physical, hormonal or genetic features that are –

(a) neither wholly female nor wholly male; or

(b) a combination of female and male; or

(c) neither female nor male.

Jacobs/XYY Syndrome: An intersex variation involving an extra Y chromosome so that the individual's karyotype is 47 XXY, stemming from an extra copy of the Y chromosome inherited via the sperm gamete. Individuals with this variation tend to be male, and considered taller than average.

Kallmann Syndrome: An intersex variation affecting people of varying sexes; during the individual's embryonic development the neurons responsible for releasing gonadotropin-releasing hormone (GnRH neurons) do not migrate into the hypothalamus. Individuals with this variation either do not go through or complete a puberty, and have an absent or reduced sense of smell (taste).

Klinefelter Syndrome: See 47 XXY.

Leydig Cell Hypoplasia: An intersex variation involving an autosomal recessive genetic and endocrine pattern. Individuals with this variation do not respond to luteinizing hormone (LH), necessary for the testes to produce testosterone and other androgen sex hormones. Impacts include reduced development of genitalia, hypogonadism, reduced or absent puberty (lack of development of secondary sexual characteristics), infertility, or issues with menstruation.

Micropenis: An intersex variation or impact usually understood to involve having a penis that is smaller than socially or medically 'expected' for the body part (the shaft is small with the urethra opening at the top, scrotum and perineum are present, testes may or may not be descended), although there is nothing inherently wrong with the penis. It can be related to testicular dysgenesis, Klinefelter syndrome, Leydig cell hypoplasia, 5-ARD, androgen insensitivity syndromes, inadequate pituitary stimulation, congenital hypogonadism or in utero exposure to certain types of drugs.

Mild Androgen Insensitivity Syndrome/MAIS: An intersex variation involving a milder androgen insensitivity than CAIS or PAIS, which impacts the genetically male individual such that they develop the typical external genitalia of a genetic male, despite being somewhat insensitive to androgens and having some secondary sexual characteristics develop less strongly at puberty for example.

Mosaicism/Chimericism involving 'sex' chromosomes: An intersex variation or impact involving different (not matching) karyotypes of sex chromosomes in some of an individual's cells, such that they carry two differing types of sex chromosomes. This can impact people of varying sexes, and stems from having a different pattern of cell division during early development. An individual with this variation may for example carry XX and XY cells, or other variations (X and XX, XY and XXY, XO and XY etc.). Mosaicism can occur in some forms of Turner or Klinefelter Syndromes.

Mullerian agenesis/MRKH/vaginal agenesis/congenital absence of vagina/Mullerian (Duct) aplasia: An intersex variation or impact involving an excess of androgens and no or incomplete development of the Müllerian duct impacting the internal genitalia in genetic females (generally 46 XX). It is sometimes discovered at an age when menses, intercourse or reproduction may be hindered or due to having a hernia for example. An individual with this variation will have pubic hair and a female presentation in general, but complete or partial absence of the cervix, uterus, and/or vagina.

Orchiopexy/orchidopexy: is a surgery/surgical treatment(s) to move and permanently fix one or both undescended testicle/s into the scrotum, or complete work on related testicular issues.

Ovo-testes/formerly 'true hermaphroditism': An intersex variation or impact which involves having one or both of one's gonads combining testicular and ovarian aspects/tissues, experienced by people of any genetic sex. It is sometimes associated with gonadal dysgenesis, mosaicism, 47 XXY, 46XX/46XY, or 46XX/47XXY. Individuals with this variation may present as mainly male, female, or otherwise. This variation was once mistakenly termed 'true hermaphroditism' because ovo-testes are a common feature of some hermaphroditic animals (e.g. slugs) but human ovo-testes do not fully function in both reproductive roles like actual (plant or animal) hermaphrodites.

Pansexual or Omnisexual: People whose sexual and romantic feelings are for people of any sex/gender; rejecting the gender binary of male/female only models.

Partial Androgen Insensitivity Syndrome/PAIS: An intersex variation involving the partial inability of cells to respond to androgenic hormones, impacting a genetically male individual such that their external genitalia is partially masculinised, and impacting later secondary sexual characteristics at puberty. It does not impact someone who is genetically female's genital or sexual development. Genetic males with this variation may have a male, female or ambiguous gender identity and/or bodily presentation. Individuals may experience micropenis or other genital impacts, hypospadias and/or some degree of impotence or erectile function issues; or alternately labial fusion and enlarged clitoris; or may have genitalia somewhere between an enlarged clitoris and small phallus and a single perineal orifice connecting the urethra and vagina (urogenital sinus).

Persistent Mullerian Duct Syndrome (PMDS): An intersex variation involving an autosomal recessive pattern and/or deficiency of anti-Müllerian hormone (AMH), in which a genetic male may be born with a uterus/uterine tissues and sometimes other Müllerian duct derivatives. Individuals with this variation tend to have male genitalia and may also have undescended testes (cryptorchidism). The uterine tissue may be discovered due to the experience of a bulge or hernia for example.

Poly-cystic Ovary Syndrome (PCOS)/Hyperandrogenism: PCOS is constructed by some people with the syndrome as an intersex variation where it involves androgen excess; approximately three quarters of Americans diagnosed with PCOS experienced varying levels of hyperandrogenemia for example (Huang et al., 2010). This likely genetic condition involves growth of cysts on the individual's ovaries which can increase the production of androgens and therefore impact hormones overall. This can lead to irregular periods or stop ovulation/prevent fertility entirely, promote acne, lead to thinning hair on the scalp, and/or increase facial and body hair growth.

Progestin Induced Virilisation: An intersex variation related to prenatal exposure to artificial/drug-related androgens (often progestin, a drug historically used to prevent miscarriage). There may be impacts to the individual's primary or secondary sex characteristics.

Queer: Queer is an anti-identity rejecting restrictive normative notions of strict consistent sexual orientations.

Sex: Sex is commonly expressed as a binary and used to divide people into males and females. However, in reality, sex is a complex relationship of genetic, hormonal, morphological, biochemical, and anatomical differences which variably impact both the physiology of the body and the sexual differentiation of the brain. Although everyone is assigned a sex at birth, researchers argue that approximately 2-4% percent of the population have an intersex variation.

Sexual Orientation: The direction of one's sexual and romantic attractions and interests toward members of the same, opposite or both sexes, or all genders. Similar to 'Sexual Preference'.

SRY Test: A test for the SRY gene, which is found on the Y-chromosome, used in some gender tests (formerly in Olympic tests) to identify males or intersex athletes potentially 'disguised' as females. It was abolished in most sporting tests, considered ultimately inconclusive in identifying maleness.

Strap on: A dildo/external prosthesis strapped on to the outside of the body/worn with a harness, which may be used in sex, but is sometimes used for packing (to fill out clothing for example).

Streak Gonads: Impacts of some intersex variations can include gonads (testes or ovaries) mainly composed of fibrous, functionless tissue. These gonads do not produce or stimulate hormones such that individuals with streak gonads do not experience a puberty without aid, develop no secondary sex characteristics, and are infertile.

Swyer Syndrome/XY gonadal dysgenesis: An intersex variation involving the absence of functional gonads/sex glands, affecting genetic males (karyotype 46 XY). Individuals with this variation present as females and have gonads termed 'gonadal streaks', fairly undeveloped tissue replacing the testes or ovaries. Individuals will not develop secondary sex characteristics generally due to the lack of gonadal/hormonal production.

Trans/Transgender: A broad umbrella term, including people/a person who identifies as a sex different to the one assigned at birth and who may or may not choose to undergo sex affirmation/reassignment surgery(ies). Describes a broad range of non-conforming gender identities and/or behaviours.

Transition or Sex Affirmation: Refers to the process of socially, physically and/or legally changing or affirming ones' gender presentation/sex to some extent (whether slightly through to wholly). This process can involve changing how the person refers to/sees themselves, dresses or presents themselves (hairstyle and so forth), is referred to/seen by others (pronouns like he/she/they), and/or changing one's social role or role in relationships if relevant. It might also involve changing one's body through hormonal therapies/cosmetic procedures/a range of surgeries, and/or changing the way one is identified by sex on legal or reporting documents (birth certificate, passport, license, records).

Turner Syndrome/Ullrich-Turner Syndrome/Gonadal Dysgenesis/45 X0/45 X: Intersex variations involving the absence/difference of all or part of an X chromosome in genetic females (such that they have a karyotype 45 XX sometimes called 45 XO or 45 X; meaning individuals have 45 rather than 46 full chromosomes with only one functioning X chromosome). Sometimes the chromosome is missing in all cells and sometimes only in some (with mosaicism/Turner mosaicism). Individuals with the variation generally do not have functional ovaries or menstruation, and may experience infertility. They may be short, broad-chested, have a low hairline and low-set ears, have a webbed neck or experience swelling of hands and feet. Related health concerns may include heart and kidney issues, hypothyroidism, diabetes, obesity, vision or hearing concerns, and/or autoimmune diseases. Some individuals experience difficulties with memory, spatial or mathematical skills.

Triple-X Syndrome/XXX/triplo-X, trisomy X, XXX syndrome, 47 XXX aneuploidy: An intersex variation involving the presence of an extra X chromosome in all cells of a genetic female (or in some cells in the mosaic type). Individuals may inherit the extra X from either parent, and generally have the karyotype 47 XXX, rather than 46 XX. An individual with this variation can be effected to different extents depending on the ratio of XXX to XX cells, but usually has no noticeable visible impacts to their appearance. Since X chromosomes operate such that only one is largely dominant at a given time, impacts are mild or unnoticeable and females are usually unaware of their chromosomal difference. Thus impacts are not widely known or agreed, but possibly include increased height, small head, vertical skinfolds over the eyes' inner corners, speech and language learning difficulties (e.g. dyslexia), weak muscle tone, and/or potential social anxieties for example.

XY/XO Mosaics: An intersex variation involving XO chromosomes in some cells. An individual with this variation may have female presentation with an enlarged clitoris and internal 'streak gonads', or may for example have male presentation and be fully fertile. Early chromosomal studies of people with intersex variations include those exploring XY/XO Mosaics (De La Chapelle & Hortling, 1962; H. Turner et al., 1963).

XY-Turner's Syndrome: An intersex variation involving chromosomal difference. Individuals with this variation may have a chromosomal mosaic in the form 46 XY/45X or other types. An individual usually doesn't have all the associated traits of TS and may experience other intersex features.

> *The intersex community changed my life. Becoming connected and becoming an activist and educator changed everything. I love my intersex body and have found partners that do, too. My fears about being a freak and being rejected as an adult simply haven't played out.*

Lily, intersex female with MRKH/congenital absence of vagina, 31yrs

> *I have fully developed male genitalia, male hair profile, both high and low voice tones, female skeleton, soft skin, breasts (noticeable if you know what you are looking at), long legs, and wide hips and pelvis. My hair takes days to regrow (even on my face) if I shave …my Adam's Apple is barely visible and I can suck it in! I have had no treatments. My variation is not at all noticeable, people never notice. It wasn't until I found out this is a condition than even I saw all the signs.*

Sheldon, intersex male with De la Chapelle/XX Male Syndrome, 31yrs

> *I had an inguinal hernia at 3years old. Upon surgery, the doctor did a biopsy on the gonad and returned it to the sac. The histology of the gonad was that of testes or ovo-testes. The diagnosis was 'externally feminized male intersex'. This meant I did not have a uterus and only a short vagina. I did not develop breasts or any sign of adolescent hair until oestrogen therapy began. My sister has the same condition. We are 18 months apart. 'The Conversation Hour' (interview) with Phoebe Hart was enlightening and terrific to hear, and affected me. Such down to earth and honest discussion about her life experiences. Very positive! I related closely to that.*

Izzy, female with Cryptorchidism, 59yrs

> *I live with my wife [...] we have sex at least twice a month. But I have erection problems. Without adequate hormonal therapy, my sexual desire is zero. I cannot reproduce due to treatments/surgeries related to my congenital sex variation (I was sterilised). Knowledge helps us to live well. Research must continue to allow everyone a better quality of life.*

Blake, male with XXY/47, 49yrs

This book need not end here...

At Open Book Publishers, we are changing the nature of the traditional academic book. The title you have just read will not be left on a library shelf, but will be accessed online by hundreds of readers each month across the globe. We make all our books free to read online so that students, researchers and members of the public who can't afford a printed edition can still have access to the same ideas as you.

Our digital publishing model also allows us to produce online supplementary material, including extra chapters, reviews, links and other digital resources. Find *Intersex* on our website to access its online extras. Please check this page regularly for ongoing updates, and join the conversation by leaving your own comments:

http://www.openbookpublishers.com/isbn/9781783742080

If you enjoyed this book, and feel that research like this should be available to all readers, regardless of their income, please think about donating to us. Our company is run entirely by academics, and our publishing decisions are based on intellectual merit and public value rather than on commercial viability. We do not operate for profit and all donations, as with all other revenue we generate, will be used to finance new Open Access publications.

For further information about what we do, how to donate to OBP, additional digital material related to our titles or to order our books, please visit our website: http://www.openbookpublishers.com

OpenBook
Publishers
Knowledge is for sharing

Intersex

Stories and Statistics from Australia

T. Jones, B. Hart, M. Carpenter, G. Ansara, W. Leonard, and J. Lucke

Sex is complex. Humans are simultaneously more similar in their sex development, and more diverse, than is commonly appreciated or understood. Females and males are not made of wildly different ingredients. The potential to have intersex variations—to be born with atypical sex characteristics—exists for all humans in the first few weeks of their prenatal development. 1.7% of people actually go on to be born intersex.

However, most of us know little about intersex variations. This is only partly due to their occasional invisibility. Intersex people have historically faced deep social stigma—the assumption that they were simply bizarre aberrations from the human norm. Furthermore, intersex infants have been widely subjected to systematic institutional mistreatment, particularly within medical settings. Finally, some people with intersex variations have simply tried to integrate themselves unnoticed into the socially accepted categories of male and female.

Drawing on stories and statistics from the first national study of intersex the book argues for a distinct 'Intersex Studies' framework to address intersex issues and identity—foregrounding people with intersex variations' own goals, perspectives and experiences. Collected in 2015 and arranged in thematic chapters, the data presented here on 272 individuals gives a penetrating account of historically and socially obscured experience. This book is an important and long-overdue contribution to our understanding of human sexuality and a must-read for people with intersex variations, health practitioners, psychologists, advocacy groups, students, and anybody interested in knowing more about our diverse human make-up.

This book is important and radical not only because it is a social analysis of a group of people who have been stigmatised and maligned by society and in some cases mutilated by the medical profession when they were too young to have a choice, this book also challenges society's 'need' to think of the animal kingdom in terms of only two sexes, male and female. [...] Over the last twenty years we have seen research underpin social change in regard to attitudes to lesbian and gay people and more recently to trans people. Intersex people are the next important group to have their needs brought to the fore. —Prof Lynne Hillier, La Trobe University

This book is well written and compelling and an essential reading for policy makers, educators, and journalists. The data is one-of-a kind [...], I'm really excited about this book!' —Prof. Georgiann Davis, University of Nevada

Cover image: Purple&Yellow Wall – Kinsale (2008), photo by Sonia Luna.

OpenBook
Publishers