

## 'It's a... does it matter?' Theorising 'boy or girl' binary classifications, intersexuality and medical practice in New Zealand

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### Abstract

This paper presents findings from my doctoral research on the medical management of intersexuality in New Zealand, as well as the type of support for intersex New Zealanders and their families. Specifically, I discuss the implications of New Zealand's small population on both medical management and undertaking research on what can be considered a rare condition and sensitive topic respectively. One such implication is that clinicians in New Zealand hospitals encounter a smaller number of intersex births compared to Australia, for example, and therefore have little experience or awareness of intersex conditions. Another implication is the difficulty of maintaining confidentiality in a small population. In New Zealand, providing anonymity is difficult compared to larger-populated countries such as the USA. I also discuss poststructuralist theorising about power structures in society – particularly in New Zealand, where there appears to be a connection amongst every New Zealander. And while New Zealand boasts about being an accepting, egalitarian nation, my findings show that judgemental attitudes towards a lesser-known condition still exist in parts of New Zealand society. I argue that New Zealanders' connectedness contributes to maintaining power structures to silence and isolate individuals for the fear of being found out – because their anatomies do not meet societal assumptions of male and female (binary) norms.

### Key words

*intersexuality, medicalisation, methodology, communities, gender identity*

### Introduction

This article presents my findings from my recently-completed doctoral research on the medical management of intersexuality in New Zealand, and support for intersex New Zealanders and their families. It also presents material which was not included in the final version of my doctoral thesis.<sup>1</sup> My research includes findings from recorded interviews with five intersex New Zealanders, six parents of intersex children, three registered nurses, two specialist clinicians, a midwifery programme director, four community/support organisation representatives (one of whom is also a parent), a counsellor and a former MP.

*Intersexuality* is a biological variation, in which an individual with an *intersex condition* is often born with ambiguous genitalia which do not appear typically male or female. Individuals are also born with either a combination of male and female internal sex organs – as with *true hermaphrodites* (Grumbach, Hughes & Conte, 2003, pp. 908-909), or internal sex organs which are discordant with their external genitalia – as with *male* and *female pseudohermaphrodites* (Forest, 2001, pp. 1986-1989, 1997).

The following questions form the basis of my arguments, analysis and conclusions:

- What are the medical rationales for managing intersex conditions with regard to health concerns, and how do traditional assumptions about gender and sexuality relate to medical decision-making?
- What are the understandings of intersex people, parents, clinicians, nurses and community/support organisation representatives in New Zealand about clinical procedures and gender?
- What are the understandings of the aforementioned people about support and acceptance of intersexuality in New Zealand, especially with its small population and apparent connectedness?

1 My doctoral thesis can be accessed online at <http://researcharchive.vuw.ac.nz/handle/10063/2845>

- What are the links between my findings, and feminist and gender theories?

Specifically, I will discuss the implications of New Zealand's small population size on the research process itself, the medical management of intersexuality, and support for intersex New Zealanders and their families. I will also discuss an issue that emerges from my findings: *privacy in small communities*, which compel some people to remain silent about a lesser-known condition.

## Incidence of intersexuality in New Zealand

Present research does not indicate whether the incidence of intersex conditions in New Zealand is higher than elsewhere. The Ministry of Youth Development states that '[t]here is no reliable data on the number of intersex or transgender young people in New Zealand' (Ministry of Youth Development, 2013). Statistics New Zealand also, in their discussion paper *Considering Sexual Orientation as a Potential Official Statistics*, states that these populations are not included, as 'the transgender and intersex populations are assumed to be very small with information gathering about these topics still in its infancy' (Statistics New Zealand, 2008, p. 6).

The Human Rights Commission also notes that, from consultations with intersex people, one of the themes which emerged about the current status of intersex people was 'lack of data' and that '[t]here is no... framework for data collation and analysis' (Human Rights Commission, 2013). Data collection can also be problematic in other countries. Rainbow Health Ontario in Canada states that '[s]ince intersex people are a minority, and due to the history of secrecy surrounding intersex diagnoses, statistically representative data on intersex people is lacking' (Rainbow Health Ontario, 2011).

However, a survey of medical publications from 1955 to 2000 concluded that the frequency of intersex conditions "may be as high as 2% of live births" (Blackless, et al., 2000, p. 151). Some intersex conditions are also more frequent than others. Turner's syndrome<sup>2</sup> appears in approximately one in 2500 live births (Forest, 2001, p. 1981), whereas the condition 46,XX male<sup>3</sup> (also called "sex reversal syndrome") occurs in approximately 1 in every 100,000 individuals (Quigley, 2009). It is also noted that some intersex conditions have a higher incidence amongst ethnicities such as Yupik Eskimos and Moroccan Jews (Blackless et al., 2000, p. 156).

## Researching intersexuality in New Zealand

Initially I had hoped to interview many people with intersex conditions in New Zealand, in order to get a broad range of perspectives, but only five people agreed to participate. A probable reason why I did not find a greater number of intersex participants was that I was a *complete outsider*. I do not have an intersex condition nor was I, for example, a parent of a child with an intersex condition – nor, indeed, do I have any children. Alessandro Portelli comments that, when theorising oral history, a 'boundary' between what actually occurs 'outside the narrator and what happens inside', and between what involves an individual person and a wider group of people, will result in 'more elusive' sources compared to 'established written' sources (Portelli, 1991, p. 49). Lesbian academic and oral historian Alison Laurie comments that Elizabeth Labovsky Kennedy and Madeline Davis interviewed 45 lesbians in Buffalo, New York, as they were 'trusted insiders' (Laurie, 2004, p. 61). But in New Zealand little information has been

2 Individuals with *Turner's syndrome* (first described by American endocrinologist Henry H Turner in 1938) have a 45,XO or 45,X/46,XX 'mosaic' chromosome type, gonadal dysgenesis (streak gonads), short stature and a webbed neck (Forest, 2001, pp. 1981-1982).

3 *46,XX males* have testicular development, XX chromosomes and no 'normal' Y chromosome (Forest, 2001, p. 1980). *46,XX males* have a 'normal male' outward physical appearance but at puberty 75 percent of affected individuals develop gynaecomastia (breast development in males), 'some degree of testosterone deficiency' and impaired production of sperm in the testis (ibid., p. 1980).

gathered about lesbians in New Zealand as they 'led secret lives of concealment in order to protect themselves and their relationships' (ibid., p. 61). The fact that I was not an insider is a possible reason why some intersex people were reluctant to participate in my research, as they may have felt that I did not have similar experiences to them.

Recruitment of participants was attempted by first contacting and meeting with representatives from many community/support and GLBTIQ-type<sup>4</sup> organisations throughout New Zealand. Some organisations also published a short article about my research in their newsletters which reached out to a wide range of people. I subsequently gave presentations about my research at meetings and conferences organised by some organisations. I believed that this method would enable trust-building to occur from participants who would not only see me *in person* and judge me accordingly, but give them the opportunity to ask me questions about my research.

Following some presentations, a 'snowballing' method occurred when some organisation representatives invited me to give further presentations at other meetings and conferences. A goal achieved from this method was that I obtained willing participants whom I undertook recorded interviews with. Interviewing was another effective snowballing (word-of-mouth) method as this enabled access to other participants. This occurred when some participants suggested I contact other people who were, for example, active in GLBTIQ community/support work.

I suggest that an implication of undertaking research, particularly in New Zealand, is the difficulty of maintaining confidentiality. Because of New Zealand's small population, providing anonymity is more difficult compared to larger-populated countries such as the USA as there always appears to be a connection amongst New Zealanders (Hall, 2004, p. 159). New Zealand's connectedness may have made some intersex people feel reluctant about participating in recorded interviews. This is not only because of the fear of being found out by others (former school peers, for example), but because they may have regarded my research topic to be a very personal and private matter that they did not wish to disclose. As stated previously, while I had hoped to interview many New Zealanders with intersex conditions, only five people agreed to participate.

Another possible reason is that some intersex New Zealanders did not want to revisit traumatic experiences of hospitals, such as being 'shown' to groups of medical students as if they were research objects, and being denied full and truthful explanations of why they were in hospital. My extensive background reading (and viewing of documentaries) of intersex people's accounts made me acutely aware of this, and I endeavoured to approach possible participants with the utmost sensitivity and respect. Despite my efforts, it is possible that my research, with its strong focus on medical management, may have caused some intersex people to feel reluctant about participating. Rogena, an intersex person, remarks that 'many intersex people now don't trust medical professionals' (Rogena, 2011, interview), and intersex activist Mani Mitchell has met other intersex people 'who were paraded naked in front of medical students, in a lecture-type situation' (Mitchell, 2010, interview). However, I wanted my thesis to give a fair and broad viewpoint about the medical management of intersexuality: that is, letting *everyone* – be they clinicians, intersex people, parents and so on – have the chance to speak. As well as hearing people's voices from the so-called 'margins', I felt it was only fair to include the voices from the so-called 'elite' (Spivak, 1988, p. 25). What I found was that some clinicians were very receptive to learning more about gender issues.

As mentioned previously, New Zealand's connectedness creates difficulties in maintaining confidentiality. In order to honour participants' wishes I transcribed recorded interviews and e-mailed the transcripts to participants. Subsequently, some participants indicated that they were comfortable about disclosing full information while others requested that information be

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4 GLBTIQ = gay, lesbian, bisexual, transgender, intersex and queer/questioning.

modified further. Some participants felt that their initial unmodified transcripts contained ‘too many details’ that could identify them – particularly if they lived in rural or provincial areas in New Zealand. Some participants are identified by their full names while others, as requested, are only identified by their first names. Other participants requested that a pseudonym be used while others wished to remain completely anonymous. I have also withheld details of exact locations and hospitals in New Zealand at the request of some participants. This relates to the issue of *deductive disclosure*, also known as ‘internal confidentiality’, which occurs when interview participants, for example, can be identified in published research by their traits (Kaiser, 2009, p. 1632). A well-known case of deductive disclosure was when Carolyn Ellis published her research on a small and remote community in the book *Fisher Folk* in 1986 (*ibid.*, p. 1632). While the participants were not identified by their real names, they felt ‘betrayed and humiliated’ and community relations became strained (*ibid.*, p. 1632). Karen Kaiser, a postdoctoral fellow at the University of Illinois, remarks that this case made researchers more conscious about how participants are described in publications, and ‘how easily it might be to identify specific people’ (*ibid.*, p. 1632).

Archiving oral histories has a significant importance in preserving the voices of the less powerful (see Thompson, 1988, p. 28), so that they may be heard by future generations. In contrast, some participants firmly requested that their recorded interviews were deleted, despite my comments that their interviews may assist others such as health professionals in training. One participant stated that she did not want her details ‘getting in the system’ as she ‘[did not] trust large organisations’, which suggests that her experiences of medical institutions may have been embarrassing or traumatic (see Klempler, 2000, p. 201).

## Narratives about medical management in New Zealand

Because of New Zealand’s small population, the number of babies born with intersex conditions per year is small compared to countries such as the USA, for example. Plastic surgeon Chris McEwan remarks that the Mayo Clinic in the USA, where he worked for three years, ‘[has] a significant practice in intersex’ (McEwan, 2010, interview). The Mayo Clinic itself states that it is ‘one of the few institutions specialising in a multidisciplinary approach to the treatment of more comprehensive urologic disorders’ which include intersex conditions (Mayo Clinic, 2013). The Children’s Hospital Boston also has a multidisciplinary clinic which specifically focuses on intersex conditions, and assists transgender children and young people considering medical procedures (Children’s Hospital Boston, 2007). Compared to the USA, my findings suggest that some New Zealand clinicians may have never encountered a child with an intersex condition, and therefore may have little experience or awareness of intersexuality. A mother recalls a New Zealand hospital’s apparent lack of experience when her newborn child’s sex was questioned by a registrar:

He [registrar] said, ‘I’m not quite sure, but I have...’ – he had printed off a couple of pieces of paper, and he said to me, ‘I think what your baby may have is CAH [congenital adrenal hyperplasia]<sup>5</sup>...’ ... He said, ‘I don’t know much about it myself, but I’ve gone back and I’ve photocopied some papers.’ So he gave me the papers to look at, and I was just like... what’s going on? ...he said to me, ‘At this stage we don’t know what the sex of the baby is.’ And he said, ‘No one knows what to do from here.’ (*Anonymous 1, 2010, interview*).

5 *Congenital adrenal hyperplasia (CAH)* occurs during prenatal development in genetic males (46,XY) and females (46,XX), and results from deficiencies in specific enzymes in the adrenal glands (Forest, 2001, pp. 1986, 1997; Grumbach et al., 2003, p. 917). Genetic females with CAH are commonly born with masculinised genitalia with clitoral enlargement (Forest, 2001, p. 1997), while enzyme deficiencies in genetic males with CAH impairs the synthesis of testosterone to produce male sexual characteristics (*ibid.*, p. 1986). A health concern for all CAH individuals is salt loss which can be life-threatening, and mineralocorticoid and glucocorticoid replacement medication is often prescribed (*ibid.*; pp. 1988-1989, 1997).

New Zealand's smaller number of intersex cases also has implications for New Zealand paediatric/urological surgeons, compared to such surgeons at American hospitals who may encounter intersex cases more frequently. Consequently New Zealand children are commonly referred to Royal Children's Hospital in Melbourne, in our neighbouring country Australia, which is regarded amongst the New Zealand medical community as a centre of excellence (P. Hofman, personal communication, 25 February 2010). Jacqui (pseudonym), a woman with CAH, remarks that, while she has 'nothing against' clinicians in New Zealand, New Zealand's smaller population – and smaller number of CAH individuals – can be problematic for the establishment of specialised surgical procedures:

...and that's why I think it's so important to keep those communication lines open with Australia – especially for us CAH girls. (*Jacqui, 2010, interview*).

Jacqui, who underwent about four (she cannot confirm the exact number) surgeries during infancy, childhood and adolescence, underwent her last surgery in 2007 at the Royal Mercy Hospital in Melbourne:

...it's [gynaecological surgery] just so, so worth it. I mean, had I not had that surgery I couldn't have had my son [who was delivered via caesarean section]... Just very, very lucky to have the most understanding husband in the world, who – we were engaged for six or seven years before that, and we've basically a nil sex life so how many guys put up with that! So yeah I was very, very lucky with that. And then we went over [to Melbourne] and we got it sorted, and it was very successful. (*Jacqui, 2010, interview*).

Paediatric endocrinologist Professor Paul Hofman and another specialist clinician appear to recognise that New Zealand's small population has implications on establishing specialised medical care for intersex conditions. The clinician and his New Zealand colleagues have been liaising with their counterparts in Australia which, because of its larger population, has a greater number of intersex diagnoses:

We have been in negotiation with Australia as well, because they have as many if not more problems than we have at this moment with the management of DSDs. I wouldn't be surprised if it expanded to form an Australasian group in due course. (*Anonymous clinician, 2010, interview*).

## **'What's that?' – parents' experiences and strategies in close-knit communities**

Feminist poststructuralist theory analyses how power works by not only forcing people 'into particular ways of being', but by making those ways 'desirable' so that people adopt them as their own (Davies & Gannon, 2005, p. 318). In relation to this theoretical perspective, in this section I discuss how New Zealand's connectedness maintains power structures by compelling parents, for example, to keep silent about their children's intersex conditions for the fear of being found out. I will also discuss parents' experiences and strategies when dealing with prurient or judgemental attitudes from others.

While New Zealand boasts about being an accepting, egalitarian nation, my findings show that judgemental attitudes towards a lesser-known condition still exist in parts of New Zealand society. Bronwyn (pseudonym), a mother of four children – the two eldest of whom have intersex conditions, strongly advises parents to 'remain firm' against pressure from people asking about a newborn baby's sex – particularly in a small rural community:

Be strong for the future's [*sic*] sake of your child because later on that child is going to grow up – in our case, in a very small community where everybody knows, and they will then have to face the fact that you said that you didn't know what sex it was, or you didn't know, or you announced male when it was female or whatever. And that child is going to grow up – unless you're going to move away – in that community. So stay strong – don't announce it. And for your child's future don't announce it – no matter how much pressure you get,

because it will matter one day. At the moment, to you, well it may not matter, but in the future that child will have to face – and somebody will say, when you're at a very vulnerable age: 'My mum said there was this story, when you were born you were a boy. Are you a boy?' So hold out, stick to your guns and don't announce it. (*Bronwyn, 2010, interview*)

Bronwyn's view reflects her experience about wanting to protect her second child from stigmatisation – particularly hurt caused by gossip and rumours. Because of society's ingrained binary sex/gender system, many people only acknowledge the categories of male and female which makes it difficult for them to understand gender fluidity. Many people are also simply unaware about a relatively lesser-known condition compared to Down's syndrome, for example. Bronwyn's comment about being asked a potentially personal question 'at a very vulnerable age' echoes the issue of silence – that intersexuality is something never to tell to anyone (Chase, 1998, p. 211).

After being 'assured' by a paediatrician that their second child was male, Bronwyn and her husband Murray (pseudonym) placed a birth notice in their local newspaper that they had had a son (Murray, 2010, interview). Two weeks later a chromosome test confirmed that their child's sex chromosomes were female (46,XX) and a second test confirmed the same result (Bronwyn, 2010, interview). Murray recalls his feelings during this waiting period:

So I guess from that, that was a pretty traumatic time when you've then got to tell your community – a close-knit community, that "We've had a boy but now we've actually got a girl". (*Murray, 2010, interview*).

Murray's comment that the time of the confirmed test results was 'traumatic', when he and Bronwyn had already publicly announced that their child was male, suggests a lack of awareness about intersexuality in their community. However, many people in other New Zealand locations (both rural and urban) and overseas only assume a male/female binary system. Information on Murray and Bronwyn's children's conditions, particularly during the time when their two eldest children were born, may have not only been scarce but difficult to access which may have exacerbated their stress. Visiting a library (the internet was non-existent then) in the nearest town – a considerable distance from their farm – would have been difficult because of Murray and Bronwyn's busy roles as farmer and mother of two then small children (she now farms alongside her husband), respectively.

While Bronwyn comments on 'what a corny society we live in' and that 'we are all on a [gender] continuum anyway', she maintains that society's pressure to be male or female is particularly reinforced during childhood:

As a child you're wearing a girl's school uniform or a boy's school uniform... you have to be one or the other. Every single child in New Zealand – and when they are growing up alongside other little children, every child knows that everybody's either a boy or a girl. Children are black and white. Adults can be grey as much as they want to, but children are not. (*Bronwyn, 2010, interview*).

Hofman also commented about societal attitudes towards intersex conditions associated with 'major ambiguity':

[There is] ignorance in society, particularly amongst parents who feel isolated – they don't want to talk about it. I think support is fragmented, no parents want the school to know their child is different, such as a cubicle or changing room situation [e.g. for sports or swimming]. (*P. Hofman, personal communication, 25 February 2010*).

Hofman's comments suggest that other parents, like Bronwyn, want to protect their children from societal prejudices towards difference. Concerns about teasing and bullying compel parents to keep silent about their children's variance, which relates to poststructuralist theorising on how societal power structures are maintained. Bronwyn also recalled a midwife who was particularly helpful when her children were small, and her comments suggest there was an undercurrent of prurience in a local Plunket group:

She helped me in practical ways to “face” the other young mothers – that is, being aware that nappy-changing needed to be done away from the [Plunket] group, as I didn’t feel comfortable having curious eyes looking on – if something is seen, it imprints on the brain, and I wanted to protect our daughters from that. (*Bronwyn, 2010, interview*).

Prurience also maintains societal power structures which again compel some parents to conceal their children’s differences – though this is understandable as some parents want to protect their children from being the subject of gossip. Jo, another mother of an intersex child, told me her strategy of dealing with prurience:

...you get the odd morbid fascination from people, who every time you see them they go “What’s your daughter got again?!” And it’s like [sighs]... but you just deal with those people. I just make sure I use the most complicated terms possible when I’m dealing with them, so that they feel a bit thick... (*Jo, 2010, interview*).

Some people’s prurience towards intersexuality also echoes its ‘circus freak’ connotations (HRC, 2007, p. 81) – the assumption that intersexuality is a supposedly unfortunate condition. Other findings, however, suggest that having an intersex condition is not as bad as some people or media sources convey. A woman with CAH remarked that:

It’s [intersex condition] not as bad as people say it is, it’s the way people I guess comprehend the meaning of it. If they actually understood and had the information then maybe they’d be more supportive. (*Anonymous 3, 2010, interview*).

Anonymous 1 offered a similar narrative. While she was stressed when her newborn baby’s sex was not immediately confirmed by clinicians, and while her now-older child undergoes regular health-related tests because of her intersex condition, Anonymous 1 enthused about her child’s energetic activities:

Every time my child has one of her registrar appointments we do the bloods and our endocrinologist sits down, and she said to me, “CAH children are sometimes sickly children but...” My child is one of those children who’s really full of life, she plays rugby league, she won the cross-country, she’s won everything in athletics, she’s one of those really highly competitive girls.

When you watch her on the rugby league field she’s just – oh my God, she’s just out there! Compared to other girls her age she’s just really into it, and she loves sports... (*Anonymous 1, 2010, interview*).

## Support in New Zealand

My findings show that the work of support organisations is of particular importance in New Zealand. This is not only with regard to advice about sensitive matters of a sexual nature, but support appears to be particularly crucial for adolescents who may feel vulnerable amongst their peers. Sarah (pseudonym), who founded a support group for parents of intersex children,<sup>6</sup> talked about the difficulties that teenage girls can encounter after undergoing vaginal surgery, and how her support organisation helped one girl who lived in a rural part of New Zealand:

So say they have top-up [genital] surgery as an adolescent and say they get a set of dilators,<sup>7</sup> which you have to order specially and, you know, it’s all embarrassing for a teenager. ...this girl I’m thinking of, who would have been in her late teens, had a set of dilators... she could find no one to teach her how to use them because she lived in the wops.<sup>8</sup> She was trying to insert them, and she was actually inserting them into the urogenital sinus rather than the vagina... So she was getting excruciating pain using these dilators, couldn’t make them work... She’s not in Melbourne [where surgery was performed] – like, she’s a million miles away from Melbourne, there’s nobody there for follow-up.

6 As requested by Sarah, the name of this organisation has been withheld.

7 Individuals who have undergone vaginal surgery (either to construct a vagina or ‘open up’ a vaginal cavity) are often prescribed a set of dilators in different widths to prevent the vagina from narrowing or closing up.

8 *Wop-wops*, or *wops* (NZ slang): an isolated or remote area, especially a rural area far away from a town or city.

...

So you can see that even if they might go over to Melbourne and have excellent care, then gaps occur because we don't get follow-up care. ...you might need counselling and there aren't people. ...that's one of the functions of our [support] group... that at least they can ring and say, "Hey this is happening, what do you think?" I'll say, "It's tricky, I don't have an answer, and what I'm wondering about is can you build up a relationship with a GP... gently build up a relationship with someone who could help you with this?" That's what this girl did, and it worked. (*Sarah, 2010, interview*).

This finding shows that New Zealand's small population can be problematic on establishing specialist medical care for a relatively rare condition, which Jacqui commented about previously. However, this finding also shows how a support group can counter the implications of New Zealand's small population and apparent lack of specialised medical care. A single telephone call to a support group contact person, who has *first-hand experience* of intersex issues, can indeed help someone overcome barriers of silence and embarrassment in relation to sexual issues. While the internet has enabled instant access to extensive information in the privacy of one's own home, and has enabled support networks to be more easily-accessible, the information that someone posts on a website can be difficult or even impossible to verify as legitimate (see Portelli, 1991, p. 51). Lisa (pseudonym), a woman with CAH, cautioned that information on the internet should not be regarded as gospel:

Yeah, it's [internet] good but it can also be... it can lead you astray too. I've done a little bit of looking before and you've got to be careful not – to take everything as a grain of salt and, like, what is good and what's actually not good, so what's proper research and what's just hearsay.

*[I ask Lisa to elaborate]*

I think the thing with the internet is it's very hard to know, the person who's written that, what are their qualifications and – like it could be just a name, and it's so easy just to put information on the internet, which looks just as official as someone official. ...like you're a research student, you know how to research – you'll research the name before you research the research... whereas for Joe Bloggs, they will just say, "Oh it's on the internet, it must be correct." So it's very easy just to get information there which hasn't actually got much standing, it's just someone with just their point of view, which is OK but you've got to be aware that there's scientific information and there's points-of-view information, which is...

GC: *'Just some people's opinions.'*

Yeah that's exactly it and it's that sort of thing which you've got to be careful with what you're doing. I think that's probably more what I was more relating to... is it actually good proper information or is it something else? There are good websites out there like the CAH [support organisation]<sup>9</sup> website, it has got links to the research which they know is good and proper and stuff like that. (*Lisa & Geraldine, 2010, interview*).

Indeed, as I only interviewed five intersex people I visited online discussion forums in order to view other intersex people's narratives. However, echoing Portelli's (1991, p. 51) argument, it was impossible to determine which online discussion forums and websites on intersex issues were legitimate. While I used extensive word searches on the Google search engine, with words such as 'intersex', 'gender', 'surgery' and 'discussion', many search results appeared fetish-like, voyeuristic and pretentious.

Jacqui recommended that there should be more psychological-type support services in New Zealand:

There needs to be more – I think this is the right word, psychological support. ... They're [clinicians] excellent in dealing with the physical stuff, they are not that great with dealing with the emotional side of things. Now over in Melbourne I was offered that extra support if I wanted it, and I was staunch in whatever enough then – I said, "I'm fine, I don't need that." ... There needs to be open information for parents of kids, and that's becoming more and more, especially with the CAH support group... (*Jacqui, 2010, interview*).

9 In order to ensure confidentiality I have withheld details about this support group.



She also remarked that such support is particularly important during adolescence:

Yes, yes, and around the major events – you know, like the surgeries and things. I've suffered from depression on and off for a number of years, and I think that's probably because of that. I'm free of it again at the moment and hopefully it will remain, but that probably started to become an issue when I – it might have been when I was little, still at home. But when I left home... I had the most awesome parents who were very, very supportive, but I think there needs to be that – maybe counselling available, *easy* to get hold of, and not to dump you in a – as a psych case basically... (Jacqui, 2010, interview).

The issue of stigma emerges from Jacqui's last comment, which suggests that she may have had negative experiences with a counsellor or psychologist. This also shows that psychological support or counselling should *empower* individuals, instead of making them feel that they 'have a serious problem' and that 'there is something wrong with me'.

Rogena commented that counselling and support is also important for *parents* of intersex children:

One, they [parents] need to be taught what causes this – the fact that it's naturally occurring. Actually this has been occurring since time began and there's nothing abnormal. Two, they need to be given counselling as to how to support, how to love that child. OK, it could be a bit of a grieving time because they're expecting... but if they're given the counselling and support they can overcome this. And three, the education of how to fight the little battles or big battles that are going to come in the future, but if they're given that support they can then overcome it. And four, how to overcome their religious beliefs to enable them to accept the child – if that's an issue, which it often can be. (Rogena, 2011, interview).

Mani Mitchell, who founded the Intersex Trust Aotearoa New Zealand (ITANZ), commented about the significance of *information* in relation to support:

Most parents are good, and want the best, but most parents are conservative. I think there's notions around the ideal that "my child is going to grow up and get married and have children and there'll be grandchildren". I think for many parents that's the fantasy. For any child, for any parent, how you accept that that may or may not happen. So I think one of the things with this intersex issue is that people go "Oh, how do we fix it?" There isn't a nice fixing, because I think this is one of our complicated social realities and really it's about difference and how we manage that, and how we move from this place of fear, shame, secrecy and silence into a new place. I think, if we're going to do anything, that's the starting process. And it's about different disciplines communicating and sharing information so the answer will come out of experts, the narratives of intersex people themselves, the narratives of parents with intersex children and out of that wealth of information the answers will emerge. The first step to that is visibility and doing what we're doing this afternoon [our interview], which is talking. (Mitchell, 2010, interview).

As well as her family, Anonymous 3 receives support from a friend with the same condition:

...we've pretty much been best friends ever since we found out we have the same condition [CAH]. ... it's been so long that we've been friends. I think we got in contact through our parents who ended up being friends, and then as we grew older and understood more we became good friends and helped each other out with questions. (Anonymous 3, 2010, interview).

This suggests that having a peer to talk to, hang out with and share experiences with can be a very uplifting and empowering experience. I also suggest that talking to someone who is *not* a clinician, psychologist or other 'professional' can eliminate feelings of stigmatisation – because that person (a friend or peer) has the same condition. Indeed, as Anonymous 3 stated previously, 'It's not as bad as people say it is.'

## Conclusion

An implication of genital surgeries is not only practical considerations (vaginal dilation, for example) but its *emotional* considerations: a teenage girl can understandably feel embarrassed and hesitant about seeking advice about a very personal matter such as vaginal dilation. I therefore conclude that easily-accessible support for intersex adolescents, which Sarah's

organisation in New Zealand offers, is particularly important. Support is also crucial for parents of intersex children. Because we live in a society with ingrained binary sex/gender assumptions, and because intersexuality is not a particularly well-known condition, parents of a newly-diagnosed newborn infant may be understandably bewildered and stressed that the classifications of 'son' or 'daughter' cannot be confirmed immediately.

Support groups are also important for intersex people and their families in terms of providing *legitimate* information. For example, parents of a newborn intersex baby – who may already be stressed – need to be careful when reading easily-accessible information on the internet. This is with regard to Portelli's (1991, p. 51) theoretical position: how do we know that a person's account posted on a website is true? This is particularly as some websites provide a 'stage' for some people who, for instance, like to boast about their 'uniqueness' for their own vanity. Some people therefore appear to romanticise lesser-known conditions for prurient appeal (akin to the 'shock' element in horror or art-house films).

Parents of a newborn intersex baby therefore need to be put in touch with other parents of intersex children, and indeed advocates such as Mani Mitchell (whose organisation's websites contain more legitimate information, as Lisa remarks). By contacting support organisations, instead of possibly becoming more stressed by sensationalist accounts on websites, parents can feel supported, comforted and empowered when listening to parents' first hand experiences – and possibly their children's too. Parents of a newborn intersex child may, I suggest, feel comforted by meeting a cheerful young woman like Anonymous 3, or a mother such as Anonymous 1 who appears to be proud of her child.

In closing, while living in New Zealand with a lesser-known condition can be problematic, support organisations can ensure that intersex New Zealanders and their families should not feel compelled to keep silent and feel isolated – despite follow-up medical care seeming far away in Australia, for instance. Having someone to exchange e-mails with, meeting another parent of an intersex child over a coffee, having someone of the same age to hang out with and talk to about a very personal matter: these activities can indeed alleviate feelings of isolation and silence amongst a small population.

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