



**Aotearoa childhood genital (re)assignment surgery:  
A case for the right to bodily integrity**

**Te mahi tīpoka huripoka taihemahema hei ira kē i te tamariki, i  
Aotearoa: He tāpaetanga take mō te tika kia noho tapu tonu te tinana**

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**Abstract**

Sex and gender are established on the appearance of two body types, male/female, boy/girl. Expressions at variance to these forms often summon the need for standardisation. Of concern is the practice of Childhood Genital (Re)assignment Surgery on intersex children. The study aimed to identify discourses and practices constituting the experience of Child Genital Reassignment Surgery (CGRS) from a perspective of an adult. A collaborative qualitative intrinsic single case study draws from personal experience and poststructuralist ideas to analyse discourses and disciplinary practices shaping CGRS. Data included a written autobiographical recollection of childhood memories of genital reassignment surgery. Thematic analysis was used to identify discourse and practices shaping the meaning of CGRS. Two predominant discourses, hetero-normativity and medicine were identified, from which four broad themes filtered: an historical context; finishing and feminising; silencing possibilities for self; and a (dis) embodied self. Each were tangential to a discursive practice. CGRS has enduring consequences for children

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**Ngā ariā matua**

He mea āta tautuhi te ira me te tuakiri ira i runga i te āhua o ngā momo tinana e rua, tāne/wahine, me te tama/kōtiro. Ina puta he rerekētanga i waho i ēnei āhuatanga e rua, ka rangona te hiahia kia whakahāngaitia ki tētahi o ēnei. Tētahi āwangawanga i ēnei rā ko ngā Tīpokātanga Huripoki Taihemahema i te Tamarikitanga mō ngā tamariki waenga-ira. Tētahi whāinga o te rangahau he tautuhi i ngā kōrero me ngā tikanga mahi o ngā wheako o Te Tīpokātanga Huripoki Taihemahema Tamariki, ki tā te pakeke titiro. Ka waihangatia tētahi rangahau putanga takitahi taketake ā-momo āhuatanga mahitahi i ngā wheako whaiaro me ngā ariā turaki maioro hei wetewete i ngā whakawhitinga kōrero me ngā tikanga ngaio e arataki ana i Te Tīpokātanga Huripoki Taihemahema te Tamariki. I roto i ngā raraunga ko tētahi kohinga haukiri i āta tuhia mō ngā maharatanga a ngā tamariki mō ngā tīpokātanga huripoki taihemahema. I whakamahia he tātaritanga ā-kōwae whakaaro hei tautuhi i ngā kōrero me ngā ritenga mahi e tārei ana i te tikanga o te Tīpokātanga Huripoki Taihemahema Tamariki. E rua ngā whakawhitinga kōrero matua i tautuhitia, ko te tāne piri ki te wahine hei huarahi mō te nuinga me ngā rongoā, ā, e whā ngā ariā whakaaro i tātaritia: ngā tātai kōrero o mua; te whakaoti me te whakawahine; te whakangū i ngā huarahi mō te tuakiri; me te tuakiri whai tinana, (kore-tinana). I haere tahi ēnei mea katoa me tētahi kawenga mahi toro-whānui. He whānui, he mauroa hoki te Tīpokātanga Huripoki Taihemahema Tamariki mā te



and adults alike. Nurses can make a difference by supporting parents' informed decisions as to their child's care while respecting a child's right to bodily integrity.

## Keywords/Ngā kupu matua

Sex-gender binary/ Takirua ira-tuakiri ira, intersex/ waenga ira, hetero-normativity/ tāne piri ki te wahine hei huarahi mō te nuinga, pathologizing/ te kī māuiui.

## Introduction

Childbirth is an important life event for families; an event instilled with great expectations as to the baby's sex, being one of two options; male or female. Once the sex is established, gender is then summoned to give meaning to what it is to be a boy or girl; man or woman. Variations from these is binary classifications tend to generate anxiety, invoking the need for normalisation. Intersex is one such variation, defined by the Human Rights Commission (HRC) (2007, p. 13) as a generic term "...for a variety of conditions in which a person is born with reproductive or sexual anatomy that does not seem to fit with typical biological definitions of female or male". Classified in medical discourse as Disorders of Sex Development (DSD), differences in sex development at birth can vary from 1 in 2000 (Preves, 2003), to 1 in 4500 (Warne & Mann, 2011).

The intention of Childhood Genital Reassignment Surgery (CGRS) is to shape genitalia that is consistent with the gender assigned at birth. The reasoning behind the surgery is controversial (Davis, 2015). Notwithstanding the significance of potentially serious associated medical conditions such as Congenital Adrenal Hyperplasia, are countless calls for a ban on normalising surgery until children can make their own fully informed decisions (Bauer & Truffer, 2014; Commissioner for Human Rights, 2015; Davis, 2015; Tamar-Mattis, 2013).

tamariki, mā te pakeke anō hoki. Ka taea e ngā tapuhi te āwhina mā te tautoko i ngā hiahia a ngā mātua mō te tiaki i ā rātou tamariki, me te whakamana hoki i te tika o te tamaiti kia noho kotahi tonu tōna tinana.

The French philosopher Michel Foucault (1926-1984) argued discourses are "...practices that systematically form the objects of which they speak" (2002, p. 54). Arising from disciplinary practice, discourses have the power to define and construct norms for those objects of interest. Discourses too offer an array of subject positions from which identities may unfold with sex and gender being reference points for identity development (Greenwood, 2005). Furthermore, knowledge about sex and gender sits uneasily between essentialist and social constructionist understanding of bodies. While essentialism assumes sex and gender derive from physical bodies, social constructionism holds that meanings attached to bodies are socially shaped (Holmes, 2007). It is upon this contested terrain that knowledge about sex and gender is negotiated. While we believe the materiality of the body has importance for experience, we recognise that meanings attached to embodied experience are socially shaped through discourses encountered in every-day life.

As co-researchers, Jeanie and Mani have worked in collaboration to create this publication. Mani is the Executive Director of Intersex Trust Aotearoa New Zealand (ITANZ), a charitable trust providing education and guidance on matters of intersex for individuals and professional organisations. Mani identifies as non-binary



gender that is fluid in spirit, evolving with time. Mani was first to 'out' as intersex in Aotearoa New Zealand in the mid-1990s and has worked as an educator, counsellor, change-agent and clinical supervisor. Mani prefers gender neutral pronouns; they, them, their(s)<sup>1</sup> and themselves (Lesbian, Gay, Bisexual, Transgender Resource Centre Resource Centre, 2017). Jeanie is currently a board member of ITANZ. Jeanie's interests lie in gender and sexuality allied to socio-political matters in health. Jeanie performs as a cis woman, believing sex and gender identity to be both malleable and non-binary and responds to pronouns she, her, hers, herself. Ethics approval for the research was attained from the Human Ethics Committee, Victoria University.

## Background

The history of intersex is well documented in the critiques and chronicles of Davis (2015), Dreger (1998), Karkazis (2008), and Preves (2003). Previously labelled hermaphroditism, the term 'intersex' was adopted in the 1990s by the inaugural advocacy group, Intersex Society of North America, as preferable. In 2005, the taxonomy, Disorder of Sex Development, was accepted by consensus (Hughes, Houk, Ahmed, & Lee, 2006). While controversial this redefinition was deemed a more integrated approach to the care for children with intersex traits (Davis, 2015). However, as Davis suggests, the accord appears to have fallen short of its promise in continuing to circumscribe non-compliant bodies within the narrow essentialist precinct of hetero-sex.

Foucault (1980) reports, from the mid-19th century, intersex gradually came under the domain of medicine. For Foucault it was the profound and poignant suicide of Adélaïde Herculine Barbin (also known as Alexina or Abel Barbin) in 1868 that became a forerunner for medical authority over matters related to intersex. Barbin's memoirs prompted Foucault to question the need for a "true sex" (p. vii) and were to become both pivotal and prophetic in heeding the first-hand embodied

experience of intersex persons as these self-narratives were typically missing in medical discourse.

Genital surgery for normalising purposes was instituted in the 1950s through the pioneering work of John Money and colleagues at John Hopkins University, in the United States of America. For Money (1968), variations in sexual development were simply "sexually unfinished" (p. 46) and therefore in need of fixing. His belief in a "critical period" for establishing gender identity, paralleled language development because of its role in initiating gender differentiation (Money & Ehrhardt, 1972, p.13). Surgery prior to 18 months of age was considered appropriate for enabling sex reassignment should wrongful assignment arise.

Remnants of Money and colleagues' model linger today, despite mounting criticism in the decades to follow (Davis, 2015; Diamond & Sigmundson, 1997; Karkazis, 2008). Escalating discontent culminated in the 1990s with the formation of intersex advocacy groups alongside feminist scholarship (Davis, 2015). Davis reports how the internet enabled the Intersex Society of North America to bring together intersex citizens into a community that fostered understanding of their bodies and networking with others alike. These early years of activism were essential in listening to the voices of intersex citizens.

The early 21st Century witnessed an emphasis on the rights of the child, alongside the protection of bodily integrity including the protection of the human rights of intersex citizens in health care settings (Aotearoa New Zealand Sexual Orientation, Gender Identity and Intersex Coalition, 2013; Bauer & Truffer, 2014; Commissioner for Human Rights, 2015; Mendez, 2013; Tamar-Mattis, 2013). In Aotearoa New Zealand, concern for the rights of intersex peoples came to the attention of the HRC (2007) during an inquiry into discrimination and injustices experienced by transgender peoples. Disconcerting practices encountered by intersex citizens in health systems were exposed. Recommendations

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<sup>1</sup> M prefers 'their' as a possessive pronoun.



echoed concerns around infant genital normalising surgery, reinforcing calls to listen and learn from intersex peoples' experiences.

## Methodology

Our study draws from personal experience and poststructuralist ideas to examine the practice of CGRS. Poststructuralism makes no claim for a unified truth about reality. Meanings that people give to their world are shaped by various discourses and discursive practices they encounter in everyday living (Weedon, 1997). We chose a collaborative qualitative intrinsic single case study due to the uniqueness of Mani's experience (Stake, 2005). Context too has important application in case study research for describing the background within which an activity occurred (Baxter & Jack, 2008). Storytelling is a powerful means for amplifying and transforming the experiences of people with intersex traits so that others can learn from those experiences (Davis, 2015).

## Data collection

A verbatim autobiographical depiction of the events in Mani's childhood was facilitated through an open question regarding their experience with CGRS. Mani's use of self enabled a rich source of raw data that we harnessed into "mutually agreed upon data" for analysis (Berrey, 2003, p. 103). The data corpus was transferred to a data file, encompassing columns for initiating analysis. Potential power relations were diffused through continual reflection about how we were positioned in the research. Data collection was completed at the end of November 2015.

## Data analysis

A thematic analysis was undertaken to identify key themes guided by Braun and Clarke's (2006) phases for analysis. One overarching question driving analysis asked what discourses and practices shape Mani's experience of CGRS? Additional questions contemplated who was

speaking, what was said /not said, authority to speak and institution(s) that legitimise a discourse (Foucault, 2002). Following multiple readings of the data corpus, points of interest, alongside intuiting themes were logged in corresponding sections of the data file. Nascent themes were superimposed through a poststructuralist lens for discerning pertinent discourses along with subject positioning and effects of language. Analysis continued at an interpretive level moving beyond the text to unpack dormant meanings (Braun & Clark, 2006). Meanings formed discursive themes before coding into discourses and subthemes. Ongoing analysis was strengthened from the literature and we met regularly, face to face, for agreement on thematic identification, analysis, interpretation and writing up.

## Trustworthiness

As co-researchers, we were intimately involved in the research process thus facilitating the trustworthiness of the study's findings through ongoing reflexive dialogue (Braun & Clarke, 2006). Mani's use of 'self' in data collection offered authenticity to the data, enabling others with similar experience to inform their own decision-making (Simons, 2009). Importantly, Mani's account has the potential to inform policymakers and practitioners alike in the interests of improving health services for all intersex citizens and their families.

## Findings

Two predominant discourses, heteronormativity and medicine, were identified each sustaining the other. Discerned from these were four broad themes, transposed within a discursive practice: An historical context; Finishing and feminising; Silencing possibilities for self; and a (Dis)embodied self.

## Historical context: 'Paternalism's heyday':

As a post war baby, Mani's story represents a context in which family life took precedence, presumed to reinstate a routine disrupted by World War 2. Suffused



through the institution of family came great expectations, particularly so for Mani's parents, having settled in a small rural community to begin family life.

*My name is Mani(...) and this story is my reality, 'stitched' together from dispirited sources and events prompted following my mother's premature death at the age of 62. I was a post war baby, born in 1953. (...). My mother had already experienced three miscarriages prior to becoming pregnant with me and so in the imaginings of my parents, great expectations incurred in anticipating my birth.*

Mani's childhood appeared discursively constructed from reflective moments occasioned following their mother's death. Mani's portrayal of a reality 'stitched together' invokes images of a frayed past for Mani's mother. A history of recurrent miscarriages enacted the need for medical surveillance in future pregnancies. Since antenatal monitoring was not available in small rural communities, Mani's parents were confronted with an intermittent separation. Their mother stayed in Auckland with friends for the remainder of her gestation. Events leading to Mani's birth depicted the challenges facing their parents, concomitant with the hope of normalcy once baby was born. This optimism soon paled in significance on encountering the health system. It was 20 years before Mani was to uncover the events surrounding their birth. In the morning of March 10, 1953, Mani's mother's labour commenced, necessitating a hasty drive by her husband to the maternity ward.

*Upon their arrival at the hospital, an austere matron, arms folded firmly across her chest in an archetypical manner, pronounced to my mother that she could not have her baby then because there were no doctors around. Despite this chilling edict, my mother was ushered to the birthing suite by a young nurse and told to wait. I understand I was born some 20 minutes later.*

The context encumbered cultural ideas when medicalisation of childbirth was on the rise in Aotearoa New Zealand. Austere attitudes often brought fear and alienation in the birth space (Coney, 1993). Such flagrant authoritarianism constituted an era that typified "paternalism's heyday" (Dreger, 1998, p. 187). Allied to a history of recurrent miscarriages lay the potential to undermine Mani's mother's confidence in decision-making. Autonomy for women in childbirth was to remain deep beneath the surface of professional struggles for decades (Douché, 2007). The 'matron' in Mani's account is positioned as an agent of paternalism as it extended to childbirth; an era when hospitals became a site of surveillance for birthing populations and a location for monitoring societal norms (Papps & Ollsen, 1997). Medical discourse had positioned Mani's mother as impassive, effectively silencing possibilities of self.

### **Silencing possibilities of self: The practice of secrecy**

Silence was a means through which Mani's mother's fragile self was sustained for the moment; disrupted when in their early twenties, Mani asked her mother:

*"What happened when I was born?" My mother proceeded to inform me that as the nurse bent down to pick me up she rather tactlessly exclaimed "oh my god, it's a hermaphrodite!" and having recalled this sequence of events she began to scream and fled the room, leaving me in unimaginable shock. (...) ...not so much from the utterance of the phrase, for I had heard the expression before (...). What was so upsetting was that I had never seen my mother so distraught. On her return to the room some ten minutes later, with reddened eyes, my mother looked out at a perfectly blue Raglan sky and uttered... "You know what dear; I think it's going to rain. Let's go and get the washing in." And as we gathered in the washing neither my mother nor myself talked about the events of that sunny afternoon again.*



Opportunity for celebrating Mani's birth was silenced by an outburst invoked by fear, showing how language, far from being impartial, has effects (Peterson, 2002). What was said and not said had remained behind a wall of silence that shadowed Mani's mother for two decades, sustained through stoicism until Mani's reflection momentarily interrupted the hush. Silence can manifest either through stigmatization or concealment of information (Davis, 2015). Other writers point to secrecy as having ramifications for the emotional wellbeing of some intersex children (Paterski, Pretice, & Hughes, 2010).

A subsequent encounter with a family friend provided Mani with new insight regarding their mother's distress:

*Following my mother's death, I resumed my own search of what transpired. As events unfolded, it is my understanding that my mother's distress following my birth (...) was so intense it was judged by the medical staff at the time, that she be heavily sedated. In the interim I was removed from her care...*

With the legacy of 'twilight sleep' of the 1920s and 30s still lingering (Douché, 2007), it is not hard to imagine the flow on effect of heavy sedation on Mani's mother's memory. Nonetheless, the culmination of stressful events was to have a sombre bearing on the relationship between mother and child; a delicate kinship which was to last the remainder of Mani's mother's life, as is evident in Mani's reflection.

*Now in my early 60s, as I reflect upon the events disclosed in my self-narrative, it's easy to imagine the terrible toll they had on my mother. Our fragile relationship had been given neither the opportunity to heal nor the support to enable the healing process. Consequently, our fragmented natures engaged each other in silence and bewilderment.*

The fragility of Mani's affiliation was sustained through an implicit nonverbal agreement of silence. Mani's mother re-living her experience, some two decades on, attests to her stoicism over that time. Her flash-back, some 20 years on equates with contemporaneous understandings of post-traumatic stress and is testament to how the pejorative handling of significant life events such as childbirth, can impact on identity. Germane too, was the absence of support groups available to Mani's parents for fostering shared experiences for families and intersex adults alike. For Mani, silence resounded as a potent force in piecing together their fragmented self; a negotiation corroborated by other studies. In their study of adult intersex experience, MacKenzie, Huntington and Gilmour (2009) describe how intersex persons negotiated a hazy sense of being different through a precarious yet courageous journey from 'silence to voice'.

### **Finishing and feminising the body: A normalising practice**

Heteronormative discourse has constituted genital variations as a "medical emergency" (Davis, 2015 p.133). Such urgency privileges both coital and reproductive functions over protecting body integrity and its pleasures. Despite pressure to ratify Mani's sex at birth, their gender remained in limbo for another year.

*...after several days of rigorous examination, a decision was made to assign me the sex of a male infant. (...). I was given the name, BML and raised as a male child for the first year of my life. My official birth records at the time listed my gender as indeterminate. I remained as 'indeterminate' until just before my first birthday...*

Mani's birth coincided at a time, when ideas that babies were gender neutral at birth were surfacing in psychological and medical discourse (Money, 1968).



Following birth, Mani was assigned the sex of male and raised as boy for their first year of life. At age one they were recalled to hospital for further investigations.

*The findings from the laparotomy summoned yet another change in my gender to that of a girl with a consequential name change (...). The operation brought about the erasure of the facts of my first year of life from the public record and concomitant alteration of my sex in the birth register.*

Mani was reassigned as a girl with the subsequent erasure of any former gender identity. Sorting a child's gender early was deemed necessary to circumvent "gender identity confusion" (Dreger, 1998, p.197). This anxiety is nuanced when around the age of ten, Mani was summoned to undergo plastic surgery on both ears to maintain their (re)assigned feminine self.

*Memories of my previous experience of hospitals came flooding back (...). In retrospect, the surgical procedures undertaken were an attempt to fix and feminise my body.*

In the process of fixing Mani's 'recalcitrant' body came the inevitable loss of bodily agency. The effect of this (dis)embodiment, induced through the discourses of heteronormativity and medicine is an uneasy enigma; the depiction of difference as pathological.

### **A (dis)embodied self: A pathologizing practice**

Davis (2015) attests that much concern from the intersex community stems from the medicalisation of intersex and its allegiance to pathology. The pathologizing intersex qualities had the potential to render Mani susceptible to the gaze of sexual predators.

*In the ensuing years, I was examined by specialists on a semi regular basis and while the frequency of these visits may elude me, what has become indelibly etched on my mind is that these sessions*

*were painful, humiliating and fearful (...) intensified through silence. What I can remember was there was something profoundly wrong with my body that must never be referred to or spoken of. The tragic consequence of this silence was that I had become easy prey for predators of sexual abuse.*

In adulthood, haunting memories of childhood unravel a traumatic past of covert events that elicited a tacit understanding that Mani's body was flawed. At age eight Mani was admitted to hospital for an operation shrouded in mystery.

*Devoid of any explanation as to my incarceration, I at once felt abandoned, confused, impassive and alone. The remainder of my internment became a succession of medical line-ups (...) only to be prodded, poked and peered at (...). These experiences evoked memories of a sexual abuser I had once encountered who vowed to cut 'it' off should I divulge 'our' secret.*

Mani's reminiscence of hospitalisation is analogous to incarceration and medical lines-ups, tantamount to voyeurism. Positioned in the text as a victim of sexual abuse, an awkward irony is discerned where 'prodding, poked and peered at' in medical discourse was ordained to be in Mani's best interest. Paradoxically, Mani's ordeal had the potential to conflate those doing the treatment with those doing the mishandling. Preves's (2003) analysis of intersex adults' memories of their childhood experience substantiates Mani's sense of (sexual) abuse. Mani parallels the treatment as tantamount to torture.

*...when I 'came to' I found myself up in stirrups, unable to move, struggling to breathe and in terrible pain. The pain was 'down there' that secret shame place. It manifests as an intense burning sensation, but I was unable to convey my feelings at the time. As I faded in and out of consciousness I recall becoming overwhelmed.*



It took another two years before it occurred to Mani that "...it down there" had been removed. Importantly pathologizing Mani's body highlights the reality whereby the CGRS may cause more harm than good (Karkazis, 2008). In Mani's case a lack of autonomy over what was happening to them constituted a sense of helplessness, which Preves (2003, p. 72) verifies has repercussions for a child's "coherent sense of self". A fragmented self becomes apparent in Mani's reflection:

*...through silence I learned to be compliant as well as how to hide my pain and despair. By the age of five I was already an expert in the split process despite knowing it was not okay to show and tell with respect to 'down there'. My parents were oblivious to the abuse [...] and thankfully, for their sakes, I was able to sustain the secrecy until well into my thirties.*

Compliance enabled Mani to survive the machinations of an abuser while shielding their parents from potential anguish from disclosure. Mani's (dis)embodied self was precariously positioned at the edge of survival; sustained through secrecy.

### Discussion

Mani's story depicts a context in which their discursively constructed corporeality was negotiated through heteronormative and medical discourse. Discerned through Mani's text was a painful reality of CGRS. Drawing from Karkazis (2008), confronting Mani's parents was possibly a surfeit of overpowering anxiety throughout Mani's development and beyond. Despite the uncertainty surrounding the practice vestiges of the model continue today. Lessons from Mani's story are that childhood memories have a lasting impact. Post-structuralism provides a framework for health professionals to consider constructions of binary dualisms that set a potential to eliminate other possible identity expressions. Following

Derrida (1988), these dualisms encompass a hierarchy whereby a dominant term, namely heterosex, is favoured over a subordinate one, intersex. Post-structuralist feminists (Arner & Falmagne, 2007) deconstruct notions of identity based on binary thinking, proffering that these can be transcended through terms such as "both/and" (p. 369) without privileging one over the other, bringing into play ways of being in the world that not only tolerates, but celebrates difference.

Largely absent from medical discourse has been the narratives of intersex people (Davis, 2015). Such exclusion can induce definitions at odds with the embodied experience of intersex citizens. Dalmiya and Alcott (1993, p. 231) alert to an "epistemological discrimination" as to what counts as legitimate knowledge *vis-à-vis* propositional (theoretical; knowing that), practical (knowing how) and experiential knowledge (knowledge through being). While propositional knowledge has prevailed overall, these authors argue that practical and experiential knowledge are authentic "epistemic states". Thus, knowledge attained through the embodied experience of intersex citizens, counts. Given nurses and midwives straddle all three paths to 'truth' when supporting decision-making in clinical settings, they are at the forefront of safeguarding culturally safe inclusive practice for sexually diverse citizens (New Zealand Nurses Organisation, 2016).

Greenwood (2005) suggests that "difference is political" and has implications for the establishment of trust in health settings. The acquisition of trust is contingent on a "trust moment" (Ramsden, 2002, p. 120). Drawing from Ramsden, failure of the moment to occur early in a health encounter may invoke some intersex citizens to continue shielding their difference. The material effects of differences are not of intersex citizens' making, but in how they have been treated within the context of social, institutional and disciplinary practices; the essence



which is captured in the following citation. "We are not ashamed of who we are ... those issues are created by how we are treated" (HRC, 2007, p. 81 & 87).

## Conclusion

Mani's story is an inspiring one that uncovered how discourse both serves to enable and constrain the scope of intersexual identity. Salient is pathologizing difference with potential implications for a child's health and right to bodily integrity. Nurses have a pivotal role in working with families of intersex children, respecting their right

to delay surgery until children can make a fully informed, competent decision and consent to care.

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