



“Mean As!”

The story of creating an online library about relationships and sexuality told and read by whaikaha Māori and men and women with a learning disability



Figure 1. A photograph of Janet holding her artwork: The art is an abstract collage. A painted grey CD evoking the gendered Venus symbol is foregrounded on a sea of forest green, royal blue and grey and brown crayon tracing

Janet Bailey is a mixed media artist, currently working out of the Studio2 Gallery, Ōtepoti / Dunedin.

No one knows for certain, but it is believed Janet was placed at Templeton Hospital (Christchurch) as a very young girl before being moved to Cherry Farm Hospital (on the outskirts of Dunedin). Without any traceable family, Janet would become one of the first women to be resettled from Cherry Farm as it began to close in the 1990s.

Janet loves music and dance and singing and cups of tea and stories. Appropriately, therefore, Janet created the cover art from a deconstructed accordion case and compact disc, washed in her favourite green. The work travelled Dunedin as part of the Fringe Festival event “the road less travelled.” During the event a set of suitcases began by riding the carousel at Dunedin airport before members of public picked them up and put them down about the city.

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“ Just because you don't want to be creative,
Doesn't mean you don't have something to say,
And just because you don't want to be a leader,
Doesn't mean you don't know the way.

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Southern Health and Disability Ethics Committee
(NZ/1/7B02113)

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Mā whero, mā pango ka oti ai te mahi

When the mahi (work) of unpacking each of the seven stories that now populate the “Mean As! Library was complete and the researchers with a learning disability sat down to reflect on and write their report, they imagined the project as a jigsaw. A jigsaw, they said, that couldn’t be completed without the work of many and the skills, creativity and care of each, differently shaped piece.

In this sense, therefore, “Mean As! has begun a much wider project. Namely to draw people into a community of listeners and actors, connected by the narratives of eight men and women, simply asking for the same right to live and love the way other New Zealanders do.

Placing people with a learning disability at the heart of the project transformed its kaupapa in a way that was consistent with their aim. “Everyone brought value to the project,” they wrote, “because we all saw people as equal – nobody is higher or lower.” To all those who embraced their kaupapa and brought life, vitality and resolve to the “Mean As!” Project, we are extremely grateful. Those who gifted their time, creativity and resources include;

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- **8 Storytellers**, brave enough to gift themselves to the "Mean As! Library, knowing that the stories they created would need to do the talking for them. They are the first unfiltered stories of relationship and sexuality told by whaikaha Māori and New Zealand men and women with a learning disability and therefore simultaneously represent a bequest to people with a learning disability and the wider communities of self-advocacy and a call to action to all those who find the difficulty Storytellers have living and loving the way we do, dehumanising.

William, Vanessa, Darryl and Cheryl believe the jigsaw they helped create needs to be seen as a beginning rather than a completed project. In their imagining, there are many more pieces that need to be added if people with a learning disability are to experience the same kinds of intimate citizenship other New Zealanders do. In this report, you will hear them speak of the sense of responsibility they feel to take the stories into the community and to change organisations and habits in ways that might also transform the story telling of future generations of whaikaha Māori and people with a learning disability. In a sense, theirs is a challenge to us all. To meet within the kaupapa of equity – nobody higher or lower, and to create a more human future by telling, listening and responding to each other's stories.

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Kia whakatōmuri te haere whakamua

We walk backwards into our future with eyes fixed on the past

Kia whakatōmuri te haere whakamua is a whakataukī (proverb) that speaks to the way Māori understand cosmological time. Roughly translated it means we all walk backwards into our future with eyes fixed on the past (Rameka, 2017) Within tiro ā-Māori ki tōna ake ao (a Māori world-view), time slips seamlessly between coexistent past and present with all of identities shaped by people and places we carry (backwards) with us into the future (Rameka, 2017). A Māori conceptualisation of time and history stands, therefore, in stark contrast to a Eurocentric or Pakeha understanding of the future lying somewhere out there, linearly in front of us, waiting to be caught up.

Because the beliefs and assumptions that underwrite what we understand to be real (ontologies) and our habits of thinking and doing typically sit below the surface of our awareness, differences and divides in understanding like these can take us by surprise. And there they lie, invisible to us until we are forced to rub-up against strangers who have different ways of thinking and doing.

Like Māori, people with a learning disability have also had to carry forward moments of encounter in which the assignations of “being different” and “less civilised” made by Victorian colonisers and academics have been used to assert and explain their exclusion from the institutions of knowledge, power and privilege. This exclusion has, historically, denied them their opportunity to shake up or unsettle deeply embedded and discriminatory ways of imagining and behaving towards them.

In, the Mean As! Research Project, we sought to pull to the surface of awareness, some of the habits of thinking and doing that have become entrenched as ordinary and routine ways of severing whaikaha Māori and Pakeha men and women with a learning disability from very normal expressions of intimacy and intimate citizenship. And we hoped to accomplish this by forcing New Zealander’s to rub-up against the story telling of their imagined “other”.

By drawing on the disruptive power of storytelling employed by indigenous and other marginalised communities, creating a library of stories told and read by people with a learning disability writes large how a single, professionally authored story of impairment, has morphed the very ordinary aspirations to love and to touch and to be loved and to be touched into unethical ways of thinking and doing.

Habits that include, the routine and thoughtless surveillance of disabled lives, punishment for sexual behaviour, unconsensual sterilization, out of home placement and the heartache of custodial separation and a community’s failure to address the high rates of violence and sexual abuse experienced by women and men with a learning disability. Through their storytelling we sought to place people with a learning disability at the very centre of reimagining a more human future for all citizens of Aotearoa / New Zealand. What we discovered were stories that shake the very foundation of those assumptions of incapacity that have always policed people with a learning disability’s exclusion from ordinary forms of intimate citizenship.

By inviting people with a learning disability to be the first, authoritative readers of an emergent “Mean As! Library, the Mean As! Project also exposed the capacity of people with a learning disability to be and become “indigenous” theorists and activists in their own right, contesting the beliefs and habits of academics who have similarly policed their exclusion from those institutions that have always controlled the narratives that shape their lives.

Eight story writers and four researchers with a learning disability succeeded in re-imagining inclusive research in ways that echoed the development of other de-colonising research methodologies. In so doing, the storytellers and researchers who steered the “Mean As!” Project completed a journey research has been making, away from research “on” to “with” and outwards to research “by” people with a learning disability (Milner & Frawley, 2019). A journey rooted in the first languages of self-advocacy and which returns the authorial voice to the communities from which the stories that populate the “Mean As! Library” have come and more rightfully belong.

On both counts, the “Mean As!” Project holds the promise of fulfilling Williford’s (2009) hope that through telling stories, a more liveable – human future might become clearer, both for people with a learning disability and the communities within which their stories dwell. To achieve the promise of storytelling and reading, it is important, however, to keep our eyes fixed on the past and to acknowledge the steps that others have taken that might act as a guide.

In the following chapters, we look to the past to describe the origins of the project that Māori say we, as researchers, carried (backwards) with us in the process of co-creating the “Mean As!” Library with people with a learning disability.

Pūrākau as a decolonising narrative

And each of us has a responsibility to pass it on

“We are all”, according to Māori film and documentary maker, Merata Mita, *“born into story.”*

People are, however, not only the source of story telling, they are also the subject of political, social and scientific discourses (Meininger, 2010) that swirl about and prefigure the way we narrate our lives. The kinds of stories that, for example, inform our understanding of what is “normal”, “natural”, “common” and “ordinary,”¹ and by virtue of falling beyond the cultural prescription of normal, what might therefore be considered to be “alien”, “other” and “unnatural.”²

The rejoinder to Merata Mita’s observation that *“We are all born into story”,* is that; *“each of us [therefore] has a responsibility to pass those stories on”* (cited in Lee, 2009).

This belief that we all share a responsibility to pass on knowledge embedded and imparted through storytelling speaks to an ontological view held by Māori that knowledge is a taonga (treasure or possession) that most legitimately belongs to the community from which it came. Like other communities whose voices have been silenced, delegitimised or appropriated, Māori ask of researchers that they begin with the assumption that they are the exclusive owners of their own intellectual property (Tuhiwhai-Smith, 2012), including the stories they tell to and about each other.

In the preface to one of the stories in the Mean As! Library³, we learn that within traditional Māori society, pūrākau (the library of myth and legend passed down through successive generations of story tellers) sat alongside moteatea and waiata, whakapapa, whaikorero

and whakataukī as an important way of instilling mātauranga Māori (Māori knowledge, creativity and cultural practice). To Māori, stories and their telling represent a repository of cultural memory, inscribing philosophical thinking and ways of behaving and being together that “etch into memory who we are as a people and how we understand the world we live in.” (Lee, 2005). As a consequence of the central role story telling played within Māori society, pūrākau was understood to belonging to the whanau, iwi and hapu that gave a story its audience. Rather than being the appropriated property of an individual narrator, pūrākau was instead considered to be a taonga (treasure) that belonged to a community that included past and future generations of story tellers and listeners (Lee, 2009; Tuhiwhai-Smith, 2012).

Relationships and sexuality were the central motifs to many pūrākau. The creation narratives, tribal stories, karakia, waiata and whakairo that survived Victorian censorship, all speak boldly of love, sexual prowess, conception, breakups and reunions, jealousy and diverse sexual identity. In this way, they continue to encode and advance mātauranga Maori in ways that were radically different to the narratives that followed colonisation (Aspin & Hutchings, 2006; Kerekere, 2017).

For Māori, the arrival of Pakeha carved a sharp and Euro-centrally chiselled divide between ascribed civility and barbarism. An ontological separation that inevitably extended to sexuality. To their coloniser, the centrality of sexuality to Māori art and storytelling was

¹ “Māori” in te reo Māori

² “Pakeha” in te reo Māori

³ Ko te Pūrākau o Tipa, p.

an affront to the Victorian sensibilities the new arrivals brought with them. Prefigured within the narratives of colonists whose sails were flush with the aspirations of imperialism were largely uncontested discourses that emphasised European racial superiority, moral rightness and the certainties of a scientific method that acted to verifying the stories Pakeha told themselves.

As a consequence, Tāngata whenua quickly found themselves named, categorized and represented within Pākehā texts as the “less civilized other”, further exposing the ordinary, natural and normal expressions of Māori sexuality to tools and technologies intended to satisfy the puritanical need to contain and police the radically different moral code of their coloniser.

Included within the arsenal of, sometimes blunt instruments of colonisation, was the Pakeha practice of defacing and de-sexing Māori art, catalogued in Figure 2 by the chiselled emasculation of Amo held by the British Museum. Other taonga depicting same-sex relationships were also destroyed or spirited away and Māori pūrākau found themselves re-worded and reworked to fit the single Pākehā story of Māori sexuality.

The same sense of acting with moral certainty finds similar expression, even today, In September, 2019, seventy-eight year old Milton Wainwright was convicted of causing wilful damage in the Palmerston North District Court. Like his forebears, Milton described himself as a devoted Christian. His crime had been to remove the penis from Te Hononga Maunga. Te Hononga Maunga was one of a set of carvings that local iwi had placed to protect the scenic reserve and offer safe passage to all those who came to walk the tracks. To iwi the carving’s penis symbolically represented fertility and the regeneration of the reserve’s forest. To Milton, however, the penis was immoral. Totemic in Milton’s mind of a societal degeneration that had inevitably followed the promotion of sex for pleasure. In wielding his chainsaw, Milton unrepentantly said he was simply doing God’s work.

Writers who have interpreted French historical and post-structuralist philosopher Michel Foucault tell us that he believes what he termed the “power/knowledge complex of discourse”, is largely responsible for determining the range of possible ways we come to know ourselves (as subjects). A process he called “subjectification” (Heller, 1996; Kelly, 2009 Milner & Frawley, 2018).

Like Heidegger before him, Foucault argued that the way we think and act and see the world is, in part, “*always and already*,” in the sense that our story telling is always and already situated in activities and ways of acting that are woven into the structure of our perceptions (Kelly, 2009; Milner & Frawley, 2018). Perceptions guided by institutional stories hegemonically reproduced within the discourses of the power/knowledge complex and processes that act to elevate some voices whilst silencing and deligitimising others.

Colonisation, therefore, dislocated Māori from the traditional (and hegemonically reproduced) story telling that had always told them who they were and where they belonged. Tiro-a-Māori ki tōna ake ao was systematically undermined by the privileging of habits of thinking and doing forged half a world away that were themselves sustained and reproduced within Pākehā libraries and the myriad of other institutions within a power/knowledge complex from which Māori found themselves excluded.

Is your spirit clear? Can you fix a generator?

People’s capacity to speak for themselves is, however, the second way Michel Foucault argued that we constitute ourselves as subjects. In a quote lifted by Milner & Frawley (2018), Mark Kelly writes that Foucault believed we (as “subjects”), also create ourselves “*like pearls around foreign particles of power*” through the processes of hegemony but also, counter hegemonic resistance.

The repeated failure of Māori to recognise themselves or their ontologies in the appropriated, repolished and repurposed stories privileged by the institutions of their coloniser, ultimately led scholars

like Linda Tuhiwai Smith, Katie Irwin and Jenny Lee to argue the importance of bending the way research is transacted within Māori communities so that it better fit the way Māori understand their world and behave towards each other.

Kaupapa Māori Research and the range of emergent methodologies that cluster beneath its korowai belong to a much wider family of “indigenous” approaches to research that seek to prioritise the values and cultural practices of marginalised or colonised populations (Edwards & Brannelly, 2017). Rooted in the struggle to make research meaningful within Māori communities, Kaupapa Māori Research methods share with other indigenous methodologies the “*common aim of disrupting the imbalances of power that exist between the researcher and the researched*”, (Edwards & Brannelly, 2017).

In his book, the *Wretched of the Earth*, French West Indian psychologist, philosopher and revolutionary, Frantz Fanon (2004) cautioned the marginalised and the colonised that the kind of awakenings that might lead to their emancipation required indigenous researchers and activists to step across the line of institutionalised power “*back into community*.” Rather than seeking to pull the “outsider” into the academy, Fanon argued that indigenous researchers and activists needed to acquire the new habit of addressing their own people.

One way that Māori are decolonising the production of knowledge about themselves is by changing the way research is transacted within their own communities. In her book, *Decolonizing Methodologies: Research and Indigenous Peoples*, Māori scholar, Linda Tuhiwai-Smith (2012) writes that Māori have a long and remembered history of cultural offence, that in many ways began with their introduction to research practices that folded about the shared interests of colonial expansion and imperialism.

As a way of illustrating the dehumanising legacy of encounter that followed researchers’ failure to engage with and respect the ontologies of the cultural “other,” Tuhawai Smith (2012) (re)tells how Māori communities continue to carry the memory of events offensive to their deepest sense of humanity. Events like filling the skulls of tipuna⁴ with millet to determine the quantum of their intelligence.

The determination of Māori to reclaim the power to design the tools they felt they needed to make themselves culturally present within research extended to transforming the rules of research engagement. For example, Fanon’s (2004) belief, that “*research needs to address its own people*”, resonates with the Māori relational ethic of Kanohi kitea⁵, that in turn is nested within a prescribed set of ethical principles that articulate the responsibilities researchers have to Māori when seeking to step into a research relationship with them. The seven principles represent an alternative, relationally based, code of conduct that resonate within Māori communities as attributes that also articulate what it means to be “a good person”. They are, Linda Tuhiwai-Smith (2012) tells us, the kind of things you are likely to hear spoken on a marare (village) by kuia (older women) keeping a watchful eye on the affairs of people.

⁴ Ancestors

⁵ Kanohi kitea translates to, the “seen face” that continues to present itself to people, face-to-face

1. Aroha ki te tangata (a respect for people)
2. Kanohi kitea (the seen face, that is present yourself to people face to face)
3. Titiro, whakarongo ... korero (look, listen ... speak)
4. Manaaki kit e tangata (share and host people, be generous)
5. Kia tupato (be cautious)
6. Kaua e takahia te mana o te tangata (do not trample over the mana of people)
7. Kia mahaki (don't flaunt your knowledge)

Figure 2 Ngahua Te Awaekotuku's set of seven responsibilities researchers have to Māori communities taken from Tuhiwai-Smith (2012; p124).

Reciprocally, Māori also tell us how researchers will be met within Māori communities, including the likelihood of being asked questions that conventional research paradigms leave scholars unprepared for. Questions like; "Is your spirit clear?" "Do you have a good heart?" "What other baggage are you carrying?" "Can you fix a generator?" "Can you actually do anything at all?" (Tuhiwai-Smith, 2012).

Old ways of telling new stories

The other way that Māori are decolonising the production of knowledge about themselves is by reimagining research methods in ways that re-align inquiry and representation with Māori epistemological constructions of their world. Today, for example, the historical tradition of pūrākau is being revised and revitalised as an indigenous (Kaupapa Māori) research method capable of continuing to articulate who Māori are within the radically changed cultural landscape of the twenty-first century. Kaupapa Māori researchers like Jenny Lee (2005; 2009) are "*speaking up to*" and "*speaking back to*"⁶ the colonising academy by exploring the possibilities of the traditional pedagogical device of storytelling. In this sense, Lee (2005) argues, pūrākau represents a political site that expands the boundaries of what counts as research by reasserting Māori's right

to "*protect, develop and build upon culturally coherent ways of understanding, knowing and teaching*".

In seeking to return the authorial voice to the communities from which they came, pūrākau and other Kaupapa Māori research methods also create space for counter-hegemonic resistances to unauthorised and inauthentic storytelling to gain a foothold, in just the way Foucault suggested we are sometimes shaped by our refusal to always yield to "*foreign particles of power*."

Within this space, Māori are reclaiming ancestral knowledge as a way of better understanding their sexuality too. This project is occurring in two ways. Through a re-examination of oral and material artefacts created by tipuna and an unpacking of more contemporary discourses that, like the *Māori Sexuality Project*, have drawn on Kaupapa Māori research methods to explore how Māori understand sex and sexuality today (Aspin & Hutchins, 2007).

Through this process, Māori, like other indigenous peoples, have come to question the appropriateness of Western concepts of sexuality. In particular, many Māori now contest the Euro-centric habit of creating dichotomous sexual referents, like; homo/hetro sexual, fe/male, trans/cis gender and the ascriptions of ab/normal that often attach themselves to one side of the binary. In te reo Māori, for example, articles ("ia"), determiners ("tōna/tāna") and pronouns ("rāua/rātou") are all non-gendered referents whose meaning is situated within the context of the story or given in sentences such as "he kōtiro ia" (she is a girl).

What appears to be happening is that Māori are beginning to articulate a more fluid, flexible and contextual sexuality than the fixed pigeon holes of binary categorisation ordinarily used by Pakeha (Aspin & Hutchings, 2007). Aspin & Hutchings (2007) argue, for

⁶ "*Speaking up to*" and "*Speaking back to*" are expressions coined by Linda Tuhiwai-Smith (2012) to describe the power of indigenous methods to disrupt and destabilise the ontological and epistemological certainties of a colonising power/knowledge complex.

example, that as a consequence of the revitalisation of te reo Māori, Māori are coming to realise that they may always have been more gender fluid and are now claiming and using prior knowledge. New culturally coherent vocabularies of sexual identity are starting to emerge with some Māori preferring to use the term takatāpui to describe relationships beyond the hetero-normal. This term, known to pre-date colonisation, is being embraced by gay and lesbian Māori today as a more culturally appropriate sexual identity.

Of all of the stories in the “Mean As!” Library, it is perhaps not surprising, therefore, that Māori storyteller Tipa appears to describe his sexuality in the least bounded way. In the preface to *Ko te Pūrākau o Tipa*, Tipa tells us through his story gatherer that;

“nobody has the right to stop two people who care about each other from touching or having sex whether or not your partner was male or female, older or younger than yourself or had a disability or didn't. Tipa thought whaikaha (disabled) Māori should push against these [binaries] and that the best way to do that was by listening to people who wanted to be together.”

As far as we know, the pūrākau narrated by Tipa and the author of “I am a good man” are the first told by whaikaha (disabled) Māori with a learning disability. In the absence of other Māori voices, we know almost nothing about the way whaikaha Māori experiences of relationship and sexuality intersect with their experience of also being Māori.

To our knowledge, no mainstream sexuality, sexual health or sexual abuse services tailor support, education or social practice to the tirohanga au (world view) of whaikaha Māori either. Listening to stories like these may, therefore, provide a useful guide to health and disability providers interested in bending their own cultural practices in ways that respect and enhance the mana of whaikaha Māori.

Mean As!

Both Māori storytellers chose to work with Kairangahau Māori Researcher, Kelly Tikao (Waitaha / Kāti Māmoe / Kāi Tahu). In the discussions that passed between storyteller and story gatherer, the writing pairs decided that it would be a good idea to root or anchor (Pū) their story in the ancestral knowledge and cultural traditions that contributed to their chosen narrative form and the characters that branch out and flourish above ground, as story (rākau – tree) – Pūrākau.

Consistent with the activism expressed by revolutionary author Franz Fanon (2004) and the relational ethic of Kanohi kitea⁷, both Māori storytellers stepped into the role of narrator by imagining pūrākau as their gift to their (learning disabled) community. Both storytellers hoped the stories they were born into might fan the winds of a transformative and decolonising change for men and women, who like them, found themselves dislocated from the ordinary and normal right to intimate citizenship by the narratives of the powerful. Passing on their stories was, therefore, a responsibility both authors took seriously.

“Mean As!” is a uniquely New Zealand colloquial expression that means very cool. “Mean As!”⁸ was Tipa’s assessment of the power of his and other stories to generate change. It was the first expression he used to break the silence that trailed behind his hearing of his pūrākau spoken back to him the very first time.

⁷ Kanohi kitea translates to, the “seen face” that continues to present itself to people, face-to-face

⁸ The researchers with a learning disability also liked the way the expression “Mean As!” could also be used more literally to describe some of the less human ways people responded the ordinary ways they sought to understand and explore their sexuality.

The single “scientific” story of sex and learning disability

“Victims” and “Villans”

Sexuality is generally accepted as critical to the hauora (health) and ora (wellbeing) of all people. Sexuality is also elemental to people’s sense of who they are, whilst sensual pleasure not only adds meaning to our lives, it can also connect us to the world and to those we love or find ourselves attracted to (Liddiard, 2016; Tepper, 2000). Kirsty Liddiard (2016) argues, therefore, that sexuality and humanness are so tightly bound within culture that “socially sanctioned sex” represents a powerful cultural and political signifier, separating those human enough to access intimacy and pleasure from those who are conversely denied entry.

For people with a learning disability, being able to access the vocabularies of relational and physical intimacy may carry additional importance, protecting, as intimacy does, against the social isolation and estrangement of a cohort. Chistine Bigby (2008), Milner & Bray (2004) and Milner & Mirfin-Veitch, (2012), have all described as at risk of being “*known well by no-one*” (Bigby, 2008). Relational intimacy is also known to help people with a learning disability weather the assaults on their self-esteem that inevitably follow everyday moments of “*discrimination, abuse, intolerance or more subtle forms of personal exclusion or otherings*” (Milner & Kelly, 2009). And physical intimacy is similarly, a clear and unambiguous marker of a transition to adulthood for a cohort equivalently at risk of being infantilised, or of having their ability to exercise sexual agency gate-kept by someone else’s assessment of their “mental age.”

One of the consequences of falling two standard deviations from normal on the bell-shaped curve of “IQ” has been, however, that in relation to expressions of relational intimacy and sexuality, people

with a learning disability have been caught in patterns of “care and treatment” that, Meininger (2009) argues, have not permitted them to join the “*family of man*.”⁹

In the previous chapter, we noted Linda Tuhiwai-Smith’s (2012) observation that Māori continue to carry forward the memory of research offensive to their deepest sense of humanity.

At the turn of last century, people with a learning disability also found themselves dehumanised by the Victorian preoccupation for measuring the quantum of intelligence and a puritanical need to contain and police the sexuality of those the modernist tools of measurement, classification and treatment also positioned as the “*less civilised other*.”

More than a century ago, the New Zealand Government passed the Mental Defectives Act (1911). The purpose of the act was to greatly expand the reach of classification and the committal of people the State might then define as “socially defective.” Its passing represented a victory for the Eugenics Societies that had sprung up across New Zealand that were, at the time, using their political influence to promote the Eugenic Movement’s aim of “*protecting society from the great menace of feeble-mindedness*.”

Central to the eugenic argument was that “feeble-mindedness” was an inheritable characteristic responsible for a range of social ills and the breakdown of civic morality. According to the eugenic logic,

⁹ *The bell-shaped curve of IQ has been used to determine who ought to be steered towards a home for life in New Zealand institutions and those who were to take a seat on buses destined for one of the four killing hospitals in Nazi Germany. It is the same technology we use today to triage people into the research categories of “mild,” “moderate,” and “severe” learning disability as well as determine the quantum of people’s support funding.*

if superior people were desired, they must breed whilst imbeciles, criminals, paupers and others deemed “*palpably unfit*” must not.

Popular talk in recent years on the subject of heredity, at a time when the phases of opinion held by scientists have been under discussion and less dogmatic views are expressed by publicists, has left the man in the street wondering if there is anything in it after all. There being so many men in the street, it is well that they should be told that the leaders of all the schools are agreed that commonly the important factor which makes the difference when one individual does and another does not become insane under a like stress is a tendency which may be and commonly is transmitted by heredity. In this connection it may not be out of place to express a hope that the community will take full advantage of the Eugenics Education Societies which have been founded. The mating of individuals, as matters are, is thought to be the outcome of free choice; but to the right and left are artificial barriers which few overleap—such as social position and religion—and eyes are not turned from the path which leads to limited selection. With the spread of knowledge and higher ideals, it is not too much to hope that in time there will arise the eugenic barrier which will as naturally exclude from selection the palpably unfit.

Figure 3 Extract from the *Mental Hospitals of the Dominion Report*, ajhr, 1911; session I-H-07

Until the closing of the Kimberly Centre in October 2006 brought to an end the era of large scale congregate “care” of people with a learning disability, thousands of New Zealand men, women and children with a learning disability were physically dislocated from their families and their communities and exposed to violences that included; the enforced separation of male and female “patients,” unconsented sterilization, punishment for sexual behaviour, including the criminalising of “carnal knowledge” and a range of other human rights violations. To generations of men and women with a learning disability, these were the everyday realities of living in institutions like Mangere Hospital, the Levin Training Farm and Colony [later the Kimberley Centre], Stoke Villas at Nelson Mental Hospital, Templeton near Christchurch and Seacliff [later Cherry Farm] (Milner et al, 2008; Mirfin-Vetch & Conder, 2017).

In the chapter she wrote for *Deinstitutionalization and People with Intellectual Disabilities: In and Out of Institutions* (Johnson & Traistadóttir 2005), Jan Walmsley sought to identify the master-narrative that sat behind the campaigns for institutionalisation orchestrated by lobby groups like the New Zealand Eugenics Society. Walmsley (2005) identified “*protection from moral*

danger” as the central theme around which activism for creation of institutions mobilised. But it was a form of protectionism that she said, “*conveniently faced in two directions.*” On the one hand, campaigners argued for the need to protect people with a learning disability themselves from the abuses and exploitation of the poor house and the asylum and an otherwise uncaring community, but through which was threaded a more potent argument that society itself needed protecting from atypical or illiterate and the wanton or unnatural.

This narrative characterisation of people with a learning disability as “victims” and “villains” has continued to find uninterrupted expression in the libraries of learning disability scholarship, more than one hundred years after the emergence and then extinction of the first Eugenics societies.

When meta-narrative hardens into cliché.

In a paper he wrote about the potential of life-story to connect reader with writer, Herman Meininger (2010) cautioned that whilst meta-narratives, or larger stories give the kind of context and meaning that make the “reading” of stories possible, they can also have a much darker face. According to Meininger (2010), stories that “*harden into cliché,*” or become stereotypes into which all personal narratives might be straight-jacketed, can limit possibility and entrench inequality in the most harmful of ways for marginalised populations.

In a (post-modern) age in which the social sciences in particular have both, elevated the voice of the “outsider” and embraced the “narrative turn”, many researchers and academics have comfortably settled on an understanding of their own particular paradigms as more attuned to the voices of the disempowered. Whilst this might be a fair representation, the story-telling of the privileged and powerful has largely remained unexamined. A literature review conducted by Nathan Wilson et al (2010) represents a noteworthy exception.

Nathan Wilson (2010) and his colleagues were interested in looking at the orientation of research populating the libraries of learning disability scholarship that concerned itself with issues of gender. To determine whether gender-related differences existed in the nature of learning disability research, Wilson et al, (2010) conducted a content analysis of articles published in four major learning disability journals¹⁰ between 1996 – 2008 inclusive.

Ninety articles were included in their analysis, the content of which fell into four broad categories: Mental health, Sexual matters, Health & wellbeing, Crime & anti-social behaviour, Language & comprehension and Other.

What they found, was that sexual matters, crime and antisocial behaviour research dominated the academic discourse related to men and boys with a learning disability. Moreover, twelve of the thirteen papers that fell within the domain of sexual matters focussed specifically on problematised expressions of male sexuality, including boys and men's; "unacceptable or abusive sexual behaviours", "men who have sex in public places", "sterilization and how to suppress sexual drive", "homo-erotomania" and "educating men who have sex with other men."

Entirely absent within the literature were papers that explored:

- The very ordinary and/or positive attributes of masculinity for boys and men with a learning disability.
- How to support the equally ordinary aspirations to love and to touch or to be loved and to be touched.
- Positive gender identities beyond the hetero-normal.
- The geographies of male intimacy or belonging.
- And the experiences of men with a learning disability who love as fathers.

¹⁰ *Journal of Intellectual & Developmental Disability (JIDD), Journal of Intellectual Disability Research (JIDR), American Journal on Mental Retardation (AJMR), Journal of Applied Research in Intellectual Disabilities (JARID).*

Moreover, men's exposure to abuse, violence and exploitation fell beyond the spotlight of academic interest too.

Conversely, the primary focus of research related to girls or women with a learning disability addressed issues of health promotion or preventative health. Only two of the forty female gendered research articles reviewed addressed the sexuality of girls or women with a learning disability, both of which focussed on women as victims of male sexual abuse.

Entirely absent from the discourse were papers that explored:

- The sexual agency of girls and women with a learning disability.
- How to support the equally ordinary aspirations to love and to touch or to be loved and to be touched.
- Positive gender identities beyond the hetero-normal.
- The geographies of female intimacy or belonging.
- And the experiences of women with a learning disability who love as mothers.

Within the libraries of the academy, therefore, Nathan Wilson and his colleagues discovered that men with a learning disability were principally visible via a narrative of social pathology and women via their representation as atypically vulnerable. Exactly the same tropes of "villain" and "victim" that have always provided academics and other professionals with their point of entry into learning disabled lives.

The single story of presumed incompetence

For more than a century, academics and researchers, privileged by the power/knowledge complex, have been the pre-eminent voices – instructing others about the things that learning disability means and what therefore can and cannot be permitted.

In the absence of self-authored story telling, the narratives that swirl about the spaces and places that prefigure the lives of people with a learning disability have almost exclusively been written by those who

exercise power over them. This differential access to authorship (and therefore authority), has meant that institutions like universities and Ministries have tended to control the political, social and scientific discourses that sit below the surface of our cultural awareness, guiding in “*always and already*” ways how we feel compelled to read and respond to the sexual and relational lives of people with a learning disability.

In the preface to his book *Already doing It: Intellectual Disability and Sexual Agency*, author Michael Gill (2015) foregrounds Nigerian writer, Chimamanda Ngozi Adichie’s warning of the “*danger of a single story*” – before going on to illustrate how narratives we unconsciously assimilate shape the way we behave towards people with a learning disability. Michael Gill did this by telling a number of different stories, lifted from his own life. In one of the stories Michael described how he felt obliged to separate two female workmates by assigning them work roles at opposite ends of the workshop he worked in as a staff person. Staff at the Community Group Home where the two women lived had observed them holding hands and kissing in their bedrooms and had phoned the Vocational Centre to inform management that both they and members of the women’s family deemed the relationship to be inappropriate. Friends who ordinarily sat side by side found themselves exiled from each other’s affection. In a setting in which Michael felt staff were gifted an uncontested right to watch and intercede, he recalled having to keep a censorial eye on the two women. Thereafter monitoring for expressions of free will and interrupting moments of possible intimacy to extinguish the threat sexuality posed in the regulated space of a vocational workshop (Gill, 2015).

Gill’s (2015) purpose in sharing this and other life-stories was to make the point that disability is, in part, a cultural process in which the reading of and responding to people with a learning disability can be either marked or unmarked according to the scripts that shape the encounter.

In seeking to understand how he had assumed an almost unbridled authority to observe, redirect, discipline and define what was relationally or sexually appropriate, Michael turned to the scripts he had been orientated to in the Vocational Centre Workshop. He wrote that being instructed that learning disability meant certain things and not others over-wrote any motivation he had to understand or accommodate the diverse and divergent realities of people’s lives. And he turned to Chimamanda Ngozi Adichie who similarly observed that;

Power is the ability, not just to tell the story of another person, but to make it the definitive story of that person.”

To Michael Gill (2015), the largely uncontested assumption that underwrites the seemingly calcified assignation of people with a learning disability into the paradoxical social categories of “*asexual or oversexed and innocents or perverts*” (Brown, 1994), is the single, historically repeated story that they lack the capacity to make decisions about their sexual or reproductive lives without either harming themselves (as victims) or others (as villains). To Gill, (2015) the severing of people with a learning disability from: their families and communities, corporeal and intimate selves and the same kind of sexual and reproductive rights other citizens enjoy all represent expressions of an unquestioned policing of this, professionally authored assumption of incompetence.

“ Sexual activity [is] policed based on assumptions about, not only when and where one can be sexual, but who can be sexual. Efforts to extend sexuality based on assumptions of capacity will inevitably exclude those assumed to be incapable. Even if the individuals attempted to counteract our efforts, we hold on to our authority to act with quick and determined measures to de-sexualise individuals.”

(Gill, 2015; p.xv).

The problem isn't that people with a learning disability aren't sexual. Tom Shakespeare et al (1996, 2013), Rod Michalko (2002) and people with a learning disability themselves (Frawley & Wilson 2016, Wilson & Frawley, 2016) all tell us that, despite efforts to restrict or constrain their sexuality, people find ways to enter relationship and be sexual, even in the most regulatory of spaces. They are, to borrow Michael Gill's (2015) expression, *Already Doing It!*

To further make his point, Gill (2015) drew on Winifred Kempton & Emily Kahn's observation that the oppression of people with a learning disability, including civic and professional blindness to their sexual needs, punishment for sexual behaviour and enforced sterilisation all occur as a consequence of their sexuality, not the absence of sexual agency. Once diagnostically read as learning disabled, however, expressions of human sexuality tend to be interpreted as conforming to the pre-existing and paradoxical tropes of “*over-sexualised, promiscuous or predatory*”, on one hand, and “*vulnerable, thoughtless and naïve*”, on the other (Fish, 2016), affirming the application of tools and technologies that reinscribe the presumption of incompetence.

Such tools include, but are not limited to, therapeutic surveillance, the abuse of sexual and reproductive rights, including the high rates of children taken from learning disabled parents by child protection agencies like Oranga Tamariki¹¹, and what we tell, but perhaps more importantly, don't tell people with a learning disability about their sexual citizenship.

¹¹ Despite almost all of this project's Storytellers contemplating, being or continuing to imagine themselves as future parents, the brutal reality is that estimates suggest that 50% of New Zealand parents with a learning disability will have their children removed by a child protection agency (Conder et al, 2010, Mirfin-Veitch et al, 1991) almost all of whom lose their children in the absence of any evidence of abuse or neglect (Booth & Booth, 2003; McConnell & Sigurjónsdóttir, 2010).

Finding ways to tell, read and respond to self-crafted stories

Creating spaces for story telling (as a form of decolonisation)

One of the other stories Michael Gill told in the preface to *Already doing It: Intellectual Disability and Sexual Agency*, was how as a young boy, he was looked after by a much loved baby-sitter. A baby sitter who he would only discover as an adult, also had a learning disability.. When his parents were out, his much loved babysitter assumed the role of surrogate parent, feeding, bathing and disciplining Michael and his siblings. In this narrative, Michael described how he loved the way they played games, ate junkfood and held impromptu dance parties. And how he often wished his parents would go out on a date so she would come over.

In this, second story, learning disability almost entirely failed to code. When the roles of carer and being cared for were reversed, Michael simply failed to see learning disability. In the intimate space of his own home, disability disappeared and difference simply became a natural and ordinary expression of, what I as his reader, like to imagine as a reciprocated love that also passed between a babysitter and a much loved small boy.

One of the reasons for sharing these two diametrically different life-stories, Gill (2015) wrote, was to make the point that narratives are not necessarily fixed. He would conclude the preface to his book by describing how he is now haunted by some of the memories of the ways he acted towards the men and women in the workshop. But he also noted that those men and women played a critical role in destabilising the single (ableist) story of disability he is now committed to undermining. Gill (2015) told his readers, that the men

and women of the workshop accomplished this by pulling him into a deeper relationship with the complexities and contextuality of their own life stories.

Stories are but one expression of the landscapes within which they were formed. They are always politicised, always culturised and always socialised and as such, Dan Goodley reminds us, are almost always our best hope of “*capturing the structures that shape, divide and separate human beings*” (Goodley et al cited in Smith & Sparkes, 2008).

Stories also refute simplicity. They are unruly and refuse to be hemmed in by metanarrative and therefore, according to Susan Chase (2005, 2017), facilitate a healthy democratic, public life. By tending towards complexity, the more storytellers that take a seat at the table of humanity, the more inclined towards social justice a society becomes. In this sense, storytelling represents one of the more important engines of social change.

Testimonio

One narrative method that seeks to take a seat at the table by “speaking back” to oppression is the Latin American tradition of testimonio. In testimonio (sometimes called emergency narratives) the voice that speaks to the reader is always in the form of an “I” that stakes a claim on our attention (Chase, 2017). Profoundly political in orientation, testimonio are described as asking a reader to “bear witness,” like a jury member (Beverley, 2005; Chase, 2017) and as such demand a response, even if that response is not to act on that which can’t be ignored.

Staking a claim on the readers attention by speaking directly through the form of “I” is recognisable in all of the ways the Storytellers in the “Mean As!” Project chose to title their narratives.

- I wish we were current
- I’m a good man
- I’ve got this chance now
- Ko te Pūrākau o Tipa,
- Sometimes I write letters
- We don’t jump fences anymore
- Love yourself pretty much.’



Figure 4 The seven original “Mean As!” Library stories.

In New Zealand, however, the convention adopted by researchers seeking to gain ethical approval for their work is to define people with a learning disability as a vulnerable population. Because people with a learning disability are subsequently framed as potentially lacking the capacity to understand the full implications of sharing the stories they own, we are unable to identify the seven story tellers whose narratives populate this library. Their de-identified stories must do their talking for them.

Life-story is another research method that intentionally creates an opening for narratives to emerge that might misfit a colonist’s representation of the lived experiences of marginalised populations.

Life-story

As a research method, Life-stories share a common interest in biographical elements of a person’s life, as narrated by the person who lives them. By seeking to situate disabled voices and experiences within the library of “expert” stories Life-story (as a method) has, according to Shuttleworth (2010), the potential to destabilise professional and ableist discourses that continue to regulate disabled people’s lives and bodies.

As we noted previously, despite there being almost no shortage of stories written about the relational and sexual lives of people with a learning disability, very few have been written or told by people who carry the label of “learning disabled.”

One notable exception is the library of 25 stories of Australian men and women with a learning disability, collected and collated by Kelly Johnson, Lynn Hillier, Lyn Harrison and Patsie Frawley almost twenty years ago as part of the *Living Safer Sexual Lives* Project.

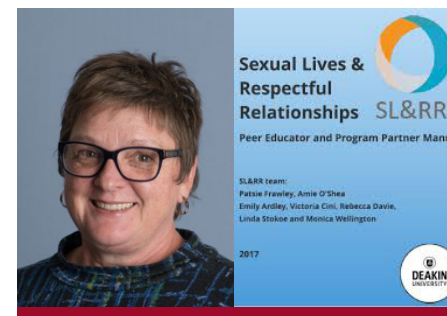


Figure 5 Patsie Frawley and the front cover of *Sexual Lives and Respectful Relationships Peer education and Program Partner Manual*

The body of work, *Living Safer Sexual Lives* was the first of its kind to use a Life-story approach to consider sexuality and relationships in the lives of people with learning disabilities as told by them. Researchers engaged with people with learning disabilities over a number of research encounters to shape their stories. The library

of 25 stories tell us that people with a learning disability are sexual, want intimacy and are capable of loving and being loved. They are straight, gay and bisexual, want, and can have children. However, they also tell of the surveillance of their sexual lives by families and carers, the unsafe sex they experience often as a direct result of this surveillance, the lack of access to education and information about sexual health and the prevalence of sexual abuse (Johnson, Hillier, Harrison & Frawley, 2001).

Importantly this body of work, uses the stories in practice and to engage people with learning disabilities in research as advisors and resource developers. The research also informed the development of *Sexual Lives and Respectful Relationships*, an Australian peer led programme co-ordinated by Patsie Frawley that uses the same library of stories as a framework for shared discussion about sexual and relationship rights. The program is run in collaboration with community based sexual health and sexual assault professionals and now engages more than 60 people with a learning disability as peer educators in 8 sites (SL&RR, 2019). Stemming from this work Amie O'Shea has led more research using the same Life story approach paired with an inclusive research design to collect the stories of people with Acquired Brain Injury (O'Shea, 2019), people with a learning disability who identify as LGBTIQ (O'Shea & Despot, 2018) and to tell 'gendered' stories of young women with a learning disability (O'Shea, 2016).

The *"Mean As!"* Project adds contemporary New Zealand stories to this increasingly transnational library by drawing on the academic tradition of Life story.

Creating spaces for indigenous / emic research methods (as a form of decolonisation)

In writing about what she described as disabled people's disqualification from forms of intimacy, Kirsty Liddiard (2016) wrote that, for disabled people, *pleasure* had been *colonised* and pathologised through the interventions of educational, medical

and social care professionals. Invoking the vocabularies of "colonisation" to describe disabled people's marginalisation from intimate citizenship, (aided by disabled people's misrepresentation within professional discourses that legitimise intervention) invites comparison with other populations whose narratives similarly mis-fit the single stories of the knowledge/power complex.

As we described previously¹², Māori, responded to the appropriation and repurposing of their stories by reclaiming the power to design the tools they need to make themselves culturally present within research. *"We don't need anyone else developing the tools which will help us come to terms with who we are,"* Māori researcher Katie Irwin (1994) wrote. *"We can and we will do that work. Real power"*, Irwin (1994) concluded, *"lies with those who design the tools. It always has."*

Inclusive Research Methods?

A small, but rapidly growing body of research is attempting to re-centre knowledge production by issuing a belated invitation to people with a learning disability to take a place at the research table as "knowers" (experts by lived experience), and as the "doers" (agents of social change in their own right) of disability-related research. For people with a learning disability, this invitation has come in the form of inclusive research methods. A reorientation that Quinetta Robertson (2006) and Melanie Nind (2014) describe as an attempt to redress the hermeneutical injustice of researchers failing to engage people with a learning disability within inquisitorial frameworks that speak to their own experiences (Milner & Frawley, 2018). Coined originally by Jan Walmsley and Kelly Johnson (2003), inclusive research was imagined as an umbrella term to describe research approaches that demonstrated a democratising turn towards including people with a learning disability as the *'initiators, doers, writers and disseminators'* of research about themselves.

¹² Described in *Is your spirit clear? Can you fix a generator* (p. 5-7)

(Bigby & Frawley, cited in Milner & Frawley, 2018). More succinctly, inclusive research is heralded as evidencing a more ethical orientation away from research “on” people with a learning disability towards researching “with” people with a learning disability (Walmsley and Johnson, 2003; Johnson, 2009).

In a paper they wrote examining the claims of Inclusive Research, Paul Milner and Patsie Frawley (2018) noted, however, that the rules to this new epistemological dance have almost entirely been choreographed from within the same knowledge-power complex that distanced people with a learning disability from research about themselves. Whilst not arguing that inclusive methods represent a more ethical orientation towards the subjectivities of people with a learning disability, Milner and Frawley (2018) suggested that this very “rightness” may have blinded researchers to the fact that the price of admission for people with a learning disability has been to acculturate to a pre-scripted paradigm. A paradigm within which both explicit and implicit rules and conventions underwrite the assimilative assumption that inclusive research is best realised when “imperfect,” social actors are trained, supported and educated to approximate members of the academy. In this sense, the very architecture of inclusive methods might be seen as carrying forward deeply embedded assumptions about the “otherness” of dis/abled in/competence. Milner and Frawley (2018) rhetorically mused, therefore, what inclusive research might look like if people with a learning disability had the same opportunity indigenous communities are now claiming, to place *themselves* at the centre of knowledge production. Emic research done “by” people with a learning disability, for people with a learning disability.

Rather than de-privileging or disempowering the professional researcher, Milner and Frawley (2017) worried that, as currently conceptualised, inclusive research might simply represent a subtle re-inscription of relational power that made the spatial invitation demanded of the praxis “*Nothing about us without us,*” but which

continued to appropriate disabled people’s experiences and theorising by continuing to position them as “other.”

In a project that sought to capture the narratives of people who had very few words in them, Paul Milner and Brigit Mirfin-Veitch (2012) would discover how much more there was to gain by entering a research encounter by relying on the storyteller to develop the tools they needed to tell us who they were (and where they belong).

Individually Responsive Methods

In 2011, a New Zealand disability support service¹³ commissioned the Donald Beasley Institute to conduct a research project to make transparent the day-to-day lives of people with high and complex support needs. Like the “*Mean As!*” Project, they chose to do this through the modality of storytelling. The aim of the project was to reach the missing voices of people with high and complex support needs. Men and women whose subjectivities are ordinarily thought to lie beyond the lexicon of traditional research methods and who as a consequence of their living on the fringes of representation, have had no chance to contest the many unauthorized representations they encounter as biographical truth (Milner & Mirfin-Veitch, 2012). As Milner and Frawley (2018) point out, this exclusion of those whose minds and bodies refuse easy accommodation has meant that, not only do the voices of those at greatest risk of experiencing human rights violations make no contribution the monitoring of disability rights, they have had no opportunity to contribute to the development of research methods that might end their silence either.

Faced with the challenge of co-creating narratives with people, the research team knew (to also borrow Tim and Wendy Booth’s expression), would need to “loan their own words”, the researchers responded by supporting each person to design their own, bespoke research presence by accepting, adapting or rejecting a range of different ways of having the “conversations” they wanted. For want

¹³ CCS Disability Action

of a way of describing the method, Milner and Mirfin-Veitch (2012) described the approach as; *Individually Responsive Methods*, and went on to describe how in thirteen separate journeys, dis/abled co-authors took their dis/abled writing partner to the outer, cutting edges of qualitative research methods and along lines of inquiry that, in Deleuzean speak, continually took unexpected and intuitive lines of flight (Milner & Frawley, 2018). Showing up being prepared to let people shape the way they were narratively visible meant that both the project method and the stories themselves could be characterised as being in a state of constant becoming.

But in the “*Mean As!*” Project, Tipa would gift us a much better way of describing the trajectory of this approach by introducing us to the Māori tradition of *Wayfinding*.

“Wayfinding” as a decolonising methodological framework

That “getting to places” is a strong theme in Māori pūrākau ought not to be a surprise. Many of the great leaders in the ancient cultures of Māori and Pacifica peoples were themselves “way-finders.” Leaders who guided others on journeys of great discovery across the Pacific.

In Ko te Pūrākau o Tipa, we learn that, unlike the Pakeha way of thinking of a journey involving a linear getting from origin to a destination, within mātauranga Māori (the body of knowledge originating from Māori ancestors) master navigators are able to hold the vision of a better place in their mind and pull it towards themselves by reading the signs of where they are and where they have come from (Hoturoa Barclay-Kerr, 2019). They will watch for the flight path of birds heading home, track stars across the heavens and feel for the currents that pass beneath the waka in the course of moving towards that which cannot be known. Great navigators also change course when the signs tell them they should no longer follow the path they are on. And they enculturate others to leadership by teaching them how to make use of the tools and technologies they have at their disposal.

Susan Chase (2017) reminds us that the very idea of story is that it “*can’t be known, predicted or prepared for in advance.*” It is, therefore, a destination best pulled into place by navigators who are free to decide what is story worthy and who can chart their own course towards it by reading the signs, adjusting course and by assembling and using tools of their own making.



Figure 6 A Mariners Compass Rose bisected by intercardinal winds and half winds

In this sense, narrative and methodological possibility are both almost limitless and the “Mean As!” Library is the product of a commitment by storytellers and story gatherers to leave open for exploration, all of the winds and half winds¹⁴ that lie between the cardinal orientations of conventional story telling. As a consequence, we think the New Zealand section of what is becoming a global library of stories is filling up with stories that are stitched together like an Indigenous tapestry, full of colour and surprise and vocabularies

and narrative forms that resonate within the community of learning disability, but which “*talk back to*” (Tuhiwai-Smith, 2012) the academy’s narrower understanding of what a story should look like.

The last word

“*Equity is not a goal to be attained* Jacques Rancière (1991) wrote *[it] must be seen as a point of departure and not as a destination.*”

His assertion, according to Ellen Myers (2016), rests on the presupposition that “equity” requires us to conduct ourselves as equals in the here and now. Equity, Rancière argues, can neither by

¹⁴ The Compas Rose is sometimes called a “Rose of the Winds”, with the points between the cardinal orientations of North, South, East and West known as half or quarter winds.

given nor claimed. It exists only through its verification. In practical experiments that assume equal intelligence and set out seeing what can be accomplished under that supposition. Failing to do so, Myers (2016) reasoned, simply reaffirms the inequities of the present.

Casting off without a clear fix on the destination, but rather seeing what might be accomplished under the presupposition of non-hierarchical intelligence quickly became the overarching kaupapa of the *“Mean As!” Project*.

As we will see in the following chapter, story gatherers presupposed storytellers had all the tools they required to write themselves into the *“Mean As!” Library*. *“I am not doing this! The story teller is!”* was the constant refrain of story gatherers, surprised and delighted by the creativity and sometimes brutal and beautiful honesty with which narrators approached their story writing.

In the end, the academic members of the research team were also yanked into the presupposition, by previously unseen and unheard theorists who, when given the opportunity, verified equality by surprising and delighting with the creativity and sometimes brutal and beautiful honesty with which they approached the task of story reading and theorising.

In defence of ignorance

In a book that can itself be read as the story of Joseph Jacotot, an exiled French school teacher who discovered a revolutionary teaching method that, for the briefest time, spread panic throughout the learned community of Europe, Jacques Rancière argued that there is no hierarchy to intelligences. It is an idea so radical that it completely undermines the logic of the bell-shaped curve of IQ used to legitimise all of the various abuses that have followed people with a learning disabilities expulsion from Meiner's (2010) family of man.

Rancière also intended the presumption of equal intelligence to be a direct challenge to what he called the explicative order. To Rancière, the very act of explaining, bifurcates people into those who know (and can therefore be invested with political authority), and unknowers (who therefore can't). In a way that turns inside out, Robert Edgerton's (1967) characterisation of people with a learning disability as seeking to draw about themselves the “cloak of competence”, Rancière asserts that it is the “explainer” and the academic instead, who seek to throw a *“veil of ignorance over everything that has to be learned [so that he can] appoint himself the task of lifting it”* (Rancière, 1991).

Within the privileged social spaces of our universities and other institutions that also understand themselves as centres of knowledge production, the roles of knower and knower are gate-kept by codes of practice that define who can say what counts as knowledge and how we come to know it. By drawing on Deleuze & Guattari's (1987) metaphor of the machine, Rancière argues that modern scholarship is geared towards embedding the presumption of incompetence and power relationships that prioritise the voices of those who control the levers of self-appointed authority. Research, (like intimate citizenship), might therefore also be considered to be an activity that polices the assumptions it carries about who can and can't be a researcher. It does this through codes, conventions and cultural practices that affirm the presumption of incapacity – a point we have attempted to make below by rewording Michael Gill's (2015) observation about the folly of seeking to extend sexual agency to those already presumed to be incapable.¹⁵

¹⁵ See *The single story of presumed incompetence* (p. 15)

“ Research Activity [is] policed based on assumptions about, not only when and where one can be a researcher, but who can be a researcher. Efforts to extend research activity based on assumptions of capacity will inevitably exclude those assumed to be incapable. Even if people with a learning disability attempted to counteract their efforts, the academy will hold on to its authority to act with quick and determined measures to de-legitimise the methods and theorizing of those who carry the label “leaning disabled.”

(With apologies to Gill, 2015; p.xv).

To Rancière, however, the central motif about which moments of emancipatory social action have always coalesced is the democratising idea that, “*yes we already can.*” A self-declaratory resistance to voicelessness that, according to Myers (2016), asserts its will based on the antithetical presumption of equal capacity.

As we noted previously, by acting on the presumption of equivalent intelligence, indigenous researchers are now disrupting the machinery of the academy by introducing new ways of knowing and alternative vocabularies that make sense to previously unheard and unseen indigenous communities. In so doing, they are redefining, not only when and where one can be a researcher, but who can be a researcher too.

When the team of academic researchers first conceptualised the “*Mean As!*” Project, we had always imagined that researchers with a learning disability would make a contribution to the reading and interpretation of the library of stories as, in a commonly evoked phrase, “*experts by lived experience.*” But, as is the habit of colonisers, we also reserved for ourselves the right to appropriate, repolish and repurpose their ideas, when it came time to report and disseminate.

To Rancière (1991), this kind of divide between the knower and unknower is, not just a pedagogical parable, but a myth that stultifies the very social change it pretends to remedy by tethering the unknowners emancipation to the knowers superior understanding of her or his oppression. “Incapacity”, forever stalls at “imperfection,” leaving the exclusionary habits of the power/knowledge complex largely untroubled and untouched.

At the heart of the parable of Joseph Jacotot is what Rancière describes as the art of distance. “The more [the explicator] knows”, Rancière writes, “*the more evident to him is the distance between his knowledge and the ignorance of the ignorant ones*” (Rancière cited in Anwarrudin, 2015).

In the “*Mean As!*” Project, we were forced to rub up against this very friction of paradigmatically created distance within our repeated (research) encounters with four researchers with a learning disability. These individuals¹⁶ steered academic members of the research team towards an understanding that they needed to “unlearn” some of the habits of qualitative research. In his defence of Rancière’s emphasis upon the importance of approaching others “unknowingly”, Karl Lewis wrote that the “*ignorant citizen and ignorant [researcher] share the same fundamental relation to democracy in that they both exhibit an ethic of trust, and a poetic sensitivity,*” each to the other (Lewis cited in Anwarrudin, 2015). A democratic passion recognisable by curiosity and an openness to others storytelling and reading.

Yielding to a state of “unknowing” allowed us to listen to the theorising of people with a learning disability that stood without need for explication or appropriation. This moment marked a moment of pivotal change in the trajectory of the “*Mean As!*” Project. For the non-disabled members of the research team, the clarity and reach

¹⁶ William Luskie, Vanessa Murphy, Darryl White & Cheryl Wallace

of their thinking demanded an answer to the question, “*who should have the last word,*” and in an intuitive and unplanned (Wayfinding) way, we made the decision not to leave our handprint on the theorising included in the project final report.

In the chapters that follow, we present extracts from seven stories told and seven stories read by people with a learning disability speaking to their own community, in their own tongue. Each story sits in the “*Mean As!*” Library of stories alongside the theorising and reflections of four researchers with a learning disability who engaged with their narratives¹⁷ within the kaupapa of “unknowing.”

But before discussing this, we wanted to share how each story was gathered and read.

¹⁷ See: Luskie, W., Murphy, V., White, D. & Wallace, C. (2019). “*Mean As!*”: People with a learning disability telling and reading their own stories of relationship and sexuality. Dunedin. Donald Beasley Institute.

Gathering a library of stories

The Storytellers

Stories, Susan Chase (2005) tells us, matter deeply to the person telling them. Although we can assume this was undoubtedly true for the eight Storytellers with a learning disability who gifted us their narratives, we are not permitted to identify them. Against the backdrop of people with a learning disability's call to be visible within research about themselves (Milner & Mirfin-Veitch, 2012) and the preference most express to be recognisably present in Life-history when given the choice (Manning, 2009), the Storytellers in the "Mean As!" Project were unable to populate their own narrative.

Following a project in which former residents of Victoria's Kew Cottages contributed to an oral history of life inside of that institution, Corrine Manning (2009) equated the practice of habitually anonymising the story telling of people with a learning disability with the habit of stripping people of their identity in asylums, first observed and described by Erving Goffmann (1961) in the 1960s. She also noted that failing to locate the voice of the narrator also denied people the opportunity to foreground their experiences or highlight the centrality of their role in shaping the history of a place. In the "Mean As!" Project, we were required to similarly strip Storytellers of their identity, leaving seven, de-identified stories to speak on their behalf.



Figure 7 The front covers of the seven de-identified stories that populate the 'Mean As!' Library

Finding Kaihoutu¹⁸

Two mainstream and one Kaupapa Māori disability support services provided the conduit to the eight Storytellers who eventually chose to participate in the "Mean As!" Project. A person within each service took responsibility for distributing the Project Information Sheet and Participant Interest Forms. They also provided a trusted point of contact for those thinking about whether to add their story to the library.

Potential Storytellers were eligible for the project if (in addition to being learning disabled)

- They were over 18 years of age.
- They were able to share ideas, thoughts and had the expressive and receptive language to narrate a Life-story that had relationship and sexuality as a primary focus.
- They were able to provide informed consent.

Consistent with Article 12 of the UN Convention on the Rights of Person's with Disability (UNCRPD), as well as guidance provided by the New Zealand Health and Disability Ethics Committee, potential story tellers were assumed to have the same legal right to choose whether to participate in the study as other New Zealand citizens.

In the research protocol, however, we sought to balance each Storyteller's right to give informed consent "free of unwarranted assumptions about their lack of competence" (HDEC, 2018) and their right to protection from undue risk and exploitation, by framing the procurement of informed consent as a continuous and ongoing process.

¹⁸ The kaihoutu is the person at the stern of a waka calling out the time to the paddlers. It was used by Tīpa in *Ko te Pūrākau o Tīpa* as an alegorical device for suggesting to his readers that it was possible for them to determine the orientation of their life.

As a first step, suitably qualified “Service Navigators” (Localities) were orientated to the Project, its aims and ethical framework - guided by an Eligibility Checklist. The Eligibility Checklist contained space for the provider to confirm that a person had the capacity to provide informed consent, as well as detail any support they might require to do so (for example, reduced language complexity, easy read materials, pictures to augment understanding), and any barriers that might impinge on the story gathering process. Service Navigators subsequently meet with potential storytellers, *kanohi ki te kanohi* (face-to-face), with the aim of supporting each potential Storyteller to learn more about the project using the Participant Information Sheet to aide discussion. The Participant Information Sheet provided a comprehensive guide to the project and its research aims and had been co-designed by people with a learning disability on the Project Research Group and by the National Self Advocacy Disabled Person’s Organisation, *Ngā Tāngata Tuatahi - People First*.

People who signaled an interest completed the Participant Interest Form, which was forwarded to the project lead, along with the completed Eligibility Checklist. Storytellers could also contact the project lead independent of the service by drawing on their own support network or trusted advisors if they wanted to keep their participation confidential.

As is described in more detail below, Storytellers chose a story gatherer to help them to assemble their narrative. The next step in the process involved the Storyteller organising a meeting between themselves and their own story gatherers to explain the project in more detail. At that meeting, a detailed plain language/Easy Read Consent Form, co-designed by people with a learning disability on the Project Research Group and by National Self Advocacy Disabled Person’s Organisation, *Ngā Tāngata Tuatahi - People First*, was used as a more formal way of fulfilling the obligation of acquiring informed consent. This process was used by experienced researchers to build a picture of each potential Storyteller’s ability to understand; what the

project was about, what the project meant for them and whether they were able to weigh up the costs and benefits of their participation. By drawing on the information provided in the Eligibility Checklist, this process was individualised for every potential Storyteller. All potential Storytellers were provided with an open invitation to take all the time they needed to decide whether they wanted to take part and were provided with additional information about who they might like to talk to help them make their decision.

Once the story gathering process began, story gatherers continued to monitor Storytellers level of comfort and understanding of the project, with additional opportunities to ensure continuing consent afforded by;

- The adoption of an Individually Responsive Research (later Wayfaring) method that folded about the stories each Storyteller wanted to tell and the tools they wanted to use to make themselves visible within the project.
- This process was augmented by peer support following each story gathering encounter. The three psychologists, a mental health nurse and disability researchers, (each with in excess of 15-years research experience) who acted as story gatherers assisted each other by providing ongoing supervision, support and reflective feedback related to any ethical issues that emerged during the gathering of library stories.
- A two-staged consent process that required storytellers to also consent to the final draft of their anonymised Life-story as being completed to their satisfaction and available for inclusion within the online library. Before signing off their narrative, Storytellers were able to listen to a spoken version of their *pūrākau* / story, read by an actor. Being able to listen to their narrative meant that differences in literacy weren’t exposed. Storyteller and story gatherer listened together, as equals.

Selecting the right “crew”

With the exception of testimonio, narrative research almost always involves someone stepping into an “other’s” private spaces and personal experiences. When the purpose of the intrusion is to learn more about the relational and sexual lives of those who carry the ascribed identities of, “asexual or oversexed and innocents or perverts” (Brown, 1994), the need to think and step carefully into relationship becomes all the more obvious. We also (correctly) anticipated being met by stories that included the kinds of abuses that inevitably follow any and all of these disability tropes, making it especially important that Storytellers stepped into the story-writing partnership with the clear understanding that it was our intention to create encounters that they could shape and control.

In the “*Mean As!*” Project, Storytellers could choose one of five very different story gathers, whose role it was to help them to realise the story they wanted to tell, in the form they wanted to tell it in. Potential Storytellers did this by viewing short video vignettes, accessible to them via YouTube, in which story gathers introduced themselves and their path to the project, all-the-while leaving a trail of cues about their age and sex and ethnicity, gender identity and sexual orientation that might be useful to those thinking about developing a writing partnership.

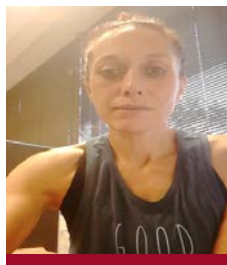


Figure 8
Kairangahau Māori
Researcher and
story gatherer Kelly
Tikau introducing
herself to potential
Storytellers via a
Youtube vignette

In this screen-shot, Kelly is introducing herself, through pepeha, before going on to explain she is māmā to five beautiful but full on tamariki as-well-as how she sees her role as a Kairangahau Māori Researcher.

In so doing, Kelly covertly codes, her knowledge of tikanga Māori including her sensitivity to kawa, comfort with the many vocabularies of te reo Māori and her heterosexuality.

The script Kelly used to introduce herself is included below as an example of the way story gatherers introduced themselves. Each introduction was, given the paths story gathers had taken to the collaboration widely different in ways that also evidenced something of the heterogeneity we expected to find within the pool of potential Storytellers.¹⁹

Aoraki matatu te iti a kai titi a manawa
No Te Wai Pounamu ahau
Ko Waitaha kati mamou Kai Tahu oku i
Ko katioku hapu
Ko Kelly Waiana Tikau toku ingoa

I’m a Maori researcher at the Donald Beasley Institute and I actually love, and I really mean that, love working for the Institute on many projects and with the wonderful staff there.

I’m a Registered Senior Nurse and I’ve been a PHD student forever but I hope to finish that very soon. Most importantly, one of the hardest jobs in my life is being a Mum or a Hakuia to five stunning yet full on tamariki, and I mean full on.

I live in Christchurch but I have been living in Dunedin. I was living in Dunedin for the last 13 years. I made the move to live closer to my marae here, on the Banks Peninsula and experience life around the whanau whanau. My colleagues, Paul and Brigit, recently rang me up – well probably a few months ago now, and asked if I would like to be involved in this project called In my Own Words and I jumped at the opportunity.

I would be honoured to support you, or someone you know, to have a voice on this important kaupapa about relationships and sexuality. Stories or narratives, to me, are creative mediums to allow you or someone you know to share their experiences. My role, I see, is to listen and help you or someone you know record these stories in a way that best expresses yours, or their, words and thoughts. I’m really really looking forward to working with you or someone you know on this project of enlightenment and knowledge sharing with respect and integrity.

Kia ora.

Figure 9 The script used by Kelly to introduce herself to potential Storytellers

¹⁹ At the inception of the project, it’s working title was “In my own words.” During the course of the project “Firstport” adopted the title for a portal it uses to collect self-submitted disability stories.

The diverse group of story gatherers that were chosen intentionally acknowledged that writing partnerships themselves are an entanglement of identity, embodiment and subjectivity (Liddiard, 2002). Providing people with an opportunity to control some of the invisible encroachments of “whiteness,” or “age difference” or “gender” or “hetero-normality,” meant that narrators could begin their journey to story by also selecting who they brought with them. Narrator’s chose their story gatherers wisely.



Figure 10 Screenshots of the five story gatherers introducing themselves to potential Storytellers

A point of departure, not a destination

Stories are not found, according to Langellier (cited in Holman-Jones, 2005), they are made. Just as a clay pot bears the blind impress of the wheel and the potters hand, stories are artefacts too, in so far as they carry and reflect the instruments that spun them into creation.

The “*Mean As!*” Project had two research strands, each with their own complementary research methods.

In the first strand, a Life-story approach was employed to achieve the aim of developing a library of self-authored stories that recalled and retold the experiences and understanding Storytellers had of their relational and sexual lives. In replicating Johnson et al’s (2001) original design, the project situated the library’s seven New Zealand narratives within a much broader tradition of resistance stories used to contest people’s marginalised status and/or the denial of

human rights (Chase 2017), here in relation to the denial of intimate citizenship.

Consistent with an Individually Responsive Method (Milner & Mirfin-Veitch, 2012; Milner & Frawley 2017), eight Storytellers were orientated to a range of different research methods by the researcher / story gatherer they chose as their writing partner during the first research encounter. The six methodological approaches included in the Information Sheet for discussion were:

- **“Just sitting and talking.”** Talking together within a loose framework of conversational themes co-designed by the Project Research Group and guided by the Storyteller.
- **“Walking and talking.”** Storytellers orientating their writing partner to their life by taking them to places that were important and telling them why as they each got in step with each other.
- **“Sharing things that say who you are.”** Storytellers selecting and sharing personal archives like photos, film, music or text that helped them to talk about their relationships.
- **“Finding creative ways to tell a story.”** Using art or poetry as a modality for thinking and talking about relationships.
- **“Relationship mapping.”** Graphically representing Storyteller’s network of interpersonal relationships and discussing their personal meaning.

Both storytellers who self-identified as Māori chose Kairangahau Māori researcher Kelly Tikao and, in so doing, were also given an opportunity to:

- **Explore Māori imagery and mythical stories** as culturally referenced ways of relating significant life events or communicating their feelings.

Research evidence suggests that the six methodological approaches are effective as ways to support people with a learning disability recall, reflect and discuss life events (Milner & Mirfin-Veitch, 2012). Aligned both with Individually Responsive Methods

and with Rancière's (1991) imagining of equity, this panoply of more conventional research methods was intended, however, to be a point of departure rather than a destination. A starting point to conversations that made room for Storytellers to determine how they were present that began with a clear understanding that they were free to adopt, adapt, reject or introduce their own ways of co-creating narrative. In this way, Storytellers were able to bring their own tools to the story writing encounter.

Makers of quilts. Weavers of stories

In his book *The Savage Mind*, French anthropologist Claude Lévi-Straus (1966) coined the phrase *bricoleur*. It is a French word used to describe craftsmen who would roam the countryside using odds and ends and materials at hand to perform fix it work (Patton, 2002). A jack of all trades or professional do it yourself person that sits well with New Zealanders' sense of themselves of being able to accomplish much with a roll of number eight wire and tools that might lie close at hand.

More latterly Denzin & Lincoln (2005) adopted the word, by describing themselves as qualitative *bricoleurs*. Professional “*makers of quilt(s)*” and “*weavers of stories*” hewn together by combining odds and ends and fragments of narrative, to create something new and unanticipated. A bricolage, therefore, carries the blind impress of a bricoleur's method. A method that, according to Weinstein & Weinstein, (cited in Yardley, 2008) is an “*emergent construction that reconfigures itself, adding new methodological tools, new forms of representation and interpretation, in response to the unpredictable and unforeseen needs of an ever-changing research environment*” (Yardley, 2008).

In the “*Mean As!*” project, story gatherers were required to step into the private spaces and personal experiences of Storyteller's lives without the comfort of a fixed method. They were, in this sense, also obliged to enter the creative possibilities of being all at sea with an “other”, feeling for the currents of story and scanning the horizon for tools with which to co-create a narrative *bricolage*.

Despite many narratives traversing some of the same experiential terrain, no two stories in the library are alike. They are wildly different in form and content as a consequence of each narrative Kaihoutu (person in charge of the all of the paddlers on the boat), steering very different courses, with equally different, but bespoke narrative tools. Perhaps, though, it is easiest to illustrate the different paths to story each Storyteller took by comparing the narrative trajectories of just two different *bricoleurs*.

We don't jump fences any more



Jess and David wrote *We don't jump fences anymore*. Theirs is a love story, realised against the backdrop of two warring houses, determined to keep them apart.

The very first decision Jess and David made was to tell their story as a couple. “*We do almost everything together. It's how we are*” they begin their story, before adding “*so we want to tell our story – together. That way it will be right.*” What follows is a polyphonic narrative in which we come to understand Jess and David's love for each other in a story that qualifies, over-talks, challenges itself and speaks to relationship by being in relationship with itself. In doing so, Jess and David also push back against the researcher's habit of thinking of story as belonging to an individual by answering with the kind of dis/autonomy, dis/independence and dis/tributed voice that Dan Goodley and Catherine Runswick-Cole say, are available to us all when we cross to the other side of the dis/human binary (Goodley & Runswick-Cole, 2016).

As Jess and David sat down with their story gatherer to think about what they might want their story to say, Jess asked David to retrieve a folder that she had intentionally kept aside. It was a blue clear-file folder that David had made for Jess that archived Jess's increasing confidence to perform at the Country and Western club they both belonged to. The folder held the lyrics and guitar chords to songs Jess had previously sung there. Jess was interested in one song in particular. She had written it for David when they lived in different community group homes. At that time, David was forbidden from seeing or speaking to Jess and staff vigilantly policed their estrangement. "It was the first song I ever wrote," Jess tells us in their story.

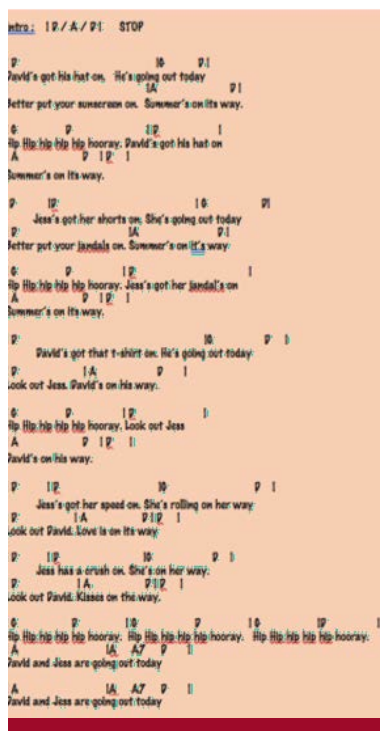


Figure 11 David's got his hat on: Lyrics, Jess Kittay; Tune Noel Gay & Ralph Butler (1932)

In the conversation that followed Jess learnt that her story gatherer could play the guitar and she asked if he could take the sheet music home so they could begin to write by singing the first song she every wrote.

As the story gathering process evolved, David's got it's hat on became the framework about which Jess and David chose to hang their story. A story in which the musical form of Introduction, Exposition and Coda were used to place Jess's singing out, above the heads of the Country and Western Club members, past the staff who she knew would stop David approaching her, onwards towards the man she loved - front-of-stage in their narrative.

In the weeks that followed, the invitation to sing together was extended to an invitation to meet Jess and David's friends at the Country and Western club. It was their way of making sure the story gatherer was in step-step-turn and slide with their lives, including also becoming situated within the landscapes and relationships within which their story was also collectively inscribed and remembered. And finally, Jess and David chose to bring the story gathering process to a close with a guided tour of the clandestine routes each took beyond the surveillance of professionals, just to be together. Sitting in the same places that they had sat and cemented a relationship forged by their shared determination to live less service authored lives lead to other stories. Like the way David's horse had followed Jess home one day after a thwarted effort to break out of her community group home to be with David. "He's a bit like you Love" David told Jess. "He was never one for being fenced in. We are both fence jumpers I guess."

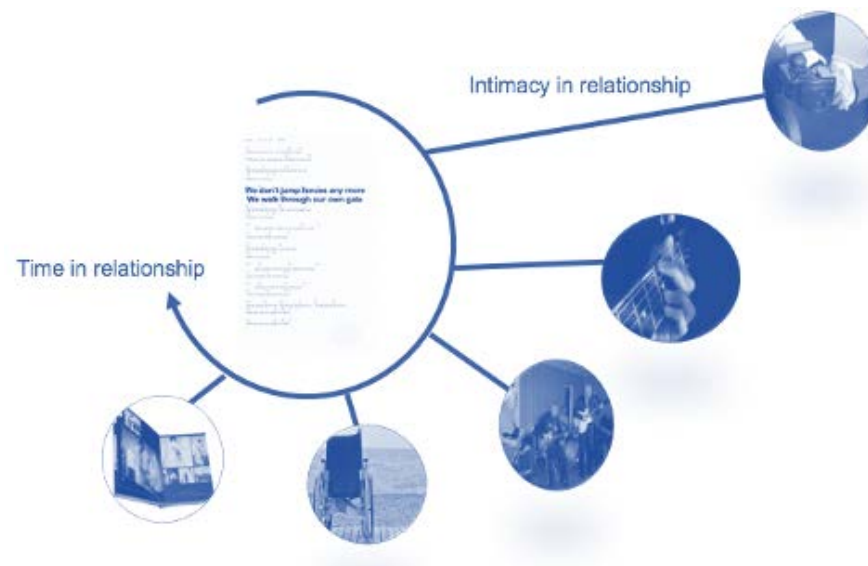
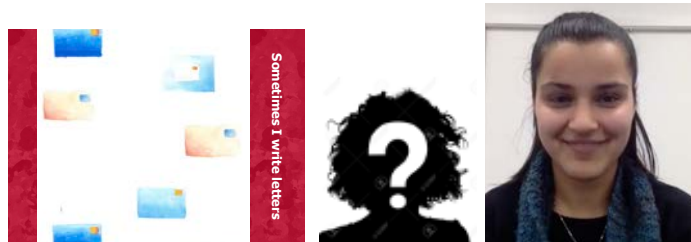


Figure 12 The methodological and relational trajectory of the story gathering process developed by Jess and David

Sometimes I write letters



The trail of encounters that eventually led to the story “*Sometimes I write letters*” began the way most did - at a meeting organised by the Storyteller. Although this time the storyteller requested that the meeting take place in secret. She was determined to tell her story, but was aware her service provider and her mum worried that its retelling may come at the cost of her mental health. The opposite would happen, perhaps as a consequence of the Storyteller’s determination to take control of the development of her own narrative, in much the same way that she had come to take control over her own recovery.

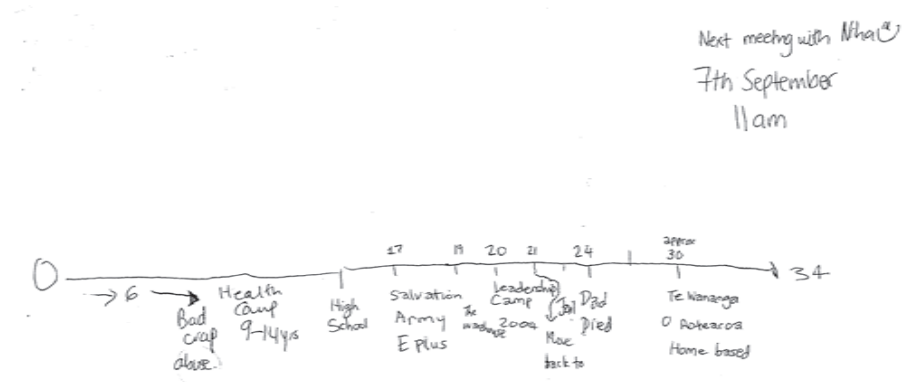


Figure 13 The topography of a changing timeline

On first meeting, the Storyteller and story gatherer took a linear approach to their bricolage, by walking forwards in time and identifying life events that might act to anchor as well as shape the

direction of a story that wanted to tell. During the conversation the Storyteller took the pad the story gatherer was using to take notes and drew her own timeline, bookended by “Bad crap” explicatively underscored by “abuse” at one end and Te Awanga o Aotearoa - Home-based, triumphantly inscribed at the other pole. As the weeks passed, the Storyteller added to the timeline, gradually constructing a more detailed topography of events that mapped the relief of her ongoing and always recovery from sexual abuse.

Between meetings, texts began to flow, each heralding new directions the Storyteller thought she might take her story, all-the-while laying down new horizons of meaning that deepened both story and emergent relationship. As her confidence grew, the Storyteller took to writing passages at home. She would bring them to the next meeting for the writing pair to discuss and work over. A pattern of ferrying passages from her past that ultimately led her to bring a hand-full of letters she kept in a box. Letters she had originally written to her rapist in her struggle to make sense of a life, she felt he had taken from her.



Figure 14 Cover illustrations commissioned by the Storyteller of *Sometimes I write letters* (Artist; Lucia Veitch)

The box of letters changed the story and its intended audience. In a Wayfinding way, the story reoriented, to talk more directly to women with a learning disability whose lives had also been fractured by the outrage of sexual abuse.

“Dear Reader,” the letter / story begins. “First of all, I want you to know that my story talks about hard things, but they are things it is important to say.”

And in reaching the unplanned destination of letter writing as a narrative form, the Storyteller also connected with the redemptive power of storytelling and the kindness and generosity of a narrative voice that was intrinsically and authentically hers.

“When I feel sad or get reminded about my abusers”, she concludes, “I also try and write letters. It helps me let everything out. It might help you too.”

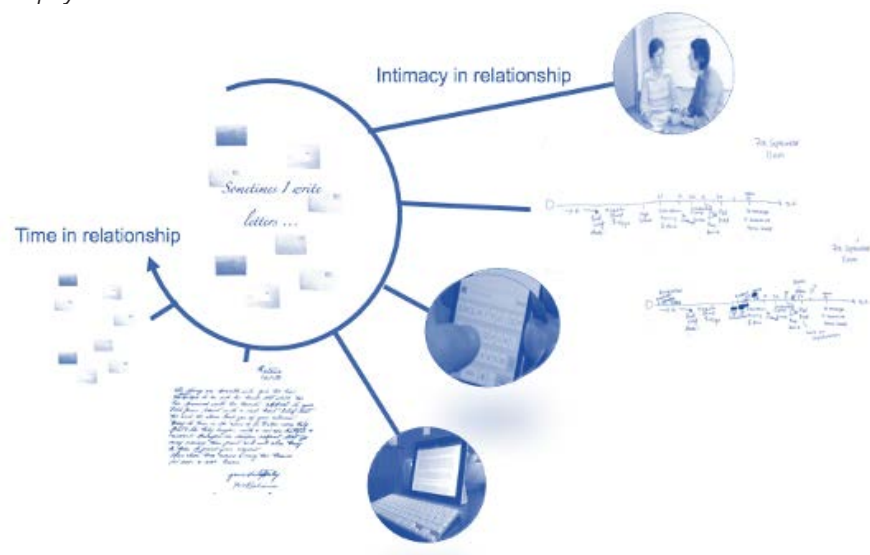


Figure 15 The methodological and relational trajectory of the story gathering process developed by the Storyteller of Sometimes I write letters

The freedom to be present with

In “We don’t jump fences anymore” and “Sometimes I write letters,” what the Storyteller has to say, and the way they go about saying it are, in their very different ways, inextricably interlaced. Both are bricolages that stitch together an author and an Individually Responsive narrative form in ways that would be weakened by their unbraiding.

Creating a space open to the creative possibilities of bricolage liberated other narratives in self-declarative ways too. We would, for example, see it in the poetic assemblage of phrases repeated, and yet changed like pool-balls rolled across felt by the author of “I am a good man”, as he crafted a narrative bifurcated by the loss of a lover. And we hear too it the chant, “Toi ate waka hi ha, he ha, Toi ate

waka hi ha”, and Tipa’s choice of pūrākau as both narrative form and a way of connecting with the languages of love his poua had gifted him in long remembered stories.

In this respect, we concur with John Beverley (2005) who argued that, sometimes (subaltern) stories can’t be captured or adequately represented within the institutional constellation of the power/knowledge complex. Institutionally conceived story telling simply creates and sustains the marginality of people betrayed by dominant forms of representation.

We also think the reclamation of storytelling by the authors who populate the “Mean As! Library” ask an important epistemological question too. Namely, under what conditions might we invite people with a learning disability to tell and to listen to stories whose power is derived from their authenticity. Herman Meining (2010) writes that the act of telling and connecting through story can itself create a new moral space. “Other” spaces within which strangeness is faced up to without yielding to the yoke of metanarrative. This desire to discover and to be discovered, Meining (2010) argued, can transform thinking and acting in ways that pull reader and writer into more intimate encounter. “Other” equitable social spaces within which, Milner and Frawley (2018) suggest might permit those who tell and read stories to experience a more elemental freedom to be present with.

And if you look at the trajectory of all of methods Storytellers invited story gatherers into as modes of discovery, they all chart a journey into more intimate and trusting ways of being and becoming together. Talking became singing, timelines became texts and meetings in meeting rooms turned into a search to find a gay artist and a community his own.



Figure 16 The methodological and ethical trajectory of all story gathering encounters

In separate journeys that began with a fixed or known origin, eight storytellers and five story gatherers who met each other presuming competence, called a new destination towards themselves in ways that also resonate with;

- The kaupapa of kuia, sitting on their marae, keeping a watchful eye on the affairs of people,
- And the theorising of four researchers with a learning disability who, in unpacking *“Sometimes I write letters”* instructed those who are required to step into their relational and sexual lives that the way to do it is inside of *“strong, trustworthy, intimate, patient, loving and caring relationship.”*

In the second strand to the project, four researchers with a learning disability engaged with the narratives as listeners and meaning-makers. In the chapter that follows, we describe the processes of story reading and theorising.

Reading and interpreting a library of stories

The co-production process

“A Narrative”, Susan Chase (2017) reminds us “*is a joint production of narrator and listener*”. Moreover, qualitative researchers also transform themselves into story tellers in the processes of first interpreting and then find ways to broadcast what they have seen and heard (Denzin & Lincoln, 2000). No two stories are, therefore, ever alike. They are changed by the processes of co-production, even when the words remain the same. Similarly, no researcher / transformed Storyteller can ever remain the same, even when applying themselves to the same task. We are all changed by what we see and hear.

In a second (and unplanned) strand to the project, the seven narratives that populate the “*Mean As!*” Library were met by the theorising of four researchers with a learning disability. William Luskie, Vanessa Jane Murphy, Darryl White and Cheryl Wallace all arrived as project researchers from different places and with very different motivations for contributing to the “*Mean As!*” Project.

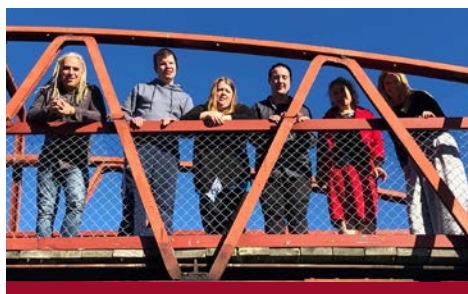


Figure 17 The “*Mean As!*” Research Team

In the Project Report they ultimately wrote²⁰, William, Vanessa, Darryl and Cheryl each profile themselves and their unconventional paths to disability research. Although we did not know it at the beginning of the project, by project close, theirs would become

the most important research voices. They changed the project, how we thought about respond to what we heard and, like us, William, Vanessa, Darryl and Cheryl would also find themselves changed by the process of reading and interpreting stories drawn from their own community.

Who should have the last word?

In the original project plan, William, Vanessa, Darryl and Cheryl were to sit amongst a constellation of community “experts (also) by experience”²¹ to lend their voices to the reading and interpretation of the emerging library of stories. Mindful of the possibility that what William, Vanessa, Darryl and Cheryl had to say might get lost in the sea of professional voices, two members of the academic research team were to introduce each narrative to the learning-disabled research team prior to bringing the larger group together. We were also interested in exploiting the opportunity the project afforded for people with a learning disability to guide professionals towards more appropriate ways to respond to stories Meetings were organised so that William, Vanessa, Darryl and Cheryl had the chance to hear discuss each story, including what they thought might help the narrators realise the aspirations they thought might lie between the lines or each narrative.

At the beginning of the project, we also set off with an ableist assumption that what we were creating was a written library. In short time, however, the Working Group, insisted we turn listening (to

²⁰ See: Luskie, W., Murphy, V., White, D. & Wallace, C. Milner, P., Mirfin-Veitch, B. Tikao, K., & Frawley, P. (2019). “*Mean As!*” People with a learning disability telling and reading stories of relationships and sexuality. Dunedin. Donald Beasley Institute.

²¹ The original project working group included community leaders in the fields of; sexual health and education, violence prevention, disability support as well as a Kairangahau Māori Researcher [Waitaha/Kāti Māmoe,/Kāi Tahu/] and whaikaha Māori leader [Ngati Porou].

spoken stories played over a Bluetooth speaker) as a much more egalitarian modality for people with a learning disability to enter and discuss Life-stories.

Storytellers, stripped of their right to be recognisably present in their own testimonio could hear themselves in the voices of others and know they were present in their own story via the echo of their own idiosyncratic turns of phrase. Listening also dissolved power differences between those who might otherwise have depended on an academic researcher to turn writing into a legible stream of consciousness.

And within the Working Group, researchers all bowed their heads to listen. Moreover, hearing the cadences of someone talking directly to you, breathed life and vitality into lifeless pages. We had forgotten, until reminded by the researchers with a learning disability, that listening and talking to stories spoke to the first languages of the self-advocacy movement. “[*Telling and listening to stories*] is what we do at *People First*,” they told us.

As the stories rolled off a slow production line, the researchers with a learning disability would meet. After catch ups and coffees the research meeting typically got down to business by one of the academic team reading back notes transcribed from the discussions that swirled about the story they had listened to the week(s) before. Hearing the story afresh and listening to their previous “readings” inevitably generated new ideas or qualifications that researchers had been mulling over in the weeks between stories. And then it was on to the next story.

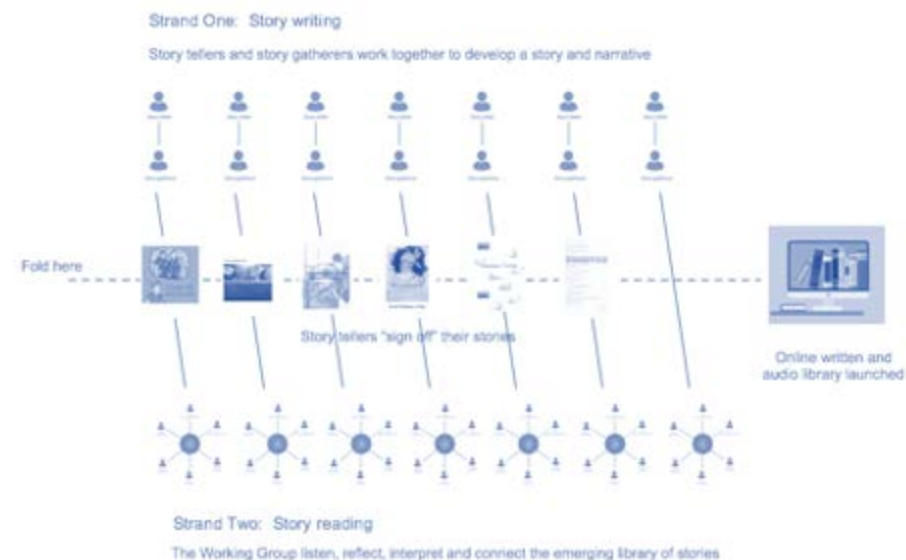


Figure 18 The two strands to the “Mean As!” Project

As co-producers of narrative, William, Vanessa, Darryl and Cheryl brought something very different. By arriving without the entanglements of previous research, their inclination was to listen more directly to the voices within the narrative. They were, in a sense, free of the threads of metanarrative and pedagogical certainty that a story might otherwise be answerable to and would, therefore, make very different connections between stories when they turned to the task of listening across the library for grander narratives.

Listening to the seven stories also brought individual members of the research team into a co-production between themselves and members of their own community. These were people they (metaphorically) knew and/or wanted to know and stories they recognised and/or may also have wanted for themselves.

Rather than, as some have done, viewing this as the embodied failure of people with a learning disability to see beyond the personal in their theorising, we experienced the things they had to say as

vital and creative and deeply political, because they were deeply personal. The researchers with a learning disability listened intently to the stories *because* each sentence could be weighed and measured against its capacity to validate similar experiences - or to change their own life story. Somewhere in the ether between listener and Bluetooth speaker, the sexual and reproductive rights of storytellers and their audience intertwined. Moreover, *because* each narrative held seeds of possibility that each researcher might recognise, either for themselves or, in their altruistic way, for friends and others who populated their every-day lives, the researchers invested in joining dots and getting things right. For them, the imperative to make the world more predictable, known beyond self and socially just that sit behind all theorising was *personally* important.

Unfettered from layers of explication, we witnessed moments of theorising that stepped well beyond the skinny library of professionally privileged stories of learning disability too.

For example, a single observation that “sex was like the needle in a haystack” ignited conversations about the constitution of the hay (not the needle!), that took theorising about the intersection between learning disability and sexuality in an entirely new direction, including a newfound appreciation of the role that silence plays in undermining intimate citizenship. It was, they said, the vagueness or absence of conversations about sex and being steered away from people and places that made conversations about sex inevitable that made the needle of sex so much harder for them to find.

Observations, rooted in an ethnographic sensitivity to Storyteller’s lives, took theorising and the project’s methodology into uncharted territory as well. The researchers with a learning disability were interested in why some stories got told the way they did and why parts of a story might remain untold. In unpacking *Ko te Pūrākau o Tipa*, the Working Group reached the conclusion that, like Tipa, we are all on a journey away from somewhere, towards somewhere

else. This single observation framed ongoing conversations about the nature of self-determination, the need for bravery, differences in the kinds of places people with a learning disability are paddling away from and the destinations they hope to call to themselves. As has already been foreshadowed, this seemingly simple navigational metaphor would also come to define the kaupapa of a radically different way of gathering the raw materials for narrative research (Wayfinding).

Moreover, the empathetic lens that William, Vanessa, Darryl and Cheryl brought to the tasks of reading and responding to stories told by those with whom they shared dis/similar life histories also introduced a new and more compassionate methodological orientation to the “*Mean As!*” Project. In sharp contrast to the clean paradigmatic delineations between researcher and researched we were at risk of orientating them to, the researchers drifted “off-script” by responding to Storytellers as if humanly present.

At the conclusion of their discussion about the Life story of person who authored *Sometimes I write letters*, they wrote this;

One of the most positive things about the story was that writing it may have helped the letter writer. We asked the story gatherer to take our comments back to the writer. We wanted to let her know how important it was for us to hear her story and what we thought after reading it. We hoped this would make her happy.

After taking our comments back to the letter writer, the story gatherer told us that the writer was proud of her story and that she had shared it with one other family member. After reading her letter, she said her family member revealed to her that they had had a similar experience. Neither knew the other was recovering from abuse.

And finally, but perhaps most importantly, the observations and insight generated by the four men and women with a learning disability who clustered about a speaker to listen to their peers was as rich and as textural as the theorising of anyone who might claim knowledge generation as their vocation.

Sometimes I write letters, was the second story the researchers with a learning disability heard. We feared that the researchers may find it an extremely difficult story to hear, not least because they themselves may have been exposed to sexual abuse. We also worried that the men in the group might be silenced by the long shadow cast by the tropes of deviance and predation that creep into the social practices of service provision and support. The opposite happened. Instead we were meet with wisdom and insight the equal of any we had been met by before. The following are direct quotes from the men and women that sat about the table that afternoon.

- “[Recovery] takes time - and work. “It’s ongoing. It’s always.”
- “[It’s important to a participant in your own recovery] She has a plan. “She knows what to do.”
- “Past experiences don’t determine who you are.”
- “She takes her own advice by being close to her family, loving her pets, talking to god Oh, and writing letters to help other people.”
- “She wanted to be a mum. She would have been a good mum – but I don’t think it’s going to happen for her.”
- “Her message is to know you have the right people in your life to support you. The right people in your life are strong, trustworthy, intimate, patient, loving, and caring.”

Taken together, the transcribed observations of the group might have been lifted from a best practice manual on how to support recovery from sexual abuse. But they weren’t. They represent the collective wisdom of men and women presumed too incompetent to transact research, or indeed, to express their sexuality without professional surveillance and supervision.

As we noted before, listening to theorising that stood without need for explication or appropriation reorientated the *“Mean As!” Project*. The decision we made that afternoon, not to filter or appropriate their theorising was an ethical one, intended to advance the radical and destabilising presumption of equivalent intelligence in the

quintessentially human domains storytelling and reading *as-well-as* the reclamation of intimate citizenship.

The consequence of that decision is that the ‘Mean As!’ Library is now populated by a companion set “Key messages” that similarly represent the unfiltered and self-edited theorising of the four researchers with a learning disability.



Figure 19 An example of the companion “Key messages” sit alongside each story in the “Mean As!” Library.

Within the project, William, Vanessa, Darryl and Cheryl assumed it was their responsibility to decipher the stories. *“It was our job”*, they said, *“to find out what each story really said to us. We tuned into them. We were hyper-tuned”*, (Luskie et al, 2019).

To do this they described asking themselves a set of questions as they *“tuned into”* a story, before breaking the silences that inevitably followed the ending of a spoken narrative by asking each other:

“ How the story made you feel. What we thought the Storyteller was trying to tell us. Why their story was important to the Storyteller and why it was important for others to hear it. Why they might have told their story that way. And what needs to change if people with a learning disability are going to tell better stories in the future.”
 (Luskie et al, 2019).

And what do you think?

Each of the companion Key messages written by the researchers with a learning disability end the same way. They ask *“what do you think?”* It is a simple invitation to self-advocates and to all of us to engage with the same kind of questions they posed themselves.



Figure 20 William, Vanessa, Darryl and Cheryl listening to and deciding upon a set of Key messages for one of the “Mean As!” narratives

How you read, react, and seek to make meaning of the stories and the research group’s theorising will add to the co-production that is *“a narrative.”* If Susan Chase (8) is right, we have no choice. We too will be changed by what we read or hear.

In describing the art of listening, Robbie McCauley, (cited in Becker, 2000), wrote, *“when you engage your vulnerability around issues that are both political and personal, something powerful can happen.”*

“What do you think?”

Drawing the two strands of the project together

Kia whakatōmuri te haere whakamua

In, the Mean As! Research Project, we set ourselves the task of pulling to the surface of reader's awareness, some of the habits of thinking and doing that have become entrenched as ordinary and routine ways of severing whaikaha Māori and Pakeha men and women with a learning disability from very normal expressions of intimacy and sexual citizenship. It was a task we sought to accomplish by inviting New Zealander's to rub-up against the story telling and theorising of people with a learning disability.

What we discovered along the way was that people with a learning disability may not be able to realise intimate citizenship without also contesting the habits of scholarship that also police their exclusion from creating and disseminating knowledge that is drawn from and more rightfully belongs within their own community.

We opened the report with the whakataukī, *Kia whakatōmuri te haere whakamua - we walk backwards into our future with our eyes fixed on the past*. We would like to draw it to a close by continuing to walk backwards, but with steps guided by the eight storytellers and four story readers who led the "Mean As!" Project.

7.2 Let's talk (openly and respectfully) about sex

In "Already Doing It", Michael Gill (2015) writes that efforts to limit sexual knowledge and/or the erasure of first hand experiences of sexuality represents the twin faces of sexual ableism. "Sex education, both in its content and omissions," Gill argues, "codes for permission, by detailing the kinds of experiences and sexual intimacies that are sanctioned - and those, therefore, that are not.

In the story they chose to tell together, Jess and David remind each other that they both knew very little about sex when they moved in together. Jess and David went to mainstream, not segregated, schools and both remembered completing an NCEA sex education unit at High School. Jess passed "*with flying colours*" – a success tempered, however, by a teaching assist who believed it was information Jess would probably never need. David, on-the-other-hand, failed spectacularly.

In the vacuum of any other conversations, David said his sense of himself as sexual was forged by the counselling he had received that only ever read him as potentially dangerous. David said he felt watched and that everything he had to say was weighed to determine whether he was a bad person or not. Jess said she had received sex education in an institutional setting too She did, she wrote, "*walking, cooking and sexual reality*". For Jess, sexual reality was an orientation to all of the things she wasn't allowed to do with a man. Her education similarly emphasised the dangers of unprotected sex, including coercively encouraging Jess to think about "*how the kids would turn out like*" should she ever get pregnant. "*They had to state their concerns I guess, didn't they?*" Jess wrote in her story.

Jess and David would later marry and explore the possibility of having children with Family Planning and their doctor, away from the unwelcome intrusions of support staff or family. Together, as a couple, they made the considered and personally well-reasoned decision not to parent, despite everyone agreeing that David would have made a great father.

For Jess and David, their ordinary, “mainstreamed” aspiration for relationship to include the possibilities of sexual intimacy and parenthood were met by discourses of (in)appropriateness, (un)fitness and (in)capacity. Sex, pregnancy and parenting were all imagined as a threat, both to themselves, and to the children they might have.

When Patsie Frawley and Nathan Wilson spoke to Australian adults with a learning disability about the content of their sex education, they described being met by the same kinds of conversations (Frawley & Wilson, 2016; Wilson & Frawley, 2016). Consistent with the research literature (Azzopardi-Lane & Callus, 2015; Slater, 2015.), the twenty-five men and women who spoke to Patsie and Nathan, said their orientation to adult sexuality was moderated by parents or carers who held deeply conservative views (Frawley & Wilson, 2016).

Being the parent of, or “caregiver/support worker” to someone with a learning disability often invites the asymmetric assumption that these roles necessarily oblige acting within a “duty of care”. The message Australian’s had for their parents and caregivers, however, was that when assumption becomes entangled with the narrative imagining of people with a learning disability as “*living in suspended adolescence*,” it can limit their access to the information, education and opportunities they needed to explore their emergent sexuality. (Frawley & Wilson, 2016). The overarching theme to the conversations Patsie Frawley and Nathan Wilson had with Australian men and women with a learning disability was that they had no control over what, or when they learnt about sex (Frawley & Wilson, 2016). Instead, “*doing sexual reality*” for them meant learning about sex via education that was pre-eminently biological and factual in its orientation and didactic and rules based in its delivery. For these men and women, any discussion about sex being ordinary or pleasurable was displaced by conversations that emphasised; the dangers of unprotected sex, disease prevention and the ever-present risks of getting a sexually transmitted infection, or of becoming pregnant. Young women with a learning disability also

said they were orientated to an equivalently ever-present risk of becoming the victims of sexual coercion, abuse and sexual violence and men, conversely, to the consequences that would inevitably follow their “ever-present” risk of failing to ensure appropriate consent – leaving both women and men “concerned,” and feeling, “scared” about sex (Frawley & Wilson, 2016).

Frawley & Wilson (2016) also wrote that their focus group participants were full of answered questions. Against the backdrop of relative silence, the men and women they spoke to took the opportunity a non-judgemental audience afforded to ask about the things that were really on their mind.

Young men asked questions about, how to treat women with respect, whether the stories they heard from others about their sexual exploits might be true or expected male behaviour, if watching pornography was deviant and how to square it with the way that they thought about women, what an orgasm was, when it might it be ok to start talking about sex without forcing someone into it, and how to meet and talk to girls in ways that opened up the possibilities of relationship. And young women wanted to know, whether they had a choice about the contraception they had been put on, how to keep control within a sexual relationship, how do you really put on a condom, whether it was ok to have sex when you weren’t married, if it was true you died if you got chlamydia and just how to be intimate with someone you really loved.

What Frawley & Wilson (2016) said the adults they spoke to wanted to know about were “*issues [that lay] beyond the rules of sex*” The kind of issues otherwise locatable in everyday stories that tend to lie beyond their knowing or hearing.

Why is this library of stories so important?

Collecting stories that lie at the intersection of disability and sexuality is not altogether new. As we noted previously, the *“Mean As!” Project* was itself inspired by a similar library of Australian stories collected by Kelly Johnson, Lynn Hillier, Lyn Harrison and Patsie Frawley almost twenty years ago (Johnson et al. 2001). Tom Shakespeare and colleagues, (Shakespeare et al, 1996)) and Kirsty Liddiard (2017) have also sought to situate the voices of physically disabled men and women amongst the myriad of expert stories that regulate their lives by bringing together similar collections of self-authored narratives.

In writing about the experience of curating other people’s stories, Kirsty drew on Plummer’s (1995) observation that realising sexual autonomy for othered populations can depend on a community of stories that together make ordinary rights plausible and possible (Liddiard, 2013). The accumulated weight of stories can do this in different ways.

Perhaps the more obvious way that storytelling creates momentum for the realisation of rights is by connecting individual authors to the broader, societal narratives within which their stories are embedded. Kearney (1999) tells us that storytelling is a moral practice, requiring, as it does, an audience to determine both why a particular story matters and whether the story teller moves through their narrative in morally understandable ways. We are, in a sense, pulled into story by the opportunity it offers to walk in the shoes of another *“as if we were the strange other”* (Meininger, 2010). For people with a learning disability, this *“impossible encounter”* (Cohen-Cruz, 2001) can pull readers into a deeper understanding of the myriad of ways ableism finds expression across a community of stories.

In the *“Mean As!” Library*, readers find themselves pulled into

- Narratives of sexual assault that weave through every story, and which are further connected by the failure of those in authority to act in ways that restore the victim’s dignity. *“They didn’t do diddly squat”,* we hear.
- The background noise of bullying and alienation *“oh you’re a retard, and the teachers really didn’t stick up for people like that”,* we hear.
- The denial of very ordinary rights to privacy and intimacy. *“Yeah we had to be very secret. Very, very, very secret”,* we hear.
- Stories of men struggling to escape the shadow of a pathological understanding. *“I didn’t want to physically touch [my wife] because I worried about getting reported to the police”,* we hear.
- And the heartache of parents forced to weather the most serious of assaults on the love they have for their children *“She rings up [my son’s caregiver], she makes the phone call. I don’t make up the phone calls, they make the phone calls and they tell me when and what time I can see him”,* we hear.

In his influential book, *Intimate Citizenship*, Ken Plummer (2003) stretches the public discourses of citizenship by seeking to also include the very private domain of human intimacy. Plummer (2003) argues that intimate citizenship ought to sit alongside other civil, political and social rights, as a way of preserving the sometimes “fragile” access disabled people exercise agency over their bodies, feelings, representations (as a positive sexual being) and gendered or erotic experiences.

When taken together, the stories that populate the *“Mean As!” Library* write large Plummer’s (1995, 2003) “fragility.” Despite these obvious violations of Plummer’s vision of fully fledged citizenship, people with a learning disability are afforded little protection from the instrument intended ensure their access to all human rights and fundamental freedoms (UNCRPD, 2019).



Article 23 – Respect for home and the family

The right of all persons with disabilities who are of marriageable age to marry and to found a family on the basis of free and full consent of the intending spouses is recognized;

Figure 21 Article 23 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)

For those seeking to apply a human rights framework to the realisation of sexual and reproductive rights, Article 23 of the UN Convention on the Rights of Persons with Disabilities (UNCRPD) provides the closest approximation of the autonomy Plummer (1995, 2003) thought ought to underwrite citizenship. A silence Lynch (2015), describes as stripping people with a learning disability of this elemental attribute of their humanity.

Importantly, therefore, the other way storytelling makes rights plausible and possible, is by creating an opening for people to reassert their elemental humanness. In a paper she wrote about a project in which twelve transgender disabled women made biopic films, Carla Rice and her colleagues from Re•Vision described the anthology as “*bequests from the past [that provide] disability legacies that refuse to accept that which is not enough*” (Rice et al, 2017).

Not only do the testimonies in the “*Mean As!*” Library make clear “*that which is not enough*”, the legacy left by Storytellers includes narratives full of the richness of human lives that can’t be contained by the narrow, dehumanising trope of learning disability. Moments of humour, and grace, and resilience, and empathy, and patience, and insight and wisdom (and, and, and) that leak out in ways that unequivocally locate Storytellers within Meininger’s (2010) “family of (the very best of) wo/man.”

In the “*Mean As!*” Library, we are also obliged to listen to

- Sexual relationships unfolding at the pace of the least confident or comfortable partner. “*Sure I want to go faster at times, but I want it to be right for both of us*” we hear.
- A care for lovers that continued beyond relationship. “*I always love my ex-girlfriends because they were part of me*” we hear.
- The irrational love we all share for our children – even when dislocated. “*When he was born I went back at night time. They brought him into the room and he was in his room with himself..... The most important thing to me is my family and friends.... And my son*”, we hear.
- New visions of parental competence and the gifts parents with a learning disability might give their children. “*If the child had a physical disability it wouldn’t matter. I know what to do and Jess would be its mum*”, we hear.
- Couples stretching the horizons of possibility for each other in scarcely imaginable ways. “*I never imagined I could live in my own house. David changed everything*”, we hear.
- Relational advice passed down through generations. “*But in the depths of his pōuritanga (sadness) he remembered what his Puaa told him and that was to honour his whakapapa, keep learning his Māori and tautoko his whanau. Kia kaha, kia maia, kia toa!*” we hear.
- Sometimes through great pain. “*I want you to carry on loving yourself..... Just try to live a life you are happy with*” we hear.
- The refusal to turn a blind eye to bullying, even when others had. “*This crap was constantly going on and so in the end I decided to go to the Needs Assessment service and say, enough is enough. I am David Austin and I am advocating on behalf of Jess Kittay,*” we hear.
- The most political of love songs sung in reprise. “*I sang it to David and I sang it to the staff person.... This man who keeps coming*

and fighting for us to be together. Jess and David are going out today” we hear.

- And the unfiltered truth about the very humanness of both sex and learning disability. *“Intimacy and sex is part of being in a relationship. A healthy, normal relationship.*

“I am normal. Sex is normal. Intimacy is normal”

By abandoning the tradition of researchers or historians assuming the role of omnipresent narrator, the “Mean As!” Library allows the heterogeneous voices of its authors to become historians for their own community. In a parallel report written at the end of the project, William, Vanessa, Darryl and Cheryl wrote about the importance of personal legacy in a community’s historiography this way;

“ While lots has been written about people with a learning disability, it hasn’t been written by us. We think the library is important for this reason. It’s our historyThis research is leaving something behind. A ‘legacy, a tattoo, a pendant. Something that is near, not far from our lives. Something that is ours, not others.”

(Luskie et al., 2019)

We think the men and women who gifted their stories to the project provide those living beyond the community of learning disability with entirely new ways of looking at and thinking about issues that have entrenched their estrangement from sexual and reproductive rights too. In writing about the liberating promise of art, or aesthetic acts like storytelling, Jacques Rancière (2006) wrote that,

“Art can be political when it helps us to imagine a world wherein things are arranged and meaning is made differently. Like politics, Art reconfigures the world, disrupting the field of what can be seen, and said and done.”

We think the first seven narratives and the many different ways each individual Storyteller chose to tell their story disrupt the field of what can be seen and said and done in ways that fulfil Willford’s (2009) hope that narrative might create a space within which a more liveable – human future becomes clearer.

One of the more important ways this library does that is by inviting prejudice backstage to look behind metanarrative.

In thinking about the film-making process Carla Rice and her colleagues (2017) first asked, how might they acknowledge and tell vulnerable histories without collapsing them into the categories of otherness that perpetuate disabling and marginalizing scripts? Michael Gill (2015) asks a similar question in his book *Already Doing It*, when he wrote about the potential for narratives of abuse to collide with pity, or to undermine the dignity required to imagine people as causal agents in their own lives. These are important questions, because, as Gill (2015) notes, *“It is impossible to be equal to anyone who pities (or demonises) you because it sures up the separation between those who experience (or perpetrate) abuse and those who prosecute, write and raise awareness.*

In the “Mean As!” Library, we hear the stories of men who describe lives shaped by implied abuse they perpetrated and stories of women struggling to recover lives shattered by sexual assault. It is possible, therefore, to read these stories as self-authored manifestations of a single story of learning disability that has been used to legitimise the professional colonisation of disabled lives. But the stories that populate the “Mean As!” Library flesh out men and women who are so much more than victims or villains.

For example, whilst our letter writer is unquestionably the victim of the worst kind of sexual assault, she is also so much more than a victim.

She is legitimately angry – but on behalf of all women.

Her story correctly locates the origin of abuse in the abuser – not the victim.

She writes in a way that also seeks to take care of her audience.

Part of her caring is to alert women with a learning disability that recovery will take time – it is not resolved by a quick professional intervention. *“It takes time - and work. “It’s ongoing. It’s always.”*

She is the architect of her own recovery. *“She has a plan. “She knows what to do.”*

Her aim is to transcend the abuse. *“Past experiences don’t determine who you are.”*

The path to recovery she has identified involves loving herself by continuing to love others. *“She takes her own advice by being close to her family, loving her pets, talking to god Oh, and writing letters to help other people.”*

She is clear and resolute that her rape hasn’t diminished her hope of being in an intimate relationship herself one day - despite a deep mistrust of men.

She refuses to extinguish the possibility of becoming a parent. *“She wanted to be a mum. She would have been a good mum – but I don’t think it’s going to happen for her.”*

And her best advice is to gravitate towards the right kind of relationship. *“Her message is to know you have the right people in your life to support you. The right people in your life are strong, trustworthy, intimate, patient, loving, and caring.”*

In choosing to tell a profoundly personal story in her own raw words, the letter writer claims she is equal with anyone by asserting *her* right to prosecute, write and raise awareness of the abuses she experienced.

For all these reasons, we align ourselves with all those who argue, stories are not only necessary, they are repositories of hope and equality.

Heart-felt, not dust-covered

In the chapter *Finding ways to tell, read and respond to self-crafted stories*, we described how, people with a learning disability have been excluded from the privileged social spaces of our universities and other centres of knowledge production, because the tools and customs of the knowledge/power complex have positioned them as “unknowers” and researchers as “knowers” and “explainers”. We also argued that we have come to know people with a learning disability, therefore, through the story-telling of professionals, many of whom have colonised disabled lives and/or who exercise power over them. And finally, we suggested that our current struggle to understand and respond to people with a learning disability beyond the metanarratives of “victim” and/or “villain” will continue for as long as we dismiss the voices and dilute the activism of men and women presumed “unequal” and “incompetent.”

In the same chapter, we introduced Jacques Rancière (1991) and his revolutionary idea that to realise equity you must see it as a point of departure and not a destination. And we went on to describe the “*Wayfaring Method*” we were steered towards by Storytellers and gatherers interested in discovering what might happen if you set off presupposing intelligence and verifying equity by creating a space for people with a learning disability to bring their own tools and ideas to the task of informing us about their relational and sexual lives.

By project end, we were surprised and delighted by the creativity and sometimes brutal and beautiful honesty with which eight narrators with a learning disability approached their story writing. We were not surprised, however, that their narratives take us well beyond the narrow tropes of “victim” and “villain” or that the narrator’s stories might place themselves at table of humanity.

In the chapter *Reading and interpreting a library of stories*, we also described how William, Vanessa, Darryl, and Cheryl had also yanked us into the presupposition of equity by surprising and delighting us with the brutal and beautiful honesty with which they approached

the task of story reading. We were not surprised, however, that their theorising stood on its own merits. And we were equally un-surprised that their ideas would take current thinking about the intersection of learning disability and sexuality well beyond discourses of the academy. In this respect, William, Vanessa, Darryl and Cheryl have created space for other researchers with a learning disability to claim their rightful place at the seat of knowledge generation as well.

And relatedly, in the chapter *Finding ways to tell, read and respond to self-crafted stories* we also questioned whether Inclusive Methods, as currently imagined, allow people with a learning disability to complete the journey from research “on” to “with” to “by” people with a learning disability. A journey that Māori are taking via the decolonising methodologies of Kaupapa Māori Research detailed at the beginning of this report. Against the backdrop of the stated goal of Inclusive Research to engage people with a learning disability as the “*initiators, doers, writers, and disseminators of research about themselves*” (Bigby & Frawley, 2010), we now wonder whether William, Vanessa, Darryl and Cheryl were also guiding us towards a new and more democratic imagining of Inclusive Research. An imagining in which knowledge generation diffuses more intentionally outwards from the subjectivity of single story teller, before being passed to disabled story reader / researchers and continuing on, outwards into the community of self-advocacy in vocabularies and ways of transacting research that people with a learning disability recognise as their own. A journey from “on” to “with” to “by” that fails to stall at the presumption of incompetence.



Figure 22 Reimagining the diffusion of Inclusive Research

In the report William, Vanessa, Darryl and Cheryl subsequently wrote, they instruct us that they want the response to the “*Mean As!*” Project to be “*heart-felt, not dust-felt.*”

In reflecting upon their work as researchers, however, William, Vanessa, Darryl and Cheryl’s first orientation was to the Storytellers. “*The[se] stories are concrete and real stories*” of New Zealander’s lives” they wrote and, despite their obvious differences, “*there is a little bit of all people with a learning disability in each one.*” Consistent with the conversations story gatherers reported having with the men and women who told their story, William, Vanessa, Darryl and Cheryl also thought of the narratives as the “[*Storytellers*] gift to give,” and they speculated that their reason for offering their story up was so that other people with a learning disability who may have had similar experiences need not feel alone. To William, Vanessa, Darryl and Cheryl it was the very personal acts of telling and listening to others people’s stories that humanised both actors required for the co-production that is narrative. “*We could all learn from them – and from our stories too,*” they reasoned “*because [our stories] are something like theirs.*” We are all, surely, somewhere in their stories.

Rather than lying dead in the libraries of the academy, William, Vanessa, Darryl and Cheryl had a different vision for the future of the stories. Whilst “they were on the page,” they said, “we need to lift them off”. The words, they felt, need to come to life in ways that honoured the vitality and hope of those brave enough to tell their story. And they had a few ideas how to do that too, beginning first with the community of people with very similar stories to tell.

Addressing your own people

According to writer and revolutionary, Franz Fanon, to realise self-determined rights, marginalised researchers and activists need to step away from institutionalised power by acquiring, what he called, the new habit of addressing your own people.

“Addressing your own people” was a habit that the Storytellers and story readers in this project didn’t need to learn. Storytellers natural inclination was to speak directly to their own community in the hope that telling their story might affect change in the lives of men and women with a learning disability.

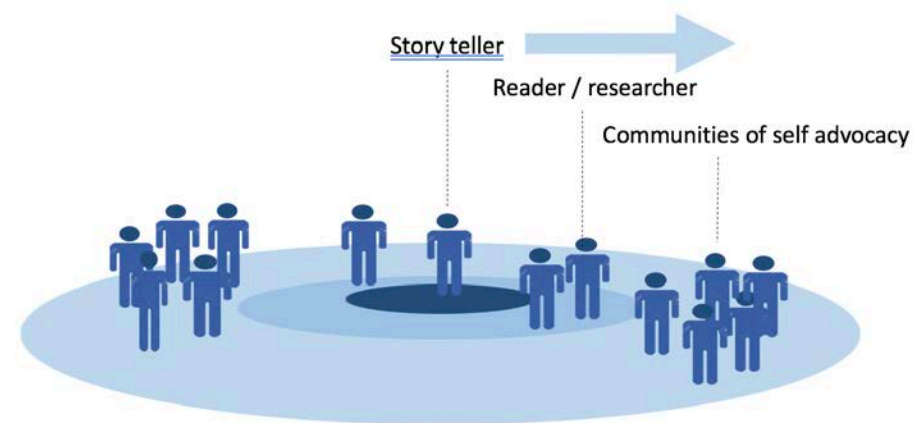


Figure 23 Addressing your own people as a first (democratising) step to disseminating Inclusive Research

In the story she wrote as a letter, the narrator who penned *Sometimes I Write Letters*...., unambiguously addresses other women, and men with a learning disability who might similarly be struggling to rearticulate or make sense of a life fractured by the violence of sexual abuse. As is the custom of letter writing, she begins, “Dear Reader”, and by the close of the letter we are left in no doubt as to the compassion she has for her intended audience.

I want you to know that abuse is not your fault and you don’t deserve all the pain and hurt. But I know it makes you wonder why me? she tells her dear reader, before more practically advising them “to carry on, keep loving yourself and get good sleep!”

Similarly, against the backdrop of a surveilled life, the author of *I wish we were current* overwrote his impulse “never to write anything down” too. In trying to solve the puzzle of his own sexuality, the author said he had never had the benefit of hearing the story of a gay man with a learning disability proudly claiming it a valid and sensual sexual identity. His principal knowing of “gay” was within discourses that positioned it as a deviant and predatory expression of learning disability and a pathological gender identity to be moderated by staff, for his and other client’s safety. In this story, the author speaks directly to men with a learning disability by telling them “that it’s ok to be gay and just because you got an ID doesn’t mean you can’t have a sexuality”. He also situates his story in an alternative narrative of, yet to be realised, love. “If you’ve got ID (intellectual disability)”, he tells them, “or whatever you call it, it doesn’t mean you can’t love or be loved”

And in *Ko te Pūrākau o Tīpa*, Tīpa takes the responsibility to pass his story on just as seriously. By choosing pūrākau as his story telling modality, trickster and shapeshifter Māui becomes the totemic mouthpiece to a story in which Tīpa sought to hide messages he felt important for his brothers and sisters with a learning disability. He tells them, that “Disabled people can have sex and if people say you can’t that’s wrong. Go hard! (Laughs). If it doesn’t work out, try

another one. There are plenty more fish in the sea and like Māui, you might hook up with the greatest one!”

Perhaps more importantly to Tipa, he also tells people with a learning disability that you can have a path, different to the one they are presently on. Tipa starts his pūrākau at the back of the waka (canoe), in charge of all of the paddlers. It was Tipa’s way of seeding the counter narrative that people with a learning disability can have some control over the places they end up. To Tipa, his pūrākau addressed his own community by reminding himself and his peers that it was possible to chart a new course if you take the role of Kaihatu – in charge of all the paddlers.

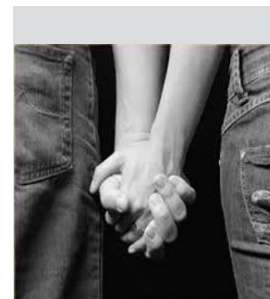
“Addressing your own people” was a habit that the story readers / researchers in this project didn’t need to learn either. Three of the four researchers with a learning disability had discovered their voices and agency, within the relational space of self-advocacy. Within that space, storytelling is the common currency of activism. Alliances are forged and social action seeded by stories traded over steaming parcels of fish and chips, or across circles of chairs turned inwards to listen, or outside in the carpark by members swopping a furtive cigarette.

Whilst listening to the stories, William, Vanessa, Darryl and Cheryl gravitated towards the same kind of activism *“[Listening],”* they said, *“is what we do in People First – I (too) share things that I have been through as a way of being supportive of other people who might have had similar experiences. It encourages people on their own life journey.”* Bending the *“Mean As!” Library* in ways that will allow all people with a learning disability to access the set of stories through the democratising modality of *“listening,”* was one way the William, Vanessa, Darryl and Cheryl charted a new course for the *“Mean As”* Project. Reimagining the *“Mean As!” Library* as a living library, including becoming a repository for new stories and resources people with a learning disability continue to co-create was another. In fact, William, Vanessa, Darryl and Cheryl had lots of ideas about

how the *“Mean As!” Project* might itself become a point of departure and not a destination.

Curating people with a learning disability’s library of hope

At the heart of the *“Mean As!” Project* was, what seemed, at first, to be the relatively straightforward aim of developing an online library of stories written by people with a learning disability about their relationships and sexuality. In this respect, the opening of the *“Mean As!” Library* represents the fulfilment of this aim.



To develop a library of self-authored stories written by people with a learning disability that self-advocates as-well-as community and disability providers can draw on to reflect upon the human rights status and relational and sexual support needs of people with a learning disability

Figure 24 The first aim of the ‘Mean As!’ Project

Each of the seven co-created stories are available to self-advocates and all those interested in responding to the self-authored relational and sexual needs of people with a learning disability via the Mean As! Library donaldbearley.org.nz/projects/mean-as.

William, Vanessa, Darryl and Cheryl also liked the way the project embraced, in its Wayfinding way, the more egalitarian modalities of *“speaking”* and *“listening”*. To promote this more democratising turn, actors and senior students from the School of Performing Arts, (University of Otago), Arcade Theatre Company, the Otago Actors Agency or who were pulled in by personal connection and the kaupapa of the project, give narrators a voice and recordings of each story captured by sound engineer and academic Dr

Mike Holland can also be found in the “*Mean As! Library*,” as an additional resource for people with a learning disability and the wider community to “click on to.”



Figure 25 Senior Theatre Performance student Brittany Sillifant (University of Otago) and sound engineer and academic Mike Holland (University of Otago Music Department) narrating and recording “Love yourself pretty much”

Also included in the “*Mean As!*” Library is a report written by William, Vanessa, Darryl and Cheryl.

When we began the “*Mean As!*” Project, we set off assuming that, whilst people with a learning disability would make an important contribution to the reading and interpretation of the library of stories, it would be acceptable for us to appropriate, repolish and repurpose their ideas, when it came time to report and disseminate. What happened was that we too would be forced to rub up against theorising as rich and textural as any available in the libraries of the academy.

The work the research group did with the stories, as they listened, responded and tuned in to every story with each story and shared their aspiration for the Library to become a living resource for self-advocates and others interested in promoting intimate citizenship for everyone, completely reorientated the “*Mean As!*” Project.

In addition to making the ethical decision to keep our hands off the reading of the stories by presenting the work of the research group alongside the stories of their peers in an unfiltered way, we also

created a space for them to write their own report. A report that, as a consequence, only includes the voices of whaikaha Māori and men and women with a learning disability speaking to their own community in their own words.



Figure 26 The Mean As! Project Report written by William, Vanessa, Darryl & Cheryl.

In this sense, Luskie, Murphy, White & Wallace’s (2019).

“*Mean As!*” Report represents the most important archive of the project. It is refreshingly short, refreshingly honest, and refreshing ‘*heart-felt – not dust-felt.*’ It also completely undermines the disabling presumption that people with a learning disability lack the capacity to transact research that speaks to their own, as-

well-as other communities, that researchers have historically used to police their exclusion from the academy.

William, Vanessa, Darryl and Cheryl’s theorising stands on its own merits. It is the equal of anyone who claims knowledge generation as their vocation and their insight and embodied reflections add to current knowledge about relationship and sexuality in ways that take us well beyond the narrow, single professionally-authored story of learning disability.

William, Vanessa, Darryl, and Cheryl, however, saw no point in the “*Mean As!*” Project, unless it acted as a catalyst for change. For them, the seven stories and their reading of them was a point of departure, not a destination too. They imagined the library, both as a living library, capable of shelving the narratives of future Storytellers with a learning disability and as a storehouse for the myriad of different ways they could think of honouring the transformative aspirations of its authors.

William, Vanessa, Darryl and Cheryl had plenty of ideas about how the stories and the work of the research group could be used to promote *the human rights status and relational and sexual support needs of people with a learning disability*.

In their report, the research group list some of their ideas about how their research might spin off into action-orientated projects.

“ We want the stories to become known and familiar to all people with a learning disability. And used by people with a learning disability and by sexuality and relationship services, advocacy, self-advocacy and disability services. They can access the stories and what we have said about them so they can know what sexuality and relationships are like for people with a learning disability’.

Three of the four researchers belonged to national self-advocacy Disabled Persons Organisation, *Ngā Tāngata Tuatahi – People First*. As a consequence, these researchers immediately recognised the national network of self-advocacy, conferences and a range of other contexts within which people with a learning disability more routinely share ideas and experiences represented one way to keep the stories and the conversation the invite, alive.

William, Vanessa, Darryl and Cheryl also thought that pamphlets and/or short animated films that picked up and reflect back some of the themes they heard repeated throughout the library would help people with a learning disability to talk more and to engage in conversations with the wider community about the lives they wanted to live. Such resources would, they felt, also provide practical advice to people with a learning disability who find themselves in the same situation as those whose stories fill the library.

But at the very heart of the *“Mean As!” Project* was a hope that an anthology of stories might become a community resource available to everyone motivated to meet the self-declaratory relational and sexual support needs of people with a learning disability – together.

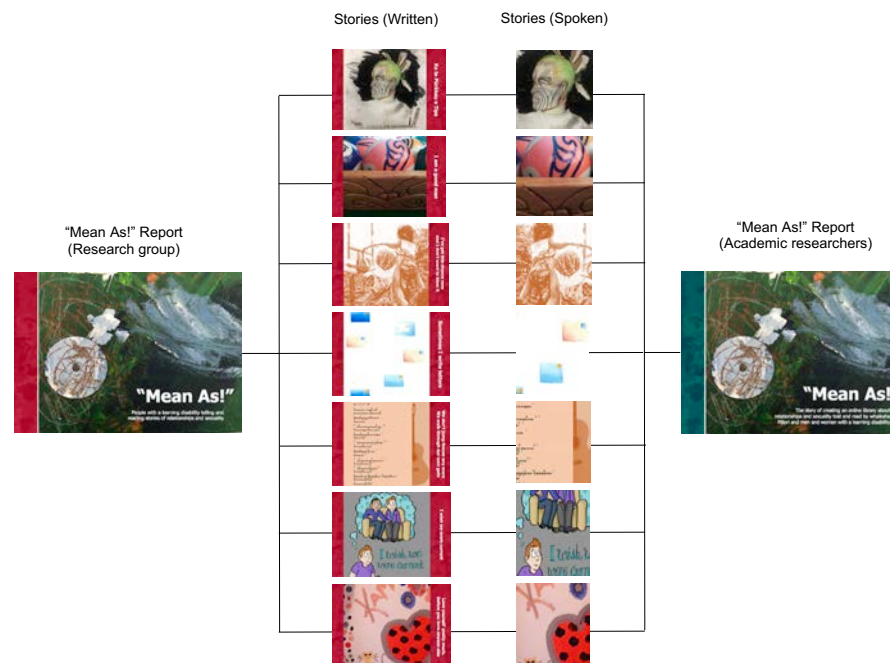


Figure 27 A flowchart that describes how the *“Mean As!” Library* is organised online. Included vertically in the picture are the front covers of: the *“Mean As!” Report* written by the Research group, seven (written) stories told by the *“Mean As!” Storytellers*, radio buttons of spoken versions of the same seven stories and the *“Mean As!” Report* written by academic members of the research team

Realising intimate citizenship within an inclusive society, “two people at a time”

In the closing paragraph of a book chapter that urged communities to seek out and to include the stories of those we have failed to include in our libraries knowing, Brigit Mirfin-Veitch and Paul Milner wrote that, “whatever else inclusion is, it can only happen two people at a time” (Milner & Mirfin-Veitch, 2016). It was a conclusion occasioned by Jane Baron’s more famous observation that “the people who most need their stories told are often those least able to tell them” (Baron, 1991; p103). In the same chapter, Milner & Mirfin-Veitch (2016) suggested that fully acknowledging humanness shared occurs when the power of storytelling dissolves boundaries between people in ways that allow them to interchangeably become both storyteller and listener. A change that can only happen two people at a time.

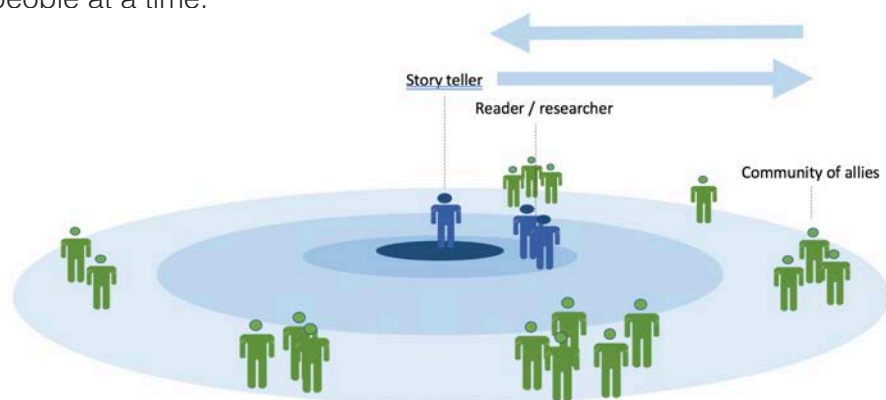


Figure 28 The way research can change communities, two people at a time

Storytelling can be the catalyst to change when listeners feel implicated in someone else’s story. Although parts of the stories that could identify the eight Storytellers who contributed to the “Mean As!” Library have been changed, enough of the social, cultural and even physical landscapes have been left intact enough for us to recognise these as quintessentially New Zealand stories. Stories from our neighbourhoods. And we catch ourselves trying to fit

people we know into the overcoat of their narrative. We think we might know them – or someone like them, obliging us to ask, what contribution we may have made to the trajectory of the narrative because of things we have or haven’t done. A question made all the more poignant by the understanding that these are real people who “act in actual time and space” (Umberto Eco cited in Beverley, 2005) beyond the last sentence of their story. They walk amongst us within and beyond their story telling.

A key aim of the project was, therefore, to stir up change within the neighbourhoods from which the stories came, by exploiting the power of personal narrative to implicate and by forging connections with those who might make a difference.

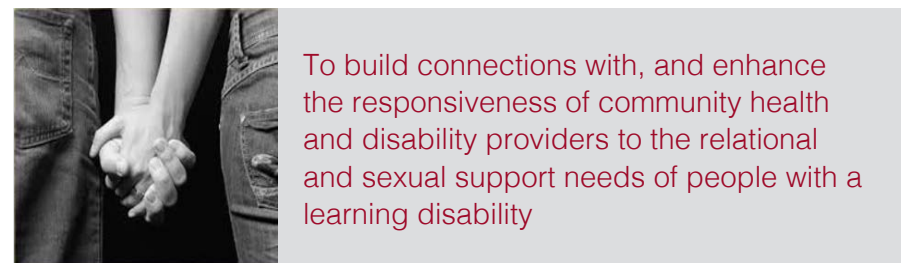


Figure 29 The second aim of the “Mean As!” Project

From the “Mean As!” Project’s inception, we were met by listeners, willing to be implicated and interested to know how they might respond to the stories they hear. Connections were forged with representatives from DHB Public Health, a Māori Service Provider (Hei Whakapiki Mauri), New Zealand Family Planning, Rape Crisis and South Island Disability Service Providers (PACT Group, Community Care Trust) who helped to guide the project’s very first steps and in turn to be guided by the Storytellers and readers with a learning disability.

When thinking about her work as a researcher, Cheryl reflected that one of the more important aspects of her role was “to be the listening ear to that person. By listening”, she told us, “we will support them

and their story". Critically, Cheryl didn't just mean becoming a listening ear for the narrators whose stories now populate the "Mean As!" Library. Cheryl also meant people whose lives and stories will inevitably interconnect and overlap if people with a learning disability are to achieve their aim of living and loving the same way other New Zealand citizens do. As a consequence, William, Vanessa, Darryl and Cheryl were interested in supporting New Zealand and Kaupapa Māori disability support providers, sexuality and sexual health educators, domestic violence and abuse services, police and community schools to tell their own stories too.

They wanted to know how the people they met at the start of the "*Mean As!*" Project read and reacted to the library and how they might help them in their work.

More specifically William, Vanessa, Darryl and Cheryl are interested to learn more about;

- Whether we (non-disabled New Zealanders and Health and Disability Providers) recognise the stories and if we have met people like the storytellers in our work?
- How we think our organisations might best respond to the stories and how people with a learning disability can help us to overcome any barriers we think we might face?
- Whether we think the stories of whaikaha Māori storytellers differ in ways that oblige us to think differently about meeting their culturally specific relational and sexual rights?
- And how we think we might help to change the narratives of future generations of people with a learning disability as we all walk backwards into our futures.

William, Vanessa, Darryl and Cheryl thought achieving this kind of reciprocity in storytelling listening and acting for change would be "Mean As!"

What do you think?

Te re Māori glossary

Amo	Bargeboard support on a meeting house.	Moteatea	A traditional chant or sung poetry often expressing sadness or grief.
Hapu	Tribe or subgroup that share a common ancestor.	Ngāti Whātua	Tribal group of the area from Kaipara to Tāmaki-makau-rau.
Hinengaro	Mind or thinking.	Pākehā	Foreigner, European or New Zealander of foreign decent.
Iwi	Large kinship group that share a common ancestor and territory.	Poua	Elderly man or grandfather.
Kaihautū	Person who calls out the time to paddlers in a canoe.	Pōuritanga	Depression or great sadness.
Karakia	Ritual chant, incantation or prayer.	Pōwhiri	Ceremonial welcome often onto a marae.
Kaumātua	Elderly man or woman usually of status within a family group.	Rongoā kino	Drugs – Bad medicine.
Kawa	Traditional customs and rituals.	Takātapui	Close, intimate friend of the same gender and preferred referent of gay and lesbian men and women.
Kia kaha, kia maia, kia toa	Be strong, keep going, be brave, be victorious.	Tama-nui-ki-te-Rangi	Adoptive father of Māui.
Kairangahau	Researcher.	Tamariki	Children or young people.
Korowai	Ornamental cloak.	Tane	Man – Male.
Kura	School or place of learning.	Tāngata whenua	Indigenous people. People of the land (whenua).
Mana	Spiritual power, prestige, status or authority.	Tangi	Funeral ritual – lament.
Mana motuhake	Separate identity, autonomy, self-determination.	Taonga	Property, possession or treasure.
Marae	Village or cluster of buildings about a tribal meeting house.	Taringa	Ears. To be deaf.
Mātauranga Māori	Māori knowledge, cultural practices or world view.	Tapatoru	Triangle.
		Tāua	Elderly woman or grandmother.
		Taurapa	The stern-post of a canoe.
		Tautoko	To support, agree or advocate.

Te Arawa	People descended from the crew of this canoe from Hawaiki who form a group of tribes in the Rotorua-Maketū area.
Te Ika a Maui	The North Island (Fish of Māui).
Te reo Māori	Māori language.
Tihei mauri ora.	The sneeze of life – call to claim the right to speak.
Tikanga	The correct procedure – customary values and practices of place.
Tinana	Body – self.
Tīpuna	Ancestors.
Tiro ā-Māori ki tōna ake	Māori world view.
Toka	Rock – Something firm and solid.
Tukutuku	Decorative lattice work.
Waiata	Song or chant.
Wairua	Spirit or soul.
Whaikaha Māori	Disabled Māori.
Whaikōrero	Formal speech making – Oration.
Whenua	Land – Territory or place.
Waka	Canoe.
Wero	Challenge.
Whakapapa	Genealogy or decent line placed or recited in the correct order.
Whakataukī	A proverb or saying.
Whānau	Extended family group.

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“Mean As!”

The story of creating an online library about relationships and sexuality told and read by whaikaha Māori and men and women with a learning disability