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**BEYOND the FORTRESS:  
Dis/ability, Community and Care**

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## ABSTRACT

Organised Disability Rights Movements have existed for nearly half a century. Despite various calls for change and engagement in social action by those involved, it could be argued that dis/abled people are yet to have experienced the civil rights movement they first envisaged all those years ago. From a New Zealand perspective, many people with dis/abilities continue to experience systemic marginalisation and social exclusion. Many of the issues one might deem important for dis/ability advancement are housed within a distinct and siloed Disability Sector. Approaches for social change within this area are contested. In recent times, there has been growing discussion linked to the idea that enhanced community, leadership, and leadership development are one of the best ways forward: a post-activism of sorts. Through ethnographic encounters within the Disability Sector and areas related to leadership development, this thesis explores some of the paradigmatic tensions, and the profound sense of dissatisfaction, that dis/abled New Zealanders have identified with the status quo. This thesis focuses on care, connection, and community. It calls for a more basic community-centred approach, and a mentoring orientation as directed towards ways by which relational practices and forms of service could be better supported. It also identifies possibilities for moving beyond the us/them, abled/disabled binary, and classification of human beings. Central to this is a focus upon culture and culture repair. Moreover, by exploring the potential to re-envisage what it means to be human, what it means to live well, and how we might do so together, this thesis advocates for a shift from sectors to systems and from dis/ability to humanity.

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## PROLOGUE

*You're eager!" a fellow conference attendee asserted. "How so?" I asked, curious to know what she was referring to. "Where do I begin? Politics. Politicking. Patch protection. Ego. It's all go in the Disability Sector. Look around: half of these people don't smile anymore, not genuinely. They haven't in years. They're in survival mode; they're desensitised, or they're on the attack. Resources. Lack of resource. Who has funding? Who doesn't? Are we going to keep ours, or lose it? Why should they have more than us? How can we fudge it to get more? There's risk, fear, insecurity, scrutiny, selling out. It's about competition and one-upmanship. 'Us' and 'them.' There are hierarchies, even between impairment groups, and between and within organisations. The same issues we've been trying to address for decades still exist. Then there's the bickering. It's entrenched here. And whatever you do, don't question the status quo. Don't rock the boat. Not unless you're prepared for kickback.*

I had no idea, at the time, just how prophetic that statement would be. Indeed, many of these sentiments have been echoed back and enacted in front of me, time and again. When I first embarked upon this research I did so with a tacit assumption that my encounters in the 'field' would lead to a *somewhat* predictable destination.<sup>1</sup> Instead, I found myself in vast and foreign terrain: bearing witness to scenarios I had not previously anticipated. This terrain was familiar, because I had been near to it in various ways throughout my life, but I was also not an indigene to it. The terrain was dis/ability.<sup>2</sup>

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<sup>1</sup> Borrowing a definition by Anthropologists, Jean-Guy Goulet and Bruce Miller (2007b), field refers to "... both the home environment of our [research] hosts and to the discipline that defines our intellectual horizon in our pursuit of knowledge" (p. 2).

<sup>2</sup> The term 'dis/ability,' broken into two parts, is used deliberately to reflect the entrenched binaries between persons with disabilities who lead with 'ability', contrasted with those who lead with *disability*, in terms of their overarching sense of identity and social position. This is also reflected in the social movements and in dis/ability and access organisations, and the ways in which related topics are commonly framed.

Upon entering the field, I quickly noted how guarded and fearful many of the people appeared. They would begin to speak, look around them to see who was in the vicinity and proceed with caution. "It's my community," they would explain. "I work within the sector; it's a small place." "I feel constantly conflicted between what I can acknowledge seeing, and what I need to turn an eye to." "I don't want to be seen to have any outward alliances." "I can't be seen to be associated with that group." "The culture of silencing? It exists." "It comes down to this: I have to be careful about my image and that of my organisations.' You don't want to get on the wrong side of people in a sector this size. There's too much at stake."

In-group and out-group parameters were drawn. Identity statements were frequently hurled and critique was reduced rather than engaged with: "He's a green-eyed monster," "she has tall poppy syndrome," "they're entitled." I listened as organisational conflicts were described in terms of "plotting", "scheming", "sequestering", "rejecting" and a "pitting of old guards against new guards." Dissent was often equated with, and dismissed as, nothing more than anger, jealousy, or obstruction.

One person I interviewed made the following observation:

"I think you can get sucked into the Disability Sector, and into the mindset, quite easily." When asked to clarify, she proceeded:

When you live with a disability you end up having to tick all these boxes. You end up being quite medicalised. You must have a medical diagnosis. And once you have that medical diagnosis it means you get put into a certain category and it means you can get "this much" help, you know. So, you get pulled into this vortex of ticking boxes and having to go down the medical route.

Touching upon the issue of funding, she added:

When you're asking for funding, you're pleading for things that you need. And, let's be honest, in funding applications we say things that we would never say in the outside world. Like 'I really, really need this. It would be so life-changing.' It's just ridiculous. You have to jump through these hoops, and justify everything, so you often get sucked into this vortex and into this mindset of 'am I going to meet this criteria?' and 'are we going to get the funding?' There's a bit of a fear thing of 'is there going to be enough money?' Because, you know, there's always



funding cuts. There's never enough money in the Disability Sector, and, how is it going to be divided up?

Many of those I spoke to observed the paradox between lack of resource and consumption.

It's funny how there's often money for corporate events, taxi rides, for trips away, for staying at hotels, for dinners, drinks, and other professional perks. Contrast that with the gross inequalities that affect many within the disability community, or even just with the lack of resource that would make a real difference in the lives of everyday people who don't have the funds to cover the extra expenditure associated with accessibility needs, and you start to question it. Who, or what, are we serving here? What's being prioritised? And what, or who, is being left behind?

Collaboration features as a prominent keyword within the Disability Sector but was also frequently acknowledged as an area of challenge. As one individual observed:

There is such a toxic culture within the Disability Sector and that hinders many opportunities for collaboration. People are out for themselves. Organisations are out for themselves. Why collaborate when doing so might put your organisation and livelihood at threat by making your role less important, or even obsolete?"

Another participant, who worked for a Disability Service Provider, explained the way in which bureaucratic process and a lack of care and responsibility can pose additional challenges. Illustrating this, she described a scenario in which her client was very unwell, with an undiagnosed terminal illness, and was unable to meet her basic needs. Attempts to receive assistance failed: she was either passed from one service provider to the next, told she did not fit the eligibility criteria, that there were no resources, or, more pointedly, she was simply denied services. One organisation ironically justified this decision by saying: "We can't send our workers into her house. It's too unhygienic." The ill woman died not long afterwards. The interviewee recounted with angst:

I remember asking, 'what do I have to do to get some action around here? This woman needs help. I can only do what I can do.' I was so appalled with the services I actually didn't ring them after she passed away. I thought 'no, bugger yas,' you know. They rang me 'oh, very sorry' and all this. Well it's far too late now.

Many of those I spoke with expressed frustration, time and again, when trying to articulate ‘what’ (from their perspective and/or that of their organisations’) needed to happen. They also faltered on the ‘how.’ Actions and approaches varied significantly. Some sought to effect change through lobbying the government and focusing on policy and legislation. Others utilised corporate models (particularly popular with the rise in Social Enterprise),<sup>3</sup> and thus drew upon approaches such as building corporate partnerships, developing a brand, marketing, and utilising business strategies. Many spent time considering how to best approach change, but this tended to be isolated to a single organisation.

I stepped back and observed different parts of the ‘sector’, noting that there was little in-sector dialogue occurring around how to best work together and create change, when change was clearly what was desired. Instead, I noted a proliferation of organisations, service provisions, and programmes, many of which were designed to ‘treat’ or ‘address’ specific concerns, whilst operating in fragmented and atomised ways. I witnessed little collective consideration for those whose voices, perspectives, and needs were to be addressed, for those who were being left behind in the process, or how to remedy this. Similarly, I witnessed ideological and practical tensions when it came to the balancing of individual development with community development, and debate as to where attention would best be directed. Take, for instance, the following statement:

There is so much systemic neglect that stems directly from the government failing to act. Politicians can be so quick to dismiss the issues. For change to happen, systems and structures have to be changed. We need to keep government accountable.

As contrasted with this observation:

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<sup>3</sup> Barraket and Anderson explain that social enterprise can, in essence, be defined as an entity that is “...led by an economic, social cultural or environmental mission consistent with a public or community benefit; they trade to fulfil their mission, derive a substantial portion of their income from trade, and reinvest the majority of their profit/surplus in the fulfilment of their mission” (2010, p. 3).

The disability community is too focused on what the rest of the world can do for them, and not on what we, as disabled people, can give to the world.

Shared visions are commonly inscribed, such as the call for an ‘inclusive world,’ although the features that would constitute such a world differ immensely from one person and/or groups’ conceptualisation to the next. Thus, there are a quagmire of questions and assumptions to attend to: what might an inclusive world look like, and to whom? What does inclusion mean? More pointedly, is the term ‘inclusion’ conducive to transformative change, or does it merely reinforce hierarchy and binarised assumptions? If ‘inclusion’ is not the aim, what is?

Amongst those I heard from, there was emphasis upon material change and ideational change conducive to supporting dis/ability and accessibility advancement.<sup>4</sup> However, even those with clear strategies for change faltered, expressing the difficulty of achieving certain goals, most particularly in terms of sustained attitudinal shifts.

My encounters in the field and my engagement with cultural materials (such as literature, policy documents, and public internet posts) demonstrated, each in their own ways, the deep sense of dissatisfaction held by so many involved with dis/ability. There was frustration with the social issues in play, disagreements, and debates were hashed out time and again, often focused upon aspects such as language, and adherence to, or the place of, theoretical and practical models. I also witnessed an explosion of ‘fortress-building’ mentalities. That is, groups of people who feel threatened and under attack, and thus become insular, exclusionary in nature (in terms of insider and outsider categories), and locked into defense of their own positions and perspectives. Fortress-building and its preservation was expressed, most prominently, in the relationship between ‘able-bodied’ and ‘disabled,’ as

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<sup>4</sup> The term ‘dis/ability,’ broken into two parts, is used deliberately to reflect the entrenched binaries between persons with disabilities who lead with ‘ability’, contrasted with those who lead with *disability*, in terms of their overarching sense of identity and social position. This is also reflected in the social movements and in dis/ability and access organisations, and the ways in which related topics are commonly framed.

well as between different organisations, and different impairment groups. In each case, the us/them binary was often firmly in place.

Perceptions of the general populous varied, and engagement with the general populous was also a challenge expressed by many.

“The mainstream? They couldn’t care less about disabled people.”

“*They’re* part of the problem.”

“Ableists!”

“I’m so sick of able-bodied people trying to speak for us, and ablesplaining!”

“Actually, engagement with the mainstream is crucial if we’re to get anywhere, but how do we achieve that?”

“People need to be given the opportunity to get to know, and believe in, people with disability.”

Pointing to the importance of intersectionality and to the issue of identity politics, one interviewee elucidated:<sup>5</sup>

I can see how I’m part of many communities, and how these communities can overlap. A person too fixated on identity politics often blocks themselves out to this, fixating on a subset of identities to the expense of others. [Disabled] people too often forget they’re still human and that those “neurotypicals” and “able-bodied” are cousins, if not brothers.

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<sup>5</sup> My understanding of intersectionality, and the way in which I use the term throughout this thesis, aligns with these definitions provided by sociologists Kathy Davis and Leslie McCall. They posit that intersectionality refers to: “... the interaction between gender, race, and other categories of difference in individual lives, social practices, institutional arrangements, and cultural ideologies and the outcomes of these interactions in terms of power. (Davis, K. 2008, p. 68); and “the relationships among multiple dimensions and modalities of social relations and subject formations” (McCall 2005, p. 1771)

The concept of leadership was posited, by many I spoke to, as a 'solution.' A solution for what, however? For the empowerment of individuals? As a tool for social change? The territory became murky when I gently posed these questions. I realised that leadership-as-solution was considered, more often than not, *a priori*. I was interested in this. I wanted to find out more about leadership, particularly in relation to disability and social change.

The journey I had embarked upon here was unexpectedly long. I participated in various leadership initiatives, courses, programmes, workshops, and attended seminars and conferences; both related to dis/ability and access, and initiatives with a broader focus. I also engaged with a great many materials related to leadership. How was leadership spoken about? What goals were in play? Was there teaching or training of future leaders, and if so, how was this approached by those who 'led' (facilitators, conveners, or those otherwise 'in charge' of the initiatives involved)? Are dominant paradigms being reproduced, or disrupted in the process? I entered these interactions, and learning opportunities, with curiosity, and a series of questions I sought to observe in practice.

I witnessed potential for change in some of the most unexpected places. Multiple themes emerged. Amongst these, a focus on hierarchies, power relationships, examples of systemic marginalisation, categorisation, a mismatch between models and goals, instances of malicious compliance, embracement of individualistic ethos, and transaction-based interactions. There were calls to be braver, or bolder, which were frequently countered by acts of censorship. What is more, I observed a phenomenon in which individual and organisational quests to openly challenge the status quo resulted in the *reproduction* of the status quo, albeit in altered forms.

Initially I had set out to explore dis/ability advancement in terms of existing approaches to 'change.' Towards the end of my fieldwork, I was confronted with the realisation that there were far bigger issues in play than I had envisaged. The Disability Sector was home to a number of contradictions that I needed to look at in context. A crisis of leadership was evident. I recognised, with clarity, that there needed to be a shift from dis/ability to humanity. With this in mind, cognitive dissonance ensued. Could I preserve, or remain beholden to, views and expectations that were now outmoded, and perhaps ran counter to

my research vision and goals? Faced with a fork in the road, I needed to decide. Would I cross this threshold, or remain at the edge, suspended in the space in-between? As Arundhati Roy, a novelist, writer, and activist, captures with elegance: “The trouble is that once you see it, you can’t unsee it. And once you’ve seen it, keeping quiet, saying nothing, becomes as political an act as speaking out. ...Either way, you’re accountable” (2001, p. 7). Put this way, the decision was obvious. I crossed the threshold and ventured forward.

I made a decision to ‘divorce,’ or walk away from, my professional involvement with the Disability Sector. No longer trying to work *with* the contradictions, but instead to see them for what they were, new considerations followed: what next, and, more specifically, how could I proceed when it felt as if my research endeavours were crumbling around me? Novelist, Pat Barker, summarised it well when she penned: “the process of transformation consists almost entirely of decay” (1991, p. 184). This was now true for my research. The discomfort and uncertainty it provoked were not signs of a research project doomed. Rather, they indicated a need to trust the process rather than yield to resistance. Taking inspiration from Lawrence Kushner, a Reform rabbi, professor, and acclaimed author on Jewish spirituality, it was:

...the setting out. The leaving of everything behind. Leaving the social milieu. The preconceptions. The definitions. The language. The narrowed field of vision. The expectations. No longer expecting relationships, memories, words, or letters to mean what they used to mean. To be, in a word: Open (Kushner 1999, p. 14).

Walking away and leaving my initial research plans behind signalled a significant moment: one in which this thesis could truly *begin*.

## INTRODUCTION

Social worlds are formed, in large part, through stories. One of the most fundamental of these stories is what it means to be *human*. What makes one human? Who is included in this category, who is excluded, and why? Normative views of personhood have long perpetuated through social and cultural stories that assume (albeit implicitly) that to be counted as a part of the accepted human group, one should fit a prescribed mould. That is, in order to have one's place within humanity legitimated, individuals are, or have been, expected to exhibit inscribed markers, and, with this, to look and function in a particular and normative manner. Dis/abled people, one group among many who do not, and often, cannot, fit such expectations have often found themselves living in hostile social worlds.

When contemplating social change we, as citizens of the world, may look to the past for clues in how to navigate such endeavours from those who have gone before. However, the world has become more globalised, more fragmented, atomised, individualistic, and technology driven. With this, new considerations inevitably come to the fore. There is no shortage of calls to action, or people to fulfil these calls. Yet, many are left wondering how to best proceed. What approaches might be needed, or best utilised, in contemporary contexts?

Historically, individuals and groups who have organised for change as part of social or identity movements have drawn upon a wide repertoire of tactics aimed at supporting their goals for change. Amongst these, are protest rallies, sit-ins, vigils, employment strikes, boycotts, lobbying, petitions, use of media, education and campaigns. Whilst many of these tactics are still used, an increasing number of individuals and organisations have also turned towards the market, toward corporate-capitalistic models, and similar ideas in search for change. The corporatisation of dis/ability derives in part from the premise that 'we' live in a capitalist world, and thinking 'from within' capitalism is inevitable. However, as geographers, J.K. Gibson-Graham (2006) have suggested, the perception that capitalism is monolithic and the inevitability of capitalist immersion and continuance are assumptions. Instead, they look to post-capitalism, asking what comes *after* capitalism? What are the possibilities that exist *now*, and into the future, in terms of positively transforming social

worlds in ways that diverge from *a priori* reliance upon capitalist relationships and processes?

Such assumptions might also guide individuals and organisations working in the areas of dis/ability advancement and other forms of social justice work. That capitalism must dominate is one of these assumptions. Another presumes social change goals or visions can be 'fit' to a prescribed mould (often re-appropriated from elsewhere), presuming that this will, in turn, create the desired results. Similarly, many hold to the idea that change requires formal organisation. More recently, leadership and leadership development have been posited as key for advancing social change agendas. By approaching ideas of social change in these, and other, predetermined ways, crucial steps may be overlooked, deliberately or otherwise, and actual opportunities for promoting positive social outcomes, missed. It is thoughts, and quandaries, such as these that have inspired this thesis and encouraged me to explore alternative possibilities within areas of emancipatory social justice work, especially within areas of dis/ability.

### ***RESEARCH QUESTIONS***

The topic of this thesis, although it is based in an ethnographic study of people linked to dis/ability and change, often by way of organisations, centres primarily upon the presence and/or absence of caring relationships between people. Over an extended period of fieldwork in this area, I became interested in how people (generally dis/abled people, identifying somewhere on the spectrum of dis/ability) talked about what they felt, what they thought, and what they wanted or felt was missing in their lived experience of being socially coded as a dis/abled human being.

I have used dis/ability, and the 'Disability Sector' as reference points through which to explore matters that are broadly associated with systemic marginalisation, visions for social transformation, and diverse understandings of connection and interdependence. Through my interest in what is sometimes called dis/ability 'advancement', I identified some of the practices and dominant approaches that are not working for many people with dis/ability and the gaps between what many people with dis/ability experience and what organisations are currently providing. This extends, also, to topics of leadership development (particularly



those focused on ‘social change’ and ‘disability leadership’) and the type of ‘support’ that is provided in leadership programmes, and some of the practices enacted within such contexts. Through engaging with people connected to these areas, a key research question that emerged was: what might be learnt from these stories of dis/ability?

Whilst a good portion of this thesis engages with contextualising and narrating these stories, I have sought to go beyond merely delineating the issues as they appear, asking a number of questions to which I return in various ways in each chapter. As I explore these topics, I attempt to respond to the repeated expressions of dissatisfaction that faced me in the field and provoked something deeper to arise in me, asking: what alternative possibilities might exist within areas of dis/ability advancement and the creation of social worlds? What alternatives are there for creating the kind of caring community that is so desired? And: what might be the benefits of a more basic, community focused leadership and mentoring orientation in areas of dis/ability advancement and social change? What might this look like in practice?

I have engaged with this research in a way that is processual, inductive, iterative and experiential. In true inductive style, and somewhat serendipitously, it felt as if the eventual focus of this thesis actually found me. Indeed, the people I met and the ethical quandaries I encountered along the way (a précis of which can be seen in the prologue to this thesis) provided me with new directions and areas of exploration. The questions, therefore, and perhaps some of the answers (?), are really theirs.

### ***THE ROLE OF ETHNOGRAPHY***

Before I proceed any further, it is necessary to first define and explain ethnography - the main approach through which this research was conducted. In terms of its etymological roots, *ethnos*, in Greek, stands for ‘folk, people’ and *grapho*, ‘to write’ (Robinson 2012). Ethnography can be understood as “...a portrait of people ...a written description of a particular culture – the customs, beliefs and behavior, based on information collected through fieldwork” (Harris and Johnson 2000, pp. 77-78). It can also provide “...a means of expressing a shared interest among cultural [scholars] for telling stories – stories about what it means to be human” (Hoey 2014, p. 3).

Ethnography is an immersive and inductive practice that seeks not to impose views upon others, but instead, to find ways to listen, observe, and learn as much as one can from them (Cloke *et al.* 2004). Indeed, as ethnographer, James Spradley elucidated:

Ethnographers adopt a particular stance toward people with whom they work. By word and by action, in subtle ways and direct statements, they say, "I want to understand the world from your point of view. I want to know what you know in the way you know it. I want to understand the meaning of your experience, to walk in your shoes, to feel things as you feel them, to explain things as you explain them. Will you become my teacher and help me understand?" This frame of reference is a radical departure from treating people as either subjects, respondents, or actors. (2016, p. 34)

Evident here is an emphasis on the levelling of power relations between the researcher and the researched. This is crucial within any emancipatory scholarship, including Critical Geography; the disciplinary orientation within which this thesis fits-

Debates, such as the legitimacy of knowledge, and the role of the researcher take different forms when approached through a transformative ethnographic imagination. Even the title of the primary method through which ethnographic data is collected – participant-observation – implies this. Indeed, researchers hold a liminal role of sorts, frequently crossing the threshold between participant and observer; insider and outsider, and often something in-between the two. In many ways this can be seen to blur, dissolve, and break down the binary categories of 'objectivism' and 'subjectivism.' The researcher themselves is the main research 'tool' within the research environment and:

...differently 'theorized' (academically and otherwise) and/or taken-for-granted world views, ways of life, self-understandings, relationships, knowledge, politics, ethics, skills, etc., are accidentally rubbed up against one another. Ethnographic findings are not therefore 'realities extracted from the field' but are 'intersubjective truths' negotiated out of the warmth and friction of an unfolding, iterative process (Cloke *et al.*, 2004, p. 170).

### *AN AUTOETHNOGRAPHICAL ENDEAVOUR*

This thesis did not begin the moment that I stepped into a formal research field. Rather, it has been years in the making and was inspired, in large part, through various life experiences within areas of dis/ability, marginality, and care (or lack thereof).

Experiences, such as being a young carer for my terminally ill mother, navigating health systems, and engaging with her acquired forms of dis/ability, provoked emotions and provided core insights that I have carried with me. Indeed, the cancer diagnosis that my mother received when I was eight years old was to be a defining moment in which I first reckoned with the fragility of life. Surgery, radiation treatments, and remission followed, but these were not to last. Her cancer returned and gradually spread throughout her body, including to her brain: leading to a loss of fine and gross motor skills. Large chunks of my childhood and early adolescence were spent with my mother in hospital whilst she attended oncology appointments, had tests, more radiation treatment, then chemotherapy. The treatments had a brutal impact upon my mother's body, and the experience, as a whole, had a similar impact upon her psyche and well-being, more generally.

I disengaged with the school system reasonably early on, and spent over two years largely caring for my mother at home, where I learnt about caring, living, and dying *in-relationship* with her. There were embodied tensions to contend with daily, beginning with an inaccessible house: there were no rails, or ramps, and aside from the basics like a chair for the shower (situated in a large, deep bath, no less), we were largely unaware of what equipment and aids were available, nor of their respective benefits. Leaving the house was a daunting task and my mother preferred not to do so. Not only was getting in and out of the house with a wheelchair, sans a ramp, difficult, but once outside my mother experienced a new phenomenon: stigma and being witness to fear reactions by members of the general populous. Social isolation was our shared daily experience. As my mother's health deteriorated, family members would stop in and nurses would make short, scheduled visits. For the most part it was often the two of us there throughout the day. My mother died just before my fifteenth birthday, and I would spend several years navigating anxiety and depression in the aftermath of this.

Simultaneous with this was the reality of my older brothers' drug addiction and mental illness. I was often in attendance at his meetings with health practitioners and service providers. I went to drug dens and squat houses with my mother, when she was well enough to check in on him. Approaches and suggested 'ways forward' were only ever temporary: focused upon containment, atomisation, and quick-fixes. Members of our own family rejected my brother as 'no good', refusing him food, entry to our house, or warmth and comfort of any kind. I watched my mother lie in order to tend to him without censure. And then she died. My brother lived a life of transience, attempted suicide on various occasions, and died when I was eighteen (in a suspected homicide). Even in death he was spoken about in dehumanising terms from individuals in the so-called 'helping' professions and classified as somehow less-than.

Professionally, in my work in early childhood education (and in various voluntary roles within the Community Sector), I witnessed the transformative potential of social engagement and education in action, but also exclusionary realities, as they played out in front of me. Children labelled 'special needs' in early education settings were relegated to the margins: becoming the 'responsibility' of a designated teacher aid, and were often spoken about in deficit ways. Similarly, within the context of voluntary work, I witnessed the impacts of stretched resources, and bureaucratic constraints that impacted negatively upon endeavours to positively transform lives or social worlds.

In retrospect, all these experiences had benefits and purpose, affording me insight that I would not otherwise have. I could recognise the flaws in dominant systems – such as that of the medical system and social or community services – early on, as I had ample opportunity to witness people surviving in broken systems. I recognised, even then, the issues with relying upon service provisions to fill gaps, and I saw and heard the impact of low resourcing or, perhaps more precisely, areas of prioritisation. It was these types of experiences that first instilled within me the desire for something different to that which I had observed for nearly all of my life.

These experiences translate into what I came to understand was an autoethnographic mode of research, that is, a combination of *autobiography* and *ethnography* (Ellis *et al.* 2011).

Inevitably, I have drawn upon my experiences, fieldwork, and broader ethnographic data in order to be reflexive in terms of my social positioning, and to further attend to relational ethics required in a project such as this. The combining of autobiographical and ethnographic experiences is also necessary in conveying the work/life collapse that has been in play throughout this research.<sup>6</sup>

In following these methods, I paid particular attention to cultural data, including behaviours, practices, rituals and cultural ideas. I learnt about different cultural rules, vernacular used, and listened to narratives on the worldviews of those I was working alongside. I also kept a research journal throughout the process, using this as an outlet for self-reflexivity, and recollection of the experiences that I had observed and participated in.

Mindful of the colonising and imperialistic approaches of certain forms of traditional research – and the impact this has had in areas such as dis/ability, I opted to analyse my data through visual mapping as a means through which to ‘scope the terrain.’<sup>7</sup> I also analysed narratives with the intention to honour the integrity of my participant’s words and ways of conceptualising their own experiences. It was thus important to me that I not jeopardise this through, for instance, seeking to impose my own explanations above theirs.<sup>8</sup> My intention, also, was to follow the wisdom of Sociologist John Law (2004) in his discussion of the ‘messiness’ of social research. Specifically, in all aspects of this project, I have embraced the

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<sup>6</sup> This research was facilitated under Human Ethics approval from the University of Canterbury (HEC 2015/36).

<sup>7</sup> That is to say, I used the software ‘iMindMap’ to visualise relationships and patterns, and to explore potential areas of significance.

<sup>8</sup> It is for this reason that I chose not to ‘code’ my data or impose a meta-structure upon it, preferring to explore narratives which appeared to be speaking about the same issues by way of juxtaposition in this text. In a similar sense, I use dis/ability related terminology/identifiers interchangeably throughout this thesis. If referring to a particular person, I have done so using the terms that the individual uses to describe themselves.

contradictions, uncertainty, and *mess* that is part of social science research, rather than perform or produce sanitised imperialisms in the name of research, or pretend to be an outsider to what is 'going on.'

### ***ENTERING THE RESEARCH FIELD***

I spent two years immersed in the field of dis/ability and leadership; not in any one geographical location, but rather involved in multiple field experiences. Amongst these: conferences, workshops, seminars, community meetings, leadership development initiatives, and everyday places and spaces of engagement (including public buildings, cafes, airports, and homes). During this time, I encountered numerous people: everyday citizens, policy makers, government ministers, dis/ability rights activists, self-described leaders, service providers, corporate organisations and their employees, social entrepreneurs, and academics alike. Some had the embodied or situated experience of dis/ability and others did not, but nearly all of them expressed a common goal, in rhetoric: that of supporting positive social outcomes, especially in terms of dis/ability and accessibility advancement. Some of my encounters were fleeting and others lasted for a much longer duration of time.

Much of my time in the research field, in fact, an orienting period, in which I sought to follow the advice of Philosopher, Bruno Latour, who has advocated for researchers to:

Follow the actors themselves... [to] catch up with their often wild innovations in order to learn from them what the collective existence has become in their hands, which methods they have elaborated to make it fit together, which accounts could best define the new associations that they have been forced to establish (2005, pp. 11-12).

Through this, affective bonds and friendships were formed with many people, including some who were actively navigating lived experiences of dis/ability and paradigmatic tensions that arise along the way. Sometimes we attended the same meetings, conferences, leadership development initiatives, or workshops. We would share plane rides, taxis and buses; take walks together, sometimes stay in the same hotels and we would sit in the lobby, having late night conversations. Food and coffees were shared, and together we navigated different public spaces and places: some inviting, others not. Time was spent in their homes and in mine, discussing the things that mattered to those present – friendships, encounters

with others, social change, love and pain for the world, perceptions of purpose, or lack thereof. There were also moments marked by vulnerability: bearing witness to the realities of physical pain, being present in times of psychological crises; listening to stories of grief – for self, and for others, and feeling that, too; sharing in and discussing transitional life experiences – mine, theirs, and ours.

Even the closing of chapters (leaving certain research visions and intentions behind in pursuit of others) came with learning opportunities and presented me with new insights. Immersion within socially contested worlds enabled me to trace and scope the terrain. I witnessed, and experienced, some of the blocks that exist within social justice work. I was confronted by the politics involved. I recognised that the topics I was seeking to engage with, and learn about, were contested, and, at times, I was involved in navigating and negotiating these experiences.

Prior to engaging in this research, I had not realised *just how transformative* the process would be. I was not simply studying a topic, but living it, too. This is of little surprise, really, given that one of my main methods was that of *radical participation*.<sup>9</sup> Anthropologists Goulet and Miller (2007a) assert the necessity of releasing fixed agendas, exposing oneself to vulnerability, and remaining as open as possible to learning and relational processes. They caution that to reject this approach in favour of a detached one is to risk developing an “impoverished understanding of human lives and social institutions” (p. 9). This is not an altogether ‘easy’ task, however. As they further highlight:

Through radical participation or experience of the ecstatic side of fieldwork, we discover new forms of engagement with others in the everyday world. We are then confronted with the realization that we often can’t find the line to know if we have passed it, that we have transcended the academically defined boundaries of the knowable and are therefore in relatively new territory. We are then confronted with an alternative: either repress the

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<sup>9</sup> Countless examples of Radical Participation, and the opportunities that emerge from it, are detailed in the edited book ‘*Extraordinary Anthropology: Transformations in the Field*’ (Goulet and Miller 2007a).

experience, or express it in an intelligible form for colleagues and the public at large to grasp (2007b, pp. 11-12).

### ***DISCIPLINARY ORIENTATIONS***

This is an emancipatory piece of research which fits under the category of human geography, and under the sub-categories of critical geography, community economies, and geographies of care. Geographer, Wendy Gibbon (2001), provides theoretical ballast through which to situate and justify the core axiological, or ethical, principles of my research and its role in promoting social justice outcomes. Critical geographers utilise a range of (sometimes radical) theoretical positions which include feminist, postmodern, critical race, and genderqueer orientations, among others. As Gibbons argues, critical geography is primarily working out of leftist, or Marxist, foundations to secure particular social outcomes, and although critical geographers work across a very wide range of areas and engage vastly different topics, they are unified by their consideration of power relations in everyday spaces and progressive social change. The politics of critical geography lean towards idealist preferences for social and cultural change, as grounded in realist (or tangible) conditions, and the research elaborated upon in this thesis conforms to this definition.

As Geographers, J.K. Gibson-Graham, Jenny Cameron, and Stephen Healey, detail in their treatise on community transformation (2013) there are many routes to an enriched and altered understanding of how we might collectively transform our worlds in more caring and community-oriented ways. Through their work, they have promulgated central questions and areas of concern that help to frame topics and introduce new possibilities in the present and through the emergent future. They ask, among other questions, two that are directly relevant to my work here. Firstly:

What do we really need to live healthy lives both materially and psychically? How do we take other people and the planet into account when determining what's necessary for a healthy life?  
*How do we survive well?*

And in a related move:



What type of relationships do we have with people and environments that enable us to survive well? How much do we know about those who live in distant places and provide the inputs that we use to meet our needs? *How do we encounter others as we seek to survive well?* (pp. xiii-xiv).

I have been inspired by these questions, looking to, and drawing upon, some of areas of exploration that Gibson-Graham *et al.*, have outlined. In particular, this thesis considers how we might survive well in our encounters *with* others, as we care for and tend to our common future. I have also used the definition of community provided by Katherine Gibson as a means through which to frame my understandings of community throughout this research. That is,

The term community really goes back to the idea that we are beings-in-common. Who are the beings? It's not just human beings. It's earth beings. ...We are here, living together, and that is really what the nature of community is. ... If we take that to heart, then the process of change becomes negotiation of how we be in-common. How do we live together? (Gibson 2016 n.p.)

### ***FOR GEOGRAPHIES OF CARE***

I have drawn upon ideas attached to Geographies of Care throughout this project, and augmented this with wider literature and thinking linked to *ethics of care*.

Many of the same principles that remain central to critical geography also tend to apply to geographies of care. That is, these geographies engage with ethical questions and concerns. Lawson (2007, p. 8) asserts that geographies of care, underpinned by care ethics, often highlight the role of power and the impacts of unequal power relationships. However, she also states an important caveat, in that even more than drawing attention to such factors, geographies of care can help to shift us “beyond critique and toward the construction of new forms of relationships, institutions, and action that enhance mutuality and well-being. Lawson argues that the need to care is perhaps more pertinent than ever, considering the proliferation of capitalist relations and market erosion within core social areas such as health care, social services, elder care, welfare, education, and environmental protection. She states that profitability often takes precedence over social good and the well-being of people and the planet. A focus upon care, care ethics, and geographies of care arguably play an important role in aiming to promote greater care, question areas of prioritisation, and support the construction of more caring social worlds.

It is useful, at this point, to define what is meant by *care* in the context of this thesis. I draw upon understandings of care as promulgated in different geographies of care (including, for instance, relational and socio-spatial considerations of care). I take note, for instance, of Milligan and Wiles distinction between the acts of *caring for* and *caring about*, which they explain as thus:

Caring *for* ... encompass[es] the performance of care-giving, including the activities undertaken by formal paid workers or informal, unpaid workers such as family, friends and volunteers. ...At its most fundamental, caring *for* is about the personal, the performance of proximate and personal care tasks, but it can also include other everyday tasks such as childminding, pet care or household tasks. At a distance it can involve arranging and monitoring paid and professional care. Caring *about* on the other hand refers to the emotional aspects of care; this might also include the generalized relational and affective elements of being caring (2010, p. 741).

I have also referred to the definition of care provided by feminist scholars Berenice Fisher and Jane Tronto:

On the most general level, we suggest that caring be viewed as a *species activity that includes everything that we do to maintain, continue, and repair our "world" so that we can live in it as well as possible*. That world includes our bodies, our selves, and our environment, all of which we seek to interweave in a complex, life-sustaining web. (1990, p. 40)

This thesis is also imbued with a wider, trans-disciplinary approach, drawing upon ideas from fields such as Anthropology, Sociology (particularly Relational Sociology), Science and Technology Studies, History, and Systems-Thinking. There are many great social and political thinkers who I have aimed to *think-with* throughout this project.<sup>10</sup> Aside from those already mentioned above, other prominent thinkers that have inspired framings and ideas

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<sup>10</sup> I am borrowing the term to 'think-with' from Maria Puig de la Bellacasa (2012); a feminist theorist and scholar in the areas of Science and Technology.

within this project are Philosopher and Ecofeminist, Val Plumwood and her work on *hyperseparation*; Political Scientist, Benedict Anderson, and his work on *imagined communities*; Sociologist, Zygmunt Bauman, and his work on *connected community*, and writer Ian Parson and his analyses of social movements and ideas linked to the *welfarisation of ordinary human needs*. I have also drawn upon the work of various Disability Scholars, activists, practitioners, and others who add support to the work of social change and provide insights into emancipatory social justice work.

### **CHAPTER OUTLINE**

The chapters in this thesis, although distinct in their coverage of a particular aspect of the work engaged in here, are designed to cross-comment upon each other, and I have chosen to lead into chapters two through to chapter five with an interlude. These interludes include historical records and accounts, ethnographic data, autoethnographic reflections, and key observations. I include them in order to capture a particular time and place that caught my attention, and ‘speaks to’ the chapter that follows with the aim of relaying a story or an observation to break out (for a moment) from the academic nature of the thesis. In chapter one — Dis/ability: Definitions, historical constructions, and origin points — I have sought to scope the terrain of dis/ability. I highlight some of the enduring debates that surround the topic; beginning with the complexities involved in attempting to define something as diverse and contested as ‘dis/ability.’ I also explain what is usually meant by references to the ‘Disability Sector.’ I have provided an historical overview and drawn links to historical legacies that persist today, and explored other related aspects, such as the significance of the social construction of normalcy (particularly in relation to dis/ability), and understandings about personhood, classification, and species membership.

Chapter two — Dis/ability and Social Change — begins by introducing the birth of Disability Rights Movements, discussing the factors thought to influence their establishment, and the visions and issues that many involved within such movements galvanised around (or diverged from, as the case may be). This chapter outlines some of the triumphs and challenges involved in Disability Rights Movements, particularly within New Zealand, including within the realms of policy. It also argues that these social movements – as they

once stood – are now fragmented, largely invisible, and lacking in numbers. I also explore the topic of social change, and in particular, some of the workings of social change. It is my aim, here, to unearth some of the *a priori* assumptions that tend to proliferate around topics of social change, to query some dominant approaches, and to point to some alternative conceptualisations that surround the topic.

Chapter three — Stories of Disconnect — maps the relationship between dis/ability and separation, or disconnection. It explores some of the ways in which real and imaginary boundaries have been constructed, and the way in which it has become the dominant trend to look to a Disability Sector or group of ‘professionals’ to resolve the issues that community will not, or perhaps cannot, resolve. It turns, then, to the topic of community and, in particular, to the creation of “claimed” dis/ability communities. This ties to fortress-building mentalities and the role and maintenance of a ‘protectionist ghetto.’ Shifting the focus, I argue for what might be missing from dominant practices, and advocate for a shift from dis/ability to humanity. I also focus upon, and call for, greater attention to three core areas: care, community, and connection.

In chapter four — Turning to Leadership — I concentrate upon the topic of leadership, querying what leadership is, and what constitutes a leader. Turning to leadership development, I highlight the *a priori* assumption that leadership, and leadership development, can be solutions to social problems and a means through which to drive what turn out to be amorphous ideas of social change. I draw upon my own experiences as a participant and researcher within the realms of leadership development, and offer a series of vignettes, aimed at capturing some of these experiences in action. I have focused upon dominant models and approaches to leadership development, highlighted some of the nuance involved in dis/ability leadership, considered the topic in relation to social change goals, and looked to the role of the hidden or unintended curriculum in shaping experiences. In the interests of anonymity, I have drawn upon a mixture of examples from various organisations and contexts – some that have a specific dis/ability leadership focus and some that do not. Here, I conclude by proposing ways in which to re-consider the notion of leadership and leadership development.

Finally, chapter five — Constructing New Worlds — is inspired by a politics of possibility (Gibson-Graham 2006). The aim in this chapter is to build upon projects and visions that are already in existence, and to offer some ideas designed to promote greater care, connection, and experience of connected community. Finally, and in the conclusion, I encourage more attention upon initiating a shift from dis/ability to humanity and from sectors to systems and communities.

## CHAPTER ONE: DIS/ABILITY: DEFINITIONS, HISTORICAL CONSTRUCTIONS, AND ORIGIN POINTS

### *DEFINING 'DISABILITY'*

The term 'disability' has featured frequently in the prologue to this thesis, but what, exactly, does it mean? The label is both amorphous and fiercely contested. It is thus important to begin by exploring the concept of disability and the way in which the term is commonly understood, particularly for establishing some context for this work.

Dictionary definitions of disability often focus upon the deficit aspects of the concepts. For instance, the Oxford Online Dictionary defines disability in the following ways:

1. A physical or mental condition that limits a person's movements, sense, or activities
2. A disadvantage or handicap, especially one imposed or recognized by law (Oxford University Press 2018, n.p.).

Here, disability is described in terms of material 'reality,' and there is a supposition that it is associated with limitation. From an historical, 'western' perspective, such definitions have been largely presented and accepted without question.<sup>11</sup> These definitions are informed by the *medical model of disability* in which impairment is positioned as an *individual deficit*.<sup>12</sup>

The above definition has been challenged through the introduction, and promotion of, *social models of disability*. Rather than framing disability as an *individual deficit* (as the medical

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<sup>11</sup> Western is placed in inverted commas to signal the acknowledgement that it refers to an ideology rather than a geographical location.

<sup>12</sup> The medical model of disability gained prominence within western contexts within the nineteenth and twentieth centuries. Essentially, this model operates on the premise that disability is an individual problem, or deficit. Responses, therefore, linked largely to the amelioration of disability: approaching the topic through means of charitable discourses, based on the notion that disability was a tragedy of the highest order (Goodley 2011).

model had done) the social model has promoted the idea that disability must instead be understood as a *social issue* (Shakespeare and Watson 2001).<sup>13</sup> The *World Health Organisation* has drawn upon the British social model of disability to offer the succeeding definition:

Disabilities is an umbrella term, covering impairments, activity limitations, and participation restrictions. ...Disability is thus not just a health problem. It is a complex phenomenon, reflecting the interaction between features of a person's body and features of the society in which he or she lives (World Health Organisation, 2014, para 1-2).

Extending on this, the *New Zealand Disability Strategy* asserts:

Disability is not something individuals have. What individuals have are impairments. They may be physical, sensory, neurological, psychiatric, intellectual or other impairments. Disability is the process which happens when one group of people create barriers by designing a world only for their way of living, taking no account of the impairments other people have (Ministry of Health, 2001, p. 1).

As noted here, the term 'impairment' is often distinguished from that of disability. In a sense, impairment can be seen to relate to biological or embodied experiences involving a particular 'condition,' and designated 'impairment groups' are comprised of individuals with a particular impairment as listed in the above definition. Impairment can also be acquired,

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<sup>13</sup> New Zealand closely follows the British social model, as initiated by the activist group '*Union of the Physically Impaired against Segregation*' in the 1970s (Shakespeare and Watson 2001). Their work was based on the premise that disabled people are an oppressed group within society. The British social model has evolved over time. Whilst the initial definition focused on physical impairment, stating: "...we define impairment as lacking all or part of a limb, or having a defective limb, organism or mechanism of the body" (Oliver 1996, p. 22), a myriad of other forms of impairment are now recognised within the model. The British social model continues to operate on the enduring conviction that disability is synonymous with oppression (Gabel and Peters 2004), whilst the North American model focuses more upon the idea of marginality and avoids "...the firm distinction between (biological) impairment and (social) disability" (Shakespeare and Watson 2001, p. 4).

for although individuals might be born with impairment, they could also become impaired through illness, accidents, or the process of ageing. They might have a single impairment, or multiple impairments, and their impairment(s) may last for a short or long time. The terms 'disability' and 'impairment' are often used interchangeably. In the social model, disablement stems from inaccessible or 'disabling' environments (so, in this sense, a person who uses a wheelchair is not *disabled* until faced with a situation such as being unable to enter a building as there are steps but no ramp in place).

Diverging from both medical and social model definitions, in favour of an *affirmative model*<sup>14</sup> Disability Scholar, Colin Cameron (2008) has re-conceptualised understandings of impairment, explaining that it can be understood as a "physical, sensory and intellectual difference to be expected and respected on its own terms in a diverse society" (p. 24). Significantly, Cameron has deliberately avoided deficit-based terms such as defects, limitations and functional 'loss' in favour of the acknowledgement that impairment is "...an ordinary rather than an extraordinary characteristic of human experience" (2010, p. 157). This definition of impairment actively challenges the notion that impairment, or disability, should be synonymous with experiences of stigma or oppression. Instead, it emphasises the power of individual and cultural intricacies in shaping understandings and experiences within these realms.

It is important to note that there is no universal definition of disability. It is, ultimately, a unique embodied experience. Sociologists Tom Shakespeare and Nicholas Watson (2001) explain it well when they write that disability is "...so complex, so variable, so contingent, so situated. It sits at the intersection of biology and society and of agency and structure.

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<sup>14</sup> The affirmative model (sometimes referred to as the minoritarian model) has a relational and strengths-based orientation which essentially highlights, and supports, positive collective and individual social identities (Swain and French 2000). It is based upon the premise that impairment is a fundamental aspect of human life. It considers impairment not as a source of conflict, or as reason to exclude others, but rather as something that can enrich the lives of not only disabled individuals, but also society as a whole.



Disability cannot be reduced to a singular identity: it is a multiplicity, a plurality” (p. 13). Indeed, various biological, religious, charitable, political and social discourses have each had distinct roles in shaping, creating and changing the construction of disability across time and place (Goodley 2011). Likewise, Sociologist Rod Michalko refers to the fluidity and “manyness” of disability, which, at its heart, encompasses social, material and individual facets (2002, p. 116). As historian, Bonnie G. Smith (2004), states the term ‘disability’ is “becoming increasingly polymorphous” and “...can suggest a set of practices, kinds of embodiment, interactions with the built environment, an almost limitless array of literary types, frames of mind and forms of relationships” (p. 1).

Individuals and groups draw upon multiple terms to express and describe their diverse lived realities. For instance, some individuals and groups prefer to be identified as ‘disabled’, and other individuals and groups prefer person-first language choices where the terms ‘disability’ or ‘impairment’ are placed secondary to their personhood. Whilst a topic of longstanding debate, there is no single term associated with dis/ability that is purported to be ‘correct’, preferable, or without problematic elements.<sup>15</sup>

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<sup>15</sup> As an example of the debates present within the field, Paul Abberley (1991) and Jenny Morris (1993) are two prominent early disability scholars who have critiqued person-first language, referring to it as rhetorical humanism. Instead they advocate for the politicisation of disability through terminology that foregrounds disablement as a form of oppression. Peña *et al.* (2016) offer a more contemporary discussion linked to disability identity and use of language, more generally. Other examples include Collier (2012) who offers discussion on person-first language, and Dunn and Andrews (2015) on person-first and identity-first language. In each instance, there are particular ideological framings of dis/ability to be mindful of. It is also important to note the diversity of perspectives and experiences amongst those ‘labelled’ dis/abled (including those with invisible impairments, and those with visible impairments, those who have had impairment since birth, and those who acquired impairment later in life (and through various circumstances)).

### ***DEFINING THE 'DISABILITY SECTOR'***

Before I proceed further, it is important to also clarify what is meant by the term disability 'sector', a concept mentioned often in this thesis. This is another nebulous concept, used frequently, but rarely consistently. The term invariably conjures a multitude of diverse images and understandings amongst individuals and groups. The Latin etymology of *sect-* is 'cut off', which I think describes the concept well. A sector (and there are many, including the Disability Sector, the Community Sector – also termed the Voluntary Sector, Not for Profit Sector, or Third Sector; the Private Sector, and the Public Sector) are considered distinct and separate from wider society and thus often operate in compartmentalised ways. New Zealand's Disability Sector has a top-down reporting and governance structure which originates with the central government position of the Minister of Health, who has the overall responsibility for the health and disability support system. The Minister of Health then works alongside the Ministry of Health, District Health Boards, Accident Compensation Corporation, and Primary Health Organisations and additional service providers to administrate part of the designated sector (Controller and Auditor-General n.d.).

The Disability Sector, in more simple terms, is often spoken about in a way that includes disabled people, their families, service providers and other professionals in associated roles. It is conceptualised variously, which became clear to me through discussions that took place as part of my research. Some view the Disability Sector purely in terms of disabled people, their families, and service providers, whilst others view it in terms of anyone who values dis/ability (so, for instance, dis/ability activists and allies). I would argue that the "Disability Sector" is not a 'concrete' entity, as much as it is a conceptual and imagined terrain (in-line with Anderson's (1991) work on *imagined communities*). I will expand on this notion further in later sections, particularly when discussing the idea of dis/ability communities.

### ***CONSTRUCTIONS OF NORMALCY***

In exploring the construction and understanding of dis/ability, it is central to note that there are very different histories and processes involved depending upon the contexts involved (in terms of both particular geographical locations and, more so, in specific cultural histories). Here, I am referring to dis/ability within 'western' contexts, and in this sense, it is

helpful to understand the role and processes involved in constructing an idea of 'normalcy.' American specialist in disability studies, Lennard J. Davis, identifies dis/ability as "...part of a historically constructed discourse, an ideology of thinking about the body under certain historical circumstances. [It is] a social process that intimately involves everyone who has a body and lives in the world of senses" (1995, p. 2).

Constructions of normalcy are entwined with dis/ability in multitudinal ways for many centuries. Enlightenment doctrines which aimed to purify and 'clean' social life, the Industrial Revolution (and its construction of 'worth' or human capital), and the project of modernity (as a whole) reoriented ideas of difference (Davis, 1995; Hughes 2002; Michalko, 2002). Modernity, in particular, is claimed to have initiated the transformation from impairment as an object of human difference into dis/ability as a social process (Hughes 2002).

Through her trans-disciplinary scholarship, Geographer Amba Sepie (2017) has traced the lineage of the *western 'normal'* and its relationship to disability and species-membership. She demonstrates that whilst modern history serves as a reference point for many, this focus reduces and limits the scope and understanding of the topic at hand. That is, the processes of normalcy, and the topic of species membership, do not have their origin points in modern history. Rather, as Sepie argues, exclusionary forces were *already in play* well before the modern era. Dis/ability (like race) had long been associated with ideas of monstrosity and otherness. Highlighting the genesis of these ideas, Sepie turns to a key cultural change: that of the progressive Christianisation of Europe, specifically in the early modern period (and those countries that have followed in its legacy, which includes (post) colonial New Zealand). Essentially, it was an early Christian interpretation of the universe that introduced a particular kind of 'normal, divinely-created, human', and, in doing so, turned dis/ability into a moral, Christian concern; rife with theological loadings. Dominant cosmological tenets of the Christian worldview were at once drawn upon, amplified, and reinforced through normalising processes. So powerful were these processes, and the cosmological tenets that supported them, that they have been maintained as core aspects of dominant, Western ideologies that continue to prevail within the contemporary westernised world. These ideologies subsequently inform the social scripts by which many live (ibid).

Normalcy categorises and regulates the societal construction of 'normal' and neurotypical.<sup>16</sup> As suggested by rhetorical theorist, Jay Timothy Dolmage, "the norm is that it acts as a noun designating culture's desire for homogeneity, and it also acts like a verb, in that this agenda is enforced. No person is immune from the power of norms - they are ubiquitous and fundamental" (2014, p. 21).

### ***CLASSIFYING PERSONHOOD***

Also significant to the construction of normalcy is the manner by which the social world is habitually framed via a series of homogenising and reductive mechanisms, including reduced concepts of functionality, and as Davis adds, *appearances* (1995). Davis comments on the bodily coding of dis/ability: "The missing limb, blind gaze, use of sign language, wheelchair or prosthesis is seen by the 'normal' observer... The power of the gaze to control, limit, and patrol the disabled person is brought to the fore" (p. 12).

Fiona Kumari Campbell (2009), a dis/ability scholar, ties the embodied corporeality of bodily standards to a notion of perfectability that inscribes a variety of appropriate societal responses and performances of inclusion and exclusion. As argued by Tobin Siebers (2008), also a dis/ability scholar, functionality is tied to the ideology of ability, versus inability, which I link to questions of personhood and the overarching concerns regarding species-membership and inclusion. What does it mean to be recognised by others as *fully* human? Siebers suggests that this rests on being able to perform – see, hear, think, walk, talk – in specific and uniform ways. The link to productivity as an economically viable 'unit' which has value (if not intrinsic) to the wider societal capitalist goals is not difficult to make. Stigma, as theorised by a number of sociological thinkers, also has a part to play here, especially as

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<sup>16</sup> Note, this is a social construction. All people function differently, and the hegemony of normalcy is (potentially) oppressive towards any perceived difference or deviation from the narrow constructs of the stipulated 'norm.' The hegemony of normalcy certainly lends itself well to the perpetuation of dualistic, us/them framings that are a habit of mind within binarised, 'western', societies. Such dualisms do not allow for contested social identities or fluctuating competencies in terms of social roles. They are, therefore, idealistic, purist, and modern, and are not a reflection of reality.

applicable to the 'everyday discomfort' that might be provoked by the presence of dis/ability: fear, the averted gaze, and the 'awkward solemnity' (as Goffman puts it) become a part of the received lived experience of inhabiting a body that is not deemed fully human (Davis, L.J. 1995; Goffman, 1963 #40).

## INTERLUDE: THE PUBLIC BIRTH OF THE DISABILITY RIGHTS MOVEMENT?

Date: April 5<sup>th</sup>, 1977

Time: 10:00AM onwards (GMT -7)

Location: San Francisco, California, United States

37.7749° N, 122.4194° W.

ALL PERSONS WITH DISABILITIES ...

**The Fed. Govt. is trying to  
STEAL our Civil Rights!!**

**DEMONSTRATE!**  
to Demand Signing of  
**504 Regulations**

SECTION 504 OF THE REHAB ACT OF 1973 WAS DEVELOPED BY CONGRESS TO PROTECT THE RIGHTS OF ALL PERSONS WITH DISABILITIES IN ANY PROGRAM RECEIVING FEDERAL FUNDS. FOR FOUR YEARS WE HAVE WAITED FOR REGULATIONS TO BE SIGNED. WE CAN WAIT NO LONGER! OUR RIGHTS TO EDUCATION, JOBS, ACCESSIBLE BUILDINGS, DAY CARE, MEDICAL SERVICES, HOUSING, TRANSPORTATION, ETC., ARE BEING WILFULLY WITHHELD BY THE CARTER ADMINISTRATION.

WHO SHOULD JOIN US? ALL PERSONS WITH DISABILITIES AND SUPPORTERS OF DISABLED RIGHTS.

**Tues. April 5**  
ALL DAY FROM 10 AM, RALLY AT NOON

**HEW Office 50 Fulton St., S.F.**  
**United Nations Plaza,** (Off BART-Civic Center

504 Emergency Coalition 2539 TELEGRAPH AVE., BERKELEY 94704  
PHONE KITT Y OR JONATHAN: DAYS 841-3790 NIGHTS 428-2286

INTERPRETER FOR PERSONS WHO ARE DEAF WILL BE PROVIDED.

- Courtesy Ken Stein

(Image provided by Ken Stein and published by Shoot 2017).

### ***RECALLING AN HISTORIC EVENT***

The first week was the toughest. We're sleeping on the floor, there were no shower facilities whatsoever. I think the feds figured, "Oh, they'll fight [with each other], or people will get cranky and get tired of sleeping on the floor, and get tired of sleeping in their sleeping bags." What they really underestimated was our determination. We were high. We were ecstatic. A lot of us who were disabled as kids had gone to crippled kids camp— we thought it was camp! [Laughs.] We didn't care. You know, we survived surgery! We survived hospitals! This was nothing! We had choices here. We could go to that inaccessible bathroom or *that* inaccessible bathroom. We could go down the halls by ourselves, we were with our friends, I mean, they were never going to get us out of there! Then they kept thinking, "Okay, we'll just wait for the leaders to screw up." What they didn't realize was we, as a community, didn't function by leaders.... The feds were looking for a model, a traditional power structure of one leader, preferably a man. What they found instead was . . . two men and six women who were primarily the leaders of the 504 sit-in— just kind of talking to the community and hanging out and helping us all. We would have meetings where we would make decisions as groups. - Corbett O'Toole (in Pelka 2012, p. 273).

The '504 demonstrations' and building occupation, of which Corbett O'Toole (a pioneering disability rights activist) captured above, is, perhaps, one of the lesser-known acts of civil disobedience to have occurred as part of a protest, or rights-based movement. Yet, this was no ordinary demonstration. On April 5<sup>th</sup>, 1977, as multiple protest demonstrations erupted throughout the United States of America; disabled individuals and groups sought to make their demands clear. Motivated by a deep dissatisfaction with the status quo and a determination to support the introduction of a seminal piece of legislation (section 504 of the Rehabilitation Act 1973), those involved demanded that their voices be heard, and that their civil rights be protected for the first time in their lives.

### ***THE CONTEXT***

In 1973, America's *Rehabilitation Act* was introduced. This contained a passage ('Section 504') which outlined a bold statement:

No otherwise qualified handicapped individual in the United States ... shall, solely by reason of his handicap, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving federal financial assistance (cited in Pelka 2012, p. 261).

This was the first example of civil rights protection for people with dis/abilities in the United States. Despite initial acknowledgement of the importance of this legislation, it was not enforced. The Nixon and Ford administrations had stalled the Act. The newly-elected Carter administration had publicly promised to sign and enforce the legislation, but later became reticent to do so.

Opposition towards the legislation mounted, with concerns surrounding economic costs and consequences of enforcement. President Carter asked Joseph Califano (the Secretary of the Department of Health, Education, and Welfare) to establish a task force to examine the legislation and its implications: a task force without disabled representation. Furthermore, it appeared as if Section 504 would be watered-down, with dominant rhetoric centred on the notion that people with disabilities would remain 'separate-but-equal.' Frustrated by this, dis/abled people and groups (particularly the umbrella group, the American Coalition of Citizens with Disabilities, or 'ACCD') insisted upon the legislation being signed, unaltered. ACCD then issued an ultimatum stating that Section 504 was to be signed by April 4<sup>th</sup> 1977, or the group would proceed with nationwide demonstrations. The legislation was not signed by this date, and nationwide protests followed on April 5<sup>th</sup>, 1977.

Part of these protest activities involved building occupations; the most prominent and long-lasting of which was the '504 sit-in' that took place in San Francisco, in the federal building for the Department of Health, Education and Welfare (Pelka 2012; Shaw 2013). This building sit-in lasted for 28-days and was participated in by approximately 150 people from diverse backgrounds, most of whom stayed there for the duration of that time. There were various official attempts to force those involved out of the building by means of cutting off phone communication, power, and water. Rumours were circulating that there was a bomb in the building and to evacuate those inside, but still, those present chose to remain there – singing, chanting, conversing, and acting in solidarity. Some decided to partake in hunger strikes, on



principle. Others were fed by members of the Black Panther Party who were not only supporting one of their members but also the cause itself. What is more, the initial obstructions to the cause were countered when George Moscone, the mayor of San Francisco, visited the protestors and invoked emergency housing regulations; organising for bedding and shower equipment to be delivered to the premises (Pelka 2012).

Those in the building were dedicated to the cause and prepared to stay for as long as it took. O'Toole recalled: "We realized about five days in that they couldn't beat us. About ten days in, the media realized that this was a great story. We were breaking the record for a sit-in." (in Pelka 2012, p. 14). The determination of those involved paid off, and Section 504 was passed, virtually unaltered. Kitty Cone, another pioneering Disability Rights Activist, described the victory as thus:

Everyone was absolutely jubilant. We held a news conference, and we talked about how happy and proud we were that for the first time there was a federal civil rights law that was going to be implemented covering people with disabilities and that we felt that we had been victorious. We planned this victory rally, and it was something else. All the media was there, all our supporters came out, and we marched out of the building and down through the UN Plaza and held a rally. You can see tapes of people coming out of the building, and they are so happy, and everybody's carrying their sleeping bag. It was probably one of the highest moments in many of our lives. I would say that there were victories on many levels that came out of the sit-in. For one thing, it was the public birth of the disability civil rights movement. People's image of themselves changed, and people felt so proud of themselves (in Pelka 2012, pp. 281-282).

## CHAPTER TWO: DIS/ABILITY AND SOCIAL CHANGE

Whilst commonly referred to in singular form, social movements linked to dis/ability rights are not a monolithic entity, but rather they have existed in multiple (often contested) forms. Disability Rights Movements (also referred to as 'DRM', or as Disability Movements) are part of a long lineage of emancipatory social and political actions that emerged globally throughout the twentieth-century. Multiple iterations of these movements and related social justice projects (for instance, impairment-specific causes, Independent Living Movements, and focus upon accessibility) have become global, guided by diverse ethos, and have manifest in different forms. Furthermore, whilst Kitty Cone, in the previous interlude, refers to the 504 sit-ins as the public birth of the disability civil rights movement, this may also be contested, depending on how disability civil rights is framed. For instance, there are many examples of resistance and collective action that predate the 504 sit-ins (including soldiers rehabilitation movements following World War I, and the shifts in public consciousness that arose in response). Examples of this are outlined in historian, John Matthew Kinder's (2015) book, 'Paying with their Bodies.' 504 was, nevertheless, one of the most prominent protest events in the area of dis/ability, and one of the first to be spoken about in terms of a civil rights movement for disability rather than in medical or rehabilitative terms. The radical efforts and demands of those involved with 504 also reached public consciousness, particularly through media coverage, and arguably inspired broader acts of resistance and pushes for change to ensue (Pelka 2012).

The scope of thesis is such that dis/ability rights efforts drawn upon and discussed from this point on will predominantly relate directly to those which have occurred, or are most relevant to my homeland: Aotearoa, New Zealand (a small, geographically isolated country, located in the South-Western Pacific Ocean).<sup>17</sup>

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<sup>17</sup> New Zealand is a bicultural nation. 'Aotearoa' is the Māori name for New Zealand and is often translated as 'land of the long white cloud.' British colonists later named the country 'New Zealand' and it is now common for both names to be used interchangeably.

### *TURNING TO NEW ZEALAND*

New Zealand's local revolutionary and pioneering spirit was stirred in the aftermath of social and identity-based movements worldwide. Indeed, movements such as the American Civil Rights Movement, Women's Movements and Disability Movements, symbolised, at their core, the extent to which change is possible by means of collective action. Drawing inspiration from this, dis/abled individuals and groups across New Zealand set about conceiving of their own Disability Movement(s) in the 1970s (Moriarity and Dew 2011). Activities organised under the banner of these social movements were quieter and less visible than the likes of the 504 building sit-in. Nevertheless, the work involved was momentous for many, and these social actions occurred at a time in which dis/abled people were generally institutionalised or, horrifically, starved following birth on the recommendations of hospital staff. Inaccessible physical and social spaces routinely excluded those outside of the dominant able-bodied citizenry (Stace 2007). In addition, there was an absence of legal protection until 1993 when the *Human Rights Act* identified dis/ability as legitimate grounds for discrimination (New Zealand Government 1993).

The lack of legal protection for those with dis/abilities, and the proliferation of institutions which characterised twentieth century New Zealand remained as 'unquestioned' normality for some time. Historically, support and care for people with dis/abilities had been framed in terms of individual responsibility. That is, it was left up to individuals and their family members to attend to the needs of dis/abled individuals or facilitate their care. This then expanded to include church-based services. One of the earliest examples of this can be traced back to the 'St Joseph Home for Incurables' which was founded at Island Bay in 1899 by Mother Mary Joseph Aubert and her Sisters of Compassion (Sullivan 2011). In 1907, they also established the Home of Compassion as a means through which to care specifically for dis/abled children (ibid).

In chapter one, I referred to the relationship between modernity and disabling social processes (Hughes 2002). This understanding is important to return to as institutionalisation follows in this tradition. That is, institutions for dis/abled people (as with prisons) played a central role in helping to 'purify,' 'sanitise,' gentrify, and make 'society'

orderly: all of which are central to the maintenance of a particular kind of designate 'normal' or 'safe' space in social life. Disabled people could be placed in institutions, criminals could be put in prisons, and those with mental illness ~~in~~ were housed in mental asylums, and thus, the unruly matter-out-of-place that was associated with anti-social behaviour or subnormativity was removed from visibility. Institutionalisation can thus be seen as a strategic part of the process of 'cleaning up.' Life within these institutions tended to be dismal and frequently characterised by human rights violations, including systemic forms of abuse (Department of Internal Department of Internal Affairs 2007).

The embracement of a socially democratic welfare state in the 1930s, marked by the election of New Zealand's first Labour Government (led by Michael Joseph Savage), saw social and political shifts ensue. It was at this point that the Social Security Act 1938 was introduced: espousing a greater ethic of care, from cradle to grave (Cheyne *et al.* 2008). Jane Kelsey (1995) highlights that it was this move that ultimately contributed to the heralding of New Zealand as the birthplace of the Welfare State, as it once stood. As a touchstone of sorts, the Social Security Act initiated improved welfare provisions. Whilst these were limited in terms of dis/ability, socially democratic ideologies, coupled with changing post-war attitudes, saw measures such as economic support and convalescence directed towards injured soldiers (Stace 2007). Advocacy groups for people with dis/ability (often established by family members) also grew throughout the 1900s (Sullivan 2011).

Through the development of social models of disability, the birth of historical Disability Rights Movements, and calls for '*Nothing About Us Without Us*'<sup>18</sup>, topics such as autonomy

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<sup>18</sup> Tracing the lineage of this term is difficult. For instance, Charlton (1998) writes that he first heard it expressed by leaders of Disabled People South Africa, who, in turn, had heard it expressed by 'someone' who came from Eastern Europe, and proclaimed it at an international disability rights conference they were attending. It is a slogan that became synonymous with Disability Movements, particularly in their earliest inceptions. As Charlton explained, control – and the wish to assert control over one's own life – has been central to Disability Movements. Many of those involved in Disability Movements drew inspiration from the social movement slogans that had gone before them: "Our

were brought to the fore from the 1970s onwards. The climate of the times began to change. Rather than accept deficit-based services of the past, which had lacked insight into, or concern for, lived experiences of dis/ability, dis/abled people pushed for change. This can be seen through the establishment of Disabled Peoples Organisations – created for, and by, disabled people in order to promote and work towards goals such as advocacy, activism, and politicisation of disability.

One of the most well-known disability rights activists in New Zealand is Robert Martin, who was institutionalised during the 1950s and the 1960s at the Kimberley Centre in Levin. Martin has played a key role in educating the public about the impacts of institutionalisation, and in supporting the realisation of disability rights. In his biography, Martin recounts his childhood, his experiences of institutional abuse and his difficulties with trust that were the legacy of his experiences. As he reveals:

We were locked away from the community. We were locked away from our families. We were the forgotten children: the secret ones. I know of people who grew up at home with their mums and dads, who only discovered as adults that they had a sister or a brother living at Kimberley. For us, the ones inside, it was a lonely life. We grew up with hundreds of people around us, but as a little boy I didn't know another human being. Not properly (McRae 2014, p. 15).<sup>19</sup>

Martin's account illustrates the high stakes involved in dis/ability advancement prior to the implementation of the Human Rights Act of 1993. The years of turmoil associated with the rise of social movements were followed by a time of improved means of communication and easier distribution of new ideas across borders. As noted by scholar, Margaret Tennant

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Bodies Ourselves" and "Power to the People" whilst simultaneously exercising caution of giving this power away to those they perceived had been at the 'hands of' their oppression (i.e. non-disabled people).

<sup>19</sup> The Kimberley Centre was an institution for intellectually disabled people, based in Levin, New Zealand. Martin was institutionalised at the Kimberley Centre from 18 months of age. It was originally called the 'Levin Mental Deficiency Colony' and was finally closed in 2006 (McRae 2014; Stace and Sullivan 2011).

(2007), there were a host of new opportunities for networking with dis/ability allies on a global scale. New Zealand dis/ability activists allied with the organisation '*Disabled Peoples International*,' and numerous other organisations (including the '*Disabled Peoples Assembly*' or, the 'DPA') were established in the 1980s. These organisations were created *by, and for,* dis/abled people (ibid).

The pervasive social inequity experienced by those with dis/abilities provoked greater motivation towards change. Brazilian Educator and Philosopher, Paulo Freire's (1972) concept of 'critical conscientization' can be drawn upon to articulate the social processes involved in the journey towards the politicisation of dis/ability. In short, conscientization involves a combination of engaged social action with self-reflexivity, leading to a conscious shift, or awakening with regard to the conditions of oppression that were previously unconscious, or invisible. Martin's biographer, John McRae (2014), offers examples which illustrate the connection between Martin's experiences and the concept put forward by Freire.

In an interview with Alison Campbell, who was one of Martin's mentors and teachers. Campbell empowered and supported her clients, including Robert and his peers – some of whom had been institutionalised, and others who had lived in assisted living scenarios. She worked with them, demonstrating different ways to 'be' in the world, and supported them in learning how to live life. This involved, for instance, the teaching of essential life skills. In addition, she mentored them and focused upon teaching them how to advocate for themselves and others. In his biography, Martin reflected upon ways in which some professionals approached him and his contemporaries (with intellectual and learning dis/abilities) in a paternalistic way. Campbell's approaches were entirely different to this, and she provided an example of the power of relational and affective bonds. Many of those that Campbell empowered, including Martin, similarly offered support to other people around *them*.

Campbell recalls how particular circumstances affected the intellectually dis/abled:

They'd lived a cloistered life. ...Now they started to see how other people lived. They started visiting my home and the homes of people whom they'd befriended ... and they were able to see

the big differences in the way they were living compared with the way we were living (McRae 2014, p. 65).

As McRae writes: “Inevitably, they began to question why their own lives were so constrained, and some began to reflect on human rights and power” (ibid). In 1982, Martin supported his peers in organising the ‘*Client Committee.*’ Here, those involved would engage in dialogue, identify social problems, and consider how they might create change.

In examples like this, what is most evident is the gradual development of confidence in self-determined futures, or an over-coming of the conditions within which dis/abled individuals had thought of themselves in much the same manner as able-bodied people; a realisation, as had happened with Civil Rights in the US, that the narrative of impairment that had been unquestioned for so long was, itself, impaired.

### ***TRIUMPHS AND CHALLENGES: DIS/ABILITY IN THE DECADES FOLLOWING***

Literature that engages with *New Zealand’s* Dis/ability Movements can be difficult to come by. Highlighting this, Stace (2007) suggests that this may be because “disabled people have often been locked away or marginalised – not for anything they had done but because of who they were. They were seen by the dominant ‘able’ culture as not fully human – ‘other’ not ‘us’” (ibid). This statement, and the relative invisibility of dis/ability history within New Zealand, raises critical questions linked to personhood and citizenship that remain unstable signifiers, covertly attached to people with dis/abilities, and potentially, perpetuating hidden stigmas.

Emancipatory social actions conducted under the banner of various Dis/ability Movements have now spanned nearly half a century. In their quest to drive and secure fundamental social and political victories, those at the forefront of these movements are often credited for contributing to a trajectory that has supported cultural and societal shifts to ensue. Concurrently, disability activism and a body of scholarship, particularly in the area of critical disability studies, have contributed to a broadened awareness and re-envisaging of personal and social positioning of dis/ability. As Dolmage explains, at its core, dis/ability rights has

been “...an identity movement – a reclamation of the symbolic power of self-determination” (2014, p. 94).

Those involved in New Zealand’s Dis/ability Movements have galvanised around visions for change, articulated goals related to dis/ability and accessibility advancement, and have engaged in various actions as means to achieve their goals. As mentioned earlier, it is not possible to measure the success of these movements directly. It is, however, possible to look at the topic of dis/ability and accessibility advancement more broadly. Since the birth of ‘the’ Disability Rights Movement within New Zealand, there have been gains, especially in terms of policy and legislation.

Dis/ability activists and allies, many of whom were associated with IHC, helped with the progressive deinstitutionalisation of New Zealand from the 1970s (McRae 2014).<sup>20</sup> The New Zealand *Building Act* was first implemented in 1991, and has been key in stipulating regulations that enable dis/abled people to “carry out normal activities and processes” within public buildings (Office for Disability Issues 2018, para 2). In 1999, New Zealand’s first Disability Minister was appointed, and in 2002, the Office for Disability Issues was established. Initiatives such as the *New Zealand Disability Strategy* (Ministry of Health 2001) and *To Have an Ordinary Life: Community membership for adults with an intellectual disability* (National Advisory Committee on Health and Disability 2003). More recently, and of potential future significance, is *Enabling Good Lives*<sup>21</sup> and the roll-out of a nationwide transformation of the Disability Support System (Ministry of Health 2018).

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<sup>20</sup> IHC is a New Zealand service provider for people with intellectual dis/abilities and their families. The organisation was founded in 1949 by a group of parents with intellectually dis/abled children. Their objective was to increase their children’s rights and access to education and health services.

<sup>21</sup> *Enabling Good Lives* began in 2011, when New Zealand’s then-Minister for Disability Issues, Hon. Tariana Turia, invited the Ministries of Health and Social Development to engage with an independent working group (comprised of stakeholders from within the ‘Disability Sector.’). They



In 2016, Robert Martin became the first intellectually dis/abled person in the world to be elected to the United Nations Committee on the Rights of Persons with Disabilities. Of this landmark moment, as Paul Gibson (New Zealand's former Disability Rights Commissioner) said: "Robert Martin hasn't just smashed through a glass ceiling, he's smashed through the ceiling and walls of institutions that locked him away for most of his early years. Every New Zealander can be proud of his incredible achievement" (New Zealand Human Rights Committee 2016, para 3).

### ***THE WORKINGS OF SOCIAL CHANGE***

In the interlude, I introduced the birth of Disability Rights Movements within America and New Zealand. Many dis/ability scholars and activists have inscribed their visions for social change, particularly as part of Disability Movements, but what exactly does this mean? Whilst the topic of social change has a long history, and contemporary relevance, the concept itself is inherently amorphous: difficult to define, and even more so to measure. Indeed, social change has become "...a catchall term referring to just about anything in a state of flux" (Goodwin 2009, p. 2). Clarifying further, Goodwin adds that most definitions of social change tend to constitute it with collective changes in behaviours, attitudes, and relationships.

Definitions of social change could be said to include any change in 'society,' which is simplistic if the role of agency in social change is queried. It is important to consider whether changes that ensue within social worlds are intentional, the result of unintended consequences, or, rather, part of a natural evolution. To illustrate this, those involved in America's Disability Rights Movements campaigned for change. The signing of Section 504 of the Rehabilitation Act followed, and thirteen years later, the Americans with Disabilities

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were tasked with developing a clean slate approach to day services for disabled people, and ideas for wider 'community' participation. The approach was tested in 2012, starting in Hamilton, Wellington, and Christchurch. Those involved in these pilots were given more autonomy and choice over aspects such as service provisions, personal care, and the way in which they chose to spend allocated funding. This led to discussions of, and plans for, wider transformation of Disability Support Systems; now underway (Office for Disability Issues n.d. )

Act 1993 was introduced. One could argue that this legislation can be directly attributed to the actions of those who campaigned against segregation and discrimination as part of Disability Rights Movements. However, this does not mean that the actions that those involved in the campaigns took were ultimately responsible for the legislative outcome, and certainly not exclusively so. Other aspects may well have been influential, including changing socio-political conditions and cultural values which may, or may not, have resulted from the campaigning itself, and to varying extents.

Many scholars have long sought to understand the workings of social change. Goodwin (2009) traces some of the first examples of this back to Ancient Greece, explaining that Aristotle was fascinated in the topic of change and was amongst the first to try and capture this idea in some kind of scientific manner. The work of Sociologist, Anthony Giddens, may also prove helpful here; particularly his theory of structuration which involves analysing the role of structure and agency in creating and reproducing social systems. According to Giddens, agency is verb: it is manifest in the *doing* of actions. More specifically it:

...concerns events of which an individual is the perpetrator, in the sense that the individual could, at any phase in a given sequence of conduct, have acted differently. Whatever happened would not have happened if that individual had not intervened. (1984, p. 9).

However, in terms of outcomes, and the cause of such outcomes, Giddens further states that it is important to separate out the question of what an agent 'does' from what is 'intended' (p. 10). As he summarises:

The consequences of what actors do, intentionally or unintentionally, are events which would not have happened if that actor had behaved differently, but which are not within the scope of the agent's power to have brought about (regardless of what the agent's intentions were). (p. 11).

Thus, in terms of social change, there are times when an activist will use their agency with the attention of accomplishing a particular goal. The result may be directly related to the activist's action and occur intentionally. However, it could instead be an unintentional consequence, or the result of societal evolution (for instance, a change in values). This makes any attempts to measure and predict social change extremely difficult.

Scholars might also look to alternative conceptualisations of change. Science and technology studies scholar, Israel Rodriguez-Giralt (2011), for instance, proposes a symmetrical approach to social action (drawing upon actor-network theory and the work of Bruno Latour and his colleagues). In doing so, he outlines the possibilities for rejecting dualistic tendencies of the social sciences, and any strong reliance upon orthodox theories of change. Essentially, the symmetrical approach which he writes about, involves a collapse (or, an intended collapse) of structure and agency, the micro and the macro, and instead turns to the performative, relational, embodied, and distributed aspects of action and change. Similarly, Geographer, Kelly Dombroski (2016) offers the framing of ‘hybrid activist collectives’ to identify, name, and understand a “...form of collectivised – yet essentially unorganised – direct action for better worlds” (p. 630). This concept was inspired by the work of Michel Callon and Vololona Rabeharisoa (2003) and Sarah Whatmore (2002).

Systems thinking is another approach, or tool, that may be utilised to view and understand topics related to social change, and action, in a broader and more nuanced way than many conventional analyses allow for (Stroh 2015). This approach can help to avoid the formation of assumptions *a priori* – recognising, instead, that all forms of change and continuity occur in wider, interdependent systems. Arguably, both change and continuity could be influenced through identification of, and engagement with, the *leverage points* that are present within any given systems (Meadows and Wright 2008). These are defined as points in a system which specific small actions can result in paradigm shifts, or significant change. It is worth noting that there are significant scholarly gap in terms of the exploration of nuanced agency, and alternative conceptualisations of change in terms of dis/ability and accessibility. It is my observation that this is particularly so within New Zealand where analyses such as those outlined above, or influenced by systems thinking, appear markedly absent.

Farouk Seif (2005), a whole systems design for social innovation scholar, poses a series of salient questions, worth noting in any explorations of social change. For instance, he asks:

...what is the *ultimate purpose* of social change? In what way can change, in a form of cultural innovation, bring about a sense of *wholeness* in a society? We often speak about *change agents*

– who are the *real* change agents? What role can a social change agent play in the process of *intervention*? And, who *decides*? (p. 4).

There are multiple paths that may be taken in the road to social change. Martin (2009) lists three of the most prominent approaches as conventional politics (by and through governments, and further classified as authoritarian, representative, or participatory in nature), violence, and nonviolence. History is replete with examples in which each of these approaches have been deliberately utilised in attempts to alter social conditions and structures. Many individuals and groups, past and present, have charted visions for change, and have drawn upon a wide repertoire of tactics aimed at making their goals a reality. Amongst these, protest rallies, sit-ins, vigils, employment strikes, boycotts, lobbying, petitions, use of media, education, and wider campaigns (Martin 2009). In recent years, tactics have grown to include the use of social media, and the adoption of corporate models and market strategies, and a rise in social laboratories.<sup>22</sup>

Work such as that offered by Gibson-Graham *et al.* (2013) and Roelvink (2016) demonstrate opportunities for re-imagining social change: by starting wherever one might find oneself, for thinking global and acting local, focusing on ethical relations and negotiations within social worlds, building pockets of community and cultivating conditions of possibility unconstrained by totalising *a priori* assumptions surrounding aspects such as the constitution of society.

Visions for anarchist scholarship, as offered by Graeber (2004) may also contribute to a re-envisaging of social change, Graeber refers to Barbara Epstein's assertion that "...anarchism has by now largely taken the place Marxism had in the social movements of the '60s" (p. 2). Defining anarchism to mean 'without rulers,' Graeber adds that the principles of anarchism, and the emancipatory project it supports, are simple and ancient: self-organisation, mutual aid, and voluntary association. Further, anarchist visions are based upon the premise that

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<sup>22</sup> Social Laboratories are defined as "...platforms for addressing complex social challenges" and are intended to be social, experimental, and systemic in nature (Hassan 2014, p. 57)

“one cannot create freedom through authoritarian means; in fact, as much as possible, one must oneself, in one’s relations with one’s friends and allies, embody the society one wishes to create” (p. 7). This requires, in essence, acts of faith and the embracement of conducive ethical discourses motivated by visions for better worlds.

Humberto Maturana (a Chilean cognitive biologist and cybernetician) has highlighted the merits of exploring not just social change but ‘cultural change’ in greater depth. As he states:

.. [O]ur actions will not change unless our emotioning changes. We live a culture centered in domination and submission, mistrust and control, dishonesty, commerce and greed, appropriation and mutual manipulation ... and unless our emotioning changes all that will change in our lives will be the way in which we continue in wars, greed, mistrust, dishonesty, and abuse of others and of nature. Indeed, we shall remain the same (Maturana and Varela 1992).

Maturana’s premise is simple: a fundamental change in ‘emotioning’ (a term that focuses upon the dynamic mechanisms and nature of emotions and relational behaviours, in action) is needed if dominant attitudes, behaviours, actions, and ways of being in the world are to also be transformed. Throughout his essay and, indeed his larger body of work, Maturana highlights the significance of relational connections; the role and impact of emotions, of language, conversation topics, beliefs, and values. One can extend the basis of this discussion and apply it to the topic of legislative mindsets, whereby it is presumed that social can be legislated. If cultural change is required for attitudinal and ideational shifts to ensue, then legislation alone will be insufficient for achieving desirous results.

This begets the question of whether social change is even possible without genuine attitudinal and behavioural shifts. Certainly, the role of attitudes is significant in any discussion centred on dis/ability and social change. Social attitudes towards dis/ability remain central to the long-term securement of social change. Dis/abled citizens occupy a liminal zone between ability and dis/ability, when there is a spectrum of humanness that involves different kinds of functionality.

New Zealand’s current Disability Rights Commissioner, Paula Tesoriero, has observed and declared that attitudes towards dis/ability need to improve, stating: “My view is that

attitudes towards disabled people remain at best indifferent, and at worst, discriminatory. These attitudes underpin how disabled New Zealanders are treated and valued for their contribution to society” (2018 para 18).

Dolmage writes that social worlds are replete with “... tropes and stereotypes about disability that shape the stories our culture holds on to” (2014, p. 6). Alison Kafer, another dis/ability scholar, narrates her own lived experience.

I have never consulted a seer or psychic; I have never asked a fortune-teller for her crystal ball... and my palms remain unread. But people have been telling my future for years. Of fortune cookies and tarot cards they have no need: my wheelchair, burn scars, and gnarled hands apparently tell them all they need to know. My future is written on my body (2013, p. 1).

Kafer conceptualises how it feels to live in a dis/abled body and links this to what she calls grim imagined futures; a kind of ‘truth’ that suggests an endless and miserable lived experience that is destined to have an absence of meaning.<sup>23</sup> In Michalko’s words, dis/ability, viewed by those ‘outside’ to it, presents as a threat to “the structure of our homeland” (2002, p. 18).

This quote, in particular, links to socio-spatial forms of exclusion and feelings, or experiences, of being displaced (Gleeson 1999; Mowl and Fuller 2001). Moreover, attitudes, or identifiable ideological blocks, are consistent with Mary Johnson’s (2003) examination of progress made in the decade following the implementation of the *Americans with Disabilities Act 1990*. She postulates that legislation itself has done little to improve the lived realities of dis/abled citizens, and nor have its philosophical tenants entered public consciousness. Indeed:

Public discussion has still not gotten around to the new ideas that underpin the disability rights vision. Reasonable accommodation, demedicalization, universal design, customization and integration are simple enough concepts to understand, but hard to implement when the society

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<sup>23</sup> Kafer also advocates for a re-envisaging of dis/ability, and for the realisation of enriched presents and futures to take the place of grim imagined futures.

you live in continues to see people with disabilities as having something wrong with them, needing cure or charitable help, or as sly malcontents trying to get some special rights they don't deserve, creating nothing but problems and extra costs for the rest of us (p. xvii).

What are the consequences, or missed opportunities, in failing to attend to attitudes and the role of cultural change? This is particularly relevant if the goal of that change is to create, or foster, widespread social betterment.

Ultimately, questions of social change – and the measuring of change (whether personal, social or cultural) are entirely subjective. There are considerations, however, that can be drawn upon. One might ask, for instance, whether the proposed or envisaged change is positive, and for whom, as well as the potential consequences of this change if successful or not. Again, it is not simply a matter of considering change in and of itself: questions of what to conserve, or aim to regenerate, are also vital.

It is here that I note that the point of this section is not to set the stage for debates of social change: what it constitutes, how it might be measured, or enacted, and why. This would be a project in and of itself and is certainly outside the scope of this thesis. Rather, it is my intention to simply highlight and acknowledge some of the complexities involved in social justice work. My project, which will be outlined in the proceeding chapters, has been motivated by a desire to 'make a difference', and draws inspiration from the framings and sentiments expressed herein, but it neither constitutes a study of the mechanisms or measurements of social change nor professes to offer more in this area than I am able to feasibly deliver. The points discussed here have been outlined to help contextualize my research and to consider in terms of exploring the enactment of, and possibilities for, more positive social outcomes.

### ***A MOVEMENT FRAGMENTED:***

In the time following the birth of New Zealand's first Disability Rights Movements, the world has become increasingly fragmented and communities are even more atomised. There has been a rise in social entrepreneurship, the introduction of new technologies, social media, and an increased spread of market ideologies and corporate influence, particularly with the rise of neoliberalism. Questions invariably arise in response to this. What might these factors

mean for dis/ability advancement in the twenty-first century, and perhaps even more so, to the realisation of more positive social outcomes?<sup>24</sup> There is also a need to consider, and balance, change and continuity<sup>25</sup>

Importantly, New Zealand's dis/ability movements are still largely invisible and lacking in support. The movement is not viewed as unified, nor as a significant player on the social stage. Rather, many of its projects are relegated to the category of 'issues to treat' from within the Community Sector or Disability 'Sector' - comprised of distinct and siloed services designed to contend with particular facets of dis/ability and accessibility. There are some instances where visions and goals for change related to dis/ability and access have been formed by organisations and promoted as a collective and agreed-upon social good. Presumably, these visions and goals will, or at least *should*, be followed as a true path to change. My participation in the field, however, demonstrated that this is not something that can be taken as read. While the idea of automatic buy-in to such visions is often taken-for-granted by institutional and corporate players, there are groups of people within and outside of the Disability Sector and related fields who actively counter imposed visions for change. Dissenting individuals: some alienated and/or operating from opposing ideological positions, who neither buy into imposed visions, nor feel included within such projects.

Sanders *et al.* (2008) offer a poignant and relevant reflection, "Organisations grow out of particular historical circumstances and have their own internal life cycles and energy phases. Some adapt and change, often momentarily so; others outlive their usefulness and social

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<sup>24</sup> It is worth noting that social justice projects of the twenty-first century – in general sense - vary tremendously. Some may mirror movements of the past; galvanising around a shared vision, and utilising orthodox tactics. Others have taken new forms; sitting outside traditional rubrics used to identify social movements. Corporatised efforts exemplify this well. For instance, social enterprise can be seen to blur the lines between business, charity, and social movements.



relevance and fade from existence” (p. 4). With these sentiments in mind, one might ask: how visible and cohesive are dis/ability or accessibility movements in New Zealand? Do the approaches employed under the auspices of such movements, and the organisations that profess to support these agendas, reflect diverse contemporary social contexts? Have the general populous yet been presented with a clear vision for change? Finally, if a cohesive vision can be identified, who does this vision connect with, reach, and empower, and who might left out, and why?

Need this be the case? And, what are the things to be mindful of when attempting to challenge, or dismantle the status quo? As Kafer writes: “In imagining more accessible futures, I am yearning for an elsewhere—and, perhaps, an “elsewhen”—in which disability is understood otherwise: as political, as valuable, as integral” (2013, p. 3).

One in four New Zealanders consider themselves to have at least one impairment, and this increases as people age.<sup>26</sup> The *2013 Disability Survey* revealed that people with disabilities have a greater probability of living in poverty and are less likely to be in paid employment. In terms of well-being, people with disabilities were reported as being 5 times more likely to feel lonely and isolated than those who are non-disabled. Similarly, people with disabilities reported feeling an average of 5 times less satisfied with their lives than non-disabled people (Statistics New Zealand 2014). The Independent Monitoring Mechanism (2014) further emphasises that whilst progress has been made in New Zealand, significant issues persist. For instance, educative barriers prevail for many disabled children and they also face higher levels of bullying and social exclusion. Additionally, New Zealanders with intellectual impairments tend to have significantly shorter lifespans than reflected in the national

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<sup>26</sup> This number is based on self-reporting of impairment and was ascertained from answers to New Zealand’s national Census, administered every five years. The criterion for which the topic of disability was assessed was based on whether informants considered themselves (or those they were filling out the form on behalf of) to have a “long-term limitation (resulting from impairment) in [their] ability to carry out daily activities” (Statistics New Zealand 2014, p. 2).

average. Indeed, based on findings from 2011, males with intellectual impairments tended to live eighteen years less than the national average and, for females, this number increased to twenty three years less.<sup>27</sup> These findings are despite the work of disability movements nationwide.

Following Kafer, whilst better futures might remain a somewhat distant hope for those living grimly, for many, the idea of 'better' seems achievable and out of reach, simultaneously. Might impairment of all kinds be reincorporated into the human spectrum, wherein dis/ability is differently imagined? Is it possible to move beyond reified deficiency? Can we re-conceive place – albeit defined as distinct geographical locations or particular facets of community – in ways that do not divide, isolate, or repress difference, but instead, would function as a space in which co-inhabitants could experience and cultivate a sense of belonging. Social justice issues remain at the junction of theory and activism, with many hyper-aware that there is a long road ahead.

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<sup>27</sup> There are, of course, many factors that can potentially impact lifespan statistics. However, those I spoke to who have worked in Disability Service Provisions, alongside people with intellectual dis/ability, expressed that they often perceived this to be partially due to systemic failures to engage with and care for people, and to address preventable illness and death through health care and adequate provisions. I was told that lifespan concerns, poverty, and social fractures were “not new issues, but something [dis/ability activists, allies and advocates] had been seeking to improve upon for decades.” One person highlighted the hierarchy that she has observed in terms of types of impairment, and her perception that intellectual dis/ability is often at the bottom of that hierarchy.

## INTERLUDE: CAPTURING LIVED EXPERIENCE

Date: July 19<sup>th</sup>, 2017

Time: 1:00PM (NZST)

Location: Aotea Square, Auckland, New Zealand

40.9006° S, 174.8860°E.

I was sitting in a public square in the heart of Auckland, with a group of friends and acquaintances. The square was packed with people: many eating lunch (surrounded by hungry pigeons, eagerly watching them), and others ice skating at a temporary ice rink that had been set up for winter. The noise of the crowd dampened as we drank our coffee and chatted about life and some of the things that mattered to us. The topic of disability came up. Most of the people in the group identified as disabled and openly shared their thoughts. With their permission, I jotted anonymised notes in my research journal; chronicling the conversation as follows:

Ivy: For the longest time I felt defective because of my disability. I thought there was something wrong with me; that I was broken. I felt so hyper-visible to others and, at the same time, invisible and invalidated. It was this weird paradox. People would either stare or avoid eye contact entirely. Or they'd stare at me, and then quickly look away. I was so self-conscious, and I hated standing out. I felt like my wheelchair signified my deficiencies and people would look at me with pity. I started to internalise that. I'd actually avoid using my wheelchair sometimes just so that I wouldn't be seen in it. That came at a cost, physically. It was a lot of pressure on my body to make myself walk, but it felt better to me than the alternative. I really had to find peace with my life and finally realise that this is the way I function; it is what it is and I am who I am. Once I accepted that, and began working on my self-worth, everything changed.

Saffron: I find it difficult with my impairment. In some ways, I can get away with it being somewhat invisible, unless I use mobility or assistant equipment that would draw attention to it, or I don't plan ahead and then encounter unexpected situations. I really don't want to be marked by it, or labelled disabled, so I avoid using tools that would actually help me with my daily living. I'll use them in certain contexts, where it's already known and I feel comfortable with those around me, but not when I'm around people who don't know me as more than my

disability and might use it to define me. That happens a lot. I've observed, really clearly, a change in attitude if I get 'outed' as disabled, or they find out before getting to know me. Especially with employment. Suddenly the potential employer's expectations of me are lowered and the emphasis shifts to what I can't do.

Rosemary: See, I feel this need to somehow 'prove' and validate my disability. Because it's largely invisible, a lot of people don't get it. They don't get why I'm chronically tired or in pain. They don't get why I'm not more social. And because they can't 'see' it; they're quick to dismiss it. They'll say things like "but you don't *look* disabled!" It's not a well-known or clear-cut impairment, either, so I don't even feel like I belong in the disability community. Sometimes I'd really like it to be more visible so that I didn't have to justify it.

Flora: In the past, I really didn't want to associate much with other disabled people. I had this stigma around it. Like, 'I'm not *just* a person with a disability. I'm not one of them. Look, I'm capable. I don't need anything extra from you because of my disability. I deal with everything behind the scenes.' Also, there was an element of rebellion there. When I was a kid, I was in a special needs class for disabled kids. I was categorised as disabled and everything centred on that. The able-bodied kids were out playing, while we were confined inside or to designated 'safe' areas. It was about rehabilitation, teacher aides, assessments, limited activities for us. They thought these methods were supporting participation, but the class was its own silo. We weren't given opportunities like my siblings and other non-disabled kids were. We were separated and put in this bubble. Later I could take part in sports but only in disabled sports games. It instilled in me this urge to overcome my disability. To leave it behind. I use a chair, sure, but I'm also really independent and capable and I have pushed that image so hard that I get respect for it, now, from the mainstream population who see that I do all these things they wouldn't necessarily think I was capable of on face value. And I get criticised by plenty of disabled people who call me an ableist in my own right – as if ableist is the ultimate insult. I don't deny that I have associated disability with reduced capability. I've seen it as an undesirable thing. That mentality is shifting now. I'm questioning my assumptions. It takes a while, though. And the us/them mentality of the disability community doesn't help.

Nikau: Us/them, yes, and "with us or against us!" It's like 'are you a "crip" or a mainstreamer? If you're not fitting with the image of a separatist and aggrieved disabled person – identity first - then you can go be a mainstreamer. Stay away from us, though, because you're essentially an ableist traitor now.' That happens with the different disability organisations too. You're either

with them or against them, I've found. Then it's like okay, so I'm mainstreamer, except I'm an outsider there, too.

Olive: Has anyone else noticed the hierarchy between impairments? I've seen instances where there's a person with a learning impairment or an intellectual impairment present at an event, for instance, even one like this, and they are treated in an appalling way. The person will be speaking, but the group aren't listening. Not really. They're not trying to connect on a human level; they're showing visible signs of impatience and they're othering the person involved. They might dismiss them, half listen, or skip over their presence or the topic of conversation initiated by the person who thinks and presents in a neurologically diverse way because it doesn't fit with what the others expect or want from a conversation or relationship. Maybe they don't have the skills, the empathy, the care, or concern. Whatever it is, their responses, even when not vocalised, say it all.

Kawakawa: I know all these people talk about wanting to be part of a disability community. I didn't want that. I didn't want to be relegated to this narrow community of people; many of whom I didn't relate to anyway. I found a lot of them bitter and argumentative. And they're mostly from an older generation, too. The sector, the community... it's got this exclusionary set up. There is this mind-set that able-bodied is bad. It's like 'how dare you speak for us.' And even different impairment groups often stick together and exclude, or have issue with, those who are not part of that impairment group. They'll say, often 'you don't understand my experience.' Or they'll be resentful if one person gets funding for something that another doesn't get. And they're usually all about the social model and how everything is the fault of an oppressive society. I don't have time for any of that. So, for the most part, I've avoided the disability scene altogether.

Ngaio: There's something really cool about having people who understand your life experience and who might have shared experience in terms of understanding chronic pain, understanding where to go that's accessible, people who know what it's like to rely on, or even be addicted to, heavy painkillers and the effects of that; people who have ideas about how to do life when experiencing the things that I experience, like pain, like the need for access. I have some mentors who I've found over the years who have been so helpful at guiding me and supporting me through things like transitioning to a wheelchair. But I don't see why that relies on only sticking to a concentrated disability community. I also have friends who are not disabled and yet I connect with them more than I do with many in the disability community.

Daisy: Before I entered the sector, and formed friendships with people with disabilities, I admit I was really fearful. How should I act, what should I say? I didn't know whether to make eye contact and acknowledge a random person with a visible disability, or to look away. I used to get quite anxious and then I'd mess up the interactions. Like it was time to sit down and rather than move the chair so that the person who uses a wheelchair could sit at the table too, I'd freeze. I didn't know whether to offer to move it, to move it without saying anything, or to leave the person to move it themselves. Then I'd made the situation awkward by over thinking it and standing in the way, doing nothing. It seems so simple in retrospect: ask the person what they'd like, but then, also there are those situations where you ask and you get snapped at as a result, and that can put people off. It shouldn't, but it does.

Kōwhai: I've had this tension my entire life: I don't want to be relegated to a disability community either. But I also find it difficult to connect with a lot of able-bodied people. I feel like they don't know how to react to my disability and it makes them nervous. They'll either avoid me, act nervous around me, or change their entire demeanour. Their tone will change when speaking to me. They'll speak slowly. They might want to be extra helpful: to do things *for* me. I don't really know how to respond to that. It used to frustrate me. I'd either get defensive or depressed and then I would actively avoid social situations. But that wasn't exactly helping the cause, and I wasn't exactly having a fun time with it, either. So, I had to think about what I could do instead. I know it's not a one-sided thing. It's just as much about my reactions as it is theirs. Now that I'm a bit older and less anxious, I'm able to approach these interactions more graciously and with educational goals in mind. And my able-bodied friends, they'll say "I didn't know how to relate to a person with a disability until I met you and learnt through the process." I get that. They were nervous about interactions too.

### CHAPTER THREE: STORIES OF DISCONNECT

“Relationships are all there is. Everything in the universe only exists because it is in relationship to everything else. Nothing exists in isolation. We have to stop pretending we are individuals that can go it alone” – Margaret J. Wheatley (2002, p. 23).

As the narratives in the previous interlude demonstrate, multiple forms of separation and disconnect occur in terms of dis/ability. These aspects will be highlighted and discussed in this chapter. Firstly, however, it is helpful to contextualise the topic through a broader lens.

Separation, isolation, disconnection, atomism – each of these, through rhetoric and in practice, are part of wider social processes that have long been in play in westernised contexts. Naturalist, educator, and author, Jon Young (2015), captures this through his assertion that “the history of westernisation is the history of disconnection.” Adding to this, he tells of the military conquests that spread throughout the world, bringing with them loss and destruction, and explicates that these conquests were marked by “terrible moment[s] where all the connective practices that your ancestors were operating with, were taken away.” As a consequence, people were left feeling “...disconnected, disempowered, weak, afraid, confused and untrusting of [those] around them” (ibid, n.p.).

As Junger (2016) muses, it is only in westernised societies that “children go through the well-known developmental stage of bonding with stuffed animals; elsewhere, children get their safety from the adults sleeping near them” (p. 24). This is particularly poignant if one considers that humans might well be hard-wired for connection with one another and isolation thus goes against fundamental neurobiological and developmental needs (see, for instance, Maturana and Varela 1992).

Discussing how social worlds have been formed through time, social thinker, Charles Eisenstein (2012) draws upon the power of cultural mythology and the way in which it informs crucial questions about what it means to be human. He, too, states that from an historical, Western perspective, the dominant story has been one of separation – premised upon scientific dogma. As Eisenstein also points out, this story has had such hold that it has manifested in multiple areas and can be seen today reflected through the embracement of

individualistic ethos, the ubiquity of capitalistic ideologies and systems, and many dominant institutional practices.

Multiple factors have influenced, perpetuated and been strengthened by stories of separation and disconnect (ibid). This includes Cartesian reductionism, and dualism, or binary oppositions (such as mind-body, nature-culture, good-evil, true-false, subject-object, individual-society). One of the most significant binary oppositions, in the context of marginalisation and social divides, is that of *us and them*: originally, a designator for recognising difference between neighbouring groups, now amplified in modern, urban contexts. This us/them framing has become a habit of mind within westernised, binarised societies that pursue (if unconsciously) purity and cleanliness. Whilst it is not a reflection of reality, the power inherent in this binarisation rarely allows for contested social identities or fluctuating competencies in terms of social roles. Val Plumwood (1993) provides a strong basis for understanding the dualistic 'self/us' – 'other' framing and the processes of hyperseparation. Fundamentally, the 'us' part of the equation is recognised as both visible and legitimate, whilst the 'them' part of the equation is invisible and illegitimate, or 'othered.'<sup>28</sup>

Critical to this understanding is that this process is so, regardless of what label groups are marginalised under. Thus, it is not a process or embodied reality that is unique to one group of people (such as dis/abled people) but rather it is one that is shared by multiple marginalised groups. Indeed, there are threads of commonality and intersectional relevance that apply to any topic relating to insider-outsider categorisations. Such groups also go

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<sup>28</sup> Philosopher Lajos L. Brons (2015) attributes the explicit introduction to the notion of “the other” to that of Simone de Beauvoir’s (1949) work. Brons also traces the lineage further back than this, arguing that in terms of scholarship, the concept of “the other” and of “othering” is rooted in Philosopher Georg Hegel’s *Master-Slave Dialectic* (Hegel and Miller 1998). Brons postulates that: “The conclusion of othering is self-other distantiating and dehumanizes the other ... the effect is a near impenetrable border between the self/in-group and the inferior and/or radically alien other/out-group... the other can be constructed as both inferior and radically alien” (p. 72).



through similar processes in the securement of rights, resources, or inclusion (consider, for example, the bid for species membership that was initially central to the Civil Rights movement in America).

### ***MAPPING DIS/ABILITY AND SEPARATION:***

From a New Zealand perspective, citizens with dis/abilities are no longer routinely sequestered and confined to state institutions (many of which were strategically placed upon hills or in other isolated areas, out of sight of the general populous); nor are they routinely subjected to human rights abuses which they had little, if any, legal protection against. Nevertheless, fundamental social issues remain. Steps such as deinstitutionalisation have not equated to the widespread liberation of dis/abled citizenry, as was hoped. Rather, in many cases, new situations which replicate former incarnations of siloed living now appear as managed 'communities.'<sup>29</sup> Independent Living (which coincided with deinstitutionalisation) present an interesting iteration in the journey of Disability Rights in that the pursuit of *independence* might have undermined the role and value of *interdependence* (particularly if, or when coupled with fortress-building ideologies and approaches). The replication of managed communities creates the same processes of separation and community exclusion historically experienced in institutions, just in altered and more widely accepted forms. As a former member of the Kimberley Centre has relayed to me: *at least we had friends there.*

Significant changes in the area of dis/ability provisions and ideological positions occurred in the 1980s, following the embracement of neoliberal market ideologies. Existing literature

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<sup>29</sup> One of the individuals I attended a leadership development initiative with provided a good example of this, asking: "Do you know how many people who are full of life, but disabled, get put in rest homes? Or encouraged to go in rest homes? Including young people. We say institutionalisation is a thing of the past but actually all you need to do is look at the way many disabled people are still housed in rest homes just because there's a lack of care or vision for alternatives." Such accounts have also been published in the news. See: (Heather 2015).

(see, for instance, Stace, 2007) often asserts that challenges within the Disability Sector were amplified by neoliberal reforms and welfare cuts of the late 1980s and the early 1990s. This process resulted in a 'marketisation' of service provisions and the creation of a persistent contracting culture. The implication within such literature is that the scarcity of resources and the embracement of an individualistic ethos heightened competition and division, thereby corroding the spirit of collaboration within the Disability Sector and, by extension, the disability movement as a whole.<sup>30</sup>

Key contemporary influences in play that can be seen to perpetuate fragmentation and division include a neoliberal 'market-based' ethos, globalisation, changes to social relationships, and an ever-changing socio-political landscape. The terms of dis/ability and accessibility advancement are thus in a state of perpetual change. Dualisms and hierarchies exist between in-groups and out-groups (dis/abled and non-disabled, different impairment groups, and organisations), and there remains a proliferation of (often disjointed and competitive) service provisions. Many approaches to, and reactions towards, dis/ability are shrouded in the language and framing of separation - some of which I outline in the remainder of this chapter.

### ***CONSTRUCTING BOUNDARIES: SEPARATION IN ACTION***

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<sup>30</sup> Whilst capitalistic ideologies, individualistic ethos and contractual obligations are all part of New Zealand's landscape and certainly have relevance to topics of separation, disconnection, and individualism, generally and in terms of the marketisation of sectors, the topic is also much broader than this focus often allows. The tendency within classical scholarship to grant society and societal 'forces' an all-encompassing explanatory power postulates a knowledge that is deductive and formed *a priori* (Latour 2005). It could be argued that such a focus merely perpetuates the quiet resignation so often present in discussions of dis/ability and accessibility.

The imaginary terrain of the Disability Sector, in which dis/ability is frequently 'housed', is a core example of separation in action. Here people, groups, and organisations are clustered and confined.

I observed, repeatedly, throughout the course of my research, just how dissatisfied people were with the Disability Sector – whether it be in form, name, or function. Whilst many would consider themselves part of it, they often did so begrudgingly, and were quick to critique it and speak about it as being a fragmented, 'broken,' and inadequate system. When asked about alternatives, there were few suggestions beyond ideas such as changing its names or the title of a group or organisation, or formulating clearer definitions of its purpose and constituents. Many still expressed the belief that they ultimately needed to operate *within* the Disability Sector (and, by extension, the Health Sector, and the Community and Voluntary Sector) rather than *outside of it*, as they saw funding that is often concentrated within sectors as being instrumental to their causes and goals. Many spoke about how isolating and counterproductive they found the Disability Sector to be. One person I talked with commented on this strongly:

So many people talk about the Disability Sector and disability communities. To me, the sector especially feels like another vehicle of exclusion. We 'belong to' and are the 'problem of' some distinct Disability Sector just because we're disabled. How does that actually help anybody?

Ian Parsons (1999) has offered the concept of the *welfarisation of ordinary human needs* to encapsulate sector-thinking and the proliferation of atomised programmes and services that are so prominent within contemporary societies. He describes it as follows:

We see people's needs being understood in terms of programmes, schemes, eligibility criteria, outcomes, outputs, and so on. It is this professionalization of human need which only serves ultimately to let the broader community "off the hook". That is, the broader community need not face its own need to change when there is a perfectly good welfare human service system already in place to cater for the specialised needs of others. Better leave the job to the people who are trained to do it properly. Society, and the people who control it, need not deal with the implications that arise from the fact that those needs only ever become "specialised" in the first place because they were not accepted as part of the ordinary, generic responsibilities of the community (p. 65).

Not only does the welfarisation (or professionalisation) of ordinary human needs point to a significant issue – that of the breakdown or atomisation of community – it also highlights a key paradox in terms of what is at stake when it comes to regenerating community and relationships. That is:

There will always be some inherent and irreconcilable conflicts between the basic human rights issues of social change and the basic human service system's need to maintain, to some degree, the status quo... [T]he human service system, itself, as a system, stands in direct conflict with a society in which human rights are fully recognised and embraced (ibid).<sup>31</sup>

Indeed, if the world is transformed in the ways social justice advocates hope, many of the services created to engage with the 'issues' would no longer be required. As it currently stands, however, the presence of social inequities and reliance on current systems provoke their continuance in a deadly spiral of dependencies. As part of my research I looked within the field, trying to ascertain the type of measures put in place to move change outside of the realms of the confined sectors, or outside the realms of administration via formal organisations. I saw very few examples of this happening, and equally, little willingness to truly conceive of alternatives at a formal, organisational level.

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<sup>31</sup> Contention surrounds Human Rights, particularly in a universalist, legislative sense. Take Tongan poet and academic, Konai Thaman's assertion, for instance, that: "[M]ost international covenants are based on Western, liberal beliefs and values, and like all beliefs and values they are embedded in a particular cultural agenda, where indigenous peoples and their assumptions and values have been disregarded and marginalised" (Thaman 1998, pp. 2-3). Mikaere (2007) provides further ballast for the ways in which human rights discourse often acts as a vehicle for western imposition. Importantly, this argument can be extended to include marginalised groups more generally and is something to remain mindful of in any such discussions.

### *UNDERSTANDING COMMUNITY*

Community is another term that is often used *a priori*. There are literally hundreds of definitions of community – subjective in nature, and often contested. Barke and MacFarlane (2001) clarify that community can be “viewed as a highly flexible phenomenon,” and that it is “rarely a coherent entity that can exist without conflict and speak with one voice. Not only are there many different types of community, but many of us belong to several at the same time” (p. 73).

Indeed, community can refer to a geographical location, such as neighbourhoods – the boundaries of which can generally be delineated with some ease. Conceptual or culturally and symbolically constructed forms of community, on the other hand, are far more ephemeral in nature and cannot be defined in terms of spatial proximity. Communities are formed, or are said to be formed, on the basis of shared classifications or identities – such as dis/ability, gender, sexual orientation, class, ethnicity or race. Interest groups are also commonly referred to in terms of community (comprised of those with shared leisure pursuits, for instance, or those interested in advancing particular socio-political agendas). These can be seen as forms of *claimed* community.

In terms of academic roots, the study of community is widely accredited to German Sociologist, Ferdinand Tönnies and his 1887 book ‘*Gemeinschaft und Gesellschaft*.’ He referred to *gemeinschaft* as a type of community that was characteristic within ‘folk’ or pre-industrial society. It involved tradition, kinship-based affective bonds and social ties that enabled members to engage in cooperative, and morally-driven, forms of social organisation. *Gesellschaft*, often translated as society, referred to a contrasting, individualised and much less personal type of social relations that were becoming dominant in industrial societies (Tönnies 1963). In the 1920s, Max Weber drew upon and developed *gemeinschaft* and *gesellschaft* as ideal types through which to track and understand ways in which social structure and order were evolving with time (Weber *et al.* 1978). Urban scholars, during the early part of the twentieth-century, further proposed that urbanisation was creating a breakdown of community and a replacement of primary relationships (characteristic of *gemeinschaft*) with secondary relationships (Barke and MacFarlane 2001). Whilst glimpses

of strong, relational forms of community have been identified and explored in scholarship (seen, for instance, in the study of some working class populations during the twentieth-century) but such examples of community are often positioned as enigmatic curiosities, rather than the norm within contemporary society (ibid).

### ***THE CREATION OF CLAIMED COMMUNITY***

The concept of a disability community (or communities) is a topic of fierce debate. Some people resonant strongly with the idea and express that they have found a place or home within such a community, whilst others express a lack of resonance toward this idea. The interlude to this chapter, in which I sought to capture lived experiences by way of informal narratives, demonstrates some of the paradigmatic tensions and lived experiences that surround dis/ability and concepts such as a disability community.

There are multiple complexities in play when it comes to relational gaps, and difficulties involved with the politics of identity (in terms of self, and 'others', or the self/other relationship). One of the main issues here links to the fact that many of the general populous simply do not know *how* to respond to dis/ability, or difference. Traditional diversity paradigms have long been utilised as means to promote 'tolerance,' 'acceptance' and 'awareness,' thus reinforcing hierarchy and dualistic assumptions, however the pervasiveness of stigma is awkwardly attended to, if it is attended to at all.

The response from the various Disability Movements has been to empower people with dis/ability to create a distinct disability identity through which to anchor their cause and establish the basis of a 'disability community.' This identity has, historically at least, been tied to the idea that dis/abled people have shared experience of embodied difference, as well as shared experiences of oppression. The issue with this is that it does not easily account for diversity. Not all dis/abled people share experiences of oppression or have the same perception of them. Some have been raised to ignore their differences and perform *as if* able-bodied. Others have been socialised into a fine-tuned awareness of societal oppression. An identity based upon experiences of oppression (particularly oppression perceived to have been directed at a person for virtue of who they are) is double-coded, depending on context,

as sometimes empowering, and sometimes disempowering. Disability scholars John Swain and Sally French capture one of the tensions here, highlighting that:

First, to be a member of an oppressed group within society does not necessarily engender a non-tragic view. There is, for instance, nothing inherently non-tragic about being denied access to buildings. Secondly, the social model disassociates impairment from disability. It, thus, leaves the possibility that even in an ideal world of full civil rights and participative citizenship for disabled people, an impairment could be seen as a personal tragedy (2000, p. 571).

A siloed effect has been created through the dominance of a social model that has historically encouraged the designation of an individual with a dis/ability to a specific support network, advocacy group, or disability 'community'. In practical terms, this involves impairment-specific advocacy, and other in-house approaches, often reticent to cross impairment boundaries, and certainly reluctant to involve, or conceive of, 'able-bodied' or 'neurotypical' allies as having an equal role.

This critique is identifying that persons with dis/abilities, under the social model, are at the 'mercy' of society in a way that is passive and potentially undermining. Consider the social change slogan of the Disability Rights Movements, *Nothing About Us Without Us*,<sup>32</sup> which may be seen as both a source of empowerment and self-determination, *and* a strategy of containment, setting up borders which expire in their usefulness as time progresses. Social

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<sup>32</sup> Tracing the lineage of this term proves difficult. For instance, Charlton (1998) writes that he first heard it expressed by leaders of Disabled People South Africa, who, in turn, had heard it expressed by 'someone' who came from Eastern Europe, and proclaimed it at an international disability rights conference they were attending. It is a slogan that became synonymous with Disability Movements, particularly in their earliest inception. As Charlton explained, control – and the wish to assert control over one's own life – has been central to Disability Movements. Many of those involved in Disability Movements drew inspiration from the social movement slogans that had done before them: "Our Bodies Ourselves" and "Power to the People" whilst simultaneously exercising caution of giving this power away to those they perceived had been at the 'hands of' their oppression (i.e. non-disabled people).

movements succeed when insider/outsider framings are allowed to break down, as opposed to perpetuating the need for there to be an on-going conflict between the 'oppressor' and the 'oppressed.' Reduction in agency, and potential discourses of disempowerment, could arguably stall social or cultural change.

### ***HISTORICAL PATTERNS***

Historically, there are some clear patterns that are important to understand in relation to claimed disability communities. Firstly, under the dominance of the medical model, people with dis/ability had no real place within their communities. Rather, they were commonly hidden away in institutions, sent to separate schools and denied the right to participate in many areas of life. In this sense the community experienced by people with disability was completely juxtaposed to that experienced or conceived of by many of the able-bodied majority.

Through social models (and further politicisation of disability) people came together to create disability communities; to bond over shared experiences, and often, to work towards shared agendas for change. However, the social model has been predominantly coupled with a mind-set whereby it is assumed that alterations to the physical environment or the enforcement of particular laws via a compliance lens will 'solve the problem' of exclusion.

Neither of these measures is adequate in creating cultural and attitudinal shifts capable of facilitating a sense of connectedness or belonging within community. Yet, successful alternatives are also scarce. Several decades ago, when faced with the prospect of deinstitutionalisation, Gleeson (2013) recalls a proliferation in "...community anxiety; aroused... by the reappearance of these "ghosts" who had long been banished to the margins of social consciousness" (p. 72). The ongoing relational blocks and experiences of social divide further suggest that this was an issue that was never adequately attended to.

Not only does the social model fail to convey the strengths and possibilities associated with disability and accessibility, its focus on disabled people as an oppressed group could, in itself, create – or at least perpetuate – a power differential. Added to this is the ongoing fortress mentality, or the building of ghettos, as frequently enacted within the context of orthodox



Disability Movements. This involves the positioning of non-disabled citizenry as part of the problem. Together, these factors could be said to increase feelings of isolation and negate the premise of community, community spirit, and belonging.

### ***THE PROTECTIONIST GHETTO***

Parsons (1999) captures the juxtaposition between building a protectionist ‘ghetto’ compared to that of an ‘inclusive’ society. He states that the ‘ghetto’ has helped oppressed groups to develop and maintain a greater sense of pride in their identity; thus providing “a place of belonging, a place of value and in this sense equips people, and nourishes them, to keep going along that pathway towards the attainment of their human rights” (p. 99). However, as Parsons also points out:

If we remember that human rights, at a broader level, is ultimately about the creation of a world in which everyone is included, and in which everyone has a place, then we see that total segregation or separatism does not and cannot achieve this level of change. It may create its own microcosmic society in which all of that society’s members are included and have a place, but it cannot challenge or change the rest of the world unless it interacts with it. So this would suggest that at least some interaction with the rest of the world is going to be important if the rest of the world is going to change and if, ultimately, human rights are to be advanced in a more global way (ibid).

Following Parson’s observation, it is pertinent to interrogate what types of interaction with the ‘rest of the world’ have occurred. Accounts of Disability Movements, and experiences from those involved in the work of dis/ability and accessibility advancement, would suggest very little broader social engagement; particularly outside of set (largely divergent, conflictual, and individualised) agendas for change.

Traditionally, groups have engaged with government (for the purposes of seeking policy and legislative change, or increased funding). More recently, the rise of social enterprise and market-based approaches has also seen wider engagement with the Private Sector. It has been my observation that many of these forms of engagement are transactional in nature and approached with a strategic agenda in mind. As part of this, there is often focus on connecting with ‘people of influence.’ Social engagement and the fostering of relationships

in diverse settings and without an agenda appear, to me, to be lacking, and yet something that is certainly needed if relational gaps are to be bridged. Such interactions are very different to those that commonly occur under the title of ‘networking’ which, I would argue, often reduces human connection to a transaction. In terms of mutual engagement, I would also ask, who is being included in efforts to foster relationships, which groups are being left out, and why might this be?

Furthermore, in terms of emancipatory social justice goals, one might query the impact of aspects such as framing and vernacular.<sup>33</sup> Those that are used in contexts such as in the building of protectionist ghettos, for instance, often upon aspects such as the idea that change needs to be *fought for* and experiences, *struggled through*. Keating (2012) makes an important reflection:

[O]ppositional approaches—wherever they occur . . . in the academy, on the street, in daily life, or in the words we speak, read, and think—are too limited to bring about the long-term transformation we need. Oppositional politics and oppositional thinking have not enabled us to radically transform society... [Such thinking] saturates us and limits our imaginations; we define “self and society” in antagonistic, conflict-driven terms. ...Without this larger vision, we remain locked in an embattled, us-against-them status quo. (p. 3).

Oppositional approaches might therefore be seen as another way in which to perpetuate experiences of separation. This point has just as much relevance to the oppositional interactions that often occur *within* the terrain of the Disability Sector (as conveyed through several of the quotes included within this thesis).

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<sup>33</sup> The power of chosen vernacular to describe one’s role and action was demonstrated to the world when, in 2016, a group of Water Protectors joined together in solidarity and prayer, as they sought to protect the water ways of Standing Rock Sioux Reservation from the construction of the Dakota Access Pipeline. Offering alternative ways of understanding social action, they resisted the imposition of labels such as ‘protestors.’ Instead, expressing the importance of being identified as *Water Protectors*, and explaining: “The term protester is a colonised term for standing up for what’s right” (Wong and Levin 2016).

### *SHIFTING THE FOCUS*

To reiterate, despite more than half a century of targeted emancipatory agendas for social justice and change, dis/abled citizenry have not experienced their own 'civil rights' breakthrough. New Zealand's 2013 *Disability Survey* (referred to earlier) paints a dismal picture, consistent with Kafer's concept of grim imagined futures. The task, then, is to counter this with the realisation of enriched presents and futures, in which people can flourish together, and acknowledge dis/ability (whether it be their own, or someone else's) as part of the human experience, rather than as a signifier of a diminished human state.

If distilled, it becomes obvious that within many of the visions for change that have already been chartered and conceptualised by dis/ability activists, advocates, allies, and leaders alike, the core desire (in rhetoric, at least) is the creation of connected communities. The nostalgia and paradoxical homesickness (professed by the likes of Kafer and Michalko, in earlier sections) centres on a 'home' that many have never actually experienced. Yet, they yearn for it, and can envisage it nonetheless. This is the kind of homecoming *feeling* that might yet be found in the form of connected communities.

Presently, there is much fragmentation, atomism, and the clustering of claimed communities, such as the "disability community." These claimed communities are imaginary communities, based on the perception that those involved are related and have shared commonalities through which they are bonded (Anderson 1991). Connected communities, on the other hand, require what Sociologist Zygmunt Bauman refers to as 'fellow-feeling'. He describes this as the ability and willingness to "...perceive other persons as subjects like us, with their own objectives and the right to pursue them, with emotions similar to ours and similar ability to feel pleasure and suffer pain" (1990, p. 40). The fostering of 'fellow-feeling' is a two-sided process, and does not flourish when dis/abled people are relegated to the margins of the social. For a connected community, you need to not only recognise commonality (through shared humanity) but also be able to engage with, and appreciate, difference.

The preceding interlude conveys how common it is to feel uncertainty as to how one 'should' act or respond in the presence (or absence) of dis/ability. Stereotypes and cultural tropes continue to have a powerful social impact. Even people *with* embodied experience of

dis/ability have demonstrated relational gaps and attitudinal blocks, whether these be directed towards themselves or occur at the interface between their interactions with the 'able-bodied' majority or those who have impairments that differ to their own. These processes begin in childhood, through socialisation and means of enculturation. However, as the narrative content quoted also reveals, these feelings of uncertainty and fear can be successfully countered through feelings of safety, the building of connection, and the fostering of relationships – features that are key to connected community.

There is an assumption (both explicit and implicit) that to step outside of a 'disability identity' (or claimed community) is to assimilate to dominant ('able-bodied' or 'neurotypical') ways of being. Traditionally this has often been the case. Parsons (1999) mentions, for instance, that Disability Rights Movements – more than other social justice or identity moments - have sought to assimilate, to be accepted as 'normal', to pass, and to fit with dominant constructions of normalcy. The deductive assumption that abandoning the confines of a disability-based identity must necessitate assimilation or adherence to a normative identity is not only overly simplistic, it also misses the point. The point is that the realisation of a connected community necessitates a broader focus upon humanity. The shift that is needed is *two-sided* and involves breaking the abled/disabled binary. At its heart, it would require venturing off the beaten track in order to query restrictive patterns and behaviours and instead work towards implementing different ways of thinking and being in the world. Questions such as how to engage with fear, how to mitigate blocks, how to challenge the status quo, to grow connection, and relate would be key. Within connected community it is thus not about 'either' party remaining stationary but rather, it is about both growing and flourishing *together*.

It is possible to model and imagine new ways of inhabiting and supporting communities that are built upon the foundation of humanity rather than restrictive identity positions and other arbitrary classifications. An interaction between Philosopher Judith Butler and artist and disability activist, Sunaura Taylor, captures this in action. The two were filmed taking a walk in San Francisco and conversing about Taylor's embodied and everyday experience as a disabled woman. The topic turned to Taylor's experience in demonstrating a different type

of human functioning, and the way in which she sought assistance within a coffee shop. Butler observed:

What's at stake here is really rethinking the human as a site of interdependency ...You're basically posing the question 'do we or do we not live in a world in which we assist each other? Do we or do we not help each other with basic needs? And, are basic needs there to be decided on as a social issue and not just my personal, individual issue, or your personal, individual issue? So, there's a challenge to individualism that happens at the moment in which you ask for some assistance with your coffee cup. And hopefully people will take it up and say 'yes I want to live in that world in which I understand that we need each other in order to address our basic needs... and I want to organize a social and political world on the basis of that recognition (Taylor *et al.* 2009).

Butler's words promulgate the necessity of interdependence as part of the universal human experience. In doing so, they also capture the potential that dis/ability offers in terms of conceptualising aspects such as what it means to be human and how we – as citizens of the world – might begin to conceive of shifts surrounding the ways in which we think about, and relate with, one another, as well as our understandings towards the commonalities and differences that form the fabric of our humanity.

## INTERLUDE: SINGING THE PRAISES OF LEADERSHIP DEVELOPMENT?

Date: Winter 2018

Time: 3:00pm (NZST)

Location: Wellington Waterfront, Wellington, New Zealand

41.2865° S, 174.7762° E.

I was having lunch with my friend and colleague, Amaranth. We had both participated in different leadership initiatives aimed at dis/ability and/or social change, and these experiences formed a large part of our dialogue on this particular day.

Amaranth: I'm noticing in Australia, and here, that there is this idea that we have entered a new era in social change. Whereas the focus used to be on advocacy, I find more people shifting away from that now. They'll say that advocacy and activism are outdated and leadership is the way *forward*.

Me: Yes, I've noticed that, too. Leadership is framed as a 'post-activism' of sorts. A *replacement* for the failed efforts of the past, and is assumed capable of succeeding where others have not...

Amaranth: A magic bullet (laughs). Is it actually succeeding though? That's my question. Even the aims of leadership development are so vague.

Me: Yeah, it's often spoken about in terms of building a critical mass of supporters, capable of driving social change.<sup>34</sup> But, explanations beyond that point tend to falter... What are the aims and goals? Is there consensus involved? What kind of difference are organisations or services hoping to make, and how? Who benefits? Who doesn't?

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<sup>34</sup> Critical mass can be understood to describe the point at which the necessary scale is reached in order for a particular system to become self-sustaining and capable of powering additional momentum. In terms of collective behaviour, critical mass can be seen as important for understanding, anticipating, or aiming to achieve particular forms of action (Ball 2004).

Amaranth: Yes! And what type of social change, and how is all of this measured? Can it even be measured? I've participated in courses and programmes here and in Australia and some of the practices that are happening in and through the leadership development services are so problematic.

Me: Can you give some examples?

Amaranth: Well, for one, I'm seeing the creation of a new 'us' and 'them' and this is being perpetuated in and through some of the leadership development initiatives themselves. There are rules in place. Choose your side. Are you with 'us,' as an organisation or programme, or are you not? If you don't align with our thinking, then you are not one of 'us,' you're one of 'them.' You're either with us, or you're an enemy of ours. The oppressed are becoming the oppressors in a way. Conflicting views are silenced. It's colonising. For some, there is a focus on how disabled people were oppressed under the label of disability, so we've gotta transcend that. 'Don't define yourself under those terms. We'll liberate you from the label.' This is, in some ways, great. I'm not a fan of labels or medicalised thinking, and there is always more to a person than their disability. The problem is that the way this is being approached runs the risk of erasing disability from the human experience. Is that not assimilation, and repression? Disability is part of humanity, too, so how do you reflect that rather than stifle it? I think the reverse is true, too. The 'be-so-very-disabled camp: have an immovable disability identity that defines who you are, speak and think of yourself through disability first language, and shun-the-ableists, or *you're part of the problem.*' Where is the mid-ground?!

Going back to the notion of the oppressed becoming the oppressor, Amaranth further observed

I think when those are the terms you're used to operating under, you don't necessarily know how to break free of them, so you perpetuate them. The disability community want to take the power back, but how do you do that? And the default is either to choose to do it through combat, or through assimilation. You want to influence government and corporations rather than antagonise? Then blend. Become part of a broken

neoliberal system that perpetuates injustice in order to count, and to not be left behind. That logic doesn't work though, It creates new forms of elitism and privilege. The disabled people who 'belong' in the mainstream, and those who don't. Often those who are wanting desperately to be part of the system start to embody it, to lose empathy, to become blind to their own financial and intellectual privileges, for example, and to promote the idea of self-responsibility, self-imposed victimhood, and a crafted image and performance that enables someone to pass within mainstream contexts. The question I come back to is who is being left out here? Is leadership, under these terms, really a solution, or is it part of the problem? The latter, I reckon, and I would be very reluctant to involve myself in leadership development again for these reasons.

Many I spoke to during my research shared the observation that there is a crisis of leadership in the imagined terrain of the Disability Sector. Equally, however, I also noted an *a priori* postulated time and again: not only is leadership thought to be the key for engaging with social issues; it is also touted as a means through which to *drive* amorphous ideas of social change. As the dialogue above suggests, leadership development does not always create social good and, in some instances, it might be seen as counter to such visions. Before accepting the *a priori* that leadership development is *the way forward*, one might query how different forms of leadership development work and to what degree. Are such initiatives creating new paradigms, or are they instead strengthening and/or reproducing existing paradigms?



## CHAPTER FOUR: TURNING TO LEADERSHIP

Leadership is a popular term within the modern lexicon. However, just like many of the other concepts discussed in this thesis, it is notoriously difficult to define. There are so many diverse and contested definitions of leadership, and the concept has been used so often in popular discourse, that it can be argued that it is no longer conceptually intact (Raelin 2016). It is important to note that leadership seems a fluid and dynamic process which is variously conceptualised and enacted. Mention the concept, and diverse images are likely to be conjured; amongst these, the idea that the role of leadership is supposed to provide direction, facilitate, guide, conduct, or organise. Leadership can be seen on a spectrum: on one end, to have the purpose of service or empowerment; and, on the other, as a means by which to manage, dominate, control, or command. Warren Bennis, a pioneer in Leadership studies, offers his simple definition of leadership, stating: "...the purpose of leadership is to 'remind people what is important'" (cited by Cashman and Forem 2003, p. 273). What is not so simple, however, is ascertaining what exactly is important and to who.

### ***LEADERSHIP STUDIES***

Throughout history, scholars have explored the idea of leadership and the formalised Western study of leadership can be traced back to the nineteenth century (Nahavandi 2015). More specifically, to the Industrial Revolution: a period which introduced, and enabled, a new focus upon production, management, and economic development (ibid). The study of leadership has therefore (and, understandably) been predominantly underpinned by westernised ideologies. Through the application of quantifiable research methods and other approaches thought to support 'scientific rigour,' scholars have atomised and disseminated the topic of leadership: searching for associated traits, qualities, and/or behaviours.

Leadership studies scholar, Afsaneh Nahavandi (2015), highlights the evolution of modern leadership theory, dividing it into distinct eras: the *Trait Era*, from the end of the 1800s through to the mid-1940s; the *Behavioural Era*, from the mid-1940s through to the early-1970s; and the *Contingency Era*, which first emerged in the 1960s and is still widely-accepted today. Nahavandi also argues that a 'new' approach has emerged more recently (first coming to prominence in the 1970s, but not actually termed an 'era') labelled the *Neo-Charismatic*

view of leadership. This iteration in leadership theory concentrates upon different aspects, such as relationships between 'leaders' and 'followers',<sup>35</sup> and explores charismatic and visionary forms of leadership (ibid). To provide further context, each of the areas that Nahavandi mentions can be précised as:

The Trait Era was shaped by the deduction that leadership is a result of heredity and was supported by 'The Great Man Theory', as promulgated by historical thinkers such as Thomas Carlyle (1897). This theory was based on the idea that certain humans were biologically superior and 'born' leaders, and prompted the utilisation of quantifying tools, such as IQ testing, thus aligning with constructions of normalcy as discussed in chapter one. The Behavioural Era saw researchers endeavour to 'objectively' search for associations between particular behaviours and leadership efficacy. In doing so, they operated on a new premise that leadership could be acquired, rather than stem from 'superior' genetics. It was this understanding that prompted the introduction of leadership training.

The Contingency Era, driven by Fred Fiedler and his introduction of the *Contingency Model*, goes beyond a focus on leadership traits and behaviours in order to highlight the role of situational factors in leadership scenarios. For example, it suggests that different situations require particular leadership styles, personalities, and behaviours.

Each of these 'eras' contains a series of assumptions surrounding ideas of leadership and the constitution of leaders. Whilst separated into distinct categories, these features can also overlap, and have not necessarily been left behind through the emergence of new iterations. When 'Neo-Charismatic' leadership was added to the list of dominant models certain attributes of other model types of leadership remained as part of its definition. Included within this category are transformational leadership (first introduced by Burns, 1978) and authentic leadership, including servant leadership (ibid).

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<sup>35</sup> Assuming, therefore, that there 'are' both leaders and followers, and as approached through a binarised lens.

The ideas that underpin servant-leadership have a long history. As a modern *movement*, and area of scholarship, however, servant leadership was first introduced by Robert K. Greenleaf, who was part of the Quaker movement and took significant inspiration from Christian teachings. He maintained, however, that servant-leadership transcends religion, and can be applied in both spiritual and secular contexts (Korac-Kakabadse *et al.* 2002). Service to others, or leading in order to serve, has become popularly referred to in leadership programmes, however evidence of its genuine application is sparse.

Although grouped under the heading ‘leadership studies,’ this is a diverse area of study and is, by its very nature, a trans-disciplinary pursuit. Many contemporary forms of leadership studies have been influenced by positive psychology (Seligman 2002) and organisational studies (Nahavandi 2015). An additional approach to leadership which is becoming increasingly prevalent and should be included as a key iteration for leadership in today’s world is that which is informed by Systems Thinking.<sup>36</sup>

### ***CULTURAL FRAMINGS OF LEADERSHIP***

Whilst many scholarly explorations of leadership are framed by western ideologies, there are also many other ways of understanding and approaching, leadership that are aligned with culturally diverse, responsive and alternative ontologies, epistemologies, and ways of being. From a New Zealand perspective, Māori worldviews can be drawn upon to inform a very different type of leadership ethos to that which often resides in the orthodoxy. Indeed, as Management scholars, Diane Ruwhiu and Graham Elkin (2016) explain, leadership can embody core principles drawn from Te Ao Māori (the Māori world). Specifically, Ruwhiu and Elkin refer to some of the Māori values that inform this type of leadership, including:

- Manakitanga: an ethic of care and generosity that informs relationships and interactions with people.

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<sup>36</sup> See the work of Nora Bateson (2016), who is a filmmaker, writer, teacher, systems thinker, and daughter of the late polymath, Gregory Bateson, for an example of this.

- Whanaungatanga: relationships and forms of kinship in which the interconnectedness of people is acknowledged, valued, and fostered.
- Wairuatanga: the nurturing of spiritual relationships, an acknowledgement of the wairua or spirit that exists in every living thing within the cosmos, and a commitment not to harm this through human actions.
- Kaitiakitanga: a commitment to protect, care for, and act as stewards of the environment.

These values compliment practices and ideologies advocated through ideas of servant leadership (ibid).

Warner and Grint (2006) provide insights into some indigenous North American ways of knowing and forms of leadership. With this, the authors profile a model of leadership titled the '*Tahdooahnippah/Warner Model*,' which considers spiritual aspects, intergenerational roles, and oral traditions.

As stated, their purpose is:

...not to develop *the* American Indian leadership model but *an* American Indian leadership model. There are some similarities across other American Indian tribes but there are also divergences; all we are trying to do here is challenge the orthodoxy of US leadership models, not replace one orthodoxy with yet another (p. 240).

Another example of indigenous leadership knowledge links to a set of leadership attributes that were passed down along intergenerational lines to Lakota Elder, Gilbert Walking Bull. These attributes were shared with founders of the *8 Shields Institute* in America, and now form a large basis of their leadership, mentoring, and connection work (Slavin and Young 2015). The work of the *8 Shields Institute* will be explored in chapter five.

Korac-Kakabadse *et al.* (2002) explore the benefits of spirituality within leadership and provide examples of ways in which leadership can be understood within different spiritual traditions, including Taoism and Confucianism. Varghese *et al.* (2017) observe that there is a crisis in leadership within many westernised contexts, and this is characterised predominantly by a lack of ethical engagement and care. To counteract this, they propose

ethical leadership approaches informed by Indian cultural values. Archetypes, such as Gandhian leadership, and attention to texts, such as the *Bhagavad Gita*, may also be drawn upon to better understand culturally and spiritually-infused forms of leadership (see, for instance, Dhiman 2016). In each of these examples, the ethical core goes beyond 'leadership' as a separate activity, and is instead integrated within one's wider ways of being within the world, which is, perhaps the biggest divergence of all when compared to westernised conceptualisations of leadership.

### ***WHAT CONSTITUTES A LEADER?***

Central to discussions of leadership is that of the composition of a *leader*. The idea of 'a leader' is often implicit within the notion of leadership, and is has a hierarchical foundation. Nahavandi (2015) draws upon popular understandings of leadership to propose the following definition: "...a leader is defined as any person who influences individuals and groups within an organization, helps them in the establishment of goals, and guides them toward achievement of those goals, thereby allowing them to be effective" (p. 25). There are some core assumptions within this definition; firstly, that to lead is to automatically influence others; secondly, that leadership is confined to organisations; and thirdly, that the presence of a leader increases, or 'allows' effectiveness.

In an interview, Margaret Wheatley (an organisational and leadership consultant) expresses the importance of *life-affirming leadership*. She posits that one of the roles of leaders is to help to create the conditions that empower those that they are working alongside to strengthen (or at least discover) their own competence and creativity. Wheatley also offers a definition that is more encompassing than most, extending the criteria by which one might be considered a leader. As she insists:

... a leader is anyone who wants to help and, more specifically, anyone who initiates action to help. It's anyone who sees something that needs to be changed in their world and then is willing to step forward to do something. So, it might be a mother who acts as a crossing guard so that her child is safe going to school every day. It might be a parent who notices that the water is dirty and polluted in his or her town or village, or it might be someone who wants to stop a certain behavior on the part of politicians. The real act of leadership is that you notice

something that needs to be changed and then have enough courage to step forward and make something happen (Madsen and Hammond 2005, p. 74).

Wheatley's conceptualisations of leadership, and what constitutes a leader, fit well with the notion of *servant leadership*. In distinguishing between leadership motivations and what underpins servant leadership, Greenleaf offered the following explanation:

...the servant leader is servant first. It begins with the natural feeling that one wants ... to serve first. Then conscious choice brings one to aspire to lead. Such a person is sharply different from one who is a leader first, perhaps because of a need to assuage an unusual power drive or to acquire material possessions. The difference manifests itself in the care taken by the servant, first to make sure that other people's highest priority needs are being served (1998, p. 123).

I follow the sentiments expressed by both Wheatley and Greenleaf and view leadership in terms of caring, meeting the needs of the group, and serving a vision based on emancipatory social goals. Therefore, anyone who acts with these motives in mind is, from my perspective, a 'leader' in their own right. In saying this, there are issues with the terms and concepts of leader, and leadership, as I outline in a later section of this chapter.

### ***TURNING TO LEADERSHIP DEVELOPMENT***

In recent decades there has been a proliferation in leadership development initiatives, with a focus upon training or preparing leaders. Prior to beginning my research, and as a part of my fieldwork, I participated in some leadership development initiatives (courses, programmes, and workshops) and attended a number of seminars about leadership. Most of these were advertised as dis/ability-based leadership and/or leadership for social change. As a researcher and a participant, I had a unique vantage point that enabled me to learn from the planned and hidden curriculum involved in areas such as leadership development.<sup>37</sup>

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<sup>37</sup> To clarify, I am using the concept of hidden curriculum to capture the unintended lessons, messages, and impacts that happen within a learning environment (or another social environment). The hidden curriculum involves aspects such as the transmission of ideologies, power, values, norms, and beliefs; these are often conveyed through relational engagement, teaching models, conceptual frameworks, strategies, group culture, structure, processes, rules, and so forth. There has been much

I observed a mismatch between the goals and visions articulated within some of these leadership initiatives, and the way in which the pedagogy and relational practices actually *played out*. Confronted and intrigued by what I had witnessed and experienced in these areas, as well as the stories that were conveyed to me by others, I recognised the potential in turning my attention to the topic of leadership development. I returned to some of the data and cultural materials I had previously gathered during my research. This time, I sought to re-examine the topic with a renewed focus. I had a series of questions in mind, as listed below:

- What is meant by leadership development?
- How is it being designed and enacted?
- What are the professed visions and goals?
- How were these visions and goals articulated to those involved?
- Was there a consensus present between those providing leadership development and those participating in the initiatives?
- How was leadership development conceptualised by those involved (participants, conveners, and related ‘parties’)?
- What nuances are involved in creating and delivering leadership development specifically intended for dis/abled people and/or other marginalised groups?
- What nuances are involved in positioning leadership development as vehicles for driving ideas of social change?
- What might be learnt from these examples in terms of ‘inclusivity’, connection, care and community?
- Does leadership development work to create new paradigms, or reproduce existing paradigms, and in what ways?

I utilised ethnographic and autoethnographic data in order to identify themes. These later formed a series of vignettes which showcase some different scenarios of leadership

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written on the topic of the hidden curriculum, particularly within the context of education. Jackson (1968) is often attributed with having first introduced the concept.

development in action. I will include these vignettes in the next section, ‘Tales of leadership development.’ These scenarios are primarily drawn from four different leadership initiatives, which have been given New Zealand native bird titles as pseudonyms: Pīwakawaka, Takahē, Karuwai, and Hōkioi. In most cases, the providers also associated their work with the promotion of social change.

### *TALES OF LEADERSHIP DEVELOPMENT*

#### *— ‘CHOOSING’ LEADERS—*

How are candidates selected for leadership development? In the leadership development initiatives that I attended, and have been told about by others, common processes are often followed. Where it is open entry, one simply registers, or is referred, and pays the fee (where applicable). Where it is limited entry, methods include attending recruitment events, completing application forms and referee checks, and participating in interviews designed to assess the suitability of potential candidates. Suitability of candidates is subjectively defined, with those involved in the selection process appearing to have different rationales behind their decisions.

Some leadership development initiatives make prior or established ‘leadership’ experience a pre-requisite. These initiatives look for ‘talented’ individuals with substantial experience within their fields. In Pīwakawaka, a leadership course designed primarily for participants with dis/ability, I had the following conversation:

Convener: “Very few people with learning impairments have made it past our application process. None at all in recent years: they haven’t even been interviewed as a potential candidate.”

Me: “Can I ask why?”

Convener: “It’s deliberate, we don’t apologise for it. The programme structure requires an advanced ability to engage with complex ideas and materials. It’s also important to realise we’re not a charity. We’re not a support group. We’re about advanced leadership development.”

Me: “Would you consider providing easy-read materials, and so forth, to make it possible?”



Convener: “No. We aren’t going to alter the programme to make it something it’s not. We can’t be all things to all people. “

Reflecting on this stance, a colleague shared their thoughts with me:

Conveners think that because there are academic readings and discussions, that it isn’t the place for people with learning or intellectual impairments. There’s no efforts to question that, to make it more accessible, to provide easy-read materials, to break down the content, to tailor it to diverse learning needs. It’s not even a consideration. “They can attend a different course, tailored to their needs,” I was told. The focus is wrong: looking to make leadership development accessible isn’t an act of charity. There’s an awful lot of variance... of diversity amongst people with learning or intellectual impairments. I’m not saying active leadership roles or leadership development programmes are for everyone, but I am questioning the assumption that one can’t be a leader in their homes, their communities, or their wider society if they have an intellectual impairment, and I question how equitable such decisions are. Some of the most dedicated and enthusiastic people I have met, who show great leadership capacities, are not neurologically typical. Just look at Robert Martin... look at what is possible when the opportunities are there. What are we missing out on when a blanket approach is applied?

One could argue that these excerpts suggest the continued prominence – or legacy – of traits-based leadership ideals. Certain questions are raised around access and perceptions, including whether there remains the view that a certain level of IQ, or normative notions of personhood, are deemed necessary for one to engage in areas of leadership. If this is so, what might the implications be?

### **—FINANCING LEADERSHIP ENDEAVOURS—**

Another question is that of financial means, and what is required in order to access leadership development. There are short courses with low or minimal monetary costs involved, but these are often narrow in scope. Many of the initiatives that go for a longer length of time, or are more comprehensive in scope, cost thousands of dollars per participant. These courses are often marketed as an investment in the leadership development of ‘marginalised groups,’ and/or the promotion of social change, and yet the costs of such

initiatives are generally exorbitant. It is not unusual for the cost to exceed one thousand dollars (NZD) per participant, per session. The total cost quoted for a leadership development course of this nature, tends to be, on average, around 15 to 20 thousand dollars per participant. How are the costs covered? Often the service provider receives a bulk amount of funding provided by the government and/or other funding providers and this is put towards the cost. There may be scholarships or external funding available, and participants are encouraged to apply for as much funding as possible, often from within the Disability or Community Sector, in order to subsidise the expenditure of the primary service provider. Where applicable, and possible, employers or other sponsors contribute towards the cost of an individual's leadership development. Some or all of the costs may also be the responsibility of the participant themselves. Whilst some individuals will have the financial resources available (either personally or through their place of work) to cover such costs, others do not. This raises questions of access, as well as questions as to the target audience for leadership development.

There are also costs that are additional to the course fees. For instance, the costs associated with taking time off from paid employment in order to attend, transportation, and, in some cases, additional costs for accommodation when such initiatives are held outside of the participant's city. From a dis/ability perspective, additional costs tend to be even greater. For instance, there are often costs associated with the funding of one's support worker, over and above their usual hourly wages. This can include covering the costs of accommodation, transportation, and/or meals (including professional catering or meals had at restaurants as part of the course set-up). In addition, a participant may require more hours with their support worker(s) to facilitate their attendance at the leadership development initiative, so they will also have these costs to attend to.

In some instances, participants require additional time off from paid employment in order to recuperate from fatigue experienced from intensive all-day sessions, and tiredness associated with potential travel to and from the course. They may also need to stay the night before, rather than travel early in the morning, in order to lessen fatigue, in which case there are often additional accommodation costs, which can also be expensive. Alongside an increased likelihood of financial hardship, people with dis/abilities also tend to have added

expenses to account for, such as medical costs and not only costs for support workers, but also for assistive technologies or devices. Other aspects, such as accessible transportation and accessible accommodation also tend to cost more.

**—*FINANCIAL EXPECTATIONS*—**

In terms of financing leadership development, there are also other dynamics to consider. In particular, there is the risk that even if a participant receives funding from the service provider in order to attend their leadership development initiative, the costs involved can be framed in transactional or ledger-based terms.

Take the ‘Karuwai’ programme for instance. The cost of the programme (thousands of dollars per participant) was highlighted on a regular basis. As part of the interview process, participants were asked if they would be willing to fundraise to contribute to the costs associated with their participation in the course. This was not framed as a requirement, however, until the course commenced. At this point, it was made clear that participants were expected to fundraise as part of their participation. A partial breakdown of costs was distributed, listing recruitment costs, venue hire, the cost of providing participants with feedback, travel and accommodation for those coming from out of town, and costs for a graduation ceremony upon completion. The conveners shared their hopes that each participant would aim to fundraise thousands of dollars towards the course costs. Some participants panicked, thinking that they would need to go into debt in order to achieve this goal. Throughout the duration of the course, there were regular group discussions, and commentary, in which conveners would state:

“It costs ‘us’ thousands of dollars in funding for you to attend. What will you do to contribute to that?”

“It’s not about what can you get from us. What can you give back? What is your responsibility here?”

“We are going to go around the room and ask that you each share with the group where you are at with fundraising for your place on the course. How much have you raised and what fundraising activities do you intend to pursue?”

Reflecting on these experiences, participants told me that this type of commentary made them feel guilty, pressured, beholden, and stressed. One participant said that she felt like a recipient of charity. Some stated that they found applying for, and being declined for funding grants a challenging process. Others shared stories of their financial hardship, explaining that they were out of employment and/or barely had enough money to cover their basic living costs. Some participants explained that they had already gone into debt, by missing work for instance, in order to attend, or pay for additional support needs. The group check-ins, in particular, caused tension and embarrassment for some participants.

One might juxtapose this with the ethic of care espoused by the likes of Jackie Clark (founder of a New Zealand non-profit organisation known as 'The Aunties'), as captured below:<sup>38</sup>

I've always said: give with love. I want to change that up. Gift with love. Resource with intent, and in a specific and client based - hate the word, it'll do for the moment - way. Bring the focus back to the person who's getting what they need, and not the person who's giving it. Because, and here's something else to think about, there is a huge power imbalance in all of this. You have something they need, they feel the pressure to be grateful. Power imbalance.

We can move from a model of charity where we act as parental, to a model where we act as equals, as much as is possible. Empower people to do whatever they need to do to bring them out of those struggles, if that's what they want to do.

Because, we don't need our community to be grateful. We just need our community to be okay. All of us. To be okay. We can do that (Clark 2018, para 10-12).

Similarly, one might query what counts in terms of contribution. Should money be privileged as the primary means of *giving back* in a way that 'counts'? What about time, the sharing of resources, and other acts of (intrinsically-driven) generosity? Furthermore, is there recognition for what is potentially sacrificed by participants in order to attend the leadership development initiative? This includes aspects such as loss of income, the use of additional hours for carer supports, and so forth.

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<sup>38</sup> More information about The Aunties can be found here: <https://www.aunties.co.nz/>

—*BEHIND THE VENEER: WHEN IMAGE MATTERS*—

“What was created by the era of the proper gentleman was excellent table manners and genocide over most of the surface of the planet” - Terence McKenna (1994, n.p.).

Image plays a significant role in some leadership development initiatives. One of my first insights into this came from writing personalised profiles, which were to be checked by a marketing team and edited in accordance. If a participant were to ask for an amendment to their profile, this request was passed to the marketing team for their approval, and sometimes involved rewording.

More significantly, some organisations or providers of leadership initiatives require that participants explicitly agree not to do anything that might damage the reputation of the organisation or brand involved, although what this may be is not generally spelt out in clear terms. Such clauses can also be accompanied by another expectation in which participants are specifically informed of their *responsibility* to either be an enforced ambassador for an organisation or brand, and/or to be committed to a lifelong membership as part of their graduate status.<sup>39</sup> Others have been informed of this caveat later on: conveyed as an implicit requirement and coming as a surprise to those involved (one participant confided “I feel like I’ve unintentionally sold my soul now”). Can a role, such as organisational ambassador, actually be enforced upon people? What might it mean in terms of agency, personhood, and self-determination? Another consideration is whether pressure to fulfil such a role is heightened, or in any way impacted, by way of guilt, ledgering, leveraging power differential, or indebtedness that might come from receiving funding from an organisation to participate in their leadership initiative.

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<sup>39</sup> One could then argue, or question whether, leadership development initiatives have an extended, self-perpetuating purpose: operating as a marketing tool and/or business strategy to bolster organisational image and produce ambassadors for the brand or organisation’s benefit. In these instances, leadership development might be considered a product, or commodity, just as much, or more than, it is a service or ‘means for creating social change.’

In one instance, the veneer of image was brought to the fore through discussions of a dress code. A participant arrived at the Takahē course venue wearing an anti-establishment inspired logo on his shirt. None of the participants had anticipated that there would be an issue with this. After-all, the conveners had praised civil disobedience on more than one occasion. These sentiments did not, however, extend to clothing choice. The conveners expressed their concerns that it was a show of disrespect and inappropriate to wear in the presence of guest lecturers who would be in attendance that day. The participant, once confronted with this reaction, walked out and went home. This upset the other participants. When challenged by their reaction to the participant's choice in clothing, the conveners mentioned that they would consider re-introducing a dress-code. This was not well received. In small group conversations, participants privately expressed concerns with censorship, perceptions of elitism, the stifling of self-expression, and "prioritisation of small issues rather than focusing upon what really matters, like important leadership issues and world crises." During a break, a participant named Fern observed:

In rhetoric, we're meant to be radical. We're meant to be challenging day to day opinions. But then, we're not. There's no congruence. It seems we're actually meant to conform to a colonisation or post-colonial type of perspective. Act like this. Present yourself like that.

I went home that night and mused about the contradictions in having censorship and malicious compliance as part of leadership development. It certainly felt as if this situation was counter to the intentions of supporting transformative change in the world.

### **—THE CLASHING OF PARADIGMS—**

I observed that within leadership development initiatives it was common for practitioners to express humanitarian goals, corporate goals, and a mixing of the two, sometimes in total opposition to one another. There was, for instance, a tendency amongst many I encountered to express some strong humanitarian goals, which they then sought to promote, or enact, through (often incompatible) corporate models. Similarly, other westernised approaches tended to dominate. Thus, there was many an occasion when paradigms clashed, and tensions ensued.

One of these examples occurred at Takahē in direct response to the scenario outlined above in which a participant was challenged for his clothing choices and walked out. During a heated group conversation, the following exchange took place:<sup>40</sup>

Convener: “Leadership is about staying on the bus. Ultimately, that participant chose to get off the bus today. That was his decision.”

Participant questions:

“Does this apply if one finds oneself on a bus headed to a destination they neither signed up for nor want to be taken to?”

“Who drives the bus?”

Convener: “We all drive the bus.”

Participant: “But do we, really? Can we actually say that?”

Convener conceded: “Well, okay, maybe we [conveners] do drive the bus, but that is part of our role.”

Participant: “Then wouldn’t it be good to make this clear, from the start? To know and discuss our roles?”

I encountered many other instances in which paradigmatic tensions were in play. I was not alone in these experiences or observations. For example, a fellow participant, Kāuri, shared his experiences at Hōkioi:

It was very Eurocentric. The facilitators were the teachers. We were meant to learn from them and from other experts, and to give deference to the experts. They didn’t overtly seek knowledge or experience from the group in any meaningful ways. The hierarchy was obvious. They controlled what happened and when. Attendance was compulsory. Attendance was often prioritised before the individual’s well-being. Different learning styles weren’t acknowledged or catered to overall. There was limited use of the whiteboard, no slideshows, music or video clips, no singing or movement, we were mostly sitting indoors. And only certain kinds of

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<sup>40</sup> This conversation was not recorded verbatim; instead it relies on recollection.

knowledge were shared within the group: ethnocentric, scientific, psychological models, corporate tools, that type of thing.

Nikau shared similar observations:

At Pīwakawaka: was very much about formalities. Only speak when called upon, or when you've raised your hand. Don't talk too often, if you're that way inclined. But talk more if you don't talk 'enough.' Either shrink yourself or elevate yourself to reach the preferred mid-way point. There were set outcomes expected too: steady flow in conversation, avoid silence, maintain eye contact, be mindful of your expressions. There are differences involved in interpersonal communication. Western approaches aren't always suitable. I guess I'd like to have seen acknowledgement of that and contemplation around, you know, what might leadership look like in other contexts? I don't mean in a tokenistic way. I mean genuine curiosity and willingness to learn more, to go outside of comfort zones. And asking: what about power dynamics? Even something like formal clothing choices, power dressing, what's the impact of that? Because it does have an impact. Even the sound of high heels on the floor. All those subtleties matter.

Another participant, Daisy, spoke about being framed as a "trouble-maker" at Takahē. "I was too radical", she explained, adding: "That's the issue with talking about social justice issues but then using a corporate model. There's a mismatch."

Acacia similarly noted:

Leadership, to me, is about supporting voices – diverse voices, not voices that sing in unison. And are these leadership programmes really creating that? To which I would say 'no.' They want to create a unison of voices; everyone singing from the same hymn sheet which is not leadership in my book.

I can relate to these reflections. In most of the courses, I watched and listened as conveners offered public feedback to participants that sometimes made me flinch. After a while, those who were privy to this feedback would voice how they intended to change their regular ways of being to 'fit' with the critiques.

"I'm trying not to ask so many questions."



“I’m going to stop offering to teach others about the things I know about or am passionate about. I’ll be a bit more contained.”

“I’ll be mindful of my role and stick to it.”

“I’ll be less like this....”

I wanted to say *“No, don’t be less. Be more. Be more you. Don’t stifle your generosity, your curiosity, your engagement, enthusiasm, or gifts. Embrace those attributes, please share them.”*

Sometimes I spoke up, but I did this with individuals more often than I did in the group setting. Why was I reticent to say these things within the group, I wondered? Was it a matter of power dynamics? Was I so overtly mindful of ‘my place’ or ‘my role’ that I didn’t want to openly challenge or contradict the conveners? Another participant, Rosemary, shared similar sentiments with me:

The more I think about it, the less comfortable I am with how mouldable I’ve become through my leadership development. I’m checking my behaviours, I’m conforming, not questioning... I don’t feel able to question, I don’t even know how to articulate what is happening. I listen to you and some of the others voicing your thoughts, especially recently, and questioning the fairness of certain actions or why we do something a certain way and I think ‘why am I too scared to do the same? Why am I quick to apologise, to deescalate if I say something that goes against the group norms?’

These questions and scenarios encouraged me to stop and observe what was happening in closer detail. I looked to the hidden curriculum, power dynamics, group culture, and ideological differences.

What might be called ‘westernised’ ways of being in, and understanding, the world can often set default modes of engagement within contemporary westernised contexts. This includes having typically western notions of time and space encoded within the dominant ideology and language (Smith, L.T. 2013). Fixed and linear notions of, and attention to, time featured strongly in leadership development initiatives I was involved in. Sequential, step-by-processes were also favoured, and often stipulated as processes not to be deviated from. One day, a participant diverged from the standard processes by posing a question at the beginning of a guest lecture, rather than at the end.

This created ripples around the room from those so used to adhering to the structures in place, and evaluating one another on the success of following each of the prescribed steps. Even the conveners reacted; one querying out-loud “*what is he doing?!*” and later admitting to the group that watching the participant deviate from the structure had created tremendous stress.

French Philosopher, Michel Foucault, suggests that the use of tools, such as timetables, are often means of socialising people and asserting disciplinary power and control (Foucault 1995). Timetables, prescribed agendas, and the allocated role of a person to act as timekeeper, were common tools utilised in the leadership development initiatives I participated within, and attention was given to the ways in which *order* was maintained. Deviating from the allotted time, for instance, often resulted in obvious discomfort for the conveners, who displayed hesitation, sideways glances, overt checking-of-time, and issued reminders to “*make it quick*” with decisions to “*end it there.*” Many participants also became anxious at the thought of going over time and monitored their actions carefully, ensuring they were adhering to the time restrictions in all instances. This meant that participants were often cut short, even when they were engaging with, or talking about, sensitive topics.

In the Pīwakawaka programme there were examples of gate keeping and instances where ‘experts’ (guest lecturers) were ‘elevated’ above the group in particular ways. Their attendance at the sessions was revered, and there were certain rules in place. One of these rules was that no participant was to contact the speakers, either in their capacity as participants or as individuals separate to the programme. Justifications were given:

It’s important that we – as an organisation – maintain our relationship with these people. They are doing our organisation a favour. Most of them are part of our network. We do not want them to be bothered by questions or contact.

One participant asked if those who came to speak could be given the choice to have additional contact if they wished to. The answer was “*no.*” “Could the group compile some follow up questions, to be submitted by the conveners?” Again, the answer was “*no.*” This provoked thoughts on the financial side of this organisation, and the idea that in a course costing

several thousand dollars, speakers were routinely presented as doing the organisation a ‘favour’. Were they being paid to speak? I wasn’t sure.

One day, a participant, Mataiī, spoke of the way in which relationships and interactions were approached and understood in different cultural contexts and he provided examples relevant to his cultural background. Once they were pointed out, one convener acknowledged cultural differences in this area and then posed a personal challenge to be mindful of these and to suspend such cultural expectations in matters of leadership. In this moment, what I heard (although it is possible that it was not necessarily intended) was a *call for assimilation*. This was a defining moment for me, in which paradigmatic tensions became startlingly apparent, and my unease began to grow.

—“*AT THE EDGE OF VULNERABILITY*”—

Leaders have always played a primordial emotional role. No doubt humankind’s original leaders—whether tribal chieftains or shamanesses—earned their place in large part because their leadership was emotionally compelling. Throughout history and in cultures everywhere, the leader in any human group has been the one to whom others look for assurance and clarity when facing uncertainty or threat, or when there’s a job to be done. The leader acts as the group’s emotional guide - Goleman *et al.* (2008, pp. 17-18).

Sharing elements of one’s life through story or presentation is commonplace in the leadership development initiatives I have attended. There is power in the sharing of these stories, in the coming together to stop and listen to those in the room – friends, acquaintances, even relative strangers. As I sat in these rooms listening to others and waiting to share my own story, I was struck by the courage of those present: individuals sharing glimpses into their lives through stories of traumatic events, death, pain, perceived loss, relationship break downs, self-doubts, and fears. This was juxtaposed, often in the very same story, by elements of clarity, curiosity, determination, regeneration, promise, and hope. In essence, many of these stories showcased the fundamental ambiguity of being human.<sup>41</sup>

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<sup>41</sup> To borrow a term from American Tibetan Buddhist, and teacher, Pema Chödrön (2012).

There were many occasions when I sat there, in awe, listening to the depth and diversity of experience all around me.

I was equipped to listen to these stories and share my own without any significant emotional impacts. However, this would not always have been the case. I had the benefit of having processed my own traumatic life experiences over a period of years, and of entering these leadership initiatives at a time in my life where I had my own version of connected community *already in play* (I'll refer to this informal, kinship-based community comprised of people who are my friends, kin, and mentors, all in one, as 'Pokotiwaha' to continue with the naming theme). When I fell, I had people who would catch me, and we would work through challenges *together*. When I spoke, they heard just as much from what I was voicing as they did from my silences. I had engaged in psychotherapeutic exercises with those who executed them with knowledge, skills, and care. I had utilised neuro-linguistic programming, with gentle reminders from those who knew the processes involved. Over a period of time I experienced a profound shift in my worldview. What is more, I had a repertoire of tools and knowledge to draw upon. Conditions of possibility were presented to me, and I was empowered and supported as I ventured into this leadership development territory. Not everybody has had such experiences to rely upon. This became evident to me whilst attending leadership development sessions, and in the private conversations that ensued.

Rosemary: Did you feel the raw emotions in the room? I felt pain, people hurting. Hurting for themselves. Hurting for others. It took a lot to actually shake that.

Dahlia: I went home and cried. I've just felt down since the last session. Some of the themes that came up in the group's stories... it took me back to a place I hadn't been in a long time, and it sort of escalated over night. My depression is returning."

Sage: We are asked to be authentic in what we share, and they talk about the need to be vulnerable in leadership. I thought I was up to it, but I wasn't. It was harder than I thought. I just needed to be totally alone afterwards, to deal with what came up from my story and from others."

Kawakawa: Some of the sessions, the content covered... I've found myself at the edge of vulnerability. And then there's the tensions that happen during certain sessions. I'm left with a

lot of questions: 'should I be finding this so exhausting? So hard?' Do I want to continue attending?'

Some conveners would advocate for psychotherapeutic methods, but they would enact this in an individualistic manner; there was nobody present to 'catch' those in attendance. Certain individual and group exercises reinforced this. At Pīwakawaka, for instance, I had participants confide in me the following:

Iris: I didn't realise how bad I feel about myself as a person until that one exercise, where we identified our perceptions of ourselves. Then others started sharing theirs, and I saw this group of people, talented caring people, with low self-worth. I became quite overwhelmed.

Bodhi: I'm so washed out. I found that session emotionally exhausting. And there's this lag... it's not resolved, but in terms of the processes and structure, it happened, now on to the next bit of leadership development. No pausing.

Flora: There's a brutal element when you start to uncover, more fully, your self-perceptions and you reactivate old emotions – even unintentionally, just by listening to others. I feel like I'm having a crisis now but I also know that they [the conveners] say that in a programme like this, lots of people lose their sense of who they are. They don't know anymore. Well, what do I do with that? Because this is two days of my life, separated by weeks in between, then it resumes all over again. And sometimes it's intense. And sometimes it's superficial. But we don't talk about the really tough parts. I don't know if anyone else experiences them like I have, and the rest of the time I'm back to my daily responsibilities and I don't know where to begin, on my own, to do this work and keep everything else afloat.

As Bauman elucidates:

Community should be a place where we can count on each other's good will. If we stumble and fall others will help us on our feet again. No-one will poke fun at us, no one will ridicule our clumsiness or rejoice in our misfortune. If we do take the wrong step, we can confess, explain, apologize and repent if necessary, no one will hold a grudge forever. And we will always have some to hold our hands in moments of sadness. (Bauman 2001, p. 2).

What happens, then, when the emotional impact of leadership development is overlooked? When the standard answer provided by those in charge is: "*We are not a support group*"?

When concerns are raised, and participants start to talk about safety, and conveners respond with sentiments such as those that follow?

“Take responsibility for yourself”

”Encourage others to take responsibility for themselves, too”

“There is nothing that we can do about that concern, it is up to the individual involved.”

“Understand the importance of being accountable”

“See this as a leadership challenge”

This provokes questions around safety and trust. In a newspaper article that examined leadership and life coaching techniques used by a facilitator, Sally Anderson, there were concerns raised about the use of psychotherapeutic techniques and approaches with participants. In particular, this article quotes Lynne Holdem (a spokesperson for the New Zealand Association of Psychotherapists), who questions whether those without the appropriate education, skills, self-awareness, and safety guards in place are positioned to assess, and care for, the psychological and emotional needs of participants. Specifically, she cautions: “If you get someone who’s quite fragile and you put them through a process where they stand up in front of a group and become very vulnerable .... [it could be] quite dangerous for someone who has a very fragile ego or trauma in their past” (Wall and Kilgallon 2018, p. 5).

Ultimately, it is important to attend to emotional safety within any leadership, or mentorship, endeavours. Negating this responsibility of care has potentially significant impacts, not just emotionally, but physiologically, and not just individually, but collectively.

### —*WHEN CHAOS ENSUES*—

I was attending a final leadership wrap-up session for Takahē. It had been an emotionally challenging two days. The day prior we had come together at a point in which the group had dissolved into a state of chaos. There was a residual sense of dissatisfaction and hurt (on all ‘sides’) that had resulted from experiences that occurred throughout the duration of the course.

This had been amplified through dissent that had come to a head a month prior, and the participant feedback that followed.<sup>42</sup> In conversation with a staff member, I was asked for input moving forward. Drawing on the work and ideas of Social Scientist Brené Brown (2017), who advocates for courageous or daring interactions, I suggested that the entire group engage in a courageous conversation, together. The intention was to have an opportunity to speak about the issues that had arisen, with the hope of finding some form of reconciliation. I recommended a radical surrendering of power, in which conveners refrained from attempting to control the process, suspended what they thought they knew about the situation, and instead remained open to the process: engaging with the participants on equal terms. I also suggested that participants be informed of what was to happen, and that time be made for the process to unfold. It appeared that this suggestion was going to be followed: an email was sent out informing participants that there would be an opportunity to engage in a courageous conversation together. However, this situation presented uncharted territory for all involved and the conversation did *not* unfold in a predictable manner.

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<sup>42</sup> Feedback was requested following each session, and then distributed amongst the group, with names removed. My own feedback from the month prior had included the following excerpts:

There was a clear opening, here, for some teachable opportunities based upon raw, honest, and vulnerable moments that had occurred throughout the weekend. There was no space made to engage unhurriedly, or at a truly deep and meaningful level. There was an opportunity here to engage in, and supportively facilitate, a courageous conversation within the group.

...Some participants who had spoken [were left] in a very vulnerable and uncertain state. It takes a lot for some people to express honest and contentious views, to then have them skipped over. The wider points raised during this discussion, once it was returned to, were sadly reduced to a narrow 'right/wrong' debate when this wasn't actually the point of what was being raised. There was no need to make it about who was 'right' or who was 'wrong', but there was an opportunity to stop and reflect upon the wider issues in play, to consider the underlying assumptions and tensions, and to use these divergent views as a learning opportunity for all. The reduction of the topic, and the silencing of conflicting views, might have been avoided had it been picked upon and engaged with by the facilitators, and had the group been supported to have this hard conversation, together.

My observation is that in a context that has been framed as 'high trust', there appears to be a level of distrust towards participants – e.g. through the reduction of choice and agency. This may not be entirely conscious, or a point that has been reflected upon before, but it does warrant interrogation. Hierarchical structures, whether intended or not, were evident this weekend and this impacted upon my experience as well as the experience of other members of the group.

Before the conversation began, the conveners acknowledged the tensions that had publicly arisen. They spoke about the hurt they had experienced as a result of participant feedback, and one mentioned that they had never encountered such 'angry feedback' before. In preparation for the courageous conversation, a few instructions were provided. Responsibility was to be placed with the group. We were told that we would have twenty minutes alone to discuss the issues. The conveners said they would leave the room and asked for a timer to be assigned. We were told that it was up to the group to organise this session, to have a conversation together, and to then invite the conveners to return and join the conversation once the twenty minutes was up. We were also advised to discuss how we would like to welcome the conveners back. The conveners said, at the time, that they would remove their professional 'hats' for this session, upon their return and enter the room as our colleagues. They then provided a caveat "After the allotted time period has passed, this will be the end of this topic. We won't be returning to it. We will be moving on from lunch time onwards."

The conveners then left the room, and the participants were left to work out what to do next. There was a lot of uncertainty expressed. The first task was to provide some background context to a participant who had been absent and had missed the tensions that had come up in the previous session. This took some time to convey. Some members of the group took up facilitative roles: expressing feelings, asking for others to comment and share their own thoughts and experiences. Heightened emotions softened as the entire group started to voice things that had, in many instances, been unvoiced since the programme had commenced months prior.<sup>43</sup>

"I didn't know if it was just me."

"I've experienced a lot of anxiety, too."

"This is how I feel..."

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<sup>43</sup> The conversations in this section are largely captured verbatim. This was also supported by notes that were shared with me, and identifying information removed.



“This is what I’d like to see...”

It turned into an informal focus group of sorts. Participants engaged in a collective act of radical honesty. There were discussions about safety, trust, and worries that had been in the background. Some pointed to the ‘baggage we carry with us into the sessions’ and the impact of that. Genuine care and support were extended to those who shared their thoughts. Some added disclaimers. There were worries about voicing some of these feelings. Slowly, though, the sense of safety grew. Participants reassured one another and listened deeply. The group experienced feelings of solidarity. Smiling, laughter, and relief ensued. The discussion was taking time, and not everybody had finished talking. There was more to discuss and to decide in terms of carrying out the structured instructions.

“What if we don’t stick to that time limit, and we tell them we need more time?”

There was a sense of concern, fear even, at the thought of going over time.

“Is that reaction, significant?” I asked, “That there is fear about the thought of going over time?”

We discussed how we could approach it and there was a consensus that more time was needed. One participant went to tell the conveners this, but the intention got lost in translation, and the conveners returned immediately. “We’re not ready. We need more time,” we told them. Tensions were apparent, but they left as we set about the next step, as we had been asked to do, and ensured that everybody had an opportunity to voice their thoughts and feelings.

“How are we going to invite them back?”

“We should move those desks from the outer position, into the circle, so that they are part of the group and sitting with us” participants suggested, and so the configuration of the room was changed in accordance.<sup>44</sup>

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<sup>44</sup> In doing this, there was an intrinsic and intellectual understanding of power dynamics. Whereas the conveners tended to be separate to the group; either positioned at the front of the room, with a distance between themselves and participants, or sitting in separate tables at the back of the room,

“Would someone like to start by thanking the conveners when they return?” We agreed this would be a good step. “What else do we want to share?”

Together we compiled a list, to discuss and offer to the conveners, in an act of transparency, and so that the conversation could be continued if they wished for this to happen.

“Co-authoring” was a goal expressed by the group, as well as:

“Moving forward, together.”

“Thinking about what might work well for future groups. Offering our learnings.”

“We won’t just point out our concerns, but also what we’ve valued about the programme, and express gratitude too.”

As it turned out, the length of time that this process was a source of conflict.

“You haven’t invited us back. You’ve talked at us. You’ve handed us a piece of paper. You haven’t invited us to be part of the conversation, you had the conversation by yourselves.”

“That wasn’t our intention, we want to talk with you,” we explained.

We were told that the session would move on at the set time, and it did. Participants suggested extending the conversation, finding time to talk together – participants and conveners all present. Tensions were evident that day. Emotions were raw. Many were on the brink of tears. This culminated in a state of external chaos the next day. One convener was absent that afternoon and another explained why:

Convener: “We [the conveners] actually felt quite othered. We came back in and you guys went how wonderful it was to talk as a group without us and that everything was okay now. We felt like everything we have done, all year, kind of didn’t matter. So feelings were really hurt by

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the formation of a circle in which we were to all sit at together felt more open and conducive to engaged dialogue. The intention, on the part of the group, was to bring the conveners back not in their formal capacity but as colleagues. For more on this, see the work of Peter Block (2008), who explores the impact of physical space in terms of power dynamics and the building of community in his book ‘Community: The Structure of Belonging.’

that. If you can't see that you're part of the problem, you can't be part of the solution and right now we feel like we are being blamed for this. We came back and we were given a summary of the outcome of your conversation. And we had also agreed that at 12 o'clock we would move on and so we did that."

Me: "We hadn't agreed to finish at 12 o'clock. You guys agreed to finish at 12 o'clock."

Convener: "Why didn't you argue with us? You didn't disagree."

Me: "We didn't feel we were able to."

Convener: "Why not?"

Me: "Because, now..."

Convener: "We weren't invited back until twenty to twelve."

Me: "That was an issue with the process. It wasn't enough time and people can't be rushed in that way. If you look at different cultural contexts, there isn't this emphasis on time and structure. We could have done it your way and we could have had a few people voice a few things and then there would have been a whole lot held in again by the participants here. It was much more productive to put it on the table and then ask how we could respect everybody involved. That was the intention. And you chose to go out of the room in the first place. And then you came back and you felt hurt by the way we had done it. If that was going to be the case...."

Participant: "We needed the structure that you wanted us to use."

Participant: "Our opening was to thank you guys for how far we have come and the fact that we could have these conversations. That's how we opened the session."

Participant: "You didn't want to wear those hats, remember? You asked not to wear those hats when you were welcomed back in."

The conversation went back and forth for what seemed like a long time. Emotions became heightened again. One participant captured the difficulty of the process, and the learning opportunities that might stem from it, speaking up in the midst of the disharmony:

It's been difficult to persist with this programme, to show up. I don't want to be here right now. It is uncomfortable. But there is something important about staying. I am staying, if for no other reason than as a mark of respect to each of you here. Some of this criticism, perhaps there is some truth in it, and some learnings to be unpacked. People have spoken their truth and if that has been hurtful at times, that's a shame, but part of leadership is just bearing that weight and taking it on the chin, as I think we've all done at different times when we've been challenged by each other.

There was a general sense of agreement in response to this. Staying *was* hard. It was tempting to flee. Those who acknowledged this also drew on the fact that they were staying for the benefit of the group. Many present also shared that there had been occasions when the course felt too much: they were anxious, exhausted, and emotionally torn. The work/life collapse was in full force: not just for me, for many involved.

A member of staff present, who had assisted with course delivery, attempted to bridge the conversation:

It feels like things have gotten lost. There's that culture of fear that's present in this room that we've all created, I think. Fear of not trusting each other and then not having those robust conversations. It sounds like together we have all created an environment where people don't feel like they can talk and they feel like they're being attacked. What is interesting that it sounds like it's happening on both sides.

The dialogue above reinforces both how subjective and contested such understandings are. This was not the first time that I had witnessed themes, such as a culture of fear and silencing, and a clashing of paradigms manifest through leadership development or group facilitation. It did, however, serve as a microcosm of the complexities in play, and it presented an important learning curve. I realised, through these experiences, the challenges involved in ideational change and blocks.

The concept of willful blindness is of particular relevance here. Heffernan (2011) explains that willful blindness occurs when "...there is an opportunity for knowledge, and a responsibility to be informed, but both are shirked" (p. 3). Instead, those involved (whether this be individuals or groups) filter out the information that poses a threat to their core or

entrenched beliefs and ideologies. As Heffernan highlights fear of change, and conflict, provides ample motivation to stay in the dark (a decision that, she states, has the potential to be particularly damaging when it occurs within organisations). “An unconscious (and much denied) impulse to obey and conform shields us from confrontation and crowds provide friendly alibis for our inertia. And money has the power to blind us, even to our better selves.” (ibid, p. 4). To change this and achieve the outcomes that so many profess as desirous in rhetoric, one must dare to ‘see,’ and know, no matter how uncomfortable this process may initially be.

### —*IMPACTS, CHECKS AND BALANCES*—

In my experience, and in many of those articulated above, leadership development initiatives can be seen to have been designed and enacted through hyperseparated and dualistic frameworks. Rather than act as a solution to complex social issues, therefore, these initiatives run the risk of creating and replicating new forms of repressive interaction. Through my experiences I encountered several individuals who had been recruited to participate within particular organisations’ initiatives for change but who entered – and left – when they didn’t relate to the messages at hand. In some cases, individuals were left struggling to make sense of what had happened. For others, the experiences that unfolded within such contexts provided contrast and motivation to deliberately query, resist, and *go against* the teachings they had been exposed to. For me, the radical restructuring of my research findings (which initially terrified me) was the ‘take-home’ quandary that remained. Whilst those designing and delivering leadership development initiatives might postulate that the act of leadership development contributes to positive social change, I found it difficult to see evidence of this.

Discussions surrounding political and social issues were certainly prominent in many of the leadership development initiatives I was involved in. Those present frequently articulated some of what they perceived was *wrong* (such as “*social and ecological crises*,” “*systems are broken*,” “*media bias*,” “*corrupt politics*”) and what was *needed* (abstractions such as “*more diversity in leadership*,” “*for people to be bolder*”). Various business-oriented models were utilised, and tools, such as the Myers-Briggs Type Indicator, introduced, and participants

categorised in accordance to their results (think: ‘these are the extroverts, those are the introverts’). Expertise was sought from the experience of established ‘leaders’, some who were involved in areas of civic engagement, social change, and social entrepreneurship, and others who worked in government or for big corporations. Their teachings and experiences were shared with participants, but conveners often stopped short at delineating, disseminating, and looking to extend the different workings of social change in ways one might expect from an initiative aimed at producing social change outcomes. These experiences in the field highlighted that engagement with social change is often indirect and vague in practice. Moreover, many of those I engaged with were intent on advocating for ‘one true path’ to social change, or more specifically, to their understanding of it.

A pertinent consideration, here, links to that of checks and balances. How might one measure or gauge the effectiveness of leadership development initiatives? What constitutes effective outcomes? Does the well-being of the participants factor into this? The most common measures I witnessed being used within the research field tended to link to financial metrics, evaluations, and feedback or ‘customer satisfaction’ scales. I also noted the prevalence with which evaluations would be premised upon reductionist questions, and feedback scales that were positively skewed. An important point here links to the fact that feedback is not often anonymous and there are other unaccounted for factors in place, such as the perceptions of fear or reticence about being ‘ungrateful’ that prevented some of the individuals I met on these initiatives from feeling they were able to leave honest and critical forms of feedback.

In terms of scholarly approaches, Nahavandi (2015) espouses the popularity of different models used to gauge indicators of success. She proposes, for instance, that one might look at factors such as goal achievement, internal processes (including group cohesion, reported levels of satisfaction amongst ‘followers’, and the efficiency of operations) and external adaptability (the group’s aptitude to change and evolution in response to fluctuating circumstances). One might also try to evaluate how participants are responding to the style of communication, building in external checks and balances to mitigate power differentials.

Moving beyond the methodical, and venturing outside of set parameters, Greenleaf shared an alternative approach for reifying the effectiveness of (servant) leadership:

The test I like best, though difficult to administer, is: Do those being served grow as persons: do they, while being served, become healthier, wiser, freer, more autonomous, more likely themselves to become servants? And, what is the effect on the least privileged person in society; will she or he benefit, or at least, not be further deprived? (Greenleaf, 1998, p. 123).

Issues can occur when there is a lack of checks and balances in place. Organisational culture, identity, and blind spots can impact the delivery of programmes and services, including leadership development. Designer, architect and proponent for systems change, John Atkinson, poses an important question: “Can you learn something that goes against the internal dialogue, formed and reinforced over... years and decades?” (n.d., para 9).

I observed, and was told by other participants, that many leadership development programmes and initiatives remain relatively unaltered over a period of years. Mapping the history of individual leadership initiatives reveals this and shows that often, the same people are involved in said initiative from genesis to articulation. This has the potential to undermine the checks and balances required in such situations (and might be confounded further by elements such as paradigmatic blocks and willful blindness).

### ***LEADERSHIP RECONSIDERED***

The vignettes included in the preceding sections highlight the extent to which the formal leadership development initiatives that I am familiar with have been designed and enacted through hyperseparated and dualistic frameworks. They also demonstrate the impoverished understandings of leadership espoused within many contemporary western contexts. Bateson captures this well in her work on liminal leadership. She writes that the concept of leadership all too often “...reeks of colonialism and lopsided history-book listings of individuals successful in taking, making, and claiming” (2016, pp. 82-83). Similarly, she contemplates whether many systemic imbalances can be attributed to cultural proclivities to consecrate individuals as leaders.

Bateson’s main issue is with the way in which leadership, as commonly postulated, continues to perpetuate the idea leadership primarily involves, and depends upon, the deeds of charismatic and iconic figures. The relationship between leadership and individualism is,

Bateson writes, an “insatiable ghost haunting the endless array of courses and manuals for developing leaders” (p. 83).

Countering this, she proposes that leadership is mutual in nature, and entangled within wider systems. This is the type of leadership that belongs not to the individual, but rather, is manifest through collective actions undertaken by citizens of the world, none of whom are elevated above the other, nor separate from the wider ecologies, histories, or experiences that serve to nourish or otherwise influence expressions of ‘leadership’ that stem forth. It is, after all, “in the combination of community and individual, hardship and support, isolation and belonging, past and future, vision and discipline, [that] there can arise a perfect storm that produces what we have, in the past, called leaders” (ibid, , p. 82).

Systems-based understandings of leadership seriously undermine the dominant premise upon which many traditional understandings of leadership are based. Bateson, for instance, raises an important question: is there an ecology of leadership? She surmises that no, there is not. That is, there are no models or ecologies in nature that support traditional ideas of leadership. “Think of trees in a forest. How did the ‘leaders’ get so tall? Were they extra courageous or charismatic?” Bateson asks, before adding: “The ecological response would observe that the other organisms mutually contributed to that growth” (p. 83).

Social and political thinker, Thom Hartmann (2009), adds to this understanding by drawing on understandings of ‘leadership’ in nature and the fallacies that surround human constructions such as that of alpha animals. Whereas there is a common perception that many animal societies are organised hierarchically, Hartmann says that very few are actually hierarchical, except in terms of choice of reproductive partners. Illustrating this further, he refers to research on group decision-making in animals, conducted by biologists Roper and Conradt (2003). As part of this research, the researchers studied red deer and alpha deer. They set up a series of cameras in trees, close to watering holes. They were interested in how the deer knew which watering hole to go to. As Hartmann emphasises: these are significant decisions to make. As he says: “If they go too soon, some members don’t get enough nutrients. If they wait too long, some might get dehydrated. They’ve got to account for young and old” (2009, n.p.). The supposition was that the alpha deer would make the decision on behalf of



the heard. Instead, the researchers observed that it comes down to democracy. Indeed, when it came time to get a drink, the deer started positioning their bodies in the direction of the different watering holes. Once they reached a 51 percent consensus, the decision is made, and the entire herd forms and moves to the chosen waterhole. The alpha, more often than not, is at the back of the herd during this process, and is in no way demonstrating any behaviours associated with leadership.

Hartmann, with others, suggests that ‘democracy is hardwired into our DNA,’ and that this applies to most animal societies: flocks of birds flying in the sky, moving in synchronicity, and schools of fish, moving from left to right, are just two examples of this, and neither incidents have a random causation. Fish, for instance, have extremely fast peripheral vision, and they vote with each motion of their bodies. There are always outliers, Hartmann explains, who try to vote to move an extra degree to the left or to the right. Ultimately, it comes down to the majority vote. If 51 percent of the fish move an extra degree, they all will.<sup>45</sup> The conclusion? There are no individual “leaders” in animal societies, and the survival and well-being of whole has “nothing to do with the alpha animal in any species” (ibid). This stands in stark juxtaposition to the preoccupation of individualism and hierarchically ordered forms of leadership so prevalent within westernised human societies.

Connection-based leadership, or cultural mentoring, as Jon Young (in Slavin and Young 2015) affirms, manifests itself as an embodied *presence* of sorts. By tending to people holistically, and by fostering connection attributes (with self, nature, and each other), the very idea of teaching or training people to specifically become leaders is *redundant*. Rather, leadership capacities activate, and embed, naturally (ibid). It is understandings such as this, coupled with my experience in different domains of leadership, that have led to me to recognise that rather than ‘teach’ leadership, ‘train’ leaders, in any prescribed manner, there is a need to envision, awaken, and empower multiple levels of mentors and teachers who can

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<sup>45</sup> Hartmann was informed of this by Roper and Conradt who, having published their research, were then contacted by numerous others: scientists and other researchers from numerous disciplines who shared their observations and research findings that also support the idea that decision-making in animal societies is a democratic process.

take up the work of relational practice and service. This is about service, stewardship, and collective endeavours. It is a way of being and living in the world, and it requires a shift from “sectors” to systems, and from dis/ability to humanity. What is more, in order to move beyond the welfarisation and professionalisation of human needs, any such goals require attention to care, connection, and community.

### INTERLUDE: BELOVED COMMUNITY

On the 1<sup>st</sup> of June 1965, Buddhist Zen Master and long-time activist, Thich Nhat Hanh wrote an open letter to Martin Luther King Jr. In this letter, he highlighted the loss of life and destruction of land that had resulted from a war that had, at that point, raged within Vietnam for twenty-years. The people of Vietnam sought to end the war and advocate for freedom and peace. In doing so, they engaged in numerous acts of love and protest. One of the ways in which this was demonstrated was through the self-immolation performed by some Buddhist monks. These individuals were neither committing suicide nor demonstrating a loss of hope or courage. Rather, they were engaging in an act of compassion, care, and service. As Thich Nhat Hanh explained in his letter:

“...the monk believes he is practicing the doctrine of highest compassion by sacrificing himself in order to call the attention of, and to seek help from, the people of the world.”

Reaching out to King, he added:

I am sure that since you have been engaged in one of the hardest struggles for equality and human rights, you are among those who understand fully, and who share with all their hearts, the indescribable suffering of the Vietnamese people. The world's greatest humanists would not remain silent. You yourself cannot remain silent...In writing to you, as a Buddhist, I profess my faith in love, in communion, and in the World's humanists, whose thoughts and attitude[s] should be the guide for all humankind (Kennedy 2012, p. 2).

***ONE YEAR LATER:***

Date: 1<sup>st</sup> June, 1966 (GMT - 5)

Location: Sheraton Grand Chicago Hotel, Chicago, Illinois

41.8781° N, 87.6298° W.

Meeting for the first time in 1966, in Chicago, Illinois, Thich Nhat Hanh and King bonded over their visions for emancipatory social change and justice. They appeared together at a press conference in which King spoke out against the war in Vietnam (Federal Bureau of Investigation n.d). Thich Nhat Hanh has long advocated for *sangha*, or beloved community. King similarly envisaged, and worked towards, the creation of beloved community through his work in the world. During their meeting in 1966, the two men concluded that without community, nobody could go far. Indeed, community, they agreed, was a crucial ingredient in the search for peace and freedom (Thich Nhat Hanh 2016).

On April 4<sup>th</sup>, 1968, at the Lorraine Motel in Memphis Tennessee, King was shot and died in hospital that evening. Thich Nhat Hanh, on the other hand, is now 91 years of age, and has continued to live and promote his vision for a beloved community for several decades now. There is such power contained within the idea of beloved community that Buddhist thought lends itself to the idea that enlightenment may, in fact, come through, and in the form of, sangha, or beloved community. As Thich Nhat Hanh suggests:

It is possible that the next Buddha will not take the form of an individual. The next Buddha may take the form of a community [sangha], a community practicing understanding and loving kindness, a community practicing mindful living. And the practice can be carried out as a group, as a city, as a nation (cited in Krajewski 2011, p. vii).

What might that look like, and how might individuals and groups support the manifestation of such communities? What are the opportunities not only for the creation of connected communities supportive of, and enriched by, experiences of dis/ability, but also humanity, more broadly?

## CHAPTER FIVE: CONSTRUCTING NEW WORLDS

“Another world is not only possible, she is already on her way. On quiet days I can hear her breathing” – Arundhati Roy (cited in Wahl 2016, p. 25)

What might a beloved and connected community look like? This is a question that resided in my mind for a very long time. Historically, I knew all too well what it didn't look like, and I felt its absence strongly. As explained earlier, from twelve years of age I was a young carer for my terminally ill mother. I existed, at the time, in 'landscapes of fear' (Tuan 2013). I was isolated, anxious, and unsure of what to do. Leadership and community were non-existent in my life during these years. Indeed, there was little support for me in my role as a young carer, and equally, there was little support for my mother as she experienced a profound loss of autonomy and faced the challenges that are associated with a terminal illness. Neither of us were prepared for the reversal of caring roles and relationships between a mother and their child. When my mother died, I faced a new task: navigating the world without her. In her place, there was trauma, loss, confusion, and grief; coupled with the absence of frameworks to make sense of any of it, or a connected community through which to seek refuge. This was true, too, with experiences linked to my brother's life and death.

As I began to re-enter the world, as an adolescent and young adult, I began to connect with others and I was reminded that this lack of connected community was not just a feature in my life, but in the lives of many others. This was perhaps especially so when it came to the lives of people who often reside at the margins. I also came to realise that tangible and powerful social outcomes rarely happen through formal organisations designed to bring people together. Indeed, in their serving of multiple masters: the system as it stands, and multiple 'stakeholders' all with varied and often competing interests, fragmentation widens and the paradigms of old are often strengthened and reproduced. Often a formal organisation will express their desire to act as vehicles for positive change in the world. However, this is contradicted by the various bureaucratic processes deemed necessary for funding and organisational survival. The status quo is upheld in these circumstances, and the welfarisation of human needs, and the financialisation of care, both perpetuated. This is reflected in language: *clients*, *service-users*, and in tools such as *needs-assessments* and

*funding applications*. I have had many a conversation, including with the conveners of leadership development programmes, in which I have highlight life difficulties people are experiencing and asked what can we do, together, to support and care for these individuals. The answers were generally the same, “very little,” “we don’t have funding for that type of thing,” and “it’s up to the individual to take personal responsibility for their lives.”

At first responses, such as those outlined above, resulted in experiences of cognitive dissonance. Then, I turned my attention elsewhere, and I recognised that positive changes *are* happening all around us. These changes are often emerging through the context of meaningful actions and relationships that occur *in the everyday*. Through these interactions, care and visions of human flourishing takes centre-stage, and people are able to experience what it is like to occupy meaningful and connected spaces within the world. Through the vantage point of the hidden curriculums that I encountered in areas such as leadership development, I also recognised *and* experienced the potential for *communitas* to be formed from the margins. This is a concept and experience best captured by Anthropologist, Edith Turner, who explains:

Communitas often appears unexpectedly. It has to do with the sense felt by a group of people when their life together takes on full meaning. It could be called a collective *satori* or *unio mystica*, but the phenomenon is far more than the mystical states. Communitas can only be conveyed properly through stories. Because it is the sense felt by a plurality of people without boundaries, there are numberless questions as to its form, provenance, and implications  
Turner (2012, p. 1)

My journeys, in life and in the field, have also reinforced how transformative an ethic of care, and a focus upon connection, can be. I found, and argue therefore, that a more basic community focused leadership and mentorship orientation can be more effective for social and cultural change, as well as being less hierarchical and more inclusive.

Calls for a community-focused leadership orientation are not new and can be identified, for instance, in the work of Thich Nhat Hanh, Martin Luther King Jr., and other change makers the world over. Emancipatory rhetoric espoused by many organisations will also highlight the importance of community. Still, the experience of *communitas*, within a connected and

beloved community, remains elusive for many. As M. Scott Peck (1990) proposed nearly thirty years ago now: “[i]n and through community lies salvation of the world” and yet it is “...virtually impossible to describe community meaningfully to someone who has never experienced it – and most of us have never had an experience of true community” (p. 17). This is not surprising given that concepts such as leadership, community, and connection are often so poorly understood and practiced.

Neither beloved communities nor experiences of *communitas* need to be so elusive. If they are to become more of a widespread reality, however, some significant shifts in perception are needed. Indeed, there must be a willingness to enter into deep engagement with others; to become more conscious of, and suspend, dominant modes of thought. In many westernised contexts where disconnection thrives and dominant individualistic ideologies prevail, this is not the easiest of tasks. It begins, however, with a recognition that neither the experience of beloved community nor connection can exist in rhetoric. Both must be *lived and experienced* as relational processes. Prescribed agendas, ego, and binarised suppositions have no place here. Instead, those seeking connection and *communitas* must “...rid themselves of their concern from status and dependence on structures, and see their fellows as they are” (Turner 2012, pp. 1-2). What might this look like, in practice? The remainder of this chapter provides some glimpses into this by drawing upon existing examples and profiling some alternative social actions. In large part, this is also a ‘feeding back’ to any interested parties.

### ***COMMUNITAS AND CHANGE***

Benjamin Johnson, Co-Founder and Director of The Free Store, a grass-roots initiative in Wellington, New Zealand, that serves to redistribute fresh, quality food to those who need it<sup>46</sup>, conceptualises inclusion through his thought piece: ‘Waking Up to Illusion of Inclusivity.’ Here, Johnson humanises and reifies the idea of inclusion; seeking to excavate its essence and challenge the way in which it is commonly thrown about as a buzzword, without credence, instead of something that is *lived*. He begins with an observation that has long

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<sup>46</sup> <https://www.thefreestore.org.nz/>

featured as a topic for social psychology: the idea that people tend to gravitate towards those who offer them a sense of familiarity. “[T]here is safety in relationships that entrench our currently-held beliefs, perspectives and identity. Exclusive, fleshly echo chambers” (2017, n.p.), he declares. Continuing:

But do we really know what [inclusion] means? Do we truly live out authentic inclusivity or do we simply tolerate? Inclusion means to actively welcome the stranger into your sphere of existence. To open and to share your life, to receive that which is different to you. And to give as much of yourself as you receive. This is dangerous and this is costly. Because it is not primarily about manufacturing another echo-chamber, but rather, bursting open the box.

What might it look like to encounter others, and to integrate authentic inclusivity within one’s being?

Johnson poses a series of scenarios, each which involve going beyond identifying classifications, and necessitate that one suspends and challenges the fear or reticence that might prevent them from engaging with those who are commonly marked by difference. He highlights that inclusivity takes multiple forms, but might include sharing meals, opening our homes to those who need refuge, learning the stories of others and weaving them with ours, traversing messy and meandering paths alongside those who are struggling, and, perhaps most importantly of all, acknowledging people: noticing, listening, recognising, and valuing them as fellow humans and kin. The Free Store acts as a medium through which to help this happen. “This is community not charity. This is not an ‘organisation’ providing ‘services’, these are average people caring for one another” (ibid). Ultimately, it is philosophies, such as this one, that are core to dismantling the dominance of the welfarisation of ordinary human need and to supporting the realisation of connected community.<sup>47</sup>

When *lived* in the ways that Johnson advocates, inclusivity, as a practice, ideology, or label, becomes *humanised*, and this stands in stark opposition to that which is often embodied

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<sup>47</sup> There is a large body of scholarship which supports the idea that the building and experiencing of relationships facilitates connection and may result in attitudinal changes. The contact hypothesis is one example of this (first proposed by Allport 1954).



through professionalised engagement. It is not about formalities, prescribed agendas, the scheduling of appointments, the maintenance of a hierarchy, or dehumanising proclivities. On the contrary, boundaries are erased, and relationships become central.

### ***QUESTIONS OF CARE***

One of the most crucial, and overlooked, components of leadership is caring for the leaders involved. It is easy to become overwhelmed and discouraged when it comes to topics of social justice work. Thich Nhat Hanh offers a simple but profound insight that has broad applications: “The best way to take care of the environment is to take care of the environmentalist” (1993, p. 132).

During my time in the field, I realised that many practitioners are missing crucial steps in their engagement with the tasks at hand: primarily surrounding care and connection. This is particularly so for any such service or programme that professes to work towards social or cultural transformation. One of the major steps that is frequently overlooked links to the way in which practitioners, or designated ‘leaders’, navigate emotionally complex terrain, or fail to do so, as the case might be. Goleman *et al.* (2004) explain that all forms of leadership have an emotive, primordial dimension.

[I]n all aspects of social life, not just love relationships, our physiologies intermingle, our emotions automatically shifting into the register of the person we’re with. The open-loop design of the limbic system means that other people can change our very physiology – and so our emotions (p. 19).

If one aims to promote and support the well-being of individuals and groups, emotional intelligence is not optional, it is vital. Whilst leaders set the emotional standard, there are also times in which those they are working with recognise that these leaders are not offering, or cannot offer, the emotional guidance sought. In such instances-group members may turn to another (or others, plural, as the case may be): “[t]his de facto leader then becomes the one who moulds others’ emotional reactions” (ibid, p. 20). One could surmise that this redistribution of power, as focused upon emotional guidance, could well result in the birth of *communitas*. This was certainly the case in some of the leadership development

scenarios that I outlined earlier. However, when there are *no others present* who are willing and/or able to offer the emotional buffers necessary, people will potentially be left in vulnerable states.

Greenleaf, when writing some fifty years ago, observed the lack of care present within society. He proposed two ways in which to create caring societies that are infused with the quality of a servant-based ethos. Firstly, he advocated that younger people, in particular, be mentored and empowered, and their servant qualities, nurtured (Greenleaf 1979). Secondly, he called for citizens of the world to participate in helping institutions (amongst these, governments, churches, corporations, health and education systems, social services, and families) to become more caring and servant-orientated (Greenleaf 1998). In proposing these steps, Greenleaf also identified and acknowledged that the greatest obstacle in the way is that of mind-set or worldview blocks (ibid).

### ***TURNING TO CULTURE***

How might greater levels of care be fostered, then? Perhaps the first step is to recognise the root of the issues faced in many westernised contexts. There are a plethora of diverse and significant issues facing the world today, and crises in leadership have been frequently highlighted. Thom Hartmann makes an important observation: the core problem in play is that of a dysfunctional western culture. He understands the wider issues, then, to be symptomatic of this dysfunctional culture. To appreciate this point, one must also understand what is meant by culture. Hartmann describes it as:

a set of assumptions, a set of stories that we all collectively tell ourselves about who we are, where we came from, where we're going, what our relation to each other is, what our relation to the world is, what our relation to economies and politics and technology ... all of those things. ... And it finds expression in how we live, how we speak, how we conduct ourselves [in] everything that we do (2009, n.p.)

Jon Young adds to this understanding of culture, eschewing the idea of culture as a noun, stating instead that: “A culture is a collection of processes, events, activities, items, concepts, that all fit together in an ecology” (Young 2013). When a culture is dysfunctional, or broken,

Young suggests that it leads to a state of disconnection. When culture is healthy, on the other hand, it *acts* in particular ways, enabling people to:

develop a deep appreciation, understanding, and connection to their own role as interdependent beings ...They basically feel connection to ancestry ...[and] to unborn generations ...They've reached a state of vital health as human beings. They actually become better citizens. They become better members of a community or a society. They become deeply dedicated to their neighbours, both human and non-human. They take better care of their ecosystem. They take better care of themselves (n.p.).

Young forms these hypotheses based on extensive, long-term interactions with, and observations of, Kalahari Sān Bushmen. Young explains that the Bushmen remain “largely true to their culture and identity” despite the constant infractions upon their way of life by the pressures of westernising processes. The Bushmen serve as an exemplar in terms of cultural health; having maintained a strong bond to their place, to themselves, each other, and their ancestors. Young and his organisation, the *8 Shields Institute*, used learnings from the Kalahari and other traditional and indigenous contexts in order to better understand culture and to formulate their models for Culture Repair and Cultural Mentoring.

Culture Repair involves the restoration of what Young terms, “the original instructions for humanity” (ibid). He extends his explanation further, stating that Culture Repair, in essence, involves acknowledging that “the loving connection that we're all meant to have as human beings was not supported,” followed by deliberate enablement processes that allow people and communities to “begin to re-activate that basic human instinct to be connected” (Young 2017b, n.p.).

### ***BUILDING RELATIONSHIPS AND STRENGTHENING CONNECTION***

It might be argued that atomising societal structures and a preoccupation with formality can drive distance between people. This became evident through my experiences within multiple leadership development initiatives. Within these contexts there was an implicit assumption that personal and professional lives could be treated as largely discrete and separate entities. Before long, many of the participants involved were more concerned with self-governing than they were with engaging in deep forms of connection with one another. Participants

spoke of the difficulties of living their lives, then returning to leadership development programmes where they were expected to 'leave their baggage' behind. Those that I knew were navigating complex life events: deaths, sickness (their own and others close to them), experiencing chronic pain, fatigue, anxiety and/or depression. They had work commitments, life commitments, relationship challenges, and financial stress. Each of these factors played a role in the participant's overall sense of well-being. Yet, there was rarely room to engage with this.

The Culture Repair and Cultural Mentoring work that happens under the umbrella of the *8 Shields Institute* demonstrates that deep listening, non-judgmental rules of acceptance, and a letting go of structure can significantly alter power dynamics. Core practices, such as greeting customs (Young 2017a) and grieving rituals (Young 2017b) demonstrate new ways of being in the world, and relating to one's self and others, whilst also revealing ways in which to establish strong forms of connection. Such practices are framed by what Young refers to as a *Culture of Allowance*. To explain further, Young relays a story of a scientist he knew, who had anxiety and a speech impairment which disappeared during his time in the Kalahari with the Sān Bushmen. When asked why he thought this happened, the man replied:

They have this culture of allowance. They allow everyone to be who they are without judgements. It's basically that unconditional listening, but it's more like unconditional allowance. They don't actually need anyone to be any particular way. They don't have an ideal that 'okay, in order to be a functional Bushman, you are going to be this way or that way. They literally accept anyone for who they are, for what they're saying, for how they think. There's no need for correction, there's no need for adjusting; just let it be. Literally, just live and let live is the spirit of it (Young 2016, n.p.).

Young, too, had experienced this Culture of Allowance when spending time with the Bushmen and, prior to this, through his own interactions with his childhood mentor, Tom Brown Jr. (a naturalist, tracker, and author). Drawing on this particular experience, Young conveyed the way in which he was invited to learn, grow, and make mistakes without any stigma attached. He explains that this occurs without any "...sort of agenda, or timeline, or expectation of any kind of performance" and he likens it to a *container of safety*. "In those

containers of safety, especially in that level of community, we gather as the village. A culture of allowance that allows for the greatest sense of safety for every individual” (ibid).

### ***THE ROLE OF CULTURAL MENTORING***

Mentoring is a key facet of Culture Repair and, indeed, is commonplace within many traditional and indigenous contexts worldwide. Within a truly healthy culture, Young explains, everybody experiences mentoring as part of their central operating system. However, it is also important to make a distinction here, and to understand just what is meant by the type of cultural mentoring Young and others within the 8 Shields Institute advocate for.

“Mentoring is a form of adoption,” Young (2013) explains. You cannot “flippantly say that you are a mentor and that you are mentoring others, because if you do that you will undermine the power and value of mentoring.” Mentoring is not a quick or superficial process. Rather, it is entering into a relationship with another, or others, who then become like family. “They’re going to come to depend on you and look to you for support for the rest of their lives” (ibid, n.p.).

Whereas many western leadership development initiatives cease after a set period of time, and there is often a lack of follow up involvement or support present, cultural mentoring and leadership, such as that described above, has no timeline. Rather, it involves sustained and caring involvement over a period of years if that is what is required for the individuals involved. Mentoring, when understood with reference to traditional models, as Young does, is a lifetime commitment between individuals that are linked together by agreements to be in-relation. There is no ‘time off’, there is no time limit on the therapeutic engagement that is required, and there is no ‘me time’ to be used as an excuse for breaching the relational contract. Young, himself, has mentoring relationships that have lasted over two decades now. This is very different to many standard forms of teaching or facilitation work. Illustrating the juxtaposition between the two approaches, Young points out:

We are told by the professional standards of our post-modern society that teaching is a professional activity and you don’t want to develop relationships with your students. You can’t actually become friends with them. You’re the expert, they’re the ones who have come to you;

you're going to impart knowledge into their heads. ...In the time and space allotted for teaching, 10am to 11.30am, Monday and Wednesday, you have a wrench that you use to open the bolts around their skull, open their head, shout a bunch of noise into it and then you close it. And you don't really pay attention to them beyond that time commitment that you have with them (ibid).

### ***COUNTERING THE COMBATIVE TERRAIN?***

A systems-based understanding of leadership, as mentioned in chapter four, focuses not upon the individual as an atomised unit (the 'leader') but rather the wider environment and systems in play. These environments and the different systems within them, act to nourish, or cultivate the conditions in which 'leadership' takes place (Bateson 2016). Following Bateson and Young, this might be thought of as an *ecological* approach to human relationships.

I have proposed that the Disability Sector, whilst often spoken about in concrete terms, is an imagined terrain. The narrative content throughout this thesis reveals that there is a toxic culture present in this terrain. Metaphors such as 'our turf,' 'their turf' and 'patch protection' have been used to describe it. There is a perception that it is comprised of old guards and new guards; each fighting for their 'place,' legitimacy, and survival within the "sector." Binarised positions are reinforced continuously: 'able-bodied' or 'neurotypical' verses 'dis/abled' or 'neuro-diverse,' and 'us' verses 'them.' My perception is that it is a largely combative, competitive, and individualistic socio-spatial terrain. There are protectionist ghettos in place and the building of fortresses. These fortress-building mentalities can seep into individual organisational cultures, even those aiming to be progressive, and are then circulated like viruses through service delivery provisions. Gate-keeping and guardedness also appear commonplace. Whilst there are discussions about collaboration, many I spoke to sought to keep information, ideas, and opportunities limited to their own surrounds and an associated in-group. Many of those I spoke to expressed their feelings of entrapment within the "sector", relying upon it for 'community,' for employment, for funding to maintain their quality of life or the existence of the organisations in which they work.

Weber's concept of *Shahlhartes Gehause* (rendered the "iron cage" by Talcott Parson's, but which translates as "shell as hard as steel") is an appropriate lens through which to think about what is happening here. That is, a cage or shell that has been outwardly imposed through capitalistic and individualising processes, and internally accepted (Weber, 1920). It need not stay there forever, but those encased within it need to recognise its presence in order to free themselves. Culture Repair might assist with this: not just through focusing upon individuals, but on organisations, and organisational cultures, including working with those who have acquired roles of 'expert' or designated 'leader' and are used to 'training' or 'developing' others. An important point here is that this is not about blame or reductionist right/wrong debates. Rather, it is acknowledging that "We don't know what we don't know. We're unconsciously incompetent in what connection is about now in modern times" (Slavin and Young 2015, n.p.).

### ***DISCOVERING WHAT MATTERS***

During my research journey I recognised that many of the visions and objectives linked to processes of social change or transformation are often anchored in the past and do not necessarily resonate with those they are purported to serve or motivate today. Social justice educator, trainer, and activist, Victor Lee Lewis postulates that one of the "most difficult and crucial challenges for social change leaders ... is to give up a sense of personal grievance, and not to organize for the redress of personal grievances primarily" (Lewis, 2017, para 54). The task, he asserts, has evolved from this point: to "awakening [...] to our role as a species in the earth community as local stewards, local human healers" (para 48).

Many of those with whom I attended leadership development initiatives spoke of experiencing a lack of resonance with much of what was going on, and yet (as signalled earlier) they also expressed some dismay that they were unable to articulate a vision of their own, at least not with the clarity or conviction they desired. They also expressed that they felt little institutional and community encouragement to nurture their own visions to fruition. Greenleaf (1998) relates the enthusiasm and vision of young people in American colleges during the 1960s, focused on creating positive change, but with little support to do so. Reflecting upon this, he argues that these young people, and their visions, were

'neglected' by their elders who could have assisted them in their tasks but instead failed to do so.

A similar 'neglect of vision' became evident to me through my experiences within leadership development initiatives and, more specifically, through my interactions with fellow participants. Many of these people knew about the issues, and wanted to make changes, but they did not know *how* they might do so. Many would also lament that whilst others seemed to have found their purposes in life, they were unsure of their own. Instead, they felt disheartened, overwhelmed and unsure of where or how to channel their creative energies. Most had little guidance or support from those they knew, and they saw few opportunities to take on formal roles conducive to the type of work they might like to do in the world.

According to Goleman, Boyatzis and McKee (2013) one of the main reasons why many leadership development initiatives fail is that there is lack of attention to participants as whole people, or to discovering and supporting participants to articulate and work towards their visions and dreams (Goleman *et al.* 2013). The additional barrier here, to recall my descriptions in earlier chapters, is the profoundly *felt* presence of dis/ability as lived experience within an already hyper-separatist westernised context, and specifically, within organisations that are promoted as routes to social and personal transformation. Thus, the discouragement I encountered when this was not the case was often profound.

It makes sense, then, that one of the first steps is to discover what one cares about and wishes to engage with. There are a series of introspective questions that may help with this.

Consultant, systems-thinker, and educator, Daniel Wahl (2016), for instance, encourages contemplation surrounding questions such as why humanity is worth sustaining.

Bateson (2016) encourages people to consider what type of civilisation they wish to live in and be part of.

Author and religious scholar, Andrew Harvey (2009), in his work on sacred activism, encourages individuals to identify what it is that they are passionate about and what



'breaks their heart.' He suggests that people might then use this information to form and contribute within collaborative groups that he refers to as 'Networks of Grace.'

Academics Felten *et al.* (2013) encourage the establishment of Formation Mentoring Communities in which people can connect, form and strengthen affective bonds, find and discuss what is meaningful for them. The intention, then, is to discuss ways in which individuals and the wider group might contribute to transformative changes.<sup>48</sup>

Gibson-Graham *et al.*, (2013) in their book: 'Take Back the Economy: An Ethical Guide for Transforming our Communities,' formulate a model based upon key concerns and the explorative questions that can be used, to reshape and literally, *take back the economy*. One of their central questions is how 'we' – as citizens of the world - might survive well, which is of particular relevance.

Joanna Macy and Molly Brown offer connection-based work, under the umbrella term '*The Work that Reconnects.*' One such example of this is their book 'Coming Back to Life, Practices to Reconnect our Lives, Our World.' This book poses contemplative questions and contains personal counsel on issues facing the world. Enabling audiences to undertake reconnective work in their own lives, the authors provide models, methods, tasks, and ideas for facilitative group work (Macy and Brown 1998).

Each of these examples provide room for exploration and provide exercises for greater self-reflexivity. Furthermore, they might well support the formation of new visions for social, personal, and ecological transformation. Each also contains the potential to take these explorations further, and to apply them in a practical sense, which may, in turn, help to bridge the chasm between theory and praxis, whilst aiding connection.

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<sup>48</sup> Felten *et al.*'s work is intended to be utilised within academic and higher learning institutions, but its nature is such that it also provides a transferable model that can be taken up by any interested or inspired party.

### *ENCOUNTERING SELVES, ENCOUNTERING OTHERS*

I follow in the assertion that “disabled people, in order to create a society which is indeed non-disablist and which secures effective, full citizenship, need[d] to foster and build alliances with their able-bodied peers, and this is best achieved through consensus building and education” (Lang 2001, p. 31). However, I also believe that it goes further than this. Whilst this thesis has drawn upon dis/ability as a reference point and there is much to be learnt from this perspective, including understandings connected to the role of interdependence and collective well-being, there is also a need to disrupt entrenched binaries. Not only does this involve a much stronger intersectional element, it also involves a broader focus upon common humanity, and collective engagement with topics such as systemic marginalisation and human flourishing.

There are many possibilities that exist in terms of engaging with, and seeking to change, forms of systemic marginalisation and outcomes that promote human flourishing. One of the key approaches, I would argue, involves going beyond the training or development of individual ‘leaders’ to awakening and empowering multiple levels of mentors and teachers, committed and able to take up the work of relational practice and service to individuals, groups, and communities. The preceding sections highlight some of these possibilities in terms of Culture Repair, mentorship, and a focus upon greater levels of care. Nina (Simons 2014) calls for ‘Full-Spectrum Leadership:’ a form of leadership, or relational practice, capable of healing relationships. In doing so, Simons points to a widespread crisis of relationship with self, others, and the earth. Narrative content throughout this thesis reveals several examples of the crisis of relationship that exists between self and others in the diverse arena(s) of dis/ability.

In terms of self-perception, I have had many conversations with people with dis/abilities who have expressed feelings of low self-worth and internalised oppression that led them to believe they were, in some way, ‘defective’ or less-than. Many of these individuals shared the impact of negative societal perceptions of dis/ability and the imposition of ‘grim imagined futures’ (a concept discussed in chapter one). Some mentioned a desire to ‘cover,’ and assimilate. I was told about situations in which the individuals did not want to be ‘marked’

or defined by their dis/ability and so they took actions such as choosing to walk rather than use a wheelchair, despite the physical impacts this posed. These aspects, and the crisis of relationship with self, were rarely – if actually ever – engaged with meaningfully in the leadership development initiatives I attended, even when marketed as forms of ‘disability leadership’ or ‘leadership for social change.’

Mentorship models have the potential to engage constructively with the sentiments outlined above and to provide support and empowerment for individuals, especially by those with shared experiences within such domains. The embodiment of a Culture of Allowance also has transformative potential for individuals and groups alike. Furthermore, there are some excellent resources that engage with encountering oneself and healing the wounds of personal disconnect or crisis of relationship. An example of this is provided by Thomas Lloyd in his TED talk, ‘Why am I so gay?’ Lloyd has been asked that question multiple times throughout his life, and he explains:

“Really, for me, it comes down to three things. One is my obligations to history; two, the realities of my own identity; and lastly, our obligations for those yet to come.”

Sharing anecdotes from his own life, Lloyd highlights the powerful role that mentors have had in his life. Lloyd’s mentor, Jonathan Cruz, the director of his high school debate team, was the first to ignite a shift in his self-perception. As Lloyd explains:

Jonathan Cruz was the first gay person I had ever met, who owned their identity unapologetically. Instead of expending his creative energy to change himself, and to cover, and to meet the standards that society wanted him to meet, he instead put his energy into building a community of dedicated students who worshiped him because he was a debate god! ... And it’s because he used his energy — he didn’t apologize for himself. By not having to cover, he was able to apply that energy into a community and into students.

Other mentors also reinforced these sentiments for Lloyd. Additionally, discovering the history of the LGBTQ+ movement cemented these perceptions further and enabled Lloyd not only to ‘own’ his identity at a personal level, but to own it with others, too. It was at this point that Lloyd recognised a core teaching. That is: “it is easier to change society, than to change your own identity. And it does much less damage that way.”

In his talk, Lloyd mentions the assimilative tendencies of some of the individuals he has met and he poses an important question, which has wide relevance:

Were we ever normal? Even if you're straight. What do you cover? What are the things that you're not hiding? When you hide these things, and other people who are similar to you, you're not building a community of similarity; you're losing out on who you authentically are (2014, n.p.).

Lloyd's message, and his strongly stated commitment to those yet to come, reinforces the importance of acting with an intergenerational focus. This is key to emancipatory social change visions and was a concern amongst many of those whom I attended leadership development initiatives with. As one participant shared:

My concern is not so much about our experiences, they have been and gone now, my interest is in the well-being of future participants within such courses. I would like it if our experiences and learnings could be used to create better conditions for those who come next. The passing of the torch, so to speak.

Returning to the topic of relationships with others, this thesis provides some important insights through narrative content. These narratives have, for instance, highlighted relational blocks and paradigmatic tensions related to the us/them binary (abled/disabled, one organisation against another, and different impairment groups). There has been mention of core issues, such as fear reactions amongst the general populous, and to feelings such as that of personal grievance or social dislocation experienced by some individuals and groups who identify as dis/abled. Each of these instances support the need for stronger and more responsive relational practices, and potentially forms of Cultural Repair. Part of this involves truly engaging with the issues, and with one another, rather than silencing dissenting views or framing topics in reductionist terms (right/wrong, comrade/enemy).

Philosopher Kwame Appiah promulgates the importance of moving from labels, classifications, and social positions, and from debates between right and wrong, to deep engagement with and between people. This involves crossing the boundaries of identity, and forms of division, in order to find and appreciate aspects of shared humanity. He adds that, psychologically, this is a very different experience, and can enable people to "...figure out how

to live together” even when we disagree (Appiah and Tippett 2013, n.p.). These steps may lead to increased fellow-feeling which, as outlined in chapter one, is a key feature of a connected, or beloved, community.

## CONCLUSIONS

Nearly half a century ago, dis/abled individuals and groups began to galvanise around visions for change. As part of this, dis/abled people envisaged the creation of more inclusive social worlds, joining Disability Rights Movements to promote and drive these aspirations. The emancipatory social actions promoted under the banner of these movements, in their quest to drive and secure fundamental social and political victories, have positively contributed to a trajectory that has supported cultural and societal shifts to ensue.

How much has changed, however? From a New Zealand perspective, marginality and inaccessible social and emotional environments continue to be largely normative experiences for dis/abled peoples, suggesting the shift they so desire is still some 'elsewhen' away (to echo Kafer). Indeed, a great deal of work remains if this is to be so, not only linked to the re-envisaging of what it means to be human, but also what it means to live well, and to do so, together.

This research has reinforced, at nearly every turn, that *the map is not the territory*.<sup>49</sup> I never set out to write about the desire for community, as expressed by a group who struggled to be recognised as fully human in a world experienced largely as hostile, and yet this is where it ended up. In some ways, it is not entirely unexpected. After all, the vision of a beloved community has been forefront in my mind for many years. Like Kafer, this was a vague hope rather than something I understood in concrete terms. Throughout the course of this research, my own life was transformed. Through mentoring relationships and connective practices I came to understand what *communitas* and kinship without bounds looks and feels like, in action. This was a seminal moment for me. It provided new bench marks through which to measure and consider topics of care and forced me to re-engage with a topic that had long been entangled with historical wounds stemming from impoverished experiences of care and connection.

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<sup>49</sup> A concept and term proposed by Polish-American scholar, Alfred Korzybski (1958).

Social, cultural, and personal change takes multiple forms. It is not about following one true path. Yet, as this thesis has shown, there is some deep dissatisfaction with social worlds as they currently stand, particularly in areas of dis/ability. What I discovered, by nature of its presentation and the sharp relief of its form, was that a profound lack of *humanity* is evident, albeit characteristic of so much of modern life. Perhaps a starting point is to recognise what it is that is not working. Rather than grandiose moves, perhaps one of the most revolutionary – and even transgressive – things one can do in today’s world is turn our attention to care.

My journeys, in life and in the research field, have reinforced how transformative an ethic of care, and a focus upon connection, can be. I found, and argue therefore, that a more basic community focused leadership and mentorship orientation can be more effective for social and cultural change, as well as being less hierarchical and more inclusive. Returns to community, whilst possible, and happening all around us, are not the easiest of feats. They require, for instance, a challenging of the welfarisation of ordinary human needs. As Tronto highlights, if we are to do a more adequate job at caring for ourselves and others, there must be a

shift in values away from the notion that the only things that matter are economic gains. There is an alternative: the more people share responsibilities for care publicly, the less they have to fear and the more easily they can trust others. From such positions of trust, the world becomes more open: more free, more equal, more just. Changing the way we think is hard, but the choice is real, and neoliberalism’s promise is a false one. Humans can organize society so that they are not only and always in constant and vicious competition with one another (2013, p. 146).

This understanding is integral for life post-capitalism. It highlights and reinforces the capacity of everyday citizens to transform the social worlds in which we collectively inhabit. It also has the potential to bridge relational gaps, and to foster concrete experiences of fellow-feeling.

In chapter five I referred to the transformative work of the Free Store. Its founder, Ben Johnson, demonstrates, through his reflections, the importance of humanising abstractions such as ‘inclusivity’ and ‘care’, whilst supporting the positive impacts that arise through a willingness to embrace a *whānau* or kinship ethic in our interactions with fellow humans.

Transformation arguably happens when fortresses are demolished, when we venture beyond imposed binaries, use names in place of labels, and dare to see, interact with, and commit to other human beings (and earth beings, to draw on Gibson's understanding of community, as highlighted in the introduction to this thesis).

One of the first steps in helping this to become a more widespread reality is to re-consider and re-commit to prioritising that which really matters. Like the vague, yet poignant, gestures toward a connected sense of community, leadership and leadership development are commonly posited within social justice work as a *way forward*. But, what is leadership, and who do we count as leaders? I argue throughout this thesis that there needs to be a commitment to going beyond just training, or even empowering individual 'leaders' through means of leadership development courses and other abstract and prescribed endeavours. There is real potential to awaken, support, and empower many people to take up the work of relational practice and service to others and the worlds in which we inhabit. Indeed:

This global whirl of interrelations and interlocked histories and futures is not waiting for leaders ... it's waiting for the courage to trust each other and to step carefully into the 'intentional community' of the 7 billion people we share the commune of life with. This is our tribe. Just the 7 billion of us... and the animals, plants and microorganisms. Those who came before, and those who will follow. That's all (Bateson 2016, p. 87).



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