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**Disability as an Entanglement:  
A New Materialist Reimagination of Disability**

A thesis  
submitted in fulfilment  
of the requirements for the degree  
of  
**Doctor of Philosophy in the Faculty of Education**  
at  
**The University of Waikato**  
by  
**Ingrid Rose-anne Jones**



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**2019**

# Abstract:

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Research and contemporary practice indicate that people labelled as learning disabled remain positioned on the margins of humanity, despite decades of hard work from the disability rights movement, support workers, and families and whānau, among many others (Goodley, 2017). In this thesis, I seek to find some answers as to why this situation persists. I seek further to investigate if this ongoing marginalisation can be challenged through using new materialist theory to reimagine disability.

The thesis begins by outlining the big picture of disability oppression in Aotearoa New Zealand and across the globe. Thereafter, literature from disability studies and the humanities more widely is drawn upon to argue that the binary notions of “learning disability” and “normal, ideal humans” are not fixed, indisputable concepts. Instead, they can be viewed as artefacts of the historical, spiritual, political and social structures which have emerged over the past few centuries in the Western world. Learning disability becomes of necessity positioned as inferior within this binary and, it can be argued further, this positioning plays a crucial role in the validation and perpetuation of disability oppression.

The key conceptual frameworks shaping policy and practice in Aotearoa New Zealand are examined. This is done with a focus on the ontological underpinning of the ideal human inherent in many of these frameworks, and how this underpinning inhibits challenge to exclusionary structures and practices.

The conceptual framework is formed from agential realism (Barad), citational chains and lines of flight (Bergson / Butler, as used by Davies), performativity (Butler), affect (Wetherell), desiring silence (Jackson and Mazzei), and disability pride (Parsons). Datum was generated through a series of nine “hui”, or research meetings. These were held with a co-facilitator and seven participants, all of whom have been assigned the label of learning disabled through diagnostic processes.

The analysis begins with participant responses to the collaborative exploration of ideas related to disability pride and ableism. Whilst there was evidence that participants enjoyed discussions related to ableism, many displayed a powerful adverse reaction to visual displays on pride. In particular, participants' *affective* responses to the videos and discussions regarding pride signalled the limitations of the view that the problem is largely discursive.

Exploring this challenge using the conceptual framework ultimately enabled me to propose a new means of conceptualising disability: disability as an ongoing series of entanglements. The entanglements which rose to the fore during data generation and analysis were the affective entanglements of disability, the desire for recognition as a viable subject, the silences regarding disability, and the drive to help. This thesis proposes that these entanglements serve to further the inferiorisation of disability and hold it in a static place of "otherness", and thus foreclose potential for radical transformation to exclusionary structures and practices. However, by drawing upon agential realism I also highlight the ever-present possibility of rupture which lies within each of these entanglements. Based on the findings of this thesis, I conclude that radical potential for change can potentially be found by understanding and reworking these entanglements.

# Acknowledgements:

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The work in this thesis was made possible thanks to the support of many people.

I would first like to thank my supervisory team – Lise Claiborne, Carol Hamilton and Alison Henderson, who provided me with unfailing support throughout the thesis journey. From my “what’s the point of theory?” days, through to the many, many chapter reviews, you were always on-hand to steer me in the right direction, and always made sure I knew that you had my back. I feel incredibly lucky to have had you as my supervisory team.

I would like to thank my friends and family whose offerings of love, time, emotional support, finances and food helped me through this journey. I would particularly like to thank my mum, who never failed to make sure I felt supported, had warm clothes and plenty of food (as I write this I have a box of home-made biscuits labelled “PhD Sustenance” sitting next to me), and my partner Matthew, who spent many an hour being an ear to my endless ramblings.

Thank you to my participant group. You were such a big help in my research. I really liked how you were honest with me about the things that were hard to talk about. I learnt a lot from the things you told me. I also really liked how keen you were to be a part of the research, to support me, and to laugh and have fun.

I also want to say thank you to my co-facilitator, Glen. You did a great job helping me to plan the hui, thinking up ideas for the different activities and resources, and facilitating the hui. Your help made a big difference.

I would like to thank the disability community in Aotearoa New Zealand, who have let me in as an honorary member, and who often provided a sounding-board for the project as it was developing. Lastly, I would like to thank the many disabled people and families who have let me into the lives over the years, and who have kept my heart in the disability sector.

Nō reira, ka nui te mihi ki a koutou katoa (my sincere thanks to all of you),

Ingrid Jones

November 2018

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# Chapter 1:

## Introduction

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I started this thesis wanting to fix things for people. After more than a decade of enriching, challenging and immensely frustrating work in the disability support sector, I came to this PhD hoping to discover ways to make life conditions better for disabled people. However, what began as a project to help “others”, has ended up as an exploration of a number of everyday practices, including the way we speak, feel and act towards disability, in which I am unmistakably complicit. These practices position people labelled as disabled as “other”, and ultimately enable disability oppression to flourish in our world.

The purpose of this thesis is thus to examine how it is that people labelled as disabled are continually positioned on the margins of humanity, and how we can start to shift this problematic positioning. In short, this thesis will explore how we think, feel and talk about learning disability in the Aotearoa<sup>1</sup> New Zealand context. This will be done through investigating how thoughts, feelings, words and subsequent actions contribute to the flourishing of disability oppression. The thesis will also contribute to a new way of conceptualising learning disability that may present a new path forward for the disability rights movement.

The work in this thesis is grounded in my personal experiences in the disability sector, and has been accomplished thanks to the generosity of the hundreds of people who have given me the gift of letting me into their lives to share in their experiences. I have worked in a wide variety of roles in the sector, and with a wide variety of people; although, mostly with people assigned the label of learning disabled. I have worked with people of all ages and types of disabilities, including people considered “profoundly” disabled, people considered “high-functioning”, and everything in between. I have worked in

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<sup>1</sup> Aotearoa is the Māori name for New Zealand.

kindergartens, schools, group homes, learning disabled people's own homes and with people who live with their families. I have done "hands-on" support and also worked as a team leader, a service coordinator, a regional advisor, a self-advocacy coordinator and as a life-planner.

These experiences and the problems that I observed have driven this thesis. To me, the fundamental issue is that while many of us are working incredibly hard in order to make things better for disabled people, little seems to change. People labelled as learning disabled stubbornly remain one of the most disadvantaged groups in society. As someone working in the disability support sector, I saw that our efforts to change this situation appeared to do little more than scratch the surface of this issue, regardless of how hard we worked or how much we tried. It is from this realisation that the desire was born to do some research to find out what is needed to shift this situation.

In this opening chapter I will outline the big picture of disability oppression, including key statistics and the role of support services, as well as other factors which cannot be captured in a statistic. I will then outline how I believe the "problem" of disability needs to be reshaped if we in the sector are to move forward, and I introduce the two key concepts which have guided and shaped the formation of this thesis.

## **A Note on Writing Style**

Throughout this thesis I move between two different styles of writing; "from a distance" and "from the inside". This approach follows that of Cath Laws (2011), whose work and writing style has inspired much of this thesis. With the exception of this chapter, the bulk of the thesis is written "from a distance", in more traditional, academic prose, as demonstrated here. This style is utilised so as to fulfil the requirements of academic writing expected in a PhD thesis.

In contrast, more personal writing "from the inside" will be placed inside a box, as demonstrated here. This style enables me to step outside of an

academic voice to draw upon my own experiences and examine the challenges, thought processes and ultimate “truths” which seemed to emerge through the research of this thesis. Because these sections pertain to my thoughts and experiences, the writing style is more casual.

Two important terms will be utilised throughout the thesis: *learning disability* and *disabled people*. These terms have been chosen because they emphasise the disabled aspect of a person’s identity as a valid and unashamed way of being. As I shall highlight through the thesis, I believe that the need to emphasise the common humanity of a person, or to downplay any aspect of their identity, contributes to the marginalisation of people labelled in those categories.

*Learning disability* is used in preference to a more commonly used term in New Zealand, *intellectual disability*. I have chosen this term because it is the label which members of People First New Zealand, a disabled persons organisation run by and for learning disabled people, have chosen as a mark of identity for themselves (People First, 2013). This terminology is consistent with a key underlying principle of this thesis, which is to support the voices of people who have been assigned the label of disabled, as fully agentic members of society with full human rights. As H. Brown and Smith (1992) note, it is important to listen to the voices of marginalised groups and accord them “the respect of using the labels they choose for themselves” (p. 127).

The second term, *disabled people*, is used in preference to a commonly used term, *people with disabilities*. *People with disabilities* and *people first* are frequently used terms within the disability sector and disability rights movement. People assigned the label disabled are viewed as *people*, first and foremost; their disabilities are secondary to the fact that they are fully-fledged human beings. However, the term *people with disabilities* can be viewed as “apologetic phrasing” (H. Brown & Smith, 1992, p. 127), which works to downplay the disabled aspect of a person’s identity. This phrase then signals shame and invalidates the disabled identity as a legitimate form of human-ness, ultimately implying the opposite of what is intended. As Emma Kahn (2017) notes:



Oh you see us as PEOPLE first? Because apparently being disabled means not being a person? Because disability negates ones humanity? (np)

In contrast, the term *disabled people* can be viewed as an identity that can be worn as a badge of pride, in the same way that someone might call themselves a woman, rather than a person who is female, or Māori, rather than a person who is Māori.

## **Disability Oppression - The Big Picture**

This section presents statistics and evidence related to disability oppression, both internationally and within Aotearoa New Zealand. Information which can be measured, including statistics relating to abuse, health, and poverty will be presented. Other elements of disability oppression which are much harder to measure, such as the emotional labour many people are expected to take on will be discussed. Information in this section largely pertains to the wider category of disability; information relating to learning disability will be included when it is available.

The World Health Organisation (2011) estimates that more than a billion people globally experience some form of disability, with approximately 1-3% of the world's population categorised as having a learning disability (Scior et al., 2015). Evidence shows that disabled people tend to have worse health outcomes and lower life expectancy compared to the general population, and face significant barriers to accessing healthcare services (Committee on the Rights of Persons with Disabilities, 2014; IHC New Zealand, 2017; Scior et al., 2015; World Health Organisation, 2011). Johnson and Walsmley (2010) note that learning disabled people in particular “are 2.5 times more likely to have health problems” (p. 6), are four times more likely to die of preventable diseases and are “58 times more likely to die before the age of 50” (p. 6) as compared with people in the general population.

Disabled people are also more likely than the general population to suffer sexual and emotional abuse, physical violence and bullying; these issues being

particularly problematic for learning disabled people (French & Swain, 2006; Goodley, 2017; Mirfin-Veitch, Bray, Moore, Walker, & Ross, 2000; Munford, Sanders, Brigit Miffin, & Conder, 2008). Given these circumstances it is not surprising to find that rates of depression and other psychiatric disorders for disabled people are three to four times higher than for the general population (J. Davis, Judd, & H Herman, 1997).

For learning disabled people in particular, there are significant barriers in relation to accessing sexual and reproductive healthcare services, as well as support to establish and maintain healthy intimate relationships (Committee on the Rights of Persons with Disabilities, 2014; Crawford & Ostrove, 2003; Hamilton, 2006; Macguire, Gleeson, & Holmes, 2019; Mirfin-Veitch, 2003). This barrier exists because of the poor availability and accessibility of services, lack of training and subsequent fear and uncertainty on the part of support workers on how best to support people with this aspect of their lives, as well as negative community attitudes leading to discriminatory practices in which sex and sexuality are seen as taboo topics that have no applicability to the lives of learning disabled people (Hamilton, 2006; Hinsburger, 1995, 2006; Macguire et al., 2019; Sitter, 2015).

Globally, learning disabled children face significant barriers to accessing regular education; it is not uncommon for learning disabled children to be excluded from education altogether (Goodley, 2017; World Health Organisation, 2011). Although all children in Aotearoa New Zealand have the legal right to attend their local school (Human Rights Commission, 2016), in practice many learning disabled children are either excluded from mainstream education, or not adequately supported to be able to achieve in mainstream education settings (IHC, n.d.; IHC New Zealand, 2017). This situation arises in no small part because, as the United Nations Committee on the Rights of Persons with Disabilities (hereafter referred to as the UNCRPD) (2014) notes, “there is no enforceable right to inclusive education” (p. 6) in Aotearoa New Zealand. Currently, IHC New Zealand, the largest provider of services for learning disabled people in Aotearoa New Zealand, has a complaint filed with the Human Rights Review Tribunal (IHC New Zealand, 2018). This complaint is in regards to the

discriminatory treatment of disabled children in New Zealand schools which, as noted earlier, has resulted in the exclusion of many learning disabled children from mainstream education.

The United Nations *Convention on the Rights of Persons with Disabilities* (2006) asserts:

[T]he right of persons with disabilities to work, on an equal basis with others; this includes the right to opportunity to gain a living by work freely chosen or accepted in a labour market and work environment that is open, inclusive and accessible to persons with disabilities. (p. 19)

Although a relatively short period of time has passed since the Convention was instituted, it is important to note that disabled people internationally continue to experience lower rates of employment than people without disabilities (van Dalen, 2017; World Health Organisation, 2011). In Aotearoa New Zealand, the disabled population has over double the unemployment rate compared to the non-disabled population: 11.4% compared with 4.5% (Statistics New Zealand, 2017a). The UNCRPD (2014) has noted its concern at the low employment rates for disabled New Zealanders, particularly for disabled Māori and Pasifika people.

According to the 2013 Disability Survey (Statistics New Zealand, 2013a), 34% of intellectually (learning) disabled people are employed. However, it is important to note that there were only 59 respondents with a learning disability in the survey, all of whom lived in private households and thus not in residential group homes. Anecdotal evidence suggests that the actual employment rate for learning disabled people is significantly lower than 34% (Cindy Johns, personal communication, November 4, 2016). Alongside the low employment rates, disabled people are more likely to work part-time (Statistics New Zealand, 2017a; van Dalen, 2017), with limited-to-no opportunities to progress from entry level positions. The hidden difficulties associated with obtaining meaningful employment have been noted in a recent research study conducted in Aotearoa New Zealand, where one participant was quoted as saying:

It's all right to have a job. Disabled people have jobs, that's awesome. But how many of them have careers?... There's a big difference between the two. (van Dalen, 2017, p. 8)

Disabled people are also often paid significantly less than non-disabled people (Statistics New Zealand, 2013a, 2017a). In a recent study, Statistics New Zealand (2017a) found that the average weekly income of disabled people was \$458; just over half of the \$833 being earned by their non-disabled counterparts. It is furthermore still legal to pay a learning disabled person less than the minimum wage (Employment New Zealand, 2018). In 2014, the UNCRPD noted that, at a time when the New Zealand minimum wage was \$13.75 per hour, there were approximately 1,200 disabled people being paid less than the minimum wage under a minimum wage exemption permit. Of those on the permit, 73.5% were paid less than \$5 an hour, and 51% were paid less than \$3 per hour (Jeffs, 2014).

As a consequence of the lower employment rates, lower incomes and higher costs of living associated with having a disability, disabled people globally are over-represented in the statistics on poverty (Goodley, 2017; United Nations, 2006; van Dalen, 2017; World Health Organisation, 2011). Aotearoa New Zealand is no exception to this situation, and in 2014 the UNCRPD noted their concerns at the poverty rates of disabled people in New Zealand. In particular, they noted that disabled children are over-represented in statistics on child poverty. This situation has had a significant impact on everyday lives, as this quotation from a recent survey reveals:

[P]eople with intellectual disabilities and their families do not have enough money for food, clothing, bills and transport – let alone for going out, holidays, celebrations or paying for additional disability costs. (IHC, 2017, np)

When set against other intersectional elements such as gender, class, sexuality, age and race, the gaps in the statistics between disabled and non-disabled people become even more pronounced (van Houten & Jacobs, 2005). In New Zealand, Māori and Pasifika disabled people have been shown to have significantly higher unemployment rates than disabled people who represent

other ethnic groups (Statistics New Zealand, 2017b). Disabled women in particular occupy a specific site of exclusion, as they are more likely to live in poverty than disabled men (Goodley, 2017), experience higher levels of abuse (Braidotti, 2013), are more likely to find public space unwelcoming and threatening (Goodley, 2017), and experience higher levels of depression (Goodley, 2017). However, within all statistics gathered in key life areas – life expectancy, access to reproductive health services, employment rates or poverty statistics – learning disabled people stand out as the most affected group in these problematic social conditions.

The figures in this chapter only give information on issues which are easily measured. What is harder to measure is how disabled people spend a significant part of each day dealing with a world which has been designed to exclude them (Keith, 1996) – both socially and physically. Cheyne (2016), Price (2016) and Sheppard (2017) discuss the added emotional labour of having a disability. Interacting with disability can be a source of discomfort for many people, and as a result disabled people often take on the emotional labour of easing this discomfort (Cheyne, 2016; Price, 2016). This affective work, which is often ongoing and tiring, involves “[p]erceiving the emotional state of someone they’re talking to or interacting with, interpreting it” (Cheyne, 2016, 22:10) and then, if the disabled person chooses or feels the need to, adjusting their behaviour accordingly.

In mulling over the statistics in this chapter, what troubles me about presenting information in this scholarly way is that it obscures a key idea on which this thesis is based: that there are real people with real stories behind every statistic. Behind every statistic I have presented in this chapter, there are people I know whose lives are circumscribed by these data. I have worked with women who want children but have been sterilised without their knowledge or consent, with families who have had to move cities because their disabled child was not able to attend any of their local schools, and with people who receive such poor healthcare that they have been forced to walk on a broken hip, or stand with a broken back, because the doctors did not believe they were in pain.

Many of the learning disabled people I know struggle to find houses to live in, money to warm their houses, and to have enough food to eat. It is not uncommon for people to be bullied, sexually harassed, have no meaningful vocation, or spend years (and sometimes a lifetime) fruitlessly searching for a job. Many are lonely and have few meaningful relationships outside of family and paid support staff.

What further troubles me about these statistics is the information which is not captured, such as the lack of opportunity for learning disabled people to have a voice and the resources necessary to challenge these situations. Often it has seemed to me that unless someone is fortunate enough to be born into a supportive and well-resourced family, there is little opportunity for learning disabled people to take charge of what is happening and get themselves out of adversity. For instance, during the period in which I was working on this thesis I witnessed people being denied the right to have a hot drink outside of approved meal times, to attend rugby matches, to choose not to eat sausages for dinner, to choose not to live with someone who regularly threatens them with physical violence, to choose not to be supported by someone they cannot stand, to use their personal savings to go on a (supported) holiday to Australia, or to buy a cat, or a remote-controlled aeroplane. In most of these situations the learning disabled people did not have any recourse when the other people in their lives – the people upon whom they rely for support to enact goals – told them “no”.

The lack of opportunity for learning disabled people to have a voice in their own lives was highlighted in a 2008 Social Services Select Committee Report. In this report, the Social Services Select Committee (2008) found that people in support services “often feel they have little control over the services they receive” (p. 10). This includes having little choice over “whom they live with, who provides them with care, what they eat, or when they get up and when they go to bed and what they do during the day” (p. 24). As a support worker I have experienced being the person who has the power to decide such things as when a person is “allowed” to shower, how much they are “allowed” to eat, and when and what they are “allowed” to spend their money on.

The issue which most vexed me about the situation outlined in this chapter was that I did not believe it was caused by large-scale malicious intent. Instead, these situations arose when disabled people's "best interests" were held in mind. I could see the role that I played in perpetuating these circumstances, while, at the same time working hard to challenge these practices. Time and time again I both witnessed and participated in people being denied basic human rights, and although I was unable to explain exactly why we kept doing it, I sensed it was because of an issue much bigger than "poor attitudes" or lack of training and understanding about disability rights.

## Rethinking the "Problem" of Disability

I came to this thesis wanting to learn what it is that we need to do differently in order to change the situation I saw around me. I came to realise that if our hardest efforts to help are not making much headway into solving the problem of disability oppression, then perhaps the solution did not lie in simply trying harder. Perhaps what we needed to do was to step back from what is happening and take a look at how we are thinking about disability and the problem we are facing, to interrogate the underlying assumptions inherent in our ways of thinking, and to see if it is possible through doing this to find a new and more promising path forward. In particular, I am drawn to a quote which Garland-Thomson (2002) drew from Nancy Eiseland (1994), in which she states, "the way we imagine disability and disabled people must shift in order for real social change to occur" (p. 23). I believe the reason we are not making much progress in challenging the "big picture" of disability is that we are asking the wrong questions. We are asking how to include people, rather than asking what is causing exclusion, and we are asking how we can help disabled people overcome the barriers to full participation, without asking what is creating the barriers in the first place. It is furthermore my belief that the theoretical tools we have been using to think about disability, including normalisation, the social model and rights-based models, have been too limited in grasping the "problem"

of disability. These tools have not enabled us to explore the full breadth of forces at play in disability oppression, and have not enabled us to explore the everyday ways in which all of us, myself included, are thoroughly complicit in this process.

The overall aim in this research is thus to examine the theoretical perspectives we have been using to think about the “problem” of disability, and to contribute to a new way of conceptualising learning disability that may inform future policy and practice in Aotearoa New Zealand.

## **Tools for Rethinking the “Problem” of Disability**

Two key concepts have helped me to rethink the “problem” of disability: ableism and pride. These have been the threads which have guided, shaped and woven this project together. I will outline each concept briefly below, and explore them in more detail in the following chapters.

### **Ableism.**

Ableism is the belief that there is such a thing as a “normal”, “ideal” person, that we should all be that person, and that to be other than that, such as to be disabled, is a problem. The assumption of this ideal norm is a phenomenon around which much of our world is shaped. Many of our homes are built assuming everyone can walk, many of our jobs are designed assuming a certain level of cognitive ability, and much of our social world is built around the assumption that people can understand social cues.

One of the key ways in which the theory of ableism shaped my thinking was that it shifted my view from the “problem” of disability as being located in disabled individuals, to the “production, operation and maintenance of ableism” (Campbell, 2009a, p. 4); that is, the assumption that everyone is meant to be the ideal norm. Shifting the focus of the problem in this way has meant that I no longer think of trying to include disabled people into “the community”, as is often asserted in human services, but rather that I look to the systems, process and individual acts which exclude people and “otherwise” people in the first place (Campbell, 2009a).



## Disability Pride.

The second key concept which proved foundational in shifting how I thought about the “problem” of disability was Pride. I first came across the notion of disability pride after reading Ian Parson’s (1999) book, *Cripples, Coons, Fags and Fems*, in which he compares the gay and lesbian rights movements, the women’s rights movement, and the aboriginal rights movement with the disability rights movement. Disability pride is about being proud *because* of disability; not in spite of disability, or in the common humanity of disabled people (Parsons, 1999). Disability pride is about the acceptance and celebration of difference; “it is about subverting negative valuation and reclaiming disability” (Shakespeare, 1996, p. 106). I believe, as I will highlight throughout this thesis, that pride can be a useful tool to challenge the ongoing inferiorisation of disability in our world.

## Conclusion

In this chapter I have argued for the need to reimagine disability if we are to move forward in tackling disability oppression. I have detailed the “big picture” of disability, focusing specifically on the various statistics and other factors related to disability oppression. I have explored some of the challenges I have faced in my work in disability support services, and what has driven the desire to do this research project. This includes the view that the “problem” we are facing is not caused by poor intentions and attitudes, but rather issues which lie beyond the scope of intentionality. Lastly, I have explored the two key concepts which have guided and shaped my (re)thinking about disability throughout this thesis.

## Thesis Structure

This thesis is broadly split into three sections. Chapters One to Three examine the background issues that set the scene for the thesis, exploring the problem underpinning the research and existing strategies and policies which seek to understand and tackle this issue. Chapters Four to Six outline how the

research was shaped, exploring the conceptual framing, methodology and method for data generation, and analysis method. Chapters Seven to Eleven constitute the analysis of the thesis, including discussion on the findings. Lastly, Chapter Twelve provides a summary of the thesis and discusses implications for policy and practice.

## Chapter Outline

Chapter Two outlines the rationale for the thesis, which is founded on the culmination of three core ideas. First, literature from disability studies and the humanities more widely are drawn upon to argue that the binary notions of “learning disability” and “normal, ideal humans” are not fixed, indisputable concepts. Instead, they are viewed as an artefact of the historical, political, spiritual and social structures which have emerged over the past few centuries in the Western<sup>2</sup> world. Second, that the notions of “disabled” and “abled” (otherwise known as “normal” or “ideal”) are born from and grafted upon each other. The concept of disability then functions as the requisite “constitutive outside” (Campbell, 2005), enabling the notion of “ideal, normal humans” to exist. Third, I argue that the positioning of disability as “naturally” inferior within this binary plays a crucial role in the validation and perpetuation of disability oppression.

Chapter Three examines the key conceptual frameworks related to learning disability in Aotearoa New Zealand, as evidenced through Government policy and strategy. These frameworks are the medical model, normalisation / social role valorisation, the social model, rights-based approaches and Māori perspectives on disability. The progress-gains from each of these frameworks are explored, as well as the limitations. With the exception of Māori perspectives on disability, each of these frameworks is underpinned by the modernist notion of

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<sup>2</sup> The use of the term “Western world” is utilised throughout this thesis to indicate a range of countries whose culture “is derived from European civilisation as distinct from oriental nations... African non-Islamic nations, and Communist states generally” (Arnold-Baker, 2001, np). Countries include United States of America and Canada, Australia, New Zealand, and those in Western Europe, although these boundaries are somewhat porous.

the ideal human. This ontological foundation inhibits the ability to challenge exclusionary structures and practices which lead to disability oppression.

Chapter Four outlines the conceptual framing for this thesis. Whilst the conceptual framing draws upon multiple frameworks and scholars, it is grounded in Barad's work on agential realism. Drawing upon the agential realist view of ontological inseparability, I propose a new means of conceptualising disability: disability as an ongoing series of entanglements. This view does not see disability as a static, bounded entity, but rather as a *difference* which emerges through the iterative entanglement of multiple, performative agencies. After coming to this view, the research centred around a key problem statement: the entanglements of disability materialise in such a way that they reiterate disability oppression. The research questions stemming from this problem statement include exploring what the entanglements of disability are, what the performative agencies within the entanglements are, how these entanglements enable disability oppression to be perpetuated, and what the entanglements present potential for.

In order to answer these research questions, I draw upon multiple other conceptual frameworks. These include citational chains, lines of flight, Butler's work on performativity, Wetherell's work on affective and social practice, and Jackson and Mazzei's work on desiring silence. I also explore the notion of disability pride, an under-theorised concept which I believe can be used as a tool to disrupt the problematic iterative entanglements of disability.

Chapter Five outlines the methodology and particular methods used in this thesis. The methodology was formed from an entanglement of methodological perspectives, including inclusive research, participatory action research, community based participatory methodologies, culturally responsive methodologies, and decolonising methodologies. These frameworks were chosen for their emphasis on power sharing, co-creation, and the desire to enact change, rather than merely investigating an existing situation. The methodological framework is further underpinned by the drive not to perpetuate the harms visited on learning disabled people through research conducted historically, and the desire to do research that works for learning disabled and does not rely solely on cognitive abilities. The data were generated through a

series of nine “hui”, or research meetings. The content of the hui was developed using a co-creation approach, working with a co-facilitator and seven participants, all of whom have been assigned the label of learning disabled. A range of resources and activities were utilised during the hui, including a series of role-plays on bullying, a topic which emerged as an important issue for participants.

Chapter Six describes the analysis method used for this thesis: diffractive analysis. This framework has been further developed by Jackson and Mazzei (2011) in their work on “plugging in”. These frameworks take into account the view that all phenomena - research questions participants, researchers, emotions, theory, and data included, necessarily affect and interfere with each other. The Deleuzian questions of *how does it work* and *what does it do not what does it mean* prove formative in the analysis. These questions are used to explore how the entanglements of disability function, and what they in turn produce.

Chapter Seven introduces the analysis of the findings. This chapter outlines a series of critical moments which happened when participants were presented with videos and discussions highlighting disability pride. These conversations were introduced in order to explore the first research question: does pride present potential for a positive reimagination of disability? From this result, the view of disability as an ongoing series of entanglements was developed. Chapter Eight explores the first territorialising force inhibiting the development of pride within the hui: affective practice, drawing upon Wetherell's (e.g., 2012) work on affective practice. Chapter Nine examines the notion of the disability identity and how this subject positioning was taken on, or not, by participants. Chapter Ten investigates participants' understanding of disability and how this understanding entangles together with the practices of silence. Chapter Eleven examines a powerful and somewhat perplexing phenomenon which arose during data generation: that of *help*. Chapter Twelve provides a concluding discussion for the thesis, including implications for policy, practice and future research. I review the key problematic entanglements of disability which were unearthed in this thesis, and summarise what these

entanglements foreclose and present potential for. I conclude by demonstrating the radical potential for change which I believe can potentially be found by understanding and reworking the entanglements explored in this thesis.

## Chapter 2:

# Conceptualising Learning Disability

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At the time I enrolled to do a PhD, I had given little thought to my own status as a “non-disabled” person, or about the permeability of the disability category. It never occurred to me to see learning disability as anything other than a fixed, essential concept which has always resided in nature; or, for that matter, to question the positioning of the people placed in this category as “other” to myself. Through the journey of the PhD I have come to question these ideas. I have realised that my lack of thought regarding my status as a non-disabled person is integrally connected with the processes which position people assigned the label of learning disabled as “naturally inferior” beings. Furthermore, I have come see that the processes which position people as inferior are entwined with the adverse material circumstances faced by the people placed in this category. I believe the view that disability is inferior is entangled within, and lays the foundation for, disability oppression.

The rationale for this thesis is founded on a combination of three core ideas outlined in this chapter. First, that learning disability is not an essential category, but rather an artefact of the historical, political, spiritual and social structures which have emerged over the past few centuries in the Western world. These structures play an integral role in shaping how the human body and mind have come to be understood (Blackmore & Hodgkins, 2012), enabling us to see people as “normal” and “disabled”. The structures are *modernism*, with its focus on the “ideal human” and the statistical norm around which this ideal is based (Yates, 2005), and *capitalism*, with its focus on “desirable”, “abled” and productive workers. Inherent within both of these structures is the notion of the individual, and ideas related to unproductive and inferior beings.

The second key idea is that the notions of “abled” and “disabled” are born from and grafted upon each other. Ableism is used as a conceptual tool to understand and critique the notions of disability and the ideal/modernist human. It is further utilised to investigate how the material and social world has been built around this ableist norm.

The third key concept relates to how disability becomes “of necessity” positioned as inferior or lacking within the ableist binary. The connection between the view of disability as inferior, and the poor material circumstances in which many people assigned the label of disabled find themselves, will be explored.

Finally, this chapter will explore how the processes which constitute learning disability as an essentialist, inferior category are not isolated phenomena. Instead, these processes are viewed as inhering within much wider processes of “othering”. In these processes, to be viewed as “different from” the norm, whether this difference relates to disability, race, sexuality or any other identity category, spells inferiority (Braidotti, 2013).

## **Truth-Claims of Learning Disability**

Marks (1999) points out that contemporary conceptualisations of learning disability are often based around a “common-sense” understanding of the term. This understanding sees disability as a flaw inherent in individuals whose bodies and minds do not “work properly”, or conform to the expected norms of society. Scior et al. (2015) note that the most common internationally adopted definitions of learning disability come from the *ICD-11 Mortality and Morbidity Statistics* (“6A00 Disorders of intellectual development”, 2018) (hereafter referred to as the ICD-11), and the *American Psychiatric Association’s Diagnostic and Statistical Manual (DSM-5)* (2013). In addition to this, the American Association of Intellectual and Developmental Disabilities (AAIDD) (2018) is another frequently cited definition of learning disability.

The ICD-11, DSM-5 and AAIDD have similar definitions of learning disability; although the ICD-11 uses slightly different phraseology to define the

term. In the ICD-11, “disorders of intellectual development” sit under the parent category of neurodevelopmental disorders, and are defined as:

[A] group of etiologically diverse conditions originating during the developmental period characterized by significantly below average intellectual functioning and adaptive behavior that are approximately two or more standard deviations below the mean (approximately less than the 2.3rd percentile), based on appropriately normed, individually administered standardized tests. Where appropriately normed and standardized tests are not available, diagnosis of disorders of intellectual development requires greater reliance on clinical judgment based on appropriate assessment of comparable behavioural indicators.  
(para 1)

Within the DSM-5 definition, “intellectual disability” is defined as:

[A] disorder with onset during the developmental period that includes both *intellectual and adaptive functioning deficits* in conceptual, social, and practical domains. (Intellectual Disabilities: Diagnostic Criteria. Para. 1, emphasis in original)

Similarly, the AAIDD defines “intellectual disability: as:

*Intellectual disability* is a disability characterized by significant limitations in both **intellectual functioning** and in **adaptive behavior**, which covers many everyday social and practical skills. This disability originates **before the age of 18**. (para 1, emphasis in original).

The use of the terms “significantly below average”, “deficit”, and “significant limitations”, as well as the need for tests to be “individually administered” in the ICD-11, highlight the definitions’ interpretation of learning disability as a *lack* inherent in individuals.

The DSM-5 notes three criteria which must be met in order to qualify for an intellectual disability diagnosis. These are deficits in intellectual functioning,



confirmed by standardized intelligence testing and clinical assessment; and deficits in adaptive functioning, which limit a person's independent functioning in daily life activities. These deficits must have evidence of onset during the early developmental period (i.e., before the age of 18) and not be the result of trauma, such as a head injury. The ICD-11 and DSM-5 definitions also categorise learning disability into four types of "severity" - mild, moderate, severe and profound. These are based deviation from the mean in the ICD-11, and on level of skill as compared with non-affected peers in the DSM-5.

In Aotearoa New Zealand, the *Operational Guideline for the Assessment of Intellectual Disability to Access Disability Support Services Contracted for People with Intellectual Disability* (Ministry of Health, 2012a) incorporates both aspects of the definitions noted above. In this country, a learning disability is defined as present in cases of "[s]ignificantly sub-average intellectual functioning" with "an IQ of approximately 70 or below" (Ministry of Health, 2012a, p. 6). The criteria also include the following:

Deficits or impairments in current adaptive functioning in at least two of the following areas: communication, self-care, home living, social and interpersonal skills, use of community resources, self-direction, functional academic skills, work, leisure, health and safety. (p. 6)

Further, these difficulties must be evident before the age of 18 (Ministry of Health, 2012a).

The definitions noted on the previous pages play a powerful role in positioning the notion of learning disability as an irrefutable claim to truth. This idea of "truth-claims" stems from the French philosopher, Michel Foucault, whose work has profoundly shaped the field of humanities, including much of the literature used in this thesis. In particular, Foucault is interested in the connection between power and knowledge, noting that claims to "truth" are inextricably bound up in regimes of power. As he notes:

Each society has its regime of truth, its 'general politics' of truth: that is, the types of discourse which it accepts and makes function

as true; the mechanisms and instances which enable one to distinguish true and false statements, the means by which each is sanctioned; the techniques and procedures accorded value in the acquisition of truth; the status of those who are charged with saying what counts as true. (1980, p. 131)

In this understanding, the notion of learning disability can be viewed as a sanctioned form of knowledge, a regime of “truth” accepted within Western society. In particular, this truth-claim is established and reinforced through predicating access to vital services or supports on receiving a diagnosis. In Aotearoa New Zealand, a diagnosis of learning disability must be established before learning disability support services will be provided (Ministry of Health, 2012a). Diagnosis assures access to the Supported Living benefit when it is needed (Ministry of Social Development, 2018); the Supported Living benefit stands in contrast to the more easily obtainable Jobseeker benefit, which provides a lower weekly payment, has numerous obligations, and can be drastically reduced if the obligations are not met (Ministry of Social Development, 2018). Furthermore, in order to receive funding for support at school, children in Aotearoa New Zealand must display significant “deficits” in any one of the following areas: learning, hearing, vision, mobility, language use and social communication (Ministry of Education, 2017); these criteria are in line with those used to determine a disability diagnosis in the ICD-11 and DSM-5. Salvador-Carulla et al. (2011) note that access to vital services in most countries are similarly predicated on a diagnosis. As they discuss, diagnostic criteria “are used throughout the world to specify which people are eligible for what health care, educational and social services under what conditions” (p. 176).

The training for many support workers for learning disabled people draws on these definitions of disability. The *New Zealand Certificate in Health & Wellbeing (Support Work) Level 3* (IHC New Zealand Incorporated, 2016) discusses the three definitions noted earlier, along with definitions from the *United Nations Convention on the Rights of Persons with Disabilities* (2006), and the *American Association on Intellectual and Developmental Disabilities* (AAIDD) (2018). All of these definitions define learning disability as a form of individual

deficit, and none suggest any level of ambiguity as to the assertion that learning disability is an identifiable and measurable phenomenon.

All of the entities noted earlier – support services, government agencies and training bodies - are positioned to shape the materiality of people’s lives. This includes ensuring people have sufficient money and support to live, enabling access to education, and granting qualifications necessary to find work. No diagnosis from a qualified medical professional means no access to learning disability support services, and less money to live. For support worker trainees, refusing to demonstrate an understanding of these definitions means no qualification, and fewer job opportunities. The power vested in these authoritative bodies ensures that the understanding of learning disability as individual deficit, and as a measurable, identifiable entity is continually established and maintained as a “truth-claim”.

Although there is a general level of international agreement regarding the view that learning disability is an essential category, there is less agreement about what specific term should be used. Variations include “intellectual disability”, the most preferred term in New Zealand (Ministry of Health, 2012a), as well as “mental handicap”, “mental retardation”, “learning difficulties” and “mental disabilities”; the latter term can be used in such a way that no distinction is made between mental illness and learning disability (Scior et al., 2015).

In the following section, I briefly detail how the claims to truth regarding what is now known as learning disability, have changed over the past millennia.

## **Pre-Contemporary Conceptualisations of Learning Disability**

Conceptualisations of disability have undergone significant shifts over time. In ancient Greece, disability was viewed as evidence of the Gods’ dismay with a community (Bragg, 1997). As a result of this thinking, many disabled people were exiled (Bragg, 1997). Aristotle (384BC – 322BC) is known for stating “...let there be a law that no deformed child shall live” (Jowett, 1885, as cited in

1932, p. 109). For both Aristotle and Plato (circa 428BC – 348 BC), “men” were separated from beasts because of their capacity for reason (Stainton, 2001). To be found wanting in respect of reason – to be what would today be called learning disabled - was to be “less than human, to lack value, to stand apart from and deserve to be cast out of the polity” (Stainton, 2001, p. 453).

In medieval Europe, disabled people were seen to belong to a sphere of mysticism, and as more intimate with God than mainstream society (Stiker, 1999). As Stiker (1999) notes, disabled people were “sites and moments for contemplation and adoration... one in whom you recognized God, one who became like a living sacrament, like the sacred itself” (p. 81). Furthermore, Bragg (1997) states that in literature from the Northern European Middle Ages, impairment was generally taken as a sign of contact with a deity. Many deities were themselves impaired and / or showed evidence of mutilation (Bragg, 1997). However, Bragg (1997) cautions that the early Middle Ages should not be viewed as a kind of golden age for disabled people. Much of the literature from this period suggests that exceptionalities, such as what is now defined as learning disabled, were undesirable. During the Renaissance period, having a child with a disability was viewed as a punishment from God for wrongs committed by the parents (Huet, 1993). In more recent times, disability has moved away from a spiritual view, towards a more medicalised understanding. In this interpretation, disability is seen as individual pathology which involves some kind of a sensory, cognitive and/or physical failing (Goodley, 2011).

To conclude this brief section, it appears that what is currently conceptualised as learning disability has undergone significant shifts through history. Contemporary conceptualisations posit that learning disability as it is understood today is an undeniable “truth-claim” which has existed throughout the ages. However, different eras have each produced differing conceptualisations and truth-claims regarding what learning disability is understood to be. What is interesting to note is that learning disability has not always been viewed as being equated with inferiority, but instead as something which can indicate a deeper connection with divine beings than non-disabled people. However, through many periods of time the notion of learning disability,

and thus the people upon whom the label is placed, is viewed as either less-than-human, or as a lesser form of human.

The next section will explore the emergence of ideas related to (learning) disability as an essentialist category. This exploration will include a focus on key social, scientific, material and political structures which have played an integral role in shaping how the human body and mind have come to be understood (Blackmore & Hodgkins, 2012).

## **Learning Disability as an Artefact of Modernity and Capitalism**

From the first half of the nineteenth century, “idiocy” became recognised as a distinct condition which could be identified through the use of scientific measurements such as the IQ test (Licia Carlson, 2005). This practice is still currently in use (Ministry of Health, 2012a; Scior et al., 2015). Various categories emerged to classify the different intellectual levels and “types” of disabilities, including “idiot” “imbecile”, “feeble-minded”, “defective”, “cretin”, “moron”, “fool” and “simpleton” (Hamilton, 2008; Marks, 1999; Simpson, 2011). In Aotearoa New Zealand, the Mental Defectives Act (1911) made use of these terms to differentiate “between persons of unsound mind, persons mentally infirm, imbeciles, the feeble minded and epileptics” (1900 to 1970, para. 4).

However, rather than viewing disability as an essential pathology, disability scholars (see Oliver, 1990, 1996; Tremain, 2001, 2005b) argue that learning disability can be seen as an artefact of the political, material and social structures which have emerged as powerful forces within Western culture. These include modernity, with its focus on “ideal” humans and the “norm” (Tremain, 2005), and capitalism, with its focus on abled and productive workers.

## **The Modernist Human, Capitalism and the Emergence of Learning Disability**

The period of Modernity emerged out of the Age of Enlightenment, during which prior held views regarding the role of church and the position of

kingship as the source of all truth were superseded (Gannon & Davies, 2007). This period is characterised by a “great faith in the ability of reason to discover absolute forms of knowledge” (Crotty, 1998, p. 185). Prior held beliefs became seen as superstition and irrationality, to be replaced with notions of universal truth, reason and logic (Crotty, 1998). Emerging from this time of reason, logic and universal truths came the notion of independent individuals from whom reason and logic necessarily emanated; individuals who are “distinct, bounded and separated from others” (Goodley & Runswick-Cole, 2016, p. 8).

“Western Man” became the standard against which all other bodies (and minds) were compared (Davies, 2016), the ideal human which all are meant to embody. Yet, for Braidotti (2013), this ideal figure was:

[N]either an ideal nor an objective statistical average or middle ground. It rather spells out a systematized standard of recognizability – of Sameness – by which all others can be assessed, regulated and allotted to a designated social location. (p. 24)

Further, the ideal individual of modernity is autonomous, always in control and self-reliant (Crotty, 1998), as well as ideally white, heterosexual, male, able-bodied, capable, responsible and middle-class (Davies, 2016; Goodley, Lawthom, & Runswick-Cole, 2014). Above all else, this individual is *rational*. These criteria continue to play a powerful role in shaping understandings of the ideal traits which all humans are expected to embody. This idea can be seen in Article 1 of the *United Nations Declaration on Human Rights* (United Nations General Assembly, 1948), which asserts:

All human beings are born free and equal in dignity and rights. They are *endowed with reason and conscience* and should act towards one another in a spirit of brotherhood. (Article 1, emphasis added)

The assumption that all humans will embody these criteria, particularly the criteria of rationality, plays a powerful role in shaping the (Western) world. For instance, the education system for children aged 5-18 in many countries,

including Aotearoa New Zealand, is built around the assumption that all children will learn to be self-reliant, will learn to be in control of their emotions and be able to learn at a “typical” speed and in a “typical” fashion (Hehir, 2002). Children who do not meet these criteria are viewed as failing to meet the expected standard and are subject to “special” conditions, such as individualised education plans and placement in “special” schools. Further, the neoliberal economic system, which plays a powerful role in shaping the behaviour of governments, institutions, communities and individuals (Davies, 2016), is founded on the assumption that humans are rational beings who make rational behavioural and economic decisions (Olssen & Peters, 2005). Modernist notions of the ideal human, and the concept of reason in particular, also play an integral role in shaping an understanding of what makes for a “good life”. As Johnson and Walmsley (2010) state, “reason is central to the good life in Western philosophy” (pp. 50-51).

These notions of reason and the ideal human also profoundly shape contemporary conceptualisations of “personhood” – that is, what is necessary in order to be considered a full person. Johnson and Walmsley for instance note that when reason is impugned, one’s status as a human being may be doubted. Scully<sup>3</sup> (2016) argues furthermore:

Entire academic careers have been devoted to articulating criteria to ascertain who is and is not a person. These criteria are often about having specific capacities such as rationality, agency, independence, self-awareness, the ability to communicate, to establish relationships, and so on. (np)

This notion of “personhood” is particularly problematic for learning disabled people because, as Scully (2016) notes, many people with learning disabilities fail to meet these standards. The exclusion of learning disability from the category of the human has at times been overtly stated and is particularly evident in Linnaeus’ *Systema Naturae* (1735) (Hughes, 2012). Here, a distinction is made between two ‘types’ of human - *homo sapiens* and *homo monstrosus*, under

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<sup>3</sup> I would like to thank Jackie Leach Scully for providing me with the notes of her presentation.

which “impairment – at its extreme and highly visible end – is excluded from the human family” (Hughes, 2012, p. 22).

Capitalism is isolated as the second key force that shaped the emergence of the category of (learning) disability. In a period that saw large numbers of people moving into factories to perform uniform tasks, a new conceptualisation of desirable workers and bodies emerged. Drawing on the work of Karl Marx, McRuer and Wilkerson (2003) highlight the powerful connection between capitalism and the notion of the able-bodied worker. As they note, “[e]mergent industrial capitalism needed ability so much that it produced a new identity, that of the able-bodied worker” (p. 14). A second, stigmatized identity emerged as the binary opposite to the ideal worker, that of disability. Any cognitive, sensory, physical and psychiatric differences impacting on productivity and educability became faults localised in individual bodies (D. Mitchell & Snyder, 2017). Those unable to meet the expectations of productivity became seen as “a particular kind of social problem” (Oliver, 1990, p. 78). Under this guise, disabled people became categorised as unproductive and viewed as forming a “surplus population” (Erevelles, 1996, 2000). Subsequently, people positioned as disabled came to be excluded from the “mainstream” community (Clapton, 2009). This situation played a powerful role in positioning disability as individual pathology (Oliver, 1990).

The relationship between capitalism and the notions of productivity, economic contribution and social worth (Clapton, 2009; Hyde, 2000) impacted heavily on people with profound physical, sensory and learning disabilities. Institutionalisation became the preferred means by which to contain and support unproductive citizens, as well as to “protect” wider society and “defectives” from each other. Institutionalisation further helped to ensure that “defectives” did not procreate and contaminate the gene pool (Clapton, 2009). These ideas remain barriers to the full inclusion of all disabled people in the life of their community in contemporary society (Wolbring, 2008).

In Aotearoa New Zealand, rapid European settlement post 1840 meant that many European ideas, including those regarding the Modernist ideal human, evolutionary fitness, economic contribution and productivity took root in this



country (Hamilton, 2018). From 1863 onwards, what were then called asylums were built in order to house “the disturbed, the dangerous, the unpredictable” (Campion, 2012, p. 12). These terms described forms of appearance or behaviour that could not be altered to fit what was socially expected at the time (Hamilton, 2018). Removing learning disabled people from the wider population furthered the positioning of this group of people as “other”.

## **The Bell Curve and the “Norm”**

One particular phenomenon which played a powerful role in shaping the modernist conception of the ideal human, and which continues to shape how disability is viewed today, is that of the norm. Foucault (1977) notes that, in the last two centuries, normalisation has become “one of the great instruments of power” (p. 184) of contemporary Euro-Western concern. Measuring individuals in relation to “the norm” enabled otherwise disparate groups of people to be divided, classified and ordered into discrete ontological categories, such as “disabled” and “normal” (Tremain, 2005b). According to Foucault (1980), the ability to group populations into discrete ontological categories was necessary as it not only enabled an increase in the utility of individuals, but also worked to ensure their subjection to governmentality. Normality became a means through which subjects could both be identified, and come to understand themselves. In turn, these processes of subjection became integral to making populations governable (Tremain, 2005).

The idea that “intelligence” might be a knowable, measurable entity can be traced back to the field of psychology around the turn of the twentieth century (Gould, 1996; Herrnstein & Murray, 1994). Key early scholars, including Francis Galton, Alfred Binet and Henry Goddard, utilised a growing body of knowledge in the field of statistical analysis in order to begin finding measures by which to assess an individual’s levels of intelligence (Gould, 1996). Alfred Binet’s work, wherein he developed tests of reasoning in order to classify children who required special educational support, proved to be immensely productive in this area. Binet was clear that intelligence could never be represented with a single measure or score, and worried greatly the results of his tests could be used as a

convenient excuse to remove disabled and other “troublesome” children from general education settings (Gould, 1996). Gould further (1996) notes that Binet was steadfast in his belief that the tests should only be used in order “to identify in order to help and improve, not to label in order to limit” (p. 182). However, as Gould (1996) remarks, Binet’s intentions regarding not positing a single score for intelligence and not using tests to label and limit children were overturned by those who built upon his work. Henry Goddard was the first person to translate Binet’s work into English and to popularise what was then termed the “Binet Scale” in the United States of America (Gould, 1996). Goddard went on to assert that scores did in fact measure a single, innate entity known as intelligence. He wished further to identify children with lower levels of intelligence in order to “limit, segregate and curtail breeding” and to “prevent further deterioration of an endangered American stock” (Gould, 1996, p. 189).

This work in statistical science and the measurement of intelligence culminated in the development of the “normal distribution” of intellectual quotient (IQ), otherwise known as the Bell Curve (see Figure 1).

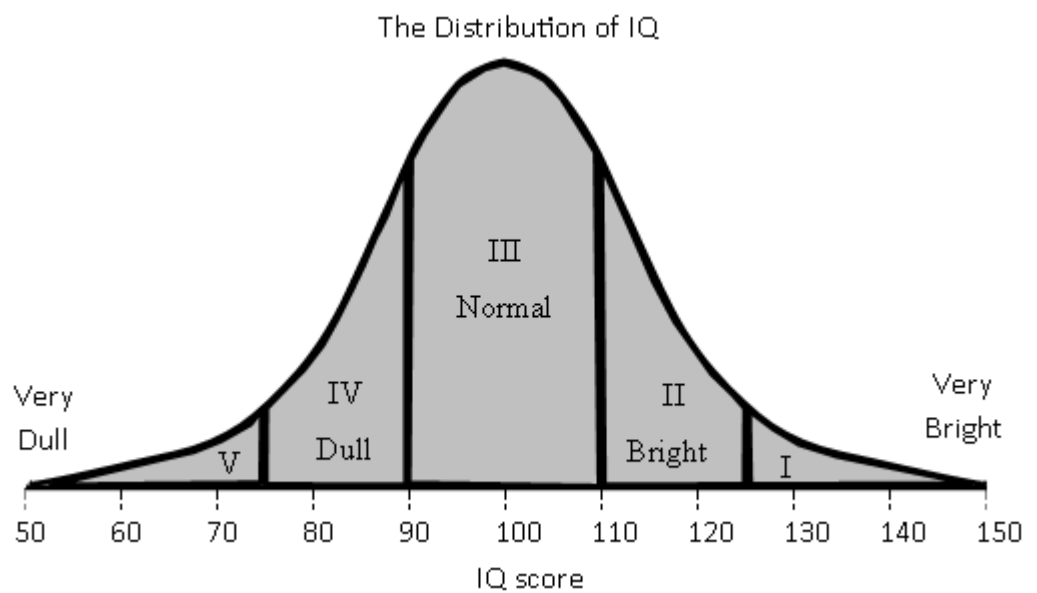


Figure 1<sup>4</sup>: Defining the Cognitive Classes (Herrnstein & Murray, 1994, p. 121). Image description: A bell curve with IQ scores across the bottom line, ranging from 50 to 150. There are five evenly spaced

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<sup>4</sup> From THE BELL CURVE: Intelligence and Class Structure in American Life by Richard J. Herrnstein & Charles Murray. Copyright © 1994 by Richard J. Herrnstein and Charles Murray. Reprinted with the permission of The Free Press, a division of Simon & Schuster, Inc. All rights reserved.

sections labelled “Very Dull”, “Dull”, “Normal”, “Bright” and “Very Bright”.

The Bell Curve is widely used today in the discipline of psychology and diagnostic processes for learning disability (see for instance Ministry of Health, 2012a).

The idea that disability is a deviation from the norm is openly used to define intellectual (learning) disability in the *Operational Guideline for the Assessment of Intellectual Disability to Access Disability Support Services Contracted for People with Intellectual Disability in New Zealand* (Ministry of Health, 2012a). In this guideline document, intellectual disability is placed at the low end of the “Standard Bell Curve of IQs of the general population” (p. 6). The Bell Curve is not explicitly used in the World Health Organisation’s World Report on Disability (2011). However, the idea that disability is a concept which deviates from the “norm” is expressed:

Disability is interpreted in relation to what is considered normal functioning, which can vary based on the context, age group, or even income group<sup>5</sup>. For example, older persons may not self-identify as having a disability, despite having significant difficulties in functioning, because they consider their level of functioning appropriate for their age. (pp. 23-24)

Internationally, it is generally accepted that an IQ score lower than 70 is the cut-off point for establishing learning disability (Scior et al., 2015). However, the Ministry of Health Operational Guidelines (2012a) and the DSM-5 (American Psychiatric Association, 2013) allow for factors associated with adaptive functioning to be taken into account if a person’s IQ is found to be marginally higher than 70. Marks (1999) notes that the use of 70 as a cut-off point was developed by Cyril Burt, who decided on this specific number by calculating the number of pupils which the special education settings at the time could accommodate. The decision to use 70 as the cut-off point thus appears to say

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<sup>5</sup> Sickness, disability and work: breaking the barriers. A synthesis of findings across OECD countries. Paris, Organisation for Economic Co-operation and Development, 2010.

more about the educational facilities in Cyril Burt's time than it does about any naturally-occurring dividing line which exists in nature (Marks, 1999). The use of 70 as a cut-off point is further called into question when other factors are taken into consideration, including the wide array of critiques regarding the inherent cultural and social biases in IQ testing (see for instance Gould, 1994, 1996; Quaye, 1995). The fact that Cyril Burt was discredited for the use of fraudulent data in his work (Gould, 1996; Marks, 1999) adds further doubt to the use of this cut-off point.

## Learning Disability and the "Norm"

The category of learning disability, as well as disability more widely, includes a wide variety of people who have little in common with each other aside from the fact that they are "different" from the statistical norm (Allen, 2005) – that is, "they have failed to be 'normal'" (Inckle, 2015). For instance, the category includes people who have acquired a disability through a sports injury, people with Down Syndrome, people who are blind, and people with autism. With the foundational role that Western science and medicine plays in asserting claims to "truth", the positing of certain types of bodies and minds as "disabled", or "not normal", came to be established as an irrefutable truth-claim (Hughes, 2005). Hughes (2005) sums this up in the following statement:

A group of people known as "the disabled" can only be constituted as a "real" population in the wake of medicine's "[plunge] into the marvellous density of perception" (Foucault, 1973, p. xiii), for in that moment, medicine reinvents itself as the rational repository of truth with respect to the biological integrity of individuals and populations. (p. 83)

The use of the standard deviation of intellectual quotient in order to measure and understand populations has had some chilling consequences for those who were unable to conform to normative expectations. For instance, Herrnstein and Murray's book *The Bell Curve* (1994) argued that, on a population level, IQ testing clearly demonstrates that black Americans were less intelligent

than white (non-Hispanic) Americans. They claim further that this difference can largely be attributed to genetic factors. Herrnstein and Murray argue that, owing to inborn cognitive limitations, people such as beneficiaries cannot be helped, that money placed in social welfare programmes is better used for gifted students, and that there should be an increase in the custodial state in order to keep people of low IQ in check (Gould, 1994, 1996; Quaye, 1995). *The Bell Curve* (1994) has been subject to heavy criticism, including for its misuse of statistical methods, as well as for justifying racism, classism and sexism (Fischer et al., 1996; Gould, 1994, 1996). However, despite these criticisms, ideas presented in *The Bell Curve* (1994) continue to be influential.

In more recent times, the notion of normality has become a moral judgement as well as a statistical measure (Stephens, 2014). The statistical average has become equated with the “average man” (L. Davis, 1995), and the norm has become “fused with average as natural” (Goodley, 2017, p. 87). As De Schauwer, Van de Putte, Blockmans, and Davies (2016) note, normality benches the conditions under which the “morally ascendant and natural state of being” (p. 4) are assessed. This leads to the idea that everyone is at the very least expected to be “average” (Goodley, 2017). When someone does not fall within the expected range, it is considered to be a flaw inherent in the individual. However, as Borgioli (2008) notes:

[B]y the very nature of distributing a population normally (e.g., applying a Bell Curve), some students will always exist in the “below average” stanines. It is impossible for all of the population to be “average” or “above average”. (p. 136)

Within the concept of the normal distribution of intelligence represented in the Bell Curve, there will *always* be elements of a population grouping who are “above” or “below average”, some significantly so. This variation enables the Bell Curve to be established.

Lastly, although the norm can be seen as pervasive, and can be taken to be the “natural order” of society, it is a concept which few people, if any, ever embody (Van der Klift & Kunc, 1994). The difficulty inherent in achieving

“normal” is highlighted in an article which discusses a competition called the “Search for Norma” (Stephens, 2014). This competition, held in 1945, was a search for the most perfectly “average” woman in America. Despite the large number of entries in the competition, no one, including the winner, came close to meeting all of the average criteria. Nor did the eventual winner look anything like the “average” female model drawn up for the competition based on the statistical averages. The “Search for Norma” competition highlights the contradictions inherent in the conception of the “norm”; whilst there is an expectation that everyone will meet this standard, it is paradoxically difficult, if not impossible, to attain.

In conclusion, the twin notions of “learning disability” and “normal people” are not natural phenomena awaiting accurate scientific interpretation. Instead, these concepts can be understood as artefacts of the political, material and social structures which emerged through the social structures of modernity and capitalism. The modernist ideals of rationality, independence, self-control and able-bodiedness continue to play a powerful role in shaping how humans are conceptualised and, most notably, in conceptualising those who do not meet the expected standards.

## **Ableism and the Concept of the Ideal Human**

The notion of the ideal human is a foundational component of the emergence of learning disability as a concept, and continues to play a powerful role in shaping the way this term is understood in contemporary Western society. Any account of how learning disability is conceptualised must therefore include tools which enable a critique of this concept; ableism has emerged as a valuable concept to facilitate this analysis.

Ableism is a nebulous concept. At times it seems easy to pin down and define, whilst on other occasions it evades identification and definition (Hodge & Runswick-Cole, 2013). Campbell (2009a) asserts that it is important not to hold to a rigid understanding or definition of ableism. She argues further that ableism should not be used as a universalised grand narrative to provide an all-encompassing conception of disability oppression. Instead, ableism should be

used to highlight exclusionary categories and ontologies in the production of the “human” (Campbell, 2009a).

This thesis utilises Campbell’s (2001) definition of ableism, which she defines as:

A network of beliefs, processes and practices that produces a particular kind of self and body (the corporeal standard) that is projected as the perfect, species-typical and therefore essential and fully human. Disability then is cast as a diminished state of being human. (p. 44)

This definition has been chosen in preference to Campbell’s later definitions (e.g., 2017a, 2017b), which do not place a strong focus on “ableism’s function in inaugurating the norm” (Campbell, 2009a, p. 5), a critical idea for this thesis. As noted earlier, the assumption of a corporeal standard, or ideal human, is a phenomenon around which much of the Western world is shaped. For instance, many homes are built assuming that everyone can walk, many jobs are designed assuming a certain level of cognitive abilities, and much of the social world is built around the assumption that everyone can understand social cues.

Imbricated within the notion of the normative ideal human comes its binary opposite – the “other” who is different, inferior, undesirable and dehumanised. (Hacking, 2007; Hodge & Runswick-Cole, 2013). Campbell’s work on ableism also highlights how contemporary understandings of learning disability can be understood as the “constitutive outside” of how humans are conceptualised (Campbell, 2005). In short, the terms “abled” and “disabled” are born from and grafted upon each other – neither can exist without the other (Campbell, 2009a). As Campbell (2005) notes:

In order for the notion of “ableness” to exist and to transmogrify into the sovereign subject of liberalism it must have a constitutive outside – that is, it must participate in a *logic of supplementarity*.... disability is *always present* (despite its seeming absence) in the ableist talk of normalcy, normalization and humanness. (p. 109, emphasis in original)

Thus, in order for the notion of the “ideal” human to exist, there is a requisite constitute outside - the “other” to the ideas of rationality, able-bodiedness and normal IQ. The “abled”, “normal” subject is only knowable through the (hidden) presence of the *disabled* subject. Simultaneously, truth-claims related to disability as an essential category are dependent upon ableism for their very legitimisation (Campbell, 2008b). As Simpson (2011) notes, drawing on the work of Derrida (2002), in any discussion of a “normal” or “typically developing” child there is a suppressed other term – that of “idiocy”, or learning disability.

### **The Inferior “Other” of the Ableist Binary**

Central to the binary logic of any form of identity and otherness – white/non-white, heterosexual/non-heterosexual, and abled/disabled – is the establishment of ascendant and subordinate terms within the binary (De Schauwer, Van de Putte, Van Goidsenhoven, et al., 2017). The ascendant term functions to signify what counts as normal and desirable, whilst the subordinated term functions to signify what is non-normative, abnormal and undesirable; that is, as a “problem” in need of fixing (De Schauwer, Van de Putte, & Davies, 2017; De Schauwer, Van de Putte, Van Goidsenhoven, et al., 2017). To be categorised in descendent terms is to be marked as “different” from the ascendant norm, where difference spells inferiority (Braidotti, 2013). This is in contrast to placement in the ascendant category where people remain unmarked and are taken to be “normal” and “naturally human” (De Schauwer, Van de Putte, Van Goidsenhoven, et al., 2017). Thus, the notion of “abled-ness” relies on disability embodying a devalued status, “in order to showcase its own capacitated desirability” (D. Mitchell & Snyder, 2017, np). It is this notion of being “normal” and “naturally human” which shaped my own lack of thought regarding my status as a non-disabled person, as noted in the introduction to this chapter.

People placed in a subordinate category are at risk of social exclusion, and are further “subjected to normative pressure to become more like those who are read as normal” (De Schauwer, Van de Putte, Van Goidsenhoven, et al., 2017, p. 1). The subsequent desire to pursue normal is thus read to be an entirely rational pursuit. The beliefs, practices and processes which enable this



inferiorisation, however, are often obscured and difficult to pin down (Hodge & Runswick-Cole, 2013). This thesis explores some of the key beliefs, practices and processes which enable this inferiorisation.

Although non-disabled people's aversion to disability appears to be an aversion to the "other", Nussbaum, Nussbaum and Nussbaum (2006) argues that it is a form of self-aversion. This idea is also argued by Bunch (2017). Drawing on Julia Kristeva's (1984a, 1984b, 2006, 2010, 2013) work on vulnerability, Bunch (2017) asserts:

Where the differently embodied person is rejected, the deficit that appears on the surface to be associated with impairment, is instead a universal kernel of anxiety that lies at the centre of every self. (p. 142)

Hughes (2012) argues this point further, noting that this aversion is a means by which we "hide from the bodily basis of our own humanity" (p.23). He argues that aversion, or what he terms "ableist disgust", derives from discomfort with bodily functions; people's oozy, sticky, leaky bodies, and the shame and embarrassment brought to bear upon people whose leakiness is exposed to others (Hughes, 2012).

Although being placed in an ascendant category requires little-to-no conscious attention by the people who are in that category, one's ascendant status is neither static nor guaranteed (De Schauwer, Van de Putte, & Davies, 2017). In particular, De Schauwer, Van de Putte, and Davies (2017) draw on Schildrick's insights about the concept of "monstrous others". They argue that one's position in an ascendant category must be continually maintained because the border between one's place in ascendant and subordinate categories cannot ever be guaranteed. As they state:

None of us exist simply on one side or the other side of the deeply problematic binary.... Our borders are much more porous than we usually imagine they are. (De Schauwer, Van de Putte, & Davies, 2017, p. 3)

Aversion to disability can thus be understood as a discomfort or anxiety which derives from the instability of one's placement in this hierarchy.

## Broader Processes of Othering

The processes through which learning disability is constituted as inferior to the norm are not isolated phenomena. Rather, they are part of a much wider process of othering. Although the term "othering" is not often noted or discussed in detail in the disability studies literature (for exceptions to this trend see Loja, Costa, Hughes, & Menezes, 2013; Mik-Meyer, 2016; Simpson, 2011), the connection between disability and various "othered" groups is well noted. Most often, this connection is made in reference to various human rights movements, to which the disability rights movement and field of disability studies are indebted (see for instance Campbell, 2009a; Goodley, 2011; Oliver, 1990; Overboe, 2012). These fields of literature (and wider rights movements), such as critical race theory, feminism and queer studies, have critiqued "the Eurocentric, masculine, heterosexist view of the Cartesian body/mind split... [which] was fabricated to justify the European man of reason as superior to other lesser bodies including women, racialised others, queer people and 'the disabled'" (Overboe, 2012, p. 114).

The concept of "othering" appears periodically in other academic discipline areas, such as geography (Van Houtum & Van Naerssen, 2002), Women's studies (Ezzell, 2009; Nnaemeka, 1997), Healthcare (Canales, 2000; J. Johnson et al., 2004; Petros, Airhihenbuwa, Simbayi, Ramlagan, & Brown, 2006) and Race studies (Jensen, 2011). However, although these fields are imbricated within previous critiques of the Eurocentric ideal man, "othering" does not appear to be a well-established and unique body of work in its own right. It is an area which deserves further investigation. The development of a new journal, *Othering and Belonging* (see [www.otheringandbelonging.org](http://www.otheringandbelonging.org)), signals an increasing interest in exploring "othering" as an area of study.

Specific practices of othering may operate differently for each "othered" group. However, these practices connect with the notion of the normative, "ideal" way of being human. This connection is highlighted in the work of Mik-

Meyer (2016), who uses interviews to explore how able-bodied co-workers “other” colleagues with impairments. Respondents in the interviews repeatedly likened their colleagues with impairments to various groups considered “other”. The range of “others” is discussed in the following quote:

Co-workers referred to people with a different ethnic background than Danish, homosexuals, drunk people, children, transvestites [sic], redheads, old women, pregnant women, blonds, people in grief, women in male [dominant] occupations, drunk drivers, Germans and Indians with poor English skills, immigrants, marginalized people in general (non-disabled), and people who were inadequate in their jobs. (Mik-Meyer, 2016, p. 1352)

The commonality amongst these different groups of people was their “different” appearance (Mik-Meyer, 2016). The notion of the ideal human clearly played a powerful role in shaping co-workers perceptions of what is considered “normal” and what is considered “different” to normal – as “other”.

Learning disabled people in particular have been one of the most profoundly othered groups in history. This problem is evident in the arguments presented by many disadvantaged groups, who have asserted their entitlement to full rights on the basis that they are *not* learning disabled. Reference to this issue can be found within the disability rights movement and disability literature. For instance, Oliver (1996) notes that “the approach of the Union of the Physically Impaired has clearly demonstrated that disabled people do not need to be talked down to in ‘lay terms’” (pp. 21-22). This statement implies that using “lay terms”, or simple language, is an insulting way to talk to a person, and that to assume someone is learning disabled is to insult them. Paul Hunt (1998) contends further:

Those of us with *unimpaired minds but severely disabled bodies* [emphasis added], have a unique opportunity show other people not only that our big difference from them does not lessen our worth, but also that *no* difference between men [sic], however

real, unpleasant and disturbing, does away with their right to be treated as fully human. (p. 13, emphasis in original)

Statements such as this leave questionable implications as to where people with impaired minds sit in regard to their right to be treated as fully human.

The issue of “othering” of learning disabled people in the disability rights movement parallels the difficulties experienced in the women’s rights movement. In this regard, Carlson (2001) highlights how “feeble-minded women” were set apart from other women with respect to both motherhood and womanhood more generally. This practice resulted in a clear division between women who were suitable to be mothers (i.e., women who were of good genetic stock), and women who were not suitable. Eugenics-related ideas were used by many feminists at the turn of the twentieth century to bolster their cause for access to contraceptive options by arguing that ““voluntary motherhood” was essential to preventing feeble-mindedness” (Carlson, 2001, p. 137, emphasis in original). Unwanted children, it was argued, would be at significant risk of being inferior, weak, deprived or defective (Carlson, 2001; L. Gordon, 1976). As L. Gordon (1976) states, “it would be near impossible to find discussions of voluntary motherhood between 1890 and 1910 which didn’t claim that unwanted children were likely to be morally and/or physically defective ” (p. 121).

## **The Real World Consequences of Inferior Positioning**

The positioning of disability as inferior and “other” to the notion of an ideal norm has significant real-world consequences for the people placed in this category. As Stainton (2008) argues, the assumption that reason is a necessary attribute of full personhood could be seen as being “at the heart of the exclusion and oppression” (p. 486) learning disabled people have faced throughout Western history. Scully (2016) notes further that when someone does not meet the criteria for full personhood, they do not have access to the same rights as individuals considered to be full persons.

The most profound and chilling impact of the inferiorisation of disability can be found in the Eugenics movement. The science of Eugenics, which is the practice of improving the genetic stock through selective breeding, was developed by Francis Galton (Locurto, 1991). Galton was one of the early instigators looking to measure intelligence. He took his cousin Darwin's ideas regarding evolutionary fitness, based in the natural sciences, and applied them to the growing field of human sciences (Gould, 1996; Locurto, 1991). Under the guise of Eugenics, learning disabled people became seen as evolutionary "defectives" (Clapton, 2009). These ideas drove the impetus for the elimination of "defective" individuals, which ultimately culminated in the drive to eradicate disabled people under the Nazi regime (Campbell, 1999; Scior et al., 2015).

Eugenic ideas regarding disabled people as evolutionary "defectives" not only played a powerful role in Nazi Germany, they also had a powerful impact in many countries around the world (Clapton, 2009). Numerous laws were passed in the United States of America in the early 20<sup>th</sup> century targeting the elimination of mental retardation (Herrnstein & Murray, 1994). In Aotearoa New Zealand, the Science of Eugenics was validated by the publication of *The Fertility of the Unfit* (Chapple, 1903) and endorsed through the 1911 Mental Defectives Act (Hamilton, 2018). The desire to prevent "defective" individuals from procreating and contaminating the gene pool formed an important part of the argument for the institutionalisation of learning disabled people in this country (Hamilton, 2018).

Although practices of eugenics are often viewed as an unfortunate practice of the past, the ongoing effects of these ideas are still evident. In particular, Shakespeare (1998) highlights two forms of eugenics still in practice - "strong" and "weak" eugenics. Strong eugenics is the drive to improve populations via state intervention of reproductive control, such as the forced sterilisation of learning disabled women. Although strong eugenics is no longer widely utilised in many countries, weak eugenics, defined as "promoting technologies of reproductive selection via non-coercive individual choices" (Shakespeare, 1998, p. 669), remains prevalent in many countries, including Aotearoa New Zealand. In these contexts, foetuses are routinely screened for

abnormalities with the explicit purpose of providing parents with the option to terminate should an abnormality be detected. The difference between the outcomes of “strong” and “weak” eugenics is not always clear-cut. In Aotearoa New Zealand, women report being strongly encouraged by medical professionals to abort if they receive a positive diagnosis for disability (see for instance H. Jackson, 2017; Nyika, 2017)<sup>6</sup>. Furthermore, close to 100% of babies with Down Syndrome are selectively aborted in Iceland (MacLean, 2017).

Underlying these ideas is the belief that the quality of life for “defective” individuals is reduced to the point that to end (or prevent) such lives is considered “mercy killing” (Morris, 1991; Scully, 2016). Scully (2016) provides a powerful link between seeing forms of identity<sup>7</sup> as spoiled or incomplete (or as defective), and the devaluation of disabled lives. As she asserts, identities which are not viewed as fully legitimate “are the first to be marginalized socially, economically and politically” (np), and are often ignored, silenced and have claims to respect ignored. Scully (2016) argues further:

[I]f to be disabled is to have a spoiled or incomplete identity, or indeed (in the case of learning disability) to have no real identity at all, that means a disabled life can never be a genuinely good life, or a flourishing one, in the way that those with unspoiled, undiminished identities can. (np)

This belief regarding a diminished identity and life leads to the conclusion that such identities cannot and should not be endorsed, and further that those identities are less worthy of preserving (Scully, 2016). As Scully (2016) states, “[t]hese lives are worth less” (np).

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<sup>6</sup> Please note that there are two authors named “Jackson” used in the thesis. For ease of reading, I have chosen to keep this reference as “H. Jackson”, as it is only referenced once. In contrast. “A. Y. Jackson” is referenced many times, and is referred to as simply “Jackson”.

<sup>7</sup> The notion of identity as I use it is not intended in the humanist sense. I outline my understanding of identity further in Chapter Four, p. 118.

## Conclusion

This chapter has explored the emergence of the category of learning disability. Rather than viewing learning disability as essential pathology residing in nature, I have argued that the concept is an artefact of the political, spiritual, material and social structures which have emerged as powerful forces shaping Western society. This is particularly in relation to how humans are conceptualised. Modernity, with its focus on universal truths, logic and reason (Crotty, 1998), was discussed as the first key structure shaping how learning disability is conceptualised. The progression of statistical science during the period of modernity, with its focus on the normal distribution, has played a powerful role in shaping standards of the ideal, “normal” citizen, particularly in relation to ideas regarding “normal” intelligence. The second key structure shaping the emergence of the category of learning disability is capitalism. Notions of “desirable workers” and “desirable bodies” arose alongside their binary opposite concepts – unproductive, disabled workers. These workers became seen as a social problem, forming a “surplus population” (Erevelles, 2000) who were often excluded from “mainstream” communities (Clapton, 2009). Both modernity and capitalism have played a powerful role in positioning disability as individual pathology.

This chapter also explored the concept of ableism. Ableism can be used as a conceptual tool to understand and critique the notion of the ideal human. The ableist binary necessarily positions disability as inferior, resulting in significant real-world consequences for the people placed in this category. These consequences include Eugenics, with a focus on the elimination of “defective” individuals, and reduced access to human rights.

Lastly, this chapter explored the intersection between disability and broader processes of “othering”. I argue that the positioning of disability as “other” is imbricated within wider processes which place anyone who does not meet the expected, “normal” standards in this category. Learning disabled people in particular have been one of the most profoundly “othered” groups in history. This is in no small part because many disadvantaged groups, including

those with physical and sensory impairments, have asserted their entitlement to full rights on the basis that they are *not* learning disabled.

The rationale for this thesis is founded on the combination of these core ideas. First, that the terms “abled” and “disabled” are not essential, knowable entities, but are instead terms grafted upon each other. Second, disability is necessarily positioned as the descendent term within the ableist binary. Lastly, the positioning of inferiority plays a crucial role in the validation and perpetuation of disability oppression.

In the next chapter, I outline the key conceptual frameworks which shape the way learning disability is viewed in the Aotearoa New Zealand context. Specifically, the chapter will focus on how these frameworks are embedded within strategy documents and disability support service practices in Aotearoa New Zealand. Key issues arising from these frameworks will be explored, including the ontological underpinning of the ideal human. The limitations these frameworks have in addressing disability oppression will also be explored.



## Chapter 3:

# Learning Disability in Aotearoa New Zealand

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In this chapter, I explore key phenomena which serve to position learning disabled people on the margins of humanity. I came to the PhD seeking to find some answers about what we need to do differently in our support practices. Through the PhD, I have come to realise that support practices are driven by particular ways of thinking about humans and the world; these ways of thinking are profoundly shaped by conceptual frameworks related to disability. Furthermore, the Government policies and strategies related to disability which play a powerful role in shaping our support practices, are often driven by these frameworks. Although this chapter largely focuses on academic texts and Government policy documents, it is fundamentally grounded in my experiences in the disability support sector. I have witnessed first-hand the elements of policies and strategies which have had a real influence on people's lives, such as the drive to ensure that residential homes look "normal", and the unquestioned practice of making decisions on behalf of people in support services. I have also observed the policies and strategies which have been "nice ideas", but which have proven ineffective in practice. One example is the assertion that learning disabled people have equal rights under the law, including the right to equal and "inclusive" education. It turns out that those "abstracted flights of fantasy" have real and profound consequences for people's lives.

What are the conceptual frameworks related to (learning) disability in Aotearoa New Zealand? What do they say about learning disability? And why have these frameworks not enabled the change that is sought, despite decades

of hard work from the disability rights movement, families and whānau<sup>8</sup>, legislators and support workers, among many others? In order to answer these questions, I turned to key Government policies, strategies and reports. Although texts such as these only provide a limited snapshot of what is happening in an area, I believe they provide a tangible artefact which highlights the social currents in Aotearoa New Zealand. Through analysing the key Government policies, strategies and reports I have identified four major conceptual frameworks guiding policy and practice: the medical model, normalisation, the social model, and rights based-based perspectives. I also examined Māori perspectives on disability, which are less evident in Government documents.

In this chapter, I explore how each of these frameworks provides different ways of conceptualising disability, assessment of where the “problem” lies, and strategies on how to address these problems. I examine how each of these perspectives has led to significant progress-gains for learning disabled people, including deinstitutionalisation and the establishment of “community-based” living, the development of legislation ensuring equal rights in law, a recognition that relationships form an integral part of the disability experience, and legislation regarding (physically) accessible buildings.

However, with the possible exception of Māori perspectives on disability, which do not appear to be widely-researched or well-known outside of Māori communities, each of these perspectives has flaws. These flaws are inherent in the ontological foundation of the frameworks, as well as how they are enacted in practice. Critically for this thesis, the ontological foundation of these frameworks is underpinned by the modernist notion of the ideal human, discussed in Chapter Two. I argued that the concepts of “disability” and “normal” form a binary, where each term serves to hold the other in place. In this regard, learning disability can be understood as the “other” to the notions of “rationality”, “abled-ness” and “normal IQ”. I asserted that much of the foundation of Western society is built upon the assumption of this ideal norm, including the education

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<sup>8</sup> Whānau is the Māori word for family. The meaning encompasses a much broader group of people than in the Western understanding of family, and is not limited to blood ties (S. J. Hickey, 2008).

system in Aotearoa New Zealand and the neoliberal economic system (Olssen & Peters, 2005). In this chapter, I investigate how the ontological conceptualisation of how humans ought to be has become particularised in these key conceptual frameworks. I will highlight how this conceptualisation has been a hindrance to the success of the disability rights movement (hereafter referred to as the DRM), and to the fight against disability oppression.

Lastly, I review several key approaches adopted in the fight against disability oppression. These approaches highlight the material impact of the ontological underpinning of the ideal human. Impacts include an absence of challenge to the “natural” inferiority of learning disability, a fervent focus on individual’s “attitudes”, and an absence of challenge to discriminatory and exclusionary structures.

It must be noted that the approaches and frameworks outlined in this chapter are not the summation of perspectives in the field of disability studies. Other approaches include critical disability studies (e.g., Goodley, 2012, 2017; Sullivan, 2011; Watson, 2012), feminist disability studies (e.g., Garland-Thomson, 2002, 2005, 2016), the minority model of disability (e.g., Hahn, 1988; Zola, 1982), and the relational model (e.g., Bjarnason, 2008; Tøssebro, 2004). However, I have found little evidence of their impact in Aotearoa New Zealand, either in Government policy and strategy, or in my personal experience working in the support sector. Two other perspectives from the field of disability studies which I have found little evidence of in Aotearoa New Zealand, but which I believe do hold promise for the future are posthuman disability studies, and ableism, which falls under the category of the cultural model of disability (Goodley, 2011). Where ableism was discussed in Chapter Two, posthuman disability studies will be explored in detail in the Chapter Four.

## **Medicalised Conceptualisations of Learning Disability**

Medicalised conceptualisations of disability are often referred to as the “medical model” in disability studies literature (Grue, 2011). According to

Goodley (2011), this model views disability as “*a medical problem that resides in the individual* – a defect in or a failure of a bodily system that is inherently abnormal and pathological” (p. 7, emphasis in original). Under this model, disability (or impairment) is understood as a pre-discursive, essential entity which is a deviation from the ableist corporeal norm (Tremain, 2001; 2005). It is thus a model founded in the modernist notion of the ideal human; disability is reduced to abnormality, and bodies and minds which do not conform to the expected norms of society are invalidated (Goering, 2010; Loja et al., 2013). This view of disability dates back to the mid-1800s (Goodley, 2011), around the time and the growth of modern, Western perspectives of the body and medicine.

Medicalised conceptions of “normal bodies” and “impairment” have led to many medical advances, which in turn have resulted in improvements in many people’s lives (Goodley, 2011). However, there are many problems arising from this view of disability. In particular, the medicalised conception of disability places the locus of the problem squarely in the disabled *individual*. The individualisation of the “problem” of disability is the subject of much criticism in the disability studies literature (Goodley, 2011; S. J. Hickey, 2008; Tremain, 2005a). Oliver (1990) is particularly critical of this model, describing it as a grand theory of “the personal tragedy of disability” (p. 1), which underpinned almost all studies of disability prior to 1990. As discussed in Chapter Two, Oliver (1990) connects the individualisation of disability within the medical model back to the emergence of capitalism. Under capitalism, he argues, the Western world saw a shift from “collectivist notions of work as the product of family and group involvement”, to the requirement for “individuals to sell their labour in a free market” (p. 44). Individuals who were unable to contribute to expected levels became seen as “a particular kind of social problem” (Oliver, 1990, p. 78).

Goodley (2011) notes that medicalised conceptions of learning disability are the dominant means of conceptualising disability. In Aotearoa New Zealand the medical model remains one of the most widely utilised means of understanding disability, including in Government policy documents (S. J. Hickey, 2008; Sullivan, 2000). For instance, the 2013 *Disability Survey* defines disability as “a long-term limitation (resulting from impairment) in a person’s ability to carry

out daily activities” (Statistics New Zealand, 2013b, p. 13). The Ministry of Health (2016) notes that Ministry-funded support services are available to “people who have a physical, intellectual or sensory disability (or a combination of these) which: is likely to continue for at least 6 months, [and] limits their ability to function independently, to the extent that ongoing support is required” (para. 1). Both of these statements indicate that disability is viewed as a limitation inherent in individuals, in line with the medical model understanding of disability. Furthermore, as discussed in Chapter Two, access to learning disability support services is predicated on meeting the criteria as outlined in the *Operational Guideline for the Assessment of Intellectual Disability to Access Disability Support Services Contracted for People with Intellectual Disability* (Ministry of Health, 2012a). These criteria describe learning disability as a deficit which resides in individuals.

One key issue emanating from this perspective is that, when the locus of the problem is placed squarely in the disabled individual, strategies to deal with this “problem” tend also to focus on individuals (Naidoo, 2009; Sullivan, 2000). This, as Abberley (1987) and Goodley (2011) note, presents disability as the consequence of a biological flaw, and does nothing to challenge exclusionary societal practices and structures. Furthermore, Oliver (1999) comments that medicalised perceptions present the notion of disability as a phenomenon which people could never be happy about. Sullivan (2000) backs this point up further, noting that the medical model “totally negates disability as a possibly positive state of being” (p. 38).

In the following section I explore one of the most influential frameworks in relation to learning disability in Aotearoa New Zealand: normalisation.

## Normalisation

One of the first conceptual frameworks which posited a non-medicalised view of learning disability is *normalisation*. Originating in Scandinavia in the 1960s, the principle of normalisation was developed during a time when many learning disabled people in the Western world lived in institutions, a situation mirrored in Aotearoa New Zealand (Hamilton, 2018). The concept has been

defined in multiple ways over the years, varying in definition, focus and practice as societies' views regarding learning disability have evolved.

The origins of the principle are credited to Nirje and Bank-Mikkelsen (Wolfensberger, Nirje, Brisenden, Perske, & Roos, 1972), both from Scandinavia. Nirje, who became one of the two most notable developers of the principle, defined normalisation as “making available to the mentally retarded patterns and conditions of everyday life which are as close as possible to the norms and patterns of the mainstream of society” (Nirje, 1976, p. 363). Nirje’s aim was to ensure that “mentally retarded” people enjoyed the same rights to quality of life as non-disabled people (H. Brown & Smith, 1992).

The second notable developer of the principle is Wolfensberger, from the United States of America. Wolfensberger travelled to Denmark and Sweden in the spring of 1969 in order to visit Nirje and Bank Mikkelsen (Wolfensberger, 1980). Deeply influenced by the work of these scholars, Wolfensberger returned to America to start developing his own adaptation of normalisation (Wolfensberger, 1980). He hoped to develop a more detailed and elaborate version of the principle which would be more applicable to a North American audience (Wolfensberger, 1980; Wolfensberger et al., 1972). Initially, Wolfensberger (1980) defined normalisation as the:

Utilization of means which are as culturally normative as possible, in order to establish, enable, or support behaviors, appearances and interpretations which are as culturally normative as possible.  
(p. 80)

Wolfensberger’s adaptation of normalisation signalled a move away from a focus on culturally normative *environments*, towards a focus on culturally normative *behaviours and appearances* in learning disabled people themselves.

Wolfensberger’s work became the target of sustained and significant criticism over many years; most notably related to the requirement for learning disabled people to conform to culturally normative expectations (e.g., Briton, 1979; Nirje & Perrin, 1985; Rhoades & Browning, 1977). Wolfensberger attempted to allay the controversy and confusion by abandoning the term

normalisation, and renamed the theory Social Role Valorisation (SRV) (Culham & Nind, 2003; Wolfensberger, 1983/2011). As Wolfensberger (1983/2011) states:

[T]he most explicit and highest goal of normalization must be the creation, support and defense of *valued social roles* for people who are at risk of social devaluation. All other elements and objectives of the theory are really subservient to this end, because if a person's social role were a societally valued one, then other desirable things would be accorded to that person almost automatically, at least within the resources and norms of his/her society. (p. 435-6, emphasis in original)

Despite the shift in emphasis, the focus for change in SRV remained directed at learning disabled people themselves, who are expected to conform to pre-established socially valued roles (H. Brown & Smith, 1992).

Over the ensuing decades, normalisation went on to become one of the most internationally influential concepts in both the lives of learning disabled people, and in the conceptualisation of learning disability (Nirje, 1985). Normalisation was effectively endorsed by the New Zealand Government in 1988 in the *Guidelines for standards for services for people with intellectual handicaps* (Department of Health, 1988). This guideline included Nirje's (1969) definition of normalisation on the inside front cover, and outlined how services could best operate, based on the principle.

It is difficult to understate the influence of normalisation in Aotearoa New Zealand's disability policies, strategies and support practices. In particular, normalisation places great onus on the value of "normal", "ordinary" and "everyday" lives for learning disabled people. The focus on "ordinary / everyday" lives and "ordinary / equal opportunities" is evident throughout numerous Government disability policies and strategies. For instance, in 2003 a strategy entitled *To Have an 'Ordinary' Life* was released (National Advisory Committee on Health and Disability, 2003). The use of the word "ordinary" throughout the document reflects the aspirations of learning disabled people to be able to

“access the everyday things that others take for granted” (National Advisory Committee on Health and Disability, 2003, p. 5). In a 2011 report released by the Cabinet Social Policy Committee, the *Choice in Community Living* initiative was said to enable learning disabled people to have “ordinary house choices” and to “take more part in normal, everyday activities” (Cabinet Social Policy Committee, 2011, p. 4). Other documents which discuss “ordinary / everyday” lives and “ordinary / equal opportunities” include the New Zealand Disability Strategies (Ministry of Health, 2001; Office for Disability Issues, 2016), *Pathways to Inclusion* (Department of Labour, 2001), *Enabling Good Lives* (Independent Working Group on ‘Day Options’, 2011), *Disability Support Services Strategic Plan 2014-2018* (Ministry of Health, 2015), and *Faiva Ora: National Pasifika Disability Plan* (Ministry of Health, 2017).

## **Normalisation and Support Services**

One of the foremost achievements of normalisation is that it can be credited for providing much of the impetus for deinstitutionalisation (Nirje & Perrin, 1985). In Aotearoa New Zealand, a Government Consultative Committee was set up in 1952 to look into the role of psychopaedic institutions (Hamilton, 2018). However, a policy of community living for learning disabled people was not formally adopted until 1985 (IHC, 2012), when normalisation was becoming widely known and utilised in Aotearoa New Zealand.

One of the key reasons normalisation had such a powerful influence in learning disability support services was that it defined practical standards which could be used as a guide for support practice. As Nirje (1985) states, the principle of normalisation:

[I]mply, when in doubt how to meet a problem, how to advise, how to plan actions, what to do... the normalization principle means that you act right when you let the handicapped person obtain the same or as close as possible to the same conditions of life as you would prefer if you were in his [sic] situation. (p. 67)



An example of this “practical advice” can be seen in the *Guidelines for Standards for Services for People with Intellectual Handicaps* (Department of Health, 1988). This guideline document states that group homes for learning disabled people were expected to have the appearance of typical homes in the surrounding neighbourhood, where:

No features except for necessary physical access adaptations should be incorporated into the home which might distinguish the intellectually handicapped people living there from other people.

(p. 10)

Normalisation became widely accepted as the ideal model of service in learning disability support services in Aotearoa New Zealand. Hamilton (2008) notes that it became so firmly entrenched that support workers were regularly trained in a way that encouraged unquestioning acceptance of the principle; doubts regarding any aspect of normalisation or SRV were firmly discouraged (H. Brown & Smith, 1992; Hamilton, 2008).

Wolfensberger’s adaptation of normalisation proved to be particularly useful in guiding learning disability support services through the process of deinstitutionalisation, including the establishment of community living for learning disabled people (Hamilton, 2008; A. Hunt, 2000). Wolfensberger developed numerous tools to guide these processes, including one which he developed with Linda Glenn: the *Program Analysis of Service System: A Method for the Qualitative Evaluation of Human Services*, more commonly known as the “PASSing” tool (Wolfensberger & Glenn, 1975). PASSing training was still being delivered in Aotearoa New Zealand in April 2018 (Synthia Dash<sup>9</sup>, Te Pou, personal communication October 4, 2018); however, less frequently than in the 1980s.

The preference for Wolfensberger’s adaptation of normalisation over Nirje’s original definition made a significant difference to support practice and the lives of learning disabled people. As noted earlier, Wolfensberger placed a

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much greater focus on “normalising” the learning disabled person themselves than on the environment (Anstey & Gaskin, 1985; Briton, 1979; H. Brown & Smith, 1992). Guided by Wolfensberger’s tools, including the “PASSing” training, support services focused on “helping” learning disabled people to look “as normal as possible”, in order to enhance individual’s social valuation. In effect, this served to encourage disabled people to assimilate into the dominant culture; that is, to “pass” for normal by hiding visible differences and downplaying disability (H. Brown & Smith, 1992). The significant impacts of “passing” and “achieving normal” faced by many learning disabled people were, regrettably, not taken into account (Hamilton, 2008). For instance, an adult would not be allowed to hold an anxiety-reducing toy truck in public, or partake in their favourite activity of playing on the swings in the park, because these are not activities that “normal” adults do. This situation undoubtedly had significant negative consequences for the well-being of many people.

### **Normalisation, the Ideal Human and Devaluing Difference**

Normalisation is founded on deviancy theory, an idea which was popular during the 1960s (Walmsley, 2001; Wolfensberger et al., 1972). Drawing upon deviancy theory, Wolfensberger and Tullman (1982) argued that differences can lead to deviancy when the difference “becomes sufficiently negatively value-charged in the minds of observers” (p. 132). Under normalisation, learning disabled people are considered sufficiently “different” from the unstated though presumed normative ideal, as to be considered deviant (Nirje, 1976; Wolfensberger & Tullman, 1982). Normalisation is thus founded on the idea that the modernist ideal human – the “normal” human – is the ideal state of being. Learning disability is then inescapably positioned as a devalued human trait.

The continual stigmatisation, social exclusion, persecution and general poor treatment faced by learning disabled people was believed to be the fault of deviancy (Wolfensberger & Tullman, 1982). The ensuing idea was that reducing deviancy would reduce its consequences (Gilbert, 2004). Any visible markers of difference were thus viewed as having negative associations. One of the key means by which deviancy was to be reduced was through the use of dispersal

strategies. Dispersal strategies advise deviant individuals to avoid congregating together (Wolfensberger, 1983/2011). As Wolfensberger (1983/2011) notes:

When deviant persons socialize intensively and perhaps exclusively with each other, it is almost inevitable that a climate or subculture of deviancy is created which exacerbates rather than reverses the deviancy of those within this climate or subculture.  
(p. 3)

Statements such as the one above highlight the inferior positioning of learning disability within normalisation and SRV. In order to achieve a socially valued status, learning disabled people are encouraged to buy into this devaluation by, for instance, disaffiliating from others who share their devalued status (H. Brown & Smith, 1992). The encouragement of dispersal strategies has led to the invidious consequence that many people are unable to form and value relationships with others who are like them (H. Brown & Smith, 1992). This situation was highlighted by a participant, Tamara, in the research conducted by Strnadová, Johnson, and Walmsley (2018). As she states:

[S]o this is why there's heaps of people with special needs that don't have any friends: it's because other people who don't have a disability think that's – I'm not being rude or anything, but this is what I got told, and this is what I know – that people think that people with disabilities are not good to be with. (p. 1098).

Dispersal strategies further deny people the opportunity to access group spaces and processes which can enable the development of a collective consciousness, culture and identity (Campbell, 2008a).

The devaluation of disability and the moral desirability of “normal” were not intended by either Wolfensberger or Nirje (Wolfensberger et al., 1972). As Wolfensberger et al. (1972) indicate, the use of the term “normative” was intended to have a statistical, rather than a moral connotation. However, as Culham and Nind (2003) note, normalisation and SRV have left “a legacy of attitudes towards normality, with “normal” thought of from a moral standpoint” (p. 28). “Normal” behaviour, “normal” appearance and “normal” society have

become equated with what is good and morally desirable (Clapton, 2009). Under normalisation, it became entirely appropriate to “impose” normalising measures on a person, if this would be seen to enhance their social valuation (see Wolfensberger et al., 1972, p. 28). At its most extreme, Wolfensberger advised that cosmetic surgery could be used to reduce or eliminate a stigma (Wolfensberger et al., 1972).

Because normalisation equates “normal” with what is good and morally desirable, it effectively forecloses the possibility of challenging societal power structures, relationships and norms which assert the preferability of the modernist ideal human, and which hold anyone designated as “different” in an inferior position (Gleeson, 1997; Shaddock & Zilber, 1991). As Culham and Nind (2003) state, “[t]he real legacy of the Normalisation movement can be seen to be a status quo that has been largely unchallenged” (p. 70). The result of normalisation is a situation where support workers, family, community members and learning disabled people work tirelessly to enhance individuals’ social valuation, whilst affirming oppressive norms and power structures which perpetuate the inferiorisation of learning disability.

In the following section I outline a later development in the field of disability studies which went on to have a powerful impact on disability in Aotearoa New Zealand: the social model.

## The Social Model

The second key conceptual theory which has been isolated as having a significant impact on the way disability is conceptualised in Aotearoa New Zealand is the *social model*. Known as the British disabled people’s movement’s “big idea” (Hasler, 1993), the origins of the social model are generally credited to a British Disabled Person’s Organisation, UPIAS (The Union of the Physically Impaired Against Segregation). Along with the Disability Alliance, UPIAS published a booklet *The Fundamental Principles of Disability* (1975), in which they were the first to define a distinction between impairment and disability. However, it was not until 1990 that the social model was developed into a robust

theoretical model by Michael Oliver in his book, *The Politics of Disablement* (1990).

Drawing its origins from neo-Marxism, and beginning a long history of Marxism's contribution to disability studies, the social model provides a materialist analysis of the capitalist foundations of disability oppression (Goodley, 2011; Oliver, 1990). In contrast to the individualising gaze of the medical model, the social model places the locus of the "problem" onto barriers in society that exclude people with perceived impairments (Barnes, 1998; Oliver, 1990). It establishes a separation between the notions of *impairment* and *disability*; where *impairment* relates to the biological characteristics of a person's body and mind, and *disability* relates to barriers in society (Oliver, 1990); for example, a person in a wheelchair has an *impairment*, but they are *disabled* by an unthinking society that, for instance, has stairs at the entrance to most buildings.

## Local and International Impacts of the Social Model

The social model has had a profound impact on the way disability is conceptualised across the Western world, as well as on government policies, strategies, and the field of disability studies (McKenzie, 2008; Terzi, 2004; Watson, 2012). The shift in the locus of the "problem" away from individuals and onto wider society proved to be transformational for many disabled people. Many people began to appreciate that the exclusion they faced was not because of a fault located in themselves, but rather because of barriers in wider society (Oliver, 1990). As Crow (1996) states:

It wasn't my body that was responsible for all my difficulties, it was external factors, the barriers constructed by the society in which I live. I was being dis-abled - my capabilities and opportunities were being restricted - by prejudice, discrimination, inaccessible environments and inadequate support. Even more important, if all the problems had been created by society, then surely society could un-create them. Revolutionary! (p. 206)

Inspired by this revelation, the disability rights movement grew in strength, eventually making significant headway into changing Government policy and legislation around the world (McKenzie, 2008; Terzi, 2004; Watson, 2012). These changes included the development of legislation for accessible buildings (Terzi, 2004) and changes to disability anti-discrimination legislation (Watson, 2012). The *United Nations Convention on the Rights of Persons with Disabilities* (2006) embraced the social model, defining disability as an evolving concept which:

[R]esults from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others.  
(p. 1)

The adoption of the social model had a significant impact on government strategies and policies in Aotearoa New Zealand. Both of the New Zealand Disability Strategies (Ministry of Health, 2001; Office for Disability Issues, 2016) adhere to social model conceptualisations of disability. In the most recent strategy, disability is defined as “something that happens when people with impairments face barriers in society; it is society that disables us, not our impairments” (Office for Disability Issues, 2016, p. 12). Evidence of alignment with the social model is also apparent in the Social Services Select Committee Inquiry (2008), *Enabling Good Lives* (Independent Working Group on ‘Day Options’, 2011), *To Have an ‘Ordinary’ Life* (National Advisory Committee on Health and Disability, 2003), the Māori Disability Action Plan, *Whāia Te Ao Mārama* (Ministry of Health, 2012b), the National Pasifika Disability Plan, *Faiva Ora* (Ministry of Health, 2017), and the *Disability Support Services Strategic Plan 2014-2018* (Ministry of Health, 2015). In these reports, the need to remove barriers in society is frequently referred to, and the term “impairments” is often used when discussing individuals.

The social model has also proved to be immensely important to the development of disability studies as an academic discipline (Oliver, 2009). From 1990 until at least the late 2000s, the social model was the dominant paradigm in the field of disability studies (Dewsbury, Clarke, Randall, Rouncefield, &

Sommerville, 2004). The field of inclusive education was also significantly influenced by the social model (Terzi, 2004), as the locus of the problem shifted from being located in children with impairments, to exclusionary classroom designs and practices.

## **The Social Model, Impairment and the Ideal Human**

The split between impairment and disability also underpins one of the key criticisms levelled at the social model (e.g., Loja et al., 2013; Morris, 1991; Shakespeare, 1999; Watson, 1998). Critics argued that by splitting impairment and disability, the social model denies the personal experience of disability (Morris, 1991), including physical, sensory and emotional experiences. The bracketing of impairment from disability was viewed as similar to the denial of biological difference by feminists in the 1970s, with the divide between sex and gender (Goodley, 2011). Overboe (2012) and Inckle (2015) note similarly that the split reinforces the binary in which the mind is privileged over the body, and reason triumphs over emotion.

One of the most significant issues with the split between impairment and disability is that it serves to relegate impairment to the medical model. Watson and Shakespeare, in particular, were critical of the lack of theorisation of impairment in the social model (e.g., Shakespeare, 2006; Shakespeare & Watson, 2001b, 2001a; Watson, 2002). The absence of theorisation leaves unquestioned the understanding that impairment is a deviation from the ableist corporeal norm. The splitting of impairment and disability contributes to the maintenance of the medical model (Goodley, 2011; McKenzie, 2013; Tremain, 2005b), positioning people with impairments as “other” to the ideal human of modernism. As Tremain (2005) notes:

Indeed, it would seem that the identity of the subject of the social model (“people with impairments”) is actually formed in large measure by the political arrangements that the model was designed to contest. (p. 10)

Tremain (2001, 2005b) provides a compelling critique of the way in which impairment is viewed as a pre-discursive<sup>10</sup> and essential entity within the social model. As she notes, viewing impairment as a natural lack or deficit conceals the power relations through which it is possible for discursive objects such as “impairments” and “normal bodies” to be materialised. This serves to extend the very arrangements viewed as being at the heart of disability exclusion and oppression (Tremain, 2001).

The privileging of the modernist human within the social model has had some significant material consequences. In particular, I would like to highlight one of the most notable effects of this privileging, which has had a significant impact on the lives of many people: the independent living agenda. This agenda has been described as the linchpin of the disability rights movement in the United States (Charlton, 1998), and plays a significant role in the DRM in the United Kingdom (Blackmore & Hodgkins, 2012; Oliver, 1996). This agenda continues to play an important role in the international DRM, and was wholeheartedly supported in the *United Nations Convention on the Rights of Persons with Disabilities* (2006).

The independent living movement has had several positive outcomes for disabled people. In particular, it has enabled a radical move away from viewing disabled people as *passive* recipients of services, towards a view of disabled people as highly agentic individuals who, given the right environment and supports, can be in control of their own lives and of the support they receive (Blackmore & Hodgkins, 2012). This shift was significant both for how disabled people viewed themselves, as well as the way disabled people were viewed by the wider community.

However, the success of the independent living movement has come at the expense of a more radical challenge to the notion of the ideal human. For instance, Blackmore and Hodgkins (2012) note that the independent living movement challenges “the ideology of disabled people as *dependent* and repositions the boundaries of autonomy and human agency” (p. 80, emphasis added). The drive for disabled people to become more “independent” was thus

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<sup>10</sup> Discourse will be covered in more detail in Chapter Four, p. 90



achieved through reaffirming the values which uphold the ableist norm as the ideal standard; that is, a person who is capable and not in need of care, and who is therefore in a superior position to what is upheld as its opposite (Reinders, 2000).

## **The Social Model and Learning Disability**

Another key critique of the social model pertinent to this thesis, is its lack of applicability to the lives of learning disabled people. Within the reasonably extensive body of social model literature that has developed since 1990, there is a notable lack of discussion in regard to learning disability (Chappell, 1998). This omission appears largely to be unintentional where, for instance, the opposite of *disabled* is defined as *able-bodied* (e.g., Barnes, 1998; Finkelstein, 1998; Hyde, 2000; Oliver, 1990). At other times, learning disability is simply omitted from the discussion, despite claims that the work has relevance for all disabilities (Chappell, 1998). As Chappell (1998) notes, “[i]t appears the best that people with learning difficulties can expect is an implicit inclusion in any writing about disability” (p. 213). The absence of discussion of inclusion of learning disability within the social model literature has resulted in the criticism that it is a theory which is largely ineffectual for learning disabled people (Chappell, 1998; McKenzie, 2008).

One of the key reasons for this lack of applicability may be due to the relegation of impairment to the medical model. There is a tacit acceptance within the social model that learning disability is a pre-discursive biological and natural phenomenon (McKenzie, 2008; Tremain, 2001). Given the lack of theorisation of impairment in the social model, this view has some significant implications. For instance, although the Social Services Committee (2008) notes that the medical model of disability has been largely superseded by the social model in Aotearoa New Zealand, there is clear evidence that the medical model still holds great sway over learning disability support services. In order to access disability support services, funding agencies require evidence of a formal diagnosis of impairment (Ministry of Health, 2012a). This diagnosis must be undertaken by “a psychologist or other suitably qualified professional” (Ministry

of Health, 2012a, p. 12). The medical profession is thus granted full authorising power to certify whether a person is or is not disabled (Campbell, 2009a), and therefore whether they qualify for support services. Furthermore, in the *New Zealand Certificate in Health & Wellbeing (Support Work) Level 3* (IHC New Zealand Incorporated, 2016), learning disability is defined as a phenomenon inherent in individuals who have an IQ lower than 70 and deficits in adaptive functioning, and who present with these challenges before the age of 18; that is, a medical model understanding of disability. Given the recent introduction of a qualification-based pay structure in the disability support sector (Ministry of Health, 2018), it can be expected that a vast number of support workers in Aotearoa New Zealand will complete this qualification. This raises a concern that a large number of support workers will continue to be trained in the medical model understanding of disability.

The use of a medical model conceptualisation of disability in contemporary training materials highlights the challenge of applying the social model to learning disability. The relegation of impairment to the medical model, and the focus for change being placed on barriers in the environment, results in a significant gap in tools to guide the practice of support workers. This absence is particularly evident when compared with the proliferation of tools and training models which emerged from the principle of normalisation. The issue is highlighted by McGregor, Bell and Wilson (2016), who note that the *United Nations Convention on the Rights of Persons with Disabilities*:

[C]learly anticipates that people with disabilities will be accommodated so that they can enjoy the same rights as others, requiring States to take appropriate steps to ensure that this occurs. *However, it is silent on how this will be achieved in practice.* (p. 122, emphasis added)

To provide a practical example of this issue, I have worked with numerous learning disabled people who struggle with numbers, and are therefore unable to manage their money independently. A limited number of adaptations can be made to a person's environment to assist them, such as establishing automatic

payments on the day their benefit is received to ensure all bills are paid. However, what I have found is most necessary in this situation is to have someone, such as a support person, who can support the person to understand and budget their money. Yet, in order to know how to do this most effectively, support workers require training and resources to assist them in their work. I have yet to see a training resource grounded in the social model which provides this level of practical advice. Quite simply, the social model does not seem to have triggered the development of any tools or advice on how to support learning disabled people in practice.

In the following section, I explore another key conceptual framework which has had a notable impact on disability policy and practice in Aotearoa New Zealand: the rights-based approach to disability.

## **The Rights-Based Approach to Disability**

The third key conceptual idea identified as having a significant impact on policy and practice in Aotearoa New Zealand is the rights-based approach to disability. The rights-based approach recognises that all people, regardless of disability or impairment status, are equal legal citizens who should have access to equal rights (Hamilton, 2008). These rights include freedom from unlawful discrimination because of disability, access to equal employment and wages, access to public places and facilities, and equal access to education (Human Rights Act 1993, 2017). This approach differs to normalisation and the social model in that it does not connect back to seminal authors and texts, and does not have a particular framework delineating what the approach is. Instead, the approach has been formed from multiple practice-based perspectives, which work towards ensuring that mechanisms are in place to support the achievement of equal rights for disabled people.

The importance of human rights in relation to learning disability is well-recognised by many governments and international entities. For instance, the World Health Organisation's *World Report on Disability* (2011) notes that

disability is a human rights issue because of many significant concerns; these concerns include being denied access to healthcare and education, experiences of multiple forms of violence, and denial of autonomy, for instance being subjected to involuntary sterilisation. Significant gains have been made in regards to the legal recognition of equal rights for learning disabled people over the past half-century, both locally and internationally. The first international legal mechanism for ensuring equal legal rights for learning disabled people was the *United Nations Declaration on the Rights of Mentally Retarded Persons* (1971). The most recent *Convention on the Rights of Persons with Disabilities* (United Nations, 2006) states its purpose as:

[T]o promote, protect and ensure *the full and equal enjoyment of all human rights* and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity. (p. 4, emphasis added)

Human rights underpin many Government disability strategies and policies in Aotearoa New Zealand. The focus on “choice and control”, a fundamental component of human rights, is the most notable way this underpinning is evidenced. For instance, the *Disability Support Services Strategic Plan 2014-2018* (Ministry of Health, 2015) states “[w]e protect the human rights of all people with disabilities”, and that disabled people and their whānau<sup>11</sup>/families should “have choice, control and flexibility over the support in their lives” (p. 1). Equal rights, choice and control are also mentioned in *Pathways to Inclusion* (Department of Labour, 2001), the *Disability Strategies* (Ministry of Health, 2001; Office for Disability Issues, 2016), the *Disability Support Services Workforce Action Plan 2013-2016* (Ministry of Health, 2013), the *Enabling Good Lives* report (Independent Working Group on ‘Day Options’, 2011) and the *Disability Action Plan 2014 -2018* (Office for Disability Issues, 2015).

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<sup>11</sup> See page 45 for the definition of whānau

## Human Rights as an Insufficient Tool

Aotearoa New Zealand is renowned for its global human rights leadership (McGregor et al., 2016). It was the first country to grant women the vote, and, as McGregor et al. (2016) note, was one of the leaders in the development and adoption of the *Universal Declaration of Human Rights* (United Nations General Assembly, 1948) and the *Convention on the Rights of Persons with Disabilities* (United Nations, 2006). The various legal instruments for pursuing human rights in Aotearoa New Zealand, such as the *Convention on the Rights of Persons with Disabilities* (United Nations, 2006), have had a positive overall impact on legislation, policy and practice in regards to human rights (McGregor et al., 2016).

However, despite this progress and the sizable number of human rights instruments, Aotearoa New Zealand has been found to have “significant fault lines” in the human rights landscape (McGregor et al., 2016, p. 175). This situation is particularly evident in regards to equal access to human rights for disabled people (Hamilton, 2008; H. Hickey & Wilson, 2017; McGregor et al., 2016). For instance, in 2011 the *Independent Working Group on ‘Day Options’* noted:

Despite service specifications and monitoring arrangements that seek to promote and protect the rights of residents many people consider that residential services unreasonably limit residents’ choice and control over the supports they receive and the lives they lead. (2011, p. 1)

The information outlined in the first chapter of this thesis in The Big Picture of Disability Oppression section (pp. 4-9) underscores further the difficulties many learning disabled people experience in accessing equal rights in Aotearoa New Zealand. Of particular note is the lack of equal access to education for learning disabled children: a disparity which exists despite the right to education being enshrined in law (IHC New Zealand, 2017).

A number of identified issues limit learning disabled people’s access to equal rights in Aotearoa New Zealand. One significant issue relates to

weaknesses within the existing human rights legislation (McGregor et al., 2016). Whilst the *Human Rights Act 1993* (2017) and the *Bill of Rights Act 1990* (2013) outline rights for all New Zealanders, McGregor et al. (2016) note that neither Act can be used to strike down proposed legislation which is inconsistent with the Acts. This results in a situation where legislation which breaches the rights accorded to all New Zealanders, as outlined in the Human Rights Act 1993 (2017) and Bill of Rights Act 1990 (2013), is able to be passed (McGregor et al., 2016). One such Act was passed in 2013, with the Government's amendment to part 4A of the *Public Health and Disability Act 2000* (New Zealand Public Health and Disability Act 2000, 2016). This amendment removed the ability of disabled family carers to use the Human Rights Act to make complaints to the Human Rights Commission on the grounds of unlawful discrimination (McGregor et al., 2016). This change was enacted after family carers won several successive court cases using the Human Rights Act, regarding payment for the provision of support to their disabled adult children (Human Rights Commission, 2018a; McGregor et al., 2016).

Another identified weakness which limits learning disabled people's access to equal rights relates to the "startling lack of parliamentary scrutiny" (McGregor et al., 2016, p. 176) over human rights instruments in this country. For instance, there is no Parliamentary Select Committee for Human Rights, despite the recommendation for one being put forward by the Human Rights Commission in 2010 (McGregor et al., 2016, p. 176). As a past Disability Rights Commissioner, Paul Gibson, notes, this issue is exacerbated by the lack of ownership in Cabinet and the wider Parliament over human rights instruments, although a few passionate individuals within Parliament and Cabinet take these issues on board (McGregor et al., 2016, p. 134). The result of this situation, according to Clear and Gleeson (2001) is a scenario where "[a]ny benefits of supportive rights legislation depend on the goodwill of government and the politics of the court system" (p. 41).

The weakness of human rights legislation to challenge exclusionary systems, structures and practices is not a phenomenon isolated to Aotearoa New Zealand, but is mirrored internationally (Clear & Gleeson, 2001; Goodley,

Lawthom, Liddiard, & Runswick-Cole, 2017). As discussed in Chapter Two, many of these exclusionary systems and structures are underpinned by the notion of the ideal human. In the following section, the role of the ideal human within the rights-based approach will be explored, with a particular focus on how this ontological foundation underpins the lack of challenge to exclusionary systems and structures.

## **Human Rights, Citizenship and the Ideal Human**

The notion of human rights is indelibly connected with ideas regarding *citizenship*, a concept which has been “a central axis of Western political philosophy” (Shafir, 2004, p. 12). The notions of citizenship and human rights each have their own unique genealogy, with citizenship relating back to Ancient Greece, and Human Rights connecting back to the period of the Enlightenment (Shafir, 2004). However, as Shafir (2004) notes, human rights was “predicated on the legacy of political citizenship” (p. 11). There is both a powerful and complex relationship between the two terms, particularly in relation to whether rights are apart from, or contingent on, membership of a political community or entity (Shafir, 2004). Citizenship and human rights are often paired, as they have a similar focus on access to rights and resources (Shafir, 2004). For instance, great emphasis was placed on human rights for disabled people during the International year of Disabled Persons in 1981 (United Nations, 2003). During that year, Mrs. Leticia Shahani, United Nations Secretariat, is quoted as stating that “[p]ersons with disabilities shall be treated as *true citizens* of their respective countries, *enjoying all the rights* man [sic] is heir to” (Chapter V. A human rights approach: the 1970s, para. 5, emphasis added).

The notion of citizenship is referred to in several Government strategies, policies and reports in Aotearoa New Zealand, often paired with the notion of rights. For instance the National Advisory Committee on Health and Disability (2003) states “New Zealand citizens enjoy a wide range of human rights” (p. 6), and the vision for the *Disability Action Plan 2014-2018* is for “[a]ll New Zealanders to experience equal rights of citizenship” (Office for Disability Issues, 2015, p. 4). Citizenship is also referred to in the *Enabling Good Lives Report*

(Independent Working Group on 'Day Options', 2011), the *Disability Support Services Strategic Plan 2014-2018*, (Ministry of Health, 2015) and the *Government response to the Social Services Select Committee* (New Zealand Government, 2009). However, the term citizenship is often referred to fleetingly in the documents, with no definition or elaboration of what is meant by the term provided.

The notion of citizenship is widely used in relation to disability activism, policies and research (Sépulchre, 2017). In particular, the DRM utilises the concept in the fight for disabled people to be recognised as full citizens with equal rights, duties and responsibilities, rather than as dependent patients (Oliver, 1990; Sépulchre, 2017). Although the concept of citizenship has been used for some time in the field of disability studies, a dramatic increase in use has been observed from 1990 onwards (Sépulchre, 2017).

However, Sépulchre (2017) notes that the increase in use has not been accompanied with an in-depth exploration of the relationship between disability and citizenship. This mirrors the lack of definition or deeper exploration evident in Government policy and strategy in Aotearoa New Zealand. A scoping review of research published on citizenship and disability from 1985 - 2015 found that, of the 295 articles in the study, 53% did not contain any explanation or definition of citizenship (Sépulchre, 2017). Where citizenship was defined, many studies utilised Marshall's (1992) definition, which describes citizenship as:

[A] status bestowed on those who are *full members of a community*. All who possess the status are equal with respect to the rights and duties with which the status is endowed. (p. 18, emphasis added)

It is this notion of *full members* of a community, otherwise known as *full persons*, which presents the key theoretical challenge for both citizenship and the rights-based approach to disability. Critically, the rights and resources afforded through citizenship and the human rights approach were not viewed as inalienable, but contingent upon meeting particular criteria. As Kotsonis (2007) states:



The question of who was deserving of human rights and liberation depended in part on who was considered mature enough to accept the responsibilities of the citizen. In this sense, the Enlightenment did not tell us all people were human; it gave us universal standards for deciding who was human, and much of the history of Europe ever since has entailed a struggle to decide where to set the boundaries. (p. 83)

It is at this point that the connection between human rights, citizenship and the ideal human becomes evident. This is because in order to be considered a citizen, or to fall within the parameters of what was defined as humanity, “one had to assume the mantle of rationality” (Shafir, 2004, p. 16). Rights and resources were afforded only to people who met the criteria for full membership; these rights were not inalienable. As was noted in the previous chapter, many learning disabled people fail to meet the requisite criteria to be considered as full persons (Scully, 2016). Many learning disabled people struggle to achieve competence in these criteria, which often include specific capacities such as rationality, independence and the ability to communicate (Scully, 2016); they are further very much connected with those of the ideal human.

Further problems arise regarding the use of citizenship and disability when the disabled body is brought into the picture (Van Houten & Jacobs, 2005). As Mol (2002, cited in Van Houten & Jacobs, 2005) notes, citizens are not expected to be bothered by bodily experiences such as hunger, pain, lust and emotions; as a consequence of this underlying assumption, discussions regarding the body and care have been largely missing from the conversation on citizenship. Van Houten and Jacobs (2005) note furthermore that research on citizenship and disability tends to be individualising, viewing each person in isolation rather than as beings who are embedded within wider social and support networks. H. Hickey (2015) mirrors this point, noting that rights-based models tend to have an individualistic focus which favours independence over dependence. She is critical of this focus, pointing out that the discussion on rights and citizenship lacks acknowledgement of the wider interdependence of all

humans; a concept which plays an integral role in te ao Māori (the Māori worldview).

The problematic and underexplored ontological foundation of the human rights and citizenship approaches presents a significant challenge for research and activism in the disability sphere. In particular, the focus on individuals not only serves to uphold the individualisation of disability, but also hinders discussion on power relationships and struggles at a more structural level (Sépulchre, 2017). As with normalisation and the social model, the ontological underpinning of the ideal human leaves unquestioned and unchallenged the “natural” inferiority of disability. This underpinning presents an obstacle to the ability to challenge exclusion at a structural level, as this exclusion is based on systems and structures which are founded on the concept of the ideal human.

However, as will be outlined in the next section, the existing problematic ontological foundations in the rights-based approach are not fixed and immutable. The Enabling Good Lives approach highlights how it is possible for citizenship and human rights-based approaches to move into a new and more promising direction that focuses on increasing rights, choice and control, without reaffirming the notion of the ideal human.

## **Citizenship and the Promise of Enabling Good Lives**

There is a promising exception to the trend of the untouched notion of the ideal human within citizenship and rights-based approaches: *Enabling Good Lives (EGL)*. Enabling Good Lives is an Aotearoa New Zealand-based initiative, founded on a partnership between disabled people, families and whānau<sup>12</sup> of disabled people, service providers, Māori and Government officials (Were, 2016). This initiative is working to transform the way disability support is delivered, based on a set of eight principles: self-determination, beginning early, person-centred, ordinary-life outcomes, mainstream first, mana<sup>13</sup> enhancing, easy to use

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<sup>12</sup> See page 45 for the definition of whānau

<sup>13</sup> Mana is a noun indicating “prestige, authority, control, power, influence, status, spiritual power, charisma - *mana* is a supernatural force in a person, place or object” (<https://maoridictionary.co.nz/word/3424>).

and relationship building (Enabling Good Lives, 2018c). Two “demonstrations” of an Enabling Good Lives approach were held in the Christchurch and Waikato areas during the time that this thesis was written (Enabling Good Lives, 2018b). Based on the findings from these demonstrations, a prototype is currently being developed in order to implement an Enabling Good Lives approach across the whole of Aotearoa New Zealand (for more information see <https://www.health.govt.nz/our-work/disability-services/disability-projects/disability-support-system-transformation>).

Enabling Good Lives seeks to ensure that disabled people and their families have “greater choice and control over the supports they receive, so that they can plan for the lives they want” (Enabling Good Lives, 2018a, para. 1). With the focus on choice and control, self-determination and ensuring that disabled people can live the life that they want, it is evident that EGL is grounded in a human rights-based approach.

Relationships form an integral part of the EGL approach. The partnership approach between disabled people and other groups is considered foundational to the initiative (Were, 2017) and, as noted, relationship building is one of the eight guiding principles. Where one of the criticisms directed at the citizenship approach is the focus on independent individuals, rather than interdependence (H. Hickey, 2015; van Houten & Jacobs, 2005), EGL recognises each person as a being who exists within wider family, community and/or support service networks (Were, 2016). Support plans are typically developed with input from family and whānau; although the degree of input is dependent on the wishes of the disabled person (Were, 2016). Family, whānau and wider communities are also often involved in the provision of support for the disabled person.

Another criticism of the citizenship and rights-based approaches which is not inherent in the EGL approach is in the challenge to systemic barriers. Much emphasis is placed on capacity and capability building for disabled people, family and whānau (Cabinet Social Policy Committee, 2017), including the need to support and invest in the development of leaders from both of these spheres (Were, 2016). As Were (2017) notes:

Leadership by disabled people must be present, prominent, visible and invested in at all levels of the Demonstration. Disabled leadership is a key factor that contributed to the early success of the Demonstration. (p. 9)

The focus on investing in leadership by disabled people indicates that power imbalances in society are acknowledged, and resources are put in place to redress the situation.

The last significant difference between EGL and citizenship and rights-based approaches is in the different views regarding who should have access to full rights. As noted earlier, much of the literature on citizenship is grounded in the modernist conception of the ideal human, which posits particular criteria which must be met in order to be considered a full person. These criteria include such things as rationality, independence and the ability to communicate (Scully, 2016). In EGL, a person-by-person approach is adopted for planning and disability supports (Were, 2017). This approach is founded on the assumption that each person is unique; an intentional contrast to the one-size-fits-most model of the existing disability support systems (Were, 2017). Whilst the EGL approach could be said to still rely on the modernist perception of humans as ontologically distinct beings, the criteria for *full personhood* are rendered inconsequential as the EGL initiative is unambiguously clear that no criteria need to be met before a person deserves full rights.

In conclusion, the EGL initiative highlights how it is possible to challenge the problematic ontological foundations of the citizenship and the rights-based approaches. Rather than dismissing the approaches because of their problematic foundations, this strategy builds upon the hard-won achievements gained through the use of citizenship and rights-based approaches, such as the development of legislation and conventions asserting equal rights. Goodley (2017) believes that this strategy of building upon previous gains, rather than dismissing them, is crucial for any rights movement to progress. The EGL approach thus offers great promise for not only transforming the disability support system in Aotearoa New Zealand, but also for reworking dominant

notions of citizenship so that, as van Houten and Jacobs (2005) assert, it can incorporate and embrace difference.

An approach also not founded in the notion of the ideal human can be seen in Māori perspectives on disability. This will be explored in the following section.

## Māori Perspectives on Disability

Before moving on to an overview of the core limitations of the medical model, normalisation, the social model, and rights-based perspectives, it is important to highlight another notable though less-known approach: Māori perspectives on disability. Māori perspectives on disability differ from the previous perspectives noted in this chapter, in that they are not founded in the notion of the ideal, individual and independent human. Instead, people are viewed as *interdependent* beings who exist as part of a wider collective, and who have powerful ancestral, relational, spiritual and environmental connections (H. Hickey, 2015). Furthermore, two core aspects of the collective identity of Māori play an integral role in Māori conceptualisations of disability. These aspects include the pivotal role of relationships, and the notion of *manaaki*, which relates to the responsibilities and obligations whānau<sup>14</sup> members have of supporting each other (H. Hickey & Wilson, 2017). Significantly, Māori do not have a word for disability (H. Hickey & Wilson, 2017; Ministry of Health, 2012b). Instead, Māori commonly refer to “a person’s ability to flourish or function in relation to their ability to contribute to either their own, or others, wellbeing” (Ministry of Health, 2012b, p. 5).

S. J. Hickey (2008) notes that despite the extensive array of health-related research in Aotearoa New Zealand, including Māori perspectives on health and well-being, little research has been done to explore Māori perspectives on disability. There are a variety of reasons for the absence of research. Firstly, as Tuhiwai Smith (2012) argues, scientific research is “inextricably linked to European imperialism and colonialism”, and is implicated in the worst excesses

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<sup>14</sup> See page 45 for the definition of whānau

of these practices. Historically, research has functioned to advance the interests and concerns of colonial researchers (Bishop, 2013). Research has been seen in terms of its “absolute worthlessness” to Māori (Tuhiwai Smith, 2012), as it misrepresented Māori perspectives for the benefit of the colonisers, told Māori things they already knew, “suggested things that would not work, and made careers for people who already had jobs” (Tuhiwai Smith, p. 3), while not providing the same benefits to Māori. Tuhiwai Smith (2012) goes as far as to state that the term research is “probably one of the dirtiest words in the indigenous world’s vocabulary” (p. 1).

Further to the problematic history of scientific research is Aotearoa New Zealand’s history of colonisation. These processes of colonisation have fostered the long-standing cultural dominance of colonial perspectives, power imbalances and systemic marginalisation of both Māori people and Māori perspectives (Bishop, 2013, p. 2013; Bishop, O’Sullivan & Berryman, as cited in Office of the Auditor-General, 2012; Tuhiwai Smith, 2012). The lingering effects of these inequities are evident in the invisibility of Māori within research on health, disability and identity (S. J. Hickey, 2008). The omission of Māori perspectives in disability is significant, particularly given the importance of culture for health and overall wellbeing (Ministry of Health, 2012b), and the impact of colonisation on Māori and on legislation related to disability (S. J. Hickey, 2008). The lack of published research furthermore makes it challenging to investigate potential weaknesses inherent in Māori perspectives on disability, and to explore how these perspectives could apply to this thesis.

The lingering effects of these historical inequities are further evidenced by the absence of Māori perspectives in Government strategies and wider documents within the disability sector in Aotearoa New Zealand. For instance, *the New Zealand Certificate in Health & Wellbeing* (IHC New Zealand Incorporated, 2016) provides no Māori perspectives in relation to defining learning disability. This absence exists despite the numerous international definitions utilised in the document, including those from the ICD-11 (2018), the *United Nations Convention on the Rights of Persons with Disabilities* (2006), the American Association on Intellectual and Developmental Disabilities (AAIDD)

(2018), and the New Zealand Ministry of Health (2012a). Furthermore, although the importance of cultural identity is acknowledged in the most recent *Disability Strategy* (Office for Disability Issues, 2016) and the *Disability Support Services Strategic Plan 2014-2018* (Ministry of Health, 2015), there is little detail beyond the recognition that this identity encompasses “language, whānau, cultural principles, practices and linkages to the land” (Office for Disability Issues, 2016, p. 13). The only exception to this situation is *Whāia Te Ao Mārama* (the Māori Disability Action Plan for Disability Support Service) (Ministry of Health, 2012b).

*Whāia Te Ao Mārama* (2012b) developed a strategy for supporting Māori disabled and their whānau, based on a culturally anchored approach. A visual of an interconnected spiral is presented, which encompasses four core elements considered necessary for providing effective support for Māori disabled (Ministry of Health, 2012b). These elements are:

- *Te ao Māori*, which relates to “a person’s ability to participate in their own whānau<sup>15</sup>, hapū [sub-tribe], iwi [tribe] and as a Māori New Zealander” (p. 6),
- *Te rangatira*, which relates to the responsibility each person has for their own lives, along with the whakamana (authority / legitimacy) each person has to take up the various roles and responsibilities that are their right
- *Te ao hurihuri*, which represents the various services, as well as the “political, economic, social and environmental trends that support, influence and affect Māori disabled” (p. 7), and
- *Tuhonohono*, which represents “the point in a person’s life where both the spirals and the space between them must connect to provide balance and harmony.” (p. 7).

*Whāia Te Ao Mārama* (2012b) focuses on the pivotal role of relationships within and between various groups, including Māori disabled, their whānau, hapū (subtribe), iwi (tribe), communities and the ministry.

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<sup>15</sup> See page 45 for the definition of whānau

While *Whāia Te Ao Mārama* (2012b) has adopted a culturally grounded approach to supporting Māori disabled, H. Hickey (2015) and H. Hickey and Wilson (2017) propose a more theoretical view, exploring a te ao Māori (the Māori worldview) perspective of disability. Rather than reaffirming Western individualistic perspectives by developing a specific Māori word for disability, H. Hickey (2015) and H. Hickey and Wilson (2017) draw upon the Māori worldview to provide a uniquely Māori, collectivist perspective on disability. They have named this approach Whānau Hauā. Whānau Hauā is defined as below:

Metaphorically, whānau hauā signifies the wind that propels whānau with member(s) who have a disability. The term whānau means to be born or give birth and refers to the extended family network who may live within or outside of a home....The word “hau” means “wind”, “gale” or “breeze”, while “ā” refers to the drive or urge that propels this wind. Depending on the mood of Tāwhirimātea [the god of wind], the wind can quickly change the environment, making it unstable. (H. Hickey & Wilson, 2017, p. 86)

H. Hickey and Wilson (2017) note that it can be a challenge for whānau hauā to achieve balance in their lives, particularly when facing unstable and unfriendly environments. Obtaining a sense of balance is not dependent on individuals alone, but on the collective efforts of whānau and other community members (H. Hickey, 2015). Whānau hauā is similar to the social model of disability, in that it views the barriers to daily life as originating in wider society rather than in the disabled person (H. Hickey & Wilson, 2017). However, the crucial point of difference for whānau hauā is the pivotal role of whānau in the lives of Māori disabled people (H. Hickey, 2015). Disability is not viewed as a trait inherent in individuals, but rather as a collective endeavour which involves many people (H. Hickey & Wilson, 2017). Furthermore, whānau hauā is not viewed as defining a person or whānau, but rather as something which is positioned in the background, moving in and out of focus depending on the situation at hand (H. Hickey & Wilson, 2017).



The following section examines the material impact of the ontological underpinning of some of the frameworks and concepts discussed in this chapter.

## **Ontological Underpinnings and the Material Impact**

As I have discussed throughout this chapter, the modernist notion of the ideal human is embedded within the ontological foundation of the key conceptual frameworks shaping policy and practice in Aotearoa New Zealand. Although this notion does not underpin Māori perspectives on disability, these perspectives do not appear to have a significant impact in shaping Government policy and strategy. This notion of the ideal human is not a phenomenon confined to theory and conceptual frameworks, but an underpinning that has significant material consequences.

The first impact noted is the absence of challenge to the ableist binary which positions learning disability as “naturally” inferior. This absence of challenge is evidenced in the frequent change of terminology to define what I currently name learning disability; “imbecile”, “idiot”, “retarded”, “mental handicap”, “special needs”, and “intellectual disability”, being some of the most commonly known terms. Many of these terms were once considered entirely acceptable names for “learning disability”, yet today they are considered a mark of great disrespect. As Sinason (1992) notes, the desire to change language in order to reflect a more respectful depiction of “learning disability” does nothing to challenge the subordination of the category. Instead, the frequent changes in terminology project a sense of “running away” from the ontological underpinning of the terms – that is, a denial of the “difference” inherent in learning disability, rather than a challenge to the inferiority of this positioning. The words may change, but the meaning behind them stays the same.

Another impact of the ontological underpinning of the ideal human is the focus on intentionality (Barad, 2007). Barad is critical of the humanist notion of intentionality. Drawing on the work of Bohr, she notes that intentions cannot be viewed as “preexisting determinate mental states of individual human beings”

(2007, pp. 22-23), nor as a phenomenon bound to individual human subjects.

Instead, intentionality is viewed as:

[A] complex network of human and nonhuman agents, including historically specific sets of material conditions that exceed the traditional notion of the individual. Or perhaps it is less that there is an assemblage of agents than there is an entangled state of agencies” (p. 23)

With the ontological assumption that human thoughts, identities, feelings and actions are always *intentional*, comes the notion of *attitudes*. Although attitudes are not specifically addressed in any of the perspectives noted earlier in this chapter, the view that attitudes are a key barrier to inclusion is evident throughout many policy and strategy documents. For instance, in the *United Nations Convention on the Rights of Persons with Disabilities* (2006) disability is defined as an evolving concept which:

[R]esults from the interaction between persons with impairments and *attitudinal and environmental barriers* that hinders their full and effective participation in society on an equal basis with others. (p. 1, emphasis added)

The *World Report on Disability* (World Health Organisation, 2011) furthermore states that “[r]aising awareness and challenging negative attitudes are often first steps towards creating more accessible environments for persons with disabilities” (p. 6). This focus is mirrored in Aotearoa New Zealand, with attitudes identified as a key barrier in both the 2001 and the 2016 Disability Strategies (Ministry of Health, 2001; Office for Disability Issues, 2016). In April 2018, the Disability Rights Commissioner Paula Tesoriero noted 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...Changing them is so much more than just a ‘nice to do’. It’s critical.” (Human Rights Commission, 2018b, para. 2-3)

However, there is a fundamental limitation in the focus on attitudes: the approach fails to take into account the role that discourses and other environmental factors have in shaping the possibilities for thought, emotions, attitudes and actions (Foucault, 1977). In this thesis I argue that the modernist conception of the ideal human plays a pivotal role in shaping the possibilities for how humans are conceptualised, including what is considered “normal”, what is “ideal” and what is “inferior”. The possibilities for “attitudes” towards disability are shaped by these processes, a practice which lies beyond the realm of intentionality and conscious action (Barad, 2007). The “problem” of disability is then not so much about disability itself, or about people’s “attitudes” towards disability, but is rather about the way in which humans are conceptualised in the Western world. A focus on “attitudes” proves insufficient to challenge these possibilities.

Another fundamental limitation of the ontological underpinning of the ideal human is the absence of challenge to a world which has been built around this ideal norm. As noted in Chapter Two, much of the foundation of Western society is built upon the assumption of the ableist norm. Examples include the education system in Aotearoa New Zealand, the design of jobs, and the neoliberal economic system (Olssen & Peters, 2005). As learning disability is held as the “constitutive outside” to the ideal norm (Campbell, 2005), it could be said that much of the foundation of Western society, at least in part, is built upon the exclusion of learning disabled people.

However, rather than challenging dominant structures in society which exclude learning disabled people, the focus for activism, policy and practice tends to concentrate on how disabled people can be included in society with a minimum level of change. As Sullivan (2000) notes, the disability movement is neither bold nor radical, but seeks approval and acceptance into the existing social order. Sullivan (2000) outlines this idea further:

I think the disability movement has stopped doing the intellectual work it needs to do if it is to be a vibrant, challenging organisation for social change. Does it, for instance, have a vision of what a nondisabling society might look like and how it might operate?

Has it started thinking about the implications a nondisabling society might have for all of its citizens? Or does it just want disabled people to be allowed to join the game as it is? (p. 44)

Two key practices are evidence of the desire to “join the game as it is” (Sullivan, 2000, p. 44): employment and wage schemes, and reasonable accommodation.

The first approach, employment and wage schemes, connects to both the social model and a long standing fight in the feminist movement for equal pay for work of equal value. In the 2001 *Disability Strategy*, there is a goal to:

Ensure disabled people have the same employment conditions, rights and entitlements as everyone else has, including minimum wage provisions for *work of comparable productivity*. (Ministry of Health, 2001, p. 17, emphasis added).

However, in order to meet the medical criteria for a learning disability diagnosis, individuals must display deficits in adaptive functioning (American Psychiatric Association, 2013; World Health Organisation, 2010). Areas of deficit include communication skills, social and interpersonal skills, self-direction skills and work skills (Ministry of Health, 2012a). Thus, I would argue that individuals who have been diagnosed as having a learning disability, almost by definition of meeting the requirements of the diagnosis, have a reduced ability to ability perform equally under current economic and workforce arrangements. This is not to say that the situation could not be different given different economic and workforce arrangements. However, in the various Government strategies and policies outlined in this chapter, including the most recent *Disability Strategy* (Office for Disability Issues, 2016), the *Workforce Action Plan 2013-2016* (Ministry of Health, 2013), and comments from Disability Rights Commissioner Paula Tesoriero at a presentation to the People First AGM (personal communication, 9 November, 2017), there is no evidence of a drive or strategy to challenge current exclusionary conditions. The only exception to this situation is a single sentence in the 2001 *Disability Strategy*, which has an action to “[e]ncourage the development of a range of employment options recognising the diverse needs of disabled people” (Ministry of Health, 2001, p. 17). The focus throughout the

various strategies is principally focused on “helping” disabled people into existing workforce structures through training, upskilling, and tackling discriminatory attitudes which “incorrectly” assume a disabled person will not be equally productive.

The second approach which demonstrates the desire to “join the game as it is” (Sullivan, 2000, p. 44) is *reasonable accommodation*. Reasonable accommodation is often used in line with the social model, and is defined in *United Nations Convention on the Rights of Persons with Disabilities (2006)* as follows:

“Reasonable accommodation” means necessary and appropriate modification and adjustment not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms. (P. 4, emphasis added).

The first notable concern with this definition of reasonable accommodation is the focus on *disproportionate or undue burden*. In a situation where including a person would impose a disproportionate or undue burden, the “reasonable” course of action appears to be that the disabled person would not be included; that is, that they do not receive equal rights. This definition is mirrored in the *New Zealand Human Rights Act 1993 (2017)*, which states under Section 60, titled *Further exceptions in relation to disability*:

Nothing in section 57 [Educational establishments] applies to a person whose disability is such that that person requires special services or facilities in that in the circumstances cannot reasonably be made available.

If achieving inclusion imposes a disproportionate or undue burden on an existing facility, such as an educational facility or employment facility (see sections 22/29, Human Rights Act 1993, 2017), there is no legal mandate to challenge exclusion.

The second notable concern with reasonable accommodation is the focus on *particular cases*. This need to challenge exclusion on a case-by-case basis

works to further individualise the problem of disability. Under this definition, exclusions always relate to “individuals” in need of certain “accommodations”, rather than a systemic problem that emanates from the ableist assumption of “normal” bodies and minds (Guillaume, 2011). This focus furthermore individualises the response to disability oppression, as exclusions happen *in particular cases*, effectively foreclosing the ability to challenge structural-level discrimination. Disabled people are thus placed in a defensive position (Clear & Gleeson, 2001) which, as Shakespeare (2001, as cited in Clear & Gleeson, 2001) notes, offers disabled people “only piecemeal change through ‘long, slow and costly litigation’” that eventually wears down “even the best resourced and most committed activists” (p. 41).

In the following section, I examine the need for a new way forward for disability studies.

## **A New Way Forward?**

In this chapter I have explored part of a key question driving this thesis: Why do learning disabled people remain positioned on the margins of humanity, despite decades of hard work from the disability rights movement, legislators, families / whānau and support workers, among many others? I have argued that a key reason for this marginality is the maintenance of the notion of the ideal human; an idea upon which much of the foundation of Western society is built, and which is built upon the otherisation, inferiorisation and exclusion of learning disabled people.

With the exception of Māori perspectives on disability, each of the conceptual frameworks noted in this chapter have the ideal human at the heart of their ontological foundation. Whilst each perspective has undoubtedly resulted in progress gains for learning disabled people, they appear to be unsuccessful in challenging the “otherisation” and “inferiorisation” of learning disability which, I argue, is at the heart of disability oppression. The ongoing proliferation of disability oppression and denial of rights, outlined in the first chapter of this thesis, is evidence that significant traction is still required in order to challenge disability oppression. As Carol Hamilton (personal communication

April 19, 2018) notes, over the past several decades we have worked to “include” learning disabled people into society, without addressing the ideas and underlying ontological assumptions which placed learning disabled people into institutions in the first place. A new way of thinking about disability, which is able to more effectively capture the phenomena involved in disability oppression, and which does not reaffirm the ideal human, is thus needed. This new approach needs to build on the gains achieved through previous approaches, whilst working to understand and dismantle key barriers to full inclusion. In Chapter Four I outline a new approach to conceptualising disability which I believe holds more promise, and which underpins the methodology for my own research.

## Conclusion

In this chapter, I have explored some of the key conceptual frameworks shaping policy and practice in the field of learning disability in Aotearoa New Zealand. Through examining key government strategies, policies and reports on disability, and guided by my experience in the disability support sector, I have identified four conceptual frameworks shaping policy and practice in Aotearoa New Zealand: the medical model, normalisation, the social model, and rights-based approaches. Whilst these frameworks cannot be considered the sum total of influences shaping policy and practice in Aotearoa New Zealand, I believe that they play a powerful role in shaping the contemporary context. I have also briefly explored Māori perspectives on disability, which do not appear to be well known in Aotearoa New Zealand outside of te ao Māori (the Māori worldview).

It would be possible to argue that each of the frameworks has led to significant progress-gains for learning disabled people. Where normalisation helped provide the impetus for deinstitutionalisation, the social model was utilised to drive the development of legislation related to (physically) accessible buildings. Rights-based models were utilised in the fight for the inclusion of disability in rights-based legislation, and Māori perspectives, while not well-known, have helped to shape the understanding that relationships form an integral part of the disability experience. However, with the exception of Māori perspectives on disability, each of these frameworks is underpinned by the

modernist notion of the ideal human. In the medical model and normalisation, this ontological underpinning is reified as ideal, and the onus for change is placed onto learning disabled people who are “helped” to be “as normal as possible”. In the social model, an attempt is made to challenge medicalised notions of ideal bodies through the separation of the notions of impairment and disability. However, this separation of impairment and disability has served to relegate impairment to the individualised medical model, ultimately reaffirming the very notion that the social model was designed to contest (Tremain, 2001). Both the rights-based perspective and citizenship approach are also founded in the notion of the ideal human, where only those who meet the criteria for “full persons” have access to full rights (Scully, 2016). As many learning disabled people do not meet the requisite criteria in order to be considered “full persons”, such as the capacity for reason, full rights are unable to be achieved in practice.

This ontological underpinning of the ideal human affects not only the theorisation of disability, where learning disability is held in a perpetual state of “otherness”, but also has significant material impacts. One of the most profound impacts for this thesis is the absence of challenge to the “natural” inferiority of learning disability. This absence of challenge is evidenced in the frequent changes in terminology to describe what I now define as learning disability. Other material impacts of the ontological underpinning of the ideal human are evidenced in the approaches employed by the DRM and in the Aotearoa New Zealand Government strategy and policy, designed to tackle disability oppression. Examples of the practices I have outlined include a focus on attitudes, and an absence of challenge to dominant structures in society which have been built around the ableist ideal norm. One of the most significant barriers to challenging exclusionary structures and processes is the focus on reasonable accommodation. This focus stipulates that inclusion is only mandatory in cases where it does not impose a disproportionate or undue burden on existing structures, foreclosing the potential for radical transformation.

The critique provided in this chapter highlights the need for a new way of conceptualising disability; one which does not hold the ideal human as an



ontological underpinning. In the next chapter, I will explore a new set of conceptual frameworks which could offer a more productive conceptualisation of learning disability, and thus enable more substantive progress towards the challenge of disability oppression.

## Chapter 4:

# Conceptual Framework

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The conceptual framing for this thesis took me somewhat by surprise. Driven by my desire to do research which could enact real change for learning disabled people, I sought to do something “practical” and “useful” when I first enrolled in the PhD programme. Theory appeared to me to be the antithesis of this goal. However, the more I delved into my research, the more I discovered the pivotal role of theory in shaping the materiality of people’s lives. I was also surprised to discover that the tools which showed the most potential were not found in my field of interest: disability studies. Instead, they have come from further afield in other areas of the humanities.

In the initial development of my conceptual framing, I was looking for something which would help shape my methodology. As my research area is learning disability, it was essential that the thesis did not focus solely on discourse, language and cognitive reasoning – areas which my participants (people assigned the label of learning disabled) are not strong in. I was mindful that focusing exclusively on these phenomena might limit my data collection.

I sought to apply ideas regarding power / knowledge, problematizing the notions of “normal” and “disability as a problem”. In particular, I drew on Foucault’s work looking at how discourse both transmits power, and holds the potential to destabilise and to thwart it (Foucault, 1978). However, there were limitations in Foucault’s work which presented a challenge. I wanted to work with the notion of pride, which is as much an emotion as an idea. Foucault’s work provided nothing in the realm of emotions, and so I turned to Wetherell’s work on affect. I also wanted to combine these ideas with Campbell’s work on ableism.

Despite my reservations about the limitations of the Foucauldian approach, I persisted with this framework in shaping the data generation, and I was pleased with the richness of the data obtained. It was not until after the

data generation, when I thought further about how to analyse the data, that I was introduced to the concepts of new materialism. New materialist perspectives seemed to capture exactly what I was trying to do, only much better; Foucauldian ideas are extended to incorporate the body and emotions. Furthermore, new materialism looks far beyond the realm of discourse, in a way which seemed to fit perfectly with the pragmatic and theoretical challenges of my research area.

What I have found has shown the most potential to answer my research questions is a complex array of theoretical perspectives. These perspectives are agential realism (Barad), citational chains and lines of flight (Bergson / Butler, as used by Davies), performativity (Butler), affect (Wetherell), and desiring silence (Jackson and Mazzei). In this chapter, I outline a theoretical framework which I believe enables a new and more promising conceptualisation of learning disability. Furthermore, I introduce the concept of disability pride as an under-theorised idea which holds great potential.

## Posthuman Disability Studies

The conceptual framing for this thesis falls under the umbrella of posthuman disability studies. In this section, I explore what a posthuman approach to disability studies means, and how it sits within the wider realm of new materialist theory. I will briefly explain my reasoning for moving along a different path than the burgeoning field of work in the area of learning disability research.

Posthuman disability studies is founded in the belief that the disability identity holds disruptive potential for troubling, reshaping and re-fashioning the human (Goodley & Runswick-Cole, 2016; Watson, 2012). As Goodley and Runswick-Cole (2016) note:

Disability has the radical potential to trouble the normative, rational, independent, autonomous subject that is so often imagined when the human is evoked, social policies are made,

social and human sciences are developed and forms of activism are enacted” (p. 2).

This emerging field of work builds upon key knowledges gained through the work of critical disability studies. These knowledges emanate from the challenge to the binary categories of “abled” (or “non-disabled”) and “disabled”, and an exploration of the political, ontological and theoretical complexities that align with the disability category (Goodley & Runswick-Cole, 2016; Watson, 2012).

One of the core tenets of a posthuman approach to disability studies is that it contests the notion of the rational and independent human of modernism. The work of Rosi Braidotti (e.g., 2013) has proven particularly influential in this area. In her writings, she provides a robust critique of “Western Man”, an idea which she asserts has been revealed as a fiction. As she states:

The starting point for me is the anti-humanist death of Wo/Man which marks the decline of some of the fundamental premises of the Enlightenment, namely the progress of mankind through a self-regulatory and teleological ordained use of reason and secular scientific rationality allegedly aimed at the perfectibility of ‘Man’.  
(p. 31)

Theorists such as Dan Goodley, Katherine Runswick-Cole, Sharon Snyder and David Mitchell have drawn upon Braidotti’s work to also contest the notion of the ideal human (e.g., Goodley et al., 2014; Goodley & Runswick-Cole, 2016; D. Mitchell & Snyder, 2017). Furthermore, posthuman disability studies contests the positioning of the “human” above “all other species and the environment” (Goodley et al., 2014, p. 346).

A particular point of difference posthuman disability studies has from the social model and critical disability studies is in the view of disability. Rather than continuing to view disability primarily as a form of social oppression, posthuman disability studies perceives the notion of disability as productive. For instance, Goodley and Runswick-Cole (2016) argue that disability can disrupt, disturb and disarm the “normative, taken-for-granted, deeply societally ingrained assumptions about what it means to be human and what it means to be able” (p.

6). Goodley et al. (2014) contend that disability challenges us to rethink what the “human” is, as well as how “humans” live in relationship with each other, the wider environment and other non-human beings. The view of disability as productive steps away from the view of disability as ontologically negative. As Goodley et al. (2014) state:

Being disabled is not a tragedy but a possibility, an affirmation, a ‘queer’ or ‘crip’ space for rethinking what it means to be human, to live a quality life and a life with quality. (p. 356)

This thesis aligns with posthuman disability studies. In particular, the notion of the ideal, bounded human is called into question, and the notion of disability is viewed as a possibility. Much of the writing produced thus far in the field has been grounded in the work of Braidotti, with a focus on the “posthuman”. As Braidotti (2013) notes:

[T]he proper study of the posthuman condition is the posthuman itself. This new knowing subject is a complex assemblage of human and non-human, planetary and cosmic, given and manufactured, which requires major re-adjustments in our way of thinking. (p. 159)

However, I have chosen to take a Baradian approach to this thesis. The key reason is that I saw great potential for utilising Barad’s work on Agential Realism, something which I did not see with Braidotti’s work. In particular, I was inspired by the use of Barad’s work by authors such as Davies, Jackson and Mazzei, Søndergaard, and Lenz Taguchi and Palmer (e.g., Davies, 2014b; Jackson & Mazzei, 2011; Lenz Taguchi & Palmer, 2013; Søndergaard, 2016). Although these writings sit outside the field of disability studies, I saw much congruency with my own project. For instance, Søndergaard (2016) explores the distributed, multi-directional flow of phenomenon related to violence in children’s lives; these phenomena are not always proximate in space and time, and entangle with children’s subjectivities and the actions of violence which they perpetuate. In this article, the notion of “violence” could easily be replaced by many other phenomena when exploring entanglements of performative agencies. “Subjects”

and “actions” do not precede, but rather are produced within these entanglements. Yet, interestingly, at the time that I was developing my conceptual framing and applying this to my analysis, I could find no examples from the field of disability studies that drew upon a Baradian approach.

Below, I detail Barad’s theory of agential realism. Thereafter I will propose a different means of conceptualising disability using agential realism; *disability as an entanglement*.

## Agential Realism

Agential realism is a conceptual framework put forward by Karan Barad, which proposes a new understanding of the materialisation of the world and all “beings” in it. The concept falls under the rubric of new materialism, a new theoretical approach which constitutes a fundamental rethinking of how the world and every “thing” in it comes to be. (Dolphijn & van der Tuin, 2012). This theory includes a rethinking of the materialisation of the “human” and the “nonhuman”, as well as material, discursive, social, scientific and cultural practices (Barad, 2007). Agential realism moves on from well-worn debates which “pit constructivism against realism, agency against structure, and idealism against materialism” (Barad, 2007, p. 26). Instead, Barad’s work rethinks the concepts which enable such binary thinking, including the notions of discourse, matter, agency, objectivity, embodiment, space and time.

Barad has drawn on a wide field of influences in the development of agential realism. These influences include poststructuralism, queer theory, feminist theory, antiracist theory, Marxism, and science studies (Barad, 2003). In particular, Barad builds on important insights from Michel Foucault, Donna Haraway, Judith Butler, Vicki Kirby and Joseph Rouse, among many others (see Barad, 2007). However, it is the work of Niels Bohr, a Nobel Prize winning quantum physicist, which has had a unique influence on Barad.

Bohr (1885-1962) is credited for being one of the founders of quantum physics. However, Bohr’s interests were not confined to the realm of physics; he was also interested in the intersection between physics and philosophy (e.g., Bohr, 1958, 1963). His work revolutionised the field of physics and, as Barad

(2007) notes, “shook the very foundation of Western epistemology” (p. 97). In the traditional view of physics, the world consists of discrete bounded entities which are each made up of individual atoms (Barad, 2007; Bohr, 1958). A clear distinction is made between object and apparatus, or the phenomenon being measured and the tools to measure it (Bohr, 1963). Many social and scientific theories are founded and shaped on this epistemological perspective; that is, that there is a clear separation between object and subject (Bohr, 1958).

Quantum physics steps away from the view that Bohr terms “classical physics”, otherwise known as Newtonian physics or atomistic metaphysics. In quantum physics, the interaction between object and subject is viewed as forming “an inseparable part of the phenomenon” (Bohr, 1963, p. 4). Bohr’s writing has a strong alignment with elements of poststructuralism and phenomenology, both of which reject the idea that “nature and culture, or biology and society, occupy separate metaphysical spaces” (Hughes, 2005, p. 78).

One of the key sources of Bohr’s insights comes from his “thought experiment”, in which he entered into the long-standing debate regarding whether light is a particle or a wave. The experiment used a two-slit interference device, first proposed by Einstein and later adapted by Bohr (Barad, 2007). Light is passed through a two-slit diffraction grating which, according to Bohr, could be manipulated in such a way that the light can be shown to exhibit both wave-like and particle-like behaviour (Bohr, 1958). In the mid-1990s, the technology had been developed to conduct Bohr’s thought experiment, and his hypothesis was confirmed (Barad, 2007).

As classical physics rests on the understanding that everything in the world can be separated into particles and waves, the experiment produced a seemingly contradictory result. What is the true ontological nature of light, if it can be shown to be both a particle and a wave? Bohr resolves this paradox by explaining that there are no “*independently existing objects with inherent characteristics*” (Barad, 2003, p. 816, emphasis in original); that is, the notions of “wave” and “particle” are not independently existing phenomena with inherent characteristics which precede the experiment. What the two-slit light experiment highlights, and what quantum physics subsequently argues, is that there are no

independently existing entities with intrinsic boundaries in the world; everything is interconnected. Whilst this idea likely comes as no surprise to many non-Westerners, including those from Te Ao Māori (the Māori worldview), this conclusion has significant implications for Western social and scientific theories. In particular, it poses a challenge to the “Cartesian belief in the inherent distinction between subject and object, and knower and the known” (Barad, 2003, p. 813); that is, it is not possible to draw a definitive boundary between light, the two-slit apparatus, the result, and the “humans” conducting the experiment.

Barad builds on this insight of interconnectivity from Bohr, applying it to the nature of matter, meaning, ontology and epistemology:

The separation of epistemology from ontology is a reverberation of a metaphysics that assumes an inherent difference between human and nonhuman, subject and object, mind and body, matter and discourse. (Barad, 2007, p. 185)

Developing the notion of ontological inseparability further, Barad proposes that ethics, knowing and being are indivisibly intertwined. She proposes the term *ethico-onto-epistem-ology*, to indicate that being, ethics, ontology and epistemology are mutually implicated. As Barad (2007) notes, “[w]e don’t obtain knowledge by standing outside the world, we know because we are *of* the world” (p. 185, emphasis in original). As such, Barad proposes a new term to express her thoughts on *how* knowing, being and ethics are intertwined: *intra-action*.

## **Intra-action**

Intra-action signifies a profound conceptual shift in the realm of social theory. The term is used in contrast to the more commonly used “inter-action” which draws on the atomistic metaphysics’ presumption of separate entities which precede their inter-action. Intra-action recognises that individual entities and agencies “do not precede, but rather emerge through, their intra-action” (Barad, 2007, p. 33). In this sense, phenomena such as “humans” and “soil”



materialise through intra-action as individual entities with apparently determinate boundaries, properties and meanings (Barad, 2007). One integral component of this process is that particular exclusions must happen in order for a phenomenon to emerge as a seemingly bounded entity (Barad, 2007). This is to say that no entity is considered to be an inherently bounded and propertied phenomenon prior to intra-action. Instead, phenomena “acquire specific boundaries and properties through the open-ended dynamics of intra-activity” (Barad, 2007, p. 172)

Given the significant conceptual shift inherent in agential realism, there are many important concepts to reconsider. Over the following pages I will detail three elements which are most pertinent to this thesis. These are the way that the human is conceptualised, the notion of agency, and the ethical implications of an agential realist perspective.

## **Conceptualising the Human, Agency and Ethics**

The notion of the human is radically rethought in agential realism. In Chapters Two and Three, I provided a critique of the modernist conception of the human. This notion, which continues to play a powerful role in shaping how humans are conceptualised, splits people into the binary categories of “normal” and “disabled”. According to Barad (2007), this view of the human is founded in the assumption that humans are discrete and bounded beings; a belief stemming from atomistic metaphysics. However, in a framework grounded in quantum physics, all beings and entities are viewed as intertwined; the modernist notion of the human cannot be sustained.

Barad’s work on agential realism is further enhanced by the long history of poststructuralism on which she draws. The notion of “discourse” is particularly important in this realm. Barad (2003) notes that according to Foucault, discursive practices are:

[T]he local sociohistorical material conditions that enable and constrain disciplinary knowledge practices such as speaking,

writing, thinking, calculating, measuring, filtering, and concentrating. (p. 819)

Discourse accounts for much more than language. As Barad (2003) notes, “[d]iscourse is not what is said; it is that which constrains and enables what can be said” (p. 819). In agential realism, discursive practices are viewed as boundary-making practices which produce, rather than merely describe, entities such as “subjects” and “objects” (Barad 2007). The modernist human as a “subject” is thus radically decentred and disassembled (MacLure, 2013). Human identities, thoughts and actions, including those related to learning disability, are not understood to be the result of “rational” thought by reasoned individuals. Instead, they are seen as phenomena which are shaped by the discourses in which people are embedded (Barad, 2007; Foucault, 1980).

Barad sees a key weakness in the poststructuralist conception of the human, in that a lack of attention is paid to the role of the body’s materiality in the workings of power (Barad, 2007; Davies, 2016). In particular, Barad is critical of the way in which Foucault implicitly reinscribes matter as passive. As she asserts, this limitation forestalls “an understanding of precisely *how* discursive practices produce material bodies” (Barad, 2003, p. 808, emphasis in original). Butler, in turn, draws heavily on Foucault in the development of her work in performativity. Barad finds that Butler’s work mitigates some of the weaknesses inherent in the work of Foucault, as she provides “an insightful and powerful analysis of some *discursive* dimensions of the materialization of real flesh-and-blood bodies” (Barad, 2007, p. 192, emphasis in original), such as those related to the formation of gender identity. However, Butler’s work is limited to the materialisation of human bodies; she does not look to phenomena outside the body, nor the material effects which humans have on each other (Barad, 2003; Davies, 2016). As a result of this, Barad finds that Butler “ultimately reinscribes matter as a passive product of discursive practices rather than as an active agent participating in the very process of materialization” (Barad, 2003, p. 821). In agential realism, Barad steps away from the view of matter as passive to focus on the discursive *and* the material elements inherent in the ongoing intra-activity of life.

Another key point of difference between agential realism and poststructuralism is in the main point of focus. As Zembylas and Bozalek (2014) state, Barad takes issue with human exceptionalism and the “assumption that humans are unique and should be the main focus of our concern” (p. 39). Instead, Barad views the “human” (and the “nonhuman”) as phenomena which are produced through the iterative boundary-making practices of intra-activity (Barad, 2007). As she states:

Bodies are not objects with inherent boundaries and properties; they are material-discursive phenomena. “Human” bodies are not inherently different from “nonhuman” ones. What constitutes the “human” (and the “nonhuman”) is not a fixed or pregiven notion, but nor is it a free-floating ideality. (Barad, 2003, p. 823).

These boundary-making practices, which constitute the “human” and the “nonhuman”, of necessity involve particular exclusions, and are always open to contestation (Barad, 2003). Furthermore, the notions of “bodies” and “environments” are always intra-actively co-constituted; humans do not stand separate from the world in which they are constituted (Barad, 2007).

The second important element of agential realism for this thesis is the notion of *agency*. Rather than viewing agency in the traditional humanist sense, that is, as something which is an attribute of humans, Barad takes a much wider perspective. In her view, all phenomena – humans, discourses, affect and matter included, are viewed as agentic. As Barad (as interviewed in Dolphijn & van der Tuin, 2012) notes, agency is an enactment; it is about the possibilities for worldly reconfigurings – as doing / being in its intra-activity. Agency is an integral component of what forms the ongoing intra-activity of life, but also emerges *through* this intra-activity (Barad, 2007).

The view that agency is located both within and beyond the human is highlighted by Jackson and Mazzei (2011), where they discuss an incident with an emerging academic, Sera. In this scenario, Sera purchases a suit after being asked to look after a registration table, and after wearing the suit at the registration table she notes:

And I remember putting on the suit feeling like I am so powerful. I couldn't get over how different I felt in the suit about answering questions and talking with people at the registration table. She didn't say wear a suit, but I figured I should. And so I bought one. And then I experienced that. (Jackson & Mazzei, 2011, p. 128)

As Jackson and Mazzei (2011) highlight, the various phenomenon present in this scenario, including Sera, the suit and positioning of Sera behind the registration table, "intra-act to both introduce and produce a topology of power relations and a subject position not previously experienced" (p. 133). In this scenario, agency is distributed over the suit, the registration table, Sera's position behind the table, institutional discourses relating to the possibilities for power at a registration table, and Sera herself.

The third important component of agential realism for this thesis is in relation to ethics. Barad is clear in her writing that human accountability is not lessened by the view that agency is distributed beyond the human (Barad, 2007). Humans, she asserts, have a constitutive role to play in the ongoing intra-active materialisation of life (Barad, 2007). Crucially, this means that much more attentiveness must be paid to existing power asymmetries (Barad, 2007). As I highlight in the box below, interactions between me and the people I supported whilst employed in a residential support service were profoundly shaped by existing power asymmetries.

I am on a sleepover shift at the house where I work and I hear a noise in the kitchen. It's late and everyone I support is meant to be in bed, so I go and investigate. In the kitchen I find Carl<sup>16</sup>, a 20-something year old gentleman, holding a muesli bar. It's obvious he is about to have a midnight snack. However, after bed-time snacks aren't provided for in the household cupboards; if Carl eats the muesli bar then there won't be enough for lunches for the week.

I feel it is my duty as a staff person to take the muesli bar off Carl, so we do not run out of food in the house. But I also want to ensure that Carl is in

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<sup>16</sup> Pseudonym

control of his own life. I work really, really hard to not act like I hold all the power as a staff person; a position which I come to learn is inescapable in a residential support service.

I imagine the typical response of a staff person is to “tell Carl off” for “stealing” food, but I decide to try a different tactic. I talk to Carl about his desire to go flatting, and how he needs to show us he is responsible if he wants to move away from the controlling residential support service. He needs to perform himself as a responsible and rational person if he wants to not have staff controlling his life. At that moment I am not conscious of the irony in telling Carl that he has to submit to the powers over him, in order to not have to submit to the powers over him. After some conversation Carl accepts my explanation, puts the muesli bar back and heads to bed.

I feel torn about this moment. On the one hand, I have adequately fulfilled my role as a staff person in maintaining the order of the house, and the situation is resolved. Yet, I believe that people should have the right to have night-time snacks. People should also have the right to choose how they live without having to prove that they are capable of not “sneaking” into their own kitchen and eating their own food outside of somebody else’s imposed meal times.

Looking at this scenario through the lens of agential realism, I can see multiple performative agencies at play. Each of these performative agencies intra-acted in this scenario, shaping my “self”, my response and the scenario. For instance, I felt that I would be shirking my responsibilities by not intervening. This conflicted with the image I hold of myself as a “good” staff person who doesn’t let the team down. Shopping only happens once per week with a cheque which is co-signed by the service manager and the team leader, and as there is no petty cash in the house, buying more food is incredibly difficult. We also have a duty of care to ensure the people we support have adequate food, so “tough luck you’ll go hungry tomorrow” seems out of the question. Carl is supported under the Residential Support Contract, a contract over which he has no say, and probably doesn’t even know exists. This contract dictates that Carl must live in one of the organisation’s houses; he is not allowed to put his name on a tenancy

agreement. There are strict rules about how a residential “facility” is to be run, including how the food purchasing works. As an employee of the organisation, it is my duty to enforce the rules. Although my job is to support Carl, I feel like my first priority is always to maintain order in the house, and ensure that everything runs as it is “supposed” to. If Carl has any say over his life, it is within the pre-determined boundaries of “acceptable” choice set by the organisation. I am constantly frustrated by my lack of ability to “let” Carl choose what happens in his own home.

Despite my attempts to not participate in what I see as oppressive support practices and to have the right “attitude”, I felt compelled to intervene. In that moment neither Carl nor I could see a path to harnessing the agency necessary to challenge these oppressive conditions. The intra-active forces in the residential service were shaping my actions and who I became as a person, even as I consciously tried to resist them.

A focus on the ethical implications of power asymmetries, such as those evident in the scenario above, forms an important part of an agential realist analysis. Rather than viewing these power asymmetries and the wider world as fixed and stable phenomena, Barad sees the world as constantly being made anew. In particular, there is a quote from Barad which expresses this idea clearly, and which proved itself important throughout the analysis: “[t]he world and its possibilities for becoming are remade with each moment” (Barad, 2007, p. 396). The ongoing oppression which any marginalised group faces, including disabled people, non-white people, and queer people, is not a stable and fixed phenomenon. Instead, it is something which is constantly being remade anew, and thus has the potential to be radically reconfigured at each moment.

In the next section, I utilise agential realism as a tool to reconceptualise the notion of disability.

## Disability as an Entanglement

How different ethics looks from the vantage point of constitutive entanglements. What would it mean to acknowledge that the “able-bodied” depend on the “disabled” for their very existence? What would it mean to take on that responsibility? What would it mean to deny one’s responsibility to the other once there is a recognition that one’s very embodiment is integrally entangled with the other? (Barad, 2007, p. 158)

In this thesis I propose a different way of conceptualising disability – *disability as an entanglement*. From an agential realist view, entanglements are seen as specific iterative configurations of phenomena (Barad, 2007). This is not to say that iterative entanglements are formed from exactly the same phenomena twice over; instead, Barad (2007) argues that each entanglement changes with each intra-action. As she notes:

In fact it is not so much that they [entanglements] change from one moment to the next or from one place to another, but that space, time, and matter do not exist prior to the intra-actions that reconstitute entanglements. (Barad, 2007, p. 74)

What is more commonly known as “context”, including the time and place of each intra-action, has a powerful impact on the iterative reconfiguring of each entanglement (Renold & Ivinson, 2014).

It is important to note that, in this view, phenomena do not need to be proximate in space and time within entanglements (Barad, 2007). Non-proximate phenomena can have powerful agency within intra-actions, including memories, legislation, theories and historical practices. As Barad (2007) notes, we are entangled in many more forces than we can possibly be aware of. As Lenz Taguchi and Palmer (2013) explain this concept in their exploration of the phenomenon of Swedish school girls ill- and well-being:

[I]n what ways do reported scientific findings ... become co-constitutive agents in the production of the phenomenon of

school girls' ill- or well-being together with other performative agents? Such agents are here understood to be entanglements of discourses, places, materialities and embodied practices in or connected to the school environment. All of these involve socio-historical aspects of gender, ethnicity, class, age, etc. in various situated ways. (Lenz Taguchi & Palmer, 2013, pp. 671–672)

Lenz Taguchi and Palmer (2013) describe the phenomena in question as “an entanglement of multiple performative agencies” (p. 673). Applying this idea to this research, I can see that *the entanglements of disability are constituted from multiple performative agencies*. Some of the performative agencies already discussed in the thesis include the modernist conception of the ideal human, capitalism with its focus on individuals, normative discourses, buildings with stairs / ramps, legislation and diagnostic practices. I will be exploring other performative agencies which arose as agentic during the data collection and analysis phases of the research.

Whilst I am naming the concept “disability as an entanglement”, it is perhaps more accurate to call it an ongoing series of entanglements. These entanglements continually materialise in such a way that they hold disability “in a static place of otherness” (De Schauwer, Van de Putte, Van Goidsenhoven, et al., 2017, p. 8). Through the materialisation of these entanglements, disability oppression is enabled, fostered and reiterated. However, this is not to say that this emergence is a state of finality, or that it must continue along this vein. To repeat an earlier cited quote from Barad (2007), “[t]he world and its possibilities for becoming are remade with each moment” (p. 396). The possibilities for the entanglements of disability are remade with each moment, and herein lies the ever-present possibility of change.

## **Difference within Entanglements**

The notion of difference is an important concept within agential realism. Like Deleuze, Barad does not view difference as negative, that is, as a difference



from (Davies et al., 2013; Hein, 2016). Instead difference is seen as a phenomenon which emerges through intra-activity. As Barad (2014) notes:

Differences are *within*; differences are formed through intra-activity, in the making of ‘this’ and ‘that’ within the phenomenon that is constituted in their inseparability (entanglement). (p. 175, emphasis in original)

Differences emerge and become salient through intra-activity. Thus, any ideas relating to “norms” and “different to the norm” are the difference effects of intra-active entanglements. This idea is highlighted well by Jackson and Mazzei (2011) when they discuss a black academic, Cassandra, whose blackness sets her apart as an “other” in her predominantly white institution. As Jackson and Mazzei (2011) state, “[i]t is not Cassandra’s “blackness” that produces her differently, it is the intra-action of bodies, discourses, and institutions that do so” (p. 125). These differences are not mere artefacts of human consciousness led astray (Barad, 2007). As Barad (2007) notes, “[d]ifference cannot be taken for granted; it matters – *indeed it is what matters*” (p. 136, emphasis added). These emergent differences have profound material consequences for people’s lives.

Disability is a difference which has come to matter in our world. This difference is an effect of the boundary-making practices which both form and emerge through intra-activity. Performative agencies such as diagnostic practices and discourses of the ideal human intra-act together through the entanglements of disability to create this difference. The frequent debates which rage about where the boundary should sit – can Asperger’s have its own diagnosis, or is it a form of autism? Is mental illness a form of disability? – evidence the permeability of this practice. Furthermore, different differences become salient in different contexts. As the social model highlights, using a wheelchair is a difference which becomes much more salient when buildings have no ramps, and deafness is a more salient difference when there are no subtitles available on TV.

The point of seeing disability as an entanglement is then to explore the entanglements of disability. What are they, what are the agentic entanglements, and what do they foreclose and present potential for?

For me, disability is a difference which very much matters. When I am talking with a learning disabled person I do a lot of mental filtering and adapting of myself - I try not to use big words, or talk too fast, or talk about complex abstract topics. When I talk with a blind person I try to remember to introduce myself each time we meet so the person doesn't have to play "guess the voice". When I talk with a Deaf person who lip reads I need to make sure I am facing the person when I speak. These are differences which very much do matter in our interactions. What matters, and how it comes to matter, can never be separated from the context in which these things are happening. In a different world, in a different place and time, these differences will matter in different ways.

In the following sections, I explore two more concepts which I will be drawing upon for this thesis. These concepts will be combined with agential realism in order to provide greater insight into how the entanglements of disability are maintained, and how they can be ruptured.

## **Citational Chains and Lines of Flight**

The next key conceptual idea shaping this thesis is a combination of two concepts – citational chains and lines of flight. See in particular Davies (e.g., 2008, 2011, 2015), and De Schauwer and Davies (2015) who draw on the work of Judith Butler, Henri Bergson, Gilles Deleuze and Félix Guattari. In this thesis I combine these two ideas with agential realism, in order to explore how the entanglements of disability are maintained and reiterated. I draw upon these concepts to consider how the entanglements of disability hold the potential for change.

Citational chains give life its sense of continuity and stability (Davies, 2015). They are comforting, and they help us to navigate the world (Davies, 2015). Judith Butler utilises the notions of citation and repetition in her work on performativity, particularly in relation to how gender norms become intelligible. As she asserts:

[Every girl is] compelled to 'cite' the norm in order to qualify and remain a viable subject. Femininity is thus not the product of a choice, but the forcible citation of a norm. (Butler, 1993, p. 232)

Davies draws upon the work of Butler in her use of citational chains (e.g., Davies, 2008, 2011). Davies defines citational chains as “a repetition, with slight variations, of the same – the same identity, the same relations of power, the same categorizations, the same patterns of meaning-making” (Davies, 2015, np). These citational chains form a crucial foundation of our world, as they “enable the chaos of the world to be reduced to discrete categories of meaning and structure” (Malins, 2007, p. 153). This understanding of citational chains is similar to Barad’s conceptualisations of discourse. In agential realism, discursive practices are understood to be a boundary-making practice which enable and constrain particular patterns of meaning-making. As Barad (2003) claims: *“discursive practices are specific material (re)configurings of the world through which local determinations of boundaries, properties, and meanings are differentially enacted”* (p. 820-1, emphasis in original).

They key to understanding the power of citational chains is that repetition is agentic. It is a crucial part of the establishment and reinforcement of meaning (Højgaard & Søndergaard, 2011). Entanglements with prominent iterations hold great potential for profoundly shaping the world. This notion of agentic repetition is the central concept being harnessed when I traverse between the terms “iterative intra-activity”, “iterative entanglements” and “citational chains”.

Davies (2015) combines the notion of citational chains with Henri Bergson’s lines of flight. In doing this, she highlights the radical potential for opening up the everyday world for examination, through rupturing the taken-for-granted ordinariness of life-as-usual. De Schauwer and Davies (2015) define lines of flight as “two contrary movements in which we are all continually caught up” (p. 91) – lines of ascent and lines of descent. In discussing Bergson’s (1911) work on lines of descent and ascent, Davies (2015) posits that:

Lines of descent are made up out of automated repetitions of those citational chains that Butler analyses, while lines of ascent take off into the not-yet-known. (np)

Lines of descent create the familiar, liveable world through repetition (Bergson, 1911; Davies, 2015). They are a normalising and territorialising force which work to hold the continuity and stability of our world, and which are dependent on repeated citations (De Schauwer, Van de Putte, Van Goidsenhoven, et al., 2017). In connecting these concepts with agential realism, lines of descent can be understood as the iterative entanglements of everyday life. Drawing on Deleuze (Deleuze, 1968/2004) and Butler (1997a), Davies (2008) contend that “that the ordinary everyday world is sedimented in repeated citations of the way the world is (and, it is believed, ought to be)” (p. 173). This unreflexive ordinariness plays a pivotal role in depriving many of “a reasonable or viable existence” (p. 173).

Lines of ascent, in contrast, are what generate the creative evolution of life (Davies, 2015). As De Schauwer et al. (2017) assert, they are a “de-territorializing force that opens up the new, the not-yet-known, and the emergent possibility of becoming different (p. 2). Lines of ascent, can be understood as the possibilities for becoming, which are remade with each moment (Barad, 2007). Lines of ascent present disruptive potential to the ongoing iterative entanglements of life-as-usual; they are, as De Schauwer and Davies (2015) state, a “space of movement, of the threshold, where everything is open to change” (p. 91). These two lines of flight are constantly at play, as they necessarily affect and depend on each other (Davies, 2015; De Schauwer, Van de Putte, Van Goidsenhoven, et al., 2017).

Extending on from Bergson’s thinking on lines of flight, Deleuze and Guattari (1987) introduce the concepts of de- and re-territorialisation. This concept helps to explain the processes of continuity and change within the ongoing intra-activity of life (Feely, 2016):

Reterritorialisation refers to the ways in which continuity, sameness, borders and boundaries are maintained within an

assemblage. Meanwhile, deterritorialisation refers to the ways in which the assemblage's borders and boundaries are simultaneously blurred, subverted or escaped, allowing for change, the proliferation of difference and processes of becoming. (pp. 877-878)

Yet, these forces of de- and re-territorialisation should not be thought of as a binary. Every intra-active entanglement contains within it forces which work to deterritorialise and take off in a new direction (Deleuze & Guattari, 1987; Feely, 2016). At the same time, each intra-action also contains within it forces which reterritorialise and work to maintain the lines of descent (Feely, 2016). These forces continually pull elements of intra-activity back to the same repetitions, into the ordinariness of life as usual. As Davies (2015) maintains, lines of ascent are "always subject to being re-territorialized and thus re-incorporated back into lines of descent and habitual repetitions and re-citations" (np).

Disruptions to the repetitive citations of the known order are also an ethical necessity of life (Davies, 2008). They are a foundational component of the challenge to the ongoing oppression faced by many marginalised groups, including learning disabled people. As Davies (2008) attests, it is in the "always-present possibility of rupture" (np) that revolutionary potential for change, or for a new line of flight, lies.

These two concepts of citational chains and lines of flight form an important component of the conceptual framing for this thesis. In my analysis I examine the iterative entanglements of disability which came to the fore during data collection. These entanglements provide insight into the forces which enable the flourishing of disability oppression, and which continue to position learning disability on the margins of humanity.

In the next section, I outline the key problem statement that data the analysis seeks to address, as well as the research questions.

## Research Aim and Questions

Due to the iterative nature of the research, the research aim and questions shifted substantially during the analysis. For this reason, I have split the research questions into two sections. The first research question was developed prior to the data generation phase:

1. Does the notion of pride present potential for a positive re-imagination of disability?

This question is explored in the first analysis chapter (Chapter Seven). The results from this question lay the foundation for the conceptual framing outlined in this chapter, including the view of disability as an entanglement. The research aim and questions which form the remainder of the analysis, emerged as a consequence of the findings from addressing this question.

Rather than focusing the research around a research *aim*, I found it more useful to engage with a *problem statement*, which emerged in the middle of the analysis:

The entanglements of disability materialise in such a way that they reiterate disability oppression.

Once I had developed this problem statement, I started to look at the separate components in order to gain a greater understanding – entanglements, entanglements of disability, disability oppression, entanglements of disability oppression. The aim of the research and the research questions thus became to explore each of these components:

2. What constitutes the entanglements of disability?
3. What are the performative agencies within these entanglements?
4. What is happening within these entanglements that enables disability oppression to be perpetuated?

5. What do these entanglements foreclose and present potential for?

These questions are not designed to be answered in their entirety. The entanglements of disability differ with each intra-action, and as such it would not be possible to provide a definitive answer to any of these questions. In the analysis chapters I explore the entanglements of disability which arose during the data collection and analysis phases, with an understanding that these results will always be partial and incomplete, and yet still valuable.

In the remainder of this chapter, I outline the conceptual frameworks which I draw upon in order to gain greater insight into the ongoing entanglements of disability. Each of these concepts will be drawn into the fray at different times; they are tools which, when read together with the data, help to illuminate agentic phenomenon within the entanglements of disability. At times the theories will be utilised on their own, whilst at other times they will be combined. However, at all times these theories sit alongside agential realism.

As a note on the writing style, the frameworks outlined in this chapter are used to think *with* particular concepts and theorists, in the vein of Jackson and Mazzei's (2011) book *Thinking with Theory in Qualitative Research*. Thus, I will refer to statements such as "*thinking with the notion of pride*" throughout the remainder of the thesis.

## Performativity

Butler's theory of performativity explores how subjects are both formulated and reformulated through "social performatives" (Butler, 1997b). Butler is particularly focused on the notion of gender, arguing that gender is not a pre-existing attribute of individuals which is merely described in language (Butler, 1997b). Instead, she argues that gender is an iterative doing – a performative, through which the subject emerges (Butler, 1997b). The performative should not be likened to a "performance", and should not be viewed as the rational act of an intentional, humanist subject (Butler 1997b).

Social performatives, Butler argues, enable subjects to be *recognisable*; that is, to be recognised as a man or a woman. This recognition is crucial, as it is required for social existence (Butler, 1997b). As Davies (2015) contends, “our very sense of personhood is linked to the desire for recognition” (np). Because of this, we are orientated to desiring the social categories through which we become recognisable (female/male, abled/disabled, white/coloured etc.), and we desire to preserve these categories. Davies et al. (2013) state that this desire for recognition happens even when the terms of recognition “exclude us, or make us less than human, offering a life that is not viable” (682-683). As Laws (2011) notes:

[I]f there were an option of being or not being, then overwhelmingly the desire would be to survive. Existing, even in subordination, is considered by most as preferable to not existing at all. (p. 119)

This desire to be recognised is both powerful and pervasively exploitable (Butler, 1997b).

Social performatives are an ongoing part of our everyday lives, and they are of fundamental importance if we are to “exist” as socially viable beings (Butler, 1997b). However, although performatives form an important part of our daily existence, they are not generally executed on a conscious level (Butler, 1997b). Part of the power of performatives is in their “everydayness” which renders them naturalized and difficult to see (Butler, 1990). It is often only when a performative is *not* repeated as usual, that such a repetition becomes apparent.

## **Performativity and Agential Realism**

Throughout this thesis, I draw upon Butler’s theory of performativity, with an agential realist extension. Barad herself draws on Butler’s theory of performativity in her development of agential realism (see Barad, 2007). Whilst Barad acknowledges the fundamental importance of Butler’s work, particularly in regards to “the psychic dimension of regulatory practices” (2007, p. 209), she finds some limitations in this idea. These stem from weaknesses inherent in



Foucault's account of power, in which he links discursive practices to the materiality of the body, but forestalls "an understanding of precisely *how* discursive practices produce material bodies" (Barad, 2003, p. 807).

Barad takes Butler's account of performativity and extends it, embracing the link between the material and the discursive. Barad proposes a posthumanist formulation of performativity, by replacing the concept of 'iterative citationality' with 'iterative intra-activity'. Barad suggests a posthumanist account of performativity, which does not incorporate "anthropocentric values in its foundations" (Barad, 2003, p. 828). This means that performativity involves much more than "human" bodies, and does not necessarily hold the "human" at its centre.

However, Butler's work on performativity has strengths which are not as developed in Barad's account. As Højgaard and Søndergaard (2011) note, Barad's work on the material-discursive apparatuses of power is "strikingly underdeveloped" (p. 347). This is particularly so when compared with her elaborate descriptions of the technical apparatuses of agential realism (Højgaard & Søndergaard, 2011). Furthermore, Butler's work on performativity has been developed and applied not only by herself but, significantly, also by a number of other authors (e.g., Davies, 2011, 2016; Davies et al., 2013; Jackson & Mazzei, 2011; Zabrodska, Linnell, Laws, & Davies, 2011). Having a more developed account of performativity, alongside numerous other examples using Butler's work, thus provided a greater understanding of how the concept of performativity can be put to work an analysis.

Utilising Butler's account of performativity with an agential realist extension in this thesis means to utilise Butler's ideas on performativity, recognition and viable lives, whilst not losing sight of the wider intra-active phenomena within intra-activity. Taking this perspective does not entail reasserting the anthropocentric foundations within Butler's work, or viewing humans as individual subjects with contained and identifiable boundaries. Instead, I will be taking the view that we are continually *becoming subjects*, and that we must perform ourselves as such subjects, through the ongoing processes

of intra-action. This means that performative acts, as well as the desire to be recognised, form an integral part of disability as an entanglement.

In the following section, I outline another key concept being utilised for the conceptual framing and analysis: Wetherell's work on affect.

## Affect

Affect theory is an area of research which has been lacking in the field of disability studies until quite recently<sup>17</sup> (Donaldson & Prendergast, 2011; Orlando, 2013). Cheyne (2016) argues that some work in the field of disability studies demonstrates suspicion towards "any kind of emotional response to disability" (27:14). This view sees any depiction of disability which is used to generate emotion in the viewer or reader as inherently problematic and exploitative (Cheyne, 2016). There has been a small increase in literature in this area since the turn of the millennium, such as the special themed issue of the *Journal of Literary & Cultural Disability Studies* (see Donaldson & Prendergast, 2011), but is an area in need of further exploration.

Despite the limited theorisation of affect in the disability studies literature, there are undoubtedly some profound affective challenges for many people with learning disabilities. Blackman (2003), for instance, highlights the lingering effects of the eugenics era, which reinforces the view that it is "a tragedy and a personal burden to have a child with a disability" (p. 25). As she asserts, this view is bound to take a toll on the emotional life of a child or young person. Building upon Blackman's (2003) work, Rolph and Atkinson (2010) argue that these young people "may feel they are a disappointment to their families, who had hoped for a 'perfect child'" (p. 58). Furthermore, being continually seen and treated as "different" and segregated from peers, such as in "special education" classroom settings, "must have an effect on the psyche of the individual with a learning disability and also on their family, influencing how members of the family relate to one another" (N. Blackman, 2003, p. 21).

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<sup>17</sup> For recent examples see Cheyne, 2016; Fritsch, 2013; Heeney, 2016; Price, 2016; Sheppard, 2017. See also (Goodley, Liddiard, & Runswick-Cole, 2018) for an excellent example which I encountered too late to incorporate into my thesis.

The limited research on affect and disability may be due in part to modernist underpinning of much disability literature to date, as outlined in Chapter Three. According to Laws (2011), the ideal human is expected to be always rational, and not disrupted by emotions. She notes further:

In the dominant rationalist discourses, the reasonable person does not have an excess of feelings and emotions... To be read as reasonable within the terms of the dominant discourses, we must detach ourselves from an excess of emotions/feelings. (p.51)

Donaldson and Prendergast (2011) argue this point, noting that emotions have historically been devalued and dismissed in the Western world (Donaldson & Prendergast, 2011). As they state, assumptions of the mind have discouraged “a more robust consideration of emotion” (Donaldson & Prendergast, 2011, p. 130). This absence has left a silence waiting to be filled (Orlando, 2013).

## Defining Affect

Affect is a tricky subject to define, in part because it is so hard to capture or point to. Pre-posthumanist scholars such as Blackman and Venn (2010; Venn, 2010), and Clough and Halley (2007), as well as post-humanist scholars such as Fritsch (2013), V. Mitchell (2016), and Zembylas and Bozalek (2014) provide some insights. However, it is Wetherell’s work on *affective practice* which I believe contributes most to the conceptual framework for this research.

In this thesis I will be using Wetherell’s work on affective practice with a Baradian extension. Wetherell is a social psychologist and, like Butler, with her work on performativity, Wetherell has a different ontological conceptualisation of the human to Barad. However, in the following section I outline how I believe that, despite the differing ontological foundations, Barad and Wetherell’s work can be productively drawn together.

Wetherell defines affect as “embodied meaning-making” (Wetherell, 2012, p. 4). This is alternatively understood as “human emotion” (Wetherell, 2012). Affect is always ongoing, continually coming in and out of focus, unfurling and becoming organised with particular rhythms (Wetherell, 2012). Affects never

have a beginning or an end point; as Wetherell (2013) notes, affective body hits are “always already occurring within an ongoing stream of meaning-making or semiosis” (p. 355).

Pile (2010) notes that there is a key issue one encounters when trying to study affect - that is, affects “cannot be grasped, made known, or represented” (Pile, 2010, p. 9). This leaves affect research without an object of study; a not insignificant problem. Because of this, Wetherell (2012) suggests that the point of focus in any analysis of affect should be directed towards *affective practice*.

Practices, according to Wetherell (2012), are defined as routinized assemblages or “ways of doing things”. This includes ways of working, moving bodies, cooking, consuming and feeling. These assemblages are sites of repetition which “provide the basic intelligibility of the world” (Wetherell, 2014, p. 12). Practices and routines are not often consciously chosen, but instead emerge unbidden and unfold “relatively automatically with little conscious monitoring” (Wetherell, 2012, p. 129). With the focus on repetition and absence of conscious choice, this understanding of practice has a strong alignment with the notions of citational chains and lines of flight outlined earlier in this chapter.

In connecting the notions of practice and affect, Wetherell (2012) describes affective practice as:

[A] figuration where body possibilities and routines become recruited or entangled together with meaning-making and with other social and material configurations. It is an organic complex in which all the parts relationally constitute each other.

(Wetherell, 2012, p. 19).

This means that rather than looking at affect per se, researchers should look to patterns and routines – at assemblages of phenomena which are repeated again and again. However, it is important to note that these assemblages are never quite the same. As with Barad’s understanding of intra-action, each time a routinized practice is enacted, different elements will come into play.

Affective practices can have different durations; some are short-lived, while others are more durable, widespread and resistant to change, forming

what can be identified as patterns over time (Wetherell, McCreanor, McConville, Moewaka Barnes, & le Grice, 2015). These patterns can be bound to specific contexts and times and can be cyclical, recurring over days, weeks and months, or even years (Wetherell, 2012). One example is the cycle of New Year's resolutions, which Wetherell 2012 calls "work on the self", "as good intentions lead to determined resolutions, to failures" (p. 12). These cycles can be short-lived, or "they may last, and be reworked, over many hundreds of years" (p. 12).

## **Connecting Affect with Agential Realism**

Barad does not specifically discuss affect in her work on agential realism. However, she does place a great deal of focus on materiality. In particular, Barad questions why matter has not been granted its own agency and historicity, most notably within poststructuralism. She argues:

Language matters. Discourse Matters. Culture matters. There is an important sense in which the only thing that does not seem to matter anymore is matter. (2003, p. 801)

I believe that affect can be understood as a material phenomenon within agential realism, one which is not bound to the "human" body. This understanding is presented much in the same way that Deleuze and Guattari see desire as a material phenomenon (Deleuze & Guattari, 1987; Dolphijn & van der Tuin, 2012). Furthermore, Barad (2003) views materiality as inseparable from discursive practices. As she states, "[d]iscursive practices and material phenomena do not stand in a relationship of externality to one another; rather, the material and the discursive are mutually implicated in the dynamics of intra-activity" (Barad, 2003, p. 822). Barad's view of embodiment is thus one of material-discursivity; as a phenomenon which is "the provisional effect of agential cuts that constitute material configurations of body and boundaries" (Juelskjaer, 2013, p. 756).

This view of embodiment as material-discursive aligns well with Wetherell's view of affective-discursive practices. Wetherell is critical of the way that affect is viewed as separate from discourse in much affect scholarship, such

as that from Massumi and Thrift (e.g., Massumi, 2002; Thrift, 2008). As she states, key authors emphasise “processes beyond, below and past discourse” (Wetherell, 2013, p. 350, emphasis in original). When viewed through this lens, affect is seen as a mysterious force which hits the body, bypassing sense making, cognition and discourse (Wetherell et al., 2015). Wetherell (2012) is clear in her belief that affect is inextricably intertwined with discourse, as well as wider meaning-making processes. As she states, “[i]t is futile to try pull them apart” (Wetherell, 2012, p. 20). Affect and discourse emerge with and through each other, she argues, granting each other power (Wetherell, 2012).

Both Barad and Wetherell are interested in meaning-making processes, and their connection to discourse and affect (for Wetherell), or materiality (for Barad). Barad, for instance, is particularly interested in *how matter comes to matter*; that is, in the boundary-making practices which are “fully implicated in the dynamics of intra-activity through which phenomena come to matter” (Barad, 2003, p. 822). Both Barad and Wetherell discuss these processes of meaning-making as being formed through entanglements; however, Barad’s view of what constitutes an entanglement is somewhat broader than Wetherell’s. In the definition of affective practice noted earlier, Wetherell (2012) describes practices as “a figuration where body possibilities and routines become recruited or *entangled together with meaning-making* and other social and material configurations” (p. 19, emphasis added). Furthermore, Wetherell discusses the pivotal role of context in shaping the mobilisation of affective-discursive practices. As she states, “[a]ffect is embedded in situated practice” (Wetherell, 2012, p. 160), and can be “very densely knotted in with connected social practices where the degree of knitting reinforces the affect and can make it resistant and durable, sometimes unbearably so” (p. 14).

## Conceptualising the (Affective) Human

As a social psychologist, Wetherell’s work on affect could be read as being tethered to the classical physics notion of the atomistically bounded human. For instance, Wetherell et al. (2015) state that they view “the patterning of the affective-discursive as the main route in for the social analysis of *human*

*affect and emotion*" (p. 58-59, emphasis added). However, much of Wetherell's work steps outside the bounds of humanism, particularly in regards to how affect is conceptualised. Wetherell does not view affect as bound to the human body or to particular subjects. As she states:

Like theories of affect without a subject, notions of affective practice also stress what could be called the 'impersonal personal'. Affective practice resembles discursive practice in this respect.... Affective performances, like words and language, are personally owned (and can feel intensely so) but are also trans-individual and collective. (2012 p. 122)

Wetherell views affect as relational, in a sense which extends beyond the human. The relational component of affect includes phenomena such as places, objects, sounds (such as music), events (such as national holidays), and much more (Wetherell, 2012). For instance, Wetherell analyses a game of hopscotch between some young girls, noting the "[l]ines drawn on pavements to represent hopscotch squares are crucial to the unfolding interaction, as are the social, institutional and spatial arrangements of play and playgrounds" (p. 88). Furthermore, Wetherell is critical of the humanist notion of reason, and the idea that affective practices are the result of rational and intentional processes which emanate from inside an individual's body. As she states, "[t]o attend to affect is to stress the limits of reason and the limits of the immediately knowable and communicable" (2013, p. 351).

This idea connects with the Baradian understanding of the human, as outlined earlier in this chapter. Barad draws upon key insights from poststructuralism, which asserts that human identities, thoughts and actions are shaped by the discourses in which people are embedded (Barad, 2007; Foucault, 1980). Building upon this idea, Barad's (2007) work on agential realism asserts that "humans", as well as their identities, thoughts and actions, emerge and are shaped by a wide array of intra-active phenomena. Affect can be understood as one of these phenomena. In particular, it can be viewed as one of the means by which power affects the body. Barad (2003) notes that Foucault "positions the

body as the locus of productive forces, the site where the large-scale organization of power links up with local practices” (p. 809). Power, Foucault (1976) asserts, is directly connected to the body – to “functions, physiological processes, sensations, and pleasures; (1980a, 152)” (Barad 2003 p. 809). Extending on from the work of Foucault, Barad (2003) states:

[I]t would seem that any robust theory of the materialization of bodies would necessarily take account of *how the body’s materiality* – for example, its anatomy and physiology- *and other material forces actively matter to the process of materialization.* (p. 809, emphasis in original)

In order to understand the workings of power, Barad (2003) asserts, we must form “understanding of the nature of power in the fullness of its materiality” (p. 810). Affect plays a powerful role in the ongoing formation of the “subject”. This includes the formation of identities and subjectivities (Wetherell, 2012), whereby particular ways of being and knowing the self and the world are made possible. In this sense, notions of “ideal humans” and inferior “others” are as much an affective register as a cognitive one. As Zembylas and Bozalek (2014) state, “[c]ritical posthumanism claims that all knowledge is embodied, political, partial, situated and accountable” (p. 38).

## Affect as Agentic

Crucial for this thesis is the view that affect plays a powerfully agentic role in the ongoing entanglements of disability. Whilst Wetherell does not specifically utilise the term agency when outlining her theory of affect, I believe her view does portray affect as agentic. As she insists:

[T]he fact that affect does circulate, and that affective practice can be communal, is crucial to the very possibility of collective action and to sociality and polity. (Wetherell 2012, p. 142-3)

In speaking of materiality, Barad (2007) points out that “the dynamics of intra-activity entail matter as an active “agent” in its ongoing materialization” (p. 151).



In this vein, affect forms an integral part of the ongoing entanglements of life. It is both a constitutive force within, and effect of, the ongoing entanglements of disability; that is, affect intra-acts within the meaning-making processes of disability. This includes the conceptualisation of what disability is, and how people identify with the identity category. In this thesis, I am interested in exploring the affective practices with the most prominent iteration and, in particular, the practices which hold “taken-for-granted” power in shaping the ordinariness of life-as-usual.

In the following section, I outline the third conceptual framework being drawn into the fray of the analysis: desiring silence.

## Desiring Silence

Another framework which is utilised to explore the ongoing entanglements of disability in this thesis is *desiring silence*. Desiring silence is a term first coined by Alecia Jackson (2008), and developed further by Jackson and Mazzei (2011), and Mazzei (2011). Desiring silence draws upon the Deleuzian notion of desire. Deleuze does not view desire as something which emanates from the desire to fill a need or a lack, as in the Lacanian understanding (Jackson & Mazzei, 2011; Mazzei, 2011). Instead, desire is viewed as a productive force, “a coming together of forces/drives/intensities that produce something” (Jackson & Mazzei, 2011, p. 92). As Jackson and Mazzei (2011) explain:

Desire’s production is active, becoming, transformative. It produces out of a multiplicity of forces which form the assemblage. We desire, not because we lack something that we do not have, but because of the productive forces of intensities and connections of desire. (p. 86)

Desire produces many other forces and phenomena, including privilege, power and voice (Jackson & Mazzei, 2011).

This view of desire does not emanate from the rational, intentional subject. Nor does this view see desire as something which indicates an individual’s true self, wants and needs, as in the humanist understanding (Laws,

2011). Instead, desire is viewed as a force formed in assemblages, or entanglements, which are shaped by collective narratives, images, and metaphors, and by our experiences over time (Jackson & Mazzei, 2011; Laws, 2011). As Renold and Ivonson (2014) assert, these assemblages are “always located in their socio-historical places” (p. 364). In short, desire is a phenomenon which is performed and constructed through the ongoing intra-activity of life (Jackson & Mazzei, 2011).

When analysing data, the focus should not be on seeking an understanding of what desire *means*, or to try to define it (Jackson & Mazzei, 2011). Instead, it means to ask how desire functions, what is producing this desire, and what the desire in turn produces (Jackson & Mazzei, 2011). As Jackson and Mazzei (2011) state, working with this understanding of desire means “to consider the forces of desire that are acting through and with our research participants, and to make sense of what results from such interaction” (Jackson & Mazzei, 2011, p. 91).

Connecting this notion of desire with silence means to seek an understanding of how desire functions to produce silence, and what this desiring silence in turn produces. In this thesis, I demonstrate how desiring silence acts as an agentic and productive force within the ongoing entanglements of disability.

In the following section I examine the last concept brought into the fold of the analysis framework, pride. I present this idea as a concept which holds potential to shift the ongoing problematic entanglements of disability.

## Pride

Pride, defined by Parsons (1999) includes:

“[R]efusing to accept the values of society which says – with its words, its attitudes, its practices – that some human identities are less valuable than others” (p. 3)

However, Carol Hamilton (personal communication, May 23, 2014) would take this definition a step further and assert that an identity of pride is not only refusing to accept the values of society, but also demonstrating the values that

society could embody moving forward. Disability pride is about the acceptance and celebration of difference; as Shakespeare (1996) notes, “it is about subverting negative valuation and reclaiming disability” (p. 106).

Parsons (1999) argues that pride is an important landmark which must be passed in order to achieve human rights. Crucially, Parsons (1999) notes that disability pride needs to be about pride *because* of disability. This stands in contrast to pride being *in spite of* disability or in the common humanity of disabled people (Parsons, 1999).

Thinking with the notion of disability pride does not mean to deny the challenges and pains associated with disability, or to deny that disability can be problematic (Scully, 2016). As Morris (1991) states, disabled people need the courage to say that “there *are* awful things about being disabled, as well as the positive things in which we take pride” (p. 71, emphasis in original). However, as Scully (2016) argues, the view of disability as purely negative ontology has major limitations. These limitations include lost possibilities in the attempt to regulate human diversity, and a loss of agency when we impose certain expectations onto bodies and minds. As Bunch (2017) highlights:

Disavowal and denial of heterogeneous embodiment also limits possible ways to imagine the good life, understand what it means to be human in all our diversity, design the kinds of social institutions that would allow all people to flourish, value different kinds of social contributions, and organize human life to engage in relationships of interdependence and care for each other. (p. 138)

Thinking with the notion of disability pride means to understand that there are innumerable ways to view disability, many of which “can offer profound and often practically useful insights” (Scully, 2016, np). For instance, Goodley (2017) argues that the notion of disability “urges a reconsideration of what it means to be human, *the* category through which to investigate the ways in which biopolitics are created and an entry point for contemplations about human nature in globalised times” (p. 208, emphasis in original). Thinking with the concept of pride means to question and explore how disability productively

colours our lives (Campbell, 2017b). This view furthermore means to recognise, as McRuer and Wilkerson (2003) argue, that “another world can exist in which an incredible variety of bodies and minds are valued and identities are shaped” (p. 14).

## The Limitations of Pride

Disability pride is not a new concept to the field of disability studies. Gill (1997) for instance notes that “through the disability rights and independent living movements, people with disabilities have... begun to proclaim their distinct value because of disabilities, claiming the potential of disability to bring unique perspectives and enriching experiences into their lives” (p. 44). More recently, S. Brown (2009) argues that disabled people need to embrace and celebrate their disabilities. He notes that there are many aspects of his disability which have been “enormously positive” in his life, and argues that, for many people, disability has led to more positive outcomes in their lives than negative ones. Discussion of disability pride can also be found in the work of Shakespeare (1996), Corbett (1994), Dunn and Burcaw (2013), and Clare (2015).

However, it is in the Deaf community that disability pride is most apparent. Scholars such as Garland-Thomson (2005), Samaha (2007), Barnartt (1996) and Dolnick (1993) emphasise the large number of Deaf people who do not consider deafness to be a deficit. Many from the Deaf community do not support the use of cochlear implants, for instance, because they are perceived as “an unhealthy urge to “fix” people who are not broken” (Samaha, 2007, p. 22). Instead, focus is placed upon Deaf community and culture which, through the use of sign language, is able to produce its own cultural works such as Deaf poetry (Garland-Thomson, 2005).

There is further evidence in the disability studies literature of a call to embrace disability which uses different terms than “pride”. For instance, the notion of “desiring disability” was explored in a special issue of *GLQ: A Journal of Lesbian and Gay Studies* (McRuer & Wilkerson, 2003), and examined further by Fritsch (2015). Bunch (2017) discusses the work of Julia Kristeva, who “proposes to radicalize liberal values within a theory based on a *positive* ontology of

disability” (p. 136, emphasis in original). Michalko (2017), furthermore, tells the story of a performer who made many “wondrous discoveries” about the experience of blindness after losing his sight.

Despite these promising pieces of work, however, the idea of a positive ontology of disability remains on the margins of disability studies. As Bogart, Lund and Rottenstein (2017) note, disability pride “is still a rare phenomenon” (p. 4). In the instances where pride is discussed in the scholarly literature it is primarily conceptual (Bogart et al., 2017), providing frustratingly little detail regarding how disability can be seen in more positive terms, or how pride can be developed.

Furthermore, Parsons (1999) and Hahn and Belt (2004) point out that pride is also a phenomenon yet to be seen in the wider disability rights movement, known only to a select group of scholars and activists. Instead of embracing and celebrating the *difference* of disability, the disability rights movement has largely focused on the *sameness* of disabled people. This is evident in the oft-cited mantra to “focus on abilities”, and the drive to focus on the common humanity of disabled people. As Parsons (1999) states:

The women’s movement does not primarily emphasise the “maleness” of women. The aboriginal movement does not primarily emphasise the “whiteness” of aborigines. The gay and lesbian movement does not primarily emphasise the “heterosexualness” of gay men and lesbians. But the disability movement does, very much emphasise the “ableness” of people with disabilities. p. 13

Parsons (1999) and Slater (2015) highlight how the strategy of focusing on sameness will ultimately never lead to the change that is necessary in society. A focus on sameness encourages assimilation into exclusionary structures which, as Slater (2015) states, reinforce “the normate’s privilege, making ‘reasonable the marginalization and oppression of those who do not/cannot/will not conform” (p. 2). Disability pride is thus an area I believe requires further investigation.

Interestingly, in the field of psychology, there is a significant body of literature about pride. These authors suggest that pride can be a useful emotion, for instance by leading to lower levels of depression and higher levels of relationship satisfaction (Bogart et al., 2017; Tracy, Shariff, & Chent, 2010; Weiner, 2000). Yet, in this literature, pride is often positioned as the binary opposite to shame, and is viewed in an individualistic rather than collectivist sense. For instance, many articles discussed pride being connected to individuals' self-esteem (e.g., Tracy et al., 2010; Weiner, 2000). Furthermore, pride is often discussed as a universal human emotion which can be measured quantitatively (e.g., Bogart et al., 2017; Weiner, 2000), and categorised into discrete types such as "authentic pride" and "hubristic pride" (Tracy et al., 2010). The incompatible conceptual framing of this field of literature means that it was not able to be drawn upon for this thesis.

## **The Agentic Potential of Pride**

Butler (1997a) argues that social performatives form an essential component of the formation of ourselves as viable subjects. As she asserts:

[T]he social performative is a crucial part not only of subject *formation*, but of the ongoing political contestation and reformulation of the subject as well. The performative is not only a ritual practice: it is one of the influential rituals by which subjects are formed and reformulated. (pp. 159-160)

Many intra-active forces are involved in this constitution, some of which will be explored further in the analysis. One key phenomenon shaping this constitution is that of the ableist binary. As discussed in Chapter Two, this binary serves as a well-established truth-claim in Western society. When someone is constituted as a disabled subject, it is often not possible to stand outside of the powerfully constitutive force of the ableist binary; that is, in rejecting the disabled subject positioning, we risk stepping outside of the terms through which we are constituted and being rendered unintelligible. In this thesis I argue that, rather than attempting to step outside of the constitutive phenomena, a greater

level of agency can be harnessed through *embracing* this constitution. Jackson and Mazzei (2011) speak of the agentic potential of stepping within the terms of constitution in relation to the black academic woman, Sera. As they note:

Sera cannot stand outside the discourse that constitutes her, but agency emerges from within discourse. To rework categories is to challenge the historicity of them, to expose the falsehood of their origins. (p. 82)

As Jackson and Mazzei (2011) highlight, a greater agentic potential lies in working *within* the discourses (and other intra-active phenomena) which constitute us. I argue that taking the disability identity on with pride holds agentic potential. This is particularly in relation to challenging the terms of constitution which render the disabled subject position inferior.

Importantly, challenging the terms of constitution of the disability category means to work with the notion of disability *identity*. Using the notion of identity can present some problems for new materialist and poststructuralist research, where identity is often viewed as a construct tethered to the stable, rational, humanist subject. However, Butler (1990) asserts that identity can be understood as a doing, rather than a fixed essence. As she states, gender is "a kind of becoming or activity... an incessant and repeated action of some sort" (Butler, 1990, p. 112). These identities are neither stable, fixed nor singular. Instead, they are viewed as fluid, ever-emergent and multiple (Kittelsaa, 2014); as a phenomenon whereby a sense of self – an "I" – emerges through the ongoing intra-activity of life. Furthermore, identity does not need to be tethered to the individual. As Clare (2001) notes:

Identity...can live in many places all at once – in the communities we make home, the food we eat, the music we play and dance to, the work we do, the people we feel wild and passionate about, the languages we speak, the clothes we wear. (p. 362)

Taking on the disability identity does not mean one needs to accept the identity as "naturally" inferior. Instead, embracing disability can be seen as a refusal to accept the inferior positioning of the disability identity. It can be viewed as a

challenge to the ableist binary itself; a challenge which, I believe, holds greater agentic potential for change than a rejection of the disability identity. Embracing the disability identity is a reconfiguration of the material-discursive apparatus of bodily production over which we can have agency.

In particular, there are two facets of the agentic potential of pride which are important in the formulation of my conceptual framework. Firstly, as Parsons (1999) and Davies (2014a) highlight, there is a critical link between identity and action. As Davies (2014a) states, “[t]hought and action are mutually entangled, just as individual beings, who know and who act, are mutually entangled” (p. 11). The way in which groups of people think and feel about themselves has a profound effect on what actions the group chooses to engage in, if any (Parsons, 1999). Without pride, Clare (2015) argues, “disabled people are much more likely to accept unquestioningly the daily material conditions of ableism: unemployment, poverty, segregated and substandard education, years spent locked up in nursing homes, violence perpetrated by caregivers, lack of access” (p. 107). Clare (2015) goes as far as to suggest that collective and individual resistance to oppression becomes nearly impossible without pride.

Secondly, pride holds agentic potential when it is viewed as a collective phenomenon. This view of pride as collective is particularly evident in the work of Parsons (1999), van Houten and Jacobs (2005), and Shakespeare (1996), who assert the paramount importance of a collective context in which to form a collective identity and discourse. As Morris (1991) notes:

One of the most important features of our prejudice is that we generally experience it as isolated individuals. Many of us spend most of our lives in the company of non-disabled people, whether in our families, with friends, in the workplace, at school and so on. Most of the people we have dealings with, including our most intimate relationships, are not like us. It is therefore very difficult for us to recognise and challenge the values and judgements that are applied to us and our lives. Our ideas about disability and about ourselves are generally formed by those who are not disabled. (p. 37).



Barnartt (1996) and Oliver (1996) argue that the view of the “problem” of disability is able to be reconceptualised within a collective context. This is particularly so when people assigned the label of disabled come to view themselves as an oppressed group, rather than as “isolated individuals with individual problems” (Barnartt, 1996, p. 6). Being connected to a disability community is considered central to the formation of a disability identity (Caldwell, 2011). As Parsons (1999) notes, “pride can begin to be transformed into power when the people who share that pride begin to organise together” (p. 5).

Taking an agential realist view, collectives can be seen as a tool to harness greater agency in the ongoing intra-activity of life. This is one of the key lessons learnt from other human rights movements, such as the civil rights movement and the queer / gay and lesbian rights movement: collectives are much more powerful than individuals alone. Put another way, collectives have much greater capacity to harness the agency necessary to produce the change that is sought. For instance, the search for employment for learning disabled people on an individualised case-by-case basis has proven to be highly ineffective, as evidenced by the statistics related to employment presented in Chapter One. However, when problems are perceived as and dealt with on a collective level – such as discrimination against women in the workforce, much greater traction is found.

In order for a collective to form, people have to be able to see themselves as collective. This means that people must accept the label of disabled as an identity which relates to them. As Feely (2016) notes, “[o]nce a subject has accepted their ‘impaired’ identity, participating in identity politics becomes possible. Thus a group of people who have been labelled as ‘impaired’ can come together as a political group” (p. 865). However, collective action is impossible when people reject the label necessary for the formation of a collective identity.

## Conclusion

The conceptual framework for this thesis is grounded in agential realism. This theory draws upon key insights from many fields, most notably from

quantum physics, and poststructuralism. Under an agential realist framework, all entities are viewed as entangled, inseparable phenomena. In sharp contrast to classical physics, agential realism does not view “humans” as independent, bounded individuals. Instead, humans are viewed as an effect of boundary-making practices: as beings which are profoundly shaped by the ongoing intra-activity of life. Furthermore, the notion of agency is not tethered to the human. Discourses, the material world, historical practices and memories are all viewed as agentic - as phenomena which shape the possibilities for the world’s becoming. This includes the possibilities for how disability is conceptualised, and the lives of learning disabled people.

Thinking with the lens of agential realism, I propose a different way of conceptualising disability: *disability as an ongoing series of entanglements*. These entanglements are formed from multiple performative agencies, which include the modernist conception of the ideal human, in/inaccessible buildings and diagnostic practices. In their current state, the entanglements of disability materialise in such a way that disability is held in a state of “otherness”, and in a state of inferiority. Crucially, disability is viewed as a difference which has come to matter through these entanglements.

Drawing on the concepts of citational chains and lines of flight provides greater insight into the maintenance of, and potential for rupture within, the ongoing entanglements of disability. Citational chains can be understood as iterative entanglements; that is, repetitions of particular phenomena, which coalesce together to form patterns. Citational chains can be understood as the lines of descent within Henri Bergson’s (1911) lines of flight. These are the lines which give life its sense of continuity and familiarity. However, these can be the lines which enable disability oppression to flourish. Lines of ascent, on the other hand, present disruptive potential to the problematic iterative entanglements of disability. I draw on both of these insights to explore key citational chains within the entanglements of disability. I utilise the notion of lines of flight to explore whether disability pride presents the potential to disrupt the problematic iterative entanglements.

Driven by this conceptual framing, I shaped the analysis around a problem statement, rather than a research aim: *the entanglements of disability materialise in such a way that they reiterate disability oppression*. The research questions stemming from this problem statement include an investigation of what constitutes the entanglements of disability, and an investigation of what the entanglements foreclose and present potential for.

In order to explore these questions in more detail, I draw upon three conceptual frameworks: Butler's work on performativity, Wetherell's work on affect, and Jackson and Mazzei's (2011) work on desiring silence. Butler's theory of performativity explores how people come to be recognised as particular types of subjects, such as men and women. This recognition is linked to our sense of personhood and is crucial for social existence. We come to desire the social categories through which we become recognisable, even when the terms of recognition offer a life that is less viable (Davies et al., 2013). In this thesis, I draw upon Butler's theory of performativity and add an agential realist extension. Butler's insights into how we come to be recognised as particular types of subjects are explored as an agentic phenomenon within the entanglements of disability.

Wetherell's work on affective practice is further drawn upon in order to explore the ongoing entanglements of disability. Like citational chains, affective practices are viewed as routinized assemblages which are not often consciously chosen. Whilst Barad and Wetherell hold different ontological conceptualisations of the human, I believe their work has a high level of alignment and can be utilised together. Both theorists stress the limits of reason, are interested in meaning-making practices, and view these practices as inhering within entanglements. Furthermore, I believe that Wetherell's work on affect helps to illuminate the affective component of the intra-active production of subjects.

Desiring silence, as developed by Jackson and Mazzei (2011), is viewed as a productive phenomenon within the ongoing entanglements of disability. This view of desire is not seen to emanate from the rational individual, nor indicate an individual's true self, wants and needs. Instead, desire is seen as a force which is formed in entanglements, and which produces many other phenomena such as

privilege, power and voice. Thinking with the notion of desiring silence means to seek an understanding of how desire functions to produce silence, and what this silence in turn produces.

Lastly, disability pride can be used as a tool to seek a disruption in the problematic entanglements of disability. Disability pride is about the acceptance and celebration of disability – of the *difference* inherent in disability. Asserting pride in disability *because* of disability and not in spite of disability, stands in contrast to many of the strategies currently employed by the disability rights movement. Thinking with the notion of pride means to question the ways in which our lives have been limited by the imposition of certain expectations onto bodies and minds, and to explore how disability productively colours our lives. By stepping within the terms which constitute us and embracing the disability identity, it is my belief that we can grasp the agency necessary to shift the ongoing problematic entanglements of disability.

# Chapter 5:

## Methodology and Methods of Data Collection

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The methodology used for this thesis is formed from an entanglement of four methodological perspectives. The perspectives were chosen for their emphasis on collaboration with the research community, power-sharing, and on enacting change, rather than simply investigating an existing situation.

These perspectives include inclusive research, a methodology which emphasises the role of learning disabled people as active co-researchers or participants within the research (Strnadová & Walmsley, 2018; Walmsley, 2004; Walmsley, Strnadová, & Johnson, 2017), and participatory action research, a methodology with a commitment to the participation of marginalised communities, and a focus on action oriented to enacting change (Baum, MacDougall, & Smith, 2006; Cocks & Cockram, 1995). The perspectives in this methodological entanglement also include: community based participatory research, a blanket term for a wide range of research approaches which are inherently inclusive of the research communities (Israel, Eng, Schulz, & Parker, 2012); decolonizing methodologies, an approach with a commitment to ensuring that research does not contribute to the othering of marginalised communities, and which subverts the more traditional top-down approach inherent in much research (Goodley & Runswick-Cole, 2012); as well as culturally responsive methodologies, an approach which focuses on collaborative research involving researchers and the research community, with an emphasis on power-sharing between these two groups (Berryman, SooHoo, & Nevin, 2013b, 2013a).

Other important elements are entangled in the methodological approach, most notably the role of ethics and the drive to avoid the harms visited on learning disabled people through research conducted in the past.

Rather than sticking to a “pure” form of any of the methodological perspectives, this project was crafted from the elements which best fitted the aims of the research, as there is no “correct” way to approach any of these methodologies in practice (Berryman et al., 2013b; Israel et al., 2012; Strnadová & Walmsley, 2018). As Walmsley (2004) states:

[T]here is no one right way to approach inclusive research.

Adjustments are needed according to the topic, the methodology and the skills of those involved. (p. 69)

In this chapter, I outline the elements from the entangled methodological perspectives which shaped the methodology and method. Thereafter, I outline the methods of data collection.

## **Ethics as Agentic: Addressing Issues of Marginalisation**

Ethics played an agentic role in shaping the methodology and methods of data collection for this research. Barad (2007) notes that in agential realism, ethics, ontology and epistemology are viewed as inseparable; what it is possible to know, and how we know what we know, are intertwined with ethics. Intra-acting responsibly means to take account of “the entangled phenomena that are intrinsic to the world’s vitality” and to be “responsive to the possibilities that might help us and it flourish” (Barad, 2007, p. 396). In this vein, research can be viewed as an entanglement of phenomena in the ongoing intra-activity of life; a practice which reconfigures the world. Conducting ethical research means being responsive to the possibilities that can enable the world and the people that are part of it to flourish, but it also means being responsive to the possibilities that can inhibit this flourishing. This is the position that I take in this research.

Learning disabled people are often viewed as a vulnerable population (Nind, 2008); as such, it is important to be responsive to the possibilities which can foster and inhibit flourishing when working alongside members of this group.

Research involving this population group has in the past caused great harm. As Mertens, Sullivan and Stace (2011) note, disabled people have been “surgically mutilated, lobotomized, euthanased, shocked into passivity, and placed in chemical and physical straightjackets” (p. 227) in the name of scientific research. Disabled people join the ranks of many other marginalised groups who have been subject to research which colonises (Goodley & Runswick-Cole, 2012). As Bishop (2013) points out, this type of research not only positions marginalised groups as “other”, it also perpetuates an ideology of cultural superiority which prioritises the wants and needs of Western man. This further delegitimises perspectives which do not fit with this world view.

One of the key means by which colonising research was oppressive was in the positioning of research “subjects” as passive (Kiernan, 1999). Research was conducted *on* people, rather than *with* them, and research subjects were viewed as data sources to be investigated (Goodley & Runswick-Cole, 2012; Kiernan, 1999). Learning disabled people in particular were viewed as objects and as “conditions, categories, and examples to be cured, ameliorated, or cared for in institutions” (Mertens et al., 2011, p. 227). Through this process, researchers’ positions as elites and decisive knowers were enhanced (Traina, 2016). Researchers had control over the entire research process, while disabled people were denied any form of agency, including choosing what was researched and how it was researched (Sullivan, 2006; Traina, 2016).

The silencing of disabled people was one of the key effects of the othering process. As Walmsley (2001) notes, “[t]here is no evidence that, before the work of Robert Edgerton in the 1960s, anyone had tried to access or represent the voices of people with learning difficulties in research terms” (p. 188). Because of this silencing, Goodley and Runswick-Cole (2012) note that disabled people have frequently had their life worlds misrepresented and exploited through research. Furthermore, the voices of parents and professionals were viewed as more valid and reliable than the disabled person’s voice, and were thus foregrounded over the voices of disabled people themselves (Goodley & Runswick-Cole, 2012, citing Watson et al. 1998). This situation furthered the misrepresentation of the lives of learning disabled people (Tuffrey-Wijne & G.

Butler, 2009)<sup>18</sup>. Today, there is a wide array of methodological approaches to draw upon, both from within disability studies and further afield, which actively seek to challenge this history of harm and to build upon what has been done well.

Despite the many decades of research involving marginalised populations as equal partners, research involving learning disabled people in a partnership approach is a relatively recent phenomenon. Nind (2008) and Walmsley (2001) note that it was not until the late twentieth century that this type of research featured in the field of disability studies. It has been largely driven by the disability rights movement, and self-advocacy organisations in particular, who, as Tuffrey-Wijne and G. Butler (2009) state, “began to demand inclusion not only as research participants but also as researchers who contribute to both the design and the execution of research” (p. 175). What is now known as the field of “inclusive research”, sought to embody the ‘call to arms’ of the disability rights movement – “nothing about us without us” (Aspis, 2000; Charlton, 1998). This partnership approach has enabled researchers to gain a greater understanding of the life-worlds of learning disabled people, and to conduct research which empowers, rather than alienates, this population group.

## **Core Elements of the Methodological Entanglement**

Two important considerations drove the methodological choice for this thesis. Firstly, I wanted a method that would enable learning disabled people to fully participate without them needing to enhance their cognitive abilities. This meant that I wanted a method that did not rely on cognitive abilities alone, but also enabled sensory, emotional and experiential abilities to come to the fore. This stands in contrast to researchers such as Gilbert (2004), who suggests that

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<sup>18</sup> Please note that there are two authors named “Butler” in this thesis. For ease of reading, I have chosen to keep this reference as “G. Butler”, as it is only referenced in Chapter Five. In contrast, “Judith Butler” is referenced many times throughout multiple chapters, and is simply referred to as “Butler”.



“a considerable investment is needed if people are to develop the skills needed to participate in the research process” (p. 307).

The second important consideration was that I wanted data generation to be conducted with a group. Parsons (1999) discusses the importance of collective strength in rights movements. He argues that an identity of pride can only develop when people from marginalised communities come together; pride is not an individual affair, it is collective. One of the key pieces of research which helped shape my methodology was conducted by Cook and Inglis (2009, 2012; Inglis & Cook, 2011). They worked with a group of men with learning disabilities to gain a greater understanding of the best ways to inform learning disabled people about research and informed consent. Working together with other learning disabled people was highlighted as being one of the most important factors supporting participant understanding. It was thus my hope that participants’ understanding of ableism and disability pride would be enhanced through working as a group.

These two key considerations, along with the desire to conduct ethical research, are what shaped the methodology for this project. In the following sections, I discuss the core elements of the methodological approaches used in this project.

## **Partnerships between Researchers and the Research Community**

One of the core elements inherent in all of the methodological perspectives is a focus on collaboration and co-creation. Research is viewed as a partnership between researchers and their research community, where participants are viewed as active doers in the project, rather than as passive subjects to be investigated (Baum et al., 2006; Israel et al., 2012; Walmsley, 2001). The inherent power imbalance which often exists between researchers and the research communities is openly acknowledged (Israel et al., 2012). Furthermore, there is a commitment to power sharing amongst researchers and participants; although, the degree to which power is shared can vary depending

on the specific details of the project (see for instance Goodley & Runswick-Cole, 2012; Israel et al., 2012).

One of the most important aspects of the power-sharing process is the relationship between researchers and participants (Baum et al., 2006; Israel et al., 2012; in New Zealand see Munford et al., 2008). In the more traditional research approach, researchers stand at a distance from participants in order to produce “objective” knowledge which has not been tainted by the researcher (Schneider et al., 2004). In contrast, the methodological approaches utilised in this thesis assert that researchers should develop strong, equitable and trusting relationships with participants (Israel et al., 2012; Nind, 2008). This relationship is considered essential if researchers are to fully engage with participants in the processes of co-creation (Munford et al., 2008), and is the approach I took in my methodology.

## **Research that is Change-Focused**

This research began with a desire to instigate change which would help learning disabled people, rather than investigating the existing situation of people’s lives. After such a profound shift in my own thinking when I encountered the notions of ableism and disability pride, I wanted to work with these concepts with learning disabled people, and see if these concepts presented potential for reimagining disability in a new and more positive way. The methodologies which are drawn upon focus on challenging social inequality through working in action with groups, movements and/or individuals (Cocks & Cockram, 1995; Gilbert, 2004). Walmsley et al. (2017) for instance state that inclusive research is:

Research that aims to contribute to social change, that helps to create a society, in which excluded groups belong, and which aims to improve the quality of their lives. (p. 8)

One of the key means by which change is achieved is through the focus on action. Within participatory action research in particular, the view is taken that “there is a vital link between knowledge generation, education, collective

action, and the empowerment of oppressed people” (Cocks & Cockram, 1995, p. 31). Action is achieved through a cyclical process whereby researchers and participants generate data, reflect upon it and determine what action should follow. This then leads to further data generation, reflection and action in what has been described as an iterative or corkscrew style approach (Baum et al., 2006; Cocks & Cockram, 1995).

This notion of reflection on reality aligns well with the Foucauldian ideas underpinning the conceptual framing for this research. Baum et al. (2006) illustrate one particular technique that can be used to help with participatory reflection. They note that the transformative power of participatory action research comes to the fore when researchers see the “inherited tradition and prevailing culture” (Baum et al., 2006, p. 856) within the “authentic” accounts of lived experience. Through highlighting the inherited tradition and prevailing culture with participants, Baum et al. (2006) note researchers and participants can be empowered to view their reality as something which is susceptible to transformation. By drawing attention to the inherited traditions and prevailing culture, such as the taken-for-granted notions of “disability”, “ability” and “normal”, participants in my research thus have an opportunity to view their reality as something which is open to transformation.

## **Researcher Embeddedness**

In the methodological perspectives that inform this research, researchers are seen as an integral, influential and embedded part of the entire research process (Baum et al., 2006; Berryman et al., 2013a). At the time I was developing the methodology and generating data with participants, I focused on the notion of reflexivity (see particularly Cunliffe, 2004; Cunliffe & Karunanayake, 2013; Fine, 1994). However, after the data generation phase of the research I encountered the work of Barad, who is critical of the notions of reflexivity and reflectivity. Drawing on Donna Haraway (1997), Barad (2007) notes that “reflexivity mirrors the geometrical optics of reflection” (p. 72). She argues that the idea that the mirror can be turned back on oneself, as in “reflexive” methodologies, is both widely utilised and flawed. This notion of reflexivity

positions researchers and participants at a distance from each other; as ontologically separate beings (Barad, 2007). Instead, Barad (2007) argues that researchers and participants are not fully formed, pre-existing subjects, but are rather beings who are intra-actively co-constituted through the processes of the research. This is the view that I have utilised throughout this thesis. Cunliffe's more recent work also places much greater emphasis on intersubjectivity (2011). She argues that what is considered "thinkable" is profoundly shaped by the interrelationships between people and their surroundings, and argues that we "are inherently embedded & embodied in historical, cultural & linguistic communities" (Cunliffe, 2011, p. 654).

## Ongoing Informed Consent

Another crucial element of the methodological approach was ongoing, informed consent. Informed consent is considered to be a basic tenet of ethical research (Cook & Inglis, 2009; Gilbert, 2004). In Aotearoa New Zealand, the notion of informed consent is enshrined in the *Health and Disability Code* (Health & Disability Commissioner, 2012), which extends rights to all New Zealanders who are receiving a health and disability service, or who are participating in research. Right 6 in the code is the "Right to be Fully Informed", and Right 7.1 states:

Services [including research] may be provided to a consumer only if that consumer makes an informed choice and gives informed consent. (np)

Ongoing informed consent is the practice of ensuring that consent is continually established throughout the research, rather than a once-off event which happens when participants sign a consent form (Knox, Mok, & Parmenter, 2000).

Several factors are involved in ensuring informed consent is obtained. Firstly, participants need to understand what research is, and what the particularities of the project are (Cook & Inglis, 2009; Strnadová, Cumming, Knox, Parmenter, & Welcome to Our Class Research Group, 2014). They must also

understand the implications of joining or not joining, and understand how any information they provide might be used (Cook & Inglis, 2012). A number of social, environmental and informational factors can enhance participants' understanding of research. These include: providing information in an easy-to-understand format, providing information through multiple means, repeating the information over several occasions, using concrete visual-aids, real-life examples from participants and role-play scenarios, and giving participants time to process information (Inglis & Cook, 2011; National Institutes of Health, 2009; Nind, 2008).

One of the most important elements in ensuring consent is the capacity participants have to decline (Dye, Hendy, Hare, & Burton, 2004; Inglis & Cook, 2011). The National Institutes of Health (2009) argues that understanding that participation in research is voluntary is more important than other aspects of consent. Furthermore, consent pertains to more than choosing whether to join the research or not (Dye et al., 2004). For consent to be ongoing and informed, participants must have the opportunity to decline to join in any aspect of the research at any time.

A culture of "constructive dissent" was also sought, in order to ensure participants were not acquiescing to someone they believed to be in a position of authority, a well-reported tendency in the learning disability population (Gilbert, 2004; Kiernan, 1999; Knox et al., 2000). This culture helped to ensure that participants understood that it was OK to say no, and to disagree with me and with each other. In the study conducted by Inglis and Cook (2009), participants tended to view disagreement as a form of criticism. This served to inhibit the exploration of divergent ideas amongst participants, a situation which I wished to avoid.

## **Methodological Limitations**

Due to the pre-determined aim of the research, it was not able to be conducted utilising a full co-creation approach. Participants had no opportunity to set the research questions or design, nor did they have any opportunity to engage with the analysis, as is advised in some literature (Strnadová et al., 2014).

However, a co-creation approach was utilised during the data generation phase as much as possible.

This methodological approach requires a significant investment of time if it is to be meaningfully conducted (Walmsley et al., 2017); the data generation phase for this project lasted eight months. The approach furthermore requires a significant personal commitment from the researcher (Cocks and Cockram, 1995); I found the data generation process physically and emotionally exhausting, particularly because of the powerful sense of ethical responsibility I felt towards to the participants.

There were no formal mechanisms holding the research project or researcher accountable to the research community, as advised in the literature (Baum et al., 2006; Schneider et al., 2004). Although the research was approved by an ethics panel at the university, there was no panel or group from the disability community whom I could run the research past. The absence of formal accountability measures is something I remain uncomfortable with; I believe such a panel would be a great asset in Aotearoa New Zealand.

The last notable limitation is a reliance on the participants' ability to talk. This is a frequently occurring problem in the field; Walmsley et al. (2017) and Kiernan (1999) note that people with profound disabilities and high support needs have largely been excluded from research. With the heavy reliance on the intellectual skills of participants noted as a key reason for this exclusion (Kiernan, 1999). In this project, the desire to discuss ableism and disability pride meant that I also largely relied on the intellectual and verbal abilities of participants.

In the following section I outline the methods of data collection used for this research.

## **Methods of Data Generation**

This section begins with a discussion regarding the method: the participants, the co-facilitator, the support that I provided, and the role of advocates. Thereafter, specific details regarding the content of the data generation will be discussed, including the activities and resources utilised.

The data for this research were generated through a series of nine “hui” with seven participants and one co-facilitator. The term hui is a Māori word, generally referring to a meeting, seminar, conference or large gathering which is “held within Māori cultural protocols or ways of engagement” (Berryman & Bateman, 2008, p. 2). Hui differ from English concepts such as a “meeting”, in that there is a much greater focus on developing, maintaining and/or restoring relationships (Berryman & Bateman, 2008). Hui are generally designed with a focus on conversation and co-creation, with a commitment for all voices to be heard. Whilst we did not follow specific Māori protocols during the hui, many Māori cultural aspects were embedded within the group culture. For instance, emphasis was placed on relationships and co-creation, we had rituals for opening and closing each hui, and we shared kai (food) at every hui. The term hui thus seemed the most fitting for the approach taken in this research.

A pilot hui was conducted in September 2015 with four participants and the co-facilitator, in order to test the suitability of the methodological approach and materials to be used. The approach and materials proved to be highly suitable, and only minor amendments were needed to the hui content; however, two hours proved an insufficient amount of time for the pilot hui, and subsequent hui were increased to three hours.

The full hui were conducted between the end of October 2015 and the middle of April 2016, and were generally held two weeks apart. However, there was a six week break over the Christmas period as many participants went away on holiday.

In the next section of the chapter I provide detailed information regarding the participants.

## **Participants**

The pre-established relationships I hold with the local learning disability community and support services made it possible for me to find participants easily. For the pilot hui, I approached a local advisory group with whom I had previously worked, and attended one of the regular monthly meetings. This meeting included ten group members and one staff person. Six members

indicated interest in the project and were provided with an information sheet at the meeting (see Appendix 1). I subsequently contacted and met with the interested members to discuss the details of the pilot hui. Participants were provided with a more detailed information sheet at this stage (see Appendix 2). Four of the six agreed to be pilot participants. These participants signed a consent form prior to attending the hui (see Appendix 3).

At the end of the pilot hui, several participants asked when the next hui would be. Although I had informed participants that this would be a one-off hui, all indicated that they would like to be involved for the full hui. Ethics approval was sought and was granted from the university ethics committee for this to happen. I had planned to have 7-8 participants, and this meant I had already found half of my proposed cohort. After this I used a purposive sampling technique. This is defined by Tongco (2007) as “the deliberate choice of an informant due to the qualities the informant possesses” (p. 147). This technique is described as a practical and efficient tool which helps to ensure that participants have the knowledge or experience required to participate in the project (Tongco, 2007). I contacted three people I knew who had interest in joining the research. These are people I knew through local advocacy organisations, or people I had previously supported. All three indicated they wanted to join the project, and were provided with an information sheet (see Appendix 4). Subsequently, all three agreed to join the research and signed a consent form (See Appendix 5) The last potential participant lived in another city, and her mother had heard about my research when it was discussed in a disability newsletter. She contacted me indicating her daughter was interested, and that they would be willing to fly her to Hamilton for the research. I visited them to discuss the research; however, it turned out that the first hui clashed with an important event for the daughter. I felt strongly that it was important all participants attended the first hui, as this was the hui which outlined informed consent. I was not comfortable having someone at the remaining hui when I could not be assured that adequate informed consent had been obtained. In total, this meant I had seven participants – three women and four men.



Over the following pages I present detailed information regarding all hui attendees in alphabetical order, including myself and the co-facilitator. This information pertains to our circumstances at the time of the hui, and is provided to help paint a picture of the participants. Information includes employment status and level of contact with disability support services. In the drive not to position participants as “other” to myself, I have chosen to include myself in this table. All participant names are pseudonyms.

<b>Hui Attendees</b>			
<b>Name</b>	<b>Age</b>	<b>Living and Support Situation</b>	<b>Attendance at Hui</b>
Carl	Mid 20s	Lived in a residential group home, attended day services and had a part-time voluntary job	Missed hui 9 due to illness
Gary	Early 50s	Lived in a residential group home and attended day services	Attended all hui
Glen (co-facilitator)	Mid 20s	Lived in a flat with friends, where staff visited on a daily basis. Attended day services and had a paid part-time job	Attended all hui
Ingrid (principal researcher)	Early 30s	Lived in a flat with friends and partner. Studied full-time at university and had two part-time paid jobs.	Attended all hui
Jonathan	Mid 20s	Lived in a flat with friends, where staff visited on a daily basis. Attended day services and had a paid part-time job	Attended all hui
Karissa	Early 30s	Lived at home with family. Attended a day service and had a part-time voluntary job	Attended all hui

Luke	Early 30s	Lived in a residential group home, attended day services and obtained a part-time paid job during the hui	Missed hui 6, 7 and 8 due to choosing to work for two hui, and having an important medical appointment which was difficult to reschedule.
Natalie	Early 20s	Lived in a flat with a friend, where staff visited several days per week. Had casual voluntary work.	Missed hui 9 due to illness
Taylor	Early 20s	Lived with her family. Had a paid job with almost full-time hours. She took time off work to attend the hui.	Attended all hui

All participants received support from learning disability support services, indicating that all have had a formal diagnosis of learning disability. All were able to communicate using a reasonably high degree of language, and live in Hamilton or within a 30 minute drive of Hamilton.

G. Butler, Cresswell, Giatras, and Tuffrey-Wijne (2012) note that paying research participants for their time and effort is good practice. I received a \$4,500 grant from Trust Waikato ([www.trustwaikato.co.nz](http://www.trustwaikato.co.nz)), which paid for all research expenses and made providing a koha (in Māori, a donation, gift or offering) to participants practicable. All participants were given a koha for each hui attended, which was a \$20 voucher for a local store which participants chose at hui one. Providing koha symbolised to participants that their experience as disabled people and role in the project was greatly valued. Participants who took public transport to get to and from the hui were also reimbursed for the cost of the fares. One participant was driven in by family and was provided with a petrol reimbursement.

I spent some time considering whether to call the participants “participants”, or “co-researchers”, both during the hui and in the written thesis. The term “co-researchers” is used frequently within participatory action research and inclusive research (Kiernan, 1999; Strnadová & Walmsley, 2018; Tuffrey-Wijne & G. Butler, 2009). Walmsley et al. (2017) note that learning disabled people and academic researchers each have a distinctive role in research, and using the term “co-researchers” suggests an equal and collaborative contribution from both parties. However, after careful consideration I concluded that “participants” was a more fitting term for this research. Participants were not involved in deciding the topic of the research, the methodological approach, or the method of analysis, and using the term “co-researchers” felt somewhat contrived. I did not want to utilise the term simply to enhance the image of participants, or to suggest they have a “socially valued role” in line with SRV, something which Walmsley (2004) suggests is what happens in much learning disability research.

## **The Role of the Co-Facilitator**

Researchers such as Tuffrey-Wijne and G. Butler (2009), and G. Butler, Cresswell, Giatras, and Tuffrey-Wijne (2012) highlight the value of having a learning disabled co-facilitator. Benefits include helping to mitigate the power imbalance between researchers and participants, and enabling more robust processes of collaboration and co-creation. Involving a co-facilitator in my research thus helped to embed the co-creation approach I sought. It ensured someone from the research community was involved in making decisions around the format and content of the hui, as well as running the hui.

I was fortunate to know a man, Glen Terry, who had proven himself to be a skilled facilitator, and is also comfortable in identifying as having a learning disability. I had been supporting Glen to participate in paid and voluntary work for a few years prior to the hui, and we had established a good working relationship. Glen was provided with an information sheet (see Appendix 6), and agreed to be part of the research (see Appendix 7).

Glen initially chose to use a pseudonym for the thesis, in order to maintain confidentiality. However, I felt uncomfortable that Glen was not able to receive any of the credit for the work he did; work which made a significant impact on the thesis. Close to the submission date we had a conversation about this, and Glen informed me that he could not remember why he had chosen to use a pseudonym, and that he was interested in discussing the matter further. We read through everything that was written about him in the thesis, and Glen informed me that he was happy for his name to be used. However, I wanted to ensure that Glen was providing informed consent, and was not acquiescing in order to please me. I wrote a document which outlined everything that was written about Glen, and included some information about the implications of giving consent or not giving consent. Glen and his key advocate read through the document together without me present, and his advocate informed me that Glen was indeed providing informed consent for his name to be used.

Throughout the data generation phase, Glen supported me in planning and conducting the hui, whilst I continued to support him with his work. Our relationship thus became more reciprocal than it had been previously; although, I also supported Glen in supporting me during the research. For instance, I ensured that the meeting dates were in his diary, that his component of the written material we used for facilitation was in a large, coloured font with sequential numbers, and I supported him in reading through the materials I had prepared, which he then supported me to modify. Glen was firm about stating his ideas and what he wanted to do during our discussions, ensuring we worked together to find solutions when we disagreed, rather than acquiescing to each other. The agenda for each meeting and discussions were largely led by me, based on what I felt needed to be done to prepare for the upcoming hui. The inequitable leadership during these discussions highlights the challenge I encountered in fully enacting a co-creation approach in the project. Glen received an hourly rate for his role, funded through the Trust Waikato grant. As Tuffrey-Wijne and G. Butler (2009) note, very few learning disabled are paid for their work as researchers. Being paid signalled to Glen that his role was viewed as both skilled and highly valuable.

Having Glen involved as a co-facilitator turned out to be pivotal to the success of the project. Glen was able to point out when my plans for conducting the hui would not work, and when the words I used were confusing or misleading. For instance, he pointed out that the term “fighting oppression” seemed violent, and that “data” could be understood as what you use for internet on your phone. Glen also helped to think up different terms that could be used instead, such as “research data”. Together, we came up with many resources and activities that were highly effective. I also found that talking ideas over with Glen helped to clarify them in my mind; at times this proved more helpful than discussing ideas with my supervisors.

Glen proved himself to be an excellent facilitator for the project. He reminded us to only have one person at a time speaking, worked to ensure each participant had a fair chance to contribute, explained questions to participants when they were unsure, and helped keep me to time. Glen also acted as a participant, often contributing equally to conversations unless we had agreed otherwise prior to the hui. This was done intentionally, as learning disabled facilitators have been found to be most effective when they are not seen as impartial. As G. Butler et al. (2012) state, having a learning disabled co-facilitator contribute as an equal helps them to connect with participants on a more equitable level, and helps participants to feel confident to contribute. Because Glen often contributed as a participant, he is generally included in my description of participant’s thoughts and actions throughout this thesis. In situations where this is not the case it will be specified.

In the following section, I outline the details for the hui.

## **Supporting Participants**

Walmsley (2004) notes that supporting participants in any form of inclusive research is a vital and skilled activity. However, she notes further that remarkably few details are published regarding what non-disabled researchers and advocates do to support disabled participants. This has led to a mystification of the processes, whereby the idea is upheld that some researchers are able to “get it right”, but the magic of how they do this is obscured (Walmsley, 2004).

This makes it difficult to train other researchers seeking to work in this field, and inhibits the ability of researchers to learn from each other (Walmsley, 2004). It is partly for this reason that I have included such a high level of detail regarding the specifics of activities, resources and support provided throughout this chapter.

I began the hui by explaining to participants that I was there as a “researcher”, rather than a “support person”, and I used different hats with logos on them to help explain this concept. However, I found this positioning was not entirely accurate, as my position as a support worker was often entangled with my position as a researcher. For instance, participants would periodically come to the hui upset about something that had happened at home. This meant I needed to support participants to talk through what was upsetting them, offer helpful comments, and make sure they were able to get into the right emotional space to participate in the hui. One participant has diabetes and Prader Willie syndrome, and needed to take medication during the hui. This meant I needed to watch how much food he ate, ensure all food was packed away after morning tea, and sign-off that his medication had been taken.

Knowing the participants, and their communication styles in particular, was an important part of being able to work well with them during the hui. It took some time to learn the particularities of some participants’ communication styles; one had a speech impediment, and another frequently used the word “not” when she meant the opposite. The pre-established relationships I held with participants, and which the participants had between themselves, proved immensely helpful in this domain.

## **The Role of Advocates**

Working with someone who knows participants well is identified as important by many researchers, including Inglis and Cook (2011), Kittelsaa (2014) and Walmsley (2004). As Walmsley (2004) states, “there is unlikely to be a substitute for working alongside people who know the individual well and can draw on the experience of what works with him or her” (p. 60). This advice was well-founded, as advocates turned out to be one of the most helpful forms of support throughout the hui.

Glen was asked to identify one key advocate, and the participants were asked to identify a first and second advocate whom I could maintain contact with throughout the hui, should it be necessary. Advocates provided support in numerous ways. One example is providing pragmatic support such as ensuring participants had transport to and from the hui, and had the dates of the hui in their diaries. Advocates were tasked with supporting participant safety throughout the duration of the hui, and were asked to contact me if they had any concerns. They also supported participants to provide information on personal safety, such as whether there were any food allergies, how I would know if a participant was upset, and how I could best respond to this (see Appendix 8). I kept in periodic contact with advocates throughout the hui, particularly after hui six where there had been some tough conversations which highlighted the challenging emotions associated with disability.

Participants and the co-facilitator signed a consent form prior to attending the hui (see Appendices 8 and 9). Although it was the participants who consented to the research, advocates were also involved in the consent process in order to ensure informed consent was obtained. Advocates helped to explain information in a way participants understood, and helped to ensure participants were not consenting on the basis of misunderstanding, or simply acquiescing to someone they viewed as being in a position of power. Auckland Disability Law (2016) defines this process as *Supported Decision Making*, something which they assert is consistent with Article 12 of the United Nations Convention on the Rights of Persons with Disabilities (2006).

## **Details of the Hui**

I went into the data generation phase with a general outline of what I wanted to do, and the activities and resources we would need to do it. However, the full detail of the content, activities and resources were developed in collaboration with Glen. Glen's input throughout the planning phase was invaluable. For instance, he helped me to see that my initial plan, which involved connecting disability pride with gay pride, would not be successful. Glen and I developed a working agreement (see Appendix 9), wherein we agreed to be

open and honest with each other, and respect each other's ideas, which included being able to disagree with each other.

The hui were conducted at a small building in central Hamilton, in a space designated for youth. This space was chosen because I was able to utilise it at no cost thanks to a friend, and because its central location made it easy for participants to get to with public transport. The room was filled with a collection of miss-matched couches, and there were many posters on the wall for the youth, which were often referred to by participants during the hui.

All hui were filmed using a camera and stand provided by the university. In hui two I used the wrong camera settings and subsequently missed thirty minutes of content. The remainder of the hui was filmed on my personal tablet. After this incident I started using a dictaphone as well as the camera. The dictaphone was positioned much closer to participants, and turned out to be useful for transcription as the sound quality was better.

The camera was set up in an obvious location and participants were always aware it was there. This placement helped to ensure that there was no element of deception, and that participants were therefore continually consenting to be on film. The camera placement was one of the means by which participants were engaged in co-creation, as participants regularly helped to ensure that no one was standing in front of the camera and blocking the view of the room.

The hui can best be described as a combination of an action-research meeting, a focus group, and a conversation. Focus groups are defined by Kitzinger (1995) as "a form of group interview that capitalises on communication between research participants in order to generate data" (p. 299). As well as enabling researchers to gain greater insight into the topic under consideration, focus groups have the added benefit of working well for people who cannot read or write (Kitzinger, 1995). Kitzinger and Barbour (1999) note that focus groups can be conducted in different ways, which do not necessarily need to follow a formulaic approach. In this sense, all nine hui could be considered a form of focus group. However, as I shall outline in the table over the following pages, different stages of the hui were run with varying degrees of direction from the



facilitators. I have chosen to utilise the term “focus group” to describe the hui in which Glen and I had a set of questions we wished to discuss with participants. These hui stand in contrast to the other hui, which had a much greater emphasis on co-creation.

<b>Hui Details</b>	
<b>Hui 1: Informed consent and culture setting.</b>	<b>Approach utilised</b>
The focus for this hui was for the group to get to know each other, decide how we wanted to work together, and ensure participants gave informed consent. We discussed what research is, the particularities of this project, and how participants can consent or decline to join in the research at any point.	This hui was largely directed by myself and Glen to ensure informed consent processes were established. Participants were invited to co-create the working culture of the group.
<b>Hui 2 and 3: Focus group – perceptions of disability</b>	<b>Approach utilised</b>
In these hui, participants were asked for their thoughts on what disability is and whether they identify as disabled. This was intended to last for one hui, however participants were eager to discuss the questions and we ended up needing two hui.	These hui were called a “focus group” because they followed a more directed approach than in later hui.
<b>Hui 4 – 7: Participatory action research.</b>	<b>Approach utilised</b>

<p>In these hui participants explored the concepts of ableism and disability pride. Participants were introduced to the notions of ableism and disability pride in hui four, and ideas were further developed in hui five. Some participants showed a high level of discomfort regarding disability pride in hui five after watching a video, and indicated they did not wish to continue discussions. Following the iterative approach, in hui six I gave a “speech” which outlined the dilemma I faced. On the one hand, it was important I listened to participants when they said they did not want to do something. However, the discomfort participants felt indicated an underlying issue I was wanting to address with the research, a topic I felt needed further discussion in order to enact change for disabled people<sup>19</sup>. This speech enabled the hui to progress, and participants indicated they would like to continue with whatever Glen and I had planned, rather than choosing an activity or topic for themselves. Glen and I conducted a role play about showing pride in the face of bullying, a topic which had emerged as a key issue for participants during our discussions on ableism. This role play then led to further discussion and drawing on the whiteboard. In hui seven, participants indicated they were interested in participating in role plays themselves. Various role plays emerged, particularly related to the subject of bullying. These</p>	<p>These hui placed a much greater emphasis on a co-creation approach. Whilst Glen and I had some activities prepared, participants were invited to take more control over the direction of the activities, and were invited to choose activities of their own volition.</p>
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<sup>19</sup> This situation will be discussed further in Chapter Seven.

<p>role plays led to further discussions and drawing on the whiteboard.</p>	
<p><b>Hui 8-9: Focus group, feedback and closing.</b></p>	<p><b>Approach utilised</b></p>
<p>In these hui, participants were again asked about their ideas related to disability and their own identity. This was done in order to establish whether their thoughts had changed over the course of the research. Preliminary findings were discussed in order to elicit participant’s perspectives, as was done by Inglis and Cook (2012). This process helped to explore whether the findings made sense to participants, and provided a small means by which participants could contribute to the analysis. Participants were also invited to discuss which aspects of the hui they enjoyed most, what made the hui work well, why participants chose to join the research and why they chose to continue coming.</p>	<p>These hui were similar to hui 2 and 3, in that they followed a more directed approach than in hui 4-7.</p>

## Hui Activities

Glen and I prepared a range of different activities, each designed to help establish a particular way of working, or present an idea related to ableism or pride. Over the following pages, I detail each of the activities.

### **Ongoing informed consent.**

In order to ensure participants gave informed consent, I dedicated a significant portion of hui one to this subject. We had a conversation with participants about what research is and why people do research, and watched a video on YouTube to help explain this further (hsu, 2013). We discussed the implications of joining the research, such as needing to give up Friday mornings to come, as well as learning and hopefully having fun. We also discussed the implications of not giving consent, which included life continuing as normal and not being able to join in, and the types of questions participants would need to ask when deciding whether to give consent or not.

In order to further the participants' understanding of research we conducted a practice piece of research on the topic "what is the best way to make a hot drink". Participants were asked to suggest different ways information could be gathered, in order to discuss the different possible ways research can be conducted (Inglis & Cook, 2011). We asked what sorts of questions would need to be asked for the research, and I wrote the questions down on the whiteboard. We then conducted the research as per the participants' questions, and discussed what we meant by "research data" once we had the results.

As noted earlier, one integral component of informed consent is ensuring that participants understand the different ways they can refuse consent (Inglis & Cook, 2011). During the course of the first hui we had several conversations about what participants could say or do if they did not want to join in an activity, answer a question, or join in the research. Participants practised different ways that consent could be declined, such as saying "I don't want to answer that question", and role-played leaving the room. Glen and I reiterated several times that participants were under no obligation to join in the research. These activities appeared to be effective, as during the course of the hui a few

participants declined to answer questions and join in activities at different points, and one participant left the room when he was uncomfortable with a conversation. Participants re-joined the activities when they felt ready.

All participants and their advocates were given my cell phone number and email address, so I could be contacted at any point during the hui. I also set up a second facebook account so that participants would be able to contact me there if that was their preferred means of communication. After the first hui I phoned each participant to check if they were still interested in being part of the research, and all said they were. Through following these processes, each participant was provided with information in a variety of ways over many occasions, and were given numerous opportunities to say if they wanted to join the research, as is advised by the National Institutes of Health (2009).

### **Constructive dissent activities.**

In order to establish the desired culture of “constructive dissent”, whereby participants understood that it was ok to “think differently” from each other and myself, Glen and I developed the Yes/No Game. In this activity we would stand in a circle and throw a ball to each other, asking a question that required a yes or no answer. It was hard for some participants to ask questions that required a yes/no answer, and some participants tried to ask questions that the other person would say yes to, at times changing the question once the person had answered so they would get a yes answer. However, this game proved to be effective, as participants appeared comfortable disagreeing with each other and sharing different ideas. Because the group showed a high level of enthusiasm for this game, it was utilised at every hui. The group also developed a mantra in hui one which was written on the whiteboard at every hui: “Everyone’s got different opinions and that’s OK”.

Initially, Glen and I also came up with various “thinking different” activities for the hui. Activities included picking a favourite item from the “bag of things”, and picking a lego person and giving them a name. However, after a few hui it became challenging to think of different activities, and I realised that the yes/no game served the purpose adequately so we dropped the “thinking different” activity.

### **Reflective practice.**

Iterative, reflexive practices form an integral component of the methodological approach (Baum et al., 2006; Israel et al., 2012). After hui one we started every hui by saying what our favourite part of the previous hui was whilst doing a stretch with a ball. At the end of every hui we would do another stretch and say what we thought was important about the hui, what our favourite part of the hui was, and what we thought we could do better. Glen and I worked further reflexive practice into the process, as we had a debrief directly after each hui. We would discuss how we thought the hui went, and what we had learnt or observed.

### **Confidentiality.**

Confidentiality was important for two key reasons; it helped trusting relationships to develop, and helped to ensure participants' personal information would not be shared outside of the hui. At the end of every hui we held a brief conversation about confidentiality. One of the signs on the wall at the venue said "what happens in this room stays in this room", and participants would always point to it during this conversation. Both the participants and I considered this discussion important, and it was thus used consistently throughout the hui.

In the final hui, participants were given two options for confidentiality (see Appendix 10); full, which meant that I would do everything possible to ensure that people were not identifiable; and limited, which meant I would make some information unidentifiable, but that participants would be able to help share the information we had learnt. Four participants chose limited confidentiality, however in the end no opportunities arose for us to co-present.

### **Hui Resources**

Glen and I developed a range of resources to utilise in the hui. These resources each held their own agency, intra-acting on and through the hui by helping to facilitate interaction, discussion, and the possibilities for action. The resources served two purposes; first, I felt it was important that we utilised our bodies during the hui, as this would help to keep us engaged. Second, the

resources helped enable sensory, emotional and experiential abilities to come to the fore, which helped to lessen the need for cognitive skills. Over the following pages, I detail each of the resources we used.

### **The “squishy” ball.**

I purchased a “squishy” ball from the \$2 shop. This ball was introduced into hui one as part of the “thinking different” activity, and participants quickly named it the “squishy”. Because participants showed a high level of enthusiasm for the “squishy”, it continued to be used at the beginning and end of every hui for the reflective activities, as well as for some other activities during the hui.

### **The whiteboard.**

I brought a 1.5m x 1.5m whiteboard to the hui. This was used to write down participants’ ideas, for participants to draw as part of the discussion, and for me to draw to help illustrate what we were talking about. Participants enjoyed drawing and writing on the whiteboard for various activities, and it was used throughout the duration of the hui.

### **The “how we will work together” poster.**

In hui one we talked about how we wanted to work together as a group. This served as a power-sharing activity at the outset, and helped to ensure a culturally responsive methodology as we worked together to establish the culture of the hui (Berryman et al., 2013b). Participants were asked to share stories about times when they were in a group and enjoyed it, and from this discussion, we came up with a list of ways we wanted to work together. I developed this into an easy-read poster (see Appendix 11). This poster was introduced in hui two and placed onto the whiteboard at every hui thereafter, although it was never discussed again.

### **The pride wall.**

I put together a “pride wall” on one side of the whiteboard. This wall was made up of A4 pieces of paper, each of which had a photo of one person in the middle. From hui four onwards, we would go around the room and either say

something we are proud of about ourselves, or something we were proud of about someone else in the room. We would then write what was said on the person's pride wall poster. Many participants described this as a favourite activity and something they considered important, and it was thus a resource we dedicated time to at every hui after it was introduced.

### **The bag of things.**

Following the example of Munford et al. (2008), I took a "bag of things" into the research. This bag included a variety of paraphernalia from around my house including a bandana, pipe cleaners, bandages, an eye patch and a walking stick. This bag was used during the hui for various activities, and helped in my preparations with Glen. For instance, the bag of things was used to help play around with various ideas when Glen and I developed the role play on bullying.

### **The "feelings cards" and "traffic light".**

I wanted to develop some resources which would ensure emotions were acknowledged during the hui. This was done to enable non-cognitive abilities to come to the fore, and to support participant safety by providing participants with a tool to let us know if they were not OK.

The first tool we developed was the "traffic light" (see Appendix 12), an A3 piece of paper with a colour picture of a traffic light. This was designed so that participants could let us know if they were "orange", which meant not really OK, or "red" which meant we needed to stop what we were doing. The traffic light remained in use throughout the entire hui, although it was not used frequently by participants.

The second resource we developed was the "feelings cards" (see Appendix 13). In order to develop these I came up with a list of 15 basic emotions. These were discussed with Glen and he narrowed them down to nine: happy, upset, sad, angry, scared, nervous, stressed, tired, and relaxed. I took photos of Glen displaying each of the emotions; he chose to use a toy dog to aid him in several of the photos. At the request of a participant a "sore" card was also added. The cards were greatly appreciated by participants and proved an immensely useful tool for enabling open discussions about emotions, and were



thus used at the beginning and end of every hui to help participants and me share how we were feeling. They were also used for some discussions during the hui.

### **Ableism resources.**

To introduce the concept of ableism I used a large piece of paper with the word “disabled” on it, a smaller piece of paper with the word “normal” on it, and a pipe cleaner which had been fashioned into a circle. I demonstrated how the small piece of paper fits easily into the circle because society has been built assuming everyone should be “normal”. I demonstrated the large piece of paper not fitting, and talked about how we tend to think there is something wrong with the paper, rather than the shape of the pipe cleaner. Because participants did not engage well with this resource, it was not used again.

The second tool I developed was a set of “ableism cards”. These were a series of cards (see Appendix 14) which had cartoon images of people with a name next to them. I sought to have a diversity of genders, disabilities, ages and skin colours in the cards, so that participants had a wide variety of pictures to draw upon. The cards were used for participants to tell stories about when their life has been hard because of their disability. Because participants enjoyed the cards, they were used in several activities.

### **The script.**

At each hui I developed a “script” with an outline of the plan and what Glen and I were going to say. This meant that I wrote down what Glen would say when introducing activities or asking questions, then read it through with him and made changes based on his feedback. Glen would point out mistakes I had made and suggest ways he would like something worded. He liked his words to be numbered, in a large font and in a different colour to the rest of the script. I am conscious that by writing Glen’s component of the script I was not following proper co-creation processes. However, I was concerned that it would have taken considerably more time to develop the script with Glen, and there was only a short time-frame between each hui. Glen and I both greatly appreciated using the script, and thus used it for all hui.

## YouTube videos.

I found an array of videos on YouTube to help explore the notions of ableism and disability pride. A number of videos were shown to Glen, who chose the ones he thought best suited the hui. Due to participants' negative responses to the videos, only a small portion ended up being used.

## Lessons Learnt

Many factors contributed to the success of the hui. These include the enthusiasm of both Glen and the participants, the strength of relationships, and the trust that developed from these strong relationships. This trust enabled us to have more open, honest, and challenging conversations with each other. Participants were supportive and patient with each other, and with me and Glen. Glen and I also had a positive working relationship, and were able to set the tone for how the group worked. For instance we intentionally worked on being open and honest, and respectfully disagreeing with each other.

Asking participants to help proved to be one of the most effective tools for engaging them, particularly during challenging conversations. I found that some of the richest sources of data came from times when I opened myself up to being vulnerable, and invited participants to help me. Berryman et al. (2013a) note that reciprocity is at the core of co-creation; it seems to me that asking participants to help can be a tool to enable reciprocity.

There were also many limiting factors in the research. I worked hard to develop a co-creation approach, and share power with participants as equally as possible. However, many factors impeded the implementation of this. The first key issue is that the project is my PhD research – I decided upon the topic, and how I wanted the research to be conducted. Having a particular topic that I wanted to discuss with participants meant that it could never be fully co-constructed. Power-sharing and co-creation processes with learning disabled people prove difficult to achieve in practice (Nind, 2008; Walmsley, 2001). The history of my positioning as a support worker, service coordinator and someone

without a disability, i.e., as someone in a position of authority, held agency within the hui in a way which could not be escaped.

There were also some tensions in applying the methodological approach, particularly around consent. I reiterated many times to participants that if they said no to something, they did not need to do it. There was frequently a tension between needing to stop activities when participants said they did not want to do them in order to ensure consent was maintained, and not wanting to be the person who had the power to dictate what happened.

One key lesson is that abstractions do not work for learning disabled people. Participants engaged best when discussions and activities related directly to their lives and personal experiences. Some of the resources I utilised, such as the YouTube videos, did not work well because they did not connect with participants' personal experiences. This correlates with the advice provided by Cook and Inglis (2011), who state that ideas need to be linked to real-life examples of participants in order to ground them in reality.

One of the greatest challenges I found using this methodological approach was the limitation it placed on the ability to prepare for the hui. Focusing on co-creation meant that it was not possible to know what would arise during the course of the research, and thus what to prepare for. This meant that I needed to prepare a large list of potential activities in advance, something which was highly time-consuming. It also meant that I needed to be prepared for the participants to want to do something I had not planned for, and meant that much of the preparation needed to be done in the two weeks between the hui.

Another challenging aspect related to the variable amount of time it took participants to do activities. Some participants took a long time to answer questions, often needing to tell a personal story, whilst other participants would answer with only a few words. This made planning content challenging, as it was impossible to know prior to the hui how much could be achieved in one hui. Transport proved to be an ongoing challenge. In my experience this is one of the unavoidable challenges inherent in organising any event with learning disabled people. It is further not unusual for learning disability research, as G. Butler et al. (2012) noted a similar challenge in their research. A considerable portion of my

time was needed to ensure participants had transport to and from the hui, which included providing transport myself and arranging friends to support with transport in some situations.

## Concluding Remarks

The methodology for this thesis is formed from an entanglement of methodological perspectives. They are inclusive research, participatory action research, community based participatory methodologies, culturally responsive methodologies and decolonising methodologies. Several core elements were taken from the various methodologies: co-creation, with a particular focus on relationships and power equity; the drive to instigate change through research; and the embeddedness of the researcher. The role of ethics underpinned all the methodologies, in relation to the drive not to perpetuate the harms visited on learning disabled people through research conducted historically, and to ensure participants gave ongoing informed consent. The methodological design was further underpinned by the desire to do research that works for learning disabled people and does not rely solely on cognitive abilities, and the desire to conduct research with a group. Limitations of the approach included the significant investment of time and personal commitment that was required, and the reliance on participants' ability to talk.

The data for this research were generated in partnership with seven learning disabled participants and one learning disabled co-facilitator, through a series of nine hui. Activities and resources for the hui were developed in partnership with the co-facilitator. These activities and resources helped to establish the culture of the hui, ensure participants gave ongoing informed consent, and helped to ensure that sensory, emotional and experiential abilities could come to the fore.

The enthusiasm of participants, the strong relationships we developed, and getting participants to help me as a methodological tool supported the success of the project. Limitations included enacting co-creation in practice, and discovering that some of the tools I had hoped to use did not work for

participants. This was largely because they did not relate directly to participants' personal experiences.

# Chapter 6:

## Diffraction Analysis

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Diffraction analysis is a tool that draws upon the ethico-onto-epistemological framework of agential realism, incorporating ideas inherent in agential realism into an explicit methodological framework. Unlike many traditional analysis frameworks, diffraction analysis does not view words, matter and bodies as separate entities. Instead, it views these phenomenon as forces which both affect and are affected by the ongoing intra-activity of life (Barad, 2007).

Barad has drawn on the work of Donna Haraway (1997) in the development of diffraction analysis. Haraway (1997) used diffraction to rethink optical notions of relationality inherent in many methodological techniques, such as those using critical reflection. Where reflection is seen to mirror reality from afar, diffraction acknowledges that it is not possible to stand at a distance from any phenomena, particularly in research. As Barad (2007) states, we are always complicit in the world's differential becomings.

Barad (2014) defines diffraction as:

Diffraction/intra-action - cutting together-apart (one move) in the (re)configuring of spacetime-mattering;  
differencing/differing/différance. (p. 168)

Diffraction is often described using an image of waves. In this metaphor, waves are understood to roll, push and transform each other, changing in intra-action with obstacles and with the accumulation of each wave (Lenz Taguchi, 2012; Lenz Taguchi & Palmer, 2013). Diffraction takes into account the agential realist notion that thinking, knowing and seeing are “never done in isolation but are always affected by different forces coming together” (Lenz Taguchi & Palmer, 2013, p. 676).

In diffractive analysis, as with the notion of intra-action, there are no definitive boundaries separating phenomena into separate, bounded entities. This means that all intra-active phenomena are seen as agentic and necessarily affect and interfere with each other through the processes of the analysis (Davies, 2014b). This includes the research questions, theory, data, emotions, and memories (Lenz Taguchi, 2012). The researcher's awareness is opened up to a much wider sphere of possibilities than whether, for instance, "A" causes "B". It is possible to view multidirectional, emergent, intra-active interferences which can all affect and interfere with each other in a non-linear and non-causal manner.

Diffractive analysis is considered to be a material practice – that is, a production of reality which has specific material consequences (Barad, 2007). Researchers do not stand at a distance from their work in order to "leave the material world behind and enter the domain of pure ideas where the lofty space of the mind makes objective reflection possible" (Barad, 2007, p. 55). Instead, researchers need to understand that theorizing, knowing, thinking and measuring "are material practices of intra-acting within and as part of the world" (Barad, 2007, p. 90).

This means that researchers, with their bodyminds, play a crucial role in affecting and interfering in any analysis (Barad, 2007; Lenz Taguchi, 2012). The methodological implications for this are profound, as researchers are required to continually try to be conscious of how the research data, theories and the researcher's own memories and emotions "*interfere[s]* with the sensibilities of our bodyminds and what this brings to the event of reading the data" (Lenz Taguchi, 2012, p. 272, emphasis in original). In this sense, the bodymind of the researcher becomes "a space of transit", as Lenz Taguchi (2012) states; "a series of open-ended systems in interaction with the material-discursive 'environment'" (p. 265). This approach does not simply place the researcher (or observer) back into the world, but rather acknowledges the ways in which researchers have always already been involved in the research (Mazzei, 2013). Furthermore, researchers do not simply affect and interfere with any research

project, but also emerge as particular types of “subjects” through the research process:

There is no ‘I’ that exists outside of the diffraction pattern, observing it, telling its story. In an important sense, this story in its ongoing (re)patterning is (re)(con)figuring me. ‘I’ am neither outside nor inside; ‘I’ am of the diffraction pattern. (Barad, 2014, p. 181, emphasis in original).

As researchers we “become something else in the process [of researching]” (Mazzei, 2013, p. 777). Researchers both constitute and are constituted by the process of materially engaging with the research, and are both “made and unmade in such a practice” (Mazzei, 2013, p. 777).

## Methodological Implications

There are several methodological implications when conducting a diffractive analysis which differ from more traditional analysis tools. Firstly, data should not be reduced to a series of already-established concepts, such as in the processes of coding (Mazzei, 2014, p. 2). Instead, the analysis should take a “rhizomatic (rather than hierarchical and linear shape) form that leads in different directions and keeps analysis and knowledge production on the move” (Mazzei, 2014, p. 2). As Davies (2014b) notes:

The analysis is emergent and unpredictable, a series of encounters with the new. It is hard, demanding work, requiring the capacity to let go of the already-known, and of tired clichés and explanations, of tired categories and coding. It involves hard epistemological, ontological and ethical work to enable the not-yet-known to emerge in the spaces of the research encounter. (p. 735)

The use of the term rhizome in these forms of analysis links back to Deleuze and Guattari’s *A Thousand Plateaus* (1987), and can be defined as “a complex subterranean tangle of interconnected root-like sprouts which spreads in a horizontal fashion and has no centre” (Feely, 2016, pp. 874–875). Rhizomatic



modes of thought establish links and connections between surprising and different places (Gannon & Davies, 2007); these links are non-linear, follow multi-directional connections, and never lead to final closure of any particular link or thought (Feely, 2016). As Deleuze and Guattari (1987) note, “[a]ny point of a rhizome can be connected to anything other, and must be” (p. 7). The methodological implications of this are that the analysis can head in unexpected directions, linking together unexpected phenomena and keeping knowledge production always on the move (Mazzei, 2014).

One of the strengths of an agential realist framework is that it highlights the complexity and entanglements within any situation. It is not so much about isolating particular phenomena to study them, but rather to highlight intra-actions in their fullness, addressing multiple agentic forces at play: the points at which the rhizomes connect in unexpected ways. However, it is important to take care to resist the lines of flight (or rhizomatic off-shoots) which can tempt researchers to head towards too many concepts, theorists and data (Jackson & Mazzei, 2011). Holding the research aim and questions in mind can prove helpful in discerning which lines of flight to pursue, and which lines will lead to confusion and clutter in the analysis.

For me, navigating the rhizomatic lines of flight proved to be one of the most challenging parts of the analysis. When everything is connected with everything else, how does one go about writing the linear, coherent narrative that is required for the thesis? Where do you start when you need all of the concepts in order to understand all of the other concepts, and when your whole point is that everything is intertwined and cannot ever really be seen as separate phenomena? How do you write in a way which is coherent and clear, and yet doesn’t lose hold of the complexities inherent in the entanglements?

What helped me through this process was to take to my whiteboard with some markers and write the ideas down, then rework what was on the whiteboard again and again, until I found a way to tell the story of the analysis. When this failed, talking things out with my supervisory team proved immensely helpful, before I returned to my whiteboard. And when the rhizomes were taking

me off into too many different directions, I found I needed to step back from the individual chapter I was working on and look at the project as a whole. I tried to think about the story I was trying to tell with the thesis, and which parts needed to be told in each individual chapter.

Another methodological implication pertinent to this thesis is the focus on boundary-drawing and difference. In agential realism, boundaries and differences are viewed as an effect of intra-action, rather than essential phenomena (Barad, 2003). The researcher's focus is placed on how differences are constructed and what is excluded in the process of constituting a "difference" (Barad, 2007). The point of this, as Barad (2007) notes, is to look at "which differences matter, how they matter, and for whom" (p. 90). Binaries and dualistic thinking, such as human/non-human and abled/disabled, as well as notions of identity and difference are queered, questioned and rethought within the processes of a diffractive analysis; no single phenomenon is fixed in advance of the analysis (Barad, 2014). This means that researchers do not seek to uncover the "truth" of any data or phenomenon, but rather to uncover "a reality that already exists among the multiple realities being enacted in an event, but which has not previously been 'disclosed'" (Lenz Taguchi, 2012, pp. 274–275, emphasis in original). A key point of focus for this project is on the material-discursive, boundary-drawing practices of disability, including what constitutes "disability", what is excluded in the processes of this constitution, and how this comes to matter.

Another important methodological implication in diffractive analysis is the way in which space, time and matter are understood. Within an agential realist framework, notions of space, time and matter are all "queered" – that is, they are not viewed as linear, separate phenomena. Instead, they are understood as phenomena which materialise through iterative intra-actions, which are non-causal and non-linear, and which are all inextricably intertwined in a process of spacetime-mattering (Barad, 2007). As Barad (2007) notes:

[T]ime and space, like matter and meaning, come into existence, are iteratively reconfigured through each intra-action, thereby

making it impossible to differentiate in any absolute sense between creation and renewal, beginning and returning, continuity and discontinuity, here and there, past and future. (p. ix)

In this understanding each intra-active entanglement, even when it is described as an “iterative entanglement” (as I do throughout this thesis), is never exactly the same twice over, as “[e]ntanglements of intra-acting phenomena are always located in time, history and place” (Renold & Iverson, 2014, p. 364). Attention to fine detail is important, as “[s]mall details can make profound differences” (Barad, 2007, p. 92). Furthermore, in connecting the concept of spacetime mattering with the concept of the rhizome, we can see that it is possible to make connections between phenomena which “do not appear to be proximate in space and time” (Barad, 2007, p. 74). In a diffractive analysis, the analysis phase of the project is not something that is considered to occur purely in the post-fieldwork stage of a project. Instead, the meaning-making processes of the analysis emerge over time, including before the research begins and during the planning and data collection phases (Ringrose & Renold, 2014).

## **Choice of Data for Analysis: Hot Spots**

Guided by MacLure (2013), I have chosen to utilise the notion of “hot spots” in identifying the data with which to work for this project. Illuminating the work of MacLure (2013) further, V. Mitchell (2016) defines hot spots as data or phenomena which “have an intensity and force on the researcher, creating hot spots that glow” (p. 240). These hot spots can disconcert, creating a sense of discomfort, or create a sense of wonder and piqued interest in the researcher. In these instances, the data “glow” with an intensity in various moments through the processes of the research (MacLure, 2013). The affective response a researcher has to the data plays an important role in identifying hot spots. In particular, dilemma, trouble and contradiction within the data prove good starting points for identifying potential phenomena for analysis. In a sense, as

MacLure (2013) notes, data have their ways of making themselves intelligible to us.

The notion of hot spots proves an interesting point of focus when viewed through the agential realist lens of spacetimemattering. When space, time and matter are viewed as non-linear and intertwined, hot-spots can be both brief, intense moments which glow white-hot, as well as “slow burning intensities that propel the creation and generation of research encounters and data” (Ringrose & Renold, 2014, p. 775). As Barad (2014) notes, diffractions are not singular events which happen in defined moments of space and time, but are rather “a dynamism that is integral to spacetimemattering” (p. 169). She explains further:

Diffractions are untimely. Time is out of joint; it is diffracted, broken apart in different directions, non-contemporaneous with itself. Each moment is an infinite multiplicity. ‘Now’ is not an infinitesimal slice but an infinitely rich condensed node in a changing field diffracted across spacetime in its ongoing iterative repatterning. (Barad, 2014, p. 169).

Choosing the data with which to work is probably not an easy feat for any research project, and this project was no exception. With around 30 hours of video, transcriptions of the videos, my notes from the data collection phase and my journal, I was faced with the luxurious problem of having so much rich data that I had to seriously consider which hot spots glowed the brightest. Or, to put this another way, I needed to spend time examining which data appeared to hold the most agency over me in the ongoing intra-active processes of the analysis.

It was often my feelings about phenomena which alerted me to potential hot spots. My body became a space of transit through which the data and theory moved, often in ways which I was not conscious of. There would be powerful chunks of data to which I had a strong emotional reaction, or a theory or article about which I would become corporeally excited. I learnt to sit in long uncomfortable periods of disconcertion, and through this process I learnt to discover what *felt wrong/right*. Furthermore, my memories and experiences in the field of disability played an integral role, as I sensed what I had heard many

times before and what was unexpected or new.

At times it felt as if the data was silently screaming at me, telling me that it would be neglectful of me to miss them out. I had a sense that particular pieces of data would sit on my shoulder and follow me around for the rest of my life if I did not involve them. At other times the hot spots were more of a slow-burning intensity, emerging after simmering over time, or after I read particular articles and theories which spoke to me. Articles which particularly spoke to me included *Bullying as Intra-active Process in Neoliberal Universities* (Zabrodska et al., 2011), and *New Materialist Analyses of Virtual Gaming, Distributed Violence, and Relational Aggression* (Søndergaard, 2016), both of which helped me to see the power in looking beyond discourse and bringing a wider array of intra-active phenomena into the space of the analysis.

Below I outline the process I went through to choose the data for the analysis:

- I put all of the transcripts and my personal reflection notes into an analysis software, Nvivo. By placing the data chunks into folders which could be cross-categorised, I became more familiar with the data and started see patterns.
- I went through the information in the folders and made an excel spreadsheet with brief information on what happened throughout the hui and key phenomena which emerged, such as the role of affect. I included thoughts I had on each of these phenomena.
- Through this process of working with data again and again, alongside reading theory, I came to see where the rhizomes connected and to sense where the hot spots were – I could feel that data had their own agency in speaking to me.
- Thorough this entire process I was guided by the research questions and the problem which drove me to the research: that despite our hardest efforts, disability oppression does not seem to be shifting very far beyond the status quo.

## Reading Data and Theory through Each Other

Although Barad details what is meant by diffraction and diffractive analysis, there is very little detail in her work which outlines exactly *how* diffractive analysis is done. Fortunately, Jackson and Mazzei (2011) drew upon diffractive analysis for their own work, and provide some useful detail on how they went about this process. In particular, they use the concept of *plugging in*, which is further illuminated by Mazzei (2014). Plugging in was drawn from Deleuze and Guattari's *A Thousand Plateaus* (1987). It is defined as a process rather than a concept; it is not about layering sets of codes or theoretical concepts onto data, but rather about plugging theory and data into each other. As Mazzei (2014) states, it is about "reading-the-data-while-thinking-the-theory" (p. 2). This understanding illuminates Barad's (2007) description of diffraction, which she describes as "reading insights through one another" (p. 25). The process of reading insights through one another means understanding that both theory and data are a constitutive force (Lenz Taguchi, 2012). In this process, we open up our bodymind faculties and "experience the entanglement of discourse and matter in the event of reading the data" (Lenz Taguchi, 2012, p. 274).

The process of plugging in involves at least three moves. The following extended quote from Jackson and Mazzei (2011) outlines the process of plugging in:

1. putting philosophical concepts to work via disrupting the theory/practice binary by decentering each and instead showing how they *constitute or make one another*,
2. being deliberate and transparent in what analytical questions are made possible by a specific theoretical concept (deconstruction, marginality, power/knowledge, performativity, desire, intra-activity) and how the questions that are used to think with *emerged in the middle* of plugging in; and
3. working the same data chunks repeatedly to "deform [them], to make [them] groan and protest" with an overabundance of meaning, which in turn not only creates new knowledge but also shows the *suppleness of each when plugged in*. (Jackson & Mazzei,

2011, p. 5, emphasis in original, and citation of Michel Foucault, *Power/Knowledge* (1980): *Selected Interviews and Other Writings: 1972 – 1977*, translated by Leo Marshall Colin Gordon, John Mepham and Kate Soper, pp. 22 –23).

Jackson and Mazzei (2011) also utilise the concept of the “threshold” to help guide them in the processes of plugging in. Thresholds, such as doorways, are defined as being “in the middle of things” (Jackson & Mazzei, 2011, p. 6). They are both an entry and an exit; a passageway which has “no function, purpose or meaning until it is connected to other spaces” (p. 6). Using the concept of the threshold in diffractive analysis reminds researchers not to stray too far from either the theory or the data. It is in the threshold that a site of diffraction exists, and where researchers become aware of how data and theory constitute each other. As Jackson and Mazzei (2011) note, in the threshold, “divisions among, and definitions of, theory and data collapse” (p. 137).

One of the key concepts which I held in the space of the threshold was a set of questions developed by Deleuze and Guattari (1987), and used by Jackson and Mazzei (2011): “how does it work” and “what does it do”, *not* “what does it mean”. These questions originate from Deleuze’s focus on desire, where he “would not have us look for reasons or causes, but to be once again confronted with the question of how desire works and who it works for” (Jackson & Mazzei, 2011, p. 101).

Looking at research data this way works well with an Agential Realist framework, particularly in regards to the nature of intentionality. As noted in Chapter Four, Barad does not view intentionality as a phenomenon which is ascribed solely to human subjects. Instead, she sees intentionality as a distributed phenomenon which, as Lenz Taguchi and Palmer (2013) note, “emerges from a complex network of human and nonhuman agents, including historically specific sets of material conditions, thus exceeding the notion of being assigned to an individual who produces intention that pre-exists an activity” (p. 676). This enables researchers to step outside of a humanistic lens,

which can focus attention on the intended meaning behind a subject's words and actions.

Using Jackson and Mazzei's (2011) process of plugging in helped me to understand that many of the key theorists and theories, research questions and problem statements with which I worked were emerging fluidly through the process of the analysis. At times I became stuck, unsure of how to progress forward, until I realised that I was attempting to look for the results the analysis would give me, in order to frame the analysis. Or, conversely, that I had strayed too far from the data in my desire to explore theory. When I became stuck, I would bring myself back to the threshold where I held the research problem, the theory and the data. This did not always occur in a linear sense of time; I had to learn to sit in the threshold for long, often uncomfortable periods, unsure what to do with a particular "hot spot" of data, before I would read some theory and suddenly see a powerful connection. At other times I needed to sit with particular theories for long periods, allowing the theory to slowly work on and through me before a connection would suddenly come to the fore in moments of "aha!", often happening when I was not consciously placing myself into the threshold, such as when I was at lunch or driving. Furthermore, I tried to be conscious of the way in which my own "situatedness" impacted on the research. This includes being a Pākehā (non-Maori) white New Zealander, non-disabled, middle-class, cis-gendered, heterosexual woman.

The following phenomena were what I found situated within the threshold:

- The fundamental problem that I came to the PhD with – i.e., that disability oppression exists and that, despite our hardest efforts, does not seem to be shifting very far
- The research data (videos, transcripts and notes of my time with participants)



- The key theories and theorists I used (as outlined in the conceptual framing chapter), which emerged rhizomatically through the process of the PhD
- The key Deleuzian questions of “how does it work?” and “what does it do?”, not “what does it mean?”
- My bodymind, including my emotions and memories associated with the topic area.

To help make sense of the analysis as it progressed, I utilised a variety of methods. The most helpful method was to keep all my notes, which included notes from other scholars and my own thoughts, in large documents labelled by subject. These documents started with a wide mix of notes, which slowly became categorised, sub-categorised and re-categorised over time. The notes in these documents formed the basis of all of my chapters, and proved immensely helpful when I needed to go back and check for accuracy or more information in a particular area. Alongside the notes documents, I kept a journal of my thoughts, and drew mind maps on my whiteboard to help me work through the entanglements of concepts and data.

## **Transcription Symbols**

In order to code the transcriptions of the hui, I used Conversation Analysis transcription symbols, as per the National Institutes of Health (n.d.) guideline, which can be found at:  
<http://www.esourceresearch.org/eSourceBook/ConversationAnalysis/10TranscriptionSymbols/tabid/531/Default.aspx>

Descriptions of the symbols utilised are provided in the table on the following page, and will be used in each of the following analysis chapters where quotes from the transcriptions are discussed:

<b>Transcription Symbols</b>	
[word]	Words in brackets have been inserted by me to help ensure readability of text
(word)	Parenthesised words are words that I am uncertain of
((word))	<i>Double parentheses in italics contain descriptions of non-verbal utterances and actions, such as laughter and hand and eye movements</i>
<word>	Words between these symbols indicates two people speaking at the same time
-	Hyphens indicate words which are cut-off, including stutters
°	The degree sign indicates the person is speaking quietly

## **Concluding Remarks**

In conclusion, diffractive analysis is a tool which draws upon the ethico-onto-epistemological framework of agential realism. This view takes into account that all phenomena – research questions participants, researchers, emotions, theory, data and much more, necessarily affect and interfere with each other. This means that the role of the researcher and their own “situatedness”, such as gender, ethnicity and disability status, is openly acknowledged as having a crucial role to play in the analysis.

Data for the analysis were chosen utilising MacLure’s (2013) notion of hot spots. This was the data which “spoke” most to me, holding an intensity over me which was as much embodied as it was cerebral. The data were analysed following Jackson and Mazzie’s (2011) process of plugging in. This process works to highlight how theory and data constitute one another, operating through the bodymind of the researcher in ways which researchers are not always conscious of. Furthermore, rather than fitting data into neat, pre-established concepts, diffractive analysis takes a rhizomatic approach. The line of questioning within an analysis can take off in unexpected directions, connecting together phenomena which are not connected in space or time.

# Chapter 7:

## Engaging with Pride and the Truth-Claims of Inferiority

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In this chapter, I examine whether the notion of pride presents potential to disrupt the “truth-claims” of inferiority connected to disability. I then outline how this examination ultimately has led to the development of the concept of disability as an entanglement. To do so I describe a series of critical moments which happened during the hui and which fundamentally (re)shaped the formation of the analysis. These critical moments focused on participants’ responses to discussions and visual resources on the idea of pride, and my response to participants’ reactions. A discussion about the development of a series of role plays utilising a co-creation approach is included.

As this chapter begins the analysis, a significant portion is dedicated to detailing the substance of these key moments. Particular aspects of these moments are explored; however, other facets are covered in more detail in the subsequent chapters.

### **Truth-Claims of Disability as Inferior**

This chapter begins with a glaring, white-hot spot of data which emanated from the research. As with all the excerpts in this thesis, this is not done in order to showcase the “authentic” voice and thoughts of participants. As discussed in Chapter Six, “voice” is understood as a distributed phenomenon which is not tethered to individual subjects. It is viewed as a complex network of human and non-human agents which are all entangled together (Mazzei, 2016). The excerpts of voice detailed in this chapter should be read as hot-spots which highlight a powerful enactment of agencies; that is, as intra-active moments

which are produced through multiple, performative agencies, and which emerge as productive forces in the ongoing entanglements of disability.

Throughout the chapter I alternate between the terms “hot-spots”, “moments” and “excerpts”. These words are used interchangeably to indicate phenomena which arose during the hui, and which I discuss in the analysis. I have chosen to maintain the use of all three words as they serve different purposes in the text; where “excerpt” pertains to the specific words placed on the page, “moment” is used to describe instance/s when phenomena arose. “Hot-spots”, in contrast, refer to data or phenomena which “have an intensity and force on the researcher, creating hot spots that glow” (V. Mitchell, 2016, p. 240). These are as much about the researcher’s affective response to the data as they are about the data themselves. Crucially, the phenomena within excerpts, moments and hot spots are not always viewed as being proximate in space and time.

The hot spot presented below is contained in an observation from Taylor. This comment arose during hui two, when participants were asked to describe disability. The word “Disability” was written on the whiteboard, and Taylor suggested that it could be changed to “Dis/ability”. She then suggested that we could use this word to discuss some of the positive and negative aspects of disability. Whilst discussing some of the negative aspects of having a disability, participants noted the similar treatment which disabled people and immigrants face, in that they are both bullied for being “different”; Taylor’s comment came forth unexpectedly:

Taylor: I’ve got something that people with disabilities, not some people with disabilities might not feel but um, I think if I didn’t, if was still job hunting I think I would feel like I’m not worth anything, like I’m not, like ((*pause*)), why is it me that has a disability and that doesn’t have a job and stuff, like, um, am I worth anything and stuff so and sometimes I think if you, if you do get a job like me then you think you are worth something

because people are giving you more chances to  
have a job.

Taylor's comment highlights a phenomenon which I headed into data generation seeking to highlight and disrupt: that of the "truth-claims of disability as inferior". These claims to truth play a profound role in shaping how disability is conceptualised, and, as Taylor's comments highlight, shape the formation of one's subjectivity: of the sense of "self". Her remark, "if I was still job hunting I think I would feel like I'm not worth anything" highlights the powerful role of capitalism in the intra-active production of the self. Those who are unable to meet the expectations of economic contribution and productivity, necessitated through employment, are deemed to have less social worth (Clapton, 2009; Hyde, 2000). As Shakespeare (1996) notes, "disabled people are socialised to think of ourselves as inferior" (p. 103). This totalising view of disability as "naturally" inferior is perhaps most evident in the view that many people would rather be dead than disabled (Fritsch, 2015).

These messages of inferiority sink beneath the skin (Clare, 2001), seeping into "the psychological, emotional and relational lives of non/disabled people" (Goodley, 2017, p. 109). It seems that Taylor has taken on the messages regarding human worth, "why is it me that has the disability"; along with the capitalist demand for employment "like, um am I worth anything?". As C. Gordon (1980) suggests, this positioning of inferiority plays a significant role in providing "the very rationality which grounds the establishment of a regime of acceptability" (pp. 257-258) in validating and perpetuating disability oppression.

Part of the power of these truth-claims lies in the absence of messages which present an alternative view of disability. Scholars such as Garland-Thomson (2002, 2005), Goodley (2011), Morris (1991) and Titchkosky and Michalko (2012) highlight the almost total lack of positive language regarding disability. As Campbell (2009a) writes, "[i]t is difficult, if not impossible in this present moment, to *speak of disability as desirous or desirable* given the overwhelming influence of such negative [inferior] ontologies" (p. 169, emphasis in original). While Taylor suggests that her view as a disabled person regarding

worth and work may not apply to everyone, “some people with disabilities might not feel...” it is difficult for her to maintain this position in relation to her comments about herself.

Garland-Thomson (2005) argues further that the cultural narratives available to disabled people today are similar to those available in historical gender and race systems. These narratives are prejudicial, oppressive and disempowering, due in part to the lack of ways to understand disability which are not oppressive. There are few exceptions to these totalising views, and their power is limited. As Garland-Thomson (2002) notes, “[o]ur culture offers profound disincentives and few rewards to identifying as disabled” (p. 22).

Truth-claims of disability as inferior are perhaps most profoundly evident when the learning disability identity category is brought into the picture. This category has been variously described as toxic, damaging, a stigma, a master status that obscures all other identities (Caldwell, 2011; Goffman, 1963; Kittelsaa, 2014), and as a “profoundly inferior anomalous Otherness” (Clapton, 2009, p. 209).

There is ample evidence in the literature that many learning disabled people are aware of the stigma attached to the label of learning disability, and go to great lengths to hide their disabilities – to “pass” as “normal” (Brune & Wilson, 2013; Caldwell, 2011; Edgerton, 1967; Kittelsaa, 2014). In 1967, Edgerton noted the extreme lengths many ex-institution patients went to in order to “pass”, covering themselves with what he terms a protective “cloak of competence”. Tactics involved in applying this cloak included people not speaking in public so they did not risk saying anything foolish, lying to spouses regarding their history of institutionalisation and the sterilisation they were forced to undergo in order to leave the institution, for fear of rejection, wearing a broken watch so they could ask for the time without having to admit they cannot read a clock, and acquiring various high-esteem objects in order look “normal”, including hoarding mail found in rubbish bins, photos of other people found at second-hand stores, and keeping broken-down cars which they claim are going to be fixed.

The desire learning disabled people themselves have to not to be identified as disabled is not surprising given that, as Taylor highlights, disability has such a profound unfavourable connection to social worth. However, as Brune and Wilson (2013) highlight, the strategy of “passing” often takes a psychological toll on the learning disabled person, and has the effect of reinforcing, rather than challenging, the stigma of the label.

In the following section, I examine what happened in the hui when I attempted to rupture the “truth-claims of inferiority”.

## An Exploration of Pride

Guided by the work of Foucault, I headed into the hui seeking to highlight and disrupt the idea of “truth-claims of disability as inferior”, through the notion of pride. Here, disability pride involves “refusing to accept the values of society which says – with its words, its attitudes, its practices – that some human identities are less valuable than others (Parsons, 1999, p. 3). It is also about demonstrating the values that society could embody moving forward. Disability pride is about the acceptance and celebration of the *difference* inherent in disability, rather than the *sameness* of disabled people in relation to non-disabled “others”.

While pride was a central aim, it was also important to keep in mind that researchers play a crucial role affecting and interfering in the research process, both within the methodological and analysis frameworks (Baum et al., 2006; Lenz Taguchi, 2012). My desire to achieve a state of “pride” with participants would undoubtedly have had an impact on participants’ response throughout the hui, and shaped the hot-spots which emerged through the analysis. I needed to be cautious to avoid, where possible, seeking out data which “fitted” the research aim and what I hoped to achieve at the outset. I worked therefore to ensure that the data had its own “voice”, highlighting the many contradictions and points at which the data did not show what I was hoping for. In this sense, I needed to be conscious of how the data, theory and research aim interfered with the sensibility of my bodymind through processes of the analysis, as well as the





wheelchair doing stunts (Hardy, 2013). This conversation was halted at the request of Carl:

Carl: Ah excuse me Ingrid.  
Ingrid: Mmm hmmm?  
Natalie: <Getting a lot of support>  
Carl: <Can can you> stop talking about the wheelchair please. (But) I a little panic.

Carl and Jonathan informed us that they did not want to watch a video of someone having a good time in a wheelchair. As part of the processes of ongoing informed consent, participants were repeatedly reminded that they could say “no” to any conversation or activity at any time. I read Carl’s request for us to stop talking about wheelchairs, followed by his explanation of “I a little panic”, as a clear “no” to conversations regarding wheelchairs. Thus, following the methodological importance of ongoing consent, I moved onto the next item on the agenda, a video which showcased a man with one leg (Sundquist, 2014).

Prior to showing this video, participants were asked whether they thought there could be anything good about having one leg. Participants struggled to think of any positive aspects to having one leg, and many showed signs of discomfort whilst watching the video. When the video was finished, a few participants commented that they enjoyed it. For instance, Natalie laughed and commented on the Halloween costumes that appeared in the clip, as well as the man’s ability to share shoes with another man who had had the opposite foot amputated:

Natalie: *((She speaks with laughter in her voice))*  
Halloweeny person dressed up as a flamingo ... he had lots of fun finding the other guy that had the same, dressed up as, in the opposite, that was amputated.

However other participants had a different response to this light-hearted clip:

Luke: Well I found that quite weird.  
Ingrid: Yeah?  
...  
Ingrid: What do you think, Jonathan?  
Jonathan: I didn't really look at the video.  
Ingrid: What was that sorry?  
Jonathan: I didn't really look at the video, because I didn't watch it.  
Ingrid: Oh how come?  
Jonathan: Just °feels weird° *((he screws up his face and clasps his hands together))*  
Ingrid: It feels weird seeing someone with one leg?  
Karissa: Yeah.  
Jonathan: Yeah.  
Carl: Yeah so am I.

Below I detail the ethical dilemma I faced after encountering this response from participants, where the need to ensure I kept to the processes of ongoing informed consent conflicted with the need to address the issue which participants were pointing to. [NB: This excerpt is further analysed in Chapter Eight].

## An Ethical Dilemma

The response by most participants to this choice of video was a surprise. I had anticipated that talking about ableism would be challenging, but that talking about pride would be fun and enjoyable. Certainly, my conversations with Glen indicated that he enjoyed the videos. Initially, their response as a collective made me think that I needed to find a new way to approach the topic of

disability pride with participants. However, my supervisors advised me that this discomfort was productive, and was something I needed to address.

This situation presented an ethical dilemma for me. As part of the processes of ongoing informed consent, participants were repeatedly informed that they could say no at any time, and did not have to join in any activity or discussion. The participants were clearly telling me “no” to watching videos and talking about specific disabilities in a positive way. However, my supervisors pointed out that respecting the participants does not mean that I have to respond by closing down discussions. Instead, I could leave the issue on the table for participants to deal with, in the spirit of co-construction.

I spent some time considering why I felt the need to address this issue with participants, especially given that I had concerns about consent and the potential to cause harm to participants by continuing conversations they were uncomfortable with. In my consideration, I was brought back to my rationale for the research – that disability oppression is profound, and that despite our hardest efforts, this situation does not seem to be changing. This situation needed to be addressed. But then, why my participants? Why did I feel the need to address this issue with this group, given my concerns for harm?

It was at this point that the power of diffractive analysis came to the fore. I realised that the question I was asking myself about why I felt the need to address the issue with participants was uncomfortable, and that I had unconsciously pushed it away and moved on to another point. Once I was conscious of my desire to avoid the question, I stepped back to it and acknowledged my discomfort, realising that this feeling meant there was an important issue to address. I saw that the ethical dilemma was much more complex than whether I would cause harm to my participants by addressing the issue; by stepping away from the conversation I was leaving the wider issue of disability oppression unaddressed. Participants were highlighting the key truth-claim I believed needed to be ruptured – that seeing (and feeling) that disability is inferior leads to disability oppression. But my own engagement with the effects of this truth claim made it hard for me to see how I was going to move forward. I too had become stuck in the un-sayability of this sensitive truth claim

By leaving these effects unaddressed, I was foreclosing an opportunity to make headway into changing the very situation I was asking my participants to try to confront. Was leaving the issue unaddressed really the ethical option? I did not believe it was, and proceeded with the advice of my supervisors.

I decided that the best strategy to deal with this issue of participants wanting to shut down conversations was to follow the co-creation approach as advised. Opening myself up to being vulnerable with participants, I came to realise, was an integral part of this approach. So I prepared and gave a “speech”, laying out the dilemma faced, and leaving space for participants to choose what they wanted to do with this dilemma. Participants responded well to my speech, and indicated that they wished to continue with the hui. Glen and I asked participants what they wanted to do next; however, the participants indicated that they enjoyed the pre-prepared activities and that they wished to do whatever Glen and I had planned.

In the following section, I discuss the activity that Glen and I conducted with participants which drew upon the possibility of using the disability identity as a tool to enact change.

## **An Attempt at Rupture**

After the “weird” response from participants, Glen and I spent some time together working through ideas. I wanted to explicate and problematize the truth-claim of “disability as inferior”, as well as the connection between thinking something is inferior, and our subsequent actions. However, how this might be achieved required re-thinking. Glen and I tipped the “bag of things” onto the floor and played around with different resources, until the topic of bullying came up. Bullying had emerged as one of the key issues participants face in our discussions about ableism. I had also recently read the article by Davies (2011), *Bullies as Guardians of the Moral Order or an Ethic of Truths?*. Davies’ idea, that bullying is one of the means by which the normative moral order is established and maintained, seemed relevant.

The discussion with Glen reminded me of an incident in high school when someone attempted to bully me for being short. A tall young man came and stood over me, saying “you’re really short!” in a derogatory tone of voice. My reply of “...yeah”, spoken as if to say “that is very obvious. So what?”, seemed to confuse him. The young man seemed unsure what to do about my refusal to accept the inferiority of shortness, and simply walked away. Glen and I role-played this scene, then swapped the notion of shortness for that of disability. I was the bully, and Glen replied with something like “yeah”, and “I don’t care I’m proud of it”. Glen enjoyed the role play, and to me it seemed perfect. It both highlighted and disrupted the notion of “disability as inferior”, and further emphasised how thinking something is inferior, and the actions one takes, are entangled.

After my “speech” in hui six, participants indicated that they were enthusiastic about watching Glen and I do a role play. Below, I detail several excerpts which highlight what happened during the role plays, as well as the participants’ responses:

Ingrid:       *((I am standing on a stool so I look tall))* Alright, so one time. This person, this boy, he was quite tall, and he came up to me at school and, Glen do you want to come right here?? *((I motion to the spot in front of the chair))*

Glen:           *((Moves over to stand in front of the chair))*

Ingrid:       Yeah, so he came right up to me *((I fold my arms, look down at Glen, and speak in a mean-sounding voice))*. You're really short! *((I change to my normal voice))*. Yeah, so he was trying to pick on me cuz I'm short. And he thought that being short was a problem. So what would you do in that situation Glen? Someone comes up to you and goes you're short!

Glen: I will... ah, damn I need to, um... *((Glen appears as if he is trying to remember what we did in our earlier role plays))*

Ingrid: Just what, what, what is your instinct? What do you think you would do?

Glen: Well for me I would walk away and, like, like, ignore that person. Like that *((he avoids eye contact with me and walks off))*.

Ingrid: Yeah. OK. So what about if instead, I came up to you, and I went *((I hop off the stool, stand in front of Glen with my arms folded, and speak in a mean-sounding voice))* "you play rugby!"

Jonathan: Yeah *((spoken with an intonation indicating he means "so what?"))*.  
*((pause))*

Ingrid: What do you think about that?

Taylor: I know, you can say back to them, yeah, so *((said to indicate "so what?"))*.

Ingrid: Yeah. Yeah, what do other people think?

Jonathan: Um, I reckon yeah I play sp-, I play rugby, and you could say what team you're in.

Ingrid: Yeah. So you think if someone came up to you and went "you play rugby!" you'd just be like *((I lift my arms up, indicating "so what?"))*

Jonathan: Yeah.

Natalie: Yeah so.

Jonathan: Yes.

By bringing in the notion of rugby to the role-play bullying, I was drawing upon the notion which Davies (2011) had identified. Rugby is not the subject of bullying in Aotearoa New Zealand, because it is not deemed a source of inferiority within the normative, moral order. When Glen was being bullied for being short, he indicated that he would walk and ignore the bully, as is often

advised as a method to stop bullying. However, participants understood that this technique would not be necessary in the case of bullying about rugby: they would say “yeah so”, and, as Jonathan comments, say what team they are in.

After this role play, Glen and I moved on to the disability role play we had developed. In doing this, I sought to harness the line of flight established in the rugby role play, where participants did not participate in the inferiorisation of rugby; replying “yeah so”, as if playing rugby was nothing to be embarrassed about. It was my hope that this line of flight could be transferred across to the notion of disability:

Ingrid: Ok. What about if I came up to Glen and I went *((I fold my arms and speak in a mean-sounding voice))* "you're disabled!".

Glen: So what? *((Glen unfolds his arms and holds them out to emphasize the “so what”))*.

Doing the bullying role play with Glen reminded several participants of their own experiences of bullying. Jonathan in particular seemed at least momentarily to pick up on the new line of flight; however, this line was soon reterritorialized onto a line of descent:

Jonathan: I had the, I had the same, I had a similar thing.  
Um, it was, he was actually picking on me but he thought I was disabled.

Ingrid: Yeah.

Jonathan: Back when I was young.

Ingrid: Mmm hmm.

Jonathan: Ummm, he thought, he thought that, me being disabled that young. That he said, you shouldn't be disabled like that. Um, because um, he thought he was picking on me.

Ingrid: Mmm hmmm.

Jonathan: But, he said to me um, I said its OK being disabled but um, I'm changing my um answer to that. But it's half and half like, you could say yeah I'm OK with it but, I don't believe being disabled anymore. So, that helps the bully to back away.

Ingrid: Yeah? So what helped the bully back away sorry?

Jonathan: Um, that saying that I'm not disabled anymore.

Ingrid: You said that you weren't disabled?

Jonathan: Yeah.

In this excerpt, Jonathan first states “I said it’s OK being disabled”, picking up on the new line of flight introduced through the bullying role play with Glen. However, he informs us further “I’m changing my um answer to that” in his retelling of the story, indicating this was not the answer he gave to the bully at the time that the incident happened, and is perhaps not the answer he would give now if faced with the same situation again. Jonathan seems to vacillate between the lines of flight, stating “But its half and half like, you could say yeah I’m OK with it but, I don’t believe being disabled anymore”. While he initially indicates a connection with the new line of flight, he then decides that telling the bully he is “not disabled anymore” will help them to back away.

This role play about bullying built upon an idea first articulated by Foucault (1980), in which he argues that “there are no relations of power without resistances; the latter are all the more real and effective because they are formed *right at the point* where relations of power are exercised” (p. 142, emphasis added). Butler (1997a) builds upon Foucault’s work in her development of performativity, noting that a performative must continually be repeated in order to establish its legitimacy. As she asserts, “[i]f such a structure is dependent upon its enunciation for its continuation, then it is at the site of enunciation that the question of its continuity is to be posed” (p. 19). That is, the moment of repetition, whereby a (gender/disability/race etc.) identity is recited, is the achilles’ heel of power (Buchner, 2015); it is in this moment that the possibility for rupture lies. The role plays on bullying seemed to harness this very



concept; they grabbed hold of the site of enunciation, when someone is (re)constituted as a disabled subject, and took the process of subjection onto a new line of flight; it utilised “the tools of recognition in order to disturb their recognisability” (Brady & Schirato, 2011, p. 64). In Jonathan’s statement, “but um, I’m changing my um answer to that” he appears to see the possibility for a new line of flight in reframing his response to the bully, stating “I said it’s OK being disabled”. Jonathan evidences the possibility of rupture to the sedimented lines of flight when the disability identity is (re)cited; however, this rupture is soon reterritorialised as Jonathan wavers between accepting and rejecting the identity.

Furthermore, the idea of challenging power relations through reworking the constitution of the disability identity shown in this excerpt aligns well with the similar occurrences in relation to rights movements. The language regarding disability – the site of enunciation where resistance to power can be harnessed, is particularly important. Titchkosky and Michalko (2012) state, “[t]hat disability is conceptualised as a problem is what we take our problem in need of theorising” (p. 127). Similarly, Oliver (1990) asserted that, from the 1950s onwards, marginalised communities realised that the problems they were facing needed to be redefined. One of the means by which this was achieved was by challenging the sexist and racist language which underpinned the existing problems, and “creating, substituting or taking over terminology to provide more positive imagery” (p. 3).

Clare (2015) notes that language, and naming specifically, has been used to create pride and power in these rights movements. For instance, the term “Black is Beautiful” became a “rallying cry for Black community and culture” (Clare, 2015, p. 109). The term “queer” has also served as a coalition-building word, bringing together a diverse group of people with differing sexualities and gender identities (Clare, 2015). In short, the literature highlights the powerfully agentic nature of language; it can be used as a tool to establish and maintain unequal power relations, yet also be a place where resistance to these power relations can be found. As Clare (2015) highlights:

To transform self-hatred into pride is a fundamental act of resistance. In many communities, language becomes one of the arenas for this transformation. Sometimes the words of hatred and violence can be neutralized or even turned into the words of pride. To stare down the bully calling cripple, the basher swinging the word queer like a baseball bat, to say “Yeah, you’re right. I’m queer, I’m a crip. So what?” undercuts the power of those who want us dead. (p. 109)

In 1990, Oliver noted that this change in language was a phenomenon yet to be seen in the disability community. Disabled people have long challenged the use of oppressive language regarding disability – do not say “retard”, “cripple”, or “handicap” - yet this language has not been supplanted by more positive language which could foster an affirmative group consciousness or identity. It was my hope that by harnessing the moment of citation, whereby the disability identity is recited, we could enact a new line of flight by responding with pride. I hoped that, through doing this, we could begin the work of fostering more positive language in regards to disability.

## **A Moment of Rupture**

In contrast to the participants’ reactions to the videos in hui five, participants indicated that they enjoyed the role plays and discussions in hui six. They stated that they would like to do more of this, and in hui seven the participants developed their own role plays. Several participants played around with the “short” role play as well as a few other ideas. However, little productive progress into the development a new line of flight was made. After a while, Jonathan decided that he would like to conduct a role play utilising items from the “bag of things”. He picked out many of the medical supplies from the bag, winding bandages around several parts of his body, and placing an eye patch over his eye. He told us that he had just come back from the war. He also picked up my handbag and placed three hats upon his head. As no other participants wanted to join in, Jonathan invited Glen and I into the role play. I acted as a bully

against Jonathan because of his newly acquired disabilities, and we had a discussion about how I as the bully was thinking about disability. This was done once again in order to draw out the connection between thoughts and actions. Thereafter, I shifted my positioning within the role play by tying a bandana around one eye, indicating that I had become blind in that eye, and thus disabled. I opened up to being vulnerable once more, and invited participants to help me. I asked how I would feel OK about myself, having bullied someone for having a disability, then becoming disabled. Participants initially suggested that I would feel “stink”, and change my attitude, because I would understand how disabled people feel. I continued to ask how I would feel proud about myself and OK about myself with my newly acquired disability, and the conversation meandered without much progress into discussing disability in a positive way. However, this changed when Jonathan stepped up to me, as outlined below:

Ingrid: How else could I feel proud of myself?  
Jonathan: We could be mates *((steps over to me and links his arm through mine))*.  
Ingrid: Yeah.  
Natalie: Get new friends.  
Ingrid: Yeah, how would I get new friends, do you think?  
Glen: *((Walks around to the other side of me and puts his arm around my waist))*  
Carl: Ingrid.  
Taylor: From the Blind Foundation.  
Ingrid: Yeah, so I would get to meet new people, wouldn't I?  
Taylor: Mmm.  
Ingrid: That would be cool.  
Jonathan: Yeaah.  
Natalie: Other people that can help you out.  
Ingrid: Yeah? So I would get more support people then?  
Natalie: Yeah.

Although brief, this conversation was the closest we got to a new line of flight, whereby disability was talked about in a positive way with specific, rather than generalised, language. There were other small deterritorialisations throughout the hui which hinted at pride. For instance, in the excerpt from Jonathan noted earlier, he changed his story from saying that he does not believe he has a disability, to saying “it’s OK being disabled” to the historical bully. When Karissa was asked to define disability in hui eight, she stated “um, if the people comes up to you and say um I’m a disability, you say ((*shrugs*)) so what?”.

## Discussion

Despite some promising lines of flight, there was no clear evidence to indicate that, overall, a state of pride was achieved in the hui. In hui eight, participants were specifically asked whether they thought their ideas related to disability and / or themselves had changed because of the hui. No participants indicated that they had noticed any change, with the exception of Glen who felt the hui had helped him develop his public speaking and facilitation skills. However, participants continued to state that they liked the idea of disability pride, and many participants said they thought it was important. This aspect of my data collection has left me with much to speculate about, and I outline key outcome reflections below.

While it may be that the indications of pride were a result of participants responding to my desire for this to happen; that is, participants may have picked up on the “correct” answer that I was seeking in that situation, rather than a sense of pride being fully mobilised in the participants’ bodyminds, perhaps the reason pride was so hard to mobilise was because I do not have a disability. Would seeing someone in a wheelchair talk about their disability in a positive way, rather than trying to “act” have produced a different reaction in Carl? Would someone with one leg missing have elicited a different response from Luke and the participants who found the video “weird”? Perhaps the issue was that pride was not the best choice of word for the concept. Could alternative

terms such as “embracing disability” or “embracing who you are” hold more potential?

Regardless of why pride was not mobilised, I realise that the challenges we faced in mobilising pride during the hui, and in discussing disability as anything other than a truth-claim of inferiority, mean that I cannot clearly state that we achieved a state of pride in the hui. Therefore, no clear answer for research question one: “does the notion of pride present potential for a positive re-imagination of disability?” could be arrived at. However, the challenge in achieving pride is not entirely unexpected. As Campbell (2005) states, the pervasive view of disability as inferior “makes possibilities of “pride” difficult (if not impossible) to generate” (p. 117). Drawing on the work of Barad helps to illuminate this point further. As she notes, “[i]ntra-active practices of engagement not only make the world intelligible in specific ways but also foreclose other patterns of mattering” (p. 394). My attempt to change the way disability came to matter seemed to be foreclosed through forces which I was not aware of during the hui. However, the foreclosure itself presented potential for an alternative line of flight in the analysis.

Rather than viewing the research problem as “truth-claims of disability as inferior”, I came to see that the issue was a much wider and deeper one than I had initially thought. In particular, participants’ *affective* responses to the videos and discussions signalled the limitations of viewing the problem as largely discursive. I came to see that “the truth-claims of disability as inferior” involved much more than the working of a discrete discourse, and could indeed be more productively seen as an *ontology* of inferiority. What arose from the data were particular key phenomena which were agentic in foreclosing patterns of mattering in relation to disability, and that these forces were preventing the development of pride, or preventing an alternative imagination of disability. These forces can be seen to enable disability oppression to continue to flourish. In short, the challenge in achieving pride enabled me to come to the view of disability as an ongoing series of entanglements; entanglements which materialise in such a way that they reiterate disability oppression. I came to view these key problematic phenomena as territorialising forces which inhibit the

production of new lines of flight in the way people imagine the possibilities for disability.

Over the next four analysis chapters I further explore the territorialising forces of the entanglement. In particular, I examine what constitutes these entanglements, and what the performative agencies within these entanglements are. Then, I explore what is happening within these entanglements which enables disability oppression to flourish, and what these entanglements foreclose and present potential for.

## Chapter 8:

# The Affective Entanglements of Disability

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Within agential realism, all phenomena are seen as performative agencies – theories, concepts and material objects included. This chapter brings several of these performative agencies into the threshold of the analysis. These include: participant responses to visual materials on pride, agential realism, Wetherell’s work on affective practice, and the notion of disability as an ongoing series of entanglements. In particular, participants’ adverse responses to visual materials on ableism will be analysed as an affective practice; one which both emerged through, and served to shape, the problematic iterative entanglements of disability. The Deleuzian questions of *how does it work* and *what does it do* will be utilised in order to examine what constitutes the affective entanglements of disability, how these entanglements enable the perpetuation of disability oppression, and what potential for foreclosure and allowance these entanglements enable.

### **The Absence of Affect**

As part of the discussion regarding informed consent in hui one, participants were reminded that some conversations throughout the hui might be upsetting; something which had been discussed during the initial consent process. To help participants consider the importance of difficult conversations, Glen asked them to tell a story about a time when they needed to talk about something that was hard to talk about, but was important to talk about. This conversation prompted an interesting response from Luke, as per the following page:

Ingrid: Has anyone else got a story of a time when they had to talk about something that was hard but it was important to talk about it?  
*((a few people say yes simultaneously))*

Luke: Well I've got one.

Ingrid: Luke?

Luke: When my grandfather passed away.

Ingrid: Yeah.

Luke: Mum couldn't tell me for a few days.

Ingrid: Ohhhh

Luke: I said mum what's happened? She wouldn't tell me. I said are you serious, (she) won't tell me for a few days. And (everything just) *((clicks fingers))* when I was there for the weekend and Judith<sup>20</sup> just told me he died.

Luke's story of not being told about a close family death is not unusual. A similar story was told in the film *A Place of Our Own: Living with the Legacy of Institutionalisation* (Marbrook, 2009). In this film, Murray, who had previously lived in an institution, was not told for a week that his mother had died. He was not allowed to go to the funeral because people feared it would make him upset. In the above excerpt, Luke too appears to have been excluded from knowledge of a death - his mum "wouldn't tell me" and "a few days" pass before he finds out. In the end, he learns about the death from someone who may not have been a family member. Such stories raise questions about how often learning disabled people are excluded from knowledge where strong emotions are involved.

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<sup>20</sup> Pseudonym



When thinking about how the issue of silence impacted upon my own practice as a support worker, I realise that I simply cannot remember a time when I talked with someone I supported about expressing and managing emotions. As someone who loves attending training courses, I have attended almost every course offered to me over the years. Despite training packages including non-violent crisis intervention, and how to support people with mental illness, I cannot remember a single piece of training related to how to proactively support people to manage their emotions. I don't even remember a training session which told me that this is something I should do.

After this realisation, I started to notice how I and other people around me tried to protect the people we supported from having negative emotions. If someone did seem to have a negative emotion, helping the person feel "better" as soon as possible seemed almost instinctive. Looking back, I felt that it was my job to ensure that the people I supported were happy at all times. If someone was upset, I was failing as a competent support worker, and needed to work to ensure the person felt happy again. I am left wondering about the impact that this has had on the people I supported, and the impact that this practice continues to have on people currently in support services.

## **The Affective Entanglements of Disability**

At the start of the hui, I had not given a great deal of consideration to the relationship between affect and disability. Most likely, this was simply because I was not reading about it in the disability studies literature I engaged with prior to the hui in 2015. However, I had given some consideration to the role of affect in the methodology, and anticipated that affect could play a powerful role during the hui. I had worked to ensure I had robust safety systems in place for participants (see Chapter Five), so that I could respond in an ethical manner to any challenging emotions which arose during the course of our conversations. As it turned out, my preparations were highly beneficial, as many challenging incidents related to affect occurred during the hui. However, these incidences did not unfold in the way that I had anticipated.

During the consent process, I warned participants that we would be having challenging conversations about disability, and asked for consent on the basis of this knowledge. To my complete surprise, several participants became more enthused about joining the project after hearing this warning than at any other point, with one participant stating quite simply “sign me up!”. This enthusiasm for having challenging conversations was a trend which continued into the hui. Many participants were eager to talk about ableism, or “how their disabilities have caused difficulties in their lives”. However, this enthusiasm did not continue for all participants when the discussion moved to disability pride. I had assumed that discussing ableism would be challenging, and talking about pride would be “fun” and “easy”. As I will highlight throughout this chapter, my expectations were far removed from the reality of what emerged.

In Chapter Seven, I briefly discussed participant responses to discussions regarding specific disabilities in hui five. This chapter discusses participant responses to these videos in greater depth.

Glen and I had picked the video we liked most to introduce discussions regarding disability pride with participants; this video highlighted the story of Aaron “Wheelz” Fotheringham, an extreme wheelchair athlete who performs in the Nitro Circus (Hardy, 2013). Prior to watching the video, Glen asked participants what they thought could be good about being in a wheelchair. The conversation progressed as below:

Ingrid: So, what else do you guys think could be good about being in a wheelchair?

Carl: Ah excuse me Ingrid.

Ingrid: Mmm hmm?

Natalie: <Getting a lot of support>

Carl: <Can can you> stop talking about the wheelchair please. (But) I a little panic.

Ingrid: You get really what sorry? Panicked?

Carl: Yes.

Ingrid: Ok, um, well we're going to watch a video soon, which I think you might enjoy, is that OK?

Carl: *((Shakes head))* <No>

Ingrid: <You don't> want to watch a video about someone in a wheelchair having a good time?

Carl: No.

Ingrid: No you don't want to?

Jonathan: I don't want to either.

Carl informed us further that his “panic” response was because the discussion reminded him of the time he saw his nana in a wheelchair, commenting “yeah but I a little panic about my nana in wheelchair”. Is Carl’s panic because wheelchairs also function as a symbol connected to ideas about the frailty of the human condition? Wheelchairs can symbolise accidents, illness and death, serving as a reminder of human vulnerability and mortality. For Carl, seeing his nana in a wheelchair may have served as a signal of his nana’s increasing frailty and approaching death. In this intra-active moment, Carl’s experience with his nana became entangled within the discussion, serving as a territorialising force which inhibited further conversation about the empowering qualities of wheelchair use at that moment.

We moved to the next video that Glen and I had picked out. This is video of a man with one leg who wears funny Halloween costumes, such as a gingerbread man with a leg missing (Sundquist, 2014). Before watching the video, Glen asked participants what they thought could be good about having one leg. Luke responded:

Luke: Well I know a guy who's got one leg. He's got a leg wrong *((indicates chopping off motion with hand against his leg))*

Ingrid: Yeah.

Luke: And that just freaking freak me out man.

Once the video started playing and the man with one leg came onscreen, mentioning that he has one leg, Luke had a powerful affective response. He reeled back against the couch, shuddered, put his hand by his face and made what sounded like a “disturbed” noise. This event could best be described as a display of embodied repulsion. Or, as Hughes (2012) might state, a demonstration of “ableist disgust”.

It is important to remember at this point that although some participants stated that they found the video “weird”, this was not the response of all of the participants. Glen, Gary, Natalie and Karissa said that they enjoyed the video, and found the Halloween costumes amusing. However, it is the negative response to the videos and discussions which I wish to explore, as these responses can be viewed as an affective practice, in line with Wetherell’s (2012) understanding of this idea, as below. Practices are:

[A] figuration where body possibilities and routines become recruited or entangled together with meaning-making and with other social and material configurations. It is an organic complex in which all the parts relationally constitute each other. (p. 19)

These practices can be understood as routinized entanglements – as sites of repetition which emerge unbidden and unfold “relatively automatically with little conscious monitoring” (Wetherell, 2012, p. 129). Crucially, Wetherell’s quote points to the intertwining of affective practices and wider meaning-making processes. This can be seen in Luke’s response, included again below.

Luke: Well I know a guy who's got one leg. He's got a leg wrong (*indicates chopping off motion with hand against his leg*)

Ingrid: Yeah.

Luke: And that just freaking freak me out man.

What can be seen in these remarks – “He’s got a leg wrong” and “that just freaking freak me out man” – is an example of an embodied meaning-making practice of disability. Luke highlights some of the beliefs, practices and processes which enable the positioning of disability as inferior. According to Hodge and Runswick-Cole (2013), these beliefs, practices and processes are often obscured and difficult to pin down in the everydayness of life-as-usual. Luke’s response foregrounds the logic inherent in the abled/disabled binary, as discussed in Chapter Two. The notion of abled is established as the ascendant term – as the natural, normal and desirable way of being human (De Schauwer, Van de Putte, Van Goidsenhoven, et al., 2017) – hidden in this example within the phrase “a leg wrong”. In contrast, disability as the subordinate term within the binary is fully in view, signalled by what is considered non-normative, abnormal and undesirable: “a leg wrong” (De Schauwer, Van de Putte, Van Goidsenhoven, et al., 2017). The result “that just freaking freaked me out”, coupled with Luke’s embodied response, indicates the affective impact of the entanglement of these processes.

Participants’ responses to videos and discussions highlight the role of affective practice in the ongoing inferiorisation of disability; this *feeling* about disability is part of the meaning-making “beliefs, practices and processes” which enables disability to be continually positioned as “naturally” inferior. Or as Barad (2003) might say, this phenomenon is a boundary-making practice which is “fully implicated in the dynamics of intra-activity” (p. 822), through which the phenomenon of disability comes to matter.

In particular, affective practices have a powerful role to play in shaping what could be termed the normative orders of life. As Wetherell (2012) argues, affective practices are subtly woven into communal methods for developing moral and normative assessments. Affective practices form an integral component of the normative practices that shape what is considered “socially appropriate” and expected in relation to disability.

When viewed through a humanist lens, Luke’s visceral response to the video could be understood as the intentional choice of a rationally acting individual – that is, as someone who needs to “change his attitude” about

disability. However, when looking at this moment through the lens of agential realism and the framework of affective practice, Luke's response can be viewed as an embodied enactment of the normative orders of the disability entanglement, as a practice which shapes the very materiality of the body. As Foucault asserts:

The body is...directly involved in a political field; power relations have an immediate hold upon it; they invest it, mark it, train it, torture it, force it to carry out tasks, to perform ceremonies, to emit signs... power is not exercised simply as an obligation or prohibition on those who "do not have it"; it invests them, is transmitted by them and through them; it exerts pressure upon them, just as they themselves, in their struggle against it, resist the grip it has on them. (Foucault, 1977/1995, pp. 25–27)

Numerous normative orders are intertwined within the entanglements of disability. Some of the orders already outlined in this thesis include the seemingly "rational" drive to pursue normal and to become "independent", as well as the well-established truth-claims of "disability as a problem" and "disability as an essential category". What Luke and the other participants' responses highlight is that these orders are not a purely cognitive phenomenon – they are an embodied knowledge – a power relation which has an immediate hold upon the body.

This connection between the normative orders of disability and embodied, affective practice was highlighted by participants when they described the video of the one-legged man as "weird", as noted earlier. Taylor highlighted this phenomenon further when asked about her response to the video:

Taylor: I sort of think it's a bit fake.

Ingrid: Yeah? How come?

Taylor: Because. Um.

Natalie: °those costumes°

- Taylor: No not those costumes but, it wasn't like a serious YouTube clip. It was like a fun YouTube clip. Like YouTubers do.
- Ingrid: Mmm hmm?
- Taylor: In those videos. But. It was like he was joking about missing a leg, sort of.
- Ingrid: Yeah.
- Natalie: Like he didn't care if he had, if he was missing a leg.
- Ingrid: So you think if somebody has one leg missing, that, and they joke about it, it doesn't quite seem right?
- Taylor: Yeah.

Taylor's response, wherein she found the video "fake", once again highlights the territorialising force of affect within the hui. Seeing someone joke about missing a leg just "doesn't seem quite right". Taylor seems sceptical about the idea that someone could miss a leg and joke about it as if they did not care, commenting "It was like he was joking about missing a leg, sort of...Like he didn't care if he had, if he was missing a leg". In this sense, what *feels wrong/ right/ weird/ fake* in relation to disability is an affective practice – an embodiment of the normative orders of the disability entanglement which shape the possibilities for the lines of flight. Participants' affective responses highlighted the way in which disability and affect are inescapably, ontologically entangled, shaping what it is possible to think, know and feel about disability.

Furthermore, these normative orders play an integral role in the formation of the subject and their subjectivity; they are a part of the boundary-making practices through which humans are intra-actively co-constituted. As Wetherell et al. (2015) note, affective practices play an important role in "constructing legitimate and illegitimate social actors" (p. 62). Taylor and the other participants' responses to the video demonstrate this very phenomenon, as positive feelings in relation to disability were constructed as illegitimate – as

“weird” and “fake”. Wetherell et al. (2015) note further that “[t]he dance between authenticity and inauthenticity, between reason and passion, between moderation and intensity, and the variable accounts this allows, is eminently suited to the play of power” (p. 62). The formation of subjects, their “identity” and subjectivity, affective practice, and legitimacy are closely woven together (Wetherell, 2014). Or, as Barad (2007) insists, humans do not stand separate from the world in which they are constituted.

## The Agency of Memory

Another performative agency entangled within the affective practices of disability was that of memory. In hui six, I asked participants directly if their desire not to continue with the discussions and videos on disability pride was because they made them feel “uncomfortable”. However, none of the participants seemed to agree with my conclusion, and the conversation progressed as below:

Ingrid: ... but the people who said that they didn't want to watch the video and they didn't want to talk about it, is that because you felt uncomfortable about it?

*((Nobody indicates agreement))*

You're not sure?

Natalie: I think it reminds, reminds us that we know someone that's in that situation.

Ingrid: Yeah?

Natalie: And that brings up memories and stuff.

Ingrid: Yeah.

Natalie: For some people.

Ingrid: Yeah that's a good point. Yeah. And why do you think that would, do you think the memories would be unhappy memories or...



Natalie: Yeah it'd be, unhappy.

Ingrid: How come?

Natalie: Oh, like, like when I saw it. Um, when it was in a wheelchair. It reminded me of my nana being in a wheelchair and being in a rest home.

Ingrid: Yeah.

Natalie: And can't walk.

As Natalie tells us, the discussion on wheelchairs in hui five was entangled together with the memory of “nana being in a wheelchair and being in a rest home”, when she also “can’t walk”. As with Carl’s nana, this symbol could be read as a display of frailty and the closeness of death, an unpleasant experience which was remembered during the hui.

Looking further through the data, I realised that these were not isolated incidences. When participants were asked in hui two to describe disabled people they knew, memories of relatives with disabilities who had died came to the fore from several participants. This is highlighted in the excerpt below from Jonathan:

Jonathan: Um, this is really important to me. Um, this person who I know really really well was my cousin, um, he um, he since he was alive and well and um, *((Jonathan starts playing with the chord on shorts))* he got a disability um he had a disability where he can’t do anything for himself and um, he couldn’t move. He couldn’t do anything. He has a tube for his food and that what’s was, was not a good feeling for me. But um, since then um, since he passed away, because he died, and um, I found it really really hard to think about the good times what I think about him. Because he was a person in my life that I was trying to live my life and he was there

with me ((Jonathan wipes his eye, Karissa puts a hand on his shoulder)), he... ((Jonathan starts crying, Karissa puts her arm around him and starts rubbing his arm)), he was everything to me ((Jonathan's voice goes higher from crying, he sniffs and rubs his eye)), and I miss him every single day.

Jonathan's story indicates that he is still affected by the experience of his disabled cousin's death, commenting "I found it really really hard to think about the good times what I think about him" and "I miss him every single day". This affective event is still so powerfully felt that he starting crying in the hui and asked us to stop talking about death, because it was making him upset. Jonathan's story, along with the responses from Carl and Natalie, foreground the entanglement of memory, affect, disability and mortality. These memories were not something which existed purely in the mind, nor exclusively in the past. Memory is an embodied phenomenon (Hirsch & Spitzer 2009) which became re-experienced through the intra-active moments in the hui, as Jonathan so movingly highlights. Deleuze (1956) elucidates this idea further, arguing that the notion of "the past" is not constituted "*after* having been present, *it coexists with itself as present*" (as cited in Davies et al., 2013, p. 682, emphasis in original).

Jonathan's story reminded me of another gentleman, Jim<sup>21</sup>, whom I did not directly support, but who was supported by the service I worked in. Jim was a kind, loving gentleman whose daily schedule revolved around visiting his best friend, Janet, who had Alzheimer's and lived in a rest home. Every day, Jim would turn up to the rest home to feed Janet lunch and read her a story, then continue on with his other interests. I remember a service manager commenting one day that Janet's health was failing, that she would soon die, and that we should really do something to help Jim prepare for this. However, perhaps unsure about how

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<sup>21</sup> Pseudonym

exactly this should / could be done, this preparation never happened. Janet's death was traumatic for Jim, particularly because he did not understand what was happening or why the rest home staff would not let him visit Janet when she was extremely unwell. To make matters worse, Jim's mother died within a few months of Janet, something which Jim again seemed to be unprepared for. As Jim's support service, it seemed like it should have been our job to support him through these important life events, yet how were we supposed to go about doing this? As I was not directly involved with supporting Jim until later on I do not know exactly what was done or tried; however, I do know that Jim's mental health soon spiralled out of control. He went from being a cheerful, motivated man with a busy life (albeit with its ups and downs), to being an angry, severely depressed man who became violent and did not want to leave the house. He went from living in his own house with about 17 hours visiting support per week, to having 24/7 one-on-one support with staff trained in crisis intervention and keeping themselves safe.

I am left wondering what we should have done for Jim. What would his life look like today if we had provided support to help him prepare for Janet and his mother's deaths? What would this support look like? Was our inaction driven by our fear that addressing the issue poorly would be worse than not addressing it? Who do you even ask when you want help with this as a support worker? And how many other learning disabled people are left with these powerful, unresolved emotions because we are paralysed by our lack of knowledge and skills as support workers? I believe we need to seek some answers to these questions, so that the Jonathans and Jims of the world do not continue to be left in limbo.

In the following section, I examine how affect operated as a performative agency within the hui, shaping the possibilities for the lines of flight.

## Affect as Agentic

Affective practices are a performative agency within the entanglements of disability. Or, as Ria Cheyne (2016) so succinctly states, “disability makes people feel” (3:02). Crucially, this view of affective practice means that affect not only emerges through the entanglements of disability, but also shapes the emergence of the lines of flight. Discussions regarding ableism – which participants were eager to engage in – flowed relatively unproblematically with the lines of descent, wherein disability is positioned as inferior. However, discussing disability in a positive way seemed to diverge from this line of flight. The affective responses from participants appeared as a territorialising force; one which held the line of descent firmly in place, and prevented rupture to the lines of flight. Wetherell (2012) speaks of this idea when she argues that affective practices can be “very densely knotted in with connected social practices where the degree of knitting reinforces the affect and can make it resistant and durable, sometimes unbearably so” (p. 14).

This territorialising force manifested through the affective practices embodied by participants. When the situation became too discomforting, many participants asked for the conversation to stop, asked not to watch the videos, or in the case of Jonathan, simply turned away when the videos were playing. However, even when the response from participants was not to shut down what was happening, the line of descent still held strong. For many participants, the response to discussing disability in a positive way was that it felt “weird” and “fake”. These practices ensured that it was not possible in those intra-active moments to conceive of disability as anything other than an ontologically negative phenomenon.

## What Do These Entanglements Do?

At this point, I would like to bring the Deleuzian question of *what does it do* into the focus of the analysis. In exploring the entanglement between the phenomenon of affective practice highlighted in this chapter, along with the limited theorisation of affect in the disability studies literature, a key issue arises.

This is particularly in relation to the capacity to harness the agency required in order to disrupt the iterative, problematic entanglements of disability. Miller, Parker and Gillinson (2004) argue, “if you do not name that which has to be defeated, it will not be beaten” (p. 15). Not naming or discussing a phenomenon thus means a loss of agency over that particular phenomenon; it means this phenomenon is likely to continue sweeping us along, denying us the ability to challenge and disrupt it.

However, in connecting these ideas back to Barad’s (2007) quote: “[t]he world and its possibilities for becoming are remade with each moment” (p. 396), I am reminded of the always-present possibility of rupture to the lines of flight (Davies, 2008). Affective practices not only serve as a territorialising force – when harnessed effectively, they also hold potential to deterritorialise. These affective practices are constantly being remade anew, and have the potential to be radically reconfigured at each moment. As Cheyne (2016) argues:

If feelings are fundamental to prejudice and prejudicial behaviours, they are also potentially the key to changing attitudes. Affective and emotional factors are often much more powerful at changing attitudes than ideas based in reason and logic. (34:11)

Whilst an agential realist lens would look at much deeper issues than “attitudes”, Cheyne’s quote foregrounds the agentic potential of affect in shifting conceptualisations of disability; that is, in presenting potential for a positive reimagination of disability. However, if we are to challenge the affective practices of disability – these problematic lines of flight – then we have to be able to name them. As Davies (2008) argues, we have to “begin with a detailed reflexive examination of our habituated immurement in the ordinariness of life-as-usual” (Davies, 2008, p. 173). To do this, we need to identify these practices within ourselves, and in particular identify the “feelings” which arise within the entanglements of disability. Affect can be an impeding force, but it also holds the potential to be harnessed as a tool to shape the continually forthcoming lines of flight in the entanglements of disability. These disruptions, as Davies (2008)

argues, are an ethical necessity of life if we are to challenge the ongoing oppression of marginalised groups.

## Conclusion

In conclusion, this chapter has explored the affective entanglements of disability. Whilst this is an under-theorised area in the disability studies literature, affect emerged as a powerful, performative agency for participants during the hui. Through analysing some of these critical moments with participants, I explored the Deleuzian questions of *how does it work* and *what does it do*. Drawing upon Wetherell's work on affective practice, alongside Barad's work on agential realism, I examined the intertwining of affective practice and memory within the wider meaning-making practices and entanglements of disability. In particular, participant's affective responses to the stimuli in the hui can be understood as the embodied enactment of the normative orders of the disability entanglement. These practices serve to perpetuate disability oppression, as they territorialise and hold in place the existing problematic lines of flight, such as "disability as inferior". However, I have also argued that affective practice does not need to be seen solely as a phenomenon which forecloses potential for change. Instead, it can be viewed as a tool which, when harnessed effectively, can be used to shift these problematic iterative entanglements of disability.

# Chapter 9:

## Recognition and the Disability

### Identity

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This chapter explores the entanglement of the disability identity, and the desire to be recognised as a viable subject. Key hot spots of data are brought into the threshold of the analysis, alongside Butler’s work on performativity, agential realism, and the Deleuzian questions of how does it work and what does it do. The desire to be seen as “normal” and the desire to “focus on abilities” will be examined in particular, as well the desire to reject the disability identity. What the entanglements foreclose and present potential for will be discussed, including how they show the ever-present potential for rupture.

#### **The Pursuit of “Normal”**

Butler (2004) argues that the experience of *recognition* enables us to become constituted as socially viable beings. Because recognition is required for social existence, it is something we come to desire (Butler, 1997b). As Davies (2015) notes, “our very sense of personhood is linked to the desire for recognition” (np). Importantly, this means that we are oriented to desiring the social categories through which we become recognisable – including male/female, abled/disabled, and so on. In short, in order to be constituted as a socially viable being, we seek recognition within these identity categories.

In the conceptual framing chapter, I outlined an agential realist view of the processes of recognition. In this understanding, recognition is not understood as “a simple reflecting back of an entity that pre-exists the act of recognition”, but rather as “a *mutually constitutive act of becoming*, through which being is made to make sense.” (Davies et al., 2013, p. 682, emphasis in original). This means that identity is not understood as a concept which reflects a

stable, rational, humanist subject. Instead, identities are understood as social categories which enable being-ness to make sense. These identities are neither stable, fixed nor singular. Instead, they are viewed as fluid, ever-emergent and multiple (Kittelsaa, 2014); as a phenomenon whereby a sense of self – an “I”-emerges through the ongoing intra-activity of life.

In hui three, participants were asked whether they would describe themselves as having a disability. However, before exploring the participants’ engagement with the disability identity, I would like to step back to the preceding question in the hui, when participants were asked about the idea of being “treated like a normal person”. These questions should perhaps have been thought through more thoroughly, as the order appears to have had a significant impact on the answers which participants provided. As Barad (2007), notes, attention to fine detail is important, as “[s]mall details can make profound differences” (p. 92). The conversation progressed as below:

Ingrid: I notice sometimes, like, because I’ve looked at lots of um, YouTube videos and movies and stuff ... um, and I notice that on the videos people say that they, a lot of people are saying that they want to be treated like an ordinary person or they want to be treated like a normal <person>.

Jonathan: <Yeah>.

Glen: Yep.

Ingrid: Does anyone here ever feel like that?

Jonathan: I do *((raises hand))*.

Natalie: Yep *((nods))*.

Carl: Yeah I have.

Karissa: Yeah I have. Yes I do.

As can be seen in the excerpt above, five people immediately agreed with the sentiment that they would “like to be treated like an ordinary person or .... like a



normal person". Jonathan was so eager to concur that he replied "Yeah" before I had finished answering the question. Natalie also agreed that she would rather "just be treated like anyone and everyone"; however, Carl, Gary and Luke said that they had not heard of the expression. When this idea was investigated further, most of the participants were unable to explain what it meant to be "treated like a normal person" or "treated like a disabled person". Jonathan and Natalie were the only two participants to give a response, both of whom noted that disabled people are "treated differently". Jonathan commented further that if you are not disabled "you get to do things more better", and "you can do things by yourself". While none of the participants could clearly articulate what it meant to be "treated like a disabled person" at this point in the hui, there was a clear inference that it meant to be treated "differently", and that "different" was worse.

For the following question in the hui, participants were asked whether they would describe themselves as having a disability. In order to ensure that disability was not positioned as the totalising source of identity in the participants' lives, this question was prefaced by reference to earlier discussions in hui two and three, when participants were asked to describe themselves. I asked participants:

Ingrid:            So um, I'm just thinking about how everyone's described themselves, and like over the last hui and today and lots of people have said things like your family is really important and you really like music and people talked a lot about where they came from and some people have said, you've used the word disability to describe yourself today. So how... would... everyone here describe themselves, just wondering. Would you say you've got a disability or..?

Luke was the first to respond to this question, stating:

Luke:            Yeah I would say to people I'm, I'm, I'm a normal person and stuff like, I'm a normal person and I don't like to be treated like crap.

Luke's comment "I'm a normal person and I don't like to be treated like crap" seems to reference the previous conversation regarding treatment. Although he did not participate in the previous conversation and said he had not heard of the desire to be "treated like a normal person", his comment indicates a powerful connection between the way people are treated, and whether they are recognised as "normal". The inference within this statement is that to be categorised as "not normal" means to be "treated like crap".

Natalie did not go as far as Luke when asked whether she would describe herself as having a disability; however, she expressed a similar sentiment:

Natalie:        I mean, yeah I mean, I know I've got a disability but, you know, I've never wanted to be treated like a person with a disability... and I've always said that to everyone that I pretty much know.

Natalie's opening comment "yeah I mean, I know I've got a disability" comes across as somewhat defensive; she accepts the disability label in a way which suggests it is not a desirable form of recognition. She comments further "I've never wanted to be treated like a person with a disability ... and I've always said that to everyone that I pretty much know", once again drawing out the connection between "treatment" and the disability identity.

When questioned further on what it means to be "treated like a person with a disability", Natalie commented "well you get like a lot of support", noting

that when you do not have a disability you would probably only get support from family and friends, as opposed to having a support worker like her. Later on in the hui, Natalie drew out the idea of being “treated like a disabled person” further:

Natalie: ... a lot of people that don't have a disability have jobs. And few of us don't. So we get treated differently like, people with disabilities and people not with disabilities think that we can't get a job, like we're useless, you know, there's no way we can get a job. But we can, people with not disabilities don't give us a chance.

Ingrid: Mmmm. Thanks, that's a really good example.

Glen: Yeah.

Natalie: That's how we're treated differently because I mean, when I watched [a video about Taylor looking for a job], and how long Taylor's taken to get a job, you know it, it does hurt. I mean. I'm still look-I'm still looking for a job and that takes a while and yes I've got disability but you know a lot of people that don't have a disability they've all got a job, you know, takes them, you know, CV in, get a job, you know.

Ingrid: Mmm.

Natalie: As well as um, qualifications, you need a lot of qualifications and things to get jobs.

Ingrid: °Mmm°

Natalie: And it's hard for us to learn.

In these statements, Natalie is able to clearly articulate the differing treatment offered to non-disabled people. As she comments, “a lot of people that don’t have a disability they’ve all got a job, you know, takes them, you know, CV in, get a job”, suggesting that it is comparatively much easier to find a job when you do not have a disability. She further elucidates the issue of employment, observing that “you need a lot of qualifications and things to get jobs”, yet “it’s hard for us to learn”. The difficulty which Natalie faced in finding employment was shared by most of the participants in the hui, including Taylor, who had a TV show made about her long, multi-year search for a job which was eventually successful. When Taylor was asked whether she would describe herself as having a disability, she gave a different response to Luke and Natalie:

Taylor: Um, sometimes.... I do, I feel like I've got a disability but um, I think like when I do things around disability and like today and other stuff but, I think because I just wanted a whole year of, well, some of the year off like all disabil-, some disability stuff. Because like, um, I've just wanted to be treated as normal as possible, and um, I think the only part of this year that I thought of really having my disability bad is me trying to look for a job.

In this statement, Taylor appears to accept the disability identity, commenting “I feel like I’ve got a disability”. However, like Luke and Natalie she references the idea of “treatment”, stating “I’ve just wanted to be treated as normal as possible”. The wording “as normal as possible” is noteworthy; once again the idea of being treated like “normal” is restated as preferable. However, Taylor’s response indicates that it is not fully possible to be treated “like normal” when you have a disability; thus her comment “as normal as possible”. Throughout the

hui, Taylor commented that she saw herself as living in two different worlds. In hui two she observed “like with me I feel like I've got two different worlds. Like I live in two different worlds. So one's um, around disability, like it's around disability stuff. And then the other one's, um, life without a disability”. Her statement “I just wanted a whole year of, well, some of the year off like all disabil-, some disability stuff” references her desire to spend less time in the world of disability, and more time in the second, non-disabled world where she can be “treated as normal as possible”.

Both Jonathan and Gary also discussed the notion of treatment when asked whether they would identify as having a disability:

Jonathan: Um, I actually um, for my life since I was a kid and now um, I'm not known as a disability person.... But um, from years onwards till now um... since when I was a little kid I didn't have a disability because everyone was treating me fairly... When I'm not disabled. I get support when I'm not disabled, as well. I get a lot of things done.

...

Gary: I like to be treated just the same.

Ingrid: Yeah? Would you use the word disability to describe yourself or not really?

Gary: No, not really.

The only participants who did not use the term “treatment” when asked if they identified as having a disability were Carl, who responded with a hesitant “yes”, although I later discovered that Carl had no understanding of what the words “disabled” and “disability” meant; and Karissa, who responded:

Karissa: (Weeesh). Uaahhhmm, for me, I think what Taylor just said. Um (*laughs briefly*), I-, I think I don't have disability because I use able-ability.

Although Karissa preferred the term “able-ability” to the term disability throughout the duration of the hui, she did identify herself as someone who is “different” and who is thus treated differently. She told a story about a recent experience at a shopping centre called Agana<sup>22</sup>, observing:

Karissa: Some people in Agana, and they say, saying stuff about me and they were always looking at me. And I said... I turned my head around and I said what Taylor has just said (*she moves her eyes to the left, staring at the person next with a look of intrigue on her face*) "What are you looking at?". They're looking at me (*she points to herself*), because I'm different person

From these excerpts, it is evident that several participants did not recognise themselves as having a disability. Furthermore, many observed a connection between the way a person is treated and whether they are recognised as “normal” or “not normal”. Statements included “I'm a normal person and I don't like to be *treated* like crap”, “I know I've got a disability but, you know, I've never wanted to be *treated* like a person with a disability, “since when I was a little kid I didn't have a disability because everyone was *treating* me fairly”, “I like to be *treated* just the same”, and “I've just wanted to be *treated* as normal as possible”. This connection was almost certainly impacted by the entanglement of the previous discussion within these intra-active moments.

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<sup>22</sup> Pseudonym

When viewed through the lens of rational humanism, it is not difficult to understand why participants would want to be seen and treated “like a normal person”. Although most participants were unable to articulate what it meant to be “treated like a disabled person”, they seemed to understand that it meant being treated “differently”, and that “different” treatment meant worse treatment. Observations of this differing treatment included being stared at in public, having immense difficulty finding a job and having greater difficulty attaining the “qualifications and things” necessary for obtaining employment. With these remarks, participants appeared to be pointing to the issue which was outlined in the opening chapters of this thesis; that is, that being recognised as disabled and thus positioned as “other” to the ideal norm, has negative material consequences. As I argued in Chapter Two, people placed in a subordinate identity category are at risk of social exclusion, and are further “subjected to normative pressure to become more like those who are read as normal” (De Schauwer, Van de Putte, Van Goidsenhoven, et al., 2017, p. 1). In this sense, the desire to “pursue normal” can be understood as an entirely rational pursuit.

However, when these statements are read using Mazzei’s (2016) work on *Voice without Organs (VwO)*, a different understanding of the situation comes to the fore. As noted in Chapter Six, VwO is conceptualised as an assemblage which is a complex network of human and non-human agents that exceeds the traditional notion of the “individual,” the “body,” the person” (Mazzei, 2016, p. 155). This understanding does not see voice as emanating from a rational, humanist subject who understands what they mean and speaks with full intention (MacLure, 2008). Instead, as Mazzei (2016) notes, “[t]here is no separate, individual person to which a single voice can be linked – all are entangled” (p. 158). Voice can thus be understood as an entangled phenomenon within the ongoing intra-activity of life, and within the ongoing entanglements of disability.

The “voices” of participants in these excerpts appear to be mobilising a much wider force evident in society – that of the desire to preserve the normative categories of ableism, and to be recognised as belonging in this desirable group. The desire to be recognised and treated as “normal” can be

understood as an entanglement which emerges through, and has agency in shaping, the ongoing, normative orders of life. However, two problematic issues appear when looking at this phenomenon through the question of *what does this do*. First, the desire to preserve normal reaffirms the ascendancy of ability, and simultaneously serves to uphold the positioning of disability. Thus, although the desire to be “treated as normal” can be seen as a desire to escape the processes of otherisation and the inferiority of the disability identity, this strategy holds the effects of “othering” in place.

Secondly, these processes elide the interdependence of the notions of “abled” and “disabled”. As outlined in Chapter Two, notions of “abled” (or “normal”) and “disabled” are born from and grafted upon each other – neither term can exist without the other (Campbell, 2009a). Disability serves as the requisite “constitutive outside” (Campbell, 2008b) – the “other” to the ideas of rationality, able-bodiedness and normal IQ. In the desire to preserve “normal”, the ability to point to and challenge the vacuousness of this term is foreclosed.

## The Pursuit of “Ability”

A second, similar strategy to that of pursuing “normal” is the desire to “focus on abilities”. The desire was particularly notable in Jonathan, shown in the following extract from hui two:

Ingrid: How did you guys describe disability?

Jonathan: You use ability. Because ability is a good thing.

Ingrid: Yep. Can you tell me more about that?

Jonathan: Sure. Ability is like doing good things. Like if you’re doing something in the community. Like able to do things. Around town. And for abilities to people to know about how you can go around town and do things. Even though you have a



disability you are your own person. And um, from that you can um, do things more differently.

Ingrid: Yep. So what does that mean?

Jonathan: It means you can do things equally, like work in a team, work by yourself or work independently. And um, if people has a disability they have jobs or courses they do and they are proud of that and that's so people who can um, who can help others regularly more often than daily basis. And um, what ability means for as well it's um you can do things alone if you want to. And I had these meetings about you can choose your decisions wisely and um, you can use your, like make your life more easier.

When viewed through the lens of VwO, these statements can be seen as the embodiment of normative orders, particularly those connected with disability. For instance, Jonathans comments include “doing something in the community”, “work independently”, “if people has a disability they have jobs or courses they do”, “who can help others regularly”, and “do things alone if you want to”. Many of these statements align with the ideas presented in the principle of normalisation and social role valorisation, as outlined in Chapter Three. These frameworks encourage the dispersal strategy, placing a strong emphasis on participation in “the community”, as opposed to segregated settings where learning disabled people socialise exclusively with other learning disabled people and support staff (H. Brown & Smith, 1992). Having jobs, attending courses and working independently are considered “socially valued roles”, and are thus activities in which learning disabled people are strongly encouraged to participate. Moreover, many of these statements align with ideas related to

capitalism and ideal subjects; having a job, attending a course with the aim of upskilling towards employment, helping others and working independently (and thus not being a burden on others) are considered desirable activities which showcase one's status as an abled, productive citizen. In short, Jonathan's statements can be seen as the mobilisation of discourses required to showcase one's status as an ideal citizen.

Jonathan's preference for the word "ability" over "disability" was stated repeatedly throughout the hui. For instance, in hui eight, Glen asked "what does everyone think about ideas of disability pride?". Jonathan answered:

Jonathan: A-Bility pride. Um, ability pride is important because using able and, you get to do things more often. That's why I'm sticking to the word ability.

However, Jonathan was not the only participant to evidence a desire to focus on abilities. For instance, as noted earlier, Karissa stated "I think I don't have disability because I use able-ability", a term which places double-emphasis on the notion of able. Natalie also stated "I think that everyone with disability has actually got their own *ability* ((with emphasis on the word)) in things, so I think that's quite important". Natalie's statement "everyone with a disability has actually got their own *ability*" references an idea which was pointed to by many participants during the research. Regardless of whether or not the participants identified as disabled, many commented on their desire for everyone to be seen as abled. For instance, while giving feedback to participants in hui eight about the findings from the research, the following conversation happened:

Ingrid Um I've noticed that, lots of you like to use the word ability to describe yourself.

Karissa: ((nods while I'm talking))

Ingrid: Is that?

Jonathan: I just like the word.

Ingrid: You just like the word, you wouldn't use it to describe yourself?

Jonathan: I just like the word that describes everyone

...

Glen: I actually agree with Jonathan actually because we are all able to do things, but um, but yeah we all have disabilities that actually have, um, ability to do all of that stuff.

In this conversation, both Jonathan and Glen valorise the word “ability”, stating it should be used as “word that describes everyone”, and that “we [the participants] all have disabilities that actually have, um, ability to do all of that stuff”. Thus, although the participants did not view disability/ability as a binary, where one sits in one category or the other, they nonetheless upheld the notion of “ability” as preferable – as the ideal which is “naturally” superior.

Ultimately, the drive to be viewed as “normal” and to “focus on abilities” are strategies designed to focus on the *sameness* of disabled people, rather than celebrating *differences*. This desire to focus on abilities is a common strategy employed in the disability rights movement, as discussed briefly in Chapter Four. As Parsons (1999) notes, the disability rights movement has:

[B]een a movement that, rather than celebrating the *difference* of its members from the rest of society has instead asserted the “sameness”. It has, therefore, focussed its efforts on demanding the sorts of services and supports that might enable that “sameness” to be realised. (P. 28)

As with the focus on “normal”, the drive to “focus on abilities” appears to be a desire to reject the processes of otherisation, which position people labelled as disabled in an inferior category – as “other” to the ideal norm. As Natalie commented earlier, “we get treated differently like, people with disabilities and

people not with disabilities think that we can't get a job, like we're useless". However, when examined further, this strategy can be seen as a practice which disempowers in the guise of empowering (Wetherell, 2012). In particular, the drive to "focus on abilities" can be seen as part of the strategy to focus on the "common humanity" of disabled people. Bunch (2017) outlines how the approach of focusing on sameness fits into a wider process known as the "politics of assimilation". The politics of assimilation underlies many rights movements, including feminist politics and mainstream LGBT movements (Bunch, 2017). These approaches, according to Bunch (2017) are grounded in Kantian ethics, which "requires sameness for ethical recognition" (p. 133). Within the drive to focus on the "common humanity" of a person there is an unsaid implication that there is a need to emphasise a person's common humanity or sameness; this statement is never applied to someone without a disability. The emphasis on sameness in these statements implies that there is some form of deficit to overcome. As Pryde (2015) asserts:

You see, my being human is rather obvious and I am certainly no less human because I was born with unique neurology [autism], so the need to emphasize my common humanity seems wildly redundant. (para. 8)

The strategy of focusing on sameness thus appears to unwittingly perpetuate ideas related to disability and diminished personhood.

The desire to be recognised as an abled subject, as well as the desire to focus on the abilities or common humanity of disabled people, is something so well-established in many Western societies that it is often seen as something entirely "natural" or "logical". It is something that I have encountered so frequently in my years in the disability support sector that I have had to develop a skill-set of language that enables me to navigate these practices. I have learnt how to talk with people about the support they need, as well as write support plans for them, without ever mentioning the reason why we provide support – that is, the person's disability. In my years as a service coordinator, I would often

receive referrals for new clients which would state that the person does not like to be described as disabled, and that it is important we do not use the “disability” word when meeting the person. These statements were never questioned by those of us who worked with the people – we simply seemed to accept the “natural” desire not to be recognised as disabled.

This drive to “focus on abilities” can be seen across the disability community, support and business sector. For instance, a quick Google search on May 17, 2017 for “able nz” brought up: “Able”, the “television captioning and audio description service for hearing and vision-impaired audiences” (NZ On Air, 2017, top para.), “able”, a service provider for people with mental illness (able: Southern Family Support, 2015), “ableaccess”, a company which provides ramps (ableaccess, n.d.), and “accessible”, a company which offers “services that enhance independent lifestyles and equipment management” (accessible, 2017, para. 1). All of these services came up on the first page of search results.

This phenomenon of calling services “able” (as well as, for some unknown reason, not capitalising the first letter in “able”) is not limited to New Zealand. For instance in the United Kingdom there is a magazine called “able: Your favourite disability lifestyle magazine” (able, n.d.), and in Australia there is a company called “able australia”, a “non-profit organisation that provides services to people living with multiple disabilities” (able australia, 2015, para. 1). It appears as if “able” is the favourite word at the moment for anyone wanting to start up a disability service, or a magazine for their disability service.

In contrast to the focus on sameness, Bunch (2017) draws on the work of Kristeva to present a different view of ethics. While Bunch has reservations about Kristeva’s work, she also finds points which give her pause, including the assertion that “variability is the essential characteristic of all humanity” (p. 142), and that the denial of the heterogeneity of human embodiment is a denial of our own embodiment. Drawing from this, Bunch (2017) argues further that the denial of heterogeneity:

[L]imits possible ways to imagine the good life, understand what it means to be human in all our diversity, design the kinds of social

institutions that would allow all people to flourish, value different kinds of social contributions, and organize human life to engage relationships of interdependence and care for each other. (p. 138)

Instead of focusing on sameness, a Kristevan approach to ethics is “structured by a transformative openness to heterogeneity” (p. 133), and furthermore “positions diverse embodiment as a potentially powerful force of transformation to late capitalism” (p. 135).

Furthermore, in returning once again to the Deleuzian question of *what does this do*, a key question arises. That is, how are we to challenge exclusionary structures and practices related to disability, without focusing on disability? It takes somewhat of a leap of mental gymnastics to ensure that disability is factored in to new building designs, or in to the design of “inclusive” classrooms, without directing one’s attention towards disability. How are we to design a world that is truly inclusive for all, without actively thinking about those who are excluded, and the differences which lead to exclusion?

The third problematic strategy related to recognition and the disability identity will be explored in the following section – that of rejecting disability.

## Rejecting Disability

Social performatives are an ongoing part of our everyday lives, and they are of fundamental importance if we are to “exist” as socially viable beings (Butler, 1997b). However, performatives are not generally executed on a conscious level (Butler, 1997b). Part of the power of performatives is in their “everydayness” which renders them naturalised and difficult to see (Butler, 1990). It is often only when a performative is *not* repeated as usual, that such a repetition becomes apparent. On the following page, I highlight a moment from the hui in which a performative became evident when it was not repeated as usual.

The conversation between Johnathan and Taylor on the following page arose shortly after I finished my “speech” in hui six. This speech was given in response to participants’ adverse reactions to the discussions on disability pride

in hui five. We had been discussing what the participants would like to do after my speech, and Jonathan suggested that he would like everyone to do an activity as one group (rather than split into two), but that he did not want us to talk about disability. I questioned how we were going to talk about disability pride if we did not talk about disability, and repeated something which I had previously said in my speech. The conversation progressed as below:

Ingrid: I think the reason that disabled people aren't treated fairly, and the reason that disabled people get bullied and have a really hard time finding a job is because we think there's something wrong with being disabled. And talking about disability and thinking about disability makes us uncomfortable and it makes us sad and it makes us upset. But I think that it's that feeling *((I touch myself on the chest))*, where we feel uncomfortable or sad or upset. I think that feeling is the reason that we think it's OK to treat disabled people worse.

Carl: No.

Jonathan: I don't want to be disabled anymore.

Ingrid: No?

Jonathan: *((Looks down at the floor and shakes his head. Speaks quietly))* Not anymore. I just had that thought, for years now that I want that to happen.

Ingrid: Yeah<sup>23</sup>.

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<sup>23</sup> In New Zealand, 'yeah', 'mmm' and other statements of agreeance are often used to indicate to the speaker that you acknowledge what they are saying and support the right of the person to talk, rather than indicating that you agree with the person.

- Jonathan: *((Speaks quietly))* I want, I don't really want to be disabled anymore.
- Taylor: Jonathan I've sometimes, sometimes I've felt like, I've been thinking to myself why did this happen to me, like why was I the one in, well my uncle's got a disability. But why am I the one in my family that's got the disability but then I also think what's, um, what opportunities I've had living with a disability and I've like had heaps of opportunities. So just like think of what you might not have if you don't have a disability.
- Jonathan: Oh I don't really have one [a disability].  
Um, I can do actually heaps of things, like talk to mates and catch up, go for a drink, like, hang out with my brother a lot.  
Things I can do more. If I'm not disabled.  
That's easy fix.

With this statement, "I don't want to be disabled anymore" Jonathan appears to be attempting to step out of his inferior subject positioning by declaring himself to no longer be such a subject. Despite Taylor's ardent attempt to help Jonathan take a more positive view on disability, Jonathan continues in his positioning, commenting "Oh I don't actually have one". However, despite Jonathan's attempt to reject the disability identity, he does not truly escape the ongoing processes which position him as disabled. His statements are an unsuccessful form of resistance to the processes of inferiorisation; they do not successfully disrupt the processes which hold Jonathan in an inferior position, and do not disrupt the material consequences of his inferior subject positioning. Instead, this statement furthers the positioning of disability as an undesirable category.



Davies et al. (2013) note that in order to be a recognisable subject, we need to perform ourselves “within the terms that constitute us” (p. 683); we cannot stand outside the discourses and other intra-active phenomena which constitute us (A. Y. Jackson & Mazzei, 2011). That is, in order to be recognised as a legitimate, viable subject, we must perform ourselves according to a set of citational phenomena including discourses, affective practices, social practices and bodily practices. In short, we emerge as autonomous individuals through “a necessary subjection to the terms of existence” (Davies et al., 2013, p. 681). However, at the same time as these citational chains enable us to be recognised as viable subjects, they also restrict what is considered possible (Davies, 2015); citational chains both enable and restrict the range of discourses, affective practices, social practices and bodily practices that enable us to be recognisable subjects at the given time they are being drawn upon.

In *Gender Trouble* (1990), Butler asserts that gender is performative. She argues further that “the authority on which that performativity depends comes from the constitution of bodies within a heteronormative *matrix of intelligibility*” (Brady & Schirato, 2011, p. 45, emphasis added). This matrix is sometimes referred to as a grid of intelligibility, or simply cultural intelligibility. It is hard to define what precisely forms any given matrix of intelligibility, or put another way, what makes a performative act culturally intelligible. However, it is clear that some of the elements of the matrix become apparent when a performative act fails “to conform to those norms of cultural intelligibility” (Butler, 1990, p. 17) – that is, when these norms are challenged or disrupted, or, as with Jonathan’s statement, a performative act does not successfully reiterate the required citational chains. As Butler (1990) states, when certain kinds of identities fail to conform to the requisite norms of cultural intelligibility, “they appear only as developmental failures or logical impossibilities from within that domain. (p. 17)

Jonathan does not utilise the required tools of recognition within the ableist matrix of intelligibility; he does not perform himself within the terms in which he is constituted, and it is thus a failed performative. Jonathan alone does not have the agency required to shift the constitution of himself as a disabled subject, there are too many intra-active forces holding this identity in place. Nor,

as Davies (2008) argues, does Jonathan “need to be aware of the terms of [his] recognition for it to have an effect on who [he] becomes” (p. 31). Butler (1997a) argues further:

[O]ne may well imagine oneself in ways that are quite the contrary of how one is socially constituted; one may as it were, meet that socially constituted self by surprise, with alarm or pleasure, even with shock. And such an encounter underscores the way in which the name wields a linguistic power of constitution in ways that are indifferent to the one who bears the name. (p. 31)

In the box below, I highlight how these processes operated through me during the encounter with Jonathan, shaping the possibilities for thought in relation to Jonathan’s identity.

When Jonathan said “I don’t want to be disabled anymore”, and then “Oh I don’t really have one [a disability]” I initially found myself thinking that Jonathan was not properly participating in the processes of his subjectification. That is, Jonathan does not understand that he *is* disabled, and that he cannot simply choose not to be. I found this an intriguing thought; one which did not seem to match with the very arguments I pose in this thesis about disability being a social construct which does not innately exist in the world. What was happening here?

This thought process<sup>24</sup>, I have now come to realise, is a powerful example of how the entanglements of disability – including the ableist matrix of intelligibility, operate through me. These entanglements hold agency over shaping how I see myself and “others” in the world. This is not an “I” making a rational, intentional choice about whether someone is or is not disabled. Rather, it is a thought process which highlights a powerful force in the ableist matrix of intelligibility – that if you have certain forms of difference that are categorised as

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<sup>24</sup> While “thought process” implies a purely cerebral phenomenon, I am aware that this process would have happened in my “bodymind” (Price, 2015) and involved much more than a cerebral process.

disabled (in this case, Down Syndrome), you cannot escape that categorisation. This force is so powerful that its agency over how I think and see people is almost impossible to escape, even when I try to.

One of the ways in which the matrix of intelligibility works is through norms; these are the normative orders which were discussed earlier in this chapter. The desire to be seen as “normal”, and to “focus on abilities”, showcase some of the normative orders of disability. De Schauwer and Davies (2015) define norms as “a pattern regarded as typical, as the way things happen, or are said to be” (p. 85). They note further that “[t]he norm comes to be what is expected, and the expected slides quickly toward moral judgement, where *is* has turned into *ought*” (p. 85, emphasis in original). Performing ourselves within the terms of these norms, or normative identity categories, is essential for a performance to result in recognisability; if we do not perform ourselves according to these norms, our performatives fail and we cannot accomplish ourselves as recognisable subjects. Because we depend on norms for our very existence, “we come to *desire* them, and to desire to preserve them” (Davies, 2015, n.p., emphasis in original). As Davies (2015) states “[i]n that very process of coming to be, and continuing to be, we necessarily take up as our own those normative terms through which we become, and go on becoming, recognizable.” (np).

One of the normative identity categories through which humans are judged as recognisable is that of ableism. Like gender, ableism can be viewed as “a culturally sanctioned performance, a requirement that a body coheres, and continues to cohere, according to certain norms of intelligibility” (Brady & Schirato, 2011, p. 45). Ableism operates as a binary, requiring “the abjection of the qualities of the subordinated other” (Davies, 2015, np) when taking on a normative identity. This means that in order to perform ourselves as a recognisable subject, we must perform ourselves within the ableist matrix of intelligibility; on the current terms of ableism, this matrix requires both the devaluation of disability, and the valorisation of the corporeal ideal. In short, performing ourselves based on the terms of ableism means to perform ourselves

on terms which devalue disability. This is evidenced not only in Jonathan's outright desire to reject his disability, but also in the other participants' desire to be seen as "normal" and "abled".

## Disrupting the Conundrum

The processes outlined in this chapter appear to leave people labelled as disabled with a conundrum. Attempts to reject the disability identity are often rendered unintelligible. The disability identity is not a construct which can be escaped in the current context; we cannot stand outside the discourses and other intra-active phenomena which constitute us (Jackson & Mazzei, 2011). As Davies et al. (2013) note, we must perform ourselves *within* these very terms in order to be considered viable subjects. Yet, if Jonathan was to successfully participate in the processes of subjectification – that is, if he was to accept the disabled subject positioning, this would mean he would be acceding to his place as an inferior subject, complete with the concomitant material consequences. As Butler (1997b) asks:

How is survival to be maintained if the terms by which existence is guaranteed are precisely those that demand and institute subordination? On this understanding, subjection is the paradoxical effect of a regime of power in which the very "conditions of existence", the possibility of continuing as a recognizable social being, requires the formation and maintenance of the subject in subordination. (1997b, p. 27)

Furthermore, the alternative strategies of focusing on "normal" and "ability" reaffirm the existence of the ableist binary, and uphold the inferior positioning of disability within the binary. None of these strategies challenge the position of disability as "other" to the ideal norm, and none of the strategies challenge the material consequences of this positioning. The capacity to harness the agency necessary to challenge the processes of otherisation, and exclusionary practices and structures related to disability, is largely foreclosed. The question then arises as to how one can escape this conundrum.

In this thesis, I argue that rather than attempting to reject the notion of the disability identity, or to focus attention on the sameness of disabled people, a greater level of agency can be harnessed by embracing disability. This entails working *with* the ableist matrix of intelligibility and accepting the disability identity. This strategy seeks to harness the power of the matrix whilst transforming its constitution; by performing ourselves within the terms through which we are constituted, and, simultaneously, taking this constitution onto a new line of flight. As Parsons (1999) highlights, this is effectively what was done in the gay and lesbian rights movement; people rejected the idea that their identity was a source of inferiority, and embraced the queer/ gay/ lesbian (etc.) label. Parsons (1999) argues further that the strategy of asserting pride in identity is the first crucial ingredient in any successful rights movement; it is “a radical way to respond to discrimination because it takes the very basis of oppression, turns it around, and uses it as the basis for pride” (p. 3).

Showing pride in the face of bullying, a social practice which often seeks to reiterate the inferiorisation of particular identity categories, was attempted in hui six and seven with the bullying role plays. These role plays were discussed in Chapter Seven, and were connected to literature from Foucault (1980) and Butler (1990), related to the potential for disruption at the moment of citation. That is, the moment of repetition, whereby a (gender/disability/race etc.) identity is recited, is the achilles’ heel of power in the ongoing processes of subjection (Buchner, 2015). It is in this moment that the possibility for rupture lies. As Butler (1990) notes:

Indeed, precisely because certain kinds of “gender identities” fail to conform to those norms of cultural intelligibility, they appear only as developmental failures or logical impossibilities from within that domain. Their persistence and proliferation, however, provide critical opportunities to expose the limits and regulatory aims of that domain of intelligibility and, hence, to open up within the very terms of that matrix of intelligibility rival and subversive matrices of gender disorder. (p. 17)

The disability identity can thus be understood as a tool for rupture in the iterative entanglements of disability; one which can harness the possibilities for becoming which are remade with each moment (Barad, 2007).

## Conclusion

This chapter has explored the entanglement of the disability identity and the desire to be recognised as a viable subject. Three key phenomena which arose during the hui were discussed; the desire to be seen and treated as “normal”, the drive to “focus on abilities”, and the desire to reject the disability identity. Each of these phenomena can be understood as a desire to reject the processes of otherisation, which position those labelled as disabled in an inferior position.

By drawing upon Mazzei’s work on VwO, the “voices” of participants can be understood as an agentic phenomenon within the ongoing entanglements of disability. In particular, the statements from participants can be viewed as the mobilisation of forces evident in wider society – that of the desire to preserve the categories of “normal” and “abled”, and to be recognised as belonging in these ascendant categories. These processes present several problematic issues. First, they appear to reaffirm the existence of the ableist binary, inescapably positioning disability as inferior. Second, these processes keep hidden the mutual interdependence of the notions of “disabled” and “abled”, foreclosing any challenge to the truth-claims related to the notion of “normal”. Third, these processes play into the “politics of assimilation”, focusing on the *sameness* of disabled people, rather than celebrating *difference*. This practice unwittingly perpetuates the connection between disability and diminished personhood. Furthermore, these practices raise questions as to how we are to challenge exclusionary structures and practices related to disability, without focusing on disability.

In summary, the practices outlined in this chapter present something of a conundrum. By focusing on “normal” and “abilities”, one reaffirms the existence of the ableist binary, upholding the inferior position of disability within the binary. Yet attempts to reject the identity are often unsuccessful, as they do not

work with the matrix of intelligibility. In this chapter I have argued that rather than attempting to deflect attention away from disability, or reject the identity, a greater level of agency can be harnessed through embracing the identity. Embracing the disability identity works with the matrix of intelligibility, challenges the terms through which disability is constituted, and asserts that this identity is not a source of inferiority. The notion of identity can thus be viewed as a tool which holds potential to rupture the problematic iterative entanglements of disability, and take them off onto a new line of flight.

# Chapter 10:

## The Entanglements of Silence

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This chapter explores one of the problematic iterative entanglements which arose during the hui – that of silence. This entanglement will be analysed by examining participants' understanding of disability, alongside Butler's work on performativity and the framework of desiring silence. In particular, the entanglements of silence are examined alongside the desire for belonging, and the constraints of the normative order. What these entanglements produce and present potential for will be discussed.

### **A Lack of Knowledge about Disability**

This chapter begins by exploring participant's understanding of disability. In hui two, participants were asked to define disability. As part of this exploration, participants were asked to describe someone they know who has a disability, and someone they know who does not have a disability. Carl's response is of note:

Ingrid: So do you know someone who you know is disabled? Can you think of someone you know is disabled?

Carl: What is it?

Glen: Someone who is disabled like you, me, everyone here (*there is no noticeable response from anyone*)).

Carl: OK, um, yeah well I um, I two friends a long time.

Ingrid: Yeah?



Carl: Yeah I remember I hang out with Jonathan and Felix<sup>25</sup>, long time. And we, yeah my mum and I going to, yeah we go to um (inaudible), yeah we go this- this place. Yeah we go to this place and the people (inaudible) people (inaudible) and Jonathan ((*looks at Jonathan*)) to long time. I um, --hang out (inaudible) long time.

Ingrid: So one of those people that you were just mentioning we- do you-, is one of them disabled, would you think one of them is disabled, or not?

Carl: Maybe.

In Carl's response, "what is it?" he appears to be directly asking what "disabled" is. Glen replies "someone who is disabled like you, me, everyone here", and Carl goes on to tell us a story about some friends, including fellow participant Jonathan. Glen's answer to Carl's question does not seem to suffice for Carl, as he responds with an uncertain "maybe" when asked if he would think of one of his friends as disabled. A few minutes later when Carl was asked to identify someone he knows who is not disabled, he again inquired "what is it?". These answers suggest that Carl has little-to-no knowledge of what the term "disabled" means, a surprising situation for someone who has been labelled as disabled, and who lives in a learning disability support service. A similar situation can be seen in responses from other participants. For instance, when asked to identify someone who is not disabled, Luke responded, "no I don't know anybody that isn't disabled", and Gary identified his girlfriend, a woman who uses learning disability support services.

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<sup>25</sup> Pseudonym used

Furthermore, many of the participants seemed to have a lack of knowledge regarding their own disabilities, as highlighted in the conversation excerpt below:

- Glen: Hey Jono, ah, because that you are the first born out of your family, right?
- Jonathan: Yeah.
- Glen: How did you end up being disabled in that family and ... your younger brothers are not?
- Jonathan: Ah because I chose to be disabled not, not dis-not using having a disability because um, I've, when I first came in the world um I did not have a disability then. Um, now I am now because I was diagnosed cuz since I was five.
- Ingrid: Mmm hmm.
- Jonathan: Then I was diagnosed with Down Syndrome. Yeah.

These statements from Jonathan, “when I first came in the world um I did not have a disability”, and “I was diagnosed cuz since I was five... Then I was diagnosed with Down Syndrome” indicate that he is aware of the label of his diagnosis, however, he is unaware of the particularities of this condition; that is, a label that is assigned well before the age of five. The specific mention of age may be important here. Most children in Aotearoa New Zealand start school when they turn five, so this may have been the point at which the materiality of his diagnosis first became apparent to Jonathan; that is, the point at which the “difference” of his disability came to matter in Jonathan’s life. It is likely that Jonathan would have been subject to “special” conditions to aid him in the classroom, such as having a teacher aide and an individualised education programme. Whilst these supports would be intended as helpful, the material

outcome is often a positioning of children as “different”. Starting school is a time in which many children encounter the “othering” effects of their difference, particularly as it becomes harder for children categorised as learning disabled to “keep up” with the expectations set in the curriculum.

Jonathan’s seeming lack of knowledge regarding his own diagnosis poses some questions regarding the information he has received about his condition. What has he been told about Down Syndrome? Why does he have such a poor understanding about the particularities of his condition? Who has been talking to him about his condition, who has not, and when are these conversations happening, if at all? A similar situation regarding lack of knowledge was presented by the co-facilitator, Glen, who also has Down Syndrome. During the preparatory phase of the research, I asked Glen what impact Down Syndrome has had in his life, to which he responded “I wouldn’t know anything about that”. Later on that meeting, Glen and I had a conversation about why he found some of the words in the script hard to say. Initially, Glen said that he did not know why he found the big words hard to read; however, when asked if it could be because of his disability, he said yes. Glen was also diagnosed with a serious food intolerance as a teenager, and regularly confused his food intolerance with Down Syndrome, at one point mentioning that he was diagnosed with Down Syndrome as a teenager.

It seems therefore that a large number of the participants lack knowledge regarding the term “disability”, and their own diagnostic labels in particular. This lack of knowledge exists despite all participants receiving support from disability support services, and despite the significant material consequences they face because of their positioning in a society designed for the corporeal norm. This situation indicates that there are some profound silences in the lives of the participants regarding the topic of disability.

This view of silence was further informed by my own “reflections” regarding my practice as a support worker, and my practice during the hui. I came to realise how much I participate in these silences around disability; at no point did I say to Jonathan that Down Syndrome is diagnosed either prenatally or

at birth, or have any conversation about what the term might mean, despite what seemed to be a gap in his knowledge. Indeed, prior to conducting the hui, I cannot remember a single instance of having a conversation with anyone I supported about their disability. I have worked with hundreds of people in various capacities, including in a position where I wrote support plans about the support that people needed because of their disability. At times I went to great lengths to avoid writing about the person's disability, or speaking about a person's disability with them, unaware of why I did this, only knowing that it was something that must be done. Speaking with someone about their disability was such a challenging practice for me that I made a diary note about it after the conversation with Glen, where he told me that he "wouldn't know anything" about his disability: *"The fact that we were able to have that conversation today and that I was able to say to Glen about his being bad at reading is a sign I guess of our relationship building and the immense trust we have. I have to trust in Glen (I guess in his trusting of me?) to be able to say to him about his disability, where in the past I haven't felt it was something I could address with him"*.

These particularities of the phenomenon of silence in both participants and me were illuminated further when read diffractively through the framework of *desiring silence*.

## Desiring Silence

In Chapter Four I outlined the framework known as *desiring silence*, which draws upon the Deleuzian notion of desire. Contrary to Lacan, Deleuze does not view desire as something which emanates from the desire to fill a need or a lack (Jackson & Mazzei, 2011; Mazzei, 2011). Nor is it seen as a force which emanates from a rational, intentional subject; that is, as something which indicates an individual's true self, wants and needs (Laws, 2011). Instead, desire is viewed as a productive force, "a coming together of forces/drives/intensities that produce something" (Jackson & Mazzei, 2011, p. 92). Desire produces other forces and phenomena, including privilege, power, voice and, of particular

interest here, silence (A. Y. Jackson & Mazzei, 2011). Jackson and Mazzei (2011) view desire and silence as two phenomenon which at once produce and rely on each other. They note further that this production functions “much in the same way that power/knowledge operates for Foucault, [in that] they express each other, rely on each other, and produce something that is not singular to one or the other” (p. 102). Desiring silence can be viewed as an entanglement formed through the ongoing intra-activity of life, an entanglement which both shapes and is shaped by collective narratives, images, and metaphors, and by our experiences over time (Jackson & Mazzei, 2011; Laws, 2011). As with all entanglements, these are not viewed as being the same twice over. Each entanglement changes with each intra-action as “space, time and matter do not exist prior to the intra-actions that reconstitute entanglements” (Barad, 2007, p. 74).

Working with the notion of desiring silence means to question what is producing the silences around disability, and what these silences, in turn, produce. It means, as Jackson and Mazzei (2011) state, “to consider the forces of desire that are acting through and with our research participants, and to make sense of what results from such interaction” (Jackson & Mazzei, 2011, p. 91).

Whilst desiring silences appear to operate through all who participated in the hui, they were particularly evident in Jonathan. In hui seven, he expressed how desiring silence operates through him:

Jonathan: Um there's a um a few things about being disabled um, like, like for example with someone was saying that to me [that he is disabled]. And um, and I would say um, I don't care I am who I am.

Ingrid: Mmm hmmm.

Jonathan: I don't care if I'm disabled or not. Um, I just stop thinking about it when it comes back up. Because it's a good way to

change, like, it's good to start something new.

Ingrid: Sorry what do you mean by that?

Jonathan: Cuz um if someone's doing that to you, and you're not trying to think about it. And um, you just, I just move on. And do something positive.

Jonathan's comments "I just stop thinking about it when it comes back up", and "you're not trying to think about it... I just move on. And do something positive" indicate that when thoughts about disability "come up", he attempts to silence those thoughts by endeavouring to "stop thinking about it", "move on" and "do something positive". He informs us further that these "positive" activities include "going out to the community and hanging out with mates and hanging out with family", as well as going to the Special Olympics competition he had the following day. In considering "the forces of desire that are acting through and with" (Jackson & Mazzei, 2011, p. 91) Jonathan, it appears that desiring silence is productive in shaping Jonathan's thoughts, words and actions. He informs us that he is actively "not trying to think about" disability. It appears that Jonathan either has a lack of knowledge regarding the particularities of his diagnostic label, or finds it so difficult to talk about that it comes across as a lack of knowledge. Furthermore, these issues appear to stem as much from him actively seeking these silences, as from the silences of other people around him.

Desiring silence was also spoken about by Taylor. She informed us that her work colleagues have been told she has a disability, and that they "sort of treat me differently but they also treat me just as someone working there". She comments further:

Taylor: I think it's when people don't really know me, like last night me and Hayley<sup>26</sup> went

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<sup>26</sup> Pseudonym

to this lady's night and this lady was talking really fast and I couldn't understand what she was talking about...But I'm like always, like I don't always want to tell people, can you talk slowly because I've got a disability.

Ingrid: °Yeah°.

Taylor: Because it sort of makes me sad and I don't want them to make a... excuse for me. Like to, make stuff easier for me just because I've got disability. But I think it's when people don't really know me they don't know um.... like if I've got disability or not.

As Taylor notes, she “doesn’t always want to tell people, can you talk slowly because I’ve got a disability”. Taylor’s comments allude to her desire to not be treated “differently” because of her disability. To ask for an accommodation, such as for a person to talk slower or “make stuff easier”, would mean troubling the assumption that she is a “normal” and “independent” young woman who does not need assistance from others. Taylor does not want others to “make a... excuse for me”, suggesting further that she does not want to impose by asking for social accommodations, something which “normal” women are often socialised into spurning.

This idea of desiring “normal” treatment is discussed further in the following section by drawing upon Butler’s work on performativity.

## **Norms and Performativity**

Butler’s work on performativity (e.g., 1990, 1997a, 1997b) helps to illuminate the productive force of recognition, which is needed in order to be constituted as a viable subject. This recognition occurs within a matrix of intelligibility, formed in part within the constraints of normativity (Butler, 1990;

Jackson, 2008). As Jackson (2008) notes, “desire for recognition is in actuality a site of *power* where who gets to be recognized, and by whom, is governed by social norms” (p. 171, emphasis in original). This understanding of recognition has a strong alignment with Mazzei’s (2011) work on silence. As she notes, silence can be understood as “an enactment of a desire to be recognized as governed by social norms” (p. 661).

The desire to be “recognized as governed by social norms” (Mazzei, 2011, p. 661), and to not trouble the idea of one’s status as a “normal” subject, appear to play a powerful role in shaping discourses regarding disability. This is as evidenced by Taylor’s comment earlier, “I don’t always want to tell people, can you talk slowly because I’ve got a disability”. Historically, disability has been a topic which must only be discussed in a limited range of circumstances, and in a limited range of ways, giving the impression that it is a minefield of unspeakable words and topics. De Schauwer and Davies (2015) explicate this issue further, noting the many unspeakable items related to disability:

This complex, multi-directional silence forms a void around which a great deal of work with the people with a disability circulates, making the pathway to embracing multiplicity a complex dance around that which cannot be spoken. (p. 87)

However, it should be noted that progress-gains have been made in this area in recent years, particularly as social media has provided a platform for many disabled people to give voice to their experiences (see for instance Carly Findlay at <https://www.facebook.com/Tune.into.Radio.Carly/>, and Kylee Black at <https://www.facebook.com/Kylee-Black-Public-Speaker-347045309001678/>).

Participants themselves hinted at the unspeakable words related to disability. For instance, Natalie told us a story about a time when she went to the doctors to get a form signed for her annual benefit renewal with WINZ (Work and Income New Zealand), and noticed a word on her form:

Natalie: Well I had to renew, I had to renew mine  
at the doctors and there's this one word



that's on my form that's the kind of like  
the, what they call it the title under WINZ.  
It's like the worst word ever, it's actually  
worse than disability.

Ingrid: What is it, sorry?

Natalie: I don't even want to say it cuz it's horrible.  
It's called mental retardation.

Natalie speaks with great power in these comments about the unspeakable words related to disability – “it’s like the worst word ever”, so horrible that she does not even want to speak it. Natalie seems affronted by this positioning, and she goes on to tell us that she questioned the doctor, “I said to the doctor what [am] I a retard now”, and commented that “it’s harsh”. Jonathan remarked further on the unspeakable words of “mental retardation” within Natalie’s story, stating “it’s not right”. Luke also had a personal story about the unspeakable words of disability:

Luke: I had guys come and see me the [other] day. *((Luke gets quieter and has a snarly look on his face for the following section. He speaks a little muffled))*. You know what he’s called me. He called me a handicapped. You don't call me handicapped like that. I've got a problem with my, I've got behaviours, mental health, mental problems and stuff ... and this guy goes what are you (what are you doing you mental) prick. I said excuse me? So I went up there and said, don't you say it to me again. I've got a disability.

Like Natalie, Luke is affronted at the use of the term “handicapped” to describe him, declaring “You don’t call me handicapped like that”. He tells us that he was “offended” by the use of the word, and comments further “I said you come here and say it to my face, and I says, you better watch your mouth mate, I’m gonna do something stupid... °smack you in the head””. Luke’s comments highlight the powerful affective response he had to this unspeakable word; he threatens to “do something stupid... °smack you in the head””, his offense is so powerfully felt. It is interesting to note that both Luke and Natalie highlighted their preference for the term “disability” in these scenarios. Whilst Natalie consistently identified herself as disabled throughout the hui and displayed a reasonable understanding of what this subject positioning means, Luke did not share the same knowledge base. Instead, he rejected the identity label (see Chapter Seven), and appeared to have a poor understanding of what the label meant, for instance telling us that he does not know anyone who is not disabled. However, in this scenario Luke clearly states his preference to be recognised as someone who has a “disability”, rather than as someone who is “handicapped”.

Butler’s work on recognition and social norms is developed further by Zabrodska, Linnell, Laws and Davies (2011), and Jackson and Mazzei (2011). By pulling agential realism into the threshold of the inquiry, these authors highlight the way in which the desire for recognition is connected with the desire to belong in the ongoing intra-activity of life. In short, one of the reasons we desire to exist as recognisable subjects, even when existence is on terms which do not offer us a viable life, is because recognition leads to the promise of belonging. For instance, in discussing bullying in neo-liberal universities, Zabrodska et al. (2011) note:

Drawing on the concepts of intra-activity and performativity, we examined bullying in universities as it *informs and is informed by the necessity of belonging*, of being recognized as of value, and the desire to act as one and be seen to act as one who is professional and accountable within a neoliberal environment. (p. 717, emphasis added)

The issue of belonging and disability is discussed by Strnadová, Johnson and Walmsley (2018). As they note, although belonging is increasingly being seen as central to well-being, there is a “striking absence of people with intellectual [learning] disabilities in the wide literature on belonging” (p. 1093). Furthermore, in their focus groups with learning disabled people, many participants noted that disability was viewed as being “a major barrier to belonging” (p. 1098). Another major barrier to belonging was the bullying and prejudice which many of their participants faced on a daily basis; these behaviours were viewed by focus group members as a consequence of their disability (Strnadová et al., 2018).

The connection between belonging and some life-skill programmes for learning disabled people is discussed by Van der Klift and Kunc (1994). As they discuss, the intention of many life-skill programmes is to improve quality of life and create the impression of “normalcy” through increased functioning and skill development. The carrot held up to potential participants is the promise of future acceptance and belonging (Van der Klift & Kunc, 1994); that is, the closer to “normal” one achieves, the greater the promise of belonging. The desire to be recognised within the constraints of normativity and the desire to belong appear to be powerful, performative agencies within the ongoing entanglements of disability. These agencies shape the production of silences regarding disability, ultimately having an effect on the knowledge participants have access to in relation to disability, and on their ability to discuss it in the hui.

## **Silence in Disability Studies**

It is important to note that the entanglements of silence are a known issue in the disability studies literature. Oliver (1990), for instance notes “[o]n the experience of disability, history is largely silent, and when it is discussed at all, it is within the context of the history of medical advances” (p. xi). Lourens (2016) observes that from a very young age, disabled children are socialised into believing that speaking of their disability causes anxiety for others. Disabled people will not truly belong in the world, they hear, unless they make their disabilities invisible (Lourens, 2016). This is perhaps what was being pointed to in Taylor’s earlier comments: “But I’m like always, like I don’t always want to tell

people, can you talk slowly because I've got a disability". In Taylor's statement, being seen as "different" to people without disabilities appears to imply inferior treatment, and perhaps raises questions as to one's sense of belonging.

Lourens (2016) discusses her own practice of silence in relation to her disability. She comments that these silences are largely caused by "the confluence of inaccessible physical and social environments and the psychological internalisation of these worlds" (p. 1). In particular, the proliferation of messages from society which present "whole" and "perfect" bodies as desirable bodies, along with the absence of disabled bodies, serves as a reminder that disabled people fail to meet the standards of "wholeness" and normality (Lourens, 2016). This view could equally be applied to those who fail to meet the standards of "wholeness" and normality in relation to cognitive capacity; although, the particularities of how this would function in relation to invisible disabilities may be somewhat more complex. For Lourens, this view led to the belief that she had nothing of value to contribute and that her voice "carried no real weight and that no one would want to listen anyway" (p. 7). It may be that similar forces were at work in Taylor's desiring silence.

Further to Lourens' comments on the absence of disabled bodies in messages from society, the limited portrayal of disability in the media is noted by many scholars. In 2016, a study was published in which the 800 top-ranking films from 2007-2016 were analysed (Smith, Choueiti, & Pieper, 2016). This study found that only 2.4% of speaking roles were held by people with disabilities, and that 90% of those roles were minor characters. In the instances when disability is portrayed, it is often restricted to a limited trope of images. These include superheroes who overcome their disability (Overboe, 1999), objects of charity (Morris, 1991), passive recipients of (charitable) services (Blackmore & Hodgkins, 2012), and victims (Oliver, 1990).

The issue of what these silences produce will be explored further in the following section.

## What do the Entanglements of Silence do?

In bringing the analysis back to the Deleuzian question of *what does it do*, we can see that the entanglements of silence function to produce many effects in the ongoing intra-activity of life. In particular, these entanglements of silence had a profound effect on the mobilisation of a positive disability identity within the hui, and whether pride was able to be mobilised with the participants. Desiring silence, and the subsequent lack of knowledge regarding disability, served as a territorialising force inhibiting the production of pride.

Many participants did not appear to fully understand that they have been positioned as disabled subjects; most switched between identifying as disabled, not identifying as disabled, and refuting the disability label throughout the duration of the hui. This switch happened with some regularity for several participants, at times within a very brief period. For instance, in hui three, participants were asked whether they would describe themselves as having a disability. Jonathan and Karissa replied:

Jonathan: Um to describe me I don't think I have a disability

...

Karissa: (Weeesh). Uaahhhmm, For me, I think what Taylor just said. Um (*laughs briefly*), I, I think I don't have disability because I use able-ability.

Both Karissa and Jonathan articulate that they “don’t think” they have a disability, a somewhat tentative response, erring on the side of not having a disability. However, in the following question from Glen “can you tell me about a disabled person who is really successful”, Jonathan responded that he and Glen were two successful disabled people he knew. He noted further:

Jonathan: Yeah I think [of] myself as successful person. Successful disabled person. Um because um, recently I've been awarded with trophies, I'm also been awarded being a part of um, sports teams.

In this statement, made only a few minutes after he told us he does not think of himself as having a disability, Jonathan informs us that he thinks of himself as “a successful person. Successful disabled person”. Karissa also demonstrated a change in identity, noting:

Karissa: I think... I am disabled person. My family is successful... they tell me what to do and do the right things. Like ... °can't describe° ... um... I do things my own way... *((she points to herself with both hands))* on my own, by myself. I'm a great able-ability.

In this statement, Karissa both identifies herself as a disabled person, and as “a great able-ability”. This contrasts with her earlier statement, where she told her members that she does not think she has a disability, because she prefers the term able-ability.

There appeared to be a connection between participants' knowledge of disability, and whether or not they identified as disabled. Taylor and Natalie were the only participants who demonstrated a working knowledge of a “common-sense” understanding of disability, which sees disability as a flaw inherent in individuals whose bodies and minds do not “work properly” (Marks, 1999). As Natalie notes:

Natalie: We might be slow at somethings like maybe harder to get a job or, you know,

harder to do courses or something like  
that it just takes a bit of time and more  
help to do things

However, she notes further:

Natalie: I like the word ability in disability because  
all of us people with disabilities we have  
abilities in some form or another.

Throughout the hui, Taylor and Natalie were the only participants who consistently identified themselves as disabled. The remaining six participants appeared to have a significant lack of knowledge or understanding about “common-sense” understandings of disability, as well as their own disabilities / diagnosis. As discussed earlier, Carl in particular did not indicate any understanding of what the word disability means. Although the participant group was small and thus cannot be seen as a “valid representative sample” of the wider learning disability population, there appeared to be a correlation between understanding what disability is, being able to talk about their understanding of disability, and identifying as disabled. The lack of knowledge regarding disability served as a powerful, territorialising force inhibiting the mobilisation of disability pride in the hui; how can you be proud of something, if you do not know what it is?

The entanglements of silence also appeared to be productive in the maintenance of ableism. The absence of discussions of disability leave hidden any discussion regarding disability’s binary opposite – the normal, ideal human. The normative category is able to remain unmarked and un-noticed: a non-identity (De Schauwer, Van de Putte, Van Goidsenhoven, et al., 2017). This phenomenon was alluded to by participants when they were asked what word they would use to describe people who do not have a disability. Participants did not choose the anticipated words such as “normal” or ordinary”. Instead, most participants were unable to find a word, and the two participants who chose

words utilised the terms “lovable”, “encouragement” and “ability”, the latter being a term which they also ascribed to themselves. The difficulty finding a specific term, along with the choice of words “lovable”, “encouragement” and “ability”, are indicative of the unmarked, un-noticed and non-identity of people without disabilities.

Similarly, Mazzei (2011) highlights how desiring silence functions to maintain whiteness as an unmarked identity. As she notes:

Because whiteness has historically gone unnamed and unnoticed as the hegemonic norm, a failure to voice whiteness, or put differently, the choice to articulate one’s white identity by not doing so, is another strategy for maintaining power through a move to maintain the normative (and unspoken) presence of whiteness. (p. 659)

In this quote, “whiteness” can be substituted for “abled-ness”, demonstrating how “abled-ness” is maintained as an unmarked identity. By not speaking of whiteness, or abled-ness, the existing power asymmetries of race and disability remain in force. Elaborating this point further, Mazzei (2011) discusses how desiring silence ensures that those of us in an unmarked identity category continue to view those outside the category as “other”. As she notes, “they are raced, I am not” (p. 661); they are “different”, I am not. Ableist privilege remains unnamed and unchallenged.

Another way ableism is maintained through the entanglements of silence, which is connected to the absent discussions of disability, is in the inability to name and thus challenge ableism. Naming oppression is considered crucial to the struggle against it (Morris, 1991). As noted earlier by Miller, Parker and Gillinson (2004), “if you do not name that which has to be defeated, it will not be beaten” (p. 15). The lack of language and knowledge participants have to understand their positioning as disabled subjects raises some challenging questions: how do people label the problems they face as anything other than an internalised problem of the self, without this language and knowledge? How can people see those problems as systemic issues, and begin to challenge these shared barriers,



when the issues cannot be discussed? How are we to challenge ableism, if we cannot name it or speak about it?

Barad (2007) argues that in the constitutive entanglements of life, more attentiveness must be paid to existing power asymmetries. There are many power asymmetries in relation to disability, most notably in relation to what/who has the power to shape the way disability is conceptualised. Current forces which have the power to shape the way disability is defined, and the way it is subsequently treated, include medicalised perspectives, the notion of the ideal human, which includes the differing gendered standards of “ideal men” and “ideal women”, the charity-context, the limited trope of media representations noted earlier, and non-disabled people’s fears and hostility (Morris, 1991; Oliver, 1990). Many of the participants’ responses to questions about disability appear to mobilise these forces. For instance, as discussed in Chapter Eight, Luke commented that the man with one leg had “a leg wrong”, drawing upon a medicalised perspective of the corporeal norm. Further, Luke and Carl both displayed fear in their responses to the videos, with Luke commenting that seeing someone with one leg “freaking freak me out man”, and Carl commenting “I a little panic” when discussing wheelchairs. Through not speaking of disability, and not setting the terms for how disability is defined, the entanglements of silence continue to grant agency to these forces, including the always-present notion of the ableist ideal human. As Jackson and Mazzei (2011) assert, authority, privilege, and control are “maintained in a hegemonic and normative silence” (p. 99).

Morris (1991) is clear in her assertion that the silences regarding disability needs to change. As she states, disabled people need to have the courage to speak about the negative aspects of disability, as well as the positive aspects. When disabled people feel strong enough to do this, she argues, they will be able to challenge the way non-disabled people make judgements about their lives, and, in doing so, “take charge of the way in which disability is defined and perceived” (Morris, 1991, p. 71).

The intra-action of these phenomena – the lack of knowledge regarding disability, an impeded ability to define the way disability is perceived, and the

maintenance of ableist privilege produce a key inhibiting phenomenon is produced. That is, the capacity to harness the agency necessary to challenge ableism and disability oppression is significantly constrained. In particular, the entanglements of silence affect not only the voicing of disability in an individualised sense, but also inhibit the collective voicing, reshaping and reimagining of disability.

However, if one returns once again to Barad's formative quote, "[t]he world and its possibilities for becoming are remade with each moment" (396), this entanglement does not need to be seen as totalising and immovable. Instead, it appears to be the least problematic entanglement to disrupt from the other entanglements outlined in this thesis; for, in order to rupture this entanglement, we just need to start speaking of disability. This may be challenging, but is surely not impossible.

## Conclusion

The entanglements of silence function as an agentic force within the ongoing intra-activity of life, are evidenced through the participants' lack of knowledge regarding disability. This lack of knowledge included Carl asking "what is it?" when asked to identify someone with and without a disability, Luke informing us that he does not know anyone without a disability, and Jonathan informing us that he was diagnosed with Down Syndrome when he was five. When read diffractively through the framework of desiring silence, these responses can be understood as the result of "the forces of desire that are acting through and with" (A. Y. Jackson & Mazzei, 2011, p. 91) participants, shaping the desiring silences. These desires have a strong alignment with Butler's work on performativity, which illustrates the role of social norms in the processes of recognition. Furthermore, Zabrodska et al. (2011) and Jackson and Mazzei (2011) connect the desire for recognition with the desire to belong, where the closer to "normal" one achieves, the greater the promise of future acceptance and belonging.

Multiple phenomena are produced through the entanglements of silence. The participants' lack of knowledge regarding disability highlights a wider lack of

understanding of disability. This presents questions as to the participants' ability to challenge the material consequences of their subject positioning, without having the knowledge or language to identify issues beyond the view of these as individualised problems. Not speaking of disability impedes the agency necessary to reimagine the way disability is conceptualised. This silence grants other intra-active forces agency, including non-disabled people's perceptions, fears and hostility towards disability. One of the most problematic phenomenon produced through these silences, however, is the maintenance of the notion of the normal, ideal human. In this way, ableist hierarchies remain unnamed and unchallenged, leaving the notion of the ideal human untouched. The sum of these phenomena is a situation where the agency necessary to challenge disability oppression is largely foreclosed.

# Chapter 11:

## The Entanglements of Help

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In this chapter I explore a powerful and perplexing phenomenon which arose during the hui – that of *help*. I analyse this entanglement utilising Wetherell’s work on practice, alongside Butler’s work on performativity, Davies’ work on positioning and Barad’s work on agential realism. Through using the Deleuzian questions of *how does it work* and *what does it do*, I explore how the notion of help is intertwined within the ongoing entanglements of disability, what this phenomenon produces and what possibilities it forecloses. In particular, the positioning of people labelled disabled in relation to “helping” will be explored, along with the intertwining of the ideal human within these entanglements. Lastly, I will examine the disruptive potential of the entanglement of help.

### **Defining Disability and the Notion of Help**

When participants were asked to define disability in hui two, the word “help” appeared on several occasions. Unfortunately, this happened when the camera was not recording, and the specific details regarding what participants said were missed. Seeking to remedy this gap of information, participants were directly asked what was meant by the use of the word “help” in hui three. However, none of the participants seemed to remember using the word, and some suggested that perhaps we had been talking about “health”, rather than help. Yet, the word continued to pop up throughout the course of our conversations and activities in the remaining hui, as participants spoke of their desire to help disabled people, and how disabled people should be helped. In hui eight, participants were asked again how they would describe disability, and the following conversations occurred:

Ingrid: What do you think disability is Gary?  
Gary: ((Clears throat)) I-, I like, um, to help someone.  
Ingrid: To help someone?  
Gary: Yeah.

Soon after, Carl expressed a similar sentiment:

Ingrid: What about you, Carl? What do you think disability is?  
Carl: ...°um°.... um take care of people.  
Ingrid: Pardon?  
Carl: Um care of, to take care p-people.  
Ingrid: Care people?  
Carl: Yeah.  
Ingrid: To care for people?  
Carl: Yeah.  
Ingrid: Ok. Cool.  
Carl: Yeah to care people and helping people out.

Although Carl uses the word “care” more than “help”, “care” appears to be used in such a way that it indicates a similar meaning or intent to the word “help”. As the point of this analysis is not to seek an understanding of what participants *mean*, but rather how these phenomena work and what they do, I analyse this excerpt with an understanding that the terms “care” and “help” are somewhat conflated.

This notion of “caring for people” and “helping people” was by far the most perplexing phenomenon which arose from the hui. Despite the frequency of its appearance, participants themselves seemed unaware of what the connection was with disability, or why this connection existed. It was only when reading Wetherell’s work on affective practice (e.g., Wetherell, 2012, 2014;

Wetherell et al., 2015), in which she touches on the notion of social practice, that a connection finally emerged.

Wetherell (2012) defines practices as routines, assemblages, or “ways of doing things”, including ways of working, of moving our bodies, of cooking, of consuming, and of feeling. These assemblages are sites of repetition, which are made up of multiple intra-acting elements (Barad, 2007) which assemble together into patterns, and “provide the basic intelligibility of the world” (Wetherell, 2014, p. 12). Although Wetherell’s work largely centres on affective practices and affective-discursive practices, she also touches on the notion of “social practices”. For instance, she notes that affect is embedded in situated practice, and can be “very densely knotted in with connected social practices where the degree of knitting reinforces the affect and can make it resistant and durable, sometimes unbearably so” (Wetherell, 2012, p. 14). Indeed, Wetherell (2012) notes that it is not always helpful to distinguish between affective and social practices, because “[i]n some sense all social practice is affective because all human practice is embodied and comes attached with some valence” (p. 96). Viewed through this lens, “help” can be viewed as social practice; as a routinised entanglement which includes ways of moving our bodies (such as stepping in to help someone in a wheelchair up a steep curb), ways of spending money (such as donating to charities which are *for* disabled people, rather than non-profit organisations which are run *by* disabled people), and ways of feeling about disability.

Keith (1996) provides a useful plain-language description of social practice, stating:

All social encounters are governed by *rules of behaviour*. There are things that it is normally acceptable for strangers to say to each other and things that are not. For example, in the particular section of British society in which I usually mix, it is considered okay, indeed complimentary, to remark that people [usually women] are thin, but rude to say that they are fat. It is acceptable to tell people they are very tall but impolite to remark on the fact that they are unusually short. (p. 72, emphasis added)

These social practices, or “rules of behaviour”, can be viewed as performative agencies within the iterative entanglements of disability. As Davies (2008) notes, “the ordinary everyday world is sedimented in repeated citations of the way the world is (and, it is believed, ought to be)” (p. 173).

The connection between help, disability and social practice was also prompted by a video that I watched on Facebook during the time that I was reading about affective practices. In this video, a boy with CP (cerebral palsy) competes in the school cross-country race and is helped by his PE teacher and entire class, who by the end are walking next to him chanting “Let’s go Matt, Let’s go (clap clap)” (Liftable, 2017). The video could be described as a real “tear-jerker”, and as I watched the video I observed myself becoming teary and emotional, at the same time as I was perplexed by this reaction. I came to realise that what I was noticing was a powerful social practice of disability – we help disabled people. Furthermore, this social practice is entangled with affective practice, as helping the boy to finish the race like “normal” children do, with moral rather than physical assistance, *feels* “right”. It seems that helping disabled people feels so “right” that it is worthy of innumerable “inspirational” YouTube and Facebook videos showcasing this practice.

Taking on this understanding of social practice, the question then becomes what the “rules of behaviour” are in relation to disability. Furthermore, how does the notion of help connect in with these rules? This subject will be explored in the following section.

## **The “Rules of Behaviour” in the Entanglements of Disability**

Keith (1996) notes that the rules of behaviour for how we should conduct ourselves are not always clear when disability is involved. This results in “all kinds of confusions and problems” (p. 74), as Murphy (1987) states:

[T]he able bodied person... must struggle against the underlying ambiguity of the encounter, the lack of clear cultural guidelines on how to behave and perhaps his [sic] own sense of revulsion. (p. 121)

Murphy (1987) argues further that many non-disabled people look on disabled people as an almost “alien species”, a people whose reactions to conversation and offers of assistance cannot be anticipated. Because of this, many non-disabled people refrain from establishing eye contact with disabled people and go out of their way to avoid conversations with this “unknowable” species (Murphy, 1987). The specific issue of avoiding disabled people was also discussed in a recent Independent news article titled *One in four Brits admit to avoiding conversations with disabled people* (Bulman, May, 2017). In this article, Bulman (2017) notes that “fear of causing offence”, “feeling uncomfortable” and “not knowing what to talk about” were the most common reasons cited for avoiding conversations with disabled people.

During the hui, Natalie told a story about an encounter she had had in which the absence of visible disability appeared to change the rules of encounter. In this story Natalie and her flatmate were at the supermarket checkout with a support person, when her flatmate’s card was declined. Natalie described the reaction of an older gentleman behind her, who was “being really, really rude” towards her and her flatmate. Natalie explains further below.

Natalie: ((*mimicking the man*)) [He was saying]"ohhh and now I'm going to miss my bus" and everything and you know like all this bad mouthed language out of his mouth. And I'm thinking, you know, he's treating us as like a normal person, like not a person with a disability. Cuz, they won't, they won't even know.

Ingrid: Yeah.

Natalie: Um, yeah it was really bad mouthed and that. And then when we were like leaving he was like



telling people behind oh they're slow, ohhh, you know she should have had money and all that. And then, you know he was talking about the bus and stuff and we saw him walk up to his car. So he wasn't exactly catching the bus at all.

*((Ingrid and Taylor laugh a little))*

Natalie: Um, yeah so he didn't know that, you know we had a support worker with us.

Ingrid: Yeah.

Natalie: And then when like, she wasn't a family member so.

Ingrid: So <what do you think?>

Natalie: <I think> he just treated us as one of the public.

Ingrid: Yeah.

Natalie: Like everyone else.

Although there were undoubtedly some gendered practices also intertwined in this scenario, Natalie's story highlights the powerful role of visible identifiers of disability in shaping the "rules of behaviour" related to "help" between strangers. When Natalie states "they won't even know", and that the gentleman treated her and her flatmate "as one of the public...Like everyone else", she appears to be pointing to the absence of help (or patience) which arises when someone's challenge is invisible.

The work of Graham (1997) helps to elucidates Natalie's story further. Graham (1997) describes the differing "rules of behaviour" which arise when someone is seen as being responsible for their "plight", versus when they are not seen as responsible. As she notes, "when a person's need state is perceived as uncontrollable [such as a visible disability], that individual is not held responsible; the absence of responsibility tends to elicit pity and prosocial actions such as help" (p. 23). In contrast, people who are seen to be responsible for their plight, such as when they have an invisible disability like Natalie, are viewed as not exhibiting the appropriate level of personal responsibility. This often elicits anger

in others, and help is withheld as a result of this feeling (Graham, 1997). The older gentleman in this story appears to perceive Natalie's flatmate as not exhibiting the expected level of personal responsibility, stating "she should have had money and all that". The affective practices of personal responsibility become intertwined in this scenario, and the gentleman becomes angry and "really, really rude" to the three women.

Keith (1996) points out that the "rules of behaviour" in relation to disability become much clearer when a visible disability is involved, driving the desire to help. Keith (1996) tells the story of a woman who has a son with acute communication and learning difficulties. The son can walk, however he "has no concentration and is very unco-ordinated" (p. 77). She explains further:

When they are struggling together, people feel awkward and embarrassed and turn away but when he is in a wheelchair they rush to open doors and help them up kerbs or steps. People are glad to help in this case because they feel they know what to do, the rules of behaviour are clear to them. (p. 77)

It appears thus that help is one of the few clear social practices within the entanglements of disability, a practice which is strongly impacted by the *visible* presence of disability. As Carl notes, disability is "helping people out". Keith (1996) picks up on the power of this key practice in her work, arguing:

The central confusion of the relationship between us [disabled and non-disabled people] is that on the one hand they are disconcerted by our presence, and are confused about how to behave towards us or even what words they should use to describe us, but on the other hand they have a clear idea that they should be helpful and kind. (p. 81)

This practice of help appears to be a powerful, performative agency within the entanglements of disability. Indeed, it is such an agentic phenomenon that it was the first thing several participants thought of when they were asked to define disability.

In the following section, I explore how the social practices of help play an integral role in the ongoing formation of the establishment of viable subjects.

## Viable Subjects and the Practices of Help

The social practices of help can be viewed as an integral component of the establishment of what Butler (1997b) terms viable subjects. That is, there are certain practices that subjects are expected to both partake in and take up as their own if they wish to be constituted as a viable subject. Davies (2000) speaks of this phenomenon in her work, stressing that an important part of the establishment of ourselves as subjects is:

[T]o desire *as one's own*, to take pleasure in the world, as it is made knowable through the available practices, and in particular the discursive practices, the patterns of power and powerlessness and one's positioning within them. (p. 22, emphasis in original)

In relation to disability, these practices include the social practices of help, affective practices – such as the feeling that disability is a tragedy or that a disabled person is inspirational – and discursive practices, such as the silences regarding disability and the desire to speak of people as having socially valued roles.

Davies (2000) argues that taking on these practices forms an integral part of the “correct” way of taking oneself up as a subject; that is, to understand how to be positioned in a social context, and how to “position oneself as a member of the group who knows and takes for granted what other people know and take for granted in a number of settings” (p. 22).

In order to explore what the social practices of help foreclose and present potential for, I return to the key Deleuzian question of *what does it do* in the following section.

## What Does the Practice of Help Do?

In many ways, the performative agency of help presents potential for countless positive outcomes. As Graham (1990) states, “[b]eing the recipient of aid usually results in some tangible gain, at least when compared with undesirable alternatives such as failure” (p. 28). However, the performative agency of help also presents some complexities and challenges. In particular the problematic approach of state-wide interventions designed to “help” marginalised groups is the subject of scholarly discussion (e.g., K. Dunn & Kaplan, 2009; Moldovan & Moyo, 2007). As Dunn and Kaplan (2009) highlight, large numbers of people who are on death row or are sentenced to life imprisonment in the USA have engaged in various “helping” support systems over their lifetime. Similarly, Lynch (2016) discusses the “significant over-representation of individuals with neurodisabilities<sup>27</sup> in both the adult and youth justice systems” (p. 3) in Aotearoa New Zealand. Many of these individuals will have engaged with various “helping” agencies in relation to their disability diagnosis. Dunn and Kaplan (2009) argue that rather than “helping”, many of these social interventions “enforce a certain type of personhood that may or may not be in the helpee’s best interest”. Further, these authors suggest that “while the stated goal is to help, the real purpose is to get the person to conform to a certain way of being”. (p. 339)

Connecting these practices with the Foucauldian notion of the “psychological complex” or “psy-complex” (a concept first developed by Nikolas Rose, see for instance Rose, 1985), Dunn and Kaplan (2009) highlight how these state-wide helping interventions use scientific knowledge and professional expertise in an attempt “to improve people, to change their characters, attitudes, and behaviours through manipulation of their qualities and attributes” (p. 339). The interventions perpetuate a hegemonic notion of individualism, as they ignore “the sociocultural aspects of being human” (p. 364). This serves to

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<sup>27</sup> Lynch (2016) defines “neurodisabilities” as a range of disabilities which includes “learning differences such as dyslexia and communication disorders through to attention deficit hyperactive disorder (ADHD), autism spectrum disorder (ASD), traumatic brain injury (TBI), epilepsy and foetal alcohol syndrome disorder (FASD)” (pp. 2-3).

separate individual actions from the environment which is often a significant cause of the issue at hand. Thus, the “helping” interventions can be understood as a tool of the state for regulating its citizens, particularly in regards to liberalism’s focus on the individual.

Whilst such analysis of macro-level, state-wide “helping” interventions is thought-provoking, I have chosen to take a different approach in this thesis. This is largely because participants’ comments, along with the conceptual framework, led me towards a more micro-level view of these practices; that is, towards an exploration of the everyday practices through which disability oppression is fostered.

In the following section, I investigate how the social practice of help intersects with the modernist notion of the ideal human.

## **Help and the Notion of the Ideal Human**

The social practice of help brushes up against the modernist ideal of independent, autonomous, always-in-control and self-reliant individuals (Crotty, 1998; Goodley & Runswick-Cole, 2016). As highlighted by Van der Klift and Kunc (1994), whilst being a provider of help is often seen as desirable, many people are decidedly uncomfortable being the recipient of help. This discomfort, they argue, is because being the recipient of help serves as a reminder of one’s vulnerability and, within a (neo)liberal view, can suggest deficiency, burden, inferiority, and a sense of obligation to another. Being the recipient of help can call into question one’s embodiment of the expected, ideal traits. Autonomous, self-reliant individuals are not expected to need help.

In particular, this practice confronts the ideal of the always-abled subject. This point was alluded to in Natalie’s story, when the gentleman turned to the people behind them at the checkout, commenting “oh they’re slow, ohhh, you know she should have had money and all that”. Natalie comments that he was treating them “like a normal person, like not a person with a disability”. Presumably, were the man to treat Natalie and her flatmate like “a person with a disability”, they would have been afforded a higher level of “help” or patience from the man. “Normal people” are expected to be abled, to not be slow, and to

ensure they have the money they need to purchase groceries; “normal people” who act “slow” are not worthy recipients of the “help” and patience of other people.

Graham (1990) argues further that receiving help can function as a low-ability cue. As their research highlights, when children receive help they do not ask for from a teacher, the helped child is perceived as being of lower-ability than non-helped students. This view of lower ability impinges upon the capitalist demand for productive, autonomous workers (or “citizens”) who are not a “burden” on others. It appears thus that being the recipient of help can serve to question one’s status as a fully abled, ideal subject; it threatens to jeopardise one’s placement in the ascendant, “normal” category (De Schauwer, Van de Putte, & Davies, 2017).

It is also important to consider how the operation of these social practices keeps hidden the interdependence of all lives. For instance, the gentleman in Natalie’s story is helped by the checkout assistant (or machine) to pay for his food, by people who keep the shelves stocked at the supermarket, who in turn rely on the people who grow/manufacture the food and deliver it to the supermarket, and on the people who lay and maintain the roads, which the gentleman in Natalie’s story uses to drive to the supermarket, and on the list goes. These “helping” practices form an integral component of the lives of all humans; as Goodley and Lawthom (2015) argue, “[w]e need other humans and non-humans in order to live” (para. 3). The intra-active processes of normativity work to ensure that this interdependence is kept invisible (Wearing, Gunaratnam, & Gedalof, 2015). Thus, certain types of help remain naturalised and difficult to see, while other forms of help, such as the forms which disabled people often receive, are viewed as exceptional and attention-worthy (Wearing et al., 2015).

In the following section, I draw upon positioning theory to explore the key Deleuzian question of *what does this do*. In particular, I examine how the social practice of help functions to position people assigned the label *disabled* as passive and lacking in agency.

## Positioning

Positioning, as described by Davies and Harré (1990) is:

[T]he discursive processes whereby selves are located in conversations as observably and subjectively coherent participants in jointly produced storylines. There can be interactive positioning in which what one person says positions another. And there can be reflexive positioning in which one positions oneself. However it would be a mistake to assume that, in either case, positioning is necessarily intentional. (p. 48)

Alongside discursive processes, I would add the full breadth of intra-active processes which enable selves to be located as “observably and subjectively coherent participants” (p. 8). This process of positioning is part of what continually enables the materialisation of a self; one who is continually (re)constituted in ways which can be multiple and contradictory, through the various practices in which they participate (Davies & Harré, 1990). Once a person has taken up a particular position as their own (i.e. father, student, female), they inevitably see “the world from the vantage point of that position” (Davies & Harré, 1990, p. 46). Burr (1995) notes furthermore:

Once we take up a subject position in discourse, we have available to us a particular, limited set of concepts, images, metaphors, ways of speaking, self-narratives and so on that we take on as our own. This entails both an emotional commitment on our part to the categories of person to which we are allocated and see ourselves as belonging (such as male, grandfather or worker) and the development of an appropriate system of morals (rules of right and wrong). (pp. 145-146)

There is a clear alignment between this understanding of positioning, and the social practices of disability discussed previously. As Burr’s (1995) statement highlights, an important part of taking up a subject position is “the development of an appropriate set of morals (*rules of right and wrong*)” (pp. 145-6, emphasis

added). These rules of right and wrong include a sense of what it is possible and appropriate to do, and form part of what Davies and Harré (1990) describe as the ubiquitous moral order. The “rules of behaviour”, or social practices of disability, thus form an important part of the ubiquitous moral order, an order which must be taken up as one’s own if one is to be positioned as a viable subject.

In exploring the connection between positioning and the social practices of help, a key issue arises. That is, the way this practice is currently enacted tends to place the helper in a position of power over the helpee. This furthermore positions the helpee (e.g., the disabled person) as passive or lacking in agency. When someone is the recipient of help there are certain social practices which are expected. In the Western world in particular, the person receiving help is expected to be grateful. The socially desirable and expected way to be a helpee is to not challenge how help is given, nor to dictate the terms by which they are helped, or to insist that they receive help in the first place. When a person is helped they are expected to be patient and wait for help to arrive, not get angry, tell the helper they have done something wrong, or show anything other than good humour at the remarks that are given (Keith, 1996). When someone is in the position of needing help “[t]he power to decide where and when help should take place, who should help us, and whether in fact help is needed is stripped away” (Van der Klift & Kunc, 1994, p. 5). As Overall (2006) argues, this demonstration of gratitude serves as a compensation for the “burdensome” nature of the helpee.

This social expectation creates many problems for disabled people, particularly when the “help” offered is based on the helpers’ perceptions of need, rather than the helpee’s perception of what might be useful to them (Keith, 1996). A brilliant example of this is found in Janice Pink’s poem “Do Unto Others”, which is highlighted by Keith (1996). The story and the poem below bear telling in their entirety, as I fear I could not do it justice with paraphrasing:

Janice Pink’s poem ‘Do Unto Others’... tells the (true) story of her encounter with a woman at a supermarket checkout. This woman, alerting the cashier’s attention to the fact that ‘we’ve got a cripple here’, proceeds to grab Janice’s bag, declaring that it is ‘the least



that I can do/because but for the grace of God, I could be just like you!' But her 'thoughtfulness' soon turns to outrage when Janice begins to make it clear that she finds this behaviour both interfering and offensive. The poem ends with the lecture the do-gooder felt she needed to give to the ungrateful Janice.

*I know you've being very brave, but that was rather rude –  
Next time someone helps you, try to show some gratitude.  
Of course you think life isn't fair, but when you're feeling blue –  
Big smile! And then remember, there's someone worse than you!*  
(Pink, 1994). (pp. 80-81)

If people do not display the appropriate gratitude response to being helped, they are considered ungrateful and are cast as an illegitimate subject. They have not properly participated in the social practices required of them in order to be considered a viable subject. In Wetherell's (2012) terms, this is a practice which disempowers in the guise of empowering.

The expectation of gratitude is particularly sedimented in the charity model, which plays a profound role in disability support in Western society. As Keith (1996) and Morris (1991) argue, charities form an essential part of the relationship between non-disabled and disabled people. The charitable model comes with an expectation of gratitude, which, as Morris (1991) argues, "is actually about making the non-disabled person feel good about themselves. Our gratitude is the gift we are expected to make in exchange for tolerance and material help" (p. 108). This situation is especially notable in learning disability support services where, as Goodley, Hughes and Davis (2012) argue, learning disabled people are often expected to be passive, grateful recipients of charitable services.

The social practices of help, including the expectation of gratitude, can be understood as a line of descent within the iterative entanglements of disability, a line which forms part of the unreflected ordinariness of the world (Davies, 2015). The positions offered, accepted and resisted in these everyday practices are part of the intra-active processes through which "discourses and their associated

power implications are brought to life” (Burr, 1995, p. 147). Thus, it can be said that social practices of help, as they are currently enacted, are disempowering. The continually iterated line of descent is one of the means by which disabled people are repeatedly positioned as passive and lacking in agency, as holding a diminished position of power. This is one of the lines of flight which must be opened up for examination and ruptured if we are to challenge the power of the status quo. As Butler (1997a) points out, for those who are not supported by the status quo “the opening up of the foreclosed and the saying of the unspeakable become part of the very ‘offence’ that must be committed in order to expand the domain of linguistic survival” (p. 41).

Although the practice of help emerged as a problematic line of descent within the hui, it also simultaneously emerged as a phenomenon with disruptive potential. The latter point will be addressed in the following section.

## **The Disruptive Potential of Help**

As noted earlier, help emerged as an agentic phenomenon at multiple points throughout the hui. In this section, I explore several key moments when the lines of flight took off in new and unexpected directions. These moments highlight the potential of help in the production of ethical responses between beings.

The first moment of disruptive force came through in the stories of two participants. Natalie and Taylor both spontaneously told stories in hui eight about the differing behaviour they observed in people when help was required. The first story from Taylor arose while I was talking with participants about my preliminary findings from the hui. I mentioned that I had noticed that many participants liked to use the word ability to describe themselves, and then referred to a conversation from the previous hui about the ableism binary. In this conversation, I had drawn two stick figures on the whiteboard in separate circles, which Natalie referred to as the “A” and “B” boxes. Taylor’s comment arose unexpectedly while I was talking, as shown on the following page:

- Ingrid: Alright. um, I've also noticed that, remember how last time we did those two like stick figure drawings.
- Jonathan: Yeah sticky *((said with humour in his voice. Karissa laughs and they look at each other and grin))*.
- Ingrid: Ok, so um, and that, I think lot of people think of the world, so Natalie you called it the "A" and "B" boxes.
- Natalie: Mmm hmmm.
- Ingrid: Like that. So I think a lot of people think of the world in terms of
- Taylor: It sort of reminds me of something that happened yes-, that happened this morning.
- Ingrid: Yeah?
- Taylor: Um, I was like catching, I was on the bus. And then the, um, the petrol station by where, um, Pizza Hut used to be and where WINZ [the Work and Income office] is now. Um, I think a lady fell off her bike. But everyone like, there were heaps of people helping her and stuff. So, um... so everyone helps people cuz that's their, like, sense to help people. But they don't really... um... that's, oh, that's their... °forgotten the word°, but, um... people are like, some people are mean people but when someone's hurt they help out. So... yeah *((she smiles and laughs a little))*.

It is unclear from the conversation exactly what prompted Taylor's memory of the morning's accident, although it may have been stimulated by the "A" and "B" drawings on the whiteboard, which had just been re-drawn based on the illustration from the previous hui. This drawing included a stick figure with two

whole legs inside a circle (the “A” box), and a stick figure with one whole leg and one half leg inside a circle (the “B” box). It is interesting to note that the entanglement of Taylor’s memory with the conversation regarding ability, disability and the ableism binary brought up a connection between injury and disability. Many disabilities are the result of injury, particularly when someone has a visible “difference” such as missing half a leg. However, the medicalised association of disability is often vehemently rejected by many in the DRM and in the field of disability studies. Perhaps unconsciously, Taylor appears to be drawing a connection between the idea of disability, seeing someone who is injured, and the differing way that people act when they see someone in need of help.

This story from Taylor seemed to remind Natalie of her recent experience at the supermarket, wherein the older gentleman had been “really, really rude” to her and her flatmate. Directly after telling this story, Natalie told another story which aligned with what Taylor had said:

Natalie: And I noticed [a] thing another day where, you know how school kids um, I dunno if you guys catch buses around school kids time.

Taylor: *((Nods))* Mmmm.

Natalie: Um, how they like to push in and stuff and the bus comes about three o’clock and you’re like *((she puts hands up by her face and looks quite stiff and cramped for a moment))* you’re like the only one that’s not like a school kid. Everyone’s got their uniform. They’re like barging in on the bus. Well at Eastgrove<sup>28</sup> I was waiting for my bus about 3 o’clock and all the Eastgrove High School people came. And there was a lady in this like wheelchair. Ummm, you know mobility, wheelchair, I think it was. And I noticed that, they

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<sup>28</sup> Suburb and school names are pseudonyms

all stood back. Because they like to get on the bus first because it gets so full. And I noticed that, you know this, the all the school kids stood back and let that lady on first.

Ingrid: Ohhh.

Natalie: Um, instead of all <barging in>.

Ingrid: <Yeah>.

Natalie: They actually like walked back *((gestures apart with her hands))* and then they helped her get on *((gestures helping motion with hand))* and, you know. Opened the thing to get on the bus. And they also let me on as well. Cuz they usually let the public on before the school kids. Which I thought they really got, you know, nice manners.

Both Natalie and Taylor's stories highlight the agency of "help" in producing an ethical response from other beings. Where Natalie states that the school children who normally "barge in" suddenly became much more respectful with "nice manners" in the presence of a wheelchair (a visible display of disability), Taylor highlights how "some people are mean people but when someone's hurt they help out". Perhaps what participants were emphasising was the agency of help in producing an ethical response, for the "lively relationalities of becoming of which we are a part" (Barad, 2007, p. 393). As Barad (2007) argues, matter, meaning and ethics are inseparable and mutually dependent. We are always already responsible for other beings and phenomena with which we are entangled, "not through conscious intent but through various ontological entanglements that materiality entails" (p. 393). Or, as Davies (2014b) argues:

Being open, and being vulnerable to being affected by the other, is how we accomplish our humanity; it is how the communities, of which we are part, create and re-create themselves. We are not separate from the encounters that make up the community but, rather, emergent *with* them. (p. 10, emphasis in original).

Taylor and Natalie's responses to the scenarios they experienced emphasise the role of vulnerability (that is, being in a position of needing help) in affecting each other, in accomplishing our humanity and in (re)creating the communities "of which we are part" (Davies, 2014b, p. 10). For instance, Taylor comments "there were heaps of people helping" the woman who fell off her bike, reasoning further that people who are generally "mean people" respond with humanity to "help" fellow members of their community, when they see someone in a vulnerable position; that is, "mean people" *emerge* as helpful people through such encounters. Natalie commented further that the normally "rude" school children *emerge* as differing beings with "nice manners" in the presence of a wheelchair.

In the key moment outlined below, I sought to (re)create such a scenario; that is, to open myself up and be vulnerable to being affected by the participants, and see whether this presented potential to disrupt the iterative entanglements of disability. This scenario was examined previously in Chapter Seven. In this chapter, I outlined the moment in which I opened myself up to being vulnerable with participants, and invited them to help me think about how I could feel OK about myself with a newly acquired disability. Participants responded, albeit briefly, with some positive discussion about disability. The excerpt is repeated below:

Ingrid: How else could I feel proud of myself?  
Jonathan: We could be mates *((steps over to me and links his arm through mine))*  
Ingrid: Yeah.  
Natalie: Get new friends.  
Ingrid: Yeah, how would I get new friends, do you think?  
Glen: *((Walks around to the other side of me and puts his arm around my waist))*  
Carl: Ingrid.  
Taylor: From the Blind Foundation.

Ingrid: Yeah, so I would get to meet new people,  
wouldn't I?

Taylor: Mmm.

Ingrid: That would be cool.

Jonathan: Yeaah.

Natalie: Other people that can help you out.

Ingrid: Yeah? So I would get more support people then?

Natalie: Yeah.

Although there had been small moments of pride demonstrated during the hui, this was the only point at which disability was discussed in a positive way without the territorialising forces shutting down what was happening. As this moment highlights, asking participants to help me seemed to present some productive potential in shifting the lines of flight, ever so briefly. Both Jonathan and Glen stepped up to link their arms around me, demonstrating a physical act of support, and participants commented that “we could be mates”, that I could “get new friends”, such as people at the Blind Foundation, and that I would have “other people that can help [me] out”. In this response, participants’ were demonstrating the presence of collective support within the disability community; support which not only leads to “new friends”, but which can also provide a sense of community and belonging.

A similar effect of opening myself up to being vulnerable and disrupting the lines of flight was seen in hui six when I gave my “speech” to participants, as outlined in Chapter Seven. This speech arose in response to participants’ responses to videos and discussions on disability pride, in which they indicated a strong desire not to continue with these activities. In my speech, I handed the dilemma I faced to the participants in the spirit of co-construction, and asked for their help in proceeding with the hui. Participants responded well to the speech, and we were able to progress.

Participants themselves seemed to greatly enjoy being positioned as *helpers* during the hui, and several participants commented that they appreciated helping me during hui nine:

Ingrid: So Gary, what made you want to come to the hui and what made you keep coming back to the hui?

Gary: Because I like doing-, because I like doing helping you out.

...

Taylor: Um, I liked coming back and helping you out with your research. And I also liked having a day off work ((laughs)).

Karissa and Jonathan did a haka, a Māori ceremonial dance often conducted as a sign of honour and respect in Aotearoa New Zealand, to thank me for “everything”, which included allowing them to help in the research. Gary also gave me a box of chocolates, which I have placed a photo of below:

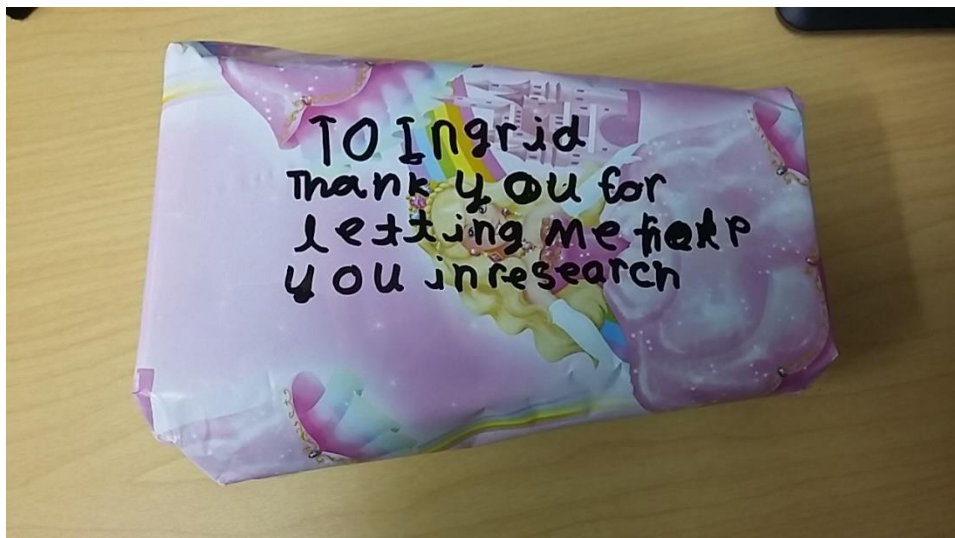


Figure two: A photo of a box of chocolates in pink wrapping paper. The words “To Ingrid. Thank you for letting me help you in research” are written in vivid.

Opening oneself up to being vulnerable is not without risk; it was a challenging, almost frightening experience as a researcher, and could have gone very differently had different intra-active elements come to play. It is thanks to the strength of the relationships we developed during the hui, and the ongoing



support and goodwill of participants, that I felt safe enough to open myself up to being vulnerable, and we were ultimately able to progress the hui. It seemed that opening myself up to being vulnerable and accepting help enabled the participants and myself to be affected by each other (Davies, 2014b) – to create and recreate our “selves”, our sense of subjectivity, and the possibilities for thought and action in relation to disability.

Perhaps the remarks from participants highlight the power of positioning in disrupting these problematic and seemingly unchangeable issues; for us as researchers to step away from the mantle of “knowledgeable experts”, and position marginalised communities as the *helpers* rather than the *helpees*. In this particular project, getting participants to help *me* as the researcher enabled us to progress past seemingly intractable “knotty points”, in which territorialising forces held the lines of flight firmly on a line of descent. Furthermore, this approach appeared to enable us to progress past these knotty points in a manner which was safe for, and accepted by, the participants. Perhaps this positioning presents potential to disrupt the problematic normative orders of research and of life, as was highlighted in the role plays on pride. It may present, as De Schauwer, Van de Putte, Van Goidsenhoven, et al. (2017) state, “a creative evolutionary or de-territorializing force that opens up the new, the not-yet-known, and the emergent possibility of becoming different” (p. 2).

## Conclusion

This chapter explored a powerful and somewhat perplexing phenomenon which arose at multiple points during the hui – that of *help*. This phenomenon was particularly noticeable when participants were asked to define disability. Two participants responded by stating that disability is “to help someone” and “to care people and helping people out”. By drawing upon Wetherell’s work on practice, the notion of help was analysed as a social practice of disability. Social practices can be understood as “rules of behaviour”, which help us understand what it is desirable to do and say, or not do and say, in relation to disability. This understanding of social practice has a strong alignment with Butler’s work on performativity and the establishment of viable subjects. As Butler outlines, there

are certain practices which subjects are expected to partake in if they wish to be constituted as a viable subject. In short, helping disabled people is a powerful social practice in relation to disability, one which enables people to establish themselves as viable subjects.

The social practices of help produce a variety of outcomes. As the examples in this chapter demonstrate, the social practices of help are deeply embedded in social complexities that produce many positive outcomes, as well as many challenges and complexities. In particular, the modernist ideal of independent, autonomous, always-in-control and self-reliant individuals is confronted, shaping the desire to give, but not receive, help. The practice further keeps hidden the interdependence of all lives, ensuring that certain types of help remain naturalised and difficult to see, while other forms of help are viewed as exceptional and attention-worthy (Wearing et al., 2015). Furthermore, as it is currently enacted, the practice of help positions helpers in a position of power over helpees. This functions to ensure that disabled people are continually positioned as passive and lacking in agency.

However, help also emerged as a force with disruptive potential during the hui. In particular, two key moments were discussed, wherein I opened myself up to being vulnerable with participants and asked for help. Participants' enthusiasm for helping me enabled us to progress past some seemingly intractable knotty points, and supported the development of positive discussions regarding disability, albeit briefly. I believe that these moments highlight the potential of help in the production of ethical responses between beings; they allow us to accomplish our humanity through opening ourselves to being affected by others and shifting the problematic iterative lines of flight.

# Chapter 12:

## Conclusion and Implications for Policy and Practice

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This thesis has centred around a key problem: why do learning disabled people remain positioned on the margins of humanity, decades of hard work from the disability rights movement (DRM), family and whānau<sup>29</sup>, legislators, academics, support workers and many more? In this chapter, I summarise the key findings related to what is producing this marginalised positioning, and outline suggestions for how this situation can be changed.

### Background Contexts

The thesis opened with an examination of what is meant by the statement, “positioned on the margins of humanity”. Statistics related to the big picture of disability oppression demonstrate that, overall, disabled people fare worse than people without disabilities on almost every life domain that is measured. Compared with people who do not have disabilities, disabled people have worse health outcomes, lower life expectancy, are subject to higher rates of abuse, higher rates of mental illness, have reduced access to education and employment, are paid less and, unsurprisingly, are more likely to live in poverty (Committee on the Rights of Persons with Disabilities, 2014; Goodley, 2017; IHC New Zealand, 2017; Scior et al., 2015; World Health Organisation, 2011). Further, people assigned the label of learning disabled stand out as the most affected group in all of these areas.

My experiences working in the disability support sector left me vexed by the sense that this situation continues despite concerted efforts to enact change.

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<sup>29</sup> See page 45 for the definition of whānau

Despite pockets of innovative work the problem has not been adequately addressed by the efforts of support workers, policy developers, or learning disabled people themselves to teach people about disability rights, and to change people's "attitudes" regarding disability. Something clearly needs to change.

In this thesis I have argued that disability is an artefact of the recent historical, political, spiritual and social structures in the Western world. Further the concept of modernity, a framework which places great focus on universal truths, logic and reason (Crotty, 1998), assisted in the development of ideas related to "normality". These ideas come together in the conceptualisation of the "ideal human"; an individual who is autonomous, always-in-control and self-reliant (Crotty, 1998), as well as ideally white, heterosexual, male, able-bodied, capable, responsible and middle-class (Davies, 2016; Goodley et al., 2014). Above all else, this ideal individual is *rational*, a point critical to the development of the conceptual framework for this thesis.

I argued further that disability functions as the "constitutive outside" for the notion of the "ideal human" to exist; that is, the idea of rationality, self-reliance and able-bodiedness require an "other" (Campbell, 2005). The ascendant term within this binary, "normal", functions to signify what is desirable, while the descendent term, "disability" functions to signify what is undesirable (De Schauwer, Van de Putte, & Davies, 2017; De Schauwer, Van de Putte, Van Goidsenhoven, et al., 2017); that is, as a "problem" in need of fixing. The positioning of disability as "naturally" inferior within this binary plays a crucial role in the validation and perpetuation of disability oppression.

The background context in Aotearoa New Zealand related to disability was also an important point of enquiry for this thesis. In particular, the key conceptual frameworks related to learning disability were examined, including the medical model, the principle of normalisation / social role valorisation (SRV), the social model, the rights-based approach and Māori perspectives on disability. Each framework has enabled significant progress gains for disabled people. Medicalised perceptions of disability have led to many medical advances which improve people's lives, normalisation / SRV underpinned the

deinstitutionalisation movement, the social model drove the development of national and international legislation regarding physically accessible environments, and rights-based perspectives enabled the inclusion of disability into rights-based legislation, such as the Human Rights Act 1993 (2017). Further, Māori perspectives helped to shape contemporary understandings that foreground relationships as an integral part of the disability experience.

However, with the exception of Māori perspectives on disability, each of the frameworks outlined is underpinned by the modernist notion of the ideal human; that is, an ontological foundation which positions learning disabled people as “other” and as inferior. One particular problem which arises from this ontological foundation is the inability to challenge exclusionary structures and practices which are founded in the assumption of the ideal human, and which lead to disability oppression. I came to understand that these frameworks are both largely invisible in the day-to-day lives of those of us in the disability sector, whilst also being powerfully agentic in shaping the thoughts and feelings of those working in the support sector, as well as learning disabled people themselves. I concluded this section of the thesis by arguing that a new way of conceptualising disability is needed if the changes sought by the DRM are to be progressed. In particular this new conceptualisation of disability cannot be founded in the notion of the ideal human, but should instead seek to *reimagine* disability outside of the bounds of rational humanism.

## Shaping the Research

In the data generation and analysis phase of the research, I wanted to explore whether the notion of pride presented potential for a positive reimagination of disability. As the results from Chapter Seven indicate, I was unable to obtain a conclusive answer as to whether pride presents this potential, because I was not able to clearly see that a state of pride had been achieved in the hui. However, the difficulty I faced in achieving a state of pride within the hui ultimately laid the foundation for a new conceptual framework, one which is grounded in Barad’s work on agential realism. In agential realism, all entities are viewed as inseparable phenomena which entangle together in the ongoing intra-

activity of life. Further, these phenomena are viewed as agentic; as having the capacity to affect and interfere with all other phenomenon, including discourses, the material world and affective practices. Stepping away from the realm of rational humanism, the notion of the “human” is radically re-conceptualised. “Humans”, Barad argues, are an effect of the boundary-making practices of intra-activity; as beings which are produced within, and go on to shape, the ongoing intra-activity of life.

Drawing upon agential realism, I propose that disability be reimagined as an entanglement, rather than as a static, bounded and always-familiar entity. In this view, disability is a *difference* which emerges as a knowable entity through the iterative entanglements of multiple, performative agencies. It is a series of entanglements which are never exactly the same twice-over, yet which have sufficient repetition to create identifiable patterns. Further I argue that, in their current state, the entanglements of disability materialise in such a way that disability is held in a perpetual state of “otherness”, and disability oppression is reiterated.

After coming to this view of disability, the analysis was framed around the following problem statement: *the entanglements of disability materialise in such a way that they reiterate disability oppression*. The research questions stemming from this problem statement include exploring what the entanglements of disability are, what the performative agencies within the entanglements are, how these entanglements enable disability oppression to be perpetuated and what potential these entanglements present.

In order to answer these research questions, I drew upon five other conceptual frameworks. These include citational chains, lines of flight, Butler’s work on performativity, Wetherell’s work on affective and social practice, and Jackson and Mazzei’s work on desiring silence. I also explored the notion of disability pride, an under-theorised concept which I suggest can be used as a tool to disrupt the problematic iterative entanglements of disability.

The methodology for this project was also shaped by an entanglement, in this case of ideas drawn from inclusive research, participatory action research, community based participatory methodologies, culturally responsive

methodologies, and decolonising methodologies. These frameworks were chosen for their alignment with the theoretical framework, and their emphasis on power sharing, co-creation, and the desire to enact change, rather than as a means of investigating an existing situation. The methodological framework was further underpinned by the drive to mitigate the potential for harm for the learning disabled participants involved, and the desire to do research that worked for people with learning disabilities; that is, it did not rely on participants' cognitive ability alone. The data were generated through a series of nine hui, which were planned and enacted utilising a co-creation approach with a learning disabled co-facilitator and a group of seven learning disabled participants.

The data were analysed utilising the framework of diffractive analysis. This analysis tool utilises ideas inherent in agential realism, taking into account the view that all phenomena – research questions, participants, emotions, theory and the researcher/s included – necessarily affect and interfere in the process of the analysis. Data were chosen for the analysis using MacLure's (2013) notion of hot spots; that is, data which hold an intensity which is as much embodied as it is cerebral. The phenomena within these hot spots were not necessarily proximate in space and time, and sometimes involved multiple "moments" which evolved over a long period.

The analysis followed Jackson and Mazzei's (2011) process of plugging in, which develops diffractive analysis into a more explicit analysis framework. Plugging in is a process which highlights how theory and data constitute one another, operating through the bodymind of the researcher in ways that researchers are not always conscious of. Rather than fitting data into neat, pre-established categories, diffractive analysis takes a rhizomatic approach. Plugging in means that the line of questioning within an analysis can take off in unexpected directions, connecting together phenomena which are not connected in space or time.

The Deleuzian questions of *how does it work* and *what does it do not what does it mean*, proved formative in the analysis. Through applying these questions to the data, I found that greater insight could be gained through

looking at what particular entanglements produce, rather than what they mean. This meant that I did not seek to uncover the “truth” of the data, but rather that I worked to uncover “a reality that already exists among the multiple realities being enacted in an event, but which has not previously been ‘disclosed’” (Lenz Taguchi, 2012, pp. 274–275, emphasis in original).

## **Territorialising Forces and the Entanglements of Disability**

One particularly generative hot spot which arose during the data generation was participants’ reactions to videos and discussions which showcased people displaying pride in their disabilities. Whilst some participants indicated that they enjoyed the videos, others had a powerful adverse response. This reaction was a surprise, as I had anticipated that participants would find the videos fun and enjoyable, as Glen (the co-facilitator) and I had. There appeared to be territorialising forces at play within the hui, holding the lines of flight firmly onto a line of descent, where disability was reiterated as an ontology of inferiority.

The first notable territorialising force was participants’ *affective* responses to the videos and discussions. In particular, Carl became “panicked” by the discussions on wheelchairs, Luke reeled back in a display of ableist disgust when watching a video of a one-legged man, and many of the participants said they found the video “weird”. Drawing upon Wetherell’s work on affective practice, alongside agential realism, I examined these reactions as the embodied enactment of the normative orders of disability. Within these normative orders, notions of disability intertwine with affective practice, memory, and discomfort regarding the frailty of the human condition. These entanglements served as a territorialising force at multiple points throughout the hui, inhibiting the production of disability pride and preventing positive discussions regarding disability.

The second territorialising force which emerged through the hui related to the disability identity. Many participants expressed a strong preference for the



word “ability” over “disability”, and expressed a desire to be treated like an “ordinary” or a “normal” person; although, most participants were unable to articulate what this meant. Further, Jonathan stated “I don’t want to be disabled anymore”, indicating a desire to reject the disability identity. Rather than viewing these responses as the “authentic” thoughts and desires of participants, they were examined as the mobilisation of forces evident in wider society. In particular, these forces shape the desire to be placed on the ascendant side of the ableist binary, and to preserve the categories of “normal” and “abled”.

However, the practices of focusing on “ability”, and focusing on being treated like “normal” and rejecting the disability identity proved to be problematic. Focusing on the *sameness* of disabled people, rather than celebrating *difference* plays into the “politics of assimilation”, and unwittingly reaffirms the questionable connection between disability and diminished personhood. Further, attempts to reject the disability identity are often rendered unintelligible, as the rejection does not work within the ableist matrix of intelligibility. These practices ensure that the disability identity is perpetuated as an ontology of inferiority, and the disability identity is not able to be taken up as a source of pride.

The entanglements of silence also arose as a territorialising force within the hui. This entanglement was particularly evident when participants’ understanding of disability was explored, showcasing a significant lack of knowledge regarding the disability category generally, and their own diagnostic labels in particular. For instance, Jonathan informed us that he was diagnosed with Down Syndrome at age five, Luke informed us that he did not know anyone without a disability, and Carl asked simply “what is it?” when asked to identify someone with and someone without a disability. These silences can be understood as an embedded practice within the social norms of disability, where disability is only to be spoken about in a limited range of ways, and in a limited range of circumstances. Further, this practice can be connected with the desire for recognition and the desire to belong, where the closer to “normal” one achieves, the greater the promise of future acceptance and belonging. The lack of knowledge regarding disability, along with the inability or reluctance to speak

of disability, served as a territorialising force within the hui; how can one be proud of disability, if one does not know what it is?

The final problematic iterative entanglement explored in this thesis is the entanglements of “help”. The notion of “help” was a powerful and perplexing phenomenon which arose at multiple points throughout the hui. In particular, several participants used the word help when asked to define disability; although, none of the participants were able to explain what this meant. Drawing once again upon Wetherell’s work on practice, I viewed the phenomenon of help as a social practice of disability. This social practice can be viewed as an integral component of the establishment of what Butler terms “viable subjects” (1997b), where subjects are expected to partake in these practices if they want to be constituted as viable.

Whilst this social practice has many positive outcomes, it also produces some complexities and challenges. In particular, the way this practice is currently enacted places the helper in a position of power over the helpee. The helpee is expected to be grateful and not tell the helper their help was unwanted, or wrongly enacted. As people labelled as disabled are often in a position of needing help, this serves to continually position people placed in this category as passive and lacking in agency, whilst reinforcing the position of those labelled as non-disabled as powerful and agentic.

## **The Agency to Rupture**

The ideas in this thesis have culminated in an exploration of agency. What are the performative agencies which constitute the problematic iterative entanglements of disability, and how can we in the sector harness the agency necessary to challenge these entanglements? I have found that the problematic iterative entanglements of disability are formed from multiple intra-active forces, many of which have significant agency in shaping how disability is conceptualised, and how the people to whom the label disabled is assigned are treated.

One particularly powerful agency shaping the entanglements outlined in this thesis is the modernist notion of the ideal human; a phenomenon which, as

outlined earlier, necessarily positions disability as inferior. The notion of the ideal human emerged through participants' embodied, affective responses to videos and discussions on pride, and through the performance of identity, where the drive to showcase one's status as an ideal subject was mobilised through participants' desire to focus on "abilities" and to reject the disability identity. Further, the notion of the ideal human emerged as a force shaping the discourses and ensuing silences regarding disability, and rubbed up against the social practice of help, shaping the desire to give, but not receive help. Through all of these entanglements, the notion of the ideal human was reified as the archetypal way of being, and was subsequently left unchallenged.

I have argued that the ontological underpinning of the ideal human is a key reason why learning disabled people continue to be positioned on the margins of humanity. This underpinning is inherent not only in the entanglements explored through the analysis chapters, but can also be seen in strategies driving the disability rights movement (DRM) and Government policy, as outlined in Chapter Three. This means that the tools being utilised to challenge exclusionary structures and practices, such as the drive to "focus on abilities" rather than speak of disability, the social model and rights-based models, are ontologically grounded in the very ideas which position learning disabled people as "other", and subsequently as inferior. As C. Gordon (1980), remarks, this ontological foundation provides the very rationality which "grounds the establishment of a regime of acceptability" (pp. 257-258) for placing particular types of people on the margins of humanity. I argue that if we are to tackle the "problem" of learning disability, we need to utilise tools which do not replicate this ontological foundation. Further, I believe that the issue of disability oppression will not adequately be addressed until new ways of thinking about ourselves as "humans" which do not rely on the pejoration of learning disability, and which enable us to embrace our full being-ness – vulnerabilities and imperfections included, are adopted.

The entanglements outlined in this thesis culminate in a situation where the ability to challenge the marginalisation of learning disabled people is largely foreclosed. The inhibiting forces extend beyond the notion of the ideal human.

When people labelled as learning disabled are not fully aware of their subject positioning, and do not have the language to understand or describe their positioning, the ability to challenge the material consequences of this positioning is significantly constrained. The desire not to speak of disability inhibits the agency necessary to reimagine disability, and continues to grant other intra-active forces agency in shaping how disability is conceptualised. Examples of these forces include medicalised conceptions of disability, and the modernist and capitalist foundations of Western society. Whilst I have explored each of the entanglements in this thesis as separate phenomena, it is important to remember that they continually intra-act and entangle with each other. For instance, how can learning disabled people take up the disability identity with pride, if they do not know what that identity is? How does one go about challenging the silences regarding disability, when it feels so wrong to do so? How are we to develop more empowering social practices related to disability, when we are working so hard to *not* focus on disability?

Harnessing the agency necessary to shift these intra-active forces is no small challenge. As Davies (2008) argues, ruptures to the citational chains, or ongoing entanglements of life, are often forcefully resisted in order to maintain the known order. However, building upon a key idea from Barad, that “[the] world and its possibilities for becoming are remade with each moment” (p. 396), I have come to see that the possibilities for rupture to the problematic iterative entanglements of disability are always at hand. The task becomes to find out what those ever-present possibilities are and how we can harness them to remake the world in a new and more promising direction. I believe the drive to make this happen already exists. The intuition that I started this project with, that disability oppression is not caused by wide-scale malicious intent, poor intentions and “bad attitudes”, has been reinforced through the findings in this thesis. I have found that many of the problematic practices which underpin disability oppression come from a place of “good” intentions. Examples include the desire to help people, the desire to belong, and the desire to be kind to one another by not calling into question one’s status as a *full person* by drawing

attention to a disability. I have discovered that I am complicit in many of these practices, at the same time as I am trying to challenge disability oppression.

## **Implications for Policy, Practice and Future Research**

There are many implications for policy and practice which arise from the entanglements outlined in this thesis. In particular, affective practices have proven to be a powerful force which I was unaware of prior to the hui, yet which function as a powerfully agentic force in the lives of the participants in this research. I now believe that more work needs to be done in this area to understand how best to support learning disabled people with these often painful, unidentified and/or unacknowledged “emotions”. Furthermore, affective practices present potential for rupturing many of the entanglements of inferiority. I agree with Cheyne (2016) who argues that, “[a]ffective and emotional factors are often much more powerful at changing attitudes [and practices] than ideas based in reason and logic” (34:11). In order to harness the agentic potential of affect, however, we need to acknowledge its existence and work to identify these practices, to be able to take them on to a new line of flight. Yet how do we do this effectively as disability service providers and community members?

One immediate implication for disability support service personnel is to start paying attention to how we engage with affect in our work with learning disabled people. The research in this thesis indicates that we need to acknowledge that the people we support have a wide variety of emotions, and to ensure we communicate to the people we support that it is OK to feel sad / angry / upset sometimes. We also need to stop trying to “fix” people when they are not happy, and to instead support them to work through their emotions.

Another implication for the DRM relates to the potential for the disability identity to be used as a tool to rupture the ongoing processes of inferiorisation and individualisation of the “problem” of disability. Whilst data from the hui did not produce the result hoped for in relation to pride enabling a positive

reimagination of disability, I believe that the concept holds potential. Perhaps “pride” is the wrong word, and another concept such as “embracing disability”, or another term which enables us to embrace our full being-ness, vulnerabilities and imperfections included, has greater agentic potential. However, regardless of the specific term chosen, I believe the concept is necessary for two reasons. Firstly, an embrace of the disability identity works *with* the matrix of intelligibility, rather than against it. The moment in which the disability identity is (re)cited is the point at which relations of power are exercised (Foucault, 1980), and it is at this point that the potential for rupture lies. In rejecting the identity, this potential is lost.

Secondly, I argue that an embrace of the disability identity is essential in order for a collective to form which has the agency necessary to challenge disability oppression. Like a rug woven from many small, individually weak strands, collectives hold greater capacity to take the entanglements of disability onto a new line of flight than individuals alone. This is an already-present possibility within the disability community, alluded to during the bullying role-plays when participants informed me that I would get “new mates” and meet “other people that can help [me] out” if I was to become blind (see Chapter 11). Yet, in order for a collective to form, people have to first *see* themselves as a collective. It is exceptionally challenging to form a large collective when people reject the label necessary for the formation of a collective identity. I have argued that by stepping within the terms which constitute us and embracing the disability identity, there is much greater potential to grasp the agency necessary to shift the ongoing problematic entanglements of disability.

The third implication for policy and practice relates to the entanglements of silence. In challenging this practice and openly speaking of disability, we may be able to confront the unnamed and unchallenged notion of the ideal human, and to acknowledge the problematic entanglements of disability. On the surface, this entanglement appears to be relatively unproblematic to rupture, for in order to shift the lines of flight, we only need to start speaking of disability. However, the entanglements of silence are also intertwined with the affective practices of disability. These entanglements were particularly notable in the responses from

Jonathan, who at various times indicated powerful emotions associated with disability, and informed us “I just stop thinking about it when it [disability] comes back up”. There may be some situations where this practice is easy to rupture, and others where the ruptures are more forcefully resisted. Furthermore, it is likely that there are many more productive forces generating the entanglements of silence than what has been outlined in this thesis. For instance, what role does the need for augmentative communication (such as picture exchange communication) play in these silences? Are these silences being actively encouraged by funding contracts, disability service providers and support workers? If so, in what way is this happening? What role does the more psychic dimension of life play in these silences, shaping what Campbell (2009) would call internalised ableism?

The entanglements of silence also intersect with my practice as a support worker. In particular, I have realised a key issue which arises from not speaking of disability with people labelled as learning disabled; when I do not speak of disability, I rarely speak with people about the way they want to be supported. I even know of support workers who were asked to call themselves “special friends” for the people they support, so that the support is entirely unacknowledged.

When thinking about the implications for support workers, this practice raises some questions. What kind of change would it make if support workers openly acknowledged the support they provide, rather than pretending it is some kind of unseen “magic” in a person’s life? How much more could we – support workers, family and the people who receive support – learn from one another by openly acknowledging the support that was provided to enable a learning disabled person to succeed, rather than pretending they were “independent” in their success? What kind of difference would it make if learning disabled people talked with each other about the support they needed, found useful and disliked? This change in practice seems simple, yet potentially

profound for learning disabled people, as it goes against the training many support workers have received.

The fourth implication for policy and practice relates to the entanglements of help. I argue that we need to find ways of providing the “help” and support which many disabled people need to survive and thrive, without continually positioning helpees as passive. What would change if support workers consciously worked to position themselves as helpees, as well as helpers? Further, we need to work to recognise the “help” which all of us rely on in our everyday lives, in order to challenge the baseless idea of “independent”, “self-reliant” citizens.

The findings from this research also present some important implications for research methodology. In particular, opening myself up to being vulnerable and positioning participants as *helpers* in this research presented some interesting possibilities, enabling us to move past seemingly intractable knotty points. This response seemed to indicate the productive potential of positioning, where I as a researcher stepped away from the mantle of “knowledgeable expert”, and positioned myself as someone in need of help. In these moments, the change in positioning seemed to disrupt the problematic normative orders of life and take us of onto a new line of flight, albeit briefly. I believe that this altered positioning presents some important implications for research methodology, and is a matter in need of further investigation.

Lastly, the research for this thesis gives support to the view of disability as an entanglement. This view offers a potential way forward in the field of disability studies, a field which seems to have lacked clear direction since the social model was soundly critiqued and cast aside. The research illustrates that there is much to be gained through using the approach outlined in this thesis to explore what Davies (2015) terms the taken-for-granted power of the ordinariness of life-as-usual. As I have highlighted, much of the foundation for disability oppression is embedded within the normative orders of life – in the “repeated citations of the way the world is (and, it is believed, ought to be)” (Davies, 2008, p. 173). More research is required to explore the entanglements of disability which were not unearthed in this thesis. For instance, what are the



entanglements which already challenge disability oppression, and how can we foster more of them? What entanglements are particular to disability support work, and what impact do these entanglements have on the lives of people who receive support? Where are the ever-present possibilities for rupture within the problematic entanglements, and what possibilities for change emerge when entanglements are ruptured? Much could be gained for learning disabled people, their families and whānau<sup>30</sup>, the wider disability community, and the field of disability support work by exploring these entanglements further. This work could explore the possibilities for enabling the entanglements of disability to materialise in ways that do not reiterate disability oppression, but rather shift the lines of flight in new and more promising directions.

## Concluding Thoughts

I set out in this journey having given little thought to my own status as a “non-disabled” person. I never questioned the positioning of myself as “other” to the people I was supporting, and I never questioned the notion of learning disability as a fixed, essential concept which has always resided in nature. This thesis has ended up being not so much about learning disability, but about the possibilities for how we think about ourselves *as humans*. I have learnt that those categorised as learning disabled are an integral part of this conceptualisation of humans, that the way I think about myself is shaped by the existence of these “others”, and that the positioning of those categorised as learning disabled as “naturally inferior” is an integral part of these processes. This thesis has been a journey which has completely reshaped how I see the world, the people in it, what we do and why we do what we do. I have come to question why it is that those of us with higher-than-average intellectual abilities are viewed as somehow “better” than others, and why it seems so natural to think that people with higher intellectual abilities should be rewarded with significantly higher pay and other forms of privilege. I find myself wondering why

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<sup>30</sup> See page 45 for the definition of whānau

we place such little value on the roles which play such an integral role in enabling society to function, but which do not require intense cognitive thinking, such as the office cleaners, the supermarket trolley collectors, and the drain layers; all of whom I rely on to function in my daily life.

I found there are many benefits to working with learning disabled people. There were countless points of reflection during the hui where I thought to myself *this would never happen with a group of people without learning disabilities*. The particular group I worked with were unfailingly kind and supportive of each other and me during the hui, in a way which I have never experienced with a group of non-disabled people. They complimented each other's "stretches" at the beginning and end of the hui, and went out of their way to help me and each other whenever possible. Furthermore, participants were honest about their thoughts and feelings in raw and unexpected ways; at times I had to remind myself that the best way to honour this gift was to foreground these phenomena in the thesis, so that others can learn from them. Thinking back, I realise that participants' were providing responses which many people would think or feel, yet which a lot of non-disabled people would not want to be open about for fear of being judged as rude or "getting it wrong" in relation to disability. Because of this honesty, I was able to see some of the powerful and painful normative orders of life which operated through the participants; these orders are much harder to access when they remain hidden and difficult to see.

I would like to finish with some final "reflections" about the ways in which our lives have been limited by the imposition of certain expectations onto bodies and minds. Much of the joy I experience from working with learning disabled people comes from non-normative encounters. During the hui, participants had many jokes and fun experiences that I cannot imagine happening with a group of non-disabled people. For example, in hui eight participants were asked to indicate which activities and resources they liked most from the hui. Some participants started raising their hands to "vote" for their favourite activities, and after a while, Natalie started "voting" by waving both her arms and her legs around. This was soon copied by other participants,

and before long there was raucous laughter. By the end of this, Jonathan, Carl and Glen somehow ended up on top of each other with their legs in the air, crying with laughter. In my experience this was entirely non-normative; I have never seen this happen with a group of non-disabled adults, and I cannot imagine it happening. These sorts of non-normative events arose at multiple points throughout the hui, and I have experienced many more like them throughout my years working in the disability support sector; they are “different”, and they are totally enjoyable.

The reflections in this research have been a huge journey for me, and I have come to realise how much all of us – myself included – are impacted and constrained by the normative orders of life. How much do we limit ourselves by trying to be and act “normal”? How much of the vivacity of life is lost in this endeavour? How much time and effort do we put into dressing “normal”, acting “normal”, and suppressing non-normative desires such as the yearning to skip or sing or laugh loudly in public? How much of our day is filled with these suppressed phenomena, and how much richer would our lives be if we were more free to express ourselves? Perhaps the task at hand is not so much about reimagining disability, but about reimagining a world which embraces disability and difference. If we can imagine and design a world that works for learning disabled people – in our education system, our political system, our social structures – would it not work better for all of us? If we stop chasing “normal” and embrace learning disabled people for being who they are, with their quirks and differences, not despite them, couldn’t we all stop having to try so much to conform, and learn to embrace our full being-ness – vulnerabilities and imperfections included?

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# Appendices

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Please note: Some appendices have been re-formatted (that is, font sizes and page layout may have changed) so as to fit within the University publication guidelines.

## Appendix 1: Call for Pilot Participants

### Call for Participants

Hi there. My name is Ingrid Jones and I am looking for people to participate in my research. I have put some information below about it. If you want join in please fill in the form at the bottom of the next page.

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#### **What is research?**

Research is when someone does a study or an activity to get information about something so they can learn something new. I am doing this research for my PhD, which is a degree from the university.

#### **What is this research about?**

This research project is looking at learning disability pride, or intellectual disability pride. I am looking for about 6-8 people with learning (intellectual) disabilities to participate in my research.

#### **Who can join?**

Anyone who has a learning disability or intellectual disability, or who uses a disability support service.

# PRIDE



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### **What will you be asked to do?**

Participants will work as a group and have one meeting, which is called a hui. The hui will be about two hours long and will be on a Thursday morning. I will let you know the date closer to the time.

At the hui you will be asked to look at some photos, videos and other things that show ideas about disability. You will be asked what you think about the ideas, and, most importantly, you will be asked to add your own ideas. There are no wrong ideas, so you don't need to worry about getting anything wrong. I want to know what you think.

Our talk will be videoed. The only people who will get to see the video are me, the co-facilitator and my supervisors at university. Supervisors are like teachers who help me with my research.

### **What will I do with the information from the research?**

When I am finished the research I will write a big book called a thesis. This will talk about what we did and what we found out together. I will also present at conferences, which are like big meetings where people come to talk and learn about different things. I will also write some articles for journals, which are like special magazines for people at university. I might also present the information in other places such as in newspapers, newsletters, other magazines, by talking to groups and possibly on television and radio.

I will make a plain-language summary of my research at the end and I will come back and talk to you about it.



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### **I'd like more information, what do I do?**

Fill in the form below and give it back to me. I will then meet with you and your key advocate to talk more about the research. I can only work with 8 people for my research. I might get a lot of people who want to join the group. Then I will have to choose. I will tell you if you have been chosen or not.

✓ Yes, I'd like to know more about this project

Full Name: \_\_\_\_\_

Phone Number: \_\_\_\_\_

Researcher contact details: Ingrid Jones

Email: [irj2@students.waikato.ac.nz](mailto:irj2@students.waikato.ac.nz)

Phone: [information removed for appendix]

Post: [information removed for appendix]

## Appendix 2: Pilot Hui Participant Information Sheet

### Information Sheet – Participants

Ingrid Jones PhD Research Project 2015

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purposes

#### **What is research?**

Research is when someone does a study or an activity to get information about something so they can learn something new. I am doing this research for my PhD, which is a degree from the university.

#### **What will I do for the project?**

This is a pilot for my research, which is like a practice. This research project is looking at learning disability pride, or intellectual disability pride. We will work as a group and have 1 meeting, which is called a hui. At the hui we will look at getting to know each other. We will also talk about what research is. You will be asked some questions and we will do some activities together. You don't have to join in the activities or answer any of the questions if you don't want. The hui will be videoed. This is so I can remember what we did and learn from it.



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#### **What will I do with the information from the research?**

When I am finished with the research I will write a big book called a thesis. This will talk about the research, what we did and what we found out. This will include plain-language sections for people who like easy-read. I will put my book on the internet so lots of people can read it. It will stay on the internet forever. I will also



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present at conferences. These are like big meetings where people come to and learn about a lot of different things. I will also write some articles for journals, which are like special magazines for people at university. I might also put something in newsletters, newspapers or other magazines, and I might talk to other people in the media such as on television and radio if I get a chance. I might also present at other seminars and talk to different groups. If you want I can come and talk more to you about it as well.

### **What will happen with the data (such as videos)?**

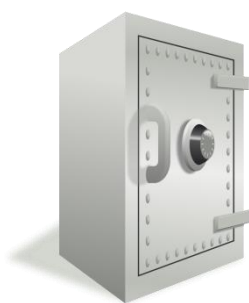


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When we have the hui I will video our time together. This helps me to remember what happened. The only people who will see the videos will be you, the other participants, the co-facilitator, me (Ingrid) and my supervisors at university. Supervisors are like teachers who help me get my research right. After the research these videos will be kept at a secure place at the university for five years. Then I will take them myself. If I want to use the videos at a conference or other place after the research is over I will come back and ask your permission first.

### **Confidentiality:**

Confidentiality means that when I write up this project and when I present at conferences people won't be able to tell who you are. There are two choices for confidentiality. You don't have to choose which one you want straight away. You can choose which one you want when we finish our research.

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**Option 1:** Full confidentiality. This means that when I am telling people about my research I will make it so that people can't tell it is you I am talking about. For instance, I might change your name and your age, or other information so people can't tell it is you. If I want to use any of the video clips at a conference or other place I will first come to you, show you the clip, and ask for permission.

**Option 2:** Limited confidentiality. After we have done the research I would like some of the group members to help me present the information. This might be at conferences or other places where we talk to people. This means that people will know that you have been in the research, and people might know you have said some things. If I want to use any video clips at a conference or other place I will first come to you, show you the clip and get your permission.

**Important:**

If you join the research project and don't like it you can leave at any time. BUT all of the information you have given will still be used. This means if come to the hui and leave part way through, I will use your information from when you were there. This is because we are doing everything as a group and it will be hard to remove one person's information. I will do my best to make sure that other people can only tell if information is from you with your permission. **If you are OK with this then it is OK to sign this form.** If you are not OK with it please do not sign the form. Talk to me about any worries.

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### **Who do I talk to if I'm worried or unhappy?**

It is very important that you feel safe in the hui. If you are unhappy or worried about anything you can talk to me. If you don't think you can talk to me, or if you have talked to me and you are still concerned, you can contact my supervisor at university. I have put our contact details below.

Researcher: Ingrid Jones

Email: [irj2@students.waikato.ac.nz](mailto:irj2@students.waikato.ac.nz)

Phone: [information removed for appendix]

Supervisor: Lise Bird Claiborne

Email: [information removed for appendix]

Phone: [information removed for appendix]



## Appendix 3: Pilot Participant Consent Form

### Consent Form for Participants

- ✓ I have been read what is on the information sheet
- ✓ I understand what the research project is about
- ✓ I know that I will be looking at videos and books about research at the hui
- ✓ I can choose not to give my opinion about anything at any time at the meetings and I do not have to say why
- ✓ I can choose to leave the research project at any time and I do not have to say why
- ✓ I understand that I will choose if my information will be used by Ingrid for her PhD at the end of the hui.
- ✓ I agree to take part in the hui
- ✓ I agree to keeping confidentiality about the meetings - what is shared in the meetings stays in the meetings
- ✓ I understand what is written on the consent form and I agree to it
- ✓ I understand that if Ingrid wants to use video later on at a conference or other place she will show me what she wants to use, and ask me first

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Full Name

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Signature

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Date

## Appendix 4: Full Hui Participant Information Sheet

### Information Sheet – Participants

Ingrid Jones PhD Research Project 2015

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for copyright  
purposes

#### **What is research?**

Research is when someone does a study or an activity to get information about something so they can learn something new. I am doing this research for my PhD, which is a degree from the university.

#### **What will I do for the project?**

This research project is looking at learning disability pride, or intellectual disability pride. We will work as a group and have 8-9 meetings, which are called hui. At the hui the group will be asked about disability and what they think of it. Then we will look at some photos, videos and other things I have got together for my research. You will be asked what you think about some of the ideas and will be asked to add your own ideas. Later on, after the photos and videos, we will talk about what our group thinks about disability. All of our talks will be videoed too. At the end of the project you can help me look at videos of our talk and tell me what you think about them if you want. This is called an analysis.



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[http://www.publicdomainfiles.com/show\\_file.php?id=13527536412839](http://www.publicdomainfiles.com/show_file.php?id=13527536412839)

## **What will I do with the information from the research?**

When I am finished with the research I will write a big book called a thesis. This will talk about the research, what we did and what we found out. This will include plain-language sections for people who like easy-read. I will put my book on the internet so lots of people can read it. It will stay on the internet forever. I will also present at conferences. These are like big meetings where people come to and learn about a lot of different things. If you want you might help me present at conferences. I will also write some articles for journals, which are like special magazines for people at university. I might also put something in newsletters, newspapers or other magazines, and I might talk to other people in the media such as on television and radio if I get a chance. I might also present at other seminars and talk to different groups. If you want I can come and talk more to you about it as well.

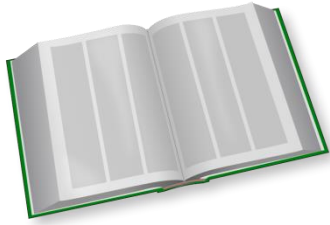


Image retrieved from:  
[https://vi.wikipedia.org/wiki/T%E1%BA%ADp\\_tin:Big\\_Book.svg](https://vi.wikipedia.org/wiki/T%E1%BA%ADp_tin:Big_Book.svg)

## **What will happen with the data (such as videos)?**

When we have the hui I will video our time together. This helps me to remember what happened. We will look at some of the videos later. The only people who will see the videos will be you, the other participants, the facilitator, me (Ingrid) and my supervisors at university. Supervisors are like teachers who help me get my research right. After the research these videos will be kept at a secure place at the university for five years. Then I will take them myself. If I want to use the videos at a conference or other place after the research is

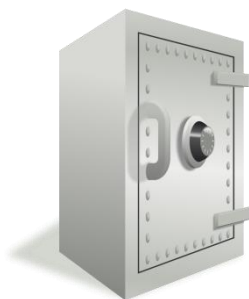


Image retrieved from:  
<http://clipart-library.com/clipart/912323.htm>

over I will come back and ask your permission first.

### **Confidentiality:**

Confidentiality means that when I write up this project and when I present at conferences people won't be able to tell who you are. There are two choices for confidentiality. You don't have to choose which one you want straight away. You can choose which one you want when we finish our research.

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for copyright  
purposes

**Option 1:** Full confidentiality. This means that when I am telling people about my research I will make it so that people can't tell it is you I am talking about. For instance, I might change your name and your age, or other information so people can't tell it is you. If I want to use any of the video clips at a conference or other place I will first come to you, show you the clip, and ask for permission.

**Option 2:** Limited confidentiality. After we have done the research I would like some of the group members to help me present the information. This might be at conferences or other places where we talk to people. This means that people will know that you have been in the research, and people might know you have said some things. If I want to use any video clips at a conference or other place I will first come to you, show you the clip and get your permission.

### **Important:**

If you join the research project and don't like it you can leave at any time. BUT all of the information you have given will still be used. This means if you do the first and second hui and then leave, I will still use your information from the two hui. This is because we are doing

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for copyright  
purposes

everything as a group and it will be hard to remove one person's information. I will do my best to make sure that other people can only tell if information is from you with your permission. **If you are OK with this then it is OK to sign this form.** If you are not OK with it please do not sign the form. Talk to me about any worries.



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[https://mbtskoudsalg.com/explore/sad-smile-png/#gal\\_post\\_4382\\_sad-smile-png.png](https://mbtskoudsalg.com/explore/sad-smile-png/#gal_post_4382_sad-smile-png.png)

### **Who do I talk to if I'm worried or unhappy?**

It is very important that you feel safe in all the hui. If you are unhappy or worried about anything you can talk to me. If you don't think you can talk to me, or if you have talked to me and you are still concerned, you can contact my supervisor at university. I have put our contact details below.

Researcher: Ingrid Jones

Email: [irj2@students.waikato.ac.nz](mailto:irj2@students.waikato.ac.nz)

Phone: [information removed for appendix]

Supervisor: Lise Bird Claiborne

Email: [information removed for appendix]

Phone: [information removed for appendix]

# Meeting Details

## Hui 1

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copyright purposes

Date: Friday October 30<sup>th</sup>

Time: 9am – 12 pm

Where: 108 Alexandra Street, Hamilton –  
WaQuY (Waikato Queer Youth)

## Hui 2

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copyright purposes

Date: Friday November 13<sup>th</sup>

Time: 9am – 12 pm

Where: 108 Alexandra Street, Hamilton –  
WaQuY (Waikato Queer Youth)

## Hui 3

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from appendix for  
copyright purposes

Date: Friday November 27<sup>th</sup>

Time: 9am – 12 pm

Where: 108 Alexandra Street, Hamilton –  
WaQuY (Waikato Queer Youth)

Contact details: Ingrid Jones  
Email: [irj2@students.waikato.ac.nz](mailto:irj2@students.waikato.ac.nz)  
Phone: [detail removed for appendix]

## Appendix 5: Full Hui Participant Consent Form

### Consent Form for Participants

- ✓ I have been read what is on the information sheet
- ✓ I understand what the research project is about
- ✓ I know that I will be looking at videos and books about disability at the hui
- ✓ I know I will be asked for my opinion about disability
- ✓ I can choose not to give my opinion about anything at any time at the meetings and I do not have to say why
- ✓ I can choose to leave the research project at any time and I do not have to say why
- ✓ I understand that I will choose if my information will be used by Ingrid for her PhD at the end of the final hui.
- ✓ I agree to take part in the hui
- ✓ I agree to keeping confidentiality about the meetings - what is shared in the meetings stays in the meetings
- ✓ I understand what is written on the consent form and I agree to it
- ✓ I understand that if Ingrid wants to use video later on at a conference or other place she will show me what she wants to use, and ask me first

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Full Name

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Signature

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Date

## Appendix 6: Facilitator Information Sheet

### Information Sheet - Facilitator

Ingrid Jones PhD Research Project 2015

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for copyright  
purposes

#### **What is research?**

Research is when someone does a study or an activity to get information about something so they can learn something new. I am doing this research for my PhD, which is a degree from the university.

#### **What will I do for the project?**

This research project is looking at learning disability pride, or intellectual disability pride. We will work as a group and have 8 meetings, which are called hui. Your job will be to facilitate the group, to ask questions and to encourage people to answer them. You will also help to look over the things we will be discussing at the group and have a chance to have some input into what we talk about. You can also help set up the room when we have the hui. This means you will need to set aside one afternoon or morning a week for the research, and you might need to have another afternoon/morning to prepare. We can talk about this together to figure out what will work best for you. You will be able to contact me at any time during the research if you have any questions or want some more information.



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[http://www.publicdomainfiles.com/show\\_file.php?id=13527536412839](http://www.publicdomainfiles.com/show_file.php?id=13527536412839)

At the hui the group will be asked about disability and what they think of it. Then we will look at some photos, videos and other things to look at some ideas from university. The group



will be asked what they think about some of the ideas. Later on, we will have another talk about what everyone thinks about disability. All of our talks will be videoed. At the end of the project you can help me look at some of the videos and tell me what you think about them if you want. This is called an analysis.

### **What will I do with the information from the research?**

When I am finished with the research I will write a big book called a thesis. This will talk about the research and what we found out together. This will include plain-language sections for people who want an easier version to read. This will be available on the internet so lots of people can read it. It will stay on the internet forever. I will also present at conferences. These are like big meetings where people come to and learn about a lot of different things. If you want you might be able to help me present at conferences. I will also write some articles for journals, which are like special magazines for people at university. I might also put something in newsletters, newspapers or other magazines, and I might talk to other people in the media such as on television and radio if I get a chance. I might also present at other seminars and talk to different groups. If you want I can make a plain-language summary of my research at the end for you to read, or I can come and talk to you about it.



Image retrieved from:  
[https://vi.wikipedia.org/wiki/T%E1%BA%ADp\\_tin:Big\\_Book.svg](https://vi.wikipedia.org/wiki/T%E1%BA%ADp_tin:Big_Book.svg)

### **What will happen with the data (such as videos)?**

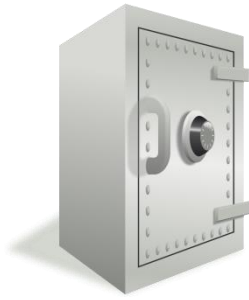


Image retrieved from:  
<http://clipart-library.com/clipart/912323.htm>

When we have the hui I will video the sessions. This helps me to remember what happened in the sessions. We will look at some of the videos later to see what happened in the research project. The only people who can see the videos will be me, people who join in the research (including you) and my supervisors at university. Supervisors are like teachers who are helping me with my research. After the research these videos will be kept at a secure place at the university for five years. If I want to use the videos at a conference after the research is over I will come back and ask your permission first.

### **Confidentiality:**

It is really important that you keep any information you get from the project confidential. This means that you don't talk to anyone except me about any personal information or personal things you have heard during the research. This is so that everyone feels safe to talk about personal things. If you have any questions or concerns you can talk to me or my supervisor Lise.

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for copyright  
purposes

You will also have a choice about how much confidentiality you want in the project for yourself. This means that when I write up what I have found from this project and when I present at conferences people won't be able to tell who you are. There are two choices for confidentiality. You don't have to choose which one you want today. You can choose which one you want when we finish our research.

**Option 1:** Full confidentiality. This means that when I am telling people about my research in writing, at conferences or other places I will make it so that people can't tell it is you I am

talking about. For instance, I might change your name and your age, or other information so people can't tell it is you. If I want to use any of the video clips at a conference I will first come to you, show you the clip, and ask for permission.

**Option 2:** Limited confidentiality. After we have done the research I would like to involve some of the group members when I present the information. This might be at conferences or other places where we talk to people. This means that people will know that you have been helping with the research, and people might know you have said some things.



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[https://mbtskoudsalg.com/explore/sad-smile-png/#gal\\_post\\_4382\\_sad-smile-png.png](https://mbtskoudsalg.com/explore/sad-smile-png/#gal_post_4382_sad-smile-png.png)

### **Who do I talk to if I'm worried or unhappy?**

It is very important that you feel safe in all the hui. If you are unhappy about something or you are worried you can talk to me. If you don't feel like you can talk to me, or if you have talked to me and you still aren't happy, you can contact my supervisor at university. I have put our contact details below.

Researcher: Ingrid Jones

Email: [irj2@students.waikato.ac.nz](mailto:irj2@students.waikato.ac.nz)

Phone: [information removed for appendix]

Supervisor: Lise Bird Claiborne

Email: [information removed for appendix]

Phone: [information removed for appendix]

## Appendix 7: Facilitator Consent Form

### Consent Form Facilitator

- ✓ I have been read what is on the information sheet
- ✓ I understand what the research project is about
- ✓ I understand what my job will be as a facilitator and agree to do the job
- ✓ I know that I will be looking at videos and books about disability at the meeting
- ✓ I know I will be asking participants for their opinions about disability, and might be able to give some of my own.
- ✓ I can choose not to give my opinion about anything at any time at the meetings and I do not have to say why
- ✓ I understand that I will choose if my information will be used by Ingrid for her PhD the end of the final hui
- ✓ I agree to keeping confidentiality about the meetings - what is shared in the meetings stays in the meetings
- ✓ I understand what is written on the consent form and I agree to it
- ✓ I understand that if Ingrid wants to use video if me later on at a conference she will show me what she wants to use, and ask me first.

---

Full Name

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Signature

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Date

## Appendix 8: Participant Safety Information

### Important Information

Ingrid Jones PhD Research Project 2015

#### Health information

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#### Safety information (How will I tell when you are upset, what will you do, what should I do)

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#### Key Advocate contact information:

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# Appendix 9: Glen and Ingrid Working Agreement

## Glen and Ingrid's Research Working Agreement

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purposes

### **Be reliable**

This means that we always put appointments in our calendars and turn up when we have agreed to meet. If we can't turn up or if we will be late, we will let the other person know.

### **Be available**

This means we make time to meet with each other and talk to each other.  
This also means that sometimes we will have to miss out on other things we would normally do so we can meet.

### **Be honest**

This means that we need to talk about how we are feeling, especially if we are unhappy.  
It also means that we need to be willing to have hard conversations

### **Respect each other's ideas**

An important part of respecting each other's ideas and being honest is that it is important to disagree

### **Keep things simple**

We will work to keep things simple so they are easy to understand

### **Say if we don't understand something**

We will speak up if we don't understand something so the other person can explain it a different way

Signed

Signed

Date 28/8/15

Date 28/8/15

## Appendix 10: Confidentiality Agreement

### Confidentiality Agreement

Ingrid Jones PhD Research Project 2015

Confidentiality means that when I write up what I have found from this project and when I present at conferences people won't be able to tell who has been talking. There are two choices for confidentiality.

**Option 1:** Full confidentiality.

When I (Ingrid) am telling people about my research at conferences or other places I will do my best to make sure that people can't tell who it is that I am talking about. I will change names, ages, addresses and other information so people can't tell who I am talking about. Choose this option if you **don't feel OK** about a lot of people finding out about what you have said. If you choose this option you won't be able to present at conferences and other places because people will know who you are.

**Option 2:** Limited confidentiality.

People will know your name and that you have been involved in the research. They will find out some of the things you have said, but sharing very personal things will be your choice alone. Choose this option if you **feel OK** about sharing your information with a lot of people. If you choose this option you may co-present at conferences and other places to help share what we have done in the research.

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for copyright  
purposes

I choose (circle Option 1 **or** Option 2)

- Option 1 (full confidentiality)
- Option 2 (limited confidentiality)

---

Full Name

---

Signature

---

Date



## Appendix 11: How we will Work Together

### How we will work together

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purposes

Work as a team – everyone does their jobs

Treat each other with respect

Respect each other's opinions

One person at a time talking

Everyone has an equal say

Talk about things that are important

Be kind

Help each other

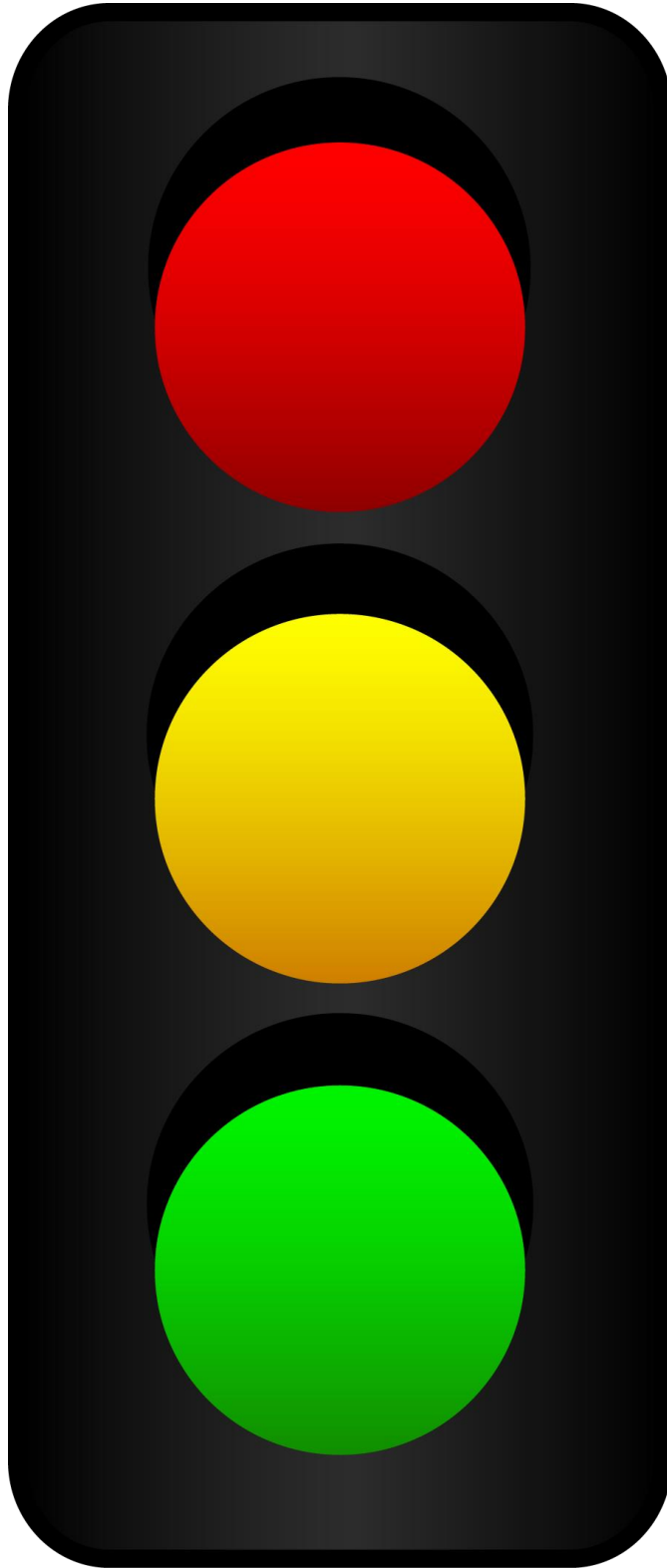
Have a good attitude

Turn up on time

We won't tell each other what to do

Make sure we finish a topic before we change topics

## Appendix 12: Traffic Light



Retrieved from: <https://goo.gl/images/fDp7Sy>

## Appendix 13: Feelings Cards

NB: the following cards were approved by Glen for publication. He chose not to include the “sore”, “sad”, “angry”, “happy” and “upset” cards.



Scared



Nervous



Stressed



Tired



Relaxed

## Appendix 14: Ableism Cards

\*Images and text size have been shrunk for placement in appendix. Place of retrieval listed under each image.



Nick

<http://climatekids.nasa.gov/revision/rainstick/missing-rain.png>



Matt

<http://previews.123rf.com/images/vectorshots/vectorshots1308/vectorshots130800428/21395996-Sad-Sales-Man-Business-Cartoon-Character--Stock-Vector.jpg>



Rosie

<http://gandoza.gandoza.netdna-cdn.com/media/catalog/product/cache/1/image/9df78eab33525d08d6e5fb8d27136e95/3/d/3d-characters-cartoon-woman-model-8.jpg>



Kahu

<http://wasteurtime.com/zone/train8.png>



Harry

<http://cliparts.co/cliparts/pT5/oG5/pT5oG5X7c.jpg>



Anne

[http://www.abceastside.com/home/wp-content/uploads/2013/04/ConfusedSeniorWoman\\_111003020.jpg](http://www.abceastside.com/home/wp-content/uploads/2013/04/ConfusedSeniorWoman_111003020.jpg)



Bob

<http://ehealthforum.com/blogs/fiddy/are-deaf-people-immune-from-schizophrenia-b42560.html>



Jill

<http://previews.123rf.com/images/tigatelu/tigatelu1404/tigatelu140400323/27657248-Smiling-business-woman-cartoon-presenting-Stock-Vector.jpg>



Sam

<https://s-media-cache-ak0.pinimg.com/236x/ac/60/f9/ac60f9034eb99ab9dc2ef8286b60746b.jpg>



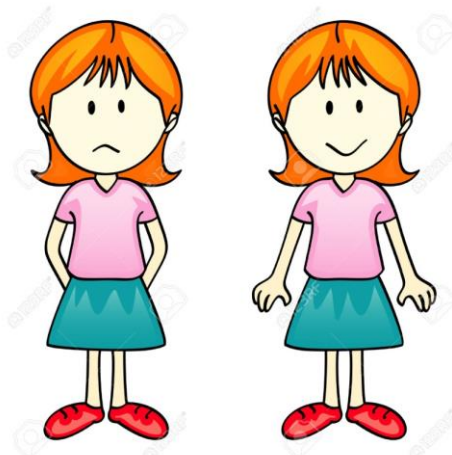
Ricky

<http://previews.123rf.com/images/Krisdog/Krisdog1203/Krisdog120300070/12985683-Cartoon-illustration-of-a-happy-boy-racing-in-his-wheelchair-Stock-Vector.jpg>



Sarah

<http://classroomclipart.com/images/gallery/Clipart/Health/girl-walking-with-crutches-831.jpg>



Kelly and Jane

[http://previews.123rf.com/images/Mr\\_Vector/Mr\\_Vector0906/Mr\\_Vector090600254/4961686-Vector-Comic-Character-Girl-Stock-Vector-sad-cartoon-girl.jpg](http://previews.123rf.com/images/Mr_Vector/Mr_Vector0906/Mr_Vector090600254/4961686-Vector-Comic-Character-Girl-Stock-Vector-sad-cartoon-girl.jpg)



Jake

<http://cliparts.co/cliparts/8T6/ooX/8T6ooXBGc.jpg>



Sally

[http://www.clker.com/cliparts/1/7/d/b/11954223591424692568Gerald\\_G\\_Girl\\_in\\_wheelchair.svg](http://www.clker.com/cliparts/1/7/d/b/11954223591424692568Gerald_G_Girl_in_wheelchair.svg)